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Advanced Clinical-Based Technologies for Monitoring Physical Function in Breast Cancer Survivors: Scoping Review

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Abstract

Background: People surviving breast cancer often face long-term impairments in physical function, significantly impacting their quality of life. In recent years, a variety of technologies have been developed to monitor and assess these functions; however, there is no consolidated synthesis linking specific technologies to targeted functional domains and real-world clinical contexts, limiting comparability and translation into practice.

Objective: This scoping review aimed to systematically explore and map the use of advanced clinic-based technologies for assessing and monitoring key physical functions, such as balance, muscle strength, and range of motion, among individuals surviving breast cancer. The purpose of this review was not only to identify which technologies have been applied but also to clarify how they are being used, the clinical settings, target physical functions, assessment protocols, and types of outcomes measured. It further summarized the current patterns of use to inform and enhance clinical assessment practices.

Methods: A comprehensive literature search was conducted across MEDLINE, Scopus, CINAHL, and Web of Science databases, with no publication date restrictions. Eligible studies included adults with breast cancer assessed using advanced clinic-based technologies to monitor physical function. Screening and selection followed PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. The data extraction captured study characteristics, participant demographics, technologies applied, and related outcomes. The extracted data were organized in Covidence and synthesized descriptively to map the types of technologies, assessed functional domains, and application settings across studies.

Results: Across the 17 included studies, the participants (N=719; age range between 30 and 75 years) were predominantly female and largely drawn from stage 0 to III breast cancer cohorts; 1 (5.9%) study reported a single male participant, and 2 (11.8%) studies did not specify participant sex. Among the 17 included studies, 11 (64.7%) were published from 2017 onward. Technologies spanned balance platforms (force plates, Technobody-PK 200 WL, Sensory Organization Test; 5/17, 29.4%), isokinetic dynamometry (Biodex systems; 4/17, 23.5%), and range of motion assessment via motion capture (3/17, 17.6%) or digital inclinometers (5/17, 29.4%). Sample sizes per study ranged from 20 to 100 participants (median 43), and follow-up durations varied from 1 session to 6 months.

Conclusions: Advanced clinic-based technologies for assessing balance, muscle strength, and range of motion in breast cancer survivors were identified across the literature, including balance platforms, isokinetic dynamometry, digital inclinometers, and markerless motion capture systems. Considerable heterogeneity in devices, outcome reporting, and study designs limited direct comparison across studies and prevented definitive conclusions about the superiority or clinical readiness of any single technology.

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Introduction

Breast cancer remains the most prevalent malignancy among women worldwide, with increasing survival rates due to advances in early detection and treatment [1]. Although breast cancer mortality has declined in recent decades, as survival rates improve, attention has shifted from survival alone to long-term recovery, quality of life, and function, with rehabilitation emerging as a central component of survivorship care [2-4]. Physical function, the ability to perform physical tasks that enable daily activities and participation, is an important factor in cancer survivorship and rehabilitation and is framed within the International Classification of Functioning, Disability, and Health (ICF) [5]. Impairments in physical function after breast cancer treatment are commonly reported and include deficits in balance, muscle strength, and range of motion (ROM) [6-8]. Women undergoing chemotherapy may experience up to a 25% loss in strength and joint dysfunction [8]. Moreover, individuals surviving cancer have highlighted difficulties with balance and walking as the most common functional issues, with prevalence rates of 19% and 24%, respectively [9]. These functional limitations have been associated with poorer health-related quality of life and reduced mobility in survivorship cohorts [10,11]. At the same time, impairments in gait and balance control have been documented as potential contributors to fall risk and reduced independence in everyday life among breast cancer survivors [6]. According to the literature on cancer survivorship, over half of individuals who have undergone cancer treatments encounter physical function impairments [12].

The American Physical Therapy Association (APTA) Oncology Evaluation Database to Guide Effectiveness (EDGE) Task Force has provided evidence-based recommendations for standardized outcome measures in oncology rehabilitation. For balance assessment, the Task Force strongly supports the use of low-cost, performance-based tools such as the Fullerton Advanced Balance Scale, gait speed, Timed Up and Go, Five Times Sit-to-Stand, and the Balance Evaluation Systems Test, all rated as reliable and clinically feasible for cancer survivors [13]. In contrast, computerized balance systems such as force plates and the Sensory Organization Test (SOT) have been less recommended due to limited clinical utility and high cost, despite growing evidence supporting their sensitivity in detecting subtle postural sway and vestibular deficits in individuals with cancer and chemotherapy-induced peripheral neuropathy [14]. For shoulder ROM, the Task Force rated passive goniometry (score 4) as a recommended tool, while for muscle strength, handheld dynamometers (HHDs) (score 3) and manual muscle testing (score 2B) were endorsed as appropriate clinical measures [15]. Although these conventional methods remain the clinical standard, their limited sensitivity and responsiveness underscore the need for more objective, automated technologies capable of quantifying subtle changes in function [16,17].

Furthermore, a variety of technologies such as wearable sensors (accelerometers/pedometers), fitness trackers, smartphone apps, and advanced motion-capture systems are increasingly used to quantify physical function in breast cancer survivorship [18-22], providing objective, high-resolution data [21,22]. However, most reported applications remain in research or specialized settings with limited protocol and outcome standardization [19,22].

Accordingly, this review aims to map and characterize the use of such advanced, clinically based technologies in assessing key physical functions, including balance, muscle strength, and ROM, among individuals surviving breast cancer. For the purposes of this review, "advanced" is defined as instruments that provide automated, objective outputs beyond unaided observation or analogue readouts. "Clinic-based" denotes systems that can be operated in clinical rooms or clinically configured spaces by routine clinical staff with minimal specialist engineering support, for monitoring and assessing physical functions. These terms were selected based on their relevance within the ICF framework and their frequent association with impairment among breast cancer survivors [6,23,24]. By examining how these technologies are currently integrated into clinical practice, this review seeks to identify gaps in the existing literature and highlight areas where further research is needed.

Methods

Search Strategy

A comprehensive literature search was conducted across the MEDLINE, Scopus, CINAHL, and Web of Science databases. The initial search strategy was developed in collaboration with an experienced academic health sciences librarian (Liz Dennett) to ensure methodological rigor and comprehensive coverage. The selection of the search terms was informed by preliminary scoping searches and key indexing terms from prior reviews in oncology rehabilitation and motion analysis. The MEDLINE strategy served as the base and was adapted for syntax variations across databases. The search was conducted in multiple stages, starting with the initial search on February 2, 2024, followed by updates on June 24, 2024. Each search was repeated across the 4 databases to ensure comprehensive coverage of the relevant literature. The final search included combinations of controlled vocabulary, such as MeSH (Medical Subject Headings) terms and free-text terms related to breast cancer, physical function, and measurement technologies. The complete search strategy and related keywords are provided in Multimedia Appendix 1. In addition to peer-reviewed databases, gray-literature searches were limited to PhD dissertations. All identified articles were imported into Covidence software (Covidence Ltd) for screening. Duplicate records were automatically identified and removed by Covidence's built-in algorithm, followed by manual verification by the reviewers to ensure accuracy.

Inclusion and Exclusion Criteria

Studies were included if they were published in English, had full-text availability online, involved adults diagnosed with breast cancer, and utilized technologies to objectively measure

one or more physical functions (balance, strength, and ROM) as primary or secondary outcomes. No publication date restrictions were applied. All study designs were considered for inclusion, excluding nonoriginal articles such as study protocols, reviews, conference abstracts, books, or editorials. Additionally, studies were excluded if they involved technologies that did not meet the criteria for being both advanced and clinically based. These technologies are intended to directly assess and monitor physical functions in patients, facilitating clinical decision-making and supporting rehabilitation processes. Technologies like Vicon, for instance, were excluded if they were not designed for clinical use. To be effective in clinical settings, technologies must be easily integrable into workflows without requiring complex setups or specialized technical expertise.

Screening and Selection Process

An initial search strategy was developed in collaboration with the academic librarian to capture studies using any technology to assess physical function in adults with breast cancer. During the title and abstract screening process, it became evident that this comprehensive approach would yield several hundred eligible studies, predominantly due to the extensive literature on accelerometers and pedometers, as well as the frequent application of laboratory-based marker-based motion-capture systems. To preserve methodological rigor and avoid redundancy with existing systematic reviews and meta-analyses focused on accelerometer and pedometer studies, while ensuring a clinically actionable synthesis, an additional consultation with the librarian was conducted to refine the eligibility criteria prior to initiating full-text review and data extraction. The inclusion criteria were subsequently refined to prioritize advanced, clinically deployable technologies for point-of-care assessment of 3 core domains of physical functions. As a result, articles that used traditional technologies, such as dynamometers or goniometers, which do not meet the established definition of advanced measurement technology for the purposes of this review; nonclinic–based accelerometers and pedometers; and some lab-based motion capture systems requiring reflective markers, multicamera stereophotogrammetry, calibration routines, and dedicated laboratory infrastructure, were excluded unless the authors explicitly described clinical deployment or adaptation for real-world clinical settings. The study selection process was conducted in several stages following established scoping review methodology. Initially, two reviewers (authors MA and AW) independently screened titles and abstracts of all retrieved references against the eligibility criteria. Discrepancies between the two reviewers at this stage were flagged within Covidence for subsequent resolution. Studies deemed potentially eligible by either reviewer advanced to full-text screening, which was similarly conducted independently by the same two reviewers (MA and AW). Following both screening phases, conflicts were systematically resolved through a structured consensus process. For any study where the two primary reviewers disagreed on inclusion or exclusion, the full text and relevant eligibility criteria were reviewed collaboratively by all three reviewers (MA, AW, and MFP) in a consensus meeting. During these discussions, each reviewer presented their rationale, and discrepancies were resolved through deliberation

until unanimous agreement was reached. If consensus could not be achieved through discussion, the third reviewer (MFP) served as the final arbiter. All final inclusion decisions and data extraction were completed through this consensus process, with regular meetings held among the three reviewers to ensure consistency in the interpretation of eligibility criteria and data extraction procedures throughout the review.

Data Extraction

Data extraction was collaboratively performed by the three reviewers (MA, AW, and MFP). For each included study, details regarding the study title, year of publication, country, aim, and design were recorded. Participant characteristics, including demographic information, inclusion and exclusion criteria, and recruitment methods and settings, were extracted. Information on sample size, cancer treatment details, and the instruments employed, including technological characteristics, was collected. We also recorded methodological features relevant to implementation and key findings reported by the original authors in relation to the use or outcomes of the measurement technology. The extracted data were organized and managed in Covidence for transparency and synthesis.

Data Synthesis

The extracted data from relevant studies were synthesized narratively and summarized in tabular format to provide a comprehensive overview of advanced clinic-based technologies used to monitor and assess functional outcomes in individuals surviving breast cancer. Studies were first categorized by the component of physical function assessed (balance, strength, and ROM) and then organized according to the specific measurement technology employed. For each technology identified, the corresponding data analysis methods used in the original studies were extracted and documented. This synthesis sought to deliver an analysis of the current knowledge and methodologies used to assess the included physical functions. The findings were analyzed to highlight common methodologies, instruments, and outcomes reported in the literature. This process defines how functional outcomes are commonly evaluated in individuals with breast cancer using advanced and clinic-based technologies and identifies potential gaps or inconsistencies in current practices, including variations in measurement protocols, differences in data normalization methods, and the range of technologies applied to assess similar functional outcomes.

Results

Study Identification

Initially, 3593 articles were retrieved from Medline, Scopus, Web of Science, CINAHL, and gray literature. After removing duplicates and nonrelevant gray literature (n=1508), a total of 2052 records were screened for eligibility. Following title and abstract screening, 314 articles were eligible for full-text review. Ultimately, 17 studies, each assigned a unique study ID (ranging from 001 to 017), were included for data extraction. These 17 studies, involving a total of 719 participants, were included in the review. The number of articles and methodologies utilized for reviewing, selecting, and verifying them at each stage of the

process is presented in a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram (Figure 1) [25]. While gray literature, including PhD dissertations, was considered, none met the inclusion criteria. Furthermore, the specific characteristics of the studies included in this study are comprehensively detailed in Table 1, providing an in-depth overview of their methodologies, sample populations, and key findings. Additionally, no formal quality assessment of the studies was conducted as part of this scoping review.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flow diagram for study selection.
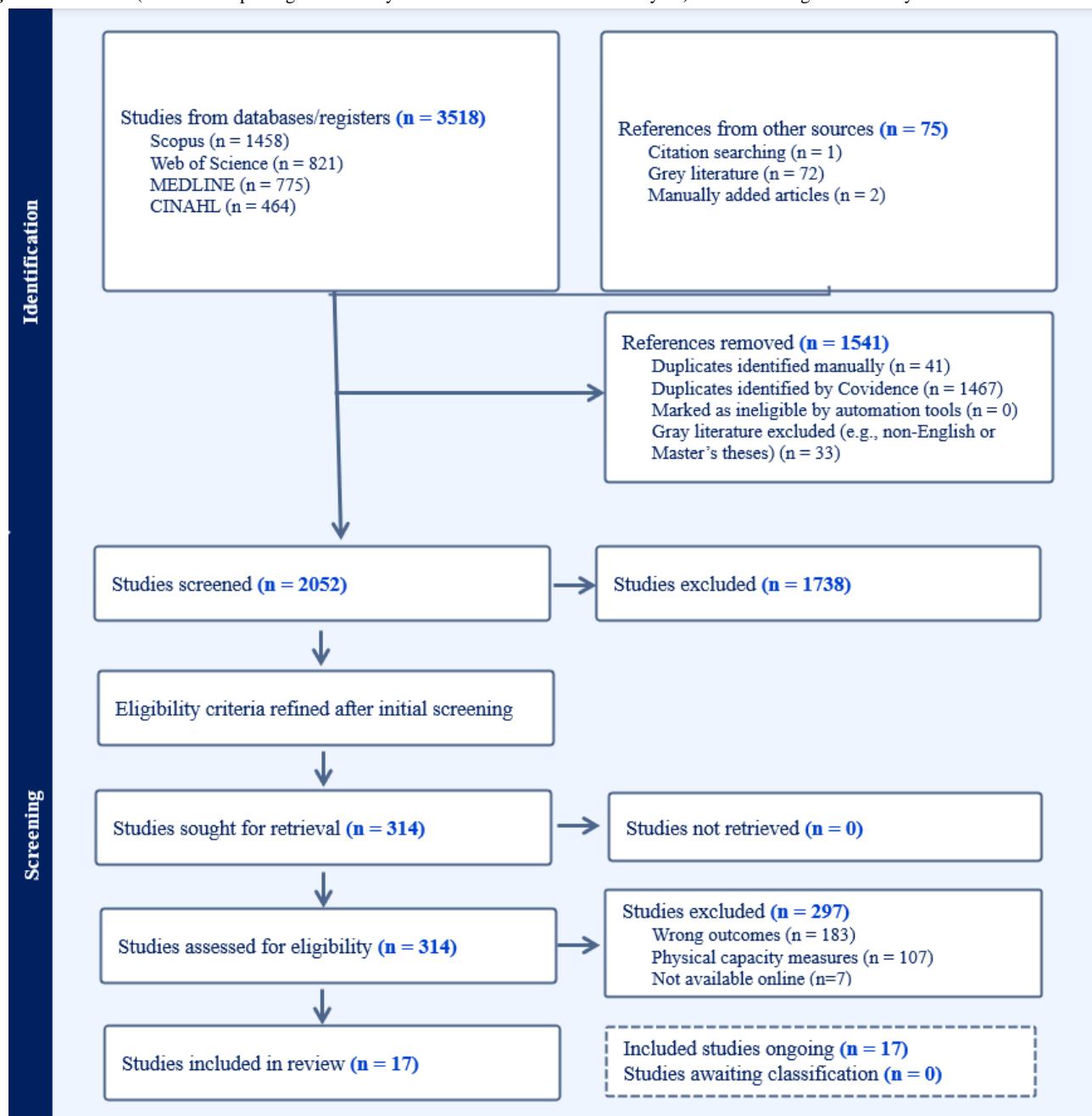
Table 1. Characteristics of the included studies.

ID	Author (s)	Pub. Year	Title	Study setting and design	Sample size and participant characteristics	Physical function	Instruments	Key findings
001	(Bertoli et al) [26]	2023	Mat Pilates improves lower and upper body strength and flexibility in breast cancer survivors undergoing hormone therapy: a randomized controlled trial (HAPiMat study).	Hospital and randomized controlled trial	n=43; stage 0-III; ≥40 years; undergoing hormone therapy; sex not reported	Hip flexor and extensor muscle strength	Biodex Medical system 4 (Shirley)	Biodex assessments showed that the Pilates group significantly improved their lower body strength, with increases in isometric flexor-extensor peak torque and enhanced concentric and eccentric flexor peak torque and mechanical work.
002	(Rao and Pattanshetty) [27]	2022	Effect of myofascial release, stretching, and strengthening on upper torso posture, spinal curvatures, range of motion, strength, shoulder pain and disability, and quality of life in breast cancer survivors.	Hospital and pre‐post experimental study	n=22; female, 35-70 years; newly diagnosed; treated with surgery, radiation, chemotherapy, or combination	Shoulder and cervical range of motion	Cervical range of motion was evaluated using a digital inclinometer	Significant improvements were observed for cervical movements.
003	(Højvig et al) [28]	2022	Donor-site morbidity following breast reconstruction with a latissimus dorsi flap - A prospective study.	Hospital and prospective observational study	n=20; female, 32-70 years; undergoing delayed breast reconstruction with latissimus dorsi flap	Shoulder Strength	Biodex System4 Pro-dynamometer	The study revealed that breast reconstruction using the LD[a] flap led to significant decreases in isometric shoulder strength for adduction and extension due to LD muscle removal, supporting its impact on shoulder girdle strength; however, isokinetic strength remained largely unchanged 12 weeks after surgery.
004	(Zabi̇t Özdemir and İyi̇gün) [29]	2022	Is there a difference in balance functions between breast cancer survivor women and healthy women?	Eastern Mediterranean University's Healthy Living Center and A prospective study	n=66; female, 35-70 years; 33 post-mastectomy survivors vs 33 healthy controls; no chemo/radiation	Dynamic balance	Computer-based Dynamic Balance Platform (Technobody-PK 200 WL)	No differences were observed between the groups in subparameter dynamic balance measurements, computer-based dynamic balance platform assessments, or Y-Balance Test results.

ID	Author (s)	Pub. Year	Title	Study setting and design	Sample size and participant characteristics	Physical function	Instruments	Key findings
005	(Wechsler et al) [30]	2022	Persistent cancer-related fatigue predicts static and dynamic balance in women with a history of breast cancer	A breast cancer center at a large urban hospital and cross-sectional study	n=43; female, 30-85 years; postchemotherapy ± radiation; stage I-III	Static and dynamic balance	Force plates (Bertec Corporation model 4060NC)	CRF[b] independently and significantly impairs both static and dynamic balance individuals surviving cancer, leading to compensatory stabilization strategies and highlighting CRF's critical role in increased postural sway and fall risk even years after treatment.
006	(Artese et al) [31]	2021	Effect of functional impact training on body composition, bone mineral density, and strength in breast cancer survivors	Laboratory and randomized controlled trial	n=44; sedentary postmenopausal women, 52-68 years; stage 0-III; ≥3 months postchemotherapy/radiation.	Isokinetic concentric knee extension and flexion	Biodex Medical System 3 (Shirley)	Both groups demonstrated significant improvements over time in lower body strength, specifically in isokinetic knee extension and flexion at all tested speeds. However, after adjusting for baseline differences and time since diagnosis, there were no significant differences in posttraining knee strength measures between the two groups.
007	(Evans et al) [32]	2021	Examination of clinical and laboratory measures of static and dynamic balance in breast cancer survivors	In the Department of Rehabilitation Services at Alamance Regional Medical Center and a cross-sectional study	n=43 (20 breast cancer survivors + 23 controls); female, 40-70 years; stage 0-III; completed chemo/radiation ≤ 5 years	Static balance	SOT[c] was conducted using the NeuroCom SMART Balance Master (Natus Medical, Pleasanton)	NeuroCom SOT equilibrium assessments revealed that individuals surviving breast cancer generally maintained similar postural stability to the healthy control group. However, they showed significantly impaired balance in Conditions 2 and 3, which rely on proprioceptive and vestibular systems for maintaining balance.

ID	Author (s)	Pub. Year	Title	Study setting and design	Sample size and participant characteristics	Physical function	Instruments	Key findings
008	(Uhm et al) [33]	2020	Usefulness of Kinect sensor-based reachable workspace system for assessing upper extremity dysfunction in breast cancer patients	Konkuk University Medical Center and a cross-sectional study	n=20; age 46-62 years; unilateral breast cancer; sex not specified	Upper extremity active range of motion	The Kinect sensor-based reachable workspace analysis system	The reachable workspace was divided into four shoulder-centered quadrants: upper medial (Q1), lower medial (Q2), upper lateral (Q3), and lower lateral (Q4). The analysis revealed that the upper quadrants (1 and 3) on the affected side had significantly smaller reachable workspace areas compared to the unaffected side, while the lower quadrants showed no differences.
009	(Ribeiro et al) [34]	2019	Three-dimensional scapular kinematics, shoulder outcome measures and quality of life following treatment for breast cancer - a case control study	An outpatient breast cancer surgery (part of a hospital) and case control study	n=42; female, 40-60 years; 21 presurgery vs 21 controls	Shoulder range of motion	Shoulder motion measured by a digital inclinometer	The breast cancer surgery group exhibited reduced range of motion compared to healthy controls.
010	(Monfort et al) [35]	2017	Gait, balance, and patient-reported outcomes during taxane-based chemotherapy in early-stage breast cancer patients	An outpatient oncology clinic setting and longitudinal study	n=33; 32 female, 1 male; 36-59 years; Stage I-3	Static balance	Balance plate (Bertec Corp)	Cumulative exposure to taxane therapy was associated with notable declines in patients' balance, indicating a detrimental effect on their physical functionality.
011	(De Groef et al) [36]	2017	Effect of myofascial techniques for treatment of upper limb dysfunctions in breast cancer survivors: randomized controlled trial	Department of Physical Medicine and Rehabilitation of the University Hospitals Leuven and randomized controlled trial	n=48; female, 38-70 years; primary breast cancer; 23 intervention vs 25 control	Active shoulder range of motion	Inclinometer	The study found no significant differences between the group receiving myofascial therapy combined with physical therapy and the group receiving physical therapy alone in terms of shoulder range of motion.
012	(De Groef et al) [37]	2016	Arm lymphoedema and upper limb impairments in sentinel node-negative breast cancer patients: a one-year follow-up study	Multidisciplinary Breast Centre of University Hospitals Leuven and longitudinal study	n=100; female, 50-70 y	Shoulder range of motion	Gravity inclinometer	One year after the sentinel lymph node biopsy, 30% of patients experienced reduced shoulder range of motion.

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ID	Author (s)	Pub. Year	Title	Study setting and design	Sample size and participant characteristics	Physical function	Instruments	Key findings
013	(Moreira et al) [38]	2015	A Kinect-based system for upper-body function assessment in breast cancer patients	Not specified and an observational study	n=48; female; 24 with lymphedema; age not reported	Upper-body joint range of motion includes shoulder, elbow, and wrist flexion/extension and shoulder abduction/adduction	Kinect-based system	The study validated a Kinect-based system for assessing upper-body function, demonstrating high accuracy in classifying normal vs. impaired function. The system, which uses kinematic data for machine learning classification, shows potential for remote monitoring and early detection of functional impairments during rehabilitation.
014	(Gritsenko et al) [39]	2015	Feasibility of using low-cost motion capture for automated screening of shoulder motion limitation after breast cancer surgery	Academic cancer center oncology clinic and descriptive study	n=20; women, 51-69 years; stage 0-III	Active and passive shoulder range of motion	Motion capture by Kinect	The study found that the low-cost Kinect motion capture system effectively identified moderate to severe shoulder motion impairments in individuals surviving breast cancer, with strong correlations to goniometric measurements for active movements.
015	(Winters-Stone et al) [40]	2011	Identifying factors associated with falls in postmenopausal breast cancer survivors: a multidisciplinary approach	Comprehensive cancer center and case-control plus prospective observation	n=59; female, 49-68 years; stage 0-III	Dynamic balance	The SOT, used in computerized dynamic posturography	Individuals surviving breast cancer had higher fall rates due to vestibular balance deficits from chemotherapy, particularly affecting dynamic balance, while static balance remained similar between fallers and non-fallers.
016	(Harrington et al) [41]	2011	Comparison of shoulder flexibility, strength, and function between breast cancer survivors and healthy participants	The Neuromuscular Research Laboratory and case-control study	n=48; female, 40-60 years; stage 0-III	Active and passive shoulder range of motion	Digital inclinometer	The study found that breast cancer survivors had reduced shoulder range of motion compared to healthy controls, particularly in flexion and external rotation.
017	(Waltman et al) [42]	2003	Testing an intervention for preventing osteoporosis in postmenopausal breast cancer survivors	In participants' homes or at convenient sites and pilot intervention study	n=21; female, 40-65 years; stage I-II	Muscle strength of the knee, hip, and wrist (flexion and extension)	Biodex System 2 multijoint testing	The study found significant improvements in muscle strength for hip flexion, hip extension, and knee flexion over 12 months.

[a]LD: latissimus dorsi.

[b]CRF: cancer-related fatigue.

[c]SOT: Sensory Organization Test.

Characteristics of the Included Studies

A review of 17 studies focusing on individuals surviving breast cancer revealed key insights into research locations, designs, timelines, participant stages, and objectives. The United States emerged as the most common location, hosting 7 (41.2%) of the included studies. The remaining research was conducted across a diverse set of countries, including Finland, Turkey, Portugal, Belgium, Brazil, South Korea, India, and Denmark. The review included 5 (29.4%) experimental studies, among which were 3 (17.6%) randomized controlled trials [26,31,36], 1 (5.9%) pretest-posttest experimental study [27], and 1 (5.9%) pilot intervention, [42] and 12 (70.6%) observational studies, including 4/17 (23.5%) cross-sectional studies [30,32,33,38], 3 (17.6%) case-control studies [34,40,41], 2 (11.8%) prospective observational studies [28,29], 2 (11.8%) longitudinal cohort studies [35,37], and 1 (5.9%) descriptive study [39]. The publication timeline indicated a growing interest in this area, with 11 (64.7%) studies published in 2017 or later, while the remaining 6 (35.3%) studies were published between 2003 and 2016 [37-42]. The studies aimed to assess different physical functions, with a particular emphasis on balance, strength, and flexibility related to breast cancer treatments. The objectives of the studies were varied, ranging from evaluating the effectiveness of specific interventions, such as mat Pilates [26] and myofascial techniques [36], to assessing the impact of cancer-related fatigue [30] on balance and postural control. Some studies also investigated the feasibility and usefulness of motion capture technologies for screening and assessing functional impairments [33,38,39].

Furthermore, the studies included in the review were conducted in multiple settings, predominantly within specialized medical facilities. Many studies took place in hospitals or hospital-affiliated centers. Isokinetic dynamometry using Biodex was reported mainly in hospital settings [26,28], with 1 (5.9%) study conducted in a laboratory environment [31]. Digital inclinometers were used across hospitals, rehabilitation services, and outpatient oncology clinics [34,36,37,41]. Kinect-based markerless motion capture (MMC) was implemented within oncology services spanning a medical center and an outpatient oncology clinic [33,38,39]. One (5.9%) study even extended its setting to participants' homes or convenient community sites [42].

In terms of recruitment strategies, many studies enrolled participants through state and hospital cancer registries, clinician referrals, and ongoing treatment facilities within large urban hospitals. Researchers also leveraged community outreach by utilizing social media platforms, distributing flyers in regional cancer hospitals, and engaging with breast cancer support groups. Local media outlets, such as newspapers and radio announcements, were employed to broaden their reach. Some studies relied on word-of-mouth, emails, and telephone contacts.

The studies included in this review primarily focused on individuals surviving breast cancer, with participants aged between 30 and 75 years, and an average age range of 50 to 60 years. Among the 15 (88.2%) studies that reported participant sex, all included only female participants except for 1 (6.7%) study, which included a single male participant [35]. A total of 2 (11.8%) studies did not report any information about participant sex [26,33]. Nine (53%) of the included studies explicitly reported participants' cancer stage; all 9 enrolled individuals with stage 0 to III disease [26,30-32,35,39-42]. Among the 17 studies, 5 (29.4%) studies involved participants undergoing or having recently completed chemotherapy [27,30-32,41], and 1 (5.9%) study specifically enrolled women receiving hormone therapy [26]. Moreover, 1 (5.9%) study focused on surgical reconstruction (latissimus dorsi flap) [28]. Two (11.8%) studies included postmastectomy survivors compared to healthy controls [29,32], and 3 (17.6%) enrolled mixed-treatment cohorts [27,30,40]. In terms of sample sizes, these varied considerably throughout the studies, ranging from as few as 20 participants to as many as 100. People with stage IV cancer and cognitive impairments were generally excluded. Additional exclusion criteria, such as uncontrolled cardiovascular or musculoskeletal conditions, severe neuropathy, or inability to provide informed consent, were applied to ensure participant safety and maintain the validity of assessment results.

Reported Instruments and Key Findings on Physical Function

This scoping review found that most studies assessed physical function using a variety of outcome measures, and ROM was reported in 8 (47.1%) of the included studies [27,33,34,36-39,41]. Balance outcomes were reported in 5 (29.4%) studies [29,30,32,35,40], and muscle strength outcomes were reported in 4 (23.5%) studies [26,28,31,42]. Of these, 3 (17.6%) studies employed motion capture technologies [33,38,39], Kinect-based systems to assess upper extremity kinematics and ROM in individuals surviving breast cancer. Inclinometers were used in 5 (29.4%) studies to further quantify shoulder movements [27,34,36,37,41]. Balance assessments were another key focus: 2 (11.8%) studies employed force plates to measure postural sway in both static and dynamic conditions [30,35], while the SOT was used in another 2 (11.8%) studies to assess balance under varying sensory inputs [32,40]. In addition, 1 (5.9%) prospective study evaluated dynamic balance using a computer-based dynamic balance platform (Technobody PK 200 WL) [29].

Moreover, strength assessments were conducted using different models of the Biodex System (2, 3, 4, and 4 Pro) to evaluate isometric and isokinetic strength in muscle groups, including the shoulder, hip, knee, and wrist [26,28,31,42]. Measurements included isometric strength normalized to body weight, as well as peak torque during isokinetic contractions at varying angles and velocities. Further details on the specific tools and data analysis methods used in each study are provided in Table 2.

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Table 2. Overview of technologies and data analysis methods.

Category and technology used	Data analysis method	Author
Strength		
Biodex System 2 multijoint testing	The highest peak torque measure, obtained during 4 repetitions, was recorded in Newton meters and used for data analysis.	Waltman et al [42]
Biodex Medical System 3	The highest peak torque value from the 3 repetitions was recorded for each speed.	Artese et al [31]
Biodex Medical Systems 4	Peak torque and mechanical work, normalized to body mass, were analyzed.	Bertoli et al [26]
Biodex System 4 pro	The data were analyzed by averaging 3 trials of isometric and isokinetic strength (in Nm/kg).	Højvig et al [28]
Digital inclinometer	Active and passive shoulder flexion/extension and external/internal rotation range of motion were measured with 3 trials averaged for data analysis.	Harrington et al [41]; Rao and Pattanshetty [27]; Ribeiro et al [34]
Gravity inclinometer	The analysis assessed the prevalence of impaired shoulder range of motion, defined as an interlimb difference of 15 degrees or more between the affected and unaffected arms. Additionally, it evaluated the number of patients who experienced a decrease in shoulder ROM[a] greater than 15 degrees from their baseline measurements, indicating a significant loss of mobility after treatment or surgery.	De Groef et al [36,37]
Range of motion		
Kinect-based system	The study used a Kinect-based system to capture 3D motion data, extracting features like range of motion, hand height, elbow flexion, and movement acceleration. These were analyzed using machine learning algorithms to classify patients as having normal or impaired upper-body function.	Moreira et al [38]
Automated motion analysis system using Microsoft Kinect	The Microsoft Kinect sensor was used to assess shoulder motion limitations. The technology tracked body landmarks and converted the captured data into joint angles using a custom algorithm.	Gritsenko et al [39]
Microsoft Kinect Sensor	The Microsoft Kinect sensor captured participants' upper extremity motion trajectories during standardized seated arm movements. These data allowed for the reconstruction of each participant's reachable workspace envelope, divided into 4 quadrants relative to the shoulder joint. The reachable surface areas for each quadrant and the total workspace were calculated and then normalized by individual arm length to account for differences among participants.	Uhm et al [33]
Force plate model 4060NC (Bertec Corp) and recorded through Motion Monitor Software (Innsport Training, Inc)	Balance was assessed using a force plate to measure postural sway in the medial-lateral and anterior-posterior planes under both static and dynamic conditions. For static balance evaluation, participants stood still for 30 seconds before and after moderate-intensity exercise. Dynamic balance was measured during the rising phase of an Instrumented Sit-to-Stand test, where participants quickly stood up from a seated position, and sway was recorded throughout this transition.	Wechsler et al [30]
Balance		
Balance plate (Bertec Corp)	Data collected from the CoP[b] included measurements of its location and displacement during standing trials, specifically focusing on the root mean squared excursion in the medial-lateral direction to evaluate postural stability and the risk of falling.	Monfort et al [35]
Technobody-PK 200 WL, a computer-based dynamic balance platform	Participants performed the "Equilibrium Assessment" and "Sleight Assessment" tests on this device, which measured parameters such as anterior/posterior and medial/lateral sleight, balance assessments, number of targets reached, perimeter, and average pace. Each test was repeated 3 times, and the best score was recorded for analysis.	Zabi̇t Özdemi̇r and İyi̇gün [29]
Computerized dynamic posturography with the SOT	Participants' sway responses were recorded under 6 sensory conditions that manipulate visual and somatosensory information.	Winters-Stone et al [40]
NeuroCom SOT[c]	Equilibrium scores from the NeuroCom SOT under 6 conditions varying platform stability and visual input, with and without the serial sevens cognitive task, were analyzed to assess static balance and the impact of cognitive load.	Evans et al [32]

[a]ROM: range of motion.

[b]CoP: center of pressure.

[c]SOT: Sensory Organization Test.

Discussion

Principal Findings

This scoping review mapped 17 studies deploying advanced clinic-based technologies to assess physical function in breast cancer survivors. The review identified technologies used to assess three domains, namely ROM, balance, and muscle strength, and documented variation in instrument type. These technologies were applied in varied clinical environments, primarily hospital-based and outpatient oncology settings, to measure specific aspects of physical function through structured protocols.

The studies used advanced methods to determine how people maintain their balance. These detailed assessments consistently revealed information that simpler, one-time tests often overlook. Studies using advanced balance equipment in clinical settings measured different aspects of postural control and consistently revealed information that simpler, one-time tests often overlook. SOT protocols showed balance problems when proprioceptive and vestibular systems were challenged, even though performance was nearly normal under easier conditions. This suggests that balance deficits in breast cancer survivors depend on the situation rather than affecting all balance tasks equally [32,40]. This pattern supports the clinical value of multi-condition batteries that probe sensory reweighting, rather than relying solely on single-task screens. Force plates quantify quiet-stance stability by deriving center of pressure (CoP) signals and summarizing them with standard sway metrics, typically medial-lateral (ML) and anterior-posterior (AP) excursion (range or root mean square (RMS)), total path length, mean sway velocity, and planar sway area (often a 95% confidence ellipse). These metrics capture both the magnitude (eg, excursion, area) and temporal dynamics (eg, velocity) of postural control. Notably, key ML CoP metrics, including mean velocity, mean amplitude, and RMS displacement, have been linked to higher prospective fall risk [43]. In the included longitudinal study of taxane-based chemotherapy, Monfort et al [35] used a laboratory force plate to track changes in CoP behavior during treatment; cumulative taxane exposure was associated with deteriorations in balance control, reflected by increased sway and concurrent gait alterations (shorter step length, slower walking speed). Complementing this, Wechsler et al [30] showed that cancer-related fatigue independently predicted poorer postural stability on force-plate measurements. Fatigued individuals showed compensatory stabilization strategies and greater body sway in both standing still and moving conditions. Together, these findings suggest that when clinically relevant stressors are present (eg, neurotoxic chemotherapy and fatigue), force-plate CoP metrics could be sensitive to subtle balance changes.

For measuring ROM, the review describes a spectrum of technologies. At one end are digital inclinometers, which are widely accessible but depend on the operator. At the other end are automated MMC systems, which provide less biased 3D assessments and show promising evidence of clinical usefulness. The successful application of MMC for upper extremity ROM assessment in breast cancer survivors was demonstrated across 3 studies in diverse settings, including oncology clinics and outpatient centers. This suggests these technologies have overcome initial feasibility barriers and may be ready for broader clinical implementation [33,38,39]. The strong correlation between Kinect-derived reachable workspace metrics and QuickDASH, a validated and widely used tool for assessing upper extremity disability in breast cancer survivors [44], and the system's ability to detect side-to-side differences in functionally relevant movement zones (overhead reaching) demonstrate practical utility for monitoring recovery [33]. However, there is significant variation in how different studies measure ROM. Studies differ in whether they assess active versus passive motion, which planes or tasks they evaluate, and whether they use absolute measurements versus side-to-side comparisons. This inconsistency makes it difficult to compare studies and develop clear, evidence-based clinical guidelines. Taken together, within the bounds of the included studies, MMC appears to have promising potential for assessing upper-extremity function in breast cancer survivors.

Muscle strength was quantified with isokinetic dynamometry in controlled clinical or laboratory settings [26,28,31,42]. Systems such as the Biodex (models 2-4/4 Pro) are seen as the top choice for testing dynamic muscle strength. They control precise, preset angular velocities and capture full torque-angle-velocity relationships together with work and power outputs. These multidimensional profiles can reveal deficits in force production and velocity-dependent behavior (eg, concentric versus eccentric weakness) that are not apparent from single-value manual grades, and their test-retest reliability in musculoskeletal [45,46]. The trade-off is practical; true isokinetic testing requires dedicated equipment, space, regular calibration, and staff skilled in positioning, stabilization, familiarization, and protocol standardization, all of which limit routine deployment outside well-resourced centers. Given these constraints, many rehabilitation services rely on portable HHDs for strength assessment. Professional guidance from the APTA Oncology EDGE Task Force recognizes HHDs as an appropriate option for cancer populations, provided that clinicians use standardized patient and tester positioning, consistent lever arms, and repeated trials to improve reliability [15].

This scoping review had some limitations. First, the inclusion of solely English-language studies raised the possibility of language bias and the exclusion of relevant work published in other languages. Additionally, the review focused solely on 3 physical functions, potentially overlooking other important aspects of physical function in individuals surviving breast cancer. While multiple databases were searched, some relevant studies may not have been captured if they were published in databases that were not included in the search strategy, which can limit the comprehensiveness of the review. Finally, the variability of the included studies in design, clinical setting, treatment phase, and outcome definitions (eg, active versus passive ROM, task/plane selection, and absolute versus interlimb metrics) precluded quantitative synthesis and limits cross-study comparability. Specifically, individuals with stage IV cancer were typically excluded from most of the included studies to focus on nonmetastatic cases.

Comparison With Prior Work

A recent scoping review by Amarelo et al (2024) [47] examined the application of technological resources in cancer rehabilitation, identifying wearable devices, web-based platforms, mobile health (mHealth) apps, virtual reality, and exergaming as commonly employed tools. Their review emphasized the wide diversity of technologies and underscored the need for further research to assess their long-term effectiveness, cost-efficiency, and successful integration into clinical practice. In contrast, our scoping review narrows the focus to advanced clinic-based technologies specifically used to assess and monitor physical functions, balance, muscle strength, and ROM in individuals surviving breast cancer. By concentrating on this particular population and key physical functions, our review offers a detailed analysis of the clinical applicability, measurement properties, and limitations of these technologies. This focused approach addresses the gap identified by the previous work [47] regarding the need for more targeted research on the integration of technological tools into cancer rehabilitation practices. Moreover, our findings corroborate a previous review that recognizes force plates as effective tools for detecting subtle balance impairments [6] and Biodex systems as the gold standard for muscle strength assessment [48].

Conclusion

This scoping review synthesized current evidence on advanced clinic-based technologies used to assess and monitor 3 key physical functions, namely balance, muscle strength, and ROM, in individuals surviving breast cancer. The review found that balance assessments predominantly utilized force plates and SOT, muscle strength was assessed using various models of the Biodex isokinetic dynamometer, and range of motion was measured using digital inclinometers and MMC systems. These studies were conducted primarily in hospitals and specialized medical facilities, with participant samples spanning various treatment phases and survivorship stages. The review documented considerable heterogeneity in measurement approaches, clinical settings, and reporting practices across the included studies. These findings underline that a diverse toolkit is currently applied to measure physical function in breast cancer survivorship, but that variability in methods limits cross-study comparability. Mapping this landscape can help us prioritize targeted validation and implementation studies and inform the development of pragmatic guidance for selecting feasible, clinically useful technologies in rehabilitation practice.

Data Availability

All data supporting the findings of this scoping review are included within the article and its supplementary materials. As this study synthesizes information from previously published literature, no new primary data were generated.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Complete search strategy and related keywords.
[DOCX File , 26 KB - cancer_v12i1e77894_app1.docx]

Multimedia Appendix 2
PRISMA-ScR (referred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews).
[DOCX File , 86 KB - cancer_v12i1e77894_app2.docx]

Multimedia Appendix 3
Responses to Reviewers comments.
[DOCX File , 94 KB - cancer_v12i1e77894_app3.docx]

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Abbreviations

AP: anterior-posterior
APTA: American Physical Therapy Association
CoP: center of pressure
EDGE: Evaluation Database to Guide Effectiveness
HHD: handheld dynamometer
ICF: International Classification of Functioning, Disability and Health
MeSH: Medical Subject Headings
ML: medial-lateral
MMC: markerless motion capture
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
ROM: range of motion
RMS: root mean square
SOT: Sensory Organization Test

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Review

Measurements and Digital Technology Solutions to Monitor Physical Activity in Patients With Pediatric Cancer: Scoping Review

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Abstract

Background: Patients with pediatric cancer often experience reduced physical activity (PA) due to treatment-related fatigue, functional limitations, and lack of structured exercise programs. Digital health solutions, including wearable sensors and augmented reality (AR)-based interventions, may offer new possibilities for monitoring and improving PA in this population.

Objective: This scoping review aims to address existing research gaps by identifying the instruments—both conventional and digital—used to monitor PA in patients with pediatric cancer during treatment. In addition, this study examines PA monitoring methods, identifies the variables collected, and explores the applicability of digital health solutions in facilitating PA engagement among patients with pediatric cancer.

Methods: In accordance with the Joanna Briggs Institute methodology, a systematic search was conducted across 8 scientific databases—ProQuest, Web of Science, EBSCO Complete, Google Scholar, ScienceDirect, Scopus, MEDLINE (PubMed), and Cochrane—on April 18 and 19, 2024. Studies were screened using the Rayyan AI-assisted review tool based on predefined inclusion criteria targeting children aged 7-19 years who were undergoing cancer treatment or were within 2 years posttreatment. Eligible studies included clinical trials and observational studies that examined objective (eg, wearable sensors) and subjective (eg, questionnaires and self-reports) approaches to PA monitoring. Keywords and controlled vocabulary (eg, MeSH [Medical Subject Headings] terms) were identified through a review of relevant literature. Data were extracted systematically to capture study characteristics, intervention types, and outcome measures. Extracted data were charted and synthesized narratively to identify patterns, technological applications, and research gaps in PA monitoring among patients with pediatric cancer.

Results: Twelve studies met the inclusion criteria and employed a range of PA monitoring tools. Digital health solutions, including Actical and Garmin VivoFit 3 devices, were used in 5 studies to assess step counts, gait cycles, and movement intensity. Self-reported measures were identified in 11 studies, most commonly the Activities Scale for Kids and the Pediatric Quality of

Life Inventory-Multidimensional Fatigue Scale, which provided insights into mobility and fatigue. Despite their feasibility, subjective assessments were limited by recall bias and motivational factors. Although digital health solutions—such as wearable sensors, gamification, and mobile applications—showed potential to improve PA adherence, their application remains underutilized, and evidence regarding their integration in pediatric oncology is limited.

Conclusions: Existing objective and subjective methods for monitoring PA provide valuable insights; however, gaps remain in the use of interactive digital health solutions, such as AR-based interventions, for PA monitoring and engagement. Future research should focus on integrating digital tools that not only track PA but also actively engage patients, enhance motivation, and support rehabilitation across both clinical and home settings.

Introduction

Every year, approximately 400,000 children and adolescents aged 0-19 are diagnosed with cancer worldwide [1]. Advances in childhood cancer treatment have significantly improved survival rates, with more than 80% of patients receiving modern cancer therapy surviving at least 5 years beyond diagnosis, and many achieving full remission [2,3]. However, despite these improvements in medical care, childhood cancer survivors remain at risk of recurrence, secondary malignancies, chronic conditions, and functional impairments [4]. These late effects of cancer and its treatment contribute to early mortality among survivors, making ongoing health management a critical concern [5]. Physical activity (PA) is increasingly recognized as a key component in mitigating the adverse effects of cancer and its treatment [6]. Nevertheless, published data indicate that fewer than 50% of patients with pediatric cancer meet PA guidelines, highlighting a serious challenge in maintaining adequate activity levels [7]. The World Health Organization (WHO) defines PA as any bodily movement produced by skeletal muscles that requires energy expenditure, including activities performed during leisure time, transportation, and daily routines—not just structured exercise [1]. Cancer-related fatigue is a major barrier to PA, contributing to sedentary behavior and reduced mobility [8]. In addition, some patients with pediatric cancer experience physical limitations that affect their ability to perform daily activities, as observed in conditions such as clear cell sarcoma, which often affects the legs, feet, arms, hands, and torso [9]. Given these challenges, implementing interventions to counteract cancer-related physical side effects is a major priority in pediatric oncology. There is growing evidence that PA is not only safe during both the acute treatment phase and survivorship [10] but also effective in reducing cancer treatment–related side effects [11,12]. Encouraging PA in patients with pediatric cancer is therefore essential; however, existing approaches face significant barriers. Currently, hospital-based PA interventions are the most common approach, led by physiotherapists, occupational therapists, and nurses who encourage children to remain active during therapy sessions [13]. However, pediatric oncology rehabilitation services are often underutilized, with few children referred for specialized rehabilitation. Medical professionals have identified a shortage of dedicated pediatric oncology rehabilitation services, while rehabilitation specialists have highlighted the lack of appropriate environments and equipment [14]. These limitations exacerbate challenges related to organizing PA, particularly for patients who experience fatigue and mobility restrictions [7]. To address these gaps, digital technology is emerging as a valuable complement to conventional PA interventions. Technologies such as wearable sensors, augmented reality (AR), and the Internet of Things offer new approaches to engaging patients with pediatric cancer in PA and monitoring their progress. For instance, wearable devices can track step counts, gait cycles, and movement patterns in real time, providing immediate feedback on PA performance [15]. Mobile health (mHealth) apps that incorporate gamification techniques have proven effective in increasing PA by offering interactive challenges and motivational feedback, thereby helping to sustain engagement among patients with pediatric cancer [16,17]. In addition, virtual reality (VR)– and AR-based interactive digital health solutions can create immersive exercise environments, helping to overcome the lack of dedicated health care—particularly rehabilitation—spaces, while providing personalized and engaging PA experiences [18]. These technologies offer scalable, flexible, and patient-centered solutions that could enhance PA participation and adherence in pediatric oncology care [19,20]. Understanding the specific individual needs of patients with pediatric cancer is crucial for developing effective PA interventions that align with their physical capabilities and treatment constraints. This scoping review aimed to address existing research gaps by identifying conventional and digital health instruments used to monitor PA in patients with pediatric cancer during treatment. Furthermore, it examined PA monitoring methods, characterized the variables collected, and explored the potential of digital health solutions to facilitate PA engagement in patients with pediatric cancer.

The research questions guiding this review are as follows:

- What conventional and digital methods are used to monitor PA in children and adolescents with cancer?
- What variables collected by conventional and digital health instruments are used to monitor PA in children and adolescents with cancer?
- What is the applicability of different conventional and digital health instruments for monitoring PA levels in children and adolescents with cancer?
- How are digital health solutions and PA monitoring tools incorporated into interventions aimed at improving PA in children and adolescents with cancer?

In addressing these questions, the authors use the term "variables" specifically to refer to objective measurements, such as step count and gait cycles/minute, distinguishing them from subjective values obtained through self-reported questionnaires. By mapping the available PA monitoring tools and interventions, this review aims to contribute to a more comprehensive understanding of how digital solutions can support PA promotion in patients with pediatric cancer.

Methods

Protocol and Registration

This scoping review was conducted between April and September 2024. The review followed the Joanna Briggs Institute (JBI) methodology for scoping reviews [21,22] and was reported in accordance with PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews; Multimedia Appendix 1) guidelines [23]. The 6-stage framework proposed by Arksey and O'Malley [24] was applied. The protocol was registered with the Center for Open Science [25], and the review was conducted without deviations from the registered protocol.

Eligibility Criteria

Overview

Based on recommendations from the JBI [21,22] and the research questions formulated to refine the focus of the scoping review and develop an effective search strategy, we defined the eligibility criteria according to the Population, Concept, and Context framework [22].

Population: Children and Adolescents With Cancer

- Children and adolescents with cancer during treatment or up to 2 years after treatment. Based on existing studies, this 2-year period—including active treatment and early recovery—is used because it allows researchers to assess how PA supports the restoration of cardiorespiratory fitness and muscle strength while helping to alleviate lingering posttreatment fatigue and physical limitations [26].
- Studies including children and adolescents aged 7-19 years. This age range was selected because it corresponds to the pediatric cancer population. Younger children are generally unable to complete questionnaires or engage in PA independently, while older age groups are typically classified as adults with cancer. Children and adolescents in this age range can effectively engage in self-directed activities and structured exercise programs. Moreover, older

adolescents face unique physical and psychological challenges during the transition to adulthood, making their inclusion essential for understanding the impact of PA during and after cancer treatment [6,13].

Concepts: Digital Health Solutions Such as Wearable Sensors, Gamification, and Mobile Apps

- Wearable sensors, AR, and gamification provide new approaches to engaging patients with pediatric cancer in PA while enabling continuous monitoring of their progress [16].
- The incorporation of AR and gamification in pediatric cancer care is justified by their demonstrated effectiveness in enhancing PA levels among children and adolescents [17,18,20].
- Digital health solutions enable objective, data-driven monitoring of PA patterns, allowing health care professionals to tailor interventions and evaluate treatment-related functional outcomes [16,20].

Context: Physical Activity

- PA, as defined by the WHO, encompasses bodily movement that enables individuals to perform daily activities effectively and engage in exercise [13].
- The term "physical activity" includes all forms of bodily movement performed in educational, recreational, home, or community settings, including but not limited to aerobic exercise, resistance training, flexibility, endurance activities, and stretching routines.
- Key parameters for evaluating PA include frequency, intensity, duration, type of activity, and distance covered. In pediatric cancer, assessing a child's engagement in daily PA can provide valuable insights into recovery and health outcomes after treatment.

Selection of Records of Evidence

Individual studies published between 2000 and March 2024 were included. The starting year of 2000 was selected to capture research conducted during the period when digital technologies began to be systematically introduced into health care and rehabilitation, marking the global transition toward digital health strategies and culminating in the WHO's Global Strategy on Digital Health 2020-2025 [27]. The selection of records for this review was guided by predefined inclusion and exclusion criteria to ensure a comprehensive and relevant assessment of digital technologies for monitoring PA in patients with pediatric cancer. Inclusion and exclusion criteria were defined according to the Population, Concept, and Context framework (Textbox 1).

Textbox 1. Inclusion and exclusion criteria.

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1. Inclusion criteria

- Population: children and adolescents diagnosed with cancer

- Concept: digital health solutions related to physical activity (eg, augmented reality, gamification, digital tools, digital environments)

- Context: physical activity outcomes

- Setting: supervised clinical environment

- Study type: original studies with any design or data type (quantitative and qualitative)

- Publication status: published in a peer-reviewed journal

- Publication language: English

- Full-text available

- Included keywords: cancer, pediatric, oncology, exercise, monitoring, physical activity, fitness, movement, digital technologies, augmented reality, gamification, digital tools, digital environment.

2. Exclusion criteria

- Population: children and adolescents more than 2 years after cancer treatment

- The study does not include patients aged 7-19

- Concept: digital technologies not related to physical activity (eg, for health management)

- Context: nonphysical activity outcomes or monitoring; specific physical fitness measures

- Setting: nonclinical

- Study type: other study types (eg, protocols, narrative reviews, or systematic reviews)

- Publication status: published without peer review, dissertations, books, conference papers, letters, or editorials

- Publication language: written in a language other than English

- Full-text not available

- Excluded keywords: drug, in vitro, animal, mice, mouse, animals, bacteria, murine, rat, fish, canine, rodents, transgenic, rodent, piglets, rabbits

- Mental health outcomes are excluded unless they are mentioned in combination with a physical activity outcome.

- Duplicate data: if studies provide overlapping datasets or are part of the same project without additional insights, they should be excluded to avoid repetition.

Information Sources and Search Strategy

A comprehensive search was conducted in ProQuest, Web of Science, EBSCO Complete, Google Scholar, ScienceDirect, Scopus, MEDLINE (PubMed), and Cochrane on April 18-19, 2024. The search strategy (Multimedia Appendix 2) combined keywords and controlled vocabulary (eg, MeSH [Medical Subject Headings] terms) related to pediatric cancer, digital technologies, PA, and outcome measurement, using Boolean operators. The final search strategy was adapted for each database. Only articles published in English were included, and gray literature was excluded. Following the database searches, all records were imported into the Rayyan AI-assisted review tool, after which the study selection process was conducted in 3 phases. First, titles and abstracts were screened, followed by full-text review to identify articles relevant to the research questions of this scoping review. In the final phase, a data extraction template was created within the Rayyan AI-assisted review tool to facilitate the systematic collection of key information from the selected articles. Given the anticipated volume of articles, all 11 coauthors participated in the selection process at each stage, with each article independently reviewed by 2 team members (AK and DB). If the Rayyan AI-assisted

review tool identified a conflict regarding inclusion or exclusion, a third reviewer (GS) resolved it. Data extraction was performed independently and cross-checked to enhance accuracy. In addition, the team met regularly online to address any issues arising during the article selection phases.

Data Charting Process

Extracted data from the reviewed articles were categorized and analyzed using a structured set of variables. Key elements of the analysis included the paper ID, first author (name and surname), journal name, and article title, providing a bibliographic foundation for the review. To contextualize the research geographically and demographically, the country of the study, study aim, and participant information (number, sex, age, diagnosis, comorbidities, treatment status, and setting) were documented. In addition, details regarding participants' diagnosis and treatment were recorded to further clarify the clinical context. The methodology of each study was assessed, including study type (eg, cross-sectional, longitudinal), applied methods (PA monitoring instruments, questionnaires, proxy reports, digital technologies), specific tools used for monitoring, and study outcomes (objectives, data type, inclusion or empowerment, intervention effectiveness, and potential effects

of monitoring methods on activity levels). In this review, the treatment period was defined as the active treatment phase, extending up to 2 years posttreatment.

Data Synthesis and Analyses

Following the final stages of the 6-stage framework for scoping reviews proposed by Arksey and O'Malley [24], data synthesis was conducted after identifying, selecting, and charting the relevant studies. Extracted information was first organized in a structured Excel (Microsoft Corporation) matrix, enabling systematic comparison across studies. The synthesis process involved 2 main phases:

- Descriptive numerical summary, where studies were grouped by publication year, country, cancer type, participant age, treatment phase, study design, and type of PA intervention or monitoring technology. Frequency counts and distributions were used to illustrate research trends and methodological characteristics.
- Qualitative thematic synthesis, where data related to intervention characteristics, PA measurement methods, feasibility, and outcomes were coded inductively by 2 reviewers (AK and DB). Codes were iteratively compared and refined through discussion among all coauthors until consensus was reached. Emerging categories were then grouped into overarching themes, including (1) feasibility and adherence of PA monitoring, (2) barriers and facilitators

to engagement, and (3) identification of digital and exercise-based interventions.

This structure enabled the systematic identification of recurring patterns, differences, and knowledge gaps across studies. Results were synthesized narratively and organized in tables to highlight key themes, relationships, and interconnections among the examined variables.

Results

Selection of Records of Evidence

Our search identified a total of 7876 records across 8 electronic databases. Of these, 2069 duplicates were removed, leaving 5807 records eligible for screening, which indicates the feasibility of our search strategy. Following the initial screening based on eligibility criteria, 5772 records were excluded, and 35 were sought for retrieval. Of these 35 records, 23 were excluded because they did not include a measure of PA, the research was conducted more than 2 years after treatment, the sample included adults, or the records were research protocols, reviews, theses, or conference papers. A total of 12 publications met all eligibility criteria and were included in this scoping review. The source and selection of evidence are presented in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram (Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of the literature search and study selection process.
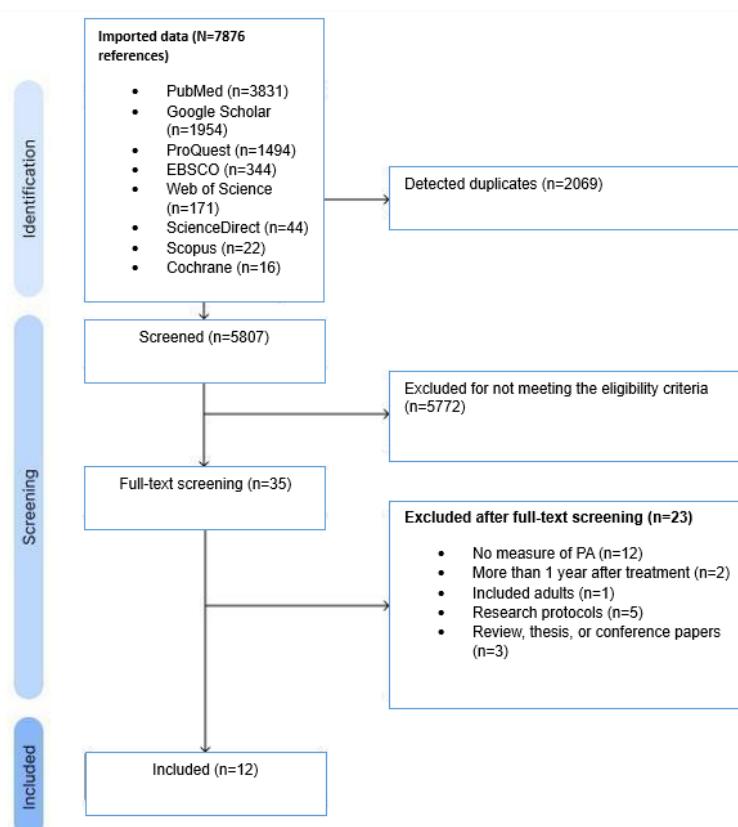
Characteristics of Included Studies

The characteristics of the 12 selected studies included in this review are summarized in Table 1. The studies encompassed

various research designs, including 4 (33%) randomized controlled trials [28-31], 1 (8%) quasi-randomized trial [32], 4 (33%) cross-sectional studies [33-36], 1 (8%) multicenter cohort study [37], 1 (8%) pilot study [15], and 1 (8%) prospective

observational study [38]. The included studies investigated PA levels, motor performance, and quality of life among children and adolescents diagnosed with cancer, both during and after treatment. Studies were conducted in Germany [16,27,33,37], the Netherlands [15,29,30,33], the United States [37,38], Hong Kong [36], and South Korea [32]. The interventions employed objective PA monitoring tools, such as accelerometers (Actical, Move 3, Step Watch 3, Garmin vívofit 3) and subjective self-report measures, including the Activities Scale for Kids (ASK), Pediatric Quality of Life Inventory (PedsQL)-Multidimensional Fatigue Scale, and other health-related quality-of-life instruments. Across the 12 studies, a total of 1083 participants (ages 3-20 years) were assessed,

with sample sizes ranging from 25 to 482. Most participants had leukemia (acute lymphoblastic leukemia or acute myeloid leukemia) or lymphoma (non-Hodgkin lymphoma or Hodgkin), while others had solid tumors (eg, bone tumors, brain tumors, neuro-oncology cases). Some studies included mixed cancer diagnoses without specific classification. Two studies examined participants posttreatment [32,35], whereas the remaining 10 focused on patients undergoing active treatment or within the first year after completion. For example, Kang et al [32] investigated a mobile game–based healthy lifestyle program for childhood cancer survivors in South Korea, while Stössel et al [35] compared PA behaviors before, during, and after cancer treatment in Germany.

Table 1. Characteristics of included studies for analysis.

Author	Country	Participants' age and setting	Disease	Research design	Objective instruments used to assess and monitor physical activity	Self-reported instruments used to assess and monitor physical activity
Gaser et al [28]	Germany	• 41 participants aged 4-18 years • During the treatment	• Acute lymphoblastic leukemia (n=25, 61%) • Non-Hodgkin lymphoma (n=12, 29%) • Acute myeloid leukemia (n=4, 10%)	Randomized controlled trial	• The accelerometer Move 3 • The Functional Activity of Daily Living Screen with everyday tasks • The Motor Performance in Paediatric Oncology test	• The Self-Reported Activities Scale for Kids
Gaser et al [31]	Germany	• 41 participants aged 4-18 years • During the treatment	• Acute lymphoblastic leukemia (n=25) • Acute myeloid leukemia (n=4) • Non-Hodgkin lymphoma (n=12) • Second primary cancer (n=2)	Randomized controlled trial	• The accelerometer Move 3 • The Functional Activity of Daily Living Screen with everyday tasks • The Motor Performance in Paediatric Oncology test	• The Self-Reported Activities Scale for Kids
Braam et al [33]	The Netherlands	• 60 participants aged 8-18 years • Treated with chemotherapy, radiotherapy, or both during or within the first year after cancer treatment	• Acute lymphoblastic leukemia (n=17) • Acute myeloid leukemia (n=8) • Brain tumor (n=8) • Hodgkin lymphoma (n=7) • Bone tumor (n=7) • Non-Hodgkin lymphoma (n=5) • Rhabdomyosarcoma (n=3) • Chronic myeloid leukemia (n=2) • Others (n=3)	Cross-sectional study	• Actical activity monitor	• PedsQL-MFS[a] • The Participation in Sports Before the Cancer Diagnosis Questionnaire; a subscale of the Self Perception Profile Questionnaire for children aged 8-11 years and for adolescents aged 12-18 years • Children's Depression Inventory

Author	Country	Participants' age and setting	Disease	Research design	Objective instruments used to assess and monitor physical activity	Self-reported instruments used to assess and monitor physical activity
Götte et al [34]	Germany	• 28 participants with a mean age of 13.8 (SD 2.8) years • During cancer treatment	• Leukemia (n=13) • Acute lymphoblastic leukemia (n=9) • Acute myeloid leukemia (n=4) • Bone tumor (n=9) • Ewing sarcoma (n=3) • Osteosarcoma (n=6) • Localized at the lower limb (n=3) • Localized at trunk/upper limb (n=6) • Lymphoma (n=2) • Other solid tumor (n=4)	Cross-sectional study design	• Step Watch 3	• Physical activity questionnaire from the German Health Interview and Examination Survey for Children and Adolescents of the Robert Koch Institute
Withycombe et al [38]	The United States	• 65 participants aged 8-17 years • Enrollment generally occurred during the first 6 months of cancer therapy, but at least 4 weeks after diagnosis and at least 3+ weeks after cancer definitive surgery (if applicable)	• Leukemia/lymphoma (n=38) • Solid tumor (n=16); • Neuro-oncology (n=11)	Cross-sectional study design	• The Garmin vívofit 3	• A 9-question ecological survey • PROMIS[b]
Rehorst-Kleinlugtenbelt et al [15]	The Netherlands	• 25 participants aged 3.1-17 years • Undergoing active cancer treatment	• Hematological malignancy (n=17) • Solid tumors (n=8)	Cross-sectional study design	• Accelerometry	• N/A[c]
Mack et al [37]	The United States		• First diagnosis of cancer of any type	Multicenter cohort study	• N/A	

Author	Country	Participants' age and setting	Disease	Research design	Objective instruments used to assess and monitor physical activity	Self-reported instruments used to assess and monitor physical activity
		• 482 caregivers • Patients were aged 7-18 years. Participants received upfront cancer treatment, including chemotherapy and radiotherapy.				• Child self-reports and caregiver proxy reports were collected for PROMIS pediatric domains, including mobility (physical functioning), pain interference, fatigue, depressive symptoms, anxiety, and psychological stress.
van Dijk-Lokkart et al [30]	The Netherlands	• 68 participants aged 7-18 years • Patients were still receiving treatment or were within the first year after cessation of treatment	• Diagnosed with any type of childhood cancer	Randomized controlled trial	• Actical activity monitor	• Cancer-related fatigue was assessed using both child self-report and parent proxy report versions of the PedsQL-MFS
Lam et al [36]	Hong Kong	• 76 participants aged 9-18 years • After treatment	• Leukemia (n=32, 42.1%), lymphoma (n=7, 9.2%), brain and spinal tumor (n=16, 21.1%), bone tumor (n=10, 13.2%), and others (n=11, 14.5%)	A cross-sectional study	• N/A	• The Chinese University of Hong Kong: Physical Activity Rating for Children and Youth • Physical Activity Self-Efficacy Questionnaire • The PedsQL cancer module version 3.0 • PedsQL
Kang et al [32]	South Korea	• 51 participants aged 6-13 years • All participants were childhood cancer survivors whose treatment was terminated at least 12 months prior	• Childhood cancer survivors	Quasi-randomized trial	• N/A	• The Child Healthy Lifestyle Profile adapted for children, parents, or guardians filling out the profile
Stössel et al [35]	Germany		• Diagnosed with any type of cancer	Cross-sectional, multicenter study	• N/A	• Physical activity questionnaire, which is in parts based on the German Health Interview and Examination Survey for Children and Adolescents (KiGGS)

Author	Country	Participants' age and setting	Disease	Research design	Objective instruments used to assess and monitor physical activity	Self-reported instruments used to assess and monitor physical activity
		• 114 patients with cancer and 37 healthy controls between 4 and 20 years of age • Completed intensive cancer treatment				
Braam et al [29]	Germany	• 66 participants aged 8-18 • During treatment or within 12 months after treatment	• N/A	Randomized controlled trial	• Cardiorespiratory fitness assessed by VO_{2peak}[d] (ml kg–1 min–1) using indirect calorimetry • Muscular strength was assessed using a hand-held dynamometer	• Overall fatigue was assessed using the child self-report version of the PedsQL-MFS (acute version) • General health-related quality of life was assessed using the Dutch self-report version of the PedsQL • Behavioral problems were assessed using the Youth Self-Report • Athletic competence and global self-worth were assessed using the corresponding subscales of the Self-Perception Profile • Depressive symptoms were assessed using the Children's Depression Inventory

[a]PedsQL-MFS: Pediatric Quality of Life Inventory-Multidimensional Fatigue Scale.

[b]PROMIS: Patient-Reported Outcome Measurement Information System.

[c]N/A: not applicable.

[d]VO_{2peak}: peak oxygen uptake.

PA Monitoring Methods and Obtained Variables in Patients With Pediatric Cancer

Both objective and self-reported methods were used to assess PA levels, motor performance, and fatigue in children and adolescents with cancer. Across the included studies, these 2 approaches complemented each other, providing quantitative and subjective perspectives on PA behavior and its relationship to treatment-related fatigue and recovery. Objective PA monitoring was employed in 5 studies [28,30,33,34,38], using accelerometers such as Actical, Move 3, Step Watch 3, and Garmin vívofit 3. van Dijk-Lokkart et al [30] used Actical accelerometers with a required wear time of at least 500 minutes/day to measure PA levels in children undergoing or recently completing cancer treatment. Similarly, Gaser et al [28] utilized the Move 3 accelerometer alongside motor performance tests to examine PA in patients with leukemia and lymphoma. Withycombe et al [38] used the Garmin vívofit 3 over a 4-day period to track step counts and correlate them with symptom reports. This illustrates that objective PA monitoring focused primarily on step counts and time spent in different intensity zones (light, moderate, and vigorous), reflecting a general shift toward using wearable accelerometers as a feasible and noninvasive method for tracking daily movement patterns during and after cancer treatment. In addition, subjective self-reported PA assessment methods were applied in 7 studies [28,30,33-37]. For example, the ASK, which includes 30 items across 7 subdomains (personal care, dressing, other skills, locomotion, play, standing up, and movement), and the PedsQL-Multidimensional Fatigue Scale were used. Gaser et al [28] combined ASK with motor performance testing to evaluate functional abilities such as mobility and locomotion, balance and coordination, strength and endurance, as well as fatigue and energy levels. Mack et al [37] employed caregiver-reported measures to assess mobility, pain interference, and fatigue, incorporating surveys that evaluated children's ability to perform daily tasks, their experience of pain, and levels of physical exhaustion. Götte et al [34] assessed

fatigue using the PedsQL-Multidimensional Fatigue Scale, which captures general, sleep-related, and cognitive fatigue. Additional self-report instruments, such as the Child Health Utility 9D used by Stössel et al [35], were applied to assess health-related quality of life, while structured questionnaires like the Pediatric Outcomes Data Collection Instrument, used by Braam et al [33], provided insights into mobility and participation in PAs. These self-reported instruments captured complementary domains—mobility, participation, fatigue, and quality of life—allowing researchers to contextualize accelerometer-derived data with patient-perceived outcomes and daily functional capacity. The integration of objective and self-reported measures provided a comprehensive understanding of patients' functional status across different stages of cancer care. For comparison, while some studies focused on the active treatment phase, others, such as Kang et al [32] and Stössel et al [35], specifically examined PA behaviors in posttreatment survivors. Kang et al [32] investigated the effects of a mobile game–based healthy lifestyle program on PA levels, sedentary behavior, and overall quality of life in childhood cancer survivors in South Korea. Stössel et al [35] analyzed PA behaviors before, during, and after cancer treatment, focusing on changes in daily activity levels, mobility patterns, and engagement in sports or recreational activities. Both studies provided valuable insights into long-term functional outcomes, highlighting the impact of cancer treatment on sustained PA and overall well-being in survivors. This comparison between active treatment and posttreatment groups revealed common patterns: patients typically exhibited reduced PA levels during therapy, with gradual improvement during recovery, although many survivors continued to experience limitations in endurance and persistent fatigue. In the included studies, PA monitoring primarily focused on assessing overall activity levels using accelerometers to calculate step counts and estimate time spent in light, moderate, and vigorous activity. None of the studies conducted detailed activity recognition beyond basic actions such as walking, running, or sitting, nor did they employ multisensor systems for body motion analysis or fatigue detection. More sophisticated approaches—such as recognizing complex daily activities, detecting nuanced movement patterns, or assessing early signs of fatigue—were absent, highlighting an important gap for future research.

Applicability of PA Monitoring Instruments in Pediatric Oncology

Overall, the studies included in this review demonstrated that PA monitoring instruments were feasible for use with patients with pediatric cancer. Feasibility was largely determined by patient adherence and device usability, both of which were reported as satisfactory in most studies. Withycombe et al [38] utilized the Garmin vívofit 3, worn on the wrist for 4 consecutive days, to measure step counts and activity patterns, observing that wearable technology effectively tracked PA, although results varied according to treatment stage and location (eg, fewer steps during hospitalization). van Dijk-Lokkart et al [30] reported good compliance with accelerometer-based PA monitoring using Actical accelerometers worn on the hip for at least 500 minutes/day over a 1-week period. Gaser et al [28]

employed the Move 3 accelerometer, also positioned on the hip, with a minimum required wear time of 5 days. Some studies imposed restrictions on PA measurement, such as excluding nonambulatory patients or requiring a minimum number of valid wear days for data inclusion [34,37]. While feasibility and compliance rates were generally acceptable, the studies also highlighted important contextual and individual barriers affecting the accuracy and consistency of PA monitoring in this population. Mack et al [37] found that fatigue, treatment side effects, and hospitalization influenced step counts and overall compliance. Braam et al [29] identified psychological factors, including lack of motivation and fear of overexertion, as key barriers to PA engagement. Lam et al [36] cited time constraints and limited access to PA resources as additional challenges for participants. Despite these barriers, authors suggested that self-monitoring through wearable devices served as a motivational tool, encouraging participants to maintain PA levels. These findings suggest that while device-based PA monitoring is technically and behaviorally feasible, its effectiveness depends on addressing both physical and psychosocial barriers that influence patient participation during cancer treatment and recovery.

Interventions for Improving PA in Pediatric Oncology

PA interventions varied across the 12 selected studies, incorporating individualized exercise programs, supervised training, and digital health tools to enhance and monitor PA levels. Intervention durations ranged from 4 weeks to 12 months, depending on study design and patient condition. Most studies reported retention rates above 80% and adherence rates ranging from 70% to 95%, indicating strong engagement with the interventions [28-30,32]. For example, Braam et al [29] reported a 92% adherence rate to supervised PA sessions, which included aerobic training, resistance exercises, and motor performance activities 2-3 times/week at moderate-to-high intensity. Similarly, Kang et al [32] reported a 90% program completion rate and high user engagement metrics (eg, daily log-ins and activity tracking) with a mobile game–based lifestyle program for childhood cancer survivors, encouraging daily movement. van Dijk-Lokkart et al [30] implemented individually tailored programs with varying intensity and duration based on the child's physical condition, reporting over 85% adherence in most participants. Gaser et al [28] also employed individualized exercise protocols for patients with leukemia and lymphoma, focusing on moderate-intensity exercises, and reported a 100% retention rate and 88% session completion. Across these interventions, personalization of exercise type, frequency, and duration emerged as a key determinant of both adherence and safety, reinforcing the importance of individualized approaches in pediatric oncology rehabilitation.

Table 2 (also see Multimedia Appendix 3) summarizes the PA monitoring methods, variables, applicability, and interventions across the studies in pediatric oncology, providing detailed information on the tools and strategies used to assess and promote PA in this population. A summary addressing each research question, accompanied by easily interpretable tables, is presented in Multimedia Appendix 4, offering an overview of how the selected studies address the research questions.

Table 2. Summary of PA[a] monitoring methods, variables, applicability, and interventions in pediatric oncology.

Reference	1. What methods are used for PA monitoring in patients with pediatric cancer?	2. What variables are collected to monitor PA in patients with pediatric cancer?	3. What is the applicability of different instruments to facilitate the PA level (monitoring) in patients with pediatric cancer?	4. What interventions are used to improve PA in patients with pediatric cancer research?
Gaser et al [28]	• The Move 3 accelerometer (movisens GmbH) • Self-reported questionnaire	• Step count, amplitude of moderate-to-vigorous PA, body position, and wear time	• Participants wore the device on the right hip during the daytime and removed the device during nighttime sleep. • Records of ≥4 days of ≥8 hours/day of wear time were included. • The younger participants (n=5, ages 4-7 years) felt more disturbed by the sensor on the hip. As a result, all of them refused the measurement. Because of the accelerometer's algorithm, the PA could be calculated only for those participants aged over 7 years.	N/A[b]
Gaser et al [31]	• The Move 3 accelerometer (movisens GmbH) • Self-reported questionnaire	• Step count	• Participants wore the device on the right hip during the daytime and removed the device during nighttime sleep. • Records of ≥4 days of ≥8 hours/day of wear time were included. • Reasons for invalid measurements were the lack of compliance and unscheduled inpatient hospitalizations.	Exercise program–specific strength training combined with a standard care exercise program (2-3 exercise sessions/week).
Braam et al [33]	• Actical accelerometer (B series; Philips Respironics Actical MiniMitter) • Self-reported questionnaires	• Counts/minute; the acceleration signal is summed over a specific time interval (epoch). A 15-second epoch was used in the study.	• The activity monitor was attached to an elastic waist belt and worn on the left hip during daytime at waking hours (between 6:00 AM and 11:59 PM) for 4 consecutive days (Wednesday-Saturday). The device was removed while bathing. • When the device was worn for less than 500 minutes/day, the measurement was considered invalid. • The memory capacity of the accelerometer did not allow assessment of PA by 15-second epoch for 7 days; therefore, 4 days were used. Missing data on 3 days within the measurement week remain a limitation.	N/A
Götte et al [34]	• Step Watch 3 sealed uniaxial Activity Monitor (Orthocare Innovations) • Self-reported questionnaire	• The volume of activity/day (gross counts/day) and intensity of activity (gross counts/minute)	• The device was attached to the ankle with an elastic strap. • Participants wore the activity monitor for 7 consecutive days from the morning after waking up to bedtime. • Days with <8 hours of wear time were excluded. • The study concluded that objective measures should be preferentially used for the assessment of PA in children and adolescents with cancer to ensure accurate and reliable data. Self-reports can complement objective measures by capturing activities or sports that are not reflected in step counts, as well as individuals' expectations and attitudes toward exercise.	N/A

Reference	1. What methods are used for PA monitoring in patients with pediatric cancer?	2. What variables are collected to monitor PA in patients with pediatric cancer?	3. What is the applicability of different instruments to facilitate the PA level (monitoring) in patients with pediatric cancer?	4. What interventions are used to improve PA in patients with pediatric cancer research?
Withycombe et al [38]	• The Garmin vívofit 3 accelerometer • Self-reported questionnaire	• Step count	• Participants wore an accelerometer for 7 days. Data were included if available for at least 4 days during a defined 7-day period. • Eligible days included a minimum of 10 hours of wear time between 6 AM and 10 PM. • Step monitoring may serve as an objective indicator for overall symptom count, fatigue, PA, and physical function.	N/A
Rehorst-Kleinlugtenbelt et al [15]	• The Actical (Philips Respironics, Mini Mitter Co, Inc)	• Step count • Counts/minute • 15-second epoch	• The device was fastened to an elastic waist belt strap and worn on the right hip. A minimum wearing time of 8 hours/day was required, with a minimum of 4 valid days a week. • Parents or participants maintained a "wearing time" activity diary. • The study found that accelerometry is suitable for the objective assessment of PA in children with childhood cancer during their treatment. The data gave a presentation of their PA behavior during the day. Accelerometers provide an objective assessment of PA and can be used in different kinds of patients.	N/A
Mack et al [37]	• Self-reported questionnaire • Caregiver proxy report	• PROMIS[c] assessments of the child's physical function (mobility) and symptoms, including pain interference, fatigue, depressive symptoms, anxiety, and psychological stress; 5 response categories. Each question's recall period is the past 7 days.	• Our findings suggest that proxy reporting is influenced by the proxy's personal experience of symptoms and function as well as the child's experience. • Caregivers tended to overestimate symptoms and underestimate function relative to children themselves.	N/A
van Dijk-Lokkart et al [30]	• Actical accelerometer (B series; Philips Respironics Actical MiniMitter) • Self-reported questionnaire • Caregiver proxy report	• Counts/minute, 15-second epoch	• The accelerometer was worn on the hip during daytime at waking hours (between 6:00 AM and 11:59 PM) on 4 consecutive days (Wednesday-Saturday), at least 500 minutes/day over a 1-week period. • Although the PedsQL-MFS[d] has acceptable psychometric properties, including content validity, internal consistency, and responsiveness, there are inconsistent reports regarding known group validity in pediatric cancer.	Cardiorespiratory and muscle strength training twice a week for 12 weeks at a physical therapy sports center near the child's home.
Lam et al [36]	• Self-reported questionnaires		• N/A	N/A

Reference	1. What methods are used for PA monitoring in patients with pediatric cancer?	2. What variables are collected to monitor PA in patients with pediatric cancer?	3. What is the applicability of different instruments to facilitate the PA level (monitoring) in patients with pediatric cancer?	4. What interventions are used to improve PA in patients with pediatric cancer research?
		- The Chinese University of Hong Kong: Physical Activity Rating for Children and Youth—score ranges from no exercise at all (0) to vigorous exercise on most days (10). - PA self-efficacy score: self-confidence in PA participation, from "not sure," "a little sure," to "very sure." - The PedsQL cancer module version 3.0: How much of a problem was a task over the last month, from 0 to 4 (0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always)?		
Kang et al [32]	- Self-reported questionnaire - Caregiver proxy report	N/A	- The healthy lifestyle program based on a mobile serious game assessed the following subdimensions: health responsibility, PA, nutrition, positive life perspective, interpersonal relations, stress management, and spiritual health. - No significant effects were observed for any subdimension except PA.	A healthy lifestyle program based on a mobile serious game that promotes healthy behaviors through the completion of 26 quests, encompassing 7 subcomponents: nutrition, exercise, hygiene, interpersonal relationships, stress management, meaning of life, and health responsibility.
Stössel et al [35]	Self-reported questionnaire	Participants rated their overall level of PA on a visual analog scale, ranging from "not at all physically active" to "very physically active." They also reported their PA across different domains, including type of activity, minutes/day, and intensity level. For analysis, total PA was calculated in minutes/week and categorized by intensity as light, moderate, or vigorous.	N/A	N/A
Braam et al [29]		Mean counts/minute (15-second time interval)		

Reference	1. What methods are used for PA monitoring in patients with pediatric cancer?	2. What variables are collected to monitor PA in patients with pediatric cancer?	3. What is the applicability of different instruments to facilitate the PA level (monitoring) in patients with pediatric cancer?	4. What interventions are used to improve PA in patients with pediatric cancer research?
	• Actical accelerometer (B series; Philips Respironics Actical MiniMitter) • Self-reported questionnaires • Caregiver proxy report		• The accelerometer was attached to an elastic waist belt and worn on the left hip during waking hours (6:00 AM to 11:59 PM). Participants wore the device for 4 consecutive days (Wednesday-Saturday). After the monitoring period, the accelerometers were returned to the research team by postal mail. Compliance with accelerometer use was low during the final study measurement week. Nonuse was primarily attributed to discomfort associated with wearing the device on a hip-mounted belt, with complaints reported particularly by girls and children who were overweight.	The 12-week intervention comprised 24 individual physical exercise sessions, consisting of two 45-minute exercise sessions/week conducted at a local physical therapy practice, and one 60-minute psychosocial training session every 2 weeks delivered to the child at the treating pediatric oncology hospital.

[a]PA: physical activity.

[b]N/A: not applicable.

[c]PROMIS: Patient-Reported Outcome Measurement Information System.

[d]PedsQL-MFS: Pediatric Quality of Life Inventory-Multidimensional Fatigue Scale.

In addition to traditional exercise and supervised rehabilitation programs, several studies integrated digital components to enhance monitoring capabilities and sustain motivation beyond clinical settings. Digital health interventions, such as Kang et al's [32] mobile game–based program, wearable step-count monitoring [15,38], and other digital tracking tools, were used across multiple studies to assess PA levels and support motivation in patients with pediatric cancer. These programs were implemented in diverse settings, including hospitals [29,38], physical therapy centers [29,30], and home-based contexts [15,32], with supervision provided by physiotherapists, pediatric oncology specialists, or through digital applications. The inclusion of gamified and interactive elements was particularly effective in maintaining engagement among children and adolescents, consistent with evidence that motivation and enjoyment play critical roles in sustaining PA behavior during and after cancer treatment. Despite challenges such as fatigue and other treatment-related side effects, studies consistently reported that structured PA programs—including those incorporating digital elements—were associated with improved adherence and participation [30,32,38]. These digital and traditional interventions targeted a range of physical and psychosocial outcomes, with variations in duration and intensity influencing their overall effectiveness. PA intervention durations varied across studies examining effects on physical functioning [29,30,38], fitness [29,31], fatigue [30,37], quality of life [32,36], and psychological well-being [29,37]. For example, Kang et al [32] evaluated a mobile game–based intervention, which increased daily activity, improved health behaviors, and enhanced self-reported well-being. van Dijk-Lokkart et al [30] implemented a structured PA program that reduced fatigue and improved functional capacity over time. Rehorst-Kleinlugtenbelt et al [15] examined a structured physical exercise intervention delivered in both hospital and home settings, which led to increased PA levels and better adherence to exercise programs over time. By contrast, Braam et al [29] examined a structured exercise intervention delivered in a hospital and at a local physical therapy practice, which showed no significant beneficial effects on physical outcomes.

Discussion

Principal Findings

This scoping review identified various PA assessment instruments, including digital solutions, used to monitor PA in patients with pediatric cancer. Self-reported questionnaires remain the most frequently used instruments due to their accessibility and cost-effectiveness [28-30,32-39]. While these instruments provide valuable insights from the patient's perspective, their reliability is limited by recall bias and motivational factors, making them inherently subjective. Although widely utilized, self-reported questionnaires have been increasingly complemented by accelerometry, which provides empirical, quantifiable measurements of PA [38,39]. Self-reported surveys are often favored because they are inexpensive, easy to administer, and adaptable to different age groups, making them feasible even in larger study settings. Self-reported questionnaires also provide important patient-centered insights by capturing subjective experiences such as fatigue, pain interference, and broader quality-of-life outcomes (eg, Götte et al [34], Mack et al [37], Stössel et al [35], Braam et al [33]). However, their accuracy is limited by recall bias, motivational influences, and social desirability, which may distort reported activity levels. While self-reported surveys offer valuable perspectives on how children and adolescents perceive their PA and related symptoms, they are less reliable for accurately quantifying activity levels. This underscores the importance of complementing self-reported surveys with objective monitoring tools to achieve a more comprehensive assessment of PA in pediatric cancer.

Self-reported questionnaires remain widely used due to their low cost, ease of administration, and ability to capture subjective patient experiences that objective measures may not assess. These instruments are also feasible for large-scale studies and adaptable to different age groups. However, subjective methods are prone to bias, social desirability, and motivational influences, which can affect the accuracy of data outcomes. In summary, self-reported questionnaires demonstrate lower reliability in quantifying PA levels compared with objective instruments such as accelerometers.

Accelerometer-based approaches provided objective data such as step counts, wear-time compliance, and time spent at different activity intensity levels (eg, Actical in van Dijk-Lokkart et al [30], Garmin vívofit 3 in Withycombe et al [38], Move 3 in Gaser et al [28]). In some studies, accelerometry was combined with motor performance testing to assess balance, coordination, strength, and endurance [28]. Other studies extended the focus to participation in recreational or social activities, linking activity patterns to broader dimensions of daily life [33,34]. Overall, accelerometers appear to be practical and feasible tools for objectively monitoring PA in patients with pediatric cancer. Accelerometers provide reliable, quantifiable data and are generally well-tolerated by participants; however, their usefulness is limited by the need for compliance, inability to capture complex or context-specific activities, and the lack of standardized protocols across studies. When used alongside complementary instruments, accelerometers can be a valuable component of PA monitoring in both research and clinical practice. Despite growing interest in interventions using digital tools, this review found that only 1 study employed a mobile game–based approach for PA tracking in patients with pediatric cancer [32], which also functioned as a mobile engagement tool. In this study, children participated in a serious game requiring completion of 26 quests, including 7 subelements (nutrition, exercise, hygiene, interpersonal relationships, stress management, meaning of life, and health responsibility), to promote a healthy lifestyle [32]. This review demonstrated the potential of digital solutions to integrate PA monitoring with the promotion of healthy lifestyle habits during cancer treatment in clinical settings. The selected studies also highlighted the limited research outcomes available to date. While digital tools may be feasible and applicable, their broader implementation in pediatric oncology remains largely unexplored.

The integration of PA monitoring with patient engagement strategies for behavior change, such as gamification and AR, holds promise for enhancing both data accuracy and patient motivation [18,32]. This highlights a research gap where interactive digital solutions could play a pivotal role in optimizing PA interventions for patients with pediatric cancer. While prior studies have extensively examined the effectiveness of digital technology in promoting PA [15,31,32,38], only a few have explored how PA monitoring itself can facilitate PA participation and adherence [30,32,38]. Although most studies relied on accelerometers and questionnaires, a gap remains regarding the use of AR and gamification specifically for PA monitoring in pediatric oncology. Studies employed a variety of methods to promote PA in children and adolescents with cancer, including self-reported questionnaires, wearable accelerometers, and digital game–based tools. Self-reported questionnaires, such as the ASK used by Gaser et al [28] and the PedsQL-Multidimensional Fatigue Scale applied by Götte et al [34], Mack et al [37], and others [33,36], captured subjective experiences of mobility, fatigue, pain, and quality of life, providing valuable patient-centered insights, though they are limited by recall bias and motivational factors. Wearable devices, including Actical accelerometers in van Dijk-Lokkart et al [30], Move 3 in Gaser et al [28], and Garmin vívofit 3 in Withycombe et al [38], offered objective, continuous measures of step counts, activity intensity, and motor performance, enhancing accuracy and enabling longitudinal monitoring, but they may fail to capture complex or context-specific activities and depend on participant compliance. Digital interventions, such as Kang et al's [32] mobile game–based program, combined PA tracking with engagement and health education, supporting adherence and motivation; however, evidence remains limited, and these tools are largely unvalidated. Hybrid approaches integrating subjective and objective measures, as applied in several studies [32,38], show promise for providing a multidimensional understanding of PA and potentially improving adherence, though they require greater resources and supervision. Overall, these findings highlight the need to further explore innovative interventions that implement digital tools designed to be both engaging and user-friendly for patients with pediatric cancer. For instance, AR-based interactive games have been proposed as a promising approach, as they may enable real-time monitoring and provide personalized support for daily PA. Such technologies have the potential to offer health care professionals accurate information about a patient's daily activity level and enhance motivation to remain active during different treatment stages. Further research is required to evaluate the impact of digital tools on physical and mental health outcomes in patients with pediatric cancer, while also addressing the limitations of current methods highlighted in this review.

Implication for Practice

This review underscores the need for a standardized approach to PA monitoring in patients with pediatric cancer, as current practices are heterogeneous and often lack consistency. While innovative digital solutions, such as AR and gamification, may offer promising approaches to enhance motivation and adherence to PA interventions, their applicability and effectiveness in pediatric oncology remain largely unexplored and require further investigation.

Additionally, this review highlighted the need for a standardized approach to PA monitoring in patients with pediatric cancer. The diversity of accelerometers [28-34,38] and self-report questionnaires [28-38] underscores the necessity for unified guidelines to ensure consistency in data collection and interpretation. Developing standardized guidelines for PA assessment would enhance comparability across studies and support the integration of digital monitoring solutions into clinical practice.

Limitations

This review has several limitations. It included only articles published in English, which may have resulted in the exclusion of relevant research published in other languages. Additionally,

the focus on children and adolescents aged 7-19 years who were undergoing treatment or within 2 years posttreatment may have limited insights into long-term PA outcomes beyond this period. Furthermore, heterogeneity in study designs, PA measurement tools, and intervention methodologies posed challenges for direct comparisons. The aim of this review was not to evaluate the validity or reliability of the selected instruments but to map the available measurement methods and digital solutions used to monitor PA in patients with pediatric cancer. The limited adoption of interactive digital solutions highlights a critical research gap, underscoring the need for further studies to evaluate their feasibility, appropriateness, and long-term impact on PA engagement in this population.

Future Directions

Our findings indicate that future research should focus on exploring how PA monitoring can actively facilitate PA participation in patients with pediatric cancer. While numerous studies have examined PA monitoring tools, only a few have assessed their impact on promoting PA. Further investigation is also needed into the use of AR-based interventions and gamification for PA monitoring in pediatric cancer. Among the 12 included studies, none involved an AR-based intervention, and the only digital engagement tool identified was a gamified mobile game by Kang et al [32]. AR represents an unexplored but promising area for future research in pediatric oncology

rehabilitation. Interactive digital interventions have the potential to both measure and enhance PA engagement by providing real-time feedback and motivation [18]. Evaluating patient acceptance, clinical integration, and long-term adherence to such technologies will be crucial to optimizing their effectiveness. Furthermore, the absence of standardized PA monitoring protocols highlights the need for unified guidelines for digital monitoring solutions tailored to patients with pediatric cancer. Establishing consistent assessment criteria would improve comparability across studies and facilitate the integration of digital monitoring solutions into routine clinical practice.

Conclusions

Despite the growing need to monitor and promote PA in patients with pediatric cancer, opportunities for interactive and engaging PA monitoring remain limited. The findings of this scoping review indicate an emerging body of literature on digital health technologies, including wearable sensors such as accelerometers, mHealth apps, and gamification, which are being explored for PA assessment and engagement. Future research should further investigate the purpose, scope, and integration of digital health technologies to facilitate interactive and personalized approaches for effectively monitoring and enhancing PA in both clinical and home-based settings for patients with pediatric cancer.

Authors' Contributions

Conceptualization: GS, AK, ED
Data curation: KA, KBK, ED, AC, GFJ
Formal analysis: AK, DB, GS, ES, KA, AC
Funding acquisition: GS, KA, ES
Investigation: MB, DB, AK, GS, KA, KBK, AC, GFJ, ED, IK
Methodology: DB, AK, GS, KA, KBK, AC, GFJ, ED, IK
Project administration: GS, KA
Resources: DB, AK, GS, KA, KBK, AC, GFJ, ED, IK
Supervision: GS, AK, DB
Validation: AK, GS, DB, ED
Visualization: KA, KBK
Writing – original draft: GFJ, KA, KBK, AC, IK, GS, ED
Writing – review & editing: GFJ, KA, KBK, AC, IK, GS, ED, AK, DB, MB

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA-ScR checklist.
[DOCX File , 3892 KB - cancer_v12i1e73889_app1.docx]

Multimedia Appendix 2
Search strategy.
[DOCX File , 2313 KB - cancer_v12i1e73889_app2.docx]

Multimedia Appendix 3
Detailed summary of physical activity monitoring methods, variables, applicability, and interventions in pediatric oncology.
[DOCX File , 23 KB - cancer_v12i1e73889_app3.docx]

Multimedia Appendix 4
Research questions.
[PDF File (Adobe PDF File), 245 KB - cancer_v12i1e73889_app4.pdf]

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Abbreviations

AR: augmented reality
ASK: Activities Scale for Kids
JBI: Joanna Briggs Institute
MeSH: Medical Subject Headings
mHealth: mobile health
PA: physical activity
PedsQL: Pediatric Quality of Life Inventory
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
VR: virtual reality
WHO: World Health Organization

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Cultural Adaptation of a Web-Based Ostomy Care Intervention for Hispanic Patients With Cancer and Caregivers: Mixed Methods Study

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Abstract

Background: Ostomy creation for cancer treatment negatively impacts the quality of life of both patients and caregivers. Hispanic patients with cancer and caregivers often face additional challenges, including limited access to supportive care programs.

Objective: This study aimed to examine the experiences and preferences of Hispanic patients with cancer living with ostomies and their caregivers to inform the cultural adaptation of an existing intervention program and the design of Ostomy Self-Care Program (Programa de AutoCuidado de Estoma [PACE]).

Methods: In this 2-stage study, conducted between March and August 2023 in San Antonio, Texas, we used a qualitatively driven mixed methods design, starting with an initial survey followed by qualitative interviews to explore the experiences, needs, and intervention preferences of Hispanic patients and caregivers managing ostomy care. We used Braun and Clarke's 6-phase thematic analysis approach to analyze the qualitative data and performed descriptive analysis for the quantitative data. Subsequently, we applied affinity diagramming and persuasive systems design principles to guide the design of PACE.

Results: In total, 14 Hispanic participants managing an ostomy (9 patients with cancer and 5 caregivers) completed a survey and participated in interviews, continuing until data saturation was reached. Participants had a mean age of 58.9 (SD 13.01, range 37‐79) years, and most (n=12) reported a high school diploma or General Educational Development as their highest education level. Around 5 (36%) participants scored below 26 on the eHealth Literacy Scale (eHEALS), indicating low digital health literacy, and the average Charlson Comorbidity Index (CCI) was 3.21 (SD 1.86, range 0‐6). Overall, 3 major themes emerged from the qualitative data analysis, namely perceptions of living with an ostomy, seeking support, and postsurgery challenges. Additionally, two primary themes emerged from participant interviews: (1) importance of preferred language and multimedia delivery and (2) patients and caregivers desire early introduction, multimodal delivery of materials, and inclusion of peer and family support. These themes informed the design and development of a culturally appropriate, web-based, bilingual PACE intervention that integrates content visualization, cultural adaptations, and persuasive technologies—strategies designed to encourage user engagement.

Conclusions: Our findings emphasize the importance of understanding the ostomy care experiences, supportive care needs, and intervention preferences of Hispanic patients and caregivers. Informed by stakeholders' insights, we culturally adapted the original intervention program using persuasive systems design principles to design and develop the PACE intervention, aiming to enhance engagement among Hispanic patients with cancer and caregivers, support effective self-management of ostomy care, and improve health outcomes.

KEYWORDS

ostomy; Hispanic; eHealth; digital platform; caregiver; patient with cancer; cultural adaptation; persuasive technology.

Introduction

Ostomy creation can be performed as part of cancer treatment for bladder, colorectal, cervical, ovarian, and uterine cancers. The surgery involves creating an opening on the anterior abdominal wall to allow defecation or urination [1]. This procedure can complicate the patient's ability to resume normal daily activities and further impact quality of life (QOL) [2]. While supportive care and management can sustain QOL after ostomy creation, a gap remains in available care resources that are tailored to minorities, including Hispanic patients with cancer and caregivers.

Compared to their non-Hispanic counterparts, Hispanic patients with cancer and their caregivers in the United States face additional challenges throughout cancer survivorship. These barriers include socioeconomic difficulties [3], limited access to health care [4], language barriers, and financial strain [5]. Additionally, this population experiences a higher rate of being uninsured [6]. Approximately 51.3% of Hispanics in the United States need translation services during medical consultations [7]. These language barriers can hinder effective communication and potentially lead to misunderstanding home care instructions [8]. Patients undergoing an ostomy creation surgery typically use more health care resources [9], which poses a further detriment to the Hispanic population, as they often face significant challenges in obtaining health care resources[10]. In addition, cultural beliefs and practices play a crucial role in illness management. In Hispanic culture, families traditionally take on the responsibility of caring for their sick members [11], and they tend to be more involved in ostomy care than any other medical or nursing tasks [12]. A study shows that involving family members in group training sessions can significantly improve outcomes among Hispanic patients and families[13]. Recognizing the needs of both Hispanic patients and their families is essential for providing adequate support and intervention in postostomy care.

Web-based interventions offer a promising way to support self-management for patients with chronic conditions and their families [14]. Research suggests that, compared to non–web-based interventions, these web-based interventions are effective in promoting knowledge acquisition and behavioral change [15]. As a cost-effective solution, they can particularly benefit underserved groups, such as Hispanic communities [16], through overcoming barriers to health care access. Offering content in Spanish further addresses language barriers and increases access [17]. Additionally, it provides a convenient way for patients to share information within their community, fostering peer support among people who have similar experiences [18].

As part of our preparatory work to address the care needs of Hispanic patients with cancer and caregivers, our multidisciplinary team previously translated the PRISMS (Patient-Reported Outcomes-Informed Symptom Management System) [19] into Spanish. PRISMS is an eHealth intervention that integrates a program with wearable devices to support patients with cancer and their caregivers during the postostomy care transition from hospital to at-home self-management. PRISMS aims to reduce preventable emergency room use and readmissions [19]. To ensure the cultural appropriateness of the translated materials, we engaged 10 bilingual translators, including clinical nurses, nursing students, and faculty, from Chile, Mexico, Puerto Rico, Argentina, and Colombia. These bilingual, native Spanish speakers translated the English version of PRISMS into Spanish to accommodate various dialects while sensitively addressing cultural nuances.

Building on previous work, our current study explored the experiences of Hispanic patients with cancer and caregivers regarding ostomy care, as well as their preferences for ostomy care interventions, to inform cultural adaptation of PRISMS-Spanish using a mixed methods approach. We presented the PRISMS-Spanish materials to participants to facilitate discussion and gather their feedback to help inform our design of a web-based ostomy care intervention program—Programa de AutoCuidado de Estoma (PACE)—tailored for this specific underserved population. While some references cited in this paper use terms, such as "Latino/Latina," we use "Hispanic" consistently throughout this study to align with the terminology used in participant recruitment.

Methods

Study Design Overview

In stage 1, we used a qualitatively driven mixed methods design with sequential data collection and parallel analysis. First, we made an initial phone call to each participant and collected quantitative data. Then we scheduled a Zoom (Zoom Communications) interview with each of them to collect qualitative data, which was typically within 1 month after the initial phone contact. The survey data provided a clear understanding of the characteristics, health literacy, and long-term mortality risk of Hispanic patients with cancer and caregivers. In contrast, the interview data and thematic analysis offered in-depth insights into their ostomy care experiences and preferences for intervention features and functions. We used Braun and Clarke's 6-phase thematic analysis approach [20] to guide our data analysis.

In stage 2, we used affinity diagramming and the Persuasive Systems Design (PSD) model developed by Oinas-Kukkonen and Harjumaa [21] to guide PACE program design for effective user engagement [22,23].

Stage 1: Exploration of Ostomy Care Experiences and Intervention Preference

We aimed to understand the experiences and information needs of Hispanic patients and caregivers. Additionally, we gathered intervention preferences based on participant feedback on PRISMS-Spanish materials.

Participants

Participants were recruited from the Mays Cancer Center in San Antonio, Texas, the seventh largest city in the United States, with a 65% Hispanic majority population [24]. Patients were eligible if they (1) were Hispanic adults with one of three types of ostomies (colostomy, ileostomy, or urostomy) for the treatment of bladder, colorectal, cervical, ovarian, or uterine cancer; (2) could read and speak Spanish; and (3) passed a cognitive assessment using the Mini-Mental State Examination [25]. Caregivers were included if they were adults serving as the patient's primary caregiver and could read and speak Spanish. Eligible participants were contacted via phone to confirm their willingness to participate and to address any questions.

Data Collection

Quantitative and qualitative data were collected through a survey administered during an initial phone call, followed by a Zoom interview that began with a presentation of the PRISMS-Spanish materials. Each participant encounter was conducted in either English or Spanish, based on their language preference. The survey questionnaires, interview guides, and intervention materials were translated into Spanish by a certified translator and reviewed by bilingual research staff and nursing students.

The trained bilingual research staff and research assistant (AV and LRR) conducted the initial phone survey before the interview in a secure, private office space at the University of Texas Health Science Center at San Antonio (UTHSA). They read each survey question aloud and recorded participants' responses into REDCap (Research Electronic Data Capture; Vanderbilt University) hosted by the UTHSA. The survey items included demographic questions, type of ostomy, cancer diagnosis, Charlson Comorbidity Index (CCI) [26], and the Electronic Health Literacy Scale (eHEALS) [27]. Participants were asked to complete the CCI and the eHEALS questionnaires

to measure comorbidities and digital health literacy, which were critical for chronic illness management and for informing the PACE design. The CCI score is the summation of the number of comorbidities that participants reported. The eHEALS score, ranging from 8 to 40, assessed participants' digital literacy, including knowledge, comfort level, and perceived abilities in using electronic health information, with scores below 26 indicating low health literacy.

Next, participants were scheduled for a Zoom interview session at their convenience. During the session, translated PRISMS-Spanish materials were first presented, either via screen share or by email if needed, followed by open-ended questions. The semistructured interview guide was collaboratively developed by the research team, informed by insights from the PRISMS study [19] and a review of existing interventions related to ostomy care, digital health literacy, and culturally tailored programs for Hispanic populations. Interview questions focused on four main areas: (1) experience of ostomy care, (2) feedback on PRISMS-Spanish materials, (3) preferences for intervention and delivery, and (4) preferred implementation strategies. Interview sessions lasted approximately 45‐60 minutes and were conducted between March and August 2023 by the research staff. All interviews were audio-recorded and transcribed verbatim via Zoom and reviewed by the project coordinator and trained research staff who had prior experience working with Spanish-speaking patients. We determined that data saturation was achieved when no new codes or themes emerged across interviews. This approach aligns with prior research indicating that qualitative data saturation often occurs within the first 12 interviews, with key themes emerging as early as 6 [28].

Data Analysis

Quantitative data from the initial phone surveys were exported from REDCap into Microsoft Excel and RStudio (Posit; version 4.4.1) for analysis. We performed descriptive statistics, including means, ranges, frequencies, SDs, and percentages, to summarize participant demographics, CCI scores, and eHEALS (Table 1). These analyses provided an overview of the sample's characteristics and informed the interpretation of qualitative findings.

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Table . Participant characteristics.

Variable	Patients (n=9), n	Caregivers (n=5), n	Both (n=14), n
Sex			
Male	4	2	6
Female	5	3	8
Race			
White	6	4	10
Other	3	1	4
Education			
<=7th-8th Grade	2	0	2
12th Grade	6	4	10
Bachelor's degree	1	1	2
Employment status			
Work	3	2	5
Retired, age/choice	2	3	5
Disability/illness	3	0	3
Unable to work/perform normal activities	1	0	1
Marital status			
Single/never married	1	0	1
Married/domestic partner	8	4	12
Partner			
Long-term partner	0	1	1
Ostomy type			
Urostomy	2	3	5
Ileostomy	3	0	3
Colostomy	4	2	6
Age (years)			
30‐39	2	0	2
40‐49	0	1	1
50‐59	3	1	4
60‐69	2	2	4
>70	2	1	3
CCI[a]			
0	1	0	1
1-2	3	1	4
3-4	3	3	6
≥5	2	1	3
eHEALS score[b]			
<26	4	1	5
>26	5	4	9

[a]CCI: Charlson Comorbidity Index.

[b]eHEALS: eHealth Literacy Scale.

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The deidentified qualitative interview data were analyzed using Braun and Clarke's 6-phase approach to thematic analysis [20]. This approach was applied to ensure a credible analysis procedure and continued until no new themes were identified. The approach is detailed as follows:

(1) Familiarization: Two researchers (AV and LRR) independently read the interview transcripts and noted initial ideas and patterns. This process allowed researchers to gain an in-depth understanding of the participants' overall experiences and needs.

(2) Generating initial codes: AV and LRR generated initial codes systematically across the entire dataset, using NVivo (Lumivero) qualitative data analysis software (version 10.2.1) and a preliminary codebook based on interview topics.

(3) Searching for themes: the research team collated the initial codes into broader themes by grouping related codes to generate potential themes to capture participants' experiences.

(4) Reviewing themes: Team meetings were held to review themes and resolve discrepancies in theme identification, aiming for a minimum coding consistency agreement of 80% [29].

(5) Defining and naming themes: 3 researchers (AV, LRR, and XW) collaboratively defined and named each theme, ensuring that each theme was distinct and related to the aim of this study. Detailed descriptions were developed for each theme, supported by illustrative quotes from participants.

(6) Producing the report: Finally, the team synthesized the findings into a cohesive report, which was used to inform the cultural adaptation of PRISMS-Spanish and the design of PACE.

Although quantitative and qualitative data were collected sequentially, analysis was conducted in parallel. Quantitative descriptive statistics (eg, demographics, CCI, and eHEALS) were reviewed with qualitative codes and themes side by side. The integration occurred during the interpretation phase, where quantitative results were used to contextualize and support qualitative findings. The integrated results were synthesized into joint displays (Tables 2 and 3) to inform the design of the PACE intervention.

Table . Hispanic patients' and caregivers' experiences with ostomy care.

Themes and subthemes	Participant quotes
Ostomy perception	
Emotion	• "Because it is kind of a shocking thing to see your internal organs hanging out of your body even though it's a little bit, it's still a hole in your belly and you got your guts or hanging out." [Female, ileostomy, patient, eHEALS[a] score=35, CCI[b]=2] • "All the ugly stuff that nobody wants to show." [Female, ileostomy, patient, eHEALS score=32, CCI=3]
Necessity	• "And as well as many other people, it definitely has changed my perception to something that is scary to something that is a necessity at times if needed." [Female, colostomy, patient, eHEALS score=38, CCI=4] • "Knowing that I had it and I needed it to save my life." [Female, colostomy, patient, eHEALS score=38, CCI=4]
Support	
Health care provider	• "But I don't feel that knowledge is there for a lot of health care workers." [Female, colostomy, patient, eHEALS score=38, CCI=4]
Family and caregiver	• "So I really depended on him (husband) to help me put a new one back on." [Female, colostomy, patient, eHEALS score=38, CCI=4] • "… but what really helped me a lot was her (wife) and my family that was a hundred percent behind me and you know they, gave me the faith because I didn't have the faith at first." [Male, colostomy, patient, eHEALS score=23, CCI=6] • "I have an alternative. I do my husband's changes for his urostomy bag. But my son also knows how to provide the care because his wife has an ostomy bag. So in a pinch if I'm not available, he can substitute for me." [Female, urostomy, caregiver, eHEALS score=32, CCI=4] • "So they supported me through the cancer, but they weren't really sure how to help me or how to feel about it because it deals with stool and . I know they were really like kind of just supporting but not really familiar with it." [Female, colostomy, patient, eHEALS score=38, CCI=4] • "I think so, that they also involve families in these talks for them to also see how family members and the sick should be treated" [Male, colostomy, caregiver, eHEALS score=29, CCI=3]
Peer support	• "I had a lot more difficulties with my ostomy then a lot of people but you know, I ended up going to peers that worked with an ostomy as opposed to the ostomy care nurses that they were giving me because they too still weren't familiar with how to take care of my problem." [Female, colostomy, patient, eHEALS score=38, CCI=4]
Self-care	• "… it depends on what the circumstances are, but I think that the patient should do as much as possible to help themselves." [Female, ileostomy, patient, eHEALS score=35, CCI=2]
Challenges	
Radiation side effects	• "I couldn't even lift up my arms after radiation ... if they have the ostomy bag for some reason, if they're also undergoing radiation. Yeah, that's bad." [Female ileostomy, patient, eHEALS score=35, CCI=2]
Chemotherapy side effects	• "here's added things so sometimes chemos depending on which one some can cause a lot of diarrheas. Some can cause constipation." [Female, colostomy, patient, eHEALS score=38, CCI=4]

Themes and subthemes	Participant quotes
Skin irritation	• "You know, a lot of times people see, okay, it's just, it's just a little rash or whatever But actually, it's maybe an infection or something else and they see it as it just being a little rash when it's really not, you know." [Male, ileostomy, patient, eHEALS score=34, CCI=0] • "The skin irritation just lasted the entire time." [Female, ileostomy, patient, eHEALS score=35, CCI=2] • "Once in a while, he'll have a little bit of irritation, but I'll just clean it." [Female, urostomy, caregiver, eHEALS score=32, CCI=4]
Leakage	• "One reason was because, you know, I was having like a leak. And we're like, well maybe, what are we doing wrong?" [Male, ileostomy, patient, eHEALS score=34, CCI=0] • "Because I'm a heavier-set girl and obesity is rampant in the Latin community. My ostomy was retracted in so it was not sticking out like normal people.it had a lot more problems with leaking because it couldn't get a good seal around the stoma." [Female, colostomy, patient, eHEALS score=38, CCI=4]
Self-isolation	• "I feel in the house we had everything organized and everything there for us to do the job, but taking it out of the houses where it was a little harder for me." [Female, colostomy, patient, eHEALS score=38, CCI=4]
Caregiver stress and emotion	• "I'm gonna say like a depression myself, but I kept it to myself." [Female, colostomy, caregiver, eHEALS score=19, CCI=1] • "We didn't know what else to do. but you know at that point my dad had lost a lot of blood." [Male, urostomy, eHEALS score=34, CCI=4]

[a]CCI: Charlson Comorbidity Index.

[b]eHEALS: eHealth Literacy Scale.

Table . Preferences for the ostomy care intervention among Hispanic patients and caregivers.

Themes and subthemes	Participant quotes
Importance of preferred language and multimedia delivery	
Content and delivery format	• "Okay, the information is really, really helpful." [Female urostomy, caregiver, eHEALS[a] score=32, CCI[b]=4] • "The YouTube (videos) really does help out a lot." [Male, ileostomy, patient, eHEALS score=34, CCI=0] • "You have some really good tips like though there was one that we were told about and it really had helped me now that I when I apply the bag on my husband." [Female, urostomy, caregiver, eHEALS score=32, CCI=4]
Language	• "… for one who does not speak English. There is nothing, there is nothing clearer than Spanish, so the explanation is excellent, it is very good." [Female, colostomy, patient, eHEALS score=25, CCI=1]
Need for early, multimodal materials and peer and family support	
Delivery platform	• "I do on a phone and do a desktop." [Female, urostomy, patient, eHEALS score=40, CCI=6] • "For me it was more telephone because that's what I used more as far as online and researching stuff." [Female, ileostomy, patient, eHEALS score=32, CCI=3] • "I happen to like computers, … but I think not a lot of people, especially if they're older ... So he's not computer savvy either. So I think maybe like a handout or in a notebook kind of form would be better. With pictures." [Female, urostomy, patient, eHEALS=40, CCI=6]
Delivery timing	• "This should be shown to the patients before they leave the hospital because they might not have the support once they get home." [Female, urostomy, caregiver, eHEALS score=32, CCI=4] • "Like before you get going home." [Female, urostomy, caregiver, eHEALS score=32, CCI=4] • "I think it'd be better if you were to be able to give them all the information ahead of time." [Male, ileostomy, patient, eHEALS score=34, CCI=0]
Family and peer support	• "We definitely needed help. So I definitely think helping caregivers or showing caregivers how to help is really important." [Female, colostomy, Patient, eHEALS score=38, CCI=4] • "I think it's very important that anybody in the family that's willing to be involved that they would get involved in case the person that normally does it for you or helps you with it is not available for whatever reason. I think other family members should be involved also." [Male, urostomy, patient, eHEALS score=33, CCI=3] • "I think it would be wise and I think it really helps if you ask somebody, somebody personal, somebody that's gone through it." [Male, ileostomy, patient, eHEALS score=34, CCI=0]

[a]CCI: Charlson Comorbidity Index.

[b]eHEALS: eHealth Literacy Scale.

Stage 2: PACE Web-Based Intervention Program Design

Overview

Findings from stage 1 informed the cultural adaptation of PRISMS-Spanish and the design of the PACE prototype. We used affinity diagramming to organize the intervention contents and materials, and the PSD model to guide the design of the PACE program. Our multidisciplinary team, including digital health researchers, nursing faculty, user interface (UI) designers, web developers, informatics specialists, and clinicians from UTHSA and the University of North Carolina at Chapel Hill,

held weekly hybrid meetings (in-person and via Zoom) over 6 months (from September 2023 to March 2024). Design decisions were made collaboratively during structured sessions focused on usability, cultural relevance, and visual accessibility, during which wireframes and prototypes were reviewed. Ideas and comments were synthesized and iteratively incorporated into the prototypes using affinity diagramming on a physical whiteboard, guided by the PSD model. A project coordinator documented meeting notes and key design decisions throughout the process.

Affinity Diagramming

We used affinity diagramming [30] to organize ostomy care materials across various web pages based on the content interrelationships to delineate the tasks and features of the new PACE program. Affinity diagramming is a commonly used user experience design approach that helps organize design ideas systematically [30]. Based on PRISMS-Spanish, the results from stage 1, and the affinity diagram, we generated 5 different types of prototypes for PACE by collaborating with a UI design class. Our multidisciplinary team analyzed and evaluated each prototype. Key features, such as website layout, visual and graphical representations, and navigation options were finalized to ensure the program would meet the needs of patients and caregivers.

Persuasive Systems Design

To ensure the appropriate application of these persuasive principles, we incorporated expert evaluation during the design process. We used PSD to guide the design of the culturally adapted PACE to optimize user engagement in the web-based intervention [31]. The PSD model includes 28 design principles across 4 categories (Textbox 1). Experts in health care, UI design, and health informatics provided feedback on the integration between the PSD model and PACE.

Textbox 1. Persuasive system design model.

Categories of persuasive techniques and system design principles

- Primary task support: reduction, tunneling, tailoring, personalization, self-monitoring, simulation, and rehearsal.

- Dialogue support: praise, rewards, reminders, suggestion, similarity, liking, and social role.

- Credibility support: trustworthiness, expertise, surface credibility, real-world feel, authority, third-party endorsements, and verifiability.

- Social support: social learning, social comparison, normative influence, social facilitation, cooperation, competition, and recognition.

Ethical Considerations

This study was approved by the University of Texas Health San Antonio's Institutional Review Board (IRB; number 20220693EX). Referred patients were contacted via phone to confirm their eligibility and willingness to participate and to answer their questions. All participants received study information and signed a written informed consent form in their preferred language (English or Spanish) after their questions were answered and before any research activities began. The consent form included the following information: (1) the primary data collection (surveys and interviews) would be used to inform intervention design; (2) interview recordings and transcripts would be deidentified and stored separately from study documents containing participants' identifiable information on a password-protected, encrypted cloud drive to ensure data security and confidentiality; and (3) each participant would receive a US $80 gift card upon completing both the survey and the interview session.

Results

Stage 1: Exploration of Ostomy Care Experiences and Intervention Preference

Participant Characteristics

Data collection and analysis continued until no new themes related to care needs and ostomy experiences emerged during the interviews. The research team successfully enrolled 9 patients and 5 caregivers, reaching data saturation with a total of 14 participants. These participants had a mean age of 58.9 (SD 13.01, range: 37‐79) years. The mean CCI score was 3.21 (SD 1.86, range 0‐6), indicating a moderate comorbidity burden. The mean eHEALS score was 29.71 (SD 6.62, range 18‐40). Most participants (n=10) reported a high school diploma or General Educational Development equivalent as their highest level of education, while 2 participants had completed up to the seventh grade, and 2 participants held a bachelor's degree. The patients and caregivers reported an annual income between US $10,000 and US $90,000. Most patients had their ostomy surgery 3‐4 years before the interview.

Thematic Analysis Results

Hispanic Patients and Caregivers' Experiences With Ostomy Care

As outlined in Table 2, the thematic analysis identified three major themes and associated subthemes among Hispanic patients with cancer and caregivers: (1) perceptions of ostomy and its impact on their lives, (2) experiences in seeking support, and (3) challenges faced following discharge from the hospital.

Perceptions of Ostomy and Its Impacts

Patients and caregivers frequently expressed fear and negative perceptions regarding ostomies and used terms like "ugly" and "shocking" to describe them (refer to "Emotion" in Table 2). On the other hand, the subtheme of necessity reflected a gradual shift in ostomy perception as patients and caregivers began to acknowledge the life-saving function of an ostomy and were able to accept and live with it (refer to "Necessity" in Table 2).

Support Seeking

Support emerged as a significant theme from the interviews, with 4 sources identified, such as health care provider support, family and caregiver support, peer support, and self-care. Many participants reported limited access to resources with sufficient knowledge for changing ostomy bags and teaching others to perform the task (refer to "Health care provider" in Table 2). As shown in the "Family and caregiver" section in Table 2, patients with CCI scores ranging from 4 to 6 emphasized the crucial role of family support. Some indicated that family members often act as backups for one another when providing care. While some patients do not formally recognize their family members as caregivers, they still rely on them for ostomy bag

changes. Additionally, patients expressed a desire to get help from people who have had similar experiences (ie, "Peer support" in Table 2. Conversely, patients with relatively low CCI scores highlighted the importance of self-reliance during postsurgical home management (refer to "Self-care" in Table 2).

Challenges Post Surgery

Patients faced significant physical and emotional difficulties after ostomy surgery. Many needed to continue cancer treatment, such as radiation and chemotherapy, which further complicated their daily ostomy care (refer to "Radiation side effects" and "Chemotherapy side effects" in Table 2). Side effects of these treatments, such as fatigue and diarrhea, made it harder for patients to manage bag changes, thereby increasing the risk of leaks. Additionally, treatments made patients' skin more sensitive and prone to irritation (refer to "Skin irritation" in Table 2). As shown in the "Leakage" section in Table 2, leakage challenges were associated with obesity, which is a common issue in the Hispanic community. Leakage not only caused feelings of helplessness but also led to self-isolation. Many patients reported feeling more secure and comfortable staying at home (refer to "Self-isolation" in Table 2). Notably, caregivers reported high levels of stress and depression while caring for patients with ostomy cancer (refer to "Caregiver stress and emotion" in Table 2).

Preference for the PACE Ostomy Care Intervention Program

"insert subheading"

Overall, participants felt excited about the existence of a program like PRISMS and expressed satisfaction with the translated PRISMS-Spanish materials provided during the interviews. They also shared their preferences regarding intervention delivery timing, devices commonly used in information searching (mobile phones, desktops, etc), and supporting resources.

Importance of Preferred Language and Multimedia Delivery

Participants reported a preference for multimedia, including text documents, audio, and videos, when presented with intervention materials. They found practical tips and tricks extremely useful, especially regarding the optimal timing for changing ostomy appliances, barrier rings, and support belts. Although some tips had been mentioned by their health care team before, participants appreciated the tips as valuable reminders (refer to "Content and delivery format" in Table 3). Participants with low eHEALS scores (<26) were more likely to be impacted by language barriers when accessing health care resources. This is supported by the "Language" (refer to "Language" in Table 3) subtheme, where participants expressed a preference for Spanish-translated materials.

Need for Early Introduction, Multimodal Materials Delivery and Peer and Family Support

Participants expressed their preference for the intervention delivery platform, including the timing and support they would like to receive. Many participants were proficient with computers and mobile devices, but some suggested that providing printed handouts with pictures would also be helpful (refer to "Delivery platform" in Table 3). Participants also stated that information about ostomy care should be provided at the preoperative appointment or, at the latest, during hospitalization, although most patients were sent home with discharge paperwork after having a nurse demonstrate a bag change (refer to "Delivery timing" in Table 3). Feedback also emphasized the importance of training multiple support people in changing an ostomy bag, depending on family dynamics (refer to "Family and peer support" in Table 3). These comments further illustrated that the program should be accessible to all relevant family members.

Stage 2 Design of the Web-Based PACE Intervention

Based on the feedback in stage 1, we developed the culturally adapted PRISMS-Spanish intervention, renamed as PACE. In this section, we focus on introducing the design of the PACE model, guided by affinity diagramming and user engagement strategies informed by the PSD model.

Content and Cultural Adaptation

Based on the interview findings and thematic analysis, we primarily focused on culturally adapting and customizing the existing PRISMS/PRISMS-Spanish program to develop the PACE intervention for Hispanic patients with cancer and their family members. PACE retained core contents from the PRISMS, including text and demonstrative videos on ostomy care, providing information on managing common complications (eg, dehydration and skin issues), performing safe physical activity, and preventing falls. Additionally, we introduced a new preoperation checklist to help patients and their families prepare thoroughly. In response to participants' preferences, we maintained the PRISMS-Spanish for information delivery using multimedia formats, including audio, video, and text. For instance, a step-by-step video demonstration of the crusting technique and a text listing situations in which patients should contact a doctor post surgery were included in PACE. To further enhance user experience, audio, and video were adapted to accommodate preferences for speaking speeds, tone, and captioning.

New culturally adaptive elements were added to engage Hispanic users by incorporating familiar visuals and culturally resonant content. For example, images of traditional Hispanic dishes, such as empanadas and ceviche, were included to promote healthy eating. Culturally significant colors like orange and blue were used to evoke a sense of energy and warmth. These cultural adaptations aimed to develop an inclusive platform for PACE that fosters connection and engagement within the Hispanic community, optimizing support for patients with cancer and caregivers.

Affinity Diagram of the PACE Website

An affinity diagram was created to organize the content in a logical and user-friendly layout (Figure 1). Each piece of material, whether text, videos, or audio files, was represented as a color-coded data point and written on sticky notes, which were mapped into meaningful sections informed by interview feedback on delivery timing. This process aided in designing a

user experience that guides users through the entire journey of ostomy care, from preoperative preparation to postsurgery

self-management at home, with specific adaptations for the Hispanic population.

Figure 1. Affinity diagram of the PACE (Programa de AutoCuidado de Estoma) website.
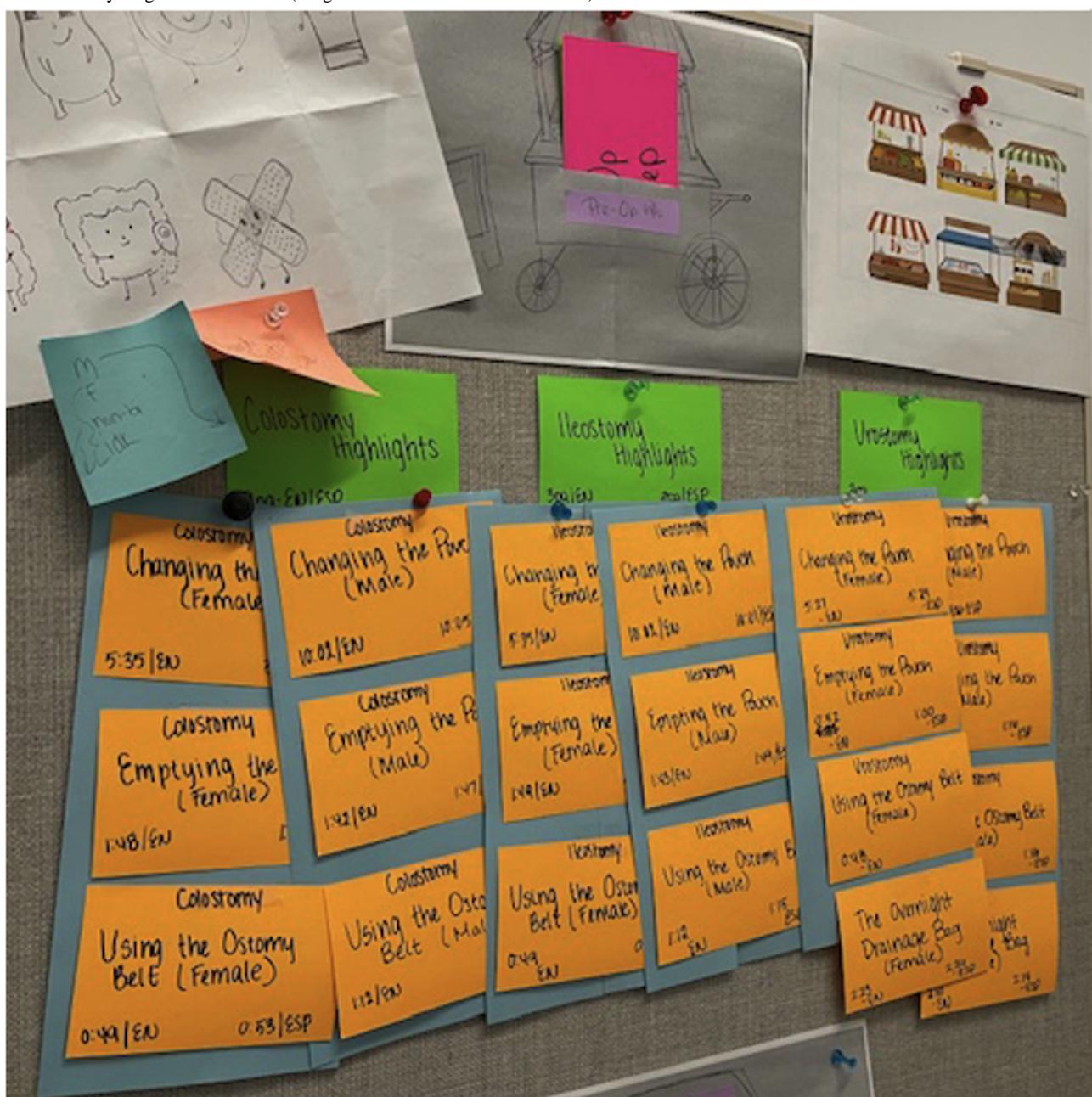
Similar to our PRISMS intervention, our team identified 6 main sections for the PACE website: "Pre-Op," "Doctor Office Visits," "Learning Your Ostomy Device," "Ostomy Care & Recovery," "General Physical Health," and "Good Mental Health" (Figure 2). "Pre-Op" offers comprehensive preoperative preparation, including a printable medication list template. "Doctor Office Visits" provides checklists for health care appointments, listing symptoms and test results to track. "Learning Your Ostomy Device" delivers essential knowledge on managing an ostomy, including changing, emptying, and understanding different types of bags and related equipment. "Ostomy Care & Recovery" addresses skin irritations, chemotherapy side effects, and common complications. "General Physical Health" offers recommendations for physical activities and tips on nutrition and dressing for fitness. Finally, "Good Mental Health" provides strategies for maintaining mental well-being for both patients and caregivers.

Figure 2. Home page of the PACE (Programa de AutoCuidado de Estoma) website.

Persuasive Elements

Overview

After analyzing the interview data and designing the website layout, the research team (LS, AV, JL, LRR, and XW) conducted an expert evaluation leading to the integration of 7 persuasive principles of the PSD Model into the website design, as detailed in Table 4.

Table . Persuasive elements in PACE (Programa de AutoCuidado de Estoma).

PSD[a] categories and selected principles for PACE[b] design	Application of PSD principles
Primary task support	
Tailoring	Users receive tailored task recommendations based on their group (Patient/Caregiver and family member).
Self-monitoring	Users can track their progress on each task.
Dialogue support	
Rewards	Users earn avatars as rewards for progress in learning sections.
Reminders	Users receive email reminders to log in to the PACE website regularly.
Credibility support	
Trustworthiness	The PACE website offers truthful, fair, and unbiased information through various media, including videos, audio, text, and images.
Real-world feel	Team members from the research and development teams are introduced on the login page.
Social support	
Social learning	An online forum is available in PACE, allowing users to write comments, ask questions, or share experiences anonymously.

[a]PSD: Persuasive Systems Design.

[b]PACE: Programa de AutoCuidado de Estoma.

Primary Task Support

We incorporated tailoring and self-monitoring principles. Thematic analysis revealed that many participants desired multiple family members to be trained in ostomy care. To address this, we applied the tailoring principle by enabling role selection and rendering customized content. During registration, users could choose roles (patient, caregiver, or other support) and have the flexibility to change roles later in the user profile settings. The content and layout of the website were rearranged according to user roles, enhancing the user experience. For UI design, our team decided to use a card layout (clickable containers with images and a brief content summary) with a progress bar at the bottom (Figure 2B) by displaying completed tasks and allowing users to resume where they left off to support self-monitoring. Users could track their progress in completing recommended videos and audios on their profile page.

Dialogue Support

To reduce fear and stress and encourage engagement, we established a reward mechanism where users could unlock new cartoon ostomy avatars and decorations after engaging with content. Additionally, email reminders were also set to prompt participants to revisit the website.

Credibility Support

To ensure the PACE program's credibility, we applied the principles of trustworthiness and real-world feel. We presented truthful, fair, and unbiased information through videos, text, and images based on user preferences. The information was developed based on scientific evidence and clinical guidelines with guidance from health care professionals. Videos were recorded by a certified Wound and Ostomy Care Nurse from the University of North Carolina at Chapel Hill. Additionally, a detailed introduction of the research team was also displayed on the login page for reference.

Social Support

The social learning principle was facilitated through an online forum, "Peer Support" (Figure 2). After logging in to the PACE website, patients and their family members could join support groups and seek advice. They could post, comment, and bookmark discussions, creating a space for the Hispanic community to not only exchange ostomy care knowledge but also provide emotional support to those community members in need, fostering a sense of belonging.

Discussion

Principal Findings

The main findings of this study revealed that Hispanic patients with cancer and caregivers experienced significant emotional distress and faced multiple challenges related to ostomy care management post surgery. Participants emphasized the need for culturally tailored interventions and expressed preferences for bilingual multimedia content, early delivery of the intervention, and the inclusion of family and peer support in ostomy care management. Drawing on these insights and feedback, our multidisciplinary team culturally adapted the PRISMS-Spanish and designed and developed the bilingual PACE intervention.

First, participants in our study highlighted a strong preference for content in Spanish alongside English, aligning with existing literature that emphasizes the importance of bilingual support in efficiently overcoming linguistic barriers [32]. Participants who completed the eHEALS survey in Spanish and scored below 26 reported difficulties reading English-language materials and expressed a strong preference for Spanish-translated content. The limited availability of Spanish-language digital resources likely limited their opportunity to access online health information, contributing to lower confidence in using digital health tools and lower self-reported digital health literacy. These findings illustrate the importance of providing bilingual digital health intervention. Thus, we developed the bilingual PACE program by integrating the original PRISMS and the PRISMS-Spanish materials, ensuring cultural and contextual relevance for Hispanic patients and caregivers. Additionally, the bilingual PACE intervention was designed to facilitate family involvement in ostomy care, particularly among Hispanic children and younger generations who are fluent in English and more acculturated to American culture [33,34]. To accommodate participants' preferences and address linguistic barriers, the bilingual platform includes Hispanic dubbing for audio and videos, in addition to text and graphics, which were recorded at appropriate speaking speeds in both English and Spanish, accommodating both patients and their family members who may not speak Spanish or English but still act as caregivers. Recent findings from the Pew Research Center indicate that approximately 65% of third- or later-generation Latinos report limited proficiency in Spanish [35]. By incorporating a bilingual focus, PACE fosters engagement with the entire family, regardless of language proficiency. Our study participants expressed satisfaction with the translation and bilingual design during interviews, highlighting its effectiveness in meeting their needs.

Second, the perceptions of our study participants also played a key role in shaping the delivery format of the PACE intervention. Hispanic patients and caregivers expressed a strong preference for content visualization through a multimedia platform, aligning with the findings of Joshi et al [36] in which Hispanic participants find multimedia programs easy to navigate and effective for obtaining relevant health information. In response, PACE delivers content in various formats, including video, audio, images, and text, to cater to diverse learning preferences. To further enhance engagement, we incorporated culturally relevant elements, such as images of Hispanic foods and vibrant colors like blue and orange, which resonate with the community. Additionally, based on participants' preferences and feedback, similar to the original PRISMS, PACE was designed to be accessible across different devices, including personal computers, mobile phones, and tablets.

Third, participants' feedback affirmed the comprehensive content of the original PRISMS and guided the design of PACE to improve QOL for patients and caregivers. Participants shared their experiences living with an ostomy, often expressing feelings of embarrassment and body image issues following surgery. By increasing knowledge and familiarity, PACE helps

Hispanic patients and caregivers integrate ostomy care into their daily lives with greater ease and positivity.

Additionally, our study revealed that family members of Hispanic cancer survivors are often expected to provide emotional support, assist with daily living, and manage overall health care [37]. This cultural expectation includes providing comprehensive information about the illness [38], treatment details, anticipated side effects, hands-on care skills [39,40], and strategies for stress reduction [41,42]. However, these informational needs are often unmet [41-44]. To fill this gap, PACE delivers tailored information for both patients and their caregivers and family members, enhancing their knowledge and skills in ostomy care. This approach not only enables them to provide better support to patients but also helps maintain their own QOL.

Finally, and most importantly, we used PSD principles to enhance user engagement in the web-based PACE interventions. A systematic review [45] demonstrates that PSD can significantly enhance adherence to web-based interventions, particularly those targeting chronic conditions and lifestyle changes [46,47]. This is especially relevant for patients with cancer living with ostomies, who face substantial changes in their health, lifestyle, behaviors, and daily routines [48]. To promote effective self-management, patients and their families must consistently engage with web-based interventions [49]. However, a notable challenge is that Hispanics are reportedly less likely to use health-related applications compared to other racial groups [50]. Moreover, the absence of user input during program development can further limit the success of these interventions [51]. In this study, we applied PSD principles in the design of the PACE intervention to enhance user engagement and ostomy care self-management. Building on the features of the original PRISMS intervention and incorporating participant feedback, we implemented key PSD principles to enhance engagement. Findings from this study are consistent with prior research [52-54], demonstrating that integrating persuasive principles into intervention design can significantly improve user engagement and support the long-term effectiveness of web-based platforms. The following are examples of how we integrate PSD principles into the design of PACE.

1. Self-monitoring: Participants were encouraged to track their progress in learning ostomy care, increasing awareness, and reinforcing skill development.
2. Rewards and reminders: These features were incorporated to foster continuous use of the program, promoting the acquisition of strong ostomy care skills [55].
3. Trustworthiness and readability: The PACE intervention ensured information was truthful, fair, and unbiased, building trust with users through a user-friendly interface.
4. Social learning: An online forum was integrated, enabling peer support and communication within the PACE intervention.

Strengths and Limitations

To our knowledge, this is the first study to apply affinity diagramming and PSD principles in the design of an ostomy care intervention. Given the limited access to high-quality online health resources among the Hispanic population [56] and building on evidence that Spanish-language, tailored health information in Spanish improves reach and effectiveness in this underserved group [57], our multidisciplinary team intentionally incorporated bilingual and culturally sensitive features to enhance patient engagement and family involvement in ostomy care. During cancer survivorship, ostomy creation as part of cancer treatment is a life-changing event. Traditional education, typically delivered through brief in-hospital demonstrations, can be overwhelming for patients recovering from surgery and coping with changes in physical function and body image. PACE addresses this gap by providing accessible, bilingual resources designed to meet the cultural and informational needs of Hispanic families. By supporting both patients and caregivers during the critical care transition from professional hospital care to self-management at home, PACE aims to improve health outcomes and support their caregivers' well-being.

However, the following limitations warrant further exploration. First, this study lacked participation from family members other than the first-line caregivers in the interviews. Participants emphasized the importance of involving additional family members in ostomy care. Future studies should address this gap by including a broader range of family members of Hispanic patients with cancer to better capture their diverse experiences and needs. Second, participants' educational attainment was at the high school level or above, which may limit the generalizability of the findings, given that a large proportion of Hispanic adults—particularly older or foreign-born individuals—have not completed high school [58]. Future research should prioritize recruiting individuals with lower educational attainment to rigorously design and evaluate digital interventions like PACE. Third, most patients in this study were more than 1 year post ostomy surgery, so their insights may differ from those who are newly diagnosed or recently discharged and still adjusting to life with an ostomy. We intentionally recruited this population because they had already navigated the postostomy survivorship journey and were likely to be more motivated, engaged, and interested in accessing online information compared with those who are fresh out of ostomy-creation surgery. While their reflection may be subject to recall bias, we encouraged them to draw on their lived experiences. Their insights were valuable in informing an intervention design that is potentially feasible and acceptable for individuals in the early stages of recovery. However, future studies should evaluate the acceptability, usability, feasibility, and effects of the intervention among patients and caregivers managing newly created ostomies to ensure its relevance and applicability across various stages of recovery.

Fourth, this study used descriptive statistics to analyze the quantitative data, which may limit the ability to draw statistical inferences about relationships between variables, such as age, education, digital literacy, comorbidities, and intervention preferences. Future studies with larger sample sizes need to incorporate statistical methods (eg, regression analysis or causal inference techniques) to examine associations between participant characteristics and engagement in digital health interventions. Finally, this study reported percent agreement to assess coding consistency, given the iterative coding approach and small sample size. Future work should consider applying

more robust methods, such as Cohen κ, to evaluate interrater reliability in large-scale studies.

Despite these limitations, the findings support the cultural adaptation of the English version of the PRISMS intervention into a user-friendly bilingual PACE web-based program for Hispanic patients and families, a population often underrepresented in clinical intervention research. Future studies should recruit participants with diverse backgrounds to evaluate the PACE intervention in other underserved communities, focusing on improving health outcomes and addressing health disparities.

Research and Clinical Implications

The PACE web-based program addresses critical challenges in ostomy care, including skin irritation, leakage, treatment side effects, and social and emotional stress with the goal of improving health outcomes for patients and caregivers. PACE provides adaptable techniques for different stages of recovery, standardizes patient and family education, and supports self-management in the hospital and at home. Its scalability and accessibility are particularly valuable for individuals in remote areas, such as those in rural Texas. By integrating findings from the PRISMS pilot feasibility study and current research, PACE is positioned for testing in a sufficiently powered clinical trial to evaluate its efficacy and effectiveness. Making the program accessible in hospital rooms could further enhance its impact on patient education and care transitions.

Conclusions

Our findings revealed the experiences of Hispanic patients and caregivers managing ostomy care for cancer treatment, including their support-seeking behaviors, postdischarge challenges, and preferences related to language, timing of intervention delivery, digital platforms, and the inclusion of family and peer support. Informed by these insights, we culturally adapted the PRISMS-Spanish program and applied PSD principles to design the bilingual, web-based PACE intervention. This tailored approach aims to enhance patient and caregiver engagement, strengthen their ostomy care skills, and ultimately improve their health outcomes. Future research will include a pilot testing for usability and feasibility of the PACE intervention among larger and more diverse Hispanic populations.

Data Availability

The datasets for this study are not publicly available due to the sensitive nature of patient and caregiver qualitative and quantitative data, as well as privacy and confidentiality requirements outlined by the University of Texas Health San Antonio's IRB. But data are available from the corresponding author on reasonable request.

Authors' Contributions

LS led the conceptualization of the study. LS, FY, AV, JL, RD, and XW supported the design of the digital platform. RS, MB, AV, and LRR contributed to participant recruitment and data collection. LS, AV, LRR, JL, NVR, and XW contributed to data interpretation. AV, LRR, JL, and XW performed the formal data analysis. FY, AV, and XM contributed to data visualization and digital platform design. AV managed, coordinated, and executed research activities. All authors contributed to the draft review and critical revision of the manuscript.

Conflicts of Interest

None declared.

Checklist 1

Mixed Methods Reporting in Rehabilitation and Health Sciences (MMR-RHS).

[PDF File, 699 KB - cancer_v12i1e70354_app1.pdf]

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Abbreviations

CCI: Charlson Comorbidity Index
eHEALS: eHealth literacy scale
IRB: Institutional Review Board
PACE: Programa de AutoCuidado de Estoma
PRISMS: Patient-Reported Outcomes-Informed Symptom Management System
PSD: Persuasive Systems Design
QOL: quality of life
REDCap: Research Electronic Data Capture
UI: user interface
UTHSA: University of Texas Health San Antonio

New Technologies and Digital Health Tools in Patients With Solid Tumors and Hematological Malignancies: Cross-Sectional Multicenter Survey Study

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Abstract

Background: Barriers to eHealth use include lack of technological infrastructure, resistance to change, and inequities in access. However, patterns of access to and use of eHealth tools in people being treated for cancer have not been fully described in the literature.

Objective: Our aim was to describe the patterns of access to and use of eHealth tools among outpatients receiving treatment for hematological malignancies and solid tumors.

Methods: We conducted a cross-sectional multicenter study using a survey offered to patients aged over 18 years receiving outpatient treatment for hematological malignancies or solid tumors at 4 teaching hospitals in Madrid, Spain, between February 1, 2021, and November 30, 2021. The survey instrument featured questions about patients' demographic and social characteristics, cancer diagnosis, use of information and communication technology (ICT), use and opinions of the Patient Portal, and changes in ICT use during the COVID-19 pandemic. To study the relationship between the different variables, 2-tailed Student t tests or ANOVA were used for variables with normal distribution, and the Mann-Whitney or Kruskal-Wallis tests were used for variables with nonnormal distribution. Statistical analyses were performed using SPSS (version 25; IBM Corp) for Windows.

Results: In total, 200 patients were included in our study. Median age was 60 (range 21‐87) years. A total of 130 (65%) patients presented with hematological malignancies. Most (n=181, 90.5%) patients considered that eHealth tools might help to improve communication with the medical team during their treatment. Retired participants (28.6% vs 71.4%; $P<.001$), those older than 60 years (26% vs 74%; $P<.001$), and those without higher education (2.6% vs 97.4%; $P<.001$) showed significantly lower rates of internet use, with no observed sex-related differences. A total of 177 (88.5%) patients found the Patient Portal useful, and 140 (70%) reported increased use of ICT due to the COVID-19 pandemic.

Conclusions: Most (177/200, 88.5%) patients viewed eHealth tools as useful and believed that it was helpful to improve communication with their care team. However, notable gaps in the use of eHealth were observed in certain groups of patients, with significant differences in use due to age, education, and employment status. Strategies to identify subgroups at risk for unequal access to digital health, as well as to facilitate access and use, are warranted.

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KEYWORDS

eHealth; oncohematology; telemedicine; survey; digital health tools; tumor; hematological malignancies; barrier; cancer; cancer care; cross-sectional study; cancer diagnosis

Introduction

Using telemedicine to provide care for patients with hematological malignancies has proven to increase access to care and levels of patient satisfaction [1] compared with face-to-face care and leads to cost savings for health care systems. The potential of technology to facilitate the care of immunosuppressed patients, such as those with hematological cancer, has been demonstrated recently during the COVID-19 pandemic [2,3]. During the pandemic, clinical guidelines recommended stopping treatment and performing remote follow-up whenever possible [4], leading to a sharp increase in the use of telemedicine in oncology, with up to 80% of centers using some form of remote care [5].

Despite a sustained increase in telemedicine as a model of care delivery in the postpandemic era, many systems are not adequately prepared for widespread implementation due to a lack of technological infrastructure [6]. Other barriers to the large-scale implementation of telemedicine in the hematology setting include resistance to change from health care providers and patients [7], and unequal access to eHealth among different patient groups based on race, age, and other sociodemographic characteristics [8,9]. Research on patient preferences regarding digital models of health care delivery shows disparate results, with a current lack of evidence as to whether the theoretical benefits of telemedicine translate into real benefits in routine clinical practice [4,5].

Our institution, a hospital network in Madrid, Spain, serving a population of more than 1 million inhabitants, launched an eHealth platform (the Quironsalud Patient Portal) in 2019. The platform allows patients to view appointments and test results, communicate with their health care providers through web dialogues, answer patient-reported outcome measurement (PROM) and patient-reported experience measurement (PREM) surveys, and access other health-related functions such as health education videos. Our study aimed to describe the patterns of access to and use of digital health tools in people with hematological malignancies and solid tumors undergoing outpatient treatment. We also aimed to describe patients' experiences with the Patient Portal and to report changes in digital health tool use caused by the COVID-19 pandemic.

Methods

Study Design

We conducted a cross-sectional, multicenter study, using a survey offered to patients with hematological malignancies or solid tumors receiving outpatient treatment at four teaching hospitals in Madrid, Spain. The primary endpoint of the study was to describe the patterns of access to and use of digital health tools across a sample of outpatients receiving treatment for hematological malignancies and solid tumors. The secondary endpoint was to report patients' opinions of the Patient Portal and identify changes in the use of digital health tools caused by the COVID-19 pandemic.

Setting and Participants

Centers included in the study were 4 publicly owned, privately managed hospitals from the Madrid Regional Health System—Fundación Jiménez Díaz University Hospital, Infanta Elena University Hospital, General Villalba University Hospital, and Rey Juan Carlos University Hospital. Patients aged over 18 years with hematological malignancies (lymphoma, myeloma, and acute leukemia) or solid tumors receiving oral or intravenous treatment as outpatients were included. On average, the 4 centers treat 2000 outpatients with cancer per month. We excluded patients who did not undergo active treatment during the study period. Recruitment for the study was conducted between February 1, 2021, and November 30, 2021.

Variables and Measurements

The survey instrument featured questions about patients' demographic and social characteristics, cancer diagnosis, use of information and communication technology (ICT), use and opinions of the Patient Portal, and changes in ICT use during the COVID-19 pandemic.

The survey was developed by 2 hematologists (ALG and RC), with survey items developed based on the results of a previous literature review featuring articles on digital health in patients with cancer published in English or Spanish from 2010 to 2020. Survey items were presented as yes or no or multiple-choice questions. Before recruitment began, a pilot questionnaire was administered to 10 patients to validate survey design and comprehension, with no changes made in the original design. The final survey included 30 items divided into 5 thematic blocks, including demographic and social characteristics, cancer diagnosis, ICT use, Patient Portal use, and COVID-19 pandemic–related aspects. Multimedia Appendix 1 shows the items featured in the survey.

All patients who visited the oncology outpatient clinic to receive intravenous treatment during the inclusion period were invited to participate in the study. After informed consent was obtained, participants were handed a paper copy of the survey by the treating physician. The completed surveys were returned in person.

Bias

We chose to administer a paper-based survey to avoid selection bias caused by the underrepresentation of patients who were not regular ICT users. Illegible or incomplete surveys were excluded.

Statistical Methods

A descriptive analysis of the population was conducted. Qualitative variables were described using frequency tables. Continuous variables that followed a normal distribution were described by mean and SD. Continuous variables that did not

follow a normal distribution were described using the median and IQR.

Normality was verified using the Kolmogorov-Smirnov test. To test for differences in the use of internet and eHealth tools between different groups (in terms of age, sex, and employment status), Student t tests or ANOVA were used for variables with normal distribution, and the Mann-Whitney or Kruskal-Wallis tests were used for variables with nonnormal distribution. Statistical analyses were performed using SPSS (version 25; IBM Corp) for Windows.

Ethical Considerations

This study was conducted in accordance with the ethical standards of the institutional research committee, Hospital Clinical Research Ethics Committee (ER_PIC018-20_FJD), and the Declaration of Helsinki. All participants provided written informed consent before participating in the study. All data were deidentified before performing statistical analysis, and the privacy and confidentiality of the research participants' data were maintained throughout the study. No compensation was offered to participants or researchers.

Results

A total of 225 questionnaires were received, with 200 (88.9%) questionnaires included in the final analysis (approximately 0.1% of the total number of eligible patients). Reasons for exclusion from the final analysis included incomplete surveys (11/25, 44%), having marked multiple options on a single-response question (4/25, 16%), and failure to meet eligibility criteria in terms of age (10/25, 40%). Demographic, clinical, and social characteristics of participants and their use of ICT are summarized in Table 1. The median age of the participants was 60 (range 21‑87) years, and 119 (59.5%) participants were male. More than half (n=116, 58%) of the participants had attended higher education institutions. Regarding employment status, 84 (42%) were actively working and 84 (42%) were retired. Most patients had hematological malignancies (n=130, 65%; Table 1).

Notably, 172 (86%) of the 200 patients owned smartphones, and 81 (40.5%) participants owned wearable devices. Regarding reported use of ICT, 136 (68%) patients reported daily use of the internet, and 85 (42.5%) patients conducted health-related research via the internet. Patients older than 60 years (26% vs 74%; *P*<.001; odds ratio [OR] 1.35, 95% CI 1.21-1.51), without higher education (2.6% vs 97.4%; *P*<.001; OR 11.05, 95% CI

3.45‑35.48) and retired (28.6% vs 71.4%; *P*<.001; OR 1.36, 95% CI 1.19-1.57) reported higher rates of never using the internet for browsing (Table 1). However, all patients used social media. Most (n=181, 90.5%) patients considered that eHealth tools might help to improve communication with the medical team during their treatment. The preferred way to communicate with the clinical team was via a smartphone via a WhatsApp-like chat (n=90, 45%).

Regarding the use of eHealth tools, no sex differences were found. Factors associated with higher rates of health-related research via the internet included being over 60 years old (67.3% vs 32.7%; *P*=.02; OR 2.43, 95% CI 1.37‑4.34) and having higher education (44.8% vs 55.2%; *P*<.001; OR 1.65, 95% CI 1.3‑2.1). In contrast, employment status was not significantly associated with the use of the internet to conduct health-related research.

Regarding use of the Patient Portal, we found that patients over 60 years (86.5% vs 13.5%; *P*=.009; OR 4.82, 95% CI 1.34‑17.35) and without higher education (85.7% vs 14.3%; *P*=.01; OR 3.31, 95% CI 1.21‑9.05) had lower Patient Portal registration rates (Table 2). Regardless of registration status, patients aged more than 60 years (78.8% vs 21.2%; *P*<.001), without higher education (94.8% vs 5.2%; *P*=.002), and with an employment status of "unemployed" or "retired" (*P*<.001), preferred not to use the Patient Portal to communicate with their care team (Table 3). Regarding the perceived usefulness of the Patient Portal, more than 80% (177/200, 88.5%) of patients reported the portal's PROMs and PREMs questionnaires as "useful." No significant differences were found between groups except regarding employment status, with almost 20% of retired patients considering the PROMs and PREMs questionnaires as "not useful" (Table 4).

When asked whether the use of ICT could improve the patient-clinician relationship, patients' answers varied. Subgroups tending to consider that ICT could worsen their relationship with the clinical team included patients over 60 years of age and retired patients. Between 20% (40/200) and 40% (80/200) of patients across all groups considered that the use of ICT did not affect their relationship with their care team. Finally, regarding the COVID-19 pandemic, 140 (70%) patients reported higher rates of ICT use. A total of 120 (60%) patients reported no perceived changes in their relationship with the care team, 60 (30%) patients reported an improvement, and 20 (10%) patients reported a decline in their relationship with the health care professional.

Table . Characteristics of the study population (N=200) and use of information and communication technologies.

Characteristics	Values
Age (y), median (range)	60 (21‐87)
Sex, n (%)	
Male	119 (59.5)
Female	81 (40.5)
Tumor type, n (%)	
Lymphoma	86 (43)
Multiple myeloma	30 (15)
Others	17 (8.5)
Leukemia	14 (7)
Breast cancer	14 (7)
Lung cancer	14 (7)
Gastrointestinal cancer	11 (5.5)
Prostate cancer	7 (3.5)
Gynecological cancer	4 (2)
Genitourinary cancer	3 (1.5)
Education, n (%)	
No or basic	84 (42)
University or superior	116 (58)
Employment, n (%)	
Student	10 (5)
Active	84 (42)
Unemployed	22 (11)
Retired	84 (42)
Department, n (%)	
Hematology	146 (73)
Oncology	54 (27)
Use of internet, n (%)	
Sometimes or always	173 (86.5)
Smartphone	172 (86)
Wearable	81 (40.5)
Internet access, n (%)	
Computer	118 (59)
Tablet	68 (34)
Smartphone	166 (83)
Health research on the internet	85 (42.5)
Preference to communicate with medical team, n (%)	
Smartphone	90 (45)
Email	42 (21)
App	26 (13)
Video call	24 (12)

Table . Demographic characteristics of patients and their correlation with Patient Portal use.

	Yes, n (%)	No, n (%)	P value	Odds ratio (95% CI)
Age (y)			.009	4.82 (1.34-17.35)
<60	93 (96.9)	3 (3.1)		
>60	90 (86.5)	14 (13.5)		
Education			.01	3.31 (1.21-9.05)
No or basic	72 (85.7)	12 (14.3)		
University or superior	111 (95.7)	5 (4.3)		
Employment			.22	__[a]
Student	10 (100)	0 (0)		
Active	79 (94)	5 (6)		
Unemployed	18 (81.8)	4 (18.2)		
Retired	76 (90.5)	8 (9.5)		

[a]Not available.

Table . Patients' preferences regarding communication with health care professionals via the Patient Portal.

	Yes, n (%)	No, n (%)	P value	Odds ratio (95% CI)
Age (y)			<.001	1.04 (1-1.08)
<60	76 (100)	0 (0)		
>60	92 (78.8)	22 (21.2)		
Education			.002	__[a]
No or basic	68 (81)	16 (19)		
University or superior	110 (94.8)	6 (5.2)		
Employment			<.001	—
Student	10 (100)	0 (0)		
Active	82 (97.6)	2 (2.4)		
Unemployed	22 (100)	0 (0)		
Retired	64 (76.2)	20 (23.8)		

[a]Not available.

Table . Patients' perception of the usefulness of the quality-of-life questionnaires.

	Yes, n (%)	No, n (%)	P value
Age (y)			.07
≤60	89 (92.7)	7 (7.3)	
>60	88 (84.6)	16 (15.4)	
Education			.54
No or basic	73 (86.9)	11 (13.1)	
University or superior	104 (89.7)	12 (10.3)	
Employment			.03
Student	10 (100)	0 (0)	
Active	78 (92.9)	6 (7.1)	
Unemployed	21 (95.5)	1 (4.5)	
Retired	68 (81)	16 (19)	

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Discussion

Principal Findings

This paper presents the results of a multicenter cross-sectional study on patients receiving outpatient cancer treatment for hematological malignancies and solid tumors. Our results demonstrate that most (181/200, 90.5%) patients considered that eHealth tools might help to improve communication with the medical team during their treatment. Retired participants (28.6% vs 71.4%; $P<.001$), those older than 60 years (26% vs 74%; $P<.001$), and those without higher education (2.6% vs 97.4%; $P<.001$) showed significantly lower rates of internet use, with no observed sex-related differences. More than 80% (177/200, 88.5%) of the patients found the Patient Portal useful, and 140 (70%) patients reported increased use of ICT due to the COVID-19 pandemic.

Comparison to Prior Work

Recent studies have demonstrated that eHealth is an effective form of health care delivery in hematology and has been catalyzed by the COVID-19 pandemic. A study focusing on the use of eHealth in patients with cancer [10] reported that patients showed an interest in applications such as managing appointments, obtaining advice about their disease, and communicating with health care professionals. Free access to eHealth tools and medical approval [10,11] are 2 facilitators for eHealth use. However, despite offering potential benefits, unidirectional tools such as SMS text message reminders are not always effective [12], as patient use of ICT predicts the effectiveness of and responsiveness to unidirectional eHealth tools [13]. Clinician reluctance to incorporate eHealth tools due to fears of a possible increase in clinical burden is another barrier to widespread integration [14]. Our study shows that most patients in an outpatient cancer care setting consider that eHealth tools are useful and facilitate communication with their care team during treatment, with the preferred method of communication being a smartphone. Furthermore, almost half (85/200, 42.5%) of the participants conducted health-related research via the internet, highlighting the importance of ensuring access to trustworthy, evidence-based information sources.

Most (140/200, 70%) participants agreed that their use of health-related ICT increased during the COVID-19 pandemic. This finding is consistent with those of many other studies in oncology and other fields of medicine [15-19]. Interestingly, many eHealth initiatives developed or scaled up during the pandemic have now become common clinical practice, with tools such as chatbots gaining increasing recognition as useful resources for patients with cancer [20,21]. While the use of eHealth is increasingly common in cancer care, the effect of ICT on the physician-patient relationship remains unclear. Many studies have concluded that, despite the increasing use of telemedicine, patients still prefer traditional, face-to-face communication over internet-based interactions with clinicians [22,23]. However, other reports suggest that patients value certain aspects of ICT-mediated communication, such as rapid response, easy access, and availability [24]. Our study suggested that most patients did not associate an increased use of eHealth with changes in their relationship with clinicians, while 30%

(60/200) of patients reported an improvement, and 10% (20/200) of patients stated that their relationship with clinicians deteriorated with increased eHealth use. Regarding new developments in the field of ICT-mediated health communication, over the last months, generative artificial intelligence–based chatbots using large language models have come to the forefront. However, while critical appraisal of these models regarding cancer-related information demonstrates high accuracy [25], their reliability in the clinical setting has yet to be validated [26], along with important aspects such as ethics, governance, patient preferences, and patient safety [27].

The complexity of oncohematological treatment, the shift toward patient-centered care, and the relevance of PROMs and PREMs in value-based health care make it necessary to introduce new digital health strategies to facilitate the flow of information between health care personnel and the patient. The importance of collecting PROMs and PREMs is growing, and eHealth tools show a high potential as a method for effective, large-scale data collection [28]. However, studies show that response rates are often low, and that the implementation of strategies to promote survey completion can be effective in improving response rates [29]. In our study, most patients perceived the quality-of-life questionnaires as useful. However, further investigation is needed to understand why certain subgroups, such as retired patients, showed lower rates of acceptance regarding PROMs and PREMs surveys.

Strengths and Limitations

The main strengths of this study include its multicenter nature and relevance to the current health care panorama. Identifying the habits and preferences of patients regarding the use of ICT and health care is essential to guarantee the success of telemedicine-based initiatives [30,31]. Characterizing subgroups of patients who find it difficult to access or adopt new technologies is an important first step toward bridging the digital divide by developing strategies to facilitate access and promote the use of eHealth in these populations [32].

This study has certain limitations. First, the lack of follow-up due to the cross-sectional nature of the study, and the fact that patients receiving inpatient cancer care were not included, were limitations of this study. However, the participation of patients with both hematological malignancies and solid tumors ensured a representative sample of outpatients receiving treatment at the 4 centers. Second, although this study examined patients' perspectives on eHealth initiatives such as the Patient Portal, it failed to investigate whether eHealth actually increased patient satisfaction, quality of care, or the overall well-being of the patients. Further studies are needed to address this question. Finally, the fact that the third wave of the COVID-19 pandemic occurred during the recruitment period (February 1, 2021-November 30, 2021), leading to heightened restrictions and disrupted delivery of care, could have influenced some of the participants' answers.

Conclusions

Technology is transforming the health care sector, including cancer care, where the use of telemedicine to ensure interdisciplinary collaboration and to connect patients with

specialist care is widespread. However, notable gaps in the use of eHealth can be observed in certain groups of patients, with significant differences in use due to age, education, and employment status. Strategies to identify subgroups at risk for unequal access to digital health, as well as to facilitate access and use, are warranted.

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

Conceptualization: AL-G, PB-A, RC
Investigation: CD-A, BG-D, CM-C, MY-P, CC-S, PL-S
Methodology: AL-G, CM-C, MY-P, PB-A, CC-S
Supervision: AL-G, JGF, PL-S, MdO-R, JS-A, JA-C, RC
Validation: CD-A, BG-D, CM-C, MY-P, PB-A, BP, CC-S
Writing – Original draft: AL-G, BP
Writing – Review and editing (including final draft): BP, JGF, MdO-R, JS-A, JA-C, RC

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey items.
[DOCX File, 16 KB - cancer_v12i1e58823_app1.docx]

Checklist 1
STROBE checklist.
[PDF File, 123 KB - cancer_v12i1e58823_app2.pdf]

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Abbreviations

ICT: information and communication technology
OR: odds ratio
PREM: patient-reported experience measurement
PROM: patient-reported outcome measurement

Patient Perspectives on AI-Powered Medical Robots in Breast and Prostate Cancer Care: Qualitative Study

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Abstract

Background: Nearly 250,000 cancer cases are diagnosed annually in Canada, with breast and prostate cancer representing 25% and 22% of new cases, respectively. Artificial intelligence (AI) applications can potentially improve the accuracy, efficiency, and timeliness of cancer care, including screening, diagnostic imaging, and early treatment. However, patient acceptability of AI in cancer care remains underexplored.

Objective: This study aimed to understand the feelings and perceptions of and acceptability to patients with breast and prostate cancer regarding the inclusion of AI-powered medical robots for cancer screening, diagnosis, and early treatment and to identify barriers and facilitators to implementation.

Methods: In this qualitative study, semistructured interviews were conducted with 15 patients with breast (n=6) or prostate (n=9) cancer. Participants (mean [SD] age 67 [12] y; range 41‐88 y) were recruited from Sunnybrook Health Sciences Centre between May and November 2022. Each participant completed 2 semistructured interviews, each approximately 1 hour in length, conducted by telephone or Zoom by a research assistant. The first interview explored initial reactions and expectations regarding AI-assisted medical technologies, allowing us to tailor questions for the second interview to better understand practical means of introducing AI into care, while further exploring salient concepts. Data were analyzed using a conventional content analysis approach. Two research assistants independently and inductively coded transcripts, iteratively generating and refining a codebook. Data saturation was assessed after 10 interviews and confirmed through analysis of all 15 participants.

Results: Three overarching categories were developed: (1) individual beliefs, understanding, and attitudes; (2) integration of AI into care; and (3) health structure, systems, and processes. Participants reported openness toward AI-assisted medical robots but emphasized the importance of reduced wait times, demonstrated safety and reliability, and patient-centered care. Patients indicated that with appropriate education and transparent communication, they would be willing to accept AI-assisted care due to its enhanced accuracy and efficiency. Key barriers included concerns about reliability, potential loss of human interaction, and inadequate mitigation strategies for technical failures. Facilitators included timely results, improved efficiency, accessible educational resources, and assurance that AI would complement rather than replace human expertise.

Conclusions: Participants demonstrated cautious willingness to accept AI-powered medical robots in cancer care if positioned as complementary to, rather than substitutes for, human-provided care. These findings underscore the need for maintaining the presence of health care providers during AI-assisted procedures, providing clear and accessible education, and ensuring transparent communication about safety and reliability. Personalizing patient education and offering multiple modes of information delivery may foster confidence and improve acceptability. While findings are exploratory and reflect the perspectives of a small,

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predominantly urban sample, they provide actionable insights into patient concerns and priorities that may inform future research and guide early implementation strategies in integrating AI into cancer care pathways.

KEYWORDS

artificial intelligence; breast and prostate cancer; cancer care; patient perspectives; patient-centered care; qualitative research; acceptability

Introduction

By the end of 2025, an estimated 248,700 new cancer cases will be diagnosed in Canada. Breast and prostate cancers are expected to account for approximately 23% of all new cancer cases [1]. For patients, receiving cancer care can be a prolonged and complicated process from screening to diagnosis and treatment [2,3]. In this article, the term *screening* is used broadly, consistent with the terminology adopted in North American cancer care research, to encompass both asymptomatic individuals undergoing high-risk surveillance (eg, breast magnetic resonance imaging (MRI) or elevated prostate-specific antigen testing) and those in the early diagnostic phase following symptom presentation or initial cancer detection. This broader operational definition reflects the continuum of early detection and diagnostic processes experienced by patients with breast or prostate cancer in the Canadian health care context. Despite the high prevalence of breast and prostate cancers, patients continue to face long diagnostic and treatment intervals, limited access to specialists, and systemic delays that negatively impact outcomes and quality of life [2-7]. Weller et al [4] refer to 3 stages of cancer care: the patient interval (symptom presentation to seeking medical attention), the diagnostic interval (seeking medical attention to obtaining a diagnosis), and the treatment interval (diagnosis to treatment) [5]. The diagnostic and treatment intervals usually include medical tests and multiple appointments with health care providers across several medical offices or hospitals [5]. Typical care pathways for prostate cancer (spanning the patient, diagnostic, and treatment intervals described by Weller et al [4]) are estimated to take between 163 and 367 days [3]. For breast cancer, the continuum from the patient interval to the completion of the treatment interval can take approximately 60 days [2]. The series of multiple diagnostic and treatment procedures contributes to long wait times and fragmented care. Such delays negatively affect quality of life, increase uncertainty, and may lead to worse health outcomes [6,7].

Timely medical attention is critical for optimal patient care, but there is a shortage of health care providers in the current Canadian health care system (ie, imaging specialists, specialized oncologists, and surgeons), which adds difficulties in meeting increasing patient demand [8,9]. Advanced-stage breast and prostate cancers may require more invasive interventions, including mastectomies and prostatectomies [10,11]. Early detection and diagnosis may allow for more targeted and less invasive treatment regimens [10,12], whereas when cancer is detected too late, less invasive options may not be possible. Across oncology and other medical specialties, health care providers experience growing workload pressures due to

increasing patient volumes, staffing shortages, and other systemic inefficiencies. This has contributed to nationally elevated burnout rates and compassion fatigue among health care providers [8,9]. The limited availability and overworking of health care providers contribute to accessibility issues for patients, especially in rural and remote regions, where accessibility and availability of specialized health resources are often even more sparse [13,14].

In a systematic review, Reece et al [7] identified several key issues regarding delayed or failed follow-up for breast cancer screening in primary care settings: physician-patient miscommunication, automated alert systems creating an overinflux of information, reduced coordination of patient medical health records, and inconvenient clinic hours and lack of availability of primary care. Urquhart et al [15] interviewed survivors of prostate cancer about their experiences with follow-up and posttreatment cancer care. Participants described various issues, including lack of information, resources, and psychosocial support, which left them feeling unprepared in their recovery process. These perceived issues in their care were related to lack of availability of health care providers and not being able to see the same health care provider throughout their care due to a staffing shortage within oncology [8,15].

Recent advances in technology, such as the use of artificial intelligence (AI) in cancer screening, represent a potential mechanism for increasing efficiency in wait times in cancer pathways, reducing the demand on health care providers, and improving accessibility within the health care system [16,17]. AI has been shown to be an effective tool for breast and prostate cancer diagnosis and in prostate cancer Gleason scoring [18]. Successful AI applications in diagnostic imaging have enabled the detection of early cancerous lesions with greater accuracy and efficiency, with trialed technology often outperforming experts [19,20]. A 2017 study showed that automated deep learning algorithms identified nodal metastases in histopathological analyses of breast tissue more accurately than an expert panel of pathologists [21]. AI deep learning algorithms have also assessed mammograms with proficiency equal to expert radiologists, with 5.7% and 9.4% reduction in false positive and false negative rates, respectively [22]. In prostate cancer screening, deep learning algorithms have demonstrated the potential to automate Gleason scoring of histopathologic images of adenocarcinomas, achieving 75% agreement with expert pathologists, demonstrating great model performance [18]. Similar AI-powered applications have been used with diffusion-weighted MRI to delineate cancerous and noncancerous prostate tissue [23]. As AI becomes more sophisticated, new opportunities in both diagnostic imaging and treatments are emerging with potential to transcend the accuracy

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and time limitations of traditional methods. Specifically, with the advent of AI and robotics, telemedicine applications are feasible and have the potential to mobilize high-quality health care, allowing interventions to be carried out by medical robots, without a highly trained specialist onsite [18,23].

While AI-powered robotic systems have the potential to expedite procedures and improve patient care, the success of these technologies is contingent on patient acceptance. The needs and preferences of patients should influence both the development and the process of implementation of such technology into the health care system. This requires a comprehensive understanding of the patients' perceptions toward the use of such technology in their care. A greater understanding of what may be deemed acceptable is necessary before conducting large-scale research evaluating the use of AI in breast and prostate cancer screening and treatment [24,25]. The present study sought to elucidate patient perceptions, feelings, and acceptability regarding AI-powered medical robots in breast and prostate cancer care and to identify barriers and facilitators to implementation using a person-centered approach.

Methods

Study Design

This study employed a qualitative descriptive approach to answer the research question: How do patients feel about the use of AI-powered medical robots for cancer screening, diagnosis, and early treatment? Study objectives were to (1) illuminate patient understandings and feelings regarding the inclusion of AI in their care and (2) identify barriers and facilitators of implementing AI-powered robotic systems into cancer screening from patients' perspectives. This study is reported in accordance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines (Checklist 1) [26]. A postpositivist stance [27] was taken, which assumes that while absolute truth cannot be fully captured, systematic qualitative methods can approximate patient perspectives and generate transferable insights. This orientation informed our design by emphasizing structured data collection (semistructured interviews), analytic rigor (systematic coding by multiple analysts), and reflexivity to minimize bias. This study was part of a larger program of work initiated by a multidisciplinary research team developing and testing AI technology for cancer care. Although not embedded within a larger trial, it was designed to inform future research protocols and ethical considerations for implementing AI-powered medical robots. The overarching program sought to explore the feasibility of systems capable of scanning, diagnosing, and treating patients within a single appointment. This qualitative study, therefore, focused on understanding patient comfort and acceptability of such technologies across the cancer care continuum, including perspectives on initiating treatment immediately following diagnosis.

Participants

Participants were recruited from breast and prostate cancer clinics at the Odette Cancer Centre at Sunnybrook Health Sciences Centre between May 2022 and November 2022. Purposive sampling was used to identify individuals at elevated risk of breast or prostate cancer, or with a recent diagnosis, to ensure that perspectives from both patient groups were represented. Potential participants were first identified by their treating physicians, who requested permission for research staff to contact them. Research staff approached participants by telephone following referral, explained the purpose of the study, and assessed their eligibility and interest. Inclusion criteria were (1) English speaking, (2) aged 18+ years, and (3) patients deemed *high risk* by their physician and in need of MRI as part of their screening process for breast cancer or diagnosed with breast cancer *or* male patients with elevated prostate-specific antigen levels and considered *high risk* for prostate cancer or diagnosed with prostate cancer.

Ethical Considerations

This study was reviewed and approved by the Research Ethics Board at Sunnybrook Health Sciences Centre (Research Ethics Board 5361). All participants provided verbal informed consent prior to participation, which was documented by the study team in accordance with institutional guidelines. To protect privacy and confidentiality, interview transcripts were deidentified during the transcription. All data were stored securely on password-protected institutional servers with access restricted to the study team. Participants were compensated with CAD $50 (US $36.03) per interview session, in recognition of their time and contribution.

Data Collection

Demographic information including sex and gender, ethnic identity, socioeconomic status, and geographic data (rural or urban) was collected prior to the first interview. While participants did report gender, they were referred based on a biological basis (ie, risk for or current diagnosis of prostate or breast cancer). Two semistructured interview sessions, each approximately 1 hour in length, were conducted over telephone or video (Zoom) by a graduate-level research assistant (TK) who had been trained in qualitative interviewing, with a background in clinical psychology, psychology, global health, and sociology. The 2 interviews were conducted approximately 2 weeks apart, allowing time for reflection and deeper meaning-making while maintaining recall continuity [28,29].

An interview guide was used, with flexibility for the interviewer to probe participants' experiences and perspectives. The interview guide included open-ended questions about participants' general perceptions of AI in health care; specific feelings about AI-powered robots in cancer screening, diagnosis, and treatment; perceived barriers and facilitators to AI adoption; and preferred communication/education strategies. The full interview guide is provided in Multimedia Appendix 1. During interviews, the interviewer clarified that the term *AI-powered medical robots* referred broadly to robotic systems enhanced with AI that could be applied to different parts of the cancer pathway, including imaging, biopsy guidance, and treatment support. This clarification was intended to provide participants with a shared reference point, while still allowing their natural perceptions and assumptions to guide their responses. Participants were not given a detailed technical briefing, as the intent was to elicit their existing awareness and spontaneous perceptions of AI technologies in health care. This approach

ensured that participant reflections represented authentic, experience-based understandings rather than those influenced by study-provided information.

All participants were informed during recruitment and reminded prior to each interview that the study focused on their cancer care experiences and their perspectives regarding AI-powered medical robots. The first interview emphasized participants' initial reactions, beliefs, and expectations about AI-powered medical robots in cancer care. The second interview revisited these themes in more depth, provided an opportunity to clarify or expand on responses, and explored additional reflections participants had after the first discussion. This consistent framing ensured that discussions remained grounded in participants' personal experiences of cancer care while allowing flexibility for individual interpretation and reflection.

Data Analysis

Interview recordings were transcribed verbatim by 2 research assistants (MH and JD). A conventional content analysis approach, which relies on inductive coding [30], was followed. Coders (1) immersed themselves in the transcripts, (2) performed line-by-line coding, (3) grouped codes into subcategories, and (4) clustered subcategories into broader categories. The codebook (Multimedia Appendix 2) was developed inductively from the data, with new codes added when concepts not captured by existing codes were identified. Iterative updates to the codebook were justified when coders encountered new or refined meanings across interviews, and changes were documented in the audit trail. To ensure rigor, MH and JD independently coded 30% of the transcripts, meeting to compare and reconcile code discrepancies. Disagreements were resolved through consultation with a third research team member (MBK), a graduate-level research coordinator with training in qualitative research methodology. Once agreement on the initial codebook was achieved, the coders each analyzed half of the remaining transcripts, routinely consulting with one another and MBK to discuss emerging ideas and refine codes as needed. The final coding tree was established by the 3 reviewers with input from a fourth member of the research team (AP) and the site principal investigator (JE). Including multiple perspectives helped limit the potential impact of biases of any given researcher.

Though formal coding began after all interviews were completed, the interviewer made informal notes on emerging themes during the interviews to assess data saturation [31] and guide iterative refinement of the interview guide. Reflexive memos were maintained to document thoughts on the saturation process. Reviewers maintained a thorough audit trail outlining the identification and adaptation of new and existing codes. Saturation was then formally assessed retrospectively, over the course of data analysis. Coders reviewed transcripts sequentially and confirmed that after the tenth interview, no new substantive codes were identified. The remaining interviews contributed additional depth and nuance but did not generate new categories, confirming that saturation had been reached. Given that

participants were recruited from a single large urban tertiary cancer center and the sample was predominantly White and urban-residing, it is possible that this relative demographic homogeneity contributed to the point at which saturation was reached. This demographic profile reflects the typical patient population served within the breast and prostate cancer clinics at Sunnybrook Health Sciences Centre.

Positionality Statement

The research team represented a range of disciplinary, cultural, and experiential backgrounds. Interviews were conducted by a female master's student and research assistant with training in clinical psychology, global health, psychology, and sociology. Coding and analysis were carried out by 2 female research assistants (BAs in psychology), a female research coordinator with a master's degree in medical sciences and formal qualitative research training, and a male research coordinator with a BA in psychology and training in clinical psychology. Team members reflected diversity in gender and cultural backgrounds, which contributed to varied perspectives in the analytic process. The site principal investigator, a female psychiatrist specializing in psychosocial oncology and trauma, and the coprincipal investigator, a male professor of surgery with expertise in intelligent robotics, provided oversight for the study.

Trustworthiness

To mitigate potential bias and increase credibility of the findings generated in this study, we used reflexive practices, including regular peer debriefing between the coders and the third reviewer, to identify, acknowledge, and reconcile assumptions and interpretations. Engaging in reflexivity as we continuously rereviewed and discussed the transcripts allowed us to ensure that patient voices remained central in the findings, which supported confirmability of the findings. We also transcribed audio recordings verbatim for analysis, kept a thorough audit trail, and have thoroughly contextualized our work and described our methods as means of increasing dependability of this work. To address transferability, we have provided a thorough description of the study methods (including the interview questions) and the participant demographics.

Results

Participant Demographics

In total, 15 participants (6 female and 9 male participants) were recruited, all of whom completed both interviews. Of the 14 participants who reported demographic data (Table 1), 80% (n=12) were White. The mean age of participants was 67 (SD 12; range 41‐88) years. 80% (n=12, 7 male and 5 female participants) of reporting participants lived in urban settings, 13% (n=2, 1 male and 1 female participant) lived in rural settings. Of the 10 participants who reported their annual household income, 7 (70%) reported an annual household income over US $60,000.

Table . Participant demographics[a].

Demographic category	Count, n (%)
Sex	
Male	9 (60.0)
Female	6 (40.0)
Ethnic identity	
White/Caucasian	12 (80.0)
Asian	1 (6.7)
Middle Eastern	1 (6.7)
Age range (y)	
40 - 49	1 (6.7)
50 - 59	2 (13.3)
60 - 69	5 (33.3)
70 - 79	5 (33.3)
80 - 89	1 (6.7)
Household income[b] (US $)	
Below 14,630 (CAD 20,000)	1 (6.7)
14,630 (CAD 20,000) - 29,258 - (CAD 39,999)	2 (13.3)
29,259 (CAD 40,000) - 43,888 - (CAD 59,999)	—[c]
43,889 (CAD 60,000) - 58,517 - (CAD 79,999)	4 (26.7)
58,518 (CAD 80,000) - 72,416 - (CAD 99,000)	—
73,148+ (CAD 100,000+)	3 (20.0)

[a]One prostate cancer participant did not report any demographic information.

[b]Household income was originally collected in Canadian dollars and converted to US dollars using a currency exchange rate of CAD $1 = US $0.73

[c]Not available.

Thematic Findings

The analysis yielded 28 codes, which were then organized into 6 subcategories and further grouped into 3 overarching categories to best understand participant feelings of integrating AI-assisted medical technologies into their cancer care. The 3 overarching categories were (1) individual beliefs, (2) understanding, and (3) attitudes, integration of AI into care, and health care structure, process, and communication (Figure 1).

Figure 1. Final coding tree: organization of codes>subcategories>categories. AI: artificial intelligence; HCW: health care worker.
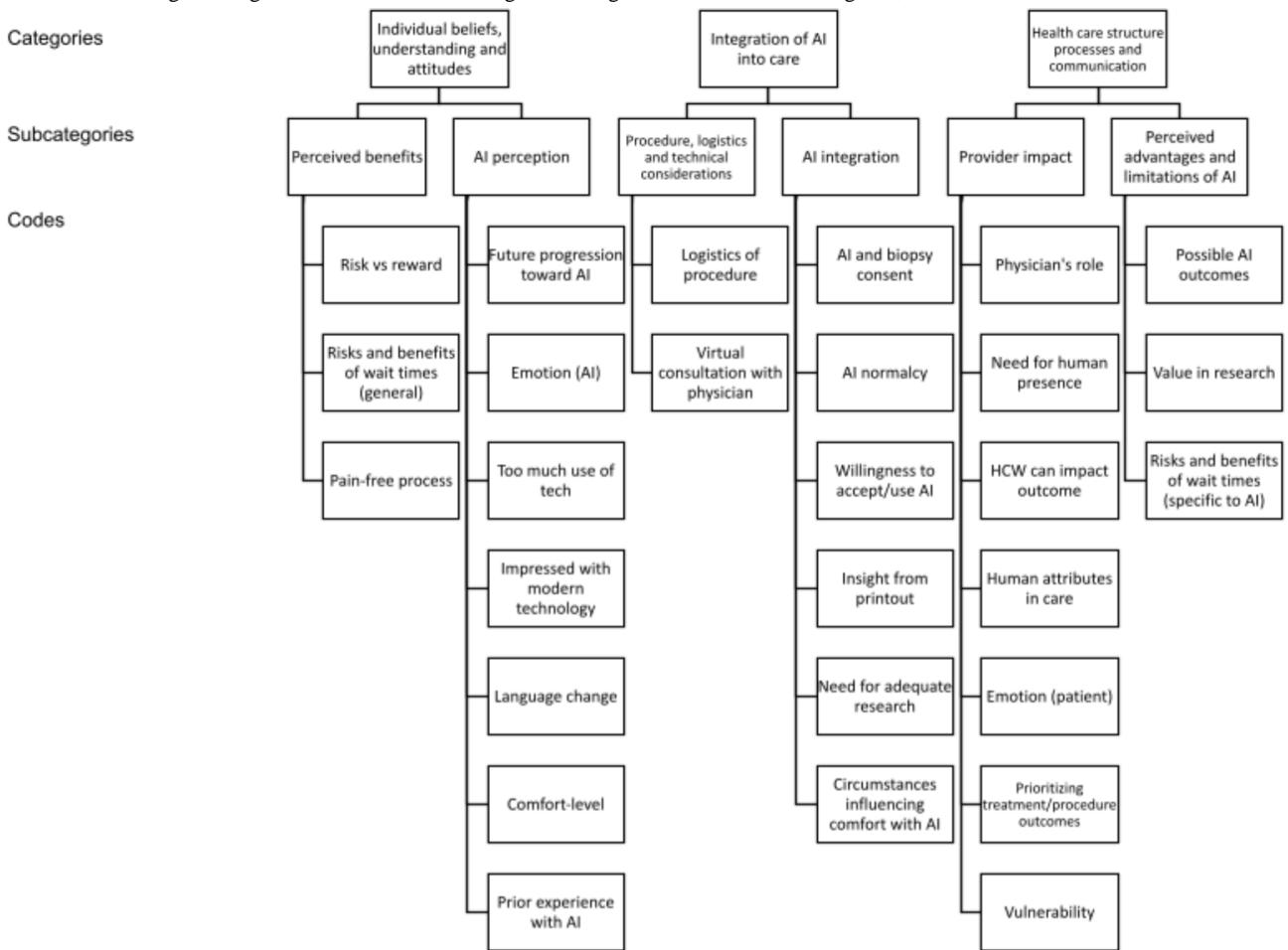
In the *individual beliefs, understanding, and attitudes* category, participants described a mix of openness and hesitancy toward AI-assisted technologies in their cancer care. Acceptability often depended on whether AI could meaningfully improve the experience of care, such as offering greater accuracy, reducing discomfort, or improving efficiency. Ongoing concerns centered on overreliance on technology, safety, and the need for clear backup plans in case of system failure. While some participants negatively described a general overreliance on technology, others noted that acceptance would increase as evidence accumulated:

> *[T]hey [are] as good as a human.* [ID 15, F, 53]

Concerns about dependability were especially salient in the context of unexpected events:

> *[C]ertain things can happen, who would be available, in an electrical shutdown and so on? [...] I don't know the capability of these machines, how reliable they are [...] it's reassuring to have help nearby to jump in.* [ID 50, M, 73]

Across participants, trust in AI was described as something that would grow through experience and familiarity.

The *Integration of AI into Care* category focused on the procedural, technical, and logistical considerations of integrating AI-robotic medical technology into cancer care, as well as general perceptions on AI integration into care. Participants distinguished between different stages and levels of invasiveness

in the cancer pathway. Many were comfortable with AI in roles such as imaging or screening but more cautious regarding AI involvement in biopsies or surgery.

As one participant summarized:

> *I think I am okay with [the machine doing] the screening, if you could speed up the wait time. For the actual surgery I think I need more proven evidence, that it is 100% positive and reliable.* [ID 30, F, 62]

Human presence, whether in-person or virtual, was consistently described as important for reassurance, oversight, and troubleshooting during procedures:

> *[K]nowing that they were there and that there was some sort of troubleshooting capacity, would be helpful.* [ID 80, M, 65]

Participants also highlighted the need for accessible explanations of how AI works, its benefits, and its limitations. They emphasized that information should be made available proactively and through multiple accessible formats, given that patients may be unfamiliar or uncomfortable with digital resources:

> *I had to take the initiative to search through the website to get [information] and knowing so many people, they are not familiar with using technology, or some seniors, I think that was, you know, it limited*

the opportunity for people to get [access to] support resources. [ID10, M, 60]

The category *health care structure, processes, and communication* described challenges within the existing health care system, particularly long wait times, fragmented communication, and limited opportunities for personalization. These issues shaped patients' broader care experiences and influenced how they envisioned AI fitting into their care. Some felt "lost in the system" [ID 45, F, 69], due to the perception that the current health care system lacks personalization.

Participants also associated long delays and fragmented care with distress and uncertainty:

I couldn't get any surgery done immediately. [...] It was very difficult. And I couldn't get care in a timely way. [ID 40, M, 78]

Several participants expressed hope that AI-assisted technologies might address some of these system-level pressures by supporting more timely and/or coordinated care, while emphasizing that technological integration should not reduce human connection in the care process.

Barriers and Facilitators

Across interviews, participants described specific conditions that shaped how acceptable AI-assisted medical technologies felt to them in their care. Consistent with qualitative studies examining patient adoption of new health technologies and with implementation science frameworks (eg, studies that explore contextual factors influencing uptake) [31], these perceived conditions are referred to as *barriers* (factors that reduced comfort or confidence) and *facilitators* (factors that increased openness or ease of acceptance). Table 2 provides an overview of the barriers to integrating AI-assisted medical robots into cancer screening, diagnosis, and treatment.

Table . Factors influencing patients' decision to accept AI[a] in cancer care (barriers and facilitators).

Factor	Barrier	Facilitator
Information	Lack of information regarding the technology left patients unable to answer whether they were comfortable using it.	Providing adequate patient education and related resources would facilitate the uptake of AI-assisted technology.
Vulnerability	These patient populations are particularly in need of human care due to the vulnerable nature of the procedures.	—[b]
Reliability of technology	Fear of technical malfunctions or similar issues.	Potential for increased precision and efficiency with the use of technology; some patients noted that the most important thing is a positive outcome, regardless of whether a doctor or robotic device is completing the procedure.
Human element	Machine lacking in compassion/bedside manner in critical thinking/problem-solving skills.	No risk of human error when using AI technology.
Reduced wait times	—	The potential for reduced time between initial appointment and treatment can improve patient outcomes and eliminate distress associated with waiting periods.
Prior use of AI-assisted technology in health care	—	Patients express prior knowledge or direct experience with some form of AI technology in health care, creating a greater sense of comfort with using AI.
Pain	—	Some participants stated that they would be more inclined to consent to the procedures if they were less painful than the standard of care.
Options available	Patients might prefer standard of care when they have the option (given that the risks/rewards are similar between these options).	If there were no other options, or standard of care came with increased risk (due to waiting times, etc), patients would be more likely to consent to use of AI-assisted technology.

[a]AI: artificial intelligence.

[b]Not applicable.

Barriers most often reflected concerns about the interpersonal and safety-related dimensions of AI-assisted care. Participants frequently worried about the absence of human qualities such as compassion, empathy, and emotional support, particularly during invasive or high-stakes procedures. Many also questioned the reliability and safety of AI systems, describing uncertainty about how unexpected complications would be managed without

a health care provider physically present. Some participants expressed apprehension that technological integration could reduce opportunities for communication with clinicians, thereby amplifying existing feelings of depersonalization within the health care system.

Facilitators described by patients centered on ways AI-assisted technologies could meaningfully improve their care experience. The potential to reduce wait times, streamline care, and deliver more timely results was consistently valued and often linked to reductions in distress, uncertainty, and logistical burden. Participants also described their confidence in AI's technical capabilities, such as accuracy and precision, as an important factor that could support acceptance. Several participants noted that when outcomes were perceived as likely to improve, the mode of delivery (human vs robot) became less central. Prior familiarity with AI in health care and the possibility of less painful or less invasive procedures further contributed to openness toward AI integration.

Discussion

Principal Findings

This study found that patients with breast and prostate cancer expressed cautious openness toward the use of AI-powered medical robots in their care, despite initial skepticism. Participants recognized potential benefits such as reduced wait times, improved accuracy, and less invasive procedures and also voiced concerns about safety, reliability, and the potential loss of human connection in care. Participants expressed enthusiasm for AI-assisted medical robots when given the choice, suggesting openness to innovation despite some skepticism. They often prioritized successful treatment outcomes over concerns of who or what delivered care, indicating that demonstrated efficacy could outweigh reservations. Trust in AI was described as something that would build gradually over time as experience and familiarity increased. Their accounts also underscored the critical need for systemic improvements in health care processes, particularly in reducing delays and streamlining care. These findings highlight the perceived potential of AI technologies to address longstanding system challenges, while also reflecting ambivalence regarding the risks of technological reliance. Notably, participants were generally open to the use of AI-powered medical robots in initial screening and imaging but were more hesitant when considering invasive steps such as biopsy or treatment, where human presence and oversight were prioritized.

As an exploratory qualitative study, the aim was to elucidate patients' feelings, understandings, and perceptions about the use of AI-powered medical robots in cancer screening, diagnosis, and early treatment and to identify barriers and facilitators to patient acceptance. Participant responses illustrated a mix of hesitancy and hope around embracing this technology for their own care, which is a typical response to technological advances or change [30,31]. Importantly, participants' reflections consistently emphasized that the human presence in care—particularly the compassion, reassurance, and emotional support provided by health care providers—is viewed as irreplaceable [32]. This emphasis on the importance and value of human presence in care (particularly that health care providers should remain central in a patient's care processes) underscores the importance of emotional support and other traits that are unique to humans. Without deliberate safeguards to preserve these aspects, the integration of AI technologies risks

exacerbating feelings of depersonalization in care. These insights, while not generalizable due to the small purposive sample, provide valuable direction for future research and early implementation strategies.

Comparison to Prior Work

Overall, participants' reflections were broadly consistent with existing research examining patient perspectives on AI and technology-assisted care. Similar to prior work, participants expressed interest in potential benefits such as improved efficiency and reduced wait times. These factors are repeatedly identified in the literature as persistent challenges in cancer care pathways [7,16,17]. Our findings align with studies showing that patients often view AI as promising when it addresses established system-level pain points, particularly diagnostic delays and fragmented processes.

Concerns regarding the loss of human connection were also consistent with previous research demonstrating resistance to medical AI when patients perceive threats to empathy, communication, or relational aspects of care [33]. Participants emphasized the irreplaceable value of compassion and reassurance, echoing patient-centered care literature, highlighting communication, emotional support, and trust as core needs during cancer care [34-36]. Prior studies similarly note that while AI may assist with technical tasks, it cannot fully replicate relational qualities valued in clinician—patient interactions [32,33].

Consistent with earlier work, participants indicated that evidence of safety and effectiveness would be central to their acceptance of AI-assisted technologies. This is in line with studies showing that patient trust in AI increases when technologies are validated, transparent, and clearly integrated within human-led care models [30,31]. The desire for clear education about AI, expressed by many participants, is also supported by previous findings emphasizing the importance of accessible, multimodal patient education to support uptake of new technologies [35,37,38]. Altogether, the results reinforce themes seen across the broader literature: patients may be cautiously optimistic about AI in cancer care when it enhances, rather than replaces, human-delivered care; when it improves timeliness and coordination; and when adequate evidence and communication support informed decision-making. These consistencies suggest that early implementation strategies should prioritize transparency, patient education, and explicit preservation of human presence, particularly during invasive or emotionally charged stages of cancer care.

Strengths and Limitations

There are several limitations to this study. First, recruitment occurred at a single large urban hospital, which may not be representative of all patient populations. Participants were drawn from a tertiary cancer center in Toronto, potentially excluding individuals from rural or underserved regions and therefore excluding perspectives from those with limited access to tertiary care. This is related to a previously established limitation regarding the disparity in who has access to high-quality health care [39]. This may have influenced findings by overrepresenting patients with greater access to resources and

technology. Future research should intentionally recruit participants from rural and underserved regions to increase transferability.

Second, the sample was predominantly White (80%), urban-dwelling, and higher-income. Urban and higher-income populations may have more exposure to and comfort with advanced technologies compared to their rural and lower-income counterparts [40]. Additionally, the perspectives of those who live in rural settings may be impacted by experiences with resource limitations and accessibility of health care [41,42]. As a result, the findings may not reflect the views of patients from more diverse racial, ethnic, or socioeconomic groups. Within the constraints of this study setting and recruitment pathways, we were unable to broaden the sample to include more diverse participants. Although participants were provided with a shared reference point for what was meant by "AI-powered medical robots" (ie, robotic systems enhanced with AI used in imaging, biopsy guidance, and treatment support), they were not given a detailed technical briefing. As such, their responses may have reflected variability in baseline knowledge. Some participant responses also appeared general in tone (eg, referring broadly to *AI* or *technology*), but these were expressed in relation to their cancer care experiences. This likely reflects natural variability in familiarity with AI concepts among participants rather than deviation from the study focus. This could be seen as a limitation in terms of consistency, but it also provided valuable insights into organic perceptions, assumptions, and information needs regarding AI in cancer care. Third, data collection took place during the COVID-19 pandemic, which may have impacted attitudes toward access to health care, or experiences with health care delays may have been impacted by the health care climate at the time [43,44]. This context likely heightened sensitivity to wait times and system inefficiencies. While this provided timely insights, future studies should examine whether similar themes emerge in nonpandemic contexts. Finally, the sample size was relatively small, though appropriate for a qualitative descriptive study. Data saturation was achieved and confirmed during analysis; however, larger samples in future research could support broader transferability of findings and capture a greater diversity of perspectives. Despite its size, the study's use of 2 interviews per participant and a multianalyst coding process strengthened the dependability and credibility of the findings. Additionally, collecting perspectives from both breast and prostate cancer populations provided a richer understanding of how AI-assisted technologies may be perceived across different cancer care experiences.

Future Directions

Future research should ensure to include perspectives from patients who represent more diverse lenses as a means of increasing transferability of findings and understanding specific needs for integrating AI-assisted medical technology into cancer care in varying regions and cultural contexts. Future studies should also aim to include perspectives from all involved in the health care process (such as physicians and oncology assistants) to better understand how to pragmatically incorporate AI-assisted medical robots into cancer care screening, diagnosis, and treatment. More work is needed to understand which implementation models work best for both health care providers and patients, including how to provide education on the technology to both, what level of human presence is deemed acceptable and appropriate, and safe mitigation strategies in the event of technical issues. Future trials should also examine patient acceptability separately across different stages of the cancer pathway (eg, screening, diagnosis, and treatment) to determine where AI integration is most feasible and where stronger human involvement is needed.

Conclusions

In conclusion, this work explored patient perspectives on the use of AI-assisted medical robots in cancer screening, diagnosis, and early treatment, highlighting barriers and facilitators to its acceptance. The findings reveal a cautious optimism among patients, tempered by concerns about the reliability of AI and the potential for reduced human contact. Patients expressed a desire for AI to complement, rather than replace, human judgment, ensuring that final decisions remain in the hands of experienced health care providers. Alongside emphasizing the need for human presence and emotional support within the health care experience, patients described a need for education and clear communication regarding the use of new technology and suggested potential methods of making these resources more accessible (eg, through media and information sessions). As a qualitative exploratory study, these conclusions should be understood as reflecting patient perceptions within the sampled group, rather than definitive statements about broader populations. Future research is required to test these perspectives in larger and more diverse samples and to evaluate whether these patient-identified barriers and facilitators translate into measurable outcomes during actual implementation.

Data Availability

The qualitative interview data generated and analyzed during this study are not publicly available due to privacy and confidentiality restrictions, as transcripts contain potentially identifiable information from patient participants. Deidentified excerpts supporting the study findings are included within the article. Researchers who wish to access the full deidentified data set may contact the corresponding author, and requests will be considered on a case-by-case basis in accordance with institutional Research Ethics Board approval requirements.

Authors' Contributions

Conceptualization: JE, MBK, MA, KB
Data curation: MBK, TK, JE, MH
Formal analysis: MH, JD, MBK, JE
Funding acquisition: JE, MA, KB, RM, AA
Investigation: JE, MA, KB
Methodology: JE, MBK, MA, KB
Project administration: MBK, MH, TK
Software: JE
Supervision: JE
Visualization: MH, JD, MBK, JE
Writing - original draft: MBK, MH, AP, JE
Writing - review & editing: JE, MBK, MA, MH, KB, TK, RM, AP

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[DOCX File, 22 KB - cancer_v12i1e69710_app1.docx]

Multimedia Appendix 2
Codes and definitions.
[DOCX File, 11 KB - cancer_v12i1e69710_app2.docx]

Checklist 1
Completed COREQ checklist.
[PDF File, 464 KB - cancer_v12i1e69710_app3.pdf]

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Abbreviations

AI: artificial intelligence
COREQ: Consolidated Criteria for Reporting Qualitative Research
MRI: magnetic resonance imaging

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Patients' Attitudes and Beliefs Toward Artificial Intelligence Use in Cancer Care: Cross-Sectional Survey Study

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Abstract

Background: Artificial intelligence (AI) is being rapidly integrated into oncologic care, yet little is known about how patients perceive these applications. Understanding patient perceptions is critical to ensuring AI applications align with their needs and preferences.

Objective: This study aimed to evaluate oncology patients' attitudes and beliefs on the use of AI across clinical touchpoints in cancer care.

Methods: We conducted a cross-sectional survey study with adult oncology patients from September to December 2024. The survey assessed patients' comfort with AI use across 8 clinical touchpoints of cancer care (eg, screening, diagnosis, treatment) on a 5-point Likert scale (1=very uncomfortable to 5=very comfortable). Patients also rated their concerns about AI, including potential harms related to its use (eg, medical errors, privacy breaches), on a 3-point Likert scale (1=not concerned to 3=very concerned).

Results: Of 383 patients approached, 330 (86.2% response rate) participated; 184 (55.9%) were male, 162 (49.4%) were aged 65 years or older, 35 (10.8%) were Black, 40 (12.1%) were Hispanic or Latino, and 233 (72.6%) were actively receiving cancer treatment. Patients were most comfortable with AI use in cancer screening (80.2%) and supportive care applications, including exercise (78.2%), diet (74.8%), and herbs/supplements (72.4%). Patients were least comfortable with AI use to assist with diagnosis (70.4%), symptom management (67.5%), treatment planning (64.8%), and prognosis (61.5%). Nonetheless, about half (49.7%) were at least somewhat concerned with the use of AI in cancer care, most commonly about the loss of human interaction and medical errors.

Conclusions: Although the majority of oncology patients had a favorable view of AI in cancer care, nearly half had concerns about potential harms. Incorporating patient perspectives into AI development is essential for patient-centered and high-quality cancer care.

Introduction

Artificial intelligence (AI) is transforming oncology, offering unprecedented capabilities to analyze vast amounts of cancer treatment data and improve care [1,2]. The integration of this technology into cancer care has centered on clinical touchpoints within the "cancer continuum," such as diagnosis, prognosis, and treatment [2,3]. AI is already capable of performing tasks across these domains, including analyzing radiographic images, predicting clinical outcomes, and assisting in decision-making [4-6].

Despite these technological advances, little is known about how patients perceive the use of AI in cancer care. Prior research has focused on the views of the general population toward AI use in health care [7-9]. Although these studies suggest that patients are generally receptive to AI, data investigating views regarding its use in oncology are lacking. As the use of AI in oncology increases, understanding patient perceptions is

essential to ensure their needs and preferences are incorporated into the implementation of AI applications. Failure to incorporate these perspectives may lead to AI tools that patients are unwilling to use, ultimately eroding trust in health care, jeopardizing the clinician-patient relationship, and reducing adherence to clinical recommendations.

To address this critical need for patient-centered implementation of AI, we conducted a cross-sectional survey with adult oncology patients at a large urban academic cancer center to evaluate their attitudes and beliefs on the use of AI in clinical touchpoints of cancer care.

Methods

Questionnaire Development

The survey was designed through a multistep process in collaboration with patients. First, a literature review informed question development on AI applications in cancer care, with some questions adapted from prior AI-in-medicine surveys [7,10,11]. A patient and family advisory council at our institution provided feedback on the survey draft. We then conducted cognitive interviews with 12 oncology patients in an outpatient clinic to assess language clarity and question relevance. The survey was then revised to incorporate patient-identified topics, including AI as a physician-supervised tool (vs standalone use), its clinical applications in oncology, and potential harms. Finally, we piloted the revised survey with 21 patients to test the survey recruitment feasibility in our clinical setting.

The finalized survey (Multimedia Appendix 1) consisted of 48 items. Participants rated their comfort with AI use across 8 clinical touchpoints of cancer care: screening, diagnosis, treatment, prognosis, symptom management, diet, herbs/supplements, and exercise. They also rated their concern with 5 potential AI use harms: privacy breaches, medical errors, loss of human interaction with doctors, difficulty understanding the technology to access care, and reinforcing discrimination in health care. Question formats included multiple choice, 5-point Likert scales (1=very uncomfortable to 5=very comfortable), and 3-point Likert scales (1=not concerned to 3=very concerned). Sociodemographic, clinical, and technology use data were collected. The survey was translated into Spanish by a certified interpreter.

Survey Administration

This study used convenience clinical sampling. We distributed the survey to patients at affiliated outpatient clinics in urban academic, urban underserved, and suburban settings. Adult patients with a history of cancer were eligible to participate. Clinic staff screened patients and notified the research staff while patients waited for appointments or treatment. The research team introduced the study and provided patients with an iPad for the survey. The survey was distributed via Research Electronic Data Capture (REDCap) [12].

Data Analysis

We followed American Association for Public Opinion Research reporting guidelines. Chi-square tests were used for subgroup analysis. Statistical Package for the Social Sciences (version 28; IBM Corp) was used for statistical analysis.

Ethical Considerations

The study was reviewed by the institutional review board at Memorial Sloan Kettering Cancer Center and determined to be exempt from review under 45 Code of Federal Regulations (CFR) 46.104(d)(2)(i), which applies to research involving educational tests, survey procedures, interview procedures, or observation of public behavior when participant identities cannot readily be ascertained. The exemption determination was issued on September 5, 2024 (protocol number X24-033). Given the anonymous nature of the survey, written informed consent was not required. Participants were presented with an electronic consent statement at the start of the survey, and consent was obtained by participants selecting "I agree" before proceeding. No compensation was provided to participants.

Results

Between September and December 2024, 383 patients were approached, of whom 330 participated (86% response rate). Of these 330 participants, 184 (55.9%) were male, 162 (49.4%) were aged 65 years or older, 35 (10.8%) were Black, and 40 (12.1%) were Hispanic or Latino (Table 1). The most commonly reported cancers were prostate (114/330, 34.5%) and breast (87/330, 26.4%) cancer, and the majority of patients were actively receiving treatment (233/321, 72.6%).

Table . Participants' demographics and baseline characteristics (N=330).

Characteristic		Participants, n[a] (%)
Age (years)		
	18 – 49	58 (17.7)
	50 – 64	108 (32.9)
	≥65	162 (49.4)
Gender		
	Male	184 (55.9)
	Female	141 (42.9)
	Other	4 (1.2)
Race		
	White	234 (72.4)
	Black/African American	35 (10.8)
	Asian	25 (7.7)
	Other	29 (9)
Ethnicity		
	Hispanic	40 (12.4)
	Non-Hispanic	283 (87.6)
Education		
	High school degree or less	73 (22.6)
	College degree or more	250 (77.4)
Cancer type[b]		
	Prostate	114 (34.5)
	Breast	87 (26.4)
	Gastrointestinal	52 (15.8)
	Genitourinary	33 (10)
	Lung	22 (6.7)
	Other	66 (20)
Treatment status		
	Receiving treatment	233 (72.6)
	Not receiving treatment	88 (27.4)
Treatment modality[b]		
	Surgery	158 (47.9)
	Radiation	180 (54.5)
	Chemotherapy	209 (63.3)
	Immunotherapy	64 (19.4)
	Other	60 (18.2)
Self-rated general health		
	Excellent to good	272 (83.7)
	Fair to poor	53 (16.3)

[a]Counts may not add up to 330 due to missing data (<5% missing data for each question).

[b]This is a "select all that apply" question. Patients could report multiple cancers/treatment modalities.

Most participants (300/330, 91%) reported knowing "a little" or "quite a lot" about AI, and 60 of 312 participants (19.2%) used web-based AI applications (eg, ChatGPT) at least once per week. The majority (264/328, 80.5%) believed that AI would make cancer care somewhat or much better over the next 5 years. Patients were most comfortable with AI use in cancer screening (264/329, 80.2%) and supportive care applications including recommendations for exercise (254/325, 78.2%), diet (247/330, 74.8%), and herbs/supplements (236/326, 72.4%). Patients were least comfortable with AI use to assist with diagnosis (231/328, 70.4%), symptom management (222/329, 67.5%), treatment planning (210/324, 64.8%), and prognosis (201/327, 61.5%) (Figure 1).

Figure 1. Patients' comfort level with AI use in different clinical touchpoints of cancer care. AI: artificial intelligence.
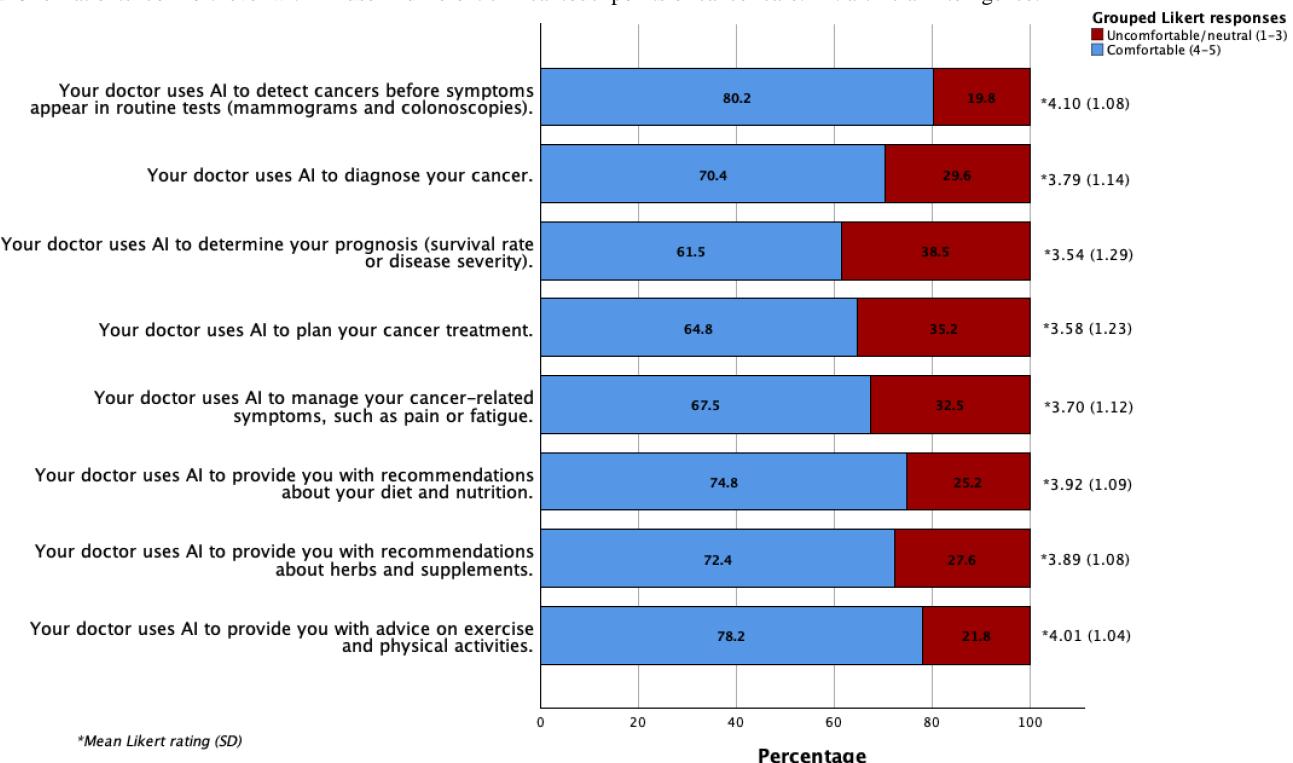
Nevertheless, 49.7% (164/330) were somewhat concerned with the use of AI in their cancer care. The most common concerns were loss of human interaction with doctors (162/330, 49.1%) and medical errors (158/330, 47.9%), followed by privacy breaches (141/330, 42.7%), difficulty understanding the technology (132/330, 40%), and reinforcing health care disparities (112/330, 33.9%).

Compared to patients who reported limited AI use, those who used it weekly were more likely to believe AI would improve cancer care (57/60, 95% vs 194/25, 77.3%; P=.006) and were less concerned about its use (18/60, 30% vs 135/252, 53.6%; P=.001). Compared to patients with less than a college degree, those with a college degree or higher were more likely to believe that AI would improve cancer care (53/73, 72.6% vs 207/248, 83.5%; P=.04), but not more likely to be concerned about its use (36/73, 49.3% vs 124/250, 49.6%; P=.97). Treatment status was not associated with differences in perceptions. Patients on active treatment were no more likely than those not on active treatment to believe that AI would positively impact cancer care (191/233, 82% vs 65/86, 75.6%; P=.20) or to express concerns about its use (114/233, 48.9% vs 44/88, 50%; P=.86).

Discussion

Principal Findings

AI holds significant potential to improve oncologic care, though successful integration of this technology must incorporate patients' perspectives, as they are the ultimate decision-makers in their care. This study highlights opportunities and challenges to optimal AI implementation in cancer care.

Although most oncology patients were receptive to AI applications, nearly half expressed concerns about potential harms, particularly loss of human interactions and medical errors. These findings align with prior studies in the general population, reflecting "cautious optimism"—patients are open to AI but emphasize the need for oversight to mitigate risks [7-9]. The most common concerns relate to previously raised ethical implications: (1) AI jeopardizing clinician-patient relationships leading to depersonalized care, and (2) overreliance on clinical support tools causing inaccurate diagnoses and recommendations [13]. These concerns echo efforts in the regulatory landscape, including the US Food and Drug Administration's evolving oversight of AI-based medical software and the EU AI Act, which designates most medical AI systems as "high-risk," requiring additional oversight measures [14]. Policymakers and developers must engage

patients during AI implementation to ensure safeguards are in place to address these concerns.

Our findings demonstrate a higher proportion of patients that were comfortable with AI than previously reported. For example, a 2019 survey of the general population found 55.4% believed AI would improve health care; in our study, 80.5% of oncology patients had this expectation [7]. Similarly, a 2022 survey found 39% of US adults were comfortable with their health care providers relying on AI for their medical care [15], while in our study, at least 60% of patients were comfortable with their doctors using AI for various clinical tasks in cancer care. These discrepancies may reflect increasing familiarity with AI in the last few years. Our findings suggest exposure to this technology may reduce patient concerns. Additionally, we observed that patients with a college degree or higher were more likely to have positive views toward the future of AI in cancer care. This is in line with another recent study that showed patients with higher education levels expressed less discomfort with AI and fewer concerns about AI technologies in clinical settings [16]. Future interventions should explore whether targeted exposures for older or less educated patients could narrow the digital divide in clinical settings.

Limitations

A limitation of this study is reliance on convenience sampling of patients at a single center in the Northeastern United States, making the sample less representative of the US cancer patient population. Furthermore, while we had a robust response rate, in-person responses may have introduced social desirability bias, as patients may have expressed more favorable views due to perceived health care expectations. The education level of our participants (77.4% with a college degree or more) was higher than the national average [17] and potentially associated with more positive views toward AI in cancer care, which may impact the generalizability of our findings.

Conclusion

Although most oncology patients had positive views of AI applications in cancer care, almost 50% had concerns, especially about loss of interaction with clinicians and potential medical errors. To optimize patient-centered care, policymakers and developers must incorporate patient input during AI implementation and address these concerns. Future research should seek to identify strategies to foster collaboration between developers and patients. Importantly, patient perceptions of AI may shift over time as public discourse and clinical exposure to AI tools evolve; therefore, a longitudinal study may better assess how these views change over time as AI becomes more integrated into oncology.

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: MST (lead), KB (equal), JJM (equal)
Data curation: MST
Formal analysis: MST (lead), KB (supporting)
Investigation: MST (lead), KB (equal)
Methodology: MST (lead), KB (equal), SC (equal), JJM (equal)
Project administration: KB
Resources: JJM
Writing: MST (lead), KB (equal), JJM (supporting), BD (supporting), AK (supporting), HX (supporting), SC (supporting)

Conflicts of Interest

JJM: grants from Tibet CheeZheng Tibetan Medicine Co Ltd and Zhongke Health International LLC. AK: stock and other ownerships with Novavax and Xtrava Health; research funding from Clovis Oncology, Merck KGaA, Varian Medical Systems.

BD: stock and other ownerships with CVS Health, Lilly, Roche/Genentech; consulting or advisory role with Varian Medical Systems and I-MAB Biopharma. ASE: honoraria from HMP Education; other relationship with UpToDate. All other authors declare no conflicts.

Multimedia Appendix 1
Survey on artificial intelligence in cancer care delivery.
[DOC File, 126 KB - cancer_v12i1e81346_app1.doc]

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Abbreviations

AI: artificial intelligence
REDCap: Research Electronic Data Capture

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Generative AI Chatbots as Digital Adjuncts for Sexual Health Information After Prostate Cancer in Men Who Have Sex With Men: Auto-Netnographic Study

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Abstract

Background: Sexual health concerns following prostate cancer treatment are common yet often insufficiently addressed in clinical practice, particularly among men who have sex with men. These individuals may face additional barriers stemming from heteronormative assumptions, limited disclosure, and a lack of culturally tailored information. As generative artificial intelligence (GenAI) chatbots become increasingly accessible, patients are using these systems to seek sensitive health information outside traditional care settings. While prior research has focused on the accuracy and safety of chatbot-generated health advice, less attention has been paid to how responses are framed and experienced in sexual minority contexts.

Objective: This study aimed to describe and compare how 4 GenAI chatbots respond to questions about sexual health following prostate cancer treatment, with a focus on the needs of a gay man, and to interpret these responses using netnographic and actor-network theory perspectives.

Methods: A qualitative exploratory study using auto-netnography was conducted. In February–March 2025, the first author interacted once with 4 widely used GenAI chatbots—ChatGPT (GPT-4o; Open AI), Claude (3.5 Sonnet; Anthropic), Copilot (GPT-4 Turbo; Microsoft), and Gemini (2.0 Flash; Google)—while assuming the role of a simulated "mock patient." Two standardized prompts were used verbatim across all platforms: an initial prompt addressing sexual health concerns after prostate cancer treatment and a supplementary prompt focusing on sexual minority–specific issues, including same-sex practices. Chatbot outputs were treated as system-generated data and analyzed qualitatively, integrating system-generated text with reflexive experiential engagement and attention to interactional framing, emotional attunement, specificity, and performative features. The analysis did not assess clinical effectiveness, safety, or generalizability.

Results: Across platforms, chatbot responses addressed treatment-related sexual health concerns using generally inclusive language, with variation in emotional tone, specificity, and cultural sensitivity. Interactional features included the scope and framing of clinical information, encouragement of dialogue, self-care advice, and explicit discussion of same-sex sexual practices. No obvious fabricated claims were identified; however, contextual inaccuracies were observed. Responses were mapped along 2 intersecting continua—logical-to-empathetic orientation and general-to-specific framing—yielding 4 interactional styles: structured overview, rational clarity, compassionate perspective, and compassionate precision. This 4-quadrant framework served as an interpretive heuristic and does not constitute an evaluation of quality or effectiveness.

Conclusions: The findings indicate that contemporary GenAI chatbots, when used as digital adjuncts, may enact communication styles that can be perceived as supportive, culturally sensitive, and LGBTQI+ (lesbian, gay, bisexual, transgender, queer, and intersex)-inclusive in specific sexual health interactions. Although these systems lack ethical consciousness and cannot replace professional care, their performative responses may complement clinical practice by facilitating reflection and access to sensitive information. The study highlights how care-like meanings may emerge through sociomaterial interactions between users and artificial intelligence systems rather than demonstrating generalized performance or clinical reliability.

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Introduction

Sexual health concerns following prostate cancer treatment are common yet often insufficiently addressed in clinical practice, particularly among men who have sex with men. Sexual minority patients may face additional challenges stemming from heteronormative assumptions, limited disclosure to health care providers, and a lack of culturally tailored information and support [1-5]. As a result, men who have sex with men treated for prostate cancer may experience unmet informational and psychosocial needs related to intimacy, sexual practices, and identity-specific concerns.

Digital technologies have become increasingly prominent sources of health information, supplementing traditional clinical encounters. Alongside websites, forums, and telehealth services, generative artificial intelligence (GenAI) chatbots are now widely accessible to patients seeking health-related guidance. These conversational systems can generate responsive, personalized text and simulate dialogic engagement, making them particularly attractive for sensitive topics, such as sexual health. At the same time, concerns have been raised about the accuracy, bias, and reliability of chatbot-generated health information in both clinical and lay contexts [6-10].

Most existing research on GenAI in health contexts has focused on evaluating the correctness, safety, and technical performance of chatbot-generated outputs, often through expert benchmarking or comparison with established clinical guidelines [9,10]. While such studies are essential, they offer limited insight into how health-related responses are framed, enacted, and experienced in interaction, particularly in sensitive, identity-linked domains, such as sexual health. Less is known about how GenAI chatbots address sexuality, intimacy, and same-sex practices after prostate cancer treatment, or how interactional styles may vary across platforms when responding to identical prompts.

Qualitative and nursing-oriented research has emphasized that health communication involves not only the accuracy of information but also interactional framing, emotional attunement, and relational context [11-13]. From sociomaterial and actor–network perspectives, digital technologies can be understood as nonhuman actors that participate in enacting meanings and practices through interaction rather than merely transmitting information [14-17]. This perspective foregrounds how health-related meanings emerge relationally through specific configurations of users, technologies, and contexts.

In nursing science, particularly within the Nordic caritative caring tradition, caring is understood as an ethical and relational practice grounded in responsibility, dignity, and communion rather than solely in information provision or technical support [18,19]. This distinction offers an important reference point for interpreting artificial intelligence (AI)–mediated interactions that may resemble caring communication yet do not constitute care in a caritative sense. Building on this tradition, Andtfolk [20] has examined the possibilities and limitations of care technologies, emphasizing that digital and robotic systems may simulate aspects of caring interaction without ethical responsibility, consciousness, or the capacity for genuine caring communion.

Rather than evaluating whether GenAI chatbots provide accurate or safe medical advice, this study examines how responses from GenAI chatbots are framed, enacted, and experienced in a situated sexual health interaction with a gay man after prostate cancer treatment. By adopting an auto-netnographic approach, the study attends to both system-generated text and the researcher's reflexive, experiential engagement with the interaction [13,21]. This approach enables exploration of interactional features, such as emotional attunement, specificity, and inclusivity without making claims about clinical effectiveness or generalizability.

The aim of this study was to describe and compare how 4 GenAI chatbots respond to questions about sexual health following prostate cancer treatment, with a focus on the needs of a gay man, and to interpret these responses using netnographic and actor–network theory perspectives.

Methods

Study Design

This study used an auto-netnographic qualitative design to explore situated interactions with GenAI chatbots [15,17,21]. Auto-netnography was chosen to enable reflexive engagement with chatbot responses and to examine how interactional framing, tone, and performativity are enacted in a specific health-related inquiry. The study followed the iterative netnographic process described by Kozinets, including initiation, immersion and interaction, analytic integration, and reflexive interpretation [17]. The study was not designed to evaluate clinical effectiveness, safety, or generalizable performance of chatbots, but rather to explore how responses are produced and experienced in a particular interactional context.

This study was reported in accordance with Standards for reporting qualitative research (SRQR) and the Chatbot Health Advice Reporting Tool (CHART) reporting guideline [22,23].

Chatbot Selection and Study Context

Four widely used GenAI chatbots were included: ChatGPT (GPT-4o, free version; Open AI), Claude (Claude 3.5 Sonnet, free version; Anthropic), Copilot (GPT-4 Turbo, enterprise subscription; Microsoft), and Google Gemini (2.0 Flash, free version). These chatbots were selected for their public availability and relevance to contemporary health information-seeking. All interactions were conducted via the chatbots' web interfaces between February and March 2025, and no technical limitations were encountered during data collection.

Interactions were carried out using a simulated "mock patient" persona enacted by the first author, drawing on his lived and professional experience as a gay man and a specialist nurse. This methodological approach was used to elicit relevant chatbot responses and does not constitute data from a real patient. Accordingly, chatbot outputs were treated as system-generated data rather than human participant data.

Prompting and Interaction Procedure

Data collection began with a standardized initial prompt presented verbatim to all 4 chatbots (Textbox 1). The prompt

described a gay man in his early fifties, recently diagnosed with prostate cancer, seeking information on how different treatment options might affect sexual health, including concerns about erections, orgasm, intimacy, and sex with a male partner.

Textbox 1. Standardized initial prompt.

I'm a 53-year-old gay man, and I've been diagnosed with prostate cancer. Will be treated with either radiotherapy or surgery, both would likely include hormonal therapy as well. I'm concerned about my sex life after treatment. Can you help me think this through?

Following the initial prompt, each chatbot generated a response and, in some cases, asked brief clarification questions (eg, about specific concerns or preferences). Follow-up replies were limited to brief clarifications (eg, one-sentence responses) and did not introduce new topics beyond the prompts. These follow-up exchanges were neither standardized nor the primary focus of the analysis.

After the initial interaction, a second standardized supplementary prompt was presented verbatim across all platforms (Textbox 2). This prompt explicitly addressed sexual minority–specific considerations, including anal sex, insertive and receptive roles, partner communication, and whether health care providers typically address these topics.

Textbox 2. Standardized supplementary prompt

Are there any specific things I need to consider as a gay man regarding my sex life after treatment for prostate cancer?

The standardized prompts used across all 4 chatbots are presented verbatim.

No modifications were made to the wording of either prompt across platforms. All interactions occurred in a single session per chatbot. Chatbot responses to both standardized prompts were captured verbatim and transferred to a spreadsheet for analysis. No responses were edited, filtered, or corrected prior to analysis. The analytic focus was on how responses were framed, enacted, and performed in this specific interactional context, rather than on response stability, reproducibility, or clinical correctness.

Positionality and Reflexivity

The first author identifies as a gay man and is a specialist nurse with longstanding clinical and research experience in sexual health and prostate cancer. The coauthors served as project supervisors; HE has expertise in netnographic and qualitative research, and LF has expertise in analytic and interpretive methods. This positionality informed the selection of prompts and the analytic focus. Reflexive field notes were recorded during and after interactions, capturing immediate impressions and evolving interpretations. Preliminary analyses were discussed among all authors to support reflexivity and analytic transparency.

Analytic Approach

The analysis was qualitative and interpretive. Consistent with auto-netnographic methodology, the first author's experiential engagement with the interaction was integral to the analytic material [21]. Rather than using a formal, predefined thematic coding framework or quantification, the analysis focused on how responses from GenAI chatbots were framed, how emotional attunement and specificity were enacted, and how interactional styles varied across platforms. The analysis was informed by netnographic principles and actor–network theory, emphasizing enactment and performativity in human–technology interaction [14-17]. Auto-netnography was used to capture the lived, situated experience of interacting with GenAI chatbots,

including affective responses, interpretive judgments, and reflexive meaning-making that extend beyond the textual content of chatbot outputs [15,21].

While the chatbot responses constitute system-generated text, the analytic material also included the researcher's experiential engagement with the interaction, which informed the interpretation of tone, responsiveness, and perceived relevance in context. The analysis began with a naïve reading of all prompt responses to gain an immediate overall understanding of the material. In the next step, responses were placed side by side to identify similarities and differences. As part of this comparative phase, a sentence-level content analysis was performed through line-by-line coding, enabling a more granular examination of interactional features and thematic patterns.

Initial line-by-line coding focused on interactional features, including tone, emotional attunement, specificity, and forms of guidance. These features were compared across chatbot responses to identify recurring contrasts, which were abstracted into 2 intersecting dimensions, namely empathetic–rational orientation and general–specific framing. The 4-quadrant analytic map was then developed as a heuristic to visualize and interpret how different interactional styles were enacted across platforms.

During the comparative phase, the theoretical framework and the first author's preunderstanding were mobilized to pose reflexive questions about the prompt responses, consistent with contemporary netnographic and auto-netnographic approaches to AI-mediated interaction [15,21]. Two questions guided the analysis: (1) What does this mean from a theoretical lens? and (2) How can I understand this (as a gay man)? These questions served as reflexive lenses for heuristic interpretation across both disciplinary and experiential horizons. This process revealed substantial variation in how the prompts addressed their intended recipients, in terms of both language and tone. To organize these comparative interpretations, the 4-quadrant analytic map (Figure 1) was used as an interpretive lens to present the study's findings, rather than as a classificatory or evaluative model.

Figure 1. An interpretive heuristic for describing chatbot interactional styles.
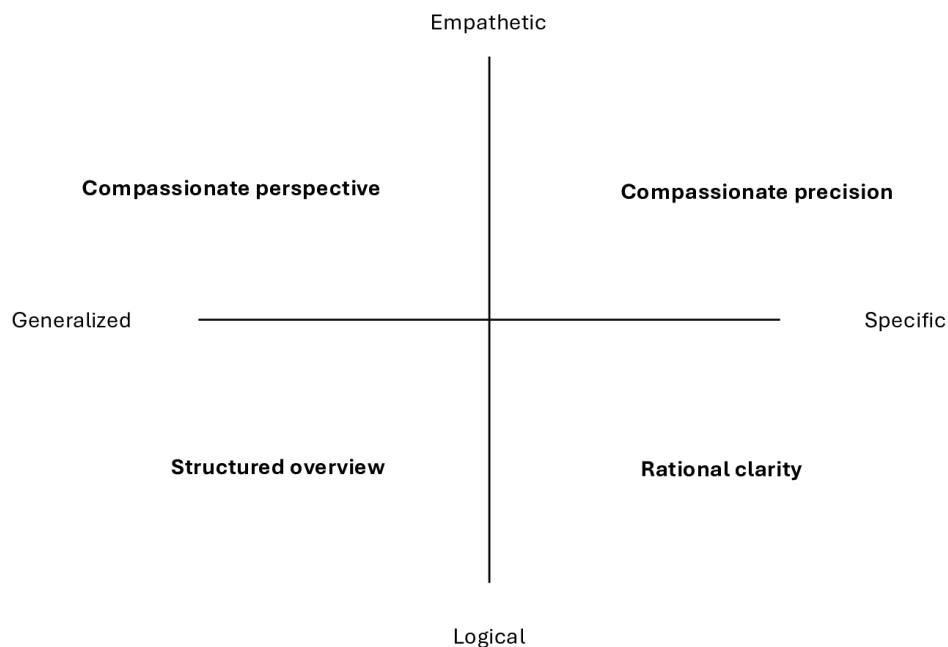
Assessments of accuracy, inclusivity, and empathy were pragmatic and reflexive. Accuracy was defined pragmatically as the absence of obvious factual errors and general alignment with established clinical knowledge familiar to the authors, rather than as a formally validated assessment. No formal scoring instruments, interrater reliability testing, or expert panel validation were used. Inclusivity was pragmatically assessed by using nonheteronormative assumptions, gender-neutral partner language, and explicit acknowledgment of same-sex practices when prompted.

Ethical Considerations

The study did not involve human participants. Chatbot outputs were treated as system-generated data. The use of a mock patient persona was a methodological strategy to elicit relevant responses, not a form of deception involving human participants. Ethical approval was obtained from the Swedish Ethical Review Authority (Dnr 2024-02924-02).

Results

The 4 GenAI-powered chatbots responded to the prompts with text addressing the specific areas outlined in the prompts (Multimedia Appendix 1). All chatbots' GenAI responses included follow-up questions or invitations to continue the dialogue. The findings include the following themes: (1) the content of the chatbot replies, (2) expressions of empathy in chatbot responses, (3) encouraging dialogue, (4) providing self-care advice, (5) discussing same-sex sexual practices, and (6) tonality and cultural sensitivity.

Content of the Chatbot Replies

Across all platforms, chatbot responses addressed treatment-related sexual health concerns using inclusive language, with variation in emotional tone and specificity. Gemini's response cited 4 published scientific papers, all of which are available with open access. Across platforms, the responses addressed commonly reported treatment-related sexual health concerns. No prominent examples of hallucinated content were identified in the analyzed outputs. However, some errors were present, such as links to support groups that mistakenly listed Swedish Hospital Services, a health service in the United States, rather than Sweden. Although occasional caveats noted that the support groups were based in the United States or Australia, it was also mentioned that some could offer online support conversations.

Building on broader discussions linking sexual health to prostate cancer treatments, a second prompt was added to examine the specific sexual issues faced by a gay man undergoing treatment (refer to Multimedia Appendix 2).

> *It's important to acknowledge that while the core medical aspects of prostate cancer treatment are the same for all men, there are specific considerations for gay men regarding their sexual health. Here's a breakdown of those key points:...* [Gemini]

Expressions of Empathy in Chatbot Responses

After the initial prompt, all chatbots responded in ways that conveyed empathy, compassion, and concern through language and tone, and an appreciation for the user's sharing of personal information. The responses used language that conveyed empathy and engagement:

> *I appreciate you sharing this with me. You're facing a big decision, and it's completely understandable to be concerned about how treatment might affect your sex life.* [ChatGPT]

> *I'm really sorry to hear about your diagnosis. It's completely understandable to be concerned about how treatment might affect your sex life. Let's break down some of the potential impacts and ways to manage them.* [Copilot]

Both of these excerpts included language commonly associated with empathic communication. However, some responses may appear more detached, emphasizing facts:

> *It's completely understandable that you're concerned about how prostate cancer treatment might affect your sex life. This is a common and valid concern for many men facing this diagnosis. Here's a breakdown of factors to consider, and how to approach this:...* [Gemini]

Encouraging Dialogue

The chatbots promoted interaction by asking open-ended questions to better engage the user and gather more detailed responses for consideration:

> *Would it be helpful to discuss specific strategies for maintaining intimacy during periods when hormone therapy might affect your libido or sexual function? Many men find creative ways to stay sexually active and maintain connections with partners even when dealing with these challenges.* [Claude]

> *Would you like to talk through the potential effects of each treatment in more detail? Or are you more interested in strategies for maintaining a fulfilling sex life post-treatment?* [ChatGPT]

In these responses, follow-up questions expanded the scope of topics addressed.

Providing Self-Care Advice

There was also advice on self-care in the responses. Several of the chatbots suggested pelvic floor exercises to improve orgasm quality:

> *Enhancing Orgasms:*
>
> *Kegel Exercises: Strengthening pelvic floor muscles may help improve orgasm intensity and control leakage.*
>
> *Mindful Arousal Techniques: Engaging in sensual touch, breathwork, and fantasy can enhance pleasure.*
>
> *Lubrication: Can help with sensation changes and dryness.* [ChatGPT]

Discussing Same-Sex Sexual Practices

Regarding same-sex sexual practices (Multimedia Appendix 2), all chatbots provided explicit descriptions of potential changes related to these practices.

> *Anal Sex:*
>
> *If you engage in receptive anal sex, this can generally be resumed after healing from either surgery or radiation (usually 4‐6 wk for surgery, timing varies for radiation).*
>
> *If you engage in insertive anal sex, erectile challenges may affect this more significantly than some other forms of sexual activity.*
>
> *Some men find they need to adjust their preferred sexual roles based on treatment effects.* [Claude]

Tonality and Cultural Sensitivity

However, the chatbots varied in tone and vocabulary. Gemini and Copilot maintained a professional, somewhat distant tone, while ChatGPT adopted a friendlier, more collegial style. The language reflected nonheteronormative sexual practices; for example, ChatGPT mentioned "Navigating hookup culture," which allows responses sensitive to different cultural backgrounds and recognizes that not everyone is in a committed or monogamous relationship.

Claude and Copilot asked about current partners to encourage communication and support:

> *Also, do you have a partner who's part of these discussions? Partners can be valuable allies in recovery and adaptation* [Claude]

> *Openly discuss any changes in your sexual function or desires with your partner. This can help maintain intimacy and understanding in your relationship* [Copilot]

All the chatbots consistently used gender-neutral, inclusive language.

Care-Related Language Interpreted Through a 4-Quadrant Analytic Map

The enactment and performativity of GenAI can be mapped along two continua: (1) one from general to specific information and (2) the other from logical to empathetic responses. The 4-quadrant framework should be understood as an interpretive heuristic rather than a validated typology. It was derived from a comparative reading of chatbot responses and is intended to support interpretation of how interactional styles may vary along two intersecting dimensions, including degree of emotional attunement (logical to empathetic) and degree of specificity (general to tailored).

The interactor was prompted to provide additional information to give the chatbot broader context for engagement. In this case, the chatbot resembled an information trader, which is at the logical end of the spectrum. The compassionate aspect of GenAI places it closer to the empathetic end.

To illustrate how interactional variation was interpreted in the analysis, four analytically derived positions are described below.

1. Structured overview: Responses are characterized by logically organized general information about treatments and side effects, with limited emotional engagement or personalization.
2. Compassionate perspective: Responses acknowledge emotional concerns and the broader life context while remaining relatively general in scope.
3. Compassionate precision: Responses combine emotional attunement with tailored, context-sensitive guidance, including explicit references to same-sex practices or minority stressors.
4. Rational clarity: Responses emphasize factual explanations, references, and clinical reasoning, with minimal affective language (Figure 1).

Three of the GenAI chatbots began with compassionate responses, expressing concern and saying they were "sorry" to hear of the diagnosis. The fourth adopted a more distant or professional tone:

> *It's completely understandable that you're concerned about how prostate cancer treatment might affect your sex life. This is a common and valid concern for many men facing this diagnosis. Here's a breakdown of factors to consider, and how to approach this.* [Gemini]

In the excerpt above, the chatbot acknowledges the interactor's concern but shows less empathy. This approach is more logical and provides a structured overview, yet it is more general and does not address the interactor's specific needs.

The chatbots played a performative role in engaging with and questioning the interactor, prompting them to provide additional details. They offered information while also seeking clarification and any further necessary data. Here, the interactional pattern resembles descriptions of person-centered communication, demonstrating compassionate precision, for example, when the chatbots used inclusive language and suggested practices for different sexual positions.

> *Yes, there are several important considerations specific to gay men dealing with prostate cancer treatment:*
>
> *Anal Sex:*
>
> *If you engage in receptive anal sex, this can generally be resumed after healing from either surgery or radiation (usually 4‐6 wk for surgery, timing varies for radiation)*
>
> *If you engage in insertive anal sex, erectile challenges may affect this more significantly than some other forms of sexual activity*
>
> *Some men find they need to adjust their preferred sexual roles based on treatment effects.* [Claude]
>
> *Your sex life will likely change, but that doesn't mean it has to end. Many men discover new ways to experience pleasure, whether through adapting physically, redefining intimacy, or exploring different forms of touch and connection. If you'd like, I can help you find LGBTQ+-friendly doctors, sex*

> *therapists, or resources specific to your area.* [ChatGPT]

Some of the chatbots attempted to provide evidence-based responses by citing open-access scientific journal papers. This approach was less compassionate and focused on presenting facts, references, and links from external sources. This illustrates rational clarity.

> *Yes, there are some specific considerations for gay men regarding their sex life after prostate cancer treatment. Here are a few key points:*
>
> *Communication with Healthcare Providers*
>
> *[Copilot]*

This compassionate perspective offered encouragement and suggestions for addressing these issues, such as:

> *Specific Considerations for Gay MenResearch indicates that gay and bisexual men might experience different challenges and lower health-related quality of life after prostate cancer treatment compared to heterosexual men4 (a provided ref.). It's important to find healthcare providers who are knowledgeable and sensitive to these differences.* [Copilot]

However, some of the care described resembled a structured summary, making it harder to distinguish differences from a compassionate perspective.

Discussion

Principal Findings

This study explored how 4 GenAI chatbots responded to a situated sexual health inquiry framed from the perspective of a gay man undergoing treatment for prostate cancer. Across platforms, chatbot responses varied in emotional attunement, degree of specificity, and attention to sexual minority–specific concerns, while consistently addressing treatment-related sexual issues and encouraging continued dialogue. Interactional features included inclusive language, provision of self-care advice, and explicit discussion of same-sex sexual practices. These variations were analytically organized using a 4-quadrant heuristic that maps emotional orientation and degree of specificity, providing an interpretive lens for understanding interactional diversity rather than for evaluating clinical performance or quality.

The findings indicate that when men who have sex with men seek health information following prostate cancer surgery, GenAI chatbots may differ not only in tone and communicative style but also in how interactional responses are organized and enacted. These differences were observed along the analytically derived dimensions of emotional attunement and informational specificity, shaping how guidance was framed and relationally positioned within the interaction. Such variation reflects different ways of presenting and contextualizing self-care–related information in sensitive health contexts, rather than stable or intrinsic properties of the systems themselves.

Building on existing research, studies on GenAI in health contexts have primarily focused on assessing the accuracy, safety, and technical performance of chatbot-generated

information [9,10]. While these evaluations are essential, they offer limited insight into how health-related responses are framed and enacted in interaction, particularly in sensitive domains, such as sexual health. Consistent with emerging qualitative and nursing-oriented research on AI-mediated communication [11,12,24,25], the present findings suggest that GenAI chatbots may simulate supportive dialogue through tone, structure, and responsiveness, despite lacking ethical agency and clinical responsibility.

Importantly, the findings do not suggest that GenAI chatbots provide care in an ethical or caritative sense. Drawing on Nordic caritative caring theory [18,19] and prior analyses of caring encounters in technologically mediated contexts [20,26,27], the observed responses are better understood as care-like enactments. In this view, caring extends beyond the delivery of correct information and encompasses relational and contextual dimensions that may be partially simulated through language and interactional form. As Andtfolk [20] has noted, digital systems may perform aspects of care without consciousness, moral responsibility, or the capacity for genuine caring communion.

From a sociomaterial and actor–network perspective, these care-like enactments emerge from specific configurations of actors, practices, and technologies rather than residing within the chatbot itself [14-17]. Chatbot responses are shaped by prompts, platform design, training data, and user expectations rather than by stable or intrinsic properties of the system. Consequently, sexual health after prostate cancer treatment is not communicated as a single, stable phenomenon but is enacted differently depending on how concerns are articulated and responded to in particular human–technology interactions.

When considered alongside nursing theories of care, this sociomaterial understanding also aligns with self-care perspectives, such as Orem's [28] theory, which emphasizes supporting individuals' capacity to reflect on and manage health-related needs. In this study, GenAI chatbots did not provide care in an ethical or caritative sense [18,19], but their care-like enactments may be understood as digitally mediated supports for reflection, sense-making, and self-management within a broader care ecology. In this way, GenAI chatbots can be conceptualized as digital adjuncts that intersect with, but do not replace, professional care.

These considerations are particularly relevant for men who have sex with men following prostate cancer treatment. The findings highlight both the potential and the limitations of GenAI chatbots as digital adjuncts in this context. Sexual minority patients have documented unmet needs in sexual health, intimacy, and disclosure after treatment [1-5]. Several chatbot responses demonstrated sensitivity to same-sex practices and sexual minority–specific concerns, aligning with frameworks

for LGBTQI+ (lesbian, gay, bisexual, transgender, queer, and intersex)-inclusive health care that emphasize recognition of sexual minority identities, practices, and relational contexts [29]. However, this sensitivity was inconsistently applied across platforms, underscoring that inclusivity in AI-mediated health communication is variable rather than assured by design.

The interactional patterns observed in chatbot responses can also be interpreted through the PLISSIT (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) model, which outlines progressive levels of sexual health communication [30]. Across platforms, chatbot responses consistently operated within the first three levels of the model. They invited questions and normalized concerns about sexuality (Permission), provided general information about treatment-related sexual effects (Limited Information), and, in some cases, offered tailored guidance on same-sex practices and self-care strategies (Specific Suggestions). Notably, none of the chatbots reached the level of Intensive Therapy, which would require individualized clinical assessment, ethical responsibility, and professional accountability. This pattern aligns with interpreting chatbot responses as care-like enactments rather than clinical care. Furthermore, it supports conceptualizing GenAI chatbots as digital adjuncts that may facilitate dialogue and reflection on sexual health without substituting for professional nursing or therapeutic expertise.

Strengths and Limitations

This study is based on a single, situated interaction per chatbot and does not aim to assess reproducibility, safety, or generalizability. The auto-netnographic approach involves interpretive judgment and reflexive engagement, which may introduce subjectivity [13,21]. Although no obviously fabricated claims were identified in this dataset, this absence should not be interpreted as evidence of accuracy, reliability, or safety, as prior studies have documented hallucinations and contextual errors in similar systems [9,25].

Conclusions

The findings suggest that contemporary GenAI chatbots, when used as digital adjuncts, may enact communication styles perceived as supportive, culturally sensitive, and LGBTQI+-inclusive in specific sexual health interactions following prostate cancer treatment. Although these systems lack ethical consciousness and cannot replace professional care [24], their performative responses may complement clinical practice by facilitating reflection, dialogue, and access to sensitive information within a broader nursing and self-care context. Rather than demonstrating generalized performance or clinical reliability, this study highlights how care-like meanings may emerge in specific sociomaterial interactions between users and AI systems.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Prompts and initial answers on sexual health after prostate cancer treatment, specifically for men who have sex with men.
[DOCX File, 26 KB - cancer_v12i1e81745_app1.docx]

Multimedia Appendix 2
Prompts and specific answers on sexual health after prostate cancer treatment, specifically for men who have sex with men.
[DOCX File, 26 KB - cancer_v12i1e81745_app2.docx]

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Abbreviations

AI: artificial intelligence
CHART: Chatbot Health Advice Reporting Tool
GenAI: generative artificial intelligence
LGBT/LGBT+/LGBTQ/LGBTQI: lesbian, gay, bisexual, transgender, queer, and intersex
PLISSIT: Permission, Limited Information, Specific Suggestions, and Intensive Therapy
SRQR: Standards for Reporting Qualitative Research

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<u>Short Paper</u>

The Role of Resilience in Coping With Future Uncertainty Among People With Brain Tumors: Cross-Sectional Study

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Abstract

Background: Adults with brain tumors learn to navigate unpredictable physical and psychological symptoms along with the possibilities of tumor recurrence. As a result, they tend to become resilient to confronting profound uncertainty and actively employ coping strategies. Yet, the impact of resilience on coping strategies among people with brain tumors has not been fully explored.

Objective: This study aimed to examine the effects of resilience on the association between future uncertainty and two distinct types of coping strategies (problem-focused coping and emotion-focused coping) among people with brain tumors in Taiwan.

Methods: A parent study recruited 95 adults with brain tumors undergoing at least 1 month of chemotherapy or radiotherapy at a veterans general hospital in northern Taiwan. We assessed resilience, future uncertainty, and coping strategies via a secondary analysis of data from the parent study collected using the Chinese versions of the Resilience Scale, the European Organization for Research and Treatment of Cancer's Quality of Life Questionnaire for brain cancer, and the revised Ways of Coping Checklist. Simple mediation models were conducted to examine the role of resilience between future uncertainty and the two types of coping strategies.

Results: Most participants demonstrated low resilience and responded to stress with both problem- and emotion-focused coping strategies. Simple mediation analyses showed a statistically significant association between an increase in resilience and adoption of each type of coping strategy. In addition, resilience was a statistically significant mediator in the association between future uncertainty and both problem- and emotion-focused coping strategies.

Conclusions: Brain tumor disease trajectories require people to effectively adopt both problem- and emotion-focused coping strategies to confront uncertainty. Health care providers play a crucial role in evaluating and fostering their patients' resilience to promote adaptability through effective coping strategies.

Introduction

Given the nature of brain tumors, uncertainty may persist throughout the cancer trajectory. In Taiwan, brain tumors account for 1.2% of cancer cases; however, the mortality rate has been rising for 2 decades [1]. The lack of clarity about prognoses leads people with brain tumors to experience ongoing uncertainty along with unpredictable symptom patterns and increases in functional dependency [2]. As a result, these sources of uncertainty may negatively affect their ability to cope with cancer [3].

According to Mishel's uncertainty in illness theory [4], an individual responds to uncertainty by assessing whether it presents a danger or an opportunity. When there is a potential

positive outcome from the uncertainty, the individual may use strategies such as selective ignoring to maintain uncertainty as a source of hope. A danger appraisal may prompt the individual to take action to mitigate the uncertainty [4,5]. For people with brain tumors, the ongoing perception of uncertainty highlights the need for effective coping strategies to support successful adaptation; this is a process that may be strengthened through resilience. The known positive association between resilience and cancer coping [6,7] suggests that cultivating resilience may enhance cognitive appraisal processes and thus increase the adoption of effective coping strategies.

Resilience is defined as the process by which an individual can, in the face of stress, flexibly utilize available external resources (eg, social support from others), internal resources (eg, individual strengths and skills), and existential resources (eg, practices of meaning-making and expressing gratitude) [8]. A qualitative study of people with brain tumors identified the need for resilience, including living in the moment and finding joy, as coping mechanisms for navigating uncertainty [9]. Other studies have shown that resilience mediates the association between symptom distress and quality of life and that resilience has effects on reducing psychological distress [10]. These findings highlight that resilience can serve as a protective factor to empower people to demonstrate flexibility in overcoming difficulties through various resources and coping strategies.

There has been little research on the impact of resilience on how individuals with brain tumors cope with uncertainty. Thus, this study, guided by the uncertainty in illness theory, investigates the effects of resilience on the association between uncertainty and individual coping strategies, including problem-focused coping and emotion-focused coping, among people with brain tumors.

Methods

Sample and Setting

This secondary analysis used data from 95 people with primary brain tumors, which was sufficient to reach the desired power of .80 to examine the effect of future uncertainty on coping strategies through resilience. Participants were recruited during an outpatient visit to a veterans general hospital in Taiwan. Eligibility criteria were (1) patients aged 20 years or older and (2) patients diagnosed with a benign or malignant primary brain tumor and receiving at least 1 month of treatment. People with a diagnosed mental illness or unable to communicate were not eligible to participate.

Ethical Considerations

The parent study was approved by the Taipei Veterans General Hospital (2014-09-007AC) institutional review board (for more details about the parent study, please see [11,12]). Before consenting, participants were informed that they could withdraw from the study at any time without penalty, and that this would not affect their treatment. In addition, no identifiable health information was collected or included in the statistical or data management programs. No compensation was provided to participants for completing the survey.

Instruments

Coping Strategies

We used the Chinese version of the Ways of Coping Checklist–Revised to assess participants' coping strategies. The Ways of Coping Checklist–Revised uses 42 items to assess 5 factors: problem-focused coping, seeking social support, self-blame, distancing, and wishful thinking [13]. We categorized the first 2 factors as problem-focused coping and the other 3 factors as emotion-focused coping [13]. All items use a 5-point Likert scale (0 to 4); higher scores indicate more frequent adoption of a strategy. The McDonald ω for the internal consistency of the total scores of problem-focused and emotion-focused coping were 0.86 and 0.83, respectively.

Future Uncertainty

Participants' future uncertainty was measured using the subscale of the European Organization for Research and Treatment of Cancer's Quality of Life Questionnaire [14]. The 4 items that measure future uncertainty are as follows: (1) Did you feel uncertain about the future? (2) Did you feel you had setbacks in your condition? (3) Were you concerned about disruption of family life? and (4) Did your outlook on the future worsen? All items were measured on a scale of 1 to 4; higher scores represent worse symptoms. The McDonald ω for the total score was 0.80.

Resilience

Participants' resilience was assessed using the Chinese version of the Resilience Scale, with 25 items in 5 domains of resilience, including meaningful life, perseverance, self-reliance, equanimity, and existential aloneness. All items use a 7-point Likert scale ranging from 1 to 7, for a total score ranging from 25 to 175 ($\geq$146=moderately high resilience; 131-145=moderate resilience; $\leq$130=low resilience) [15]. The McDonald ω for the total score was 0.97.

Data Analysis

To examine how resilience affects the effect of future uncertainty on coping, we conducted 2 simple mediation models, with resilience as the mediator and future uncertainty as the predictor of the two different outcome variables: problem-focused coping and emotion-focused coping. Each model consisted of one direct effect of future uncertainty (X) as a predictor of coping strategies (Y) and one indirect effect of future uncertainty (X) on coping strategies (Y) through resilience (M). Inferences about direct and indirect effects were estimated by bootstrapping, which generated 95% percentile bootstrap CIs [16].

Results

Participants adopted both problem-focused coping strategies (mean 58.06, SD 11.10) and emotion-focused coping strategies (mean 43.96, SD 12.06). Half (48/95, 51%) of the participants reported low resilience, and a quarter each reported moderate (24/95, 25%) and moderately high (23/95, 24%) resilience.

Two simple mediation models examined the role of resilience in the different types of coping strategies. The model for resilience as a mediator between future uncertainty and

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problem-focused coping resulted in a standardized coefficient of total effect of −0.202 (Figure 1). When the total effect of future uncertainty was partitioned into direct and indirect effects, the indirect effect of future uncertainty on problem-focused coping through resilience (Figure 1, path A × path B) was statistically different from zero (β=−0.268, SE 0.068, 95% CI −0.406 to −0.142).

The model with emotion-focused coping as the outcome resulted in a total effect of future uncertainty that was statistically significant (Figure 2). The direct effect of future uncertainty on emotion-focused coping was 0.370. The indirect effect of uncertainty through resilience was significantly different from zero (β=−0.133, SE 0.053, 95% CI −0.249 to −0.041).

Figure 1. Simple mediation model estimation results. C' is the direct effect of future uncertainty on problem-focused coping; C is the total effect of future uncertainty on problem-focused coping. *P<.05; **P<.01.
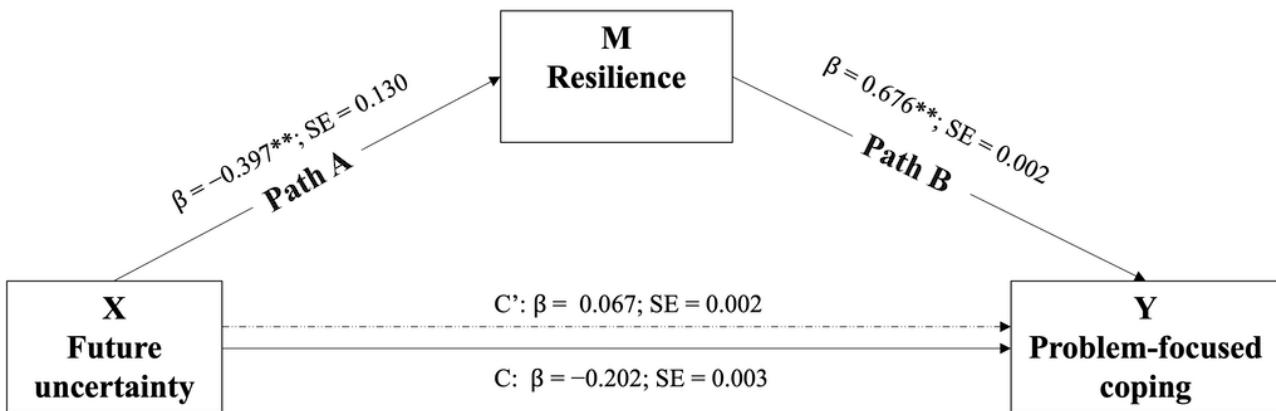
Figure 2. Simple mediation model estimation results. C' is the direct effect of future uncertainty on emotion-focused coping; C is the total effect of future uncertainty on emotion-focused coping. *P<.05; **P<.01.
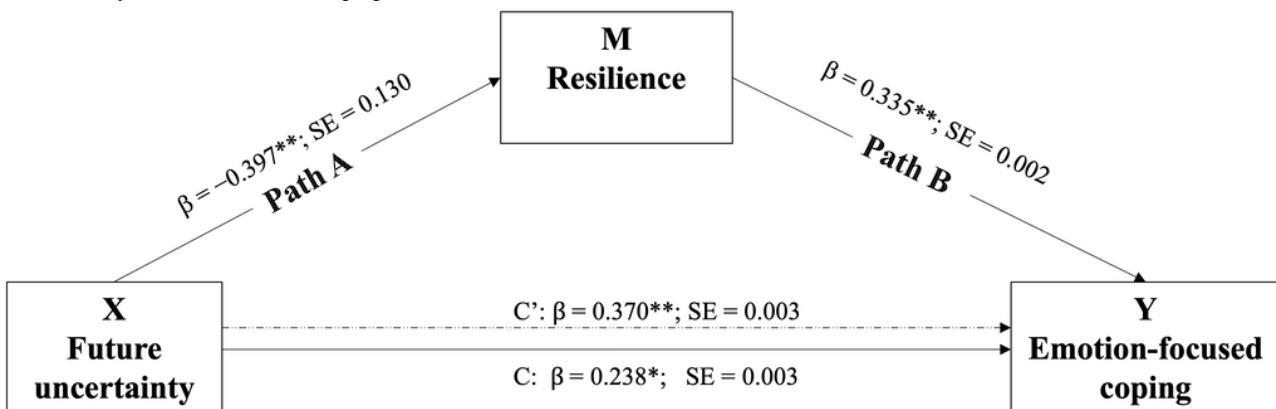
Discussion

Principal Findings

This study investigates the influence of resilience on adopting 2 distinct coping strategies amidst the uncertainty associated with brain tumors. We found that resilience positively facilitated the adoption of both problem-focused and emotion-focused coping strategies and a mediating role for resilience between uncertainty and individual coping strategies. In particular, the mediating effects of resilience appeared to be more pronounced for problem-focused coping, as the direct effect of uncertainty on problem-focused coping became nonsignificant when resilience was included. Indeed, focus group discussions among people with brain tumors revealed that constant uncertainty led to fear, despair, and adjustment difficulties. Over time, they learned to adopt problem-focused coping strategies such as planning end-of-life care to reduce caregiver burden [9]. In other words, resilience is a process of realization through awareness of accurate appraisals, available resources, and the flexible use

of coping strategies [8]. When the cause of uncertainty can be managed, awareness of available informational and instrumental social support through resilience may increase the likelihood of adopting problem-focused coping strategies with greater confidence [7,9,17].

Unclear symptom patterns and prognoses for brain tumors may prompt people to adopt emotion-focused coping strategies. People with brain tumors expressed the need to maintain hope as part of their coping strategies and to live in the present moment to mitigate the impact of psychological distress [9]. In fact, cultivating hope is integral to developing resilience [18], and it has been identified as a predictor of resilience among individuals with cancer [6]. Interestingly, our findings showed that the reduction in resilience resulting from increased uncertainty weakened the overall effect of uncertainty on emotion-focused coping. One possible explanation is that in coming to terms with their condition, people with brain tumors may ultimately cultivate hope, which in turn strengthens resilience and enables them to flexibly adopt either

problem-focused or emotion-focused coping strategies in response to uncertainty.

Limitations

This study captured participants' resilience levels at only one point in time. Our goal was to examine the impact of resilience while recruiting a sufficient sample for analysis within a feasible recruitment period. The study's sample size may limit further investigation. Although our sample shows slightly lower resilience, it remains generally comparable to other samples with brain tumors [19,20].

Clinical Implications

Health care providers can help patients with brain tumors develop resilience by recognizing and applying their external, internal, and existential resources to address uncertainty. With such assistance, the process of building resilience can be accelerated within 12 weeks [21]. Additionally, health care providers can provide meaning-making or gratitude exercises to increase resilience and facilitate successful adaptation [22].

Conclusion

This study highlights the importance of developing resilience to help people with brain tumors accurately appraise and flexibly apply effective coping strategies. The findings provide potential targets for a resilience-building intervention to reduce the impact of uncertainty.

Data Availability

The data collected during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

LTHL wrote the manuscript and analyzed the data. LTHL, AZD, and SYL are responsible for the study design. All authors reviewed and edited the manuscript.

Conflicts of Interest

None declared.

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Pathways and Roadblocks in Navigating Online Cancer Communities: Qualitative Study Among Young Adult Cancer Survivors

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Abstract

Background: Online cancer communities provide young adult (YA) cancer survivors with access to informational and emotional support that may not be available in traditional care settings. While these platforms offer vital connection opportunities, the unique pathways YA survivors take to find online communities and the challenges they encounter remain underexplored.

Objectives: This study aimed to (1) examine how YA cancer survivors locate and access online cancer communities and (2) identify barriers that impede their participation or sustained engagement.

Methods: The first author conducted semistructured interviews with 12 YA cancer survivors aged 18 to 39 years who had experience using online resources after their diagnosis. Participants were recruited through purposive and snowball sampling from YA cancer-focused nonprofit organizations and through social media. Interviews were conducted via Zoom and analyzed using thematic analysis. The analytic process followed Braun and Clarke's 6-phase framework and was supported by MAXQDA software. Codes and themes were generated inductively and refined iteratively.

Results: Participants ranged in age from 24 to 39 years (mean 32, SD 5.08 years), with an average of 3 (SD 2.98) years since diagnosis. Most identified as female (n=9, 75%) and non-Hispanic White (n=7, 58%). Over half held a graduate degree (n=7, 58%), half were employed full time (n=6, 50%), and most resided in suburban areas (n=8, 67%). Cancer diagnoses included leukemia (n=3, 25%), lymphoma (n=4, 33%), and other solid tumors such as testicular, colon, and uterine cancers. At the time of the interview, 3 (25%) participants were in active treatment and 9 (75%) had completed treatment. Participants described five primary pathways to discovering online cancer communities: (1) direct searching using hashtags or keywords, (2) community hubs on public accounts, (3) referrals from health providers or social networks, (4) algorithm-recommended content, and (5) connections formed within preexisting online interest-based groups. Despite the promise of digital tools, participants encountered five roadblocks: (1) platform fragmentation and digital literacy complicated initial discovery; (2) lack of representation made it difficult for some to find communities where they felt seen; (3) emotional overload and engagement fatigue, along with shifting group hierarchies and boundaries, further hindered sustained participation; and (5) lastly, concerns about cyberbullying discouraged open engagement, prompting some to withdraw or limit their presence in online communities.

Conclusions: YA cancer survivors navigated a fragmented and emotionally complex digital landscape in search of social support. Their ability to access and engage with online communities was shaped not only by individual agency and digital literacy but also by structural and relational factors. This study underscores the need for more discoverable, inclusive, and sustainable digital support environments. Oncology professionals and peer survivors can play a vital role in facilitating safe, informed access to online cancer communities. Multilevel psychoeducation and training with health care providers, YA cancer survivors, and online community facilitators are warranted to bridge gaps and enhance equity in digital survivorship care.

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Introduction

Before the widespread adoption of communication technologies, patients having cancer and their families largely relied exclusively on oncology providers for support and information. The rise of social media and online platforms has transformed this landscape, enabling cancer survivors to connect, share experiences, and find vital health information from the comfort of their homes. A report by the Pew Research Center revealed that 11% of adults in the United States have been following their friends' health updates on online communities, and 5% have actively engaged by sharing their own health-related information, questions, or comments [1]. A national survey showed that the general population's online support group participation grew from 5% in 2008 to 9% in 2017 [2].

Online cancer communities refer to groups of people with expressed interest in cancer who communicate using a website, social media platform, instant messaging, or app [3]. These communities, often created by patients, nonprofits, or health communication professionals, serve as supportive spaces for patients, survivors, and caregivers to seek information and emotional connection. Over time, members contribute to an evolving body of shared knowledge, fostering a sense of belonging based on common diagnoses or life circumstances. Cancer survivors report positive attitudes toward these online communities and the social support they provided [4].

Young adult (YA) cancer survivors, a distinct group of cancer survivors defined by the National Cancer Institute [5], often face unique challenges: social and developmental disruptions, feelings of isolation, and limited access to in-person support groups tailored to their needs [6]. Because YAs are often geographically dispersed, online cancer communities provide accessible spaces to exchange health information, share experiences, and find emotional and informational support among peers who understand their situations [7-9]. These communities foster empowerment as both a process and an outcome of participation, complementing traditional health care by promoting agency, peer learning, and self-management [10-12]. Participation can help survivors reclaim a sense of connection, reduce isolation, and build hope for life beyond cancer [13,14].

However, these benefits are not experienced uniformly. Engagement in online cancer communities is shaped by both individual characteristics, such as education level, health literacy, psychological well-being, and personality traits, and community-level factors like dynamics, including reciprocity, inclusiveness, and the quality of moderation [9,15,16]. Understanding how these factors interact to shape YA survivors' participation remains critical to improving access to meaningful online support.

Finding an online community that meets one's emotional and informational needs can be challenging for YA cancer survivors. Although there are various types of online cancer communities, 2 broad classifications, open forums and secret groups, pose distinct challenges for YA cancer survivors seeking meaningful support [17]. Open forums, typically hosted by charities or nonprofits, provide accessible and reliable information but foster limited personal connection, while secret groups, often patient-initiated and invitation-only, offer greater intimacy and emotional support but raise privacy concerns and require trust-building [17]. The diversity of platforms and fragmented resources can make exploration overwhelming. Privacy concerns are also particularly pressing for YAs, who fear being identified by future employers or wider social circles, making them gravitate toward more private groups that require referral to join [18]. However, the intimacy of secret groups comes at the cost of additional risks, including loss of control over shared stories [19,20], emotional distress following other members' death [13,21], and exposure to misinformation or harmful content [22,23].

Taken together, these findings highlight the need to better understand how YA cancer survivors identify and engage with online health communities that align with their emotional and informational needs. Although prior studies have documented both the benefits and challenges of these spaces, little is known about how YAs navigate online resources, find suitable communities, and sustain meaningful participation. The purpose of this qualitative study is to understand (1) how YA cancer survivors locate and access their online cancer communities and (2) what hinders their ongoing engagement.

Methods

Design

This qualitative study used semistructured interviews to explore how YA cancer survivors find, access, and engage with online cancer communities. The study aimed to understand both the pathways through which participants discovered these communities and the barriers they encountered in participating or sustaining engagement over time.

Participants

Purposive and snowball sampling was used to recruit participants. To be eligible for the study, participants needed to (1) receive a diagnosis of cancer at the age between 18 and 39 years, (2) be between 18 and 39 years at the time of the interview, (3) have experiences using social media platforms, and (4) be able to participate in a videoconference interview. The age range was based on the National Cancer Institute's definition of adolescent and young adult (AYA) cancer survivors [5] and was selected to capture the relational and developmental contexts of young adulthood, a life stage marked by key social transitions and identity formation that shape survivorship experiences [6].

The research team developed a flyer that they asked nonprofit organizations dedicated to YA cancer to post on their social media accounts. Cactus Society and Livestrong Cancer Institute, 2 US-based organizations supporting AYA cancer survivors, shared the flyer on their social media accounts. The study flyer contained study aims, the principal investigator's contact information, and a QR code of intake survey on Qualtrics. The principal investigator (QC) followed up with each potential participant to schedule Zoom interviews and gather verbal informed consent.

Data Collection

All interviews followed the same interview guide with some variations based upon the flow of conversation between the participant and interviewer (see Multimedia Appendix 1 for the interview guide, including prompts and questions). The interview guide was developed by the research team. It contained questions related to the ways YA cancer survivors connected to peer survivors on social media, including positive and negative experiences during the process. The interviews were conducted in a one-on-one setting, free from the presence of any nonparticipants. Prior to each interview, participants were instructed to join from a private location and to ensure that no nonparticipants were present or able to overhear the conversation. Interviews were video recorded and transcribed by Zoom. Transcripts were made available for participant review upon request. The interviewer (QC) read through transcripts to ensure the quality of transcription and kept field notes that captured the main points of conversation after each interview.

Data Analysis

Reflexive thematic analysis is a method for identifying, analyzing, and reporting patterns within data, defined by Braun and Clarke [24]. All the transcripts were deidentified before importing into MAXQDA (VERBI Software, 2021), a qualitative software program for data coding and comparison.

Two members of the research team, QC and LZ, independently coded all transcripts using an inductive, consensus-driven approach. The data coding approach was inductive. Codes and theme development were directed by the content of the data, rather than being theoretically driven [24]. Both coders initially reviewed a subset of transcripts to develop a preliminary codebook, which was refined through iterative discussion. Each transcript was then coded separately by both coders, followed by comparison and discussion to reconcile differences and reach agreement on code application and interpretation. Discrepancies were resolved through dialogue until full consensus was achieved, ensuring analytic consistency and rigor.

Following the six-phase process of thematic analysis, QC and LZ began with a process of (1) *data familiarization*, in which QC noted initial analytic observations about each data item and the entire dataset by reading the transcription and field notes. Two transcriptions were coded to (2) *generate initial codes* and develop the first-version codebook with columns of code category, code name, definition, eligibility, and example based on the initial codes. QC and LZ coded the other 2 interviews and revised the codebook accordingly by adding new codes, refining code's eligibility criteria, and adding second-level codes to group the existing codes. After the codebook was finalized with all 12 interviews, the data were organized into a matrix with cases and second-level codes. QC and LZ (3) *searched for themes* by reading and identifying the similarity in data across cases in the matrix. The 2 authors (4) *reviewed the themes* and gave (5) *definitions and names to the themes*. All authors reached consensus regarding the themes' consistency. The last phase was to move from semantic description to interpret the significance of patterns and their broader meaning and implications for the (6) final report.

Rigor

Steps to ensure rigor were based on the trustworthiness criteria of data analysis posited by Lincoln and Guba [25]. The criteria involved establishing credibility, dependability, confirmability, and transferability. Throughout the research process, the first author reported the coding process and reflection of the transcription with the research team to assure the credibility of the analysis. The research team provided consultation and guidance on the naming of codes and themes to ensure the accuracy of language. The first author kept an audit trail (Koch [26]) to record each decision made with modifying the research question, finalizing the data analytic approach, and coding and analyzing the pattern to improve the dependability of the finding. Qualitative software was used, as it permits greater audibility and hence increases the reliability of the data analysis process.

Confirmability was sought by regular review and discussion of the codes with the research team by discussing reflexivity and how the interactive nature of the interview process influenced data collection. Member checking was not conducted, as this study employed a reflexive thematic analysis approach in which meaning is understood as coconstructed through researcher interpretation rather than verified by participants. Following Braun and Clarke's distinction, traditional member checking assumes the existence of a single, verifiable truth and seeks to "correct" researcher subjectivity—an assumption that sits conceptually at odds with reflexive thematic analysis, where researcher subjectivity is viewed as an analytic resource, not a bias to eliminate [27]. Consistent with the interpretivist assumptions of reflexive thematic analysis, data saturation was not used as a criterion for determining sample adequacy because Braun and Clarke [28] advocated for achieving meaning through researcher interpretation.

Ethical Considerations

Institutional review board approval was granted for this study by the University of Texas at Austin (protocol STUDY00003004). All study procedures complied with institutional and national research ethics standards for research involving human participants. Participants were informed of the study purpose, confidentiality protections, the benefits and risks of participation, and their rights to withdraw at any time. Prior to participation, all participants provided verbal informed consent to take part in the study and to be video recorded. Participation was voluntary, and participants were reminded that they could decline to answer any question or withdraw from the study at any time without penalty. All data were deidentified during transcription and analysis. Identifying information such as names or specific personal details was removed or replaced with pseudonyms. Digital recordings and transcripts were stored in a secure and access-restricted folder on UT Box, accessible only to the research team. Each participant received a US $20 Amazon electronic gift card, sent via email upon completion of the interview, as compensation for their time and contribution to the study.

Positionality

The research team represents a diverse group of scholars and practitioners whose social identities, disciplinary backgrounds,

and professional experiences shaped the design and interpretation of this study. QC (Asian woman, Assistant Professor of Social Work, and a PhD candidate at the time of the study), ED (White woman, Professor of Communication), LN (Black woman, Assistant Professor of Social Work), and BJ (White woman, Professor of Social Work) are seasoned qualitative researchers with a PhD degree and extensive experience studying psychosocial oncology, communication, and health equity among AYA cancer survivors. LZ (Asian woman, social work clinician, and doctoral student), the second coder of the transcript, brought both clinical practice experience and methodological expertise in qualitative research. The interviewer QC's interest in this topic stems from her professional experience in psychosocial oncology and her commitment to addressing disparities in access to cancer support as well as the rising use and impact of communicative technology during the COVID-19 pandemic. She acknowledges that her background as a social work researcher and her own positive experiences with online communities as an immigrant may have shaped assumptions about online support and digital disparities. As someone who is not a cancer survivor herself, she remains mindful of the potential distance between her professional perspective and participants' lived experiences. QC had limited prior relationships with participants. One participant was a personal friend of QC, while all others had no prior relationship with the interviewer. Participants were informed about QC and the study through the introductory phone calls or emails and the consent form, which described QC's role as the principal investigator and explained the study's purpose, goals, and procedures. No additional personal or professional information was shared beyond what was stated in the consent materials.

Results

Participants' Characteristics

A total of 20 potential YA participants who filled out the screening questionnaire were all eligible for the study. Of these 20 YAs, 8 did not respond to the principal investigator's emails or phone calls, and 12 consented and were recruited to participate in the interviews, yielding an enrollment rate of 60%. Figure 1 presents the recruitment and analysis process flowchart. Semistructured individual Zoom interview data were collected from September 2022 to February 2023, ranging from 39 to 110 minutes (mean 67.2 min, SD 21.3 min). No repeated interview was carried out, and no participants were requested to review or edit their transcripts. The demographic information of participants is presented in Table 1. Participants had a mean age of 32 (SD 5.08; range 24‐39) years and an average of 3 (SD 2.98; range 0‐11) years since diagnosis. Most participants were identified as female (n=9, 75%). The majority were non-Hispanic White (n=7, 58%), followed by Hispanic (n=2, 17%) and Asian (n=2, 17%), and 1 (8%) identified as multiracial. Over half (n=7, 58%) of participants held a graduate degree, while 4 (33%) had completed some college or a college degree, and 1 (8%) had completed high school. In terms of employment, 6 (50%) participants were employed full-time, 2 (17%) part-time, and 4 (33%) not employed. Participants resided in 8 different states. Most participants resided in suburban areas (n=8, 67%). Cancer diagnoses among participants varied, with leukemia being the most common (n=3, 25%), followed by Hodgkin's lymphoma (n=2, 17%), testicular cancer (n=2, 17%), and individual cases of non-Hodgkin's lymphoma, colon, brain, soft tissue, and uterine cancers (each n=1, 8%). At the time of the interview, 9 (75%) participants had completed treatment, while 3 (25%) were still in active treatment.

Figure 1. Participant recruitment and thematic analysis process flowchart [24].
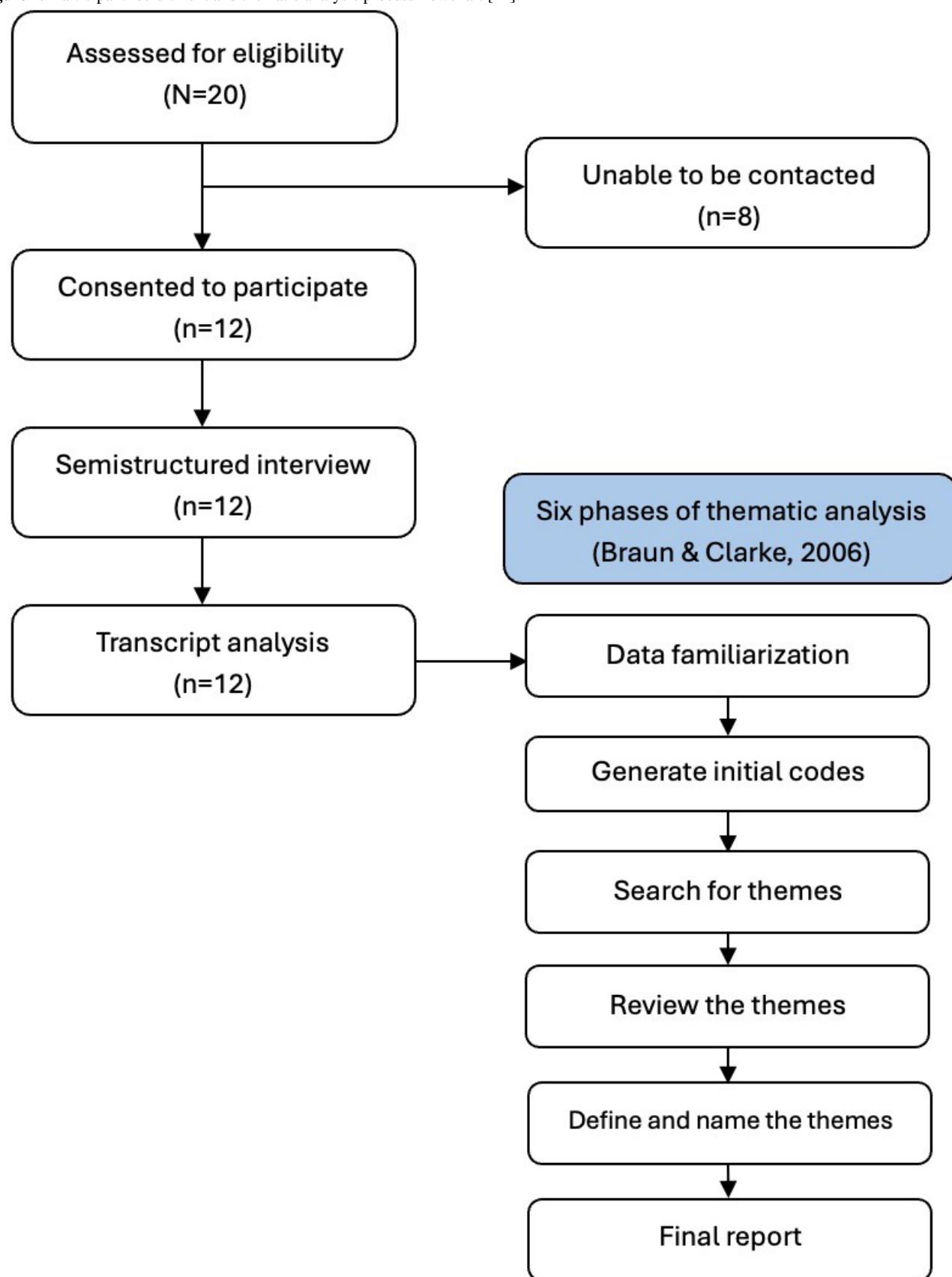
Table . Participant demographics and background information (n=12).

Demographics	Count
Age, mean (SD; range)	32 (5.08; 24-39)
Years since diagnosis, mean (SD; range)	3 (2.98; 0 ‑ 11)
Sex, n (%)	
Female	9 (75)
Male	3 (25)
Race, n (%)	
Non-Hispanic White	7 (58.3)
Hispanic	2 (16.7)
Asian	2 (16.7)
Multiracial	1 (8.3)
Education attainment, n (%)	
High school	1 (8.3)
Some college or college	4 (33.4)
Graduate school	7 (58.3)
Employment, n (%)	
Full time	6 (50)
Part time	2 (16.7)
Not employed	4 (33.3)
Location (State), n (%)	
Texas	3 (25)
New York	2 (16.7)
Illinois	2 (16.7)
Pennsylvania	1 (8.3)
Wisconsin	1 (8.3)
Florida	1 (8.3)
Maryland	1 (8.3)
Michigan	1 (8.3)
Urbanicity, n (%)	
Urban	4 (33.3)
Suburban	8 (66.7)
Cancer diagnosis, n (%)	
Leukemia	3 (25)
Hodgkin's Lymphoma	2 (16.7)
Testicular cancer	2 (16.7)
Non-Hodgkin's Lymphoma	1 (8.3)
Colon cancer	1 (8.3)
Brain cancer	1 (8.3)
Soft tissue cancer	1 (8.3)
Uterine cancer	1 (8.3)
Treatment status, n (%)	
Completed	9 (75)
In active treatment	3 (25)

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Qualitative Findings

This study explored 2 central questions: (1) how YA cancer survivors locate and access online cancer communities and (2) what challenges they encounter in sustaining engagement. The findings revealed a range of entry points that survivors used to discover supportive online spaces, as well as structural, interpersonal, and emotional factors that limited their continued participation. While participants represented a range of ages within the YA category (24‐39 y), their approaches to engaging with online cancer communities and the obstacles they experienced were broadly similar. No age-related patterns were observed in terms of search strategies, preferred platforms, or engagement levels.

The results are presented in 2 sections, corresponding to each research question. The first section, *Pathways*, included 5 themes describing how YA cancer survivors found online communities: (1) search, connect, and join/build, (2) community hubs, (3) third-party referrals, (4) algorithm recommendations, and (5) online interest-based groups. The second section, *Roadblocks*, outlined 5 themes that capture barriers to sustained engagement: (1) platform fragmentation and digital literacy, (2) group boundaries and hierarchies, (3) lack of representation, (4) emotional overload and engagement fatigue, and (5) cyberbullying. Figures 2 and 3 depicted 2 coding trees of Pathways and Roadblocks to illustrate the codes identified and themes emerged in the analysis. Table 2 presents each theme along with its definition and representative participant quotes.

Figure 2. Coding tree of "Pathways" illustrating how young adult cancer survivors discovered online cancer communities.
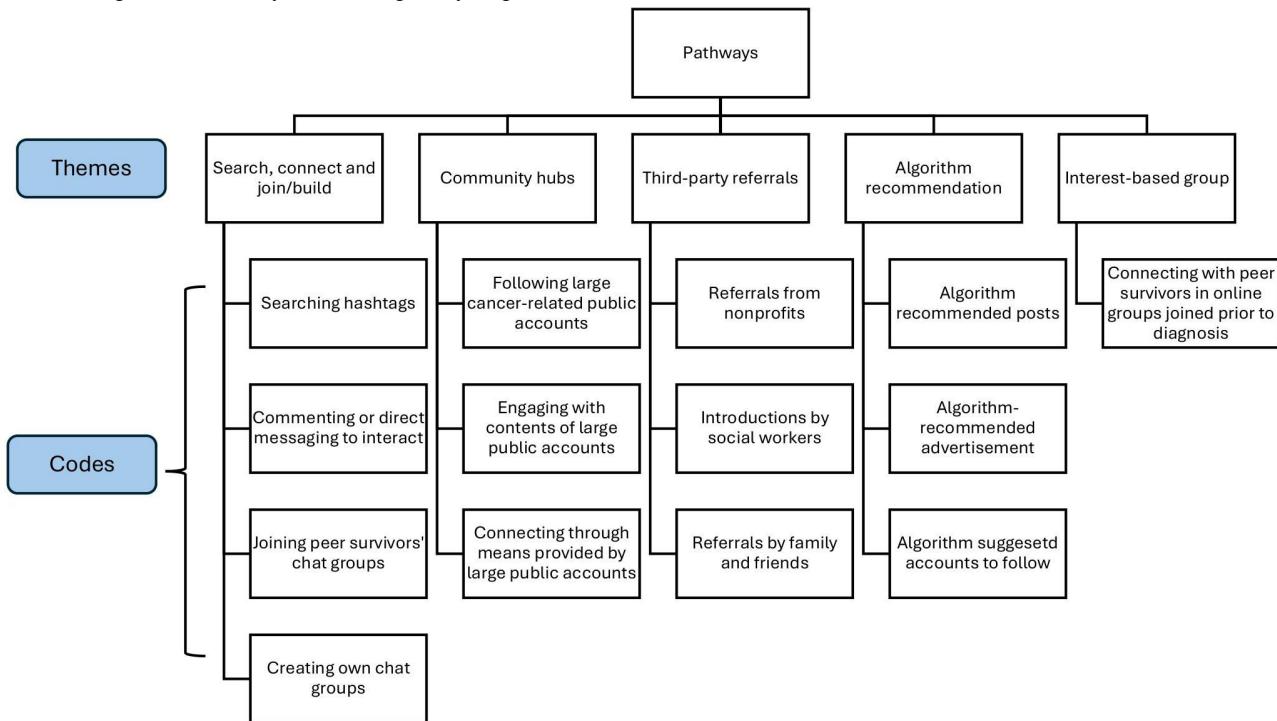
Figure 3. Coding tree of "Roadblocks" illustrating barriers that young adult cancer survivors encountered in sustaining engagement with online cancer communities.
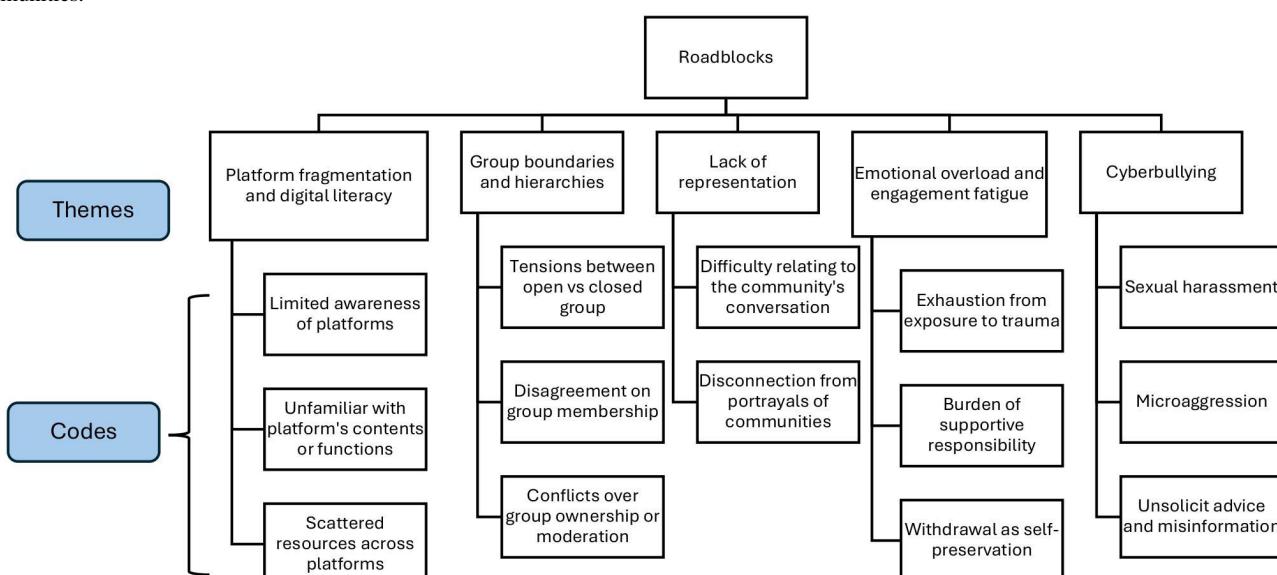
Table . Themes, description, and representative quotes: pathways and roadblocks.

Themes	Description	Representative quote
Pathways		
Search, connect, and join/build	YA survivors actively searched relevant hashtags and initiated contact with peer survivors through comments or direct messages, leading to joining an existing community or forming their own community	• *She has a decent following, so I didn't expect her to see it or anything, but she responded back. So I messaged her, and then suddenly started messaging and then exchanged phone numbers and she's like, I've met a few other girls, who also going through cancer treatment this summer. So then she made a group chat for us. And then we said we all will support each other through cancer treatment this summer, when we should like having fun or whatever. That was like eight months ago, we still talk almost like every day.* (Participant 09) • *First of all, I was adding people that were in my state to try and build a community in my state, then it widened out more and more. And we would eventually share each other's Instagrams and that's how I built it up. Sometimes I'll still search up care packages, just to see if there's any new ones to add to my list, but also to see any people out there so I can connect with them.* (Participant 10)
Community hubs	YA cancer survivors followed large public accounts serving as information hubs for peer interaction.	• *The person who runs the account made a spreadsheet where people could put their name, their age, their diagnosis, and where they lived and the Instagram handle. And then, if anybody wanted to talk to them they could reach out. So I put my information on that spreadsheet, and I had one person reach out.* (Participant 08)
Third-party referrals	Nonprofit organizations or health care providers referred YA cancer survivors to existing online groups.	• *The other organization does a weekly happy hour every Friday, and that is the same host every time, and I started going and I found out from people who go to that also go to Stupid Cancers zoom session. And so, there's a lot of cross involvement with different survivors are part of and take part in programming for different AYA groups. Some of my closest friends that I've connected with there, I have almost all of them on Instagram and/or Facebook. I talk with them on an Instagram group Chat* (Participant 06).
Algorithm recommendations	YA cancer survivors encountered groups through social media algorithm suggestions.	• *When I search for something on Google, Facebook picks up my information and pushes related content… I can even see on Facebook what I had just searched for on Google.* (Participant 01) • *That was through algorithm. I didn't search for anything during that time. I think I just got lucky that one day, and she already knew people. That was like pure luck, like it was meant to happen. I don't think I find that many people on social media share similar experiences.* (Participant 09)
Online interest-based groups	YA cancer survivors found peer support within preexisting online interest or hobby groups.	• *It wasn't a cancer group, but people there had similar ages and life experiences, so I felt connected.* (Participant 07)

Themes	Description	Representative quote
Roadblocks		
Platform fragmentation and digital literacy	YA cancer survivors struggled to locate reliable supportive communities due to scattered platforms and lack of digital literacy.	• *I didn't really use Facebook and Instagram much so I was not aware of those accounts. I used to only use Chinese-language platforms and those that are available for Chinese people. I like hanging out with other Chinese people more.* (Participant 01)
Group boundaries and hierarchies	Conflicts over group ownership, membership criteria, or tone led to disengagement.	• *Sometimes caregivers come in, and they'll tell us 'Oh, how inspirational you are.' And we just don't know how to take that because we're like, we're just trying to live our life or don't feel inspirational.* (Participant 10) • *It fell apart because there was a disagreement over who was old enough to be in the group, and that hurt some people's feelings… and another group (that was dismissed), it turned out one person was making stuff up and people just didn't want to be a part of the group.* (Participant 06)
Lack of representation	Limited diversity (age, diagnosis, culture) left survivors feeling disconnected or unseen.	• *I couldn't really find a relevant account about infertility that felt like it described my experience. I followed some infertility-related accounts that weren't cancer specific, but just about people who had infertility in general, and those accounts are mostly run by white women who are really religious and really Christian. And so I think I've decided not to engage with those accounts anymore, just because I couldn't find anybody who had experiences that were similar to me or identities that were similar to mine.* (Participant 08)
Emotional overload and engagement fatigue	Exposure to others' trauma and constant emotional demands led to burnout and withdrawal.	• *I already felt miserable and no one cared about me... but seeing them vent still made me feel awful… On top of my own problems, I have to carry others' misery… thinking about their fate makes it unbearable.* (Participant 01) • *Sometimes it can feel a little repetitive. Like there are certain types of posts that I feel like you see again and again and again. So I think that can make it hard to stay engaged.* (Participant 03)
Cyberbullying	Harassment or microaggressions led survivors to privatize accounts, reducing visibility and engagement.	• *There's a subsection of people who are really weird that like bold girls. They will message cancer patients with really graphic descriptions. I've got that kind of message.* (Participant 10)

Pathways

YA cancer survivors accessed online communities through a range of entry points that reflected both deliberate strategies and serendipitous discovery.

Search, Connect, and Join/Build

This was the most common way YA cancer survivors mentioned regarding finding and joining their online cancer community. Usually, it would start with searching for keywords related to their cancer diagnosis or type of treatment, or the hashtag #AYAcancer, #YoungAdultCancer, #AYAcancer, or #cancerinyour20s, to identify peer YA survivors who shared similar cancer experiences. Some YA cancer survivors would initiate the conversation by commenting on the post of accounts they identified, such as sending wishes and making comments on similar cancer-related situations they share, and some would directly message to connect. After the connection was established and a larger network based on similar cancer experiences was formed, sometimes a chat group/channel would be created by one of the group members. There were also some

other YA cancer survivors taking a leading role in creating a community for people they knew and actively searching out to YA cancer survivors who might be looking for support on social media.

Community Hubs

Community hubs were centralized online spaces managed by individuals or small groups, serving as anchors or gatekeepers for connection, information exchange, and peer support. We found that there were such hubs that existed for YA cancer survivors to connect: almost all of the participants followed the accounts @thecancerpatient and @NoGriefTouristAllowed on Instagram. These accounts shared similar traits: large number of followers and mostly YA cancer survivors. They served as an information hub for YA cancer survivors. A YA cancer survivor community was naturally formed based on these 2 accounts, and these accounts were acknowledged and advertised by these cancer survivors at platforms other than Instagram. These public accounts connected peer survivors through posts that reflected shared cancer experiences. People responded in the comments or initiated conversations or through "story" (posts visible for 24 h) featuring followers' requests to connect. Some accounts would create ways to collect the contact information of those who want to connect.

Third-Party Referrals

YA cancer survivors also found nonprofit organizations or social workers at the hospital or cancer center helpful in referring to reliable online support resources. Nonprofit organizations dedicated to adolescent and YA cancer care, such as Stupid Cancer, Elephants and Tea, and Cactus Cancer Society, usually host online support groups and have their own forum or social media accounts. YA cancer survivors described being connected across different organizations, participating in multiple online cancer communities, and then forming their own communities in other social media platforms. YA cancer survivors also shared that when their family and friends found related resources, they would also recommend them and encourage them to connect. For instance, one participant mentioned that her sister has been an active user on the Reddit Cancer Caregiving subreddit and recommended her to join a cancer-related Reddit channel to find the community.

Algorithm Recommendation

As algorithm recommendation technology continued to advance, YA cancer survivors also benefited from recommendations on websites and apps they visited. Some described seeing the advertisement of Leukemia Society on Facebook after multiple rounds of internet search about Leukemia and survival rates and ended up visiting the site and found peer support programs. Some described their experiences of being recommended social media personal accounts with contents that were relevant to their life experiences and being able to connect with those people.

Online Interest-Based Groups

YA cancer survivors were comfortable with communication technologies, and they browsed different online communities at an early age. Therefore, many of them were already part of some online communities before they got cancer. One participant described her experience being in one huge interest group community, and there was a subgroup with people diagnosed with different types of cancer and stages of cancer. Even though it was not specifically for YAs, the participant described that since these interest-based groups were usually formed with people of similar age, demographic, and political outlook, or shared hobbies, it was easier to feel connected to these people.

Roadblocks

While online communities offered vital spaces of support, YA cancer survivors reported a number of challenges that shaped their participation.

Platform Fragmentation and Digital Literacy

Participants described difficulties locating relevant support communities due to the fragmented nature of social media platforms. Information and resources were scattered across platforms such as Instagram, Facebook, Reddit, and organization-specific forums, many of which lacked centralized searchability. Some participants were unfamiliar with widely used platforms in the United States, particularly immigrant YA cancer survivors who previously used regional platforms to maintain relationships with family and friends back in their home countries. This limited exposure made it challenging to access content or locate established YA cancer communities on English social media platforms.

Others noted that even when they were familiar with a platform, they often lacked the knowledge of which accounts or groups to follow. Many were also unaware of nonsocial media–based online communities. For instance, one participant shared her experience of only recently learning about COLONTOWN, a web-based platform uniquely for colorectal cancer survivors. Furthermore, many shared that YAs who were connected through one platform might move to another to create their own group, sometimes choosing platforms others had never used or did not have accounts on. These access disparities underscored how platform fragmentation and varying levels of digital literacy could hinder survivors' ability to locate and engage with appropriate sources of support.

Group Boundaries and Hierarchies

Online community boundaries could be challenging to manage. In open forums, lacking group boundaries would trigger uncomfortableness and conflicts and thus decrease their interests in staying in the group. Participants stated that for some groups that also welcomed the participation of caregivers, family members, or providers would interrupt the group dynamics and disrupt the sense of safety and belonging of the community. In secret/closed groups, group hierarchy, group ownership, and group membership could also become problematic. If agreement could not be achieved between group owner and group members, it would cause conflict, and the online group would have to be dismissed if conflicts continue to escalate.

Lack of Representation

Not all online cancer communities effectively met the informational and emotional support needs of YA cancer survivors. Several participants in the study described feeling like "outsiders" in these spaces. A major barrier to meaningful

engagement was the perceived lack of inclusiveness and representation. Participants emphasized that the characteristics of community members, such as age, diagnosis, religion, health beliefs, cultural background, and treatment experience, strongly influenced their sense of connection. When these attributes did not align, it was difficult to relate to others or feel understood. For example, wide variations in treatment plans and side effects among YA patients having cancer made it challenging to find peers with similar experiences. The more disconnected participants felt from the community, the less likely they were to engage.

Some YA cancer survivors expressed discomfort with content on accounts that were community hubs and overly romanticized the cancer experience. They found such narratives to be superficial and disconnected from their own realities, making it harder to relate or feel represented. One participant shared that she avoided public accounts that presented highly curated or idealized portrayals of survivorship, as they felt inauthentic and failed to meet her informational or emotional needs.

Emotional Overload and Engagement Fatigue

For many YA cancer survivors, ongoing exposure to peers' illness narratives in online communities could generate a deep sense of emotional fatigue, like one participant said: "Everyone's unloading their trauma and it's overwhelming." (Participant 05). This exhaustion stemmed from not only the content's intensity but also the complex dynamics of shared vulnerability and responsibilities. This form of emotional overload often coexisted with a sense of obligation to support, which heightened the burden. In addition to this emotional overload, participants described seeing similar posts over time could become draining. These revealed not a loss of interest but the emotional cost of showing up, where survivors must balance their need for support with the strain of witnessing others' ongoing pain. Self-preservation, through withdrawal or silence, became a necessary response for survivors negotiating their own healing within communal spaces of vulnerability.

Cyberbullying

For people to be able to search one's posts or follow one's account, one needs to keep their account and posts public. However, being public and exposing themselves to the internet could be risky, especially for YA survivors. Many participants reported microaggression and cyberbullying on social media, such as unfriendly comments on their appearance, unsolicited advice, or even sexual harassment. As a result, YA cancer survivors who keep their accounts public to share their cancer experiences and help peer survivors connect initially would change their account setting to private to avoid these negative impacts. The unsafe environment on social media would limit the information source that peer YA cancer survivors could access.

Discussion

Overview

This study provided timely insights into how YA cancer survivors navigated the increasingly complex landscape of online cancer communities. It identified 5 key pathways to discover online communities and 5 major barriers in finding and sustaining engagement. The findings revealed that survivors' participation was influenced not only by personal agency and constraints but also by systemic factors such as platform accessibility and usability. The findings also further illuminated understudied interpersonal dynamics, such as emotional labor and shifting hierarchies and boundaries within communities, that affected survivors' sustained involvement in online communities. By centering YA cancer survivors' lived experiences in exploring online communities, this research advanced a more nuanced understanding of how to foster inclusive, meaningful, and sustainable online support communities.

Principal Findings

This study uncovers new forms of digital space navigation and structural inequity that shape survivors' ability to benefit from online support. Our findings showed that with more online platforms available, YA survivors joined or formed communities across different platforms and often switched between them. While new features such as algorithmic recommendations, hashtags, stories, and group chat channels allowed them to find or form online cancer communities more easily, the benefits of these tools were not experienced equitably. Participants' capacity to navigate and engage effectively was strongly influenced by their familiarity with functions of different platforms, many of which were not accessible to all users. For instance, immigrant survivors originally from countries where platforms like Facebook and Instagram are banned often lacked exposure to dominant US platforms. It demanded additional effort to learn and transition to a different platform solely for the purpose of accessing online support. Furthermore, limited access to certain social media platforms among users from specific cultural backgrounds results in fewer online support communities offering inclusive and culturally relevant content in their native languages. This disproportionately affected YA of color. These gaps in representation were compounded by algorithmic patterns that reinforced misinformation and unsolicited advice, disproportionately affecting those with lower health literacy or limited English proficiency. Together, these findings reveal how structural digital inequities shaped YA survivors' capacity to benefit from online support.

This study reveals that YA survivors' engagement with online cancer communities was emotionally dynamic and relationally fluid. Their interactions were marked with uncertainty and change. Navigating online cancer communities involved ongoing assessment of the relevance of the communities, negotiation of personal or group boundaries, and weighing between benefits and the risks. Some participants moved fluidly between communities or platforms as new communities emerged and migrated, while others withdrew temporarily or permanently when the emotional toll became too high. Rather than serving as a stable or consistently supportive resource, online cancer communities could also generate emotional distress, uncertainty, and exposure to unsafe or overwhelming virtual environments.

Comparison to Prior Work

This study extends prior digital health disparity research on YA survivors' online support by shifting attention from individual

constraints in digital literacy to structural inequities in virtual spaces. Prior research has largely emphasized individual-level factors such as education, socioeconomic status, or their social capital as the main drivers of digital divide in access and utilization of online resources [29,30]. Our study reveals that digital disparities persisted even among digitally savvy YA survivors, driven by the nature of online platforms. Participants' platform preferences were shaped by the habits as well as the accessibility of apps and websites of their families and social networks [30]. One prior study has similarly identified representation barriers, which noted that YA survivors often avoided older platforms such as Facebook, where most established cancer support groups exist, due to perceived misalignment with their peer networks and identity [13]. Familiarity with specific platforms, access to culturally relevant content, and the design of digital infrastructures emerged as key determinants equally impacted YA. This shift from individual to systemic explanations underscores the importance of improving platform accessibility and usability.

This study also advances existing literature by revealing how interpersonal dynamics within online communities could introduce more emotional distress and uncertainties besides support. Consistent with the prior findings, our study found that YA cancer survivors had strong needs of connecting to peer survivors [31] and they would search online proactively to find peer survivors [32]. Our study pointed out that, however, engagement was not always self-initiated; algorithms or others' suggestions often prompted participation, leading to interpersonal strain. Prior work has well documented the benefits for YA cancer survivors involving online cancer communities, emphasizing information exchange, social support, and empowerment [31,33,34]. Risks such as exposure to distressing content or misinformation have also been acknowledged, though often discussed as isolated, individual experiences [35]. One prior study has examined the dynamics of social media engagement among YA cancer survivors, but focusing primarily on individual motivation and preferences [32]. Our findings expand these understandings by showing that group-level factors such as changing boundaries, evolving hierarchies, and the associated emotional labor directly influence engagement and withdrawal. By framing these experiences as relational and evolving, this study highlights that community organizing and group moderation is necessary for virtual spaces.

Limitations

This study has several limitations. First, our sample included only participants who had internet access and prior experience using social media. It remained unclear whether YA cancer survivors without such access or experience would be open to, or able to engage with, online cancer communities. This inclusion criterion was necessary to ensure that participants could reflect meaningfully on their experiences navigating online communities. However, it may have limited the perspectives of YA cancer survivors with limited digital access or literacy or who lack interests in online cancer communities. Future studies should consider various recruitment strategies (eg, phone interviews or community-based outreach) to capture the experiences of survivors who have not been involved with any online cancer communities.

Second, the sample lacked representation from African American participants. Prior research indicated that African American cancer survivors were underrepresented in online support groups and less likely to use the internet for health information compared to their White counterparts, due in part to digital access barriers, differing help-seeking preferences, and lower trust in online health sources [36,37]. Although we recruited through multiple nonprofit networks serving diverse populations and encouraged participant referrals, our sample may have unintentionally excluded survivors not affiliated with such organizations or those relying on offline or culturally specific support systems. Future research should employ more inclusive recruitment strategies, including outreach through hospital registries, partnerships with African American survivor networks or community centers, and targeted social media campaigns or accounts that have higher number of African American followers. Addressing these structural and digital inequities is essential to advancing equity and representation in digital cancer survivorship research.

Future Directions

Future intervention research and clinical practice should focus on improving the accessibility and sustainability of online cancer communities through both structural support and individual capacity-building.

At the system level, oncology social workers have long played a critical role in connecting patients with fragmented resources [38], and our findings further confirmed this essential function. However, many social workers, particularly those outside of large cancer centers, were not well-versed in the availability of online cancer communities and virtual support groups for minority YA survivors on various scattered platforms [31]. While social support from family, peers, and health care providers can facilitate access to online communities, the active involvement of health care professionals or trained moderators in online health communities enhances trust, reduces the spread of misinformation, and mitigates risks such as cyberbullying and communication breakdowns [39,40]. Expert-led moderation has been associated with improved emotional safety, greater engagement, and more supportive peer interactions [41]. This underscores the importance of digital literacy training with health care professionals to strengthen their competencies in navigating and moderating different online cancer communities, so they can more effectively refer, prepare, and support YA survivors.

At the individual level, private or peer-led groups typically rely on YA survivors themselves to establish norms and maintain boundaries, placing added emotional and relational burdens on those already coping with cancer. Our findings indicated that many YA survivors not only passively join a group but actively take part in building or contributing to their own communities. One promising approach is to train YA cancer survivors who are interested in leadership roles in online communities on skills to identify harmful content, establish group norms, and manage conflict. Additionally, while the prevalence of cyberbullying and emotional risk in online communities has been documented [42], few interventions exist to prepare survivors for these challenges. Education around safe storytelling, self-care, and

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managing online engagement fatigue should be integrated into survivorship support programming [35]. This includes guidance on when to disengage, how to set personal boundaries, and how to respond to toxic interactions.

Conclusion

This study highlights that YA cancer survivors navigate online communities through multiple pathways but face significant barriers to sustained engagement, highlighting the need for provider training and peer moderator support. To foster safer and more inclusive online environments, health care providers should be trained to guide survivors toward reliable support resources; community moderators should be trained to manage emotional labor and maintain healthy group boundaries; and YA cancer survivors should receive survivorship support to navigate online spaces effectively. Strengthening these multilevel supports can enhance the sustainability and psychosocial benefits of online cancer communities for YAs.

Data Availability

The datasets generated or analyzed during this study are not publicly available due to the sensitive and potentially identifiable nature of qualitative interview data and the absence of participant consent for open sharing, but are available from the corresponding author on reasonable request.

Authors' Contributions

QC contributed to conceptualization, data collection, project administration, data analysis, and original draft writing. ED was responsible for conceptualization, methodology, review, and editing of the manuscript. LZ contributed to data analysis. LN contributed to methodology and review and editing. BJ was involved in conceptualization, supervision, and funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[DOCX File, 22 KB - cancer_v12i1e79893_app1.docx]

Checklist 1
COREQ checklist.
[PDF File, 381 KB - cancer_v12i1e79893_app2.pdf]

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Abbreviations

AYA: adolescent and young adult
YA: young adult

<u>Original Paper</u>

Benefits and Challenges of a Digital Exercise and Mind-Body Program During Active Cancer Treatment: Qualitative Study of Patients' Perceptions

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Abstract

Background: Individuals undergoing cancer treatment often face a high symptom burden that impairs quality of life. Exercise and mind-body therapies have been shown to reduce symptoms but are underused. We developed a digital exercise and mind-body therapy program that effectively reduces symptoms while overcoming in-person delivery barriers. Understanding patient experiences can inform treatment mechanisms and guide digital health interventions in cancer care.

Objective: This study aimed to explore patient experiences with Integrative Medicine at Home (IM@Home), a 12-week live digital program delivering exercise and mind-body therapies tailored to the needs of individuals undergoing cancer treatment.

Methods: This qualitative study was embedded in a randomized clinical basket trial (NCT05053230) evaluating the effects of IM@Home versus enhanced usual care on symptoms and acute health care utilization in adults with solid tumors undergoing active treatment and experiencing moderate or greater fatigue. Using maximum variation sampling, 20 participants were selected for semistructured interviews. Interviews explored participants' experiences with the program, its impact on outcomes, unmet needs, and suggestions for improvement. Transcripts were analyzed using a combined inductive and deductive thematic analysis.

Results: Twenty participants (mean age 63, SD 9.6 years; 18/20, 90% female) were interviewed. Five major themes emerged: (1) IM@Home alleviated symptom burden and supported symptom self-management; (2) IM@Home facilitated social support and information exchange; (3) IM@Home offered a flexible, tailored program in a group setting; (4) IM@Home facilitated accessible, cost-effective support; and (5) recommendations for program enhancement. IM@Home was perceived as an accessible, flexible, and supportive program that promoted physical and emotional well-being during treatment.

Conclusions: IM@Home demonstrates a promising model for delivering integrative supportive care during cancer treatment. Findings highlight patient-valued features such as real-time guidance, tailored content, and community support. These insights can inform future implementation, integration into clinical care, and efforts to enhance digital mind-body interventions in oncology.

Trial Registration: ClinicalTrials.gov NCT05053230; https://www.clinicaltrials.gov/study/NCT05053230

International Registered Report Identifier (IRRID): RR2-10.1038/s41746-024-01387-z

KEYWORDS

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Introduction

In 2024, an estimated 2,001,140 new cancer cases were expected in the United States [1], with most individuals undergoing systemic therapy or radiation [2]. While these treatments have significantly improved survival rates, people with cancer often experience a high symptom burden, including fatigue, pain, and insomnia, which can lead to reduced quality of life and, in some cases, treatment discontinuation [3,4]. A recent systematic review found that up to 90% of patients undergoing active cancer treatment reported unmet needs, with psychological (eg, anxiety and fear) and physical (eg, tiredness and lack of energy) challenges being most prevalent [5]. Exercise and mind-body therapies (eg, meditation, yoga) are endorsed by leading oncology organizations, including the American Society for Clinical Oncology, the Society for Integrative Oncology, and the National Comprehensive Cancer Network, as effective strategies for managing cancer treatment-related symptoms [6-10], therefore, improving treatment adherence and survival rates [11-13]. However, clinical implementation remains limited due to barriers, such as limited access, restricted modality options, and logistical challenges (eg, travel) [14-19]. Innovative delivery methods are urgently needed to address these barriers and integrate these therapies into oncology care.

Digital health technologies, including remote delivery of clinical or supportive care via telecommunications (telehealth), health services delivered through mobile health devices, and internet-based health services (eHealth), show promise for improving access [19-22] and are widely used in cancer care for symptom management [23-27], treatment supervision [28,29], and clinical trials [30-33]. Examples relevant to cancer care include mobile apps for symptom tracking and medication [34,35] and wearable activity monitors to promote physical activity and exercise [36,37]. However, their adoption for delivering exercise and mind-body therapies during cancer treatment remains limited, with concerns including ensuring safety when patients engage remotely, tailored patient-centered program design for online group formats, and addressing technical barriers [19]. To address these gaps, at Memorial Sloan Kettering Cancer Center (MSK), we developed a novel Integrative Medicine at Home (IM@Home), a 12-week live, digital telehealth program delivering group-based exercise and mind-body therapies [38,39], designed specifically for individuals with cancer. IM@Home combines multiple evidence-based modalities—including yoga, meditation, and fitness—with intensity and activities tailored to participants' needs and treatment-related limitations. Patients have unlimited access to classes, allowing them to choose sessions based on their preferences, providing flexible and ongoing support. A randomized clinical trial (NCT05053230) of 200 patients in active treatment demonstrated IM@Home is safe and effective in reducing fatigue, anxiety, and depression, while lowering acute health care utilization [40].

While quantitative data support IM@Home's clinical benefits, understanding the end user experience is essential to inform broader implementation and patient-centered refinement, particularly in oncology, where patient safety and care needs are heightened [41-43]. To fully understand how complex interventions such as IM@Home lead to change in outcomes, it is important to examine the broader context in which these interventions operate. This includes moving beyond standardized outcome assessments to actively include the voices of individuals directly targeted by the intervention, whose experiences and perspectives are crucial to refining the delivery and ensuring real-world relevance [44]. Yet, few studies have examined patient perspectives on synchronous digital mind-body interventions during active treatment, a period marked by significant physical, psychological, and logistical challenges [41,43]. This study addresses that gap by exploring participants' views on the program's digital delivery, usability, and impact on symptom relief and quality of life. The findings offer insights to support the safe, effective, and accessible integration of digital integrative oncology interventions into routine cancer care.

Methods

Study Design

This qualitative study was conducted as part of the Integrative Medicine for Patient-reported Outcomes, Values, and Experience (IMPROVE; NCT05053230) trial, a randomized clinical basket trial assessing the effects of the IM@Home program on symptoms and acute health care utilization in patients with moderate or greater fatigue undergoing active treatment for melanoma, head and neck, lung, gynecological, or breast cancer. From October 2021 to March 2023, a total of 200 participants were randomized to 12 weeks of either IM@Home intervention (live exercise and mind-body classes via Zoom [Zoom Video Communications]) or enhanced usual care (standard of care plus on-demand meditation resources). Study design, primary results, and detailed program description have been published elsewhere [38,40].

The IM@Home program offers 23 live classes per week, including movement-focused classes (eg, fitness and dance), mind-body classes (eg, yoga and tai chi), and mind-focused classes (eg, meditation and music therapy). Classes are delivered synchronously (in real time) via Zoom, each lasting 30-60 minutes, and led by licensed MSK Integrative Medicine Service clinicians—including certified fitness trainers, yoga and mindfulness instructors, and licensed music therapists with experience in oncology—who guided participants, offered modifications, and provided verbal cues and encouragement to support engagement and safety. Upon randomization, a member of the research team contacted participants by phone to introduce the program, provide an overview of class types, and assist with registration. Participants could attend as many classes as desired each week, select any combination of classes, and modify their selections as needed.

Participants

We used maximum variation sampling, targeting approximately 20% of IM@Home participants to capture diverse experiences across cancer types and different stages of program participation (study time points: Weeks 4-7, Weeks 8-12, or after study completion). The sampling framework, including the number of participants selected from each cancer type and time point, can be found in Multimedia Appendix 1. Selected participants were contacted by a member of the research team via phone to

invite them to participate in the qualitative interviews. All participants approached for interviews agreed to participate.

Data Collection

We conducted semistructured interviews with 20 IM@Home participants, led by 2 trained qualitative researchers with backgrounds in integrative therapies and psychology (KS and KB). Interviewers had previously briefly interacted with some participants during their participation in the IM@Home program, either during consent or later while providing assistance with class registration. At the start of each interview, participants were informed of the interviewers' professional roles. The research team developed and used an interview guide to explore key aspects of participants' experiences while allowing flexibility in responses (Multimedia Appendix 2). To ensure participant-driven insights, interviewers used open-ended probing questions and adapted them in real time to explore emerging topics.

Interviews were scheduled according to participant preference and availability, conducted via HIPAA (Health Insurance Portability and Accountability Act)-compliant Zoom, lasted up to 20 minutes, and were audio-recorded with the participant's consent using the Zoom recording function. Audio files were securely stored on an encrypted, password-protected institutional server accessible only to the study team. The audio recordings were transcribed verbatim (KS), reviewed for accuracy (KB), and de-identified by both coders (KS, KB) prior to analysis. Reflexive journaling and team debriefings were used to minimize interviewer bias.

Data Analysis

We analyzed all interview transcripts using a 2-phase approach that combined inductive and deductive thematic content analysis [45,46]. Our analytic process followed the 6-phase reflexive thematic analysis framework described by Braun and Clarke [46] familiarization with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the final report.

In Phase 1, two researchers (KS and KB) independently read 5 transcripts to identify key narrative content and determine the unit of analysis (eg, sentences or full passages) (Phase 1: familiarization). Through an inductive, open coding process, they developed descriptive and interpretive codes (Phase 2: generating initial codes), allowing themes to emerge from the data. The researchers then met to discuss coding and emerging themes and iteratively refined and grouped codes into higher-order categories, forming thematic units (Phase 3: searching for themes; Phase 4: reviewing themes). Analytic memo writing supported the identification of emerging patterns and conceptual relationships. This iterative process ensured that findings were grounded in participant experiences rather than predetermined categories.

In Phase 2, using a deductive approach, the finalized coding scheme was applied across all transcripts by 2 researchers (KS and KB) to assess coding consistency and intercoder agreement.

A third researcher (KD) reviewed coded transcripts to enhance credibility, with any discrepancies resolved through discussion. Once coding was completed, the final themes, categories, and representative quotes were reviewed and discussed with the broader research team (Phase 4: reviewing themes; Phase 5: defining and naming themes; and Phase 6: producing the report). To further enhance confirmability, an independent reviewer (SC) examined the coding and interpretation for potential bias or inconsistency. NVivo software (version 14; QSR International) was used to support data management and analysis. Thematic saturation was evaluated continuously throughout the analysis.

Strategies to Ensure Trustworthiness

Credibility was supported through researcher triangulation (3 coders participated in data coding, analysis, and interpretation), peer debriefing with the broader research team, and reflexive memo writing. Transferability was addressed through purposeful sampling and thick description of the context, participants, and findings. Dependability was ensured via a detailed audit trail documenting all stages of data collection, coding, and analysis, along with intercoder agreement among coders.

Confirmability was enhanced by maintaining an audit trail, practicing reflexivity, and conducting an external audit by an independent reviewer (SC) to assess for bias or inconsistency.

Ethical Considerations

The study was approved by the Institutional Review Board (IRB) at MSK (IRB# 21-369), registered at ClinicalTrials.gov (NCT05053230). The ethics approval for the qualitative interviews was part of the original IRB approval. Participant confidentiality was maintained; data were collected and stored in secure, password-protected systems and analyzed in deidentified form. Participants did not receive compensation for study participation. All participants provided written informed consent. Findings are reported per the Standards for Reporting Qualitative Research guidelines [47] and COREQ (Consolidated Criteria for Reporting Qualitative Research) extension [48]. The COREQ checklist is provided as a Multimedia Appendix 3.

Results

Participant Characteristics

All participants approached for interviews agreed to participate. Of the 20 participants interviewed (mean age 63, SD 9.6 years), a majority were female (18/20, 90%), White (17/20, 85%), and had breast cancer (9/20, 45%). Table 1 summarizes the demographic and clinical characteristics of the 20 participants included in the qualitative interviews. This qualitative study sample was broadly reflective of the overall IMPROVE trial population (N=200) and the IM@Home arm (n=99) with respect to gender, age, and cancer type, although there was a slightly higher proportion of White and Asian participants and a slightly lower proportion of Black participants compared with the IM@Home arm.

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Table 1. Participant characteristics.

Participant characteristic	Values
Age (years), mean (SD)	63 (9.6)
Gender, n (%)	
Female	18 (90)
Male	2 (10)
Race, n (%)	
Asian	2 (10)
Black	1 (5)
White	17 (85)
Ethnicity, n (%)	
Non-Hispanic or Latino	18 (90)
Hispanic or Latino	0 (0)
Unknown	2 (10)
Cancer type, n (%)	
Breast	9 (45)
Gynecological	3 (15)
Head and neck	4 (20)
Lung	3 (15)
Melanoma	1 (5)
Time of the interview, n (%)	
After study completion	2 (10)
Week 4-7	7 (35)
Week 8-12	11 (55)

Qualitative Findings

Saturation was achieved by the 17th transcript; however, all 20 interviews were coded to capture potential nuances and ensure comprehensive representation. Ultimately, 5 major thematic units were identified. These thematic findings are summarized in a narrative account below, while detailed theme descriptions, including definitions, categories, subcategories, and additional illustrative quotes, are provided in Table 2.

Table 2. Qualitative findings.

Themes and their definitions, and categories and subcategories	Example quotes

Theme 1. IM@Home alleviated symptom burden and supported symptom self-management: *IM@Home helped participants manage cancer-related symptoms by improving physical strength, reducing fatigue, alleviating stress and anxiety, and providing accessible self-coping strategies to enhance overall well-being.*

Reduced treatment-related symptom burden

- "The thing that definitely did help was also, you know, in terms of trying to sleep the guided part of getting you to relax, because I've always been a bit of an insomniac, and I think this one didn't. This whole episode of going through all this didn't help in that one. So that part definitely helped just being able to kind of visualize every part of you, relaxing and going to sleep." [P003]
- "It's hard to explain, I know it's good for me and I do it. My back hurts and my neck hurts, and whatever I'm doing…I don't know if it's the Chair yoga or one of the other things, but my back feels better. The neck, I think, got a little worse. But the back feels better, so I know, whatever I'm doing it is helpful in the long run." [P002]
- "I really like it. I feel like a different person. I feel so much looser. I just feel like 'wow', and it's not like you're sweating, and it's really tough, but you can really feel these small movements, and I just feel good. I feel so much better like it gives me quite a bounce to my day." [P017]
- "I do feel that it was um I do feel like it did give me a greater range of motion, and I do feel that I slept better." [P010]

Enhanced symptom self-management and sense of control

- "I would describe it [IM@Home program] as a tool for coping. Because I think being able to figure out how to um move in the world emotionally and physically with the illness, or the recovery from an illness is coping and coping and adapting is critical." [P010]
- "I think it's such a stressful time in your life, because you really don't know what to what to expect. What you're going through and all, you don't know how you're physically the physically going to be reacting to anything, and it's such a stressful time. I think if you can plug that [IM@Home] into your day in some way, even, maybe a couple of times a day to help you kind of get yourself grounded, and I think that that would be helpful. I think you just have to try and stay focused as much as you can, even though it's quite difficult." [P011]
- "I definitely feel more like myself […] where I'm not so consumed with cancer and treatments, like I almost feel like I can. I feel mentally better. That's one thing I would definitely say, I don't feel as upset all the time. I don't feel as down, because it was definitely getting, like, as the as the radiation went through like definitely emotional and teary and sort of feeling sorry for myself. So I definitely feel that I do feel more positive and just mentally like a bit more clear and like a bit more positive and going forward." [P017]
- "Yes, actually, psychologically better because I finished it. Finally, you got up off the couch from watching TV or something on a day when I was doing that. Not as good as I felt if I could get out shopping for three hours. That is the ultimate kick in the pants. Yeah that [IM@Home] gets me going." [P005]

Theme 2. IM@Home facilitated social support and information exchange: *the program fostered a sense of community, offering emotional support, reducing isolation, and enabling peer-to-peer learning through shared experiences and instructor guidance.*

Building a sense of community

- "There's also a sense of community because usually in the beginning, at the end there's little discussion, a talk, and you hear people talking giving little advices, there is a little community there and I like it." [P004]

Feeling seen and supported

- "Beyond the exposure to something that can provide comfort and health benefits, there is a certain companion ability among people if you attend the same class. There are some of the same people in those classes, and they do talk to the instructor primarily after the class. […] And you know, in the chat function afterwards, somebody will mention [personal stories] and just a nice kind of things that people would say, or someone talks about something they're having a hard time with, or something that went well. And there are all these other people don't know, but who are saying, you know congratulations, or you know that's tough, or maybe throw out a resource they've heard of. So it's not a big bulletin board, it's not a big chat, but there's a little bit of a sense of community I think, is nice." [P012]

Knowledge and resource sharing

- "I think it's very good for that [sharing personal experiences] it seemed like a lot of the conversations and the chats and the things that they [patients] were talking to each other. You know this is the best speaker [platform] to use. You know, I think, all that neighborliness is very useful too. I think a sense of community is always good." [P010]
- "I don't have my camera on but some people do and it builds a camaraderie, which some people might need. Thank God, I have a lot of support from friends, from family members, you know, but some people might not have that. And to get a support from the group of people, I think that that would be very beneficial." [P002]

Themes and their definitions, and categories and subcategories	Example quotes
Theme 3. IM@Home offered a flexible, tailored program in a group setting: *participants valued the program's safe, flexible, and personalized approach within a group format, allowing them to engage in oncology-tailored exercises suited to their needs, schedules, and symptom burdens.*	
Ensuring safety and personalization	• I think the most helpful was just the fact that the instructors were clear […] they made it very clear like 'Well, here's our warm-up,' and they really did make sure, like I've been to some fitness classes where there's really no emphasis on the warm-up or on the stretching afterwards. And that's such an important part of the program. So I thought that that was probably the most beneficial. And, in my opinion, is that they really did look at this holistically and say, like, here are people who are recovering and or bring in something so let's make sure that they stretch appropriately before we dive into the program, and then let's make sure at the end." [P020] • "Well, I've been sick, for almost two years, I'm getting better now, and it makes me feel good. I mean after yoga, gentle yoga it's very gentle but it's just my speed, my level and I can't believe how good it is for me and then like its wow that feels so easy, then I feel the stretches, I feel the muscles that I haven't used for a while. So [the classes] make me feel good." [P004] • "There was a large group of people of varying levels. And so instructors wanted to make sure that everybody was able to participate. I like the emphasis on breathing. I like the emphasis on just moving, being able to do what you know. Just move. Just do whatever you can to move." [P020] • "It's something that's very good for you, and you don't need like a lot of equipment, either, because that's the other thing that people find discouraging is oh, like I don't have weights. Well, you could use water bottles, or you could use towels, or you could use. I think what she said was, you could use your thumb and your index finger, like those types of modifications, were very helpful. So I think that's how I would sell it to her judgment-free, all activity levels the privacy of your own home with instructors that give you different options for your fitness, level." [P010]
Offering variety and flexibility	• "There are abundant resources through the program for it [symptoms], access to, particularly to mind, body experiences that are interesting to explore if you've never done them before, and if you've done them before they're a way to maintain a practice […] It's good for you. It feels good to do it, and it can help you step outside yourself a little bit." [P012] • "You can choose which ones you want, and there's a variety and different levels." [P015] • "I think that's what I liked best about this program that it was just at a level and at a pace where you can kind of ease into it and then modify as you got stronger." [P020] • "I didn't find it difficult or challenging, because I think people provided enough guidance to say, 'Hey, here, if you are a beginner, here's where you could do it.' This is, for example […] push-ups right, you could use a wall or a chair or the floor or do a full-on push-up. So, there's different types of push-ups you can do depending on your level. I didn't really think it was all that challenging. And then there was always the caveat that if you weren't comfortable doing that, then, you know, and just keep moving or do something else." [P020] • "It was a good variety. It gave you just different the different chances to do the different types of classes. Also, for the length of time that I had on my schedule so that I was able to do it. I thought the variety was good. Having them [classes] at the different time sequences, also the different types they had, where they kind of had you going you know mentally and all that. That was also very good, because it gave some variety." [P011]
Role of instructors	• "And the most helpful is because the instructors also say you can do this, keep going and they motivate you to go, and that helps me. It's just a way that they, I can't explain it, it's just the way that they do the classes that I enjoy and it's like, you know, like when I get tired, I just keep going." [P018] • "I think the other positive was that there was pretty good instruction, like sometimes when you do online classes. and you know, and the cameras aren't turned on for most of the people like you don't know if they're going to do something that might injure themselves, but they manager themselves. But I feel like people were, you know, in a pretty good... they gave pretty good instruction. But I know that's always a challenge with online classes, especially when you're when you have a group of people of varying levels. Making sure that no one gets hurt." [P020]
Theme 4. IM@Home facilitated accessible, affordable, and ongoing support: *the digital format removed barriers such as cost, travel, and infection risk, making exercise and mind-body therapies accessible to diverse patients while supporting long-term wellness beyond active treatment.*	

Themes and their definitions, and categories and subcategories	Example quotes
Improving accessibility and convenience	• "I would be concerned about going to the gym and even though that don't have to have a mask for indoors now I'll continue wearing a mask because I don't need to catch anything else, and a lot of people that are basically homebound at this point either because of the situation, because of COVID, or because of the way they feel. It's good to have something that they could do at home due to their fitness level. That's not difficult and is enjoyable. I would recommend it." [P002] • "Especially after surgery and radiation, when you're tired and you want to regain your energy, it's most people aren't self-motivated to join a gym or do anything like that, but just the fact that it's in privacy of your home that there are people that are there that are just like you. And that it's geared and tailored for patients." [P020] • "I was a very regular gym goer and I always would go in, lift weights and do some cardio, and would always take a yoga class. I probably did like 4 or 5 a week […] since the pandemic, I'd stopped going to the gym, for fear of infection. And because of the pandemic I'm still not there, I'm not going to a gym. I'm just not going to be in a big building with people breathing hard and no masks. So that that's the biggest benefit that it's just the ability to get back into some sort of fitness routine." [P015] • "It was simple. I mean I just chose a class clicked on it got a registration form put in my name, address phone number whatever and then the next day or I got a link to the class the simple." [P002]
Providing structure and motivation	• "Sometimes the treatment can have a very demotivating effect, and having something to look forward to, I feel helped so much, mentally." [P016] • "Even though I get tired I can keep going better than before I was doing the classes, so I really think that they're starting to help build me up again, […] which is a good thing, because I was almost to the point where I was just sitting in my chair and said, 'Forget this, I'm tired' So now I'm actually looking forward to doing the classes." [P018] • "And the most helpful is because the instructors also say you can do this, keep going and they motivate you to go, and that helps me. It's just a way that they, I can't explain it, it's just the way that they do the classes that I enjoy and it's like, you know, like when I get tired, I just keep going." [P018]

Theme 5. Recommendations for program enhancement: *participants provided several suggestions for optimizing the program's implementation and maximizing its benefits.*

Need for additional guidance	• "I think the one thing that can be a little difficult, which maybe in-person would have helped, is the Tai chi. I tried doing it, and it's so hard to, because you have like a mirror image, and the instructor is telling you to twist your body a certain way. It's hard to figure out exactly how to do that. So I think that was the only class that I was very confusing in terms of doing it online." [P016] • "One thing I will say about the course description, that I read before I went to each class, was I didn't feel that they were very clear on the type of material you should bring to the class […] I don't recall now what they said but it's like some classes, we use stretchy bands and I know [instructor], would talk a lot about what you could use to substitute and maybe you don't want to discourage people from coming you know joining thinking that they don't have all the materials that are maybe used in the class." [P006]
Expanding delivery methods	• "Let me just say this, if you could record the classes and rerun them in the evening, right the same class. So, for example, you know [instructor's name] does a tai chi class in the morning, and then you ran a recording of it at night where people couldn't attend in the morning. I mean it's I know it's a whole technological issue to get that set up and to do it, but you wouldn't have the instructor having to instruct again in the evening, you could replay a class." [P006]
Timing considerations for the program introduction	• "Having the program being offered to patients in conjunction with we start treatment and have someone help us come up with a training and exercises plan from the beginning would help to be active." [P008] • "Why can't the doctors mention it to the patients when they do like the five week follow up from their surgery and say, 'Oh, we have an Integrative program. I think it would be good for you to have exercise in your healing process to recover better.' And maybe you have to like kind of coordinate it with the doctors." [P009]

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Theme 1. IM@Home Alleviated Symptom Burden and Supported Symptom Self-Management

Participants reported that the IM@Home program was valuable for managing cancer-related symptoms during treatment, offering physical, mental, and social benefits.

Reduced Treatment-Related Symptom Burden

Participants highlighted significant improvements in physical and mental health, including reductions in cancer treatment-related symptoms, particularly radiation-related fatigue, overall stress, and anxiety. Fatigue reduction led to increased muscle strength, flexibility, and mobility, while decreased stress and anxiety enhanced their motivation to stay active.

> It really helped. I feel like my muscles are stronger, my walking is a lot easier, and I'm not as tired as I used to be. [P006]

> What I noticed was with the radiation fatigue, I think about week three, I was like, 'Wow, I'm good.' I've got my normal energy back, like there's no more fatigue. That was probably the biggest benefit, just like flipping a switch, 'I'm good!' [P015]

These improvements collectively increased their ability and willingness to continue classes and carry out daily activities and further contributed to the reduction of comorbid symptoms such as insomnia. Yoga and fitness classes were frequently mentioned for fatigue management and meditation classes for reducing stress.

Enhanced Symptom Self-Management and Sense of Control

Many participants described the challenges they faced during treatment, particularly after leaving the hospital. This was when treatment-related symptoms emerged, requiring them to manage these difficulties on their own, often leading to a sense of lost control. In this context, participants noted that IM@Home provided valuable, accessible, and easy coping skills, such as breathing techniques, to help them navigate symptoms or manage difficult moments at home. Additionally, completing classes provided participants with a sense of control, giving them the courage and confidence to continue their ongoing treatments.

> With all the stress of the diagnosis and treatment that's one [breathing and relaxation] that I realized is a good thing for the stress release […] there were days when things were happening to me, and my ability to just lay there and count my breaths or breathe through things was really a great thing. [P015]

The anticipation of classes also provided mental relief, with one participant noting, "Having something to look forward to helped so much mentally" (P016). Another participant highlighted the program's impact on self-commitment and achievement.

> At the conclusion of each class, there is a feeling of accomplishment. I did something for me, I kept a commitment to myself. I showed up and got through the whole thing. I feel good about doing it. [P012]

Theme 2. IM@Home Facilitated Social Support and Information Exchange

The program fostered a sense of community, helping participants feel less isolated. As one participant noted, "There is a feeling that you're doing this together" (P012). Another described class interactions as feeling like "a friend came into their home" (P005).

Participants valued the emotional support of being seen and not feeling alone.

> You see the other people that are in the class with you, that's comforting not to be alone, because a lot of us are alone. [P013]

Receiving support and encouragement from peers and instructors contributed to a more positive experience during the treatment process.

> It's comforting seeing the instructor and hearing them acknowledge you makes a difference. [P013]

Participants described how postclass discussions provided opportunities to exchange advice and learn from others' experiences, further enriching the program's social aspect.

> I learned a lot from the instructor's comments about the effects of radiation on muscles and fascia, which came from an exchange with another class participant […] It was enlightening for me, and it was what I was experiencing. [P012]

Theme 3. IM@Home Offered a Flexible, Tailored Program in a Group Setting

Participants described their experience with IM@Home as safe, patient-centered, and flexible. They noted differences compared to other general fitness classes they had attended, expressing that IM@Home felt safe and comfortable. The activities were tailored to fitness levels and the unique physical and mental needs of cancer patients, including those with metastatic disease and a high symptom burden.

With good tolerance and noticeable benefits, they continued engaging with IM@Home and used it as a valuable tool for maintaining their quality of life. As one participant explained,

> Exercise and [being active] can keep things from reoccurring, maximize your lifestyle and functionality, and help you regain skills you've lost. When you're living with an illness, dealing with something chronically, you need as many tools as you can to alleviate pain and symptoms and to continue to live as fully as you can, even though you're still sick. [P010]

Participants also noted the key contributions of instructors specialized in oncology care.

> The instructors were really top-notch, and they were specifically tailoring the exercises and the activity levels. [P010]

Additionally, even in a group setting, patients felt that the program was individualized to their preferences, schedules, and daily routines. IM@Home offered a variety of classes, including

yoga, meditation, and fitness, empowering participants to choose activities aligned with their preferences and physical needs. Its flexibility allowed them to continue participating in the face of such challenges as scheduling conflicts with treatment appointments, changes in symptoms or needs, or concerns about monotony.

> *I thought it was great that it would be in my own home, and with little to no equipment. All those things they thought were fantastic because when you have ongoing illness you there are things like side effects, where you might have to run to a bathroom and to physically be in a class it would make all those things difficult, whereas here you had some latitude as to when you could attend or leave the class or come back to the class, and so I thought I was primed for success at it.* [P010]

Theme 4. IM@Home Facilitated Accessible, Affordable, and Ongoing Support

Participants appreciated the program's digital format for increasing accessibility in several ways: (1) compared to in-person classes, the digital format was more cost-effective, which was important given the financial burden of cancer treatments; (2) the digital format eliminated the need for travel, reducing barriers for those with mobility limitations; and (3) it minimized infection risks for patients who could not safely attend in-person sessions, particularly those who were immunocompromised. They emphasized that the digital format allowed not only the general cancer population but also those facing significant barriers to in-person attendance to receive support and stay active.

> *I don't have to go anywhere, I don't have to travel, I turn on my computer.* [P003]

> *While you're going through this process and can't get out and do some of the things you used to, or that you thought about doing […] This is a productive and psychologically healthy way to spend some of that extra time. It feels good to do it.* [P011]

Additionally, participants emphasized the importance of having resources to maintain healthy behaviors despite treatment side effects and even after completing cancer treatments. They appreciated the online program provided ongoing access, allowing patients to engage whenever needed and supporting their commitment to long-term wellness.

> *Knowing there is an interface out there I can go to any time, if I want to do some meditation or some light exercises like chair yoga, it really helps that there is something out there I can lean on.* [P016]

> *I was not exercising at all. I was becoming very lethargic. Having this program helped me on a daily basis. I signed up, I keep signing up for more and more classes, and it keeps me starting my day with exercise and it made me feel better.* [P003]

Theme 5. Recommendations for Program Enhancement

Participants provided several suggestions for optimizing the program. Some suggested offering more detailed guidance alongside the classes to help them understand complex movements or better prepare for class participation.

> *It's so hard to figure out exactly how to do [movement]. It was very confusing in terms of doing it online.* [P016]

They also recommended incorporating additional delivery methods, besides live online classes, to benefit patients without reliable internet access or devices. Furthermore, participants proposed introducing the program earlier in the cancer care journey, such as during consultation, to maximize its benefits.

> *Could there be a consultation where, after meeting your surgeon, you also meet your oncologist and learn about programs like IM@Home to help you along the road?* [P017]

Discussion

Overview

This qualitative study explored the experiences of patients undergoing active cancer treatment who participated in a 12-week cancer-specific digital exercise and mind-body program, IM@Home. Participants described a broad range of benefits, including improved symptom management and enhanced social support, and reflected on the program's novel, patient-centered, group-based online delivery. They also identified opportunities for improvement, such as adding real-time feedback, peer mentorship, and recorded sessions to complement live classes. Taken together, the findings suggest a preliminary program model in which digitally delivered, flexible integrative medicine programming promotes symptom relief and peer connection, mechanisms that supported patients during treatment. These mechanisms appear shaped by contextual factors (eg, treatment-related fatigue, mobility limitations, and scheduling barriers) and can inform refinements to optimize delivery. Overall, these findings provide timely insights into how live, structured, digitally delivered integrative care can address supportive care needs during active treatment and reinforce prior evidence on the value of synchronous, patient-centered digital interventions in oncology.

Principal Findings

Exercise and mind-body therapies are well-documented for managing cancer-related symptoms [7,40,49-53] and for improving quality of life during treatment [40,54-60]. Our interviews' findings on symptom management (ie, reduced fatigue and mental stress) align with previous trials and are consistent with results from our randomized clinical trial [40]. This suggests these symptoms may be primary targets for online exercise and mind-body therapies in cancer care. Additionally, our findings indicate that symptom relief came not only from the interventions but also from patients' own continued efforts, as they learned self-coping strategies and received encouragement and support from other participants. Existing literature underscores the importance of self-coping in symptom management and healing [61-63], highlighting its role not only in managing symptoms during treatment but also in supporting long-term survivorship.

Our study provides valuable insights into the design and delivery of digital interventions. The increasing popularity of digital health reflects its ability to overcome traditional barriers to care such as accessibility and scheduling [64]. Remote delivery of clinical or supportive care via telecommunications (ie, telehealth) is particularly beneficial for immunocompromised patients, offering privacy and reduced infection risks [65]. However, many digital programs face implementation challenges in cancer care, such as balancing intervention effects with patients' tolerance, delivering the program in a group setting while maintaining patient-centered care, and engaging patients in routine participation without adding to their burden [19,50,66,67]. Participants indicated that IM@Home successfully addressed these challenges by integrating multiple evidence-based therapies tailored to patients with cancer, accommodating different exertion levels to ensure safety and align with patient tolerance, and allowing flexible access to various treatment modalities. This flexibility enabled participants to select activities based on preferences, symptoms, and schedules, while maintaining regular engagement. These features enhanced safety, improved adherence, and expanded access, ultimately increasing the effectiveness of the interventions.

A distinctive feature of IM@Home was its live, group-based delivery format, which fostered community, reduced feelings of isolation, and created a safe, supportive environment, crucial for maintaining quality of life and coping during cancer treatment [68,69]. Participants emphasized the unique value of real-time interaction with instructors and peers, describing the experience as supportive and empowering. This structure stands in contrast to many digital interventions that rely on asynchronous content and may lack opportunities for interpersonal connection or individualized guidance. Social support was repeatedly cited as a motivating factor, as participants found validation in shared experiences and encouragement from others. These relational aspects, often overlooked in digital health design, are critical for sustained engagement and psychological support during cancer care [70]. This finding aligns with broader calls for a "patient revolution" in the health care system, emphasizing the need to empower patients to take a more active role in their care [71]. A key component of this shift is enabling patients to seek advice and support from others who have faced similar challenges. Based on patient feedback, they received empathy, insight, and practical strategies from both peers and instructors, fostering a greater sense of control and satisfaction with care and alleviating pressure on the health care system.

Our findings underscore the need to integrate digital exercise and mind-body programs like IM@Home into standard oncology care. Early incorporation into treatment planning, perhaps during initial consultations, could maximize benefits by establishing wellness routines before treatment-related symptoms worsen. Participants also highlighted the need for additional guidance or on-demand resources to complement online classes. Potential solutions, such as enhancing real-time feedback, incorporating peer mentorship, and providing recorded sessions, should be considered in future program development. Additionally, multicenter trials are needed to assess program effectiveness across diverse populations, alongside cost-effectiveness and scalability. Furthermore, improving patient education and clinician-patient communication about the benefits of digital interventions could promote adoption and adherence. By addressing current gaps, digital exercise and mind-body programs like IM@Home can be optimized to meet the complex needs of patients with cancer and expand access to effective, comprehensive care. These insights offer actionable strategies for future program refinement and broader clinical integration.

From an implementation perspective, IM@Home demonstrates a scalable model for integrating digital exercise and mind-body therapies into routine oncology care. By reducing barriers related to cost, travel, and immunocompromise, the program has the potential to increase access and address equity gaps in supportive care. Embedding such interventions early in the cancer care trajectory—and ensuring they are adaptable to individual needs—may help improve adherence and patient-centered outcomes and promote more equitable access to evidence-based supportive care. Future adaptations might include multilingual content, device-lending strategies, or hybrid models to serve patients with limited digital access.

Limitations and Future Directions

This study has several limitations. First, the small, predominantly female and White sample limits the transferability of findings. While we used maximum variation sampling to capture a range of experiences across cancer types and study time points, the demographic homogeneity may have influenced the range of perspectives reported. Future research should aim to recruit more diverse participants to enhance the transferability of findings. Second, we did not include participants who dropped out or conduct interviews at earlier time points. Including these participants could have provided additional insights into barriers and facilitators of engagement. Third, although formal member checking—returning preliminary themes to participants to assess whether the interpretations resonate with their experiences—was not conducted, casual interactions with participants supported the credibility of the findings. Finally, future studies should also explore long-term outcomes and implementation strategies (eg, integration into routine clinical workflows and program scalability) to advance equitable integration of digital integrative care into cancer treatment pathways.

Conclusions

IM@Home represents a novel, patient-centered, and scalable model for digital integrative care. Participants viewed the program as supportive, empowering, and effective in managing treatment-related symptoms. These findings lay the foundation for refining and scaling IM@Home to benefit diverse cancer populations and inform the development of future digital health interventions.

Acknowledgments

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

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Authors' Contributions

Conceptualization: JJM, EFG, KB; Data curation: KB, KS, KD; Formal analysis: KB, KS, KD; Funding acquisition: JJM, EFG; Investigation: KB, KS, KD; Methodology: JJM, KB, SC; Project administration: KB; Supervision: JJM, EFG; Writing - original draft: KB; Writing - review & editing: KB, SS, KS, KD, XL, SC, JJM, EFG;. All authors read and approved the final manuscript.

Conflicts of Interest

JJM reports receiving grants from Tibet Tibet CheeZheng Tibetan Medicine Co Ltd and Zhongke Health International LLC to Memorial Sloan Kettering outside the submitted work and serving in an unpaid role as co-president of the Society for Acupuncture Research. JJM reports financial interest in Greatly Health. MSK has institutional financial interests relative to Greatly Health. The remaining authors disclosed no conflict of interest.

Multimedia Appendix 1
Maximum variation sampling framework for qualitative interviews.
[DOCX File , 17 KB - cancer_v12i1e80075_app1.docx]

Multimedia Appendix 2
Interview guide.
[PDF File (Adobe PDF File), 879 KB - cancer_v12i1e80075_app2.pdf]

Multimedia Appendix 3
COREQ (Consolidated criteria for Reporting Qualitative research) checklist.
[PDF File (Adobe PDF File), 495 KB - cancer_v12i1e80075_app3.pdf]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
HIPAA: Health Insurance Portability and Accountability Act
IM@Home: Integrative Medicine at Home
IMPROVE: Integrative Medicine for Patient-reported Outcomes, Values, and Experience
IRB: Institutional Review Board
MSK: Memorial Sloan Kettering Cancer Center

<u>Original Paper</u>

Surrogate Decision-Making by Family Caregivers for Hyperthermic Intraperitoneal Chemotherapy in Gastric Cancer: Qualitative Study in a High-Volume Chinese Center

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Abstract

Background: Hyperthermic intraperitoneal chemotherapy (HIPEC) has been integrated into the management of gastric cancer (GC) as a combined approach for addressing peritoneal metastasis, serving both prophylactic and therapeutic roles following GC surgery. The pivotal decision regarding HIPEC administration typically arises intraoperatively, creating a complex clinical scenario where family caregivers must act as surrogate decision-makers under substantial time constraints. This decision-making process proves particularly challenging due to limited understanding of the procedure's risk-benefit profile and long-term outcomes among nonmedical surrogates, challenges often exacerbated by the acute stress of the surgical environment.

Objective: This qualitative study aims to explore how family caregivers of patients with GC navigate the HIPEC decision-making process, specifically examining the facilitators, challenges, and the role of information acquisition that shape the shared decision-making mode.

Methods: This study adopted a qualitative approach using semistructured interviews; 15 family caregivers of patients with GC in a major tertiary hospital in Guangxi Province were selected as research objects through a purposive sampling method. Participants were asked to comment on their experience of surrogate decision-making for the HIPEC process. The Colaizzi 7-step method was used to analyze and summarize the themes.

Results: The mean age of the 15 participants was 39.8 (SD 13.29, range 20-68) years, and all patients were on average aged 56.7 (SD 10.78, range 36-74) years. The relationship to the patient was distributed as follows: 33% (5/15) spouses, 60% (9/15) children, and 6% (1/15) other relatives. Four major themes emerged from the data analysis: (1) shared decision-making participation mode (doctor-led passive decision-making and doctor-family shared decision-making); (2) decision-information sources (decision-making information came from medical-care personnel, decision-making information came from the internet, and decision-making information came from acquaintances); (3) challenges in the decision-making process (financial burden and anticipated therapeutic efficacy); and (4) facilitator in the decision-making process (positive health beliefs and cultural dimensions of perceived responsibility: a Confucian perspective).

Conclusions: HIPEC decision-making by family caregivers of patients with GC was primarily passive decision-making, and many obstacles and facilitators were encountered in the process. Medical staff should share information and encourage and guide family caregivers to participate in the decision-making process through decision assistance or decision support.

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KEYWORDS

hyperthermic intraperitoneal chemotherapy; gastric cancer; family caregivers; surrogate decision-making; qualitative study

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Introduction

Gastric cancer (GC) is 1 of the 5 most common malignant tumors in the world [1], and the cumulative risk of peritoneal metastasis (PM) is nearly 30%. It is the most common form of GC metastasis [2,3]. Systemic chemotherapy drugs have difficulty penetrating the peritoneal barrier; PM treatment is difficult, and the disease progresses rapidly. Once PM occurs, the mortality of patients is very high, which has become the main cause of death in the literature.

Developments have been made in the field of peritoneal tumors over the last decade, and hyperthermic intraperitoneal chemotherapy (HIPEC) is an emerging treatment technique. It heats an infusion-containing chemotherapy drug to the therapeutic temperature and is reinjected into the patient's abdominal cavity for a certain period of time. The main principle of HIPEC is hyperthermia, chemotherapy, and mechanical scour, which can break through the plasma-peritoneal barrier, remove the residual tissue, and free cancer cells after surgery [4,5]. HIPEC prevents PM based on radical gastrectomy and can also be combined with cytoreductive surgery to treat selected patients with resectable primary or secondary peritoneal malignancy [6,7]. The median survival of patients with advanced GC can reach 18.1 months after HIPEC [8]. However, there is some controversy about the safety and effectiveness of HIPEC. A meta-analysis reported that HIPEC failed to improve the 1-3 year overall survival and gastrointestinal complication rates, but improved long-term overall survival [9]. From the perspective of health literacy popularization, a small percentage of the public has heard of or understood HIPEC, which is a complex operation [10]. Treatment decisions in HIPEC are individualized and require patient and physician involvement. Therefore, the difficulty for patients is to question whether the disease can be successfully treated, as HIPEC is unknown. These concerns and questions can run from decision-making to treatment.

Surrogate decision-makers are more common in intensive care units, ignoring the fact that patients with cancer may also need family caregivers to make surrogate decisions [11,12]. Family caregivers often participate in decision-making, and even become the main decision-maker, when some patients with GC may have adverse psychological conditions, physical discomfort resulting in reduced decision-making ability, or surgeons need to put forward HIPEC-related treatment recommendations according to intraoperative conditions. Although the safety of HIPEC has been proven, it is associated with higher mortality, lower overall treatment morbidity, and reduced quality of life in the short term [13]. People sometimes make different medical decisions for others than they would make for themselves [14]. Family caregivers are usually concerned that surrogate decision-making will influence the patient's prognosis and lack of HIPEC experience, thus they may fall into decision-making difficulties and conflicts, resulting in possible psychological pressures such as regret, anxiety, contradiction, and unease [11]. Negative emotions will again affect the implementation of decision-making and reduce the satisfaction of patients and caregivers with medical treatment, forming a vicious circle [15].

Previous studies have been conducted to explore the surrogate decision-making process from diagnosis to treatment in patients' relatives with digestive tract tumors because their lack of understanding of treatment information leads to passive decision-making [16]. HIPEC is a special treatment for gastrointestinal tumors, and most studies focus on prognosis and adverse reactions [13]. Conversely, relatively few studies have focused on the surrogate decision-making experience of HIPEC, which may be due to the underrepresentation of families of patients with GC in HIPEC clinical trials. Different surrogate decision-makers have different views on health, disease, and participation mode of treatment, which are important for whether patients can obtain better treatment plans in time [12].

This study aims to identify the decision-making participation mode of surrogate decision-makers for patients with GC considering HIPEC, particularly their stance on the spectrum of paternalistic, physician-led decision-making and collaborative, shared decision-making, while elucidating the multilevel challenges and facilitators underlying this process. Our results can serve as a reference for formulating targeted decision-support strategies and guiding doctor-patient communication, thereby improving HIPEC decision-making efficiency, safeguarding patients' physical and mental health, and enhancing patient satisfaction with medical treatment.

Methods

Design

An exploratory qualitative study involved semistructured interviews with family caregivers of patients with GC treated with HIPEC who acted as the primary decision-makers. From January to April 2024, family caregivers of patients with GC undergoing abdominal HIPEC after gastrointestinal gland surgery in a major tertiary hospital in Guangxi were selected as the research subjects. We used face-to-face interviews to understand the real experience of family caregivers' HIPEC decision-making process. This study followed the comprehensive criteria for the reporting of qualitative research guidelines (Multimedia Appendix 1) [17].

Study Setting

This study was conducted in the Gastrointestinal Surgery Department of the First Affiliated Hospital of Guangxi Medical University, a national key clinical construction specialty, a key medical and health discipline of Guangxi, and the chief unit of the Guangxi Gastric Cancer Alliance, focusing on the diagnosis and treatment of GC. Through the combination of multiple disciplines, the department carries out accelerated rehabilitation surgery for GC and promotes the rapid rehabilitation of patients with GC. The related technology of accelerated rehabilitation surgery is in a leading position in the country. Doctors evaluate the need for HIPEC before or during surgery, and the patient or family decides whether to proceed with HIPEC after surgery. All patients underwent HIPEC within 48 h after closing the abdominal cavity. The perfused temperature was 43 °C, and each operation time was 60-90 minutes.

Research Team and Interviewer Characteristics

This study's team comprised 6 health care providers, namely, 3 postgraduate students (ZKKT, DNL, and XC), 2 specialists in gastrointestinal surgery nursing (KJ and WZT), and 1 expert in the field of oncology nursing (LY). All interviews were conducted by 2 primary researchers (ZKKT and DNL), both are female and holding MSc Nursing degrees, with over 3 years of dedicated research and academic training in oncology. Before data collection, the interviewers completed formal training in qualitative methodology, including specialized instruction in interview techniques, probing strategies, and ethical considerations. To minimize potential bias, neither researcher had established clinical relationships with any of the participants' families. This absence of prior therapeutic engagement was explicitly disclosed to all participants at the commencement of each interview session [17]. This study was supervised by KJ, a professor of nursing with extensive research experience in gastrointestinal oncology. The project was led by author LY, Director of Nursing at a major tertiary hospital in Southern China.

Recruitment and Sample

The purposive sampling method was used to recruit the participants. Participants were surrogates of adult patients with GC. We approached surrogates of nondecisional patients who required or were expected to require HIPEC after surgery. To be eligible to participate, surrogates needed to be at least 18 years of age, be fluent in the Chinese language, have clear awareness with sufficient communication skills, and self-identify as a primary decision-maker for the patient. Exclusion criteria included extraperitoneal disease, ascites >500 mL, physiologic inability to undergo HIPEC [5], surrogates of patients with recurrent disease, or those who were not involved in the treatment decision. This approach ensured that all participants had direct experience with the phenomenon of interest. Potential eligible surrogates were screened through electronic health records. After the patient completed the HIPEC treatment, the primary nurses of the patients in charge invited the respondent and confirmed eligibility. Participants were informed that their participation was entirely voluntary and that they could opt out at any time. All participant records were kept confidential.

Sample size was based on data saturation, and the calculation and evaluation methods included 3 elements, namely, base size, run length, and new information threshold [18]. Recruitment was stopped when the 2 researchers considered that the content was saturated and without new aspects emerging. Base size as denominator, the run length was the number of interviews within which we looked for and calculated new information. The new information threshold represents the proportion of new information. We will prospectively calculate saturation using a base size of 4 interviews and a run length of 2 interviews. We have selected a new information threshold of ≤5% to indicate that we have reached adequate saturation.

Data Collection

Interviews were conducted in a quiet hospital room, a doctor's office, or a classroom. The interviewers first introduced the purpose, significance, and content of the interview to the interviewees and obtained their consent. Before the interview, interviewees were required to fill in a self-made questionnaire, which included demographic variables (age, gender, education level, occupation, relationship between family caregivers, and patients) of patients and their families, as well as disease-related information (HIPEC protocol and tumor stage) of patients.

They conducted a one-to-one semistructured interview with the interviewees according to the final guide of the interview (Textbox 1), which was developed and tested in 2 preinterviews whose interview data were not included in the data analysis. During the process, they paid attention to observe and record the changes in the nonverbal communication of the interviewees. They were encouraged to express their real thoughts and ask questions. All interviews were audio recorded, transcribed verbatim, and compared with digital audio recordings to ensure the accuracy of the content [17]. Unclear or doubtful contents expressed by the interviewees were confirmed through retelling, questioning, and other ways. Induction, intervention, or judgment was prohibited. The interview duration was limited to approximately 30 minutes per participant. A recruitment diagram appears in Figure 1.

Textbox 1. Qualitative interview guide.

- I'd like to start by asking how did you decide to receive hyperthermic intraperitoneal chemotherapy (HIPEC) on behalf of the patient.

- Can you recall the process of treatment decision?

- What do you know about HIPEC?

- What made you decide to receive HIPEC?

- What concerns did you have during the decision-making process?

- Is there anything you'd like to know or want the medical staff to help you with?

Figure 1. Study enrollment diagram. HIPEC: hyperthermic intraperitoneal chemotherapy.
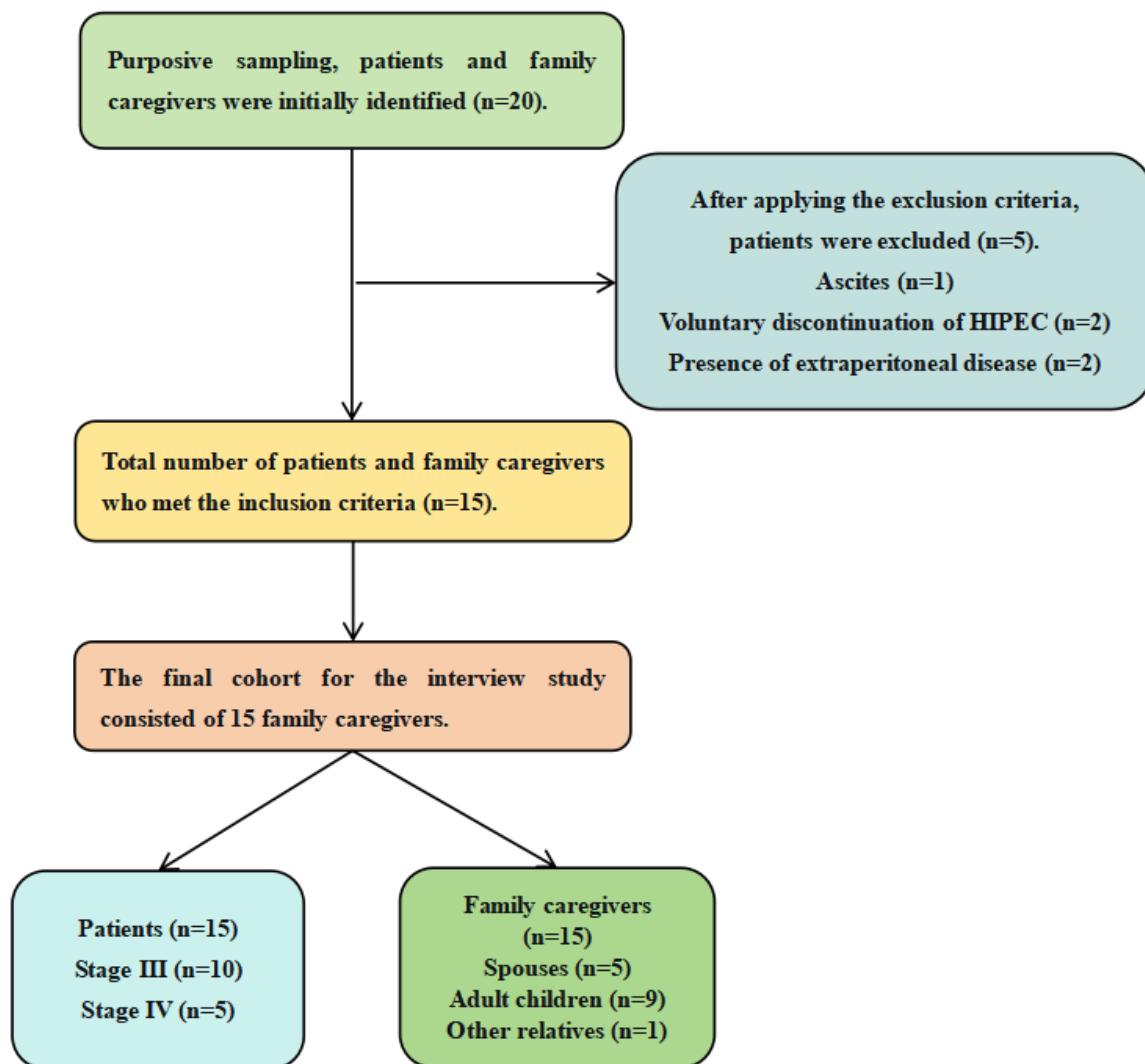
Data Analysis

The audio recordings from each interview were transcribed verbatim. Within 24 h after the interview, 2 researchers (ZKKT and DNL) independently organized the interview data, transcribed it into text, coded transcripts, and analyzed the data with the Colaizzi 7-step analysis method [19]: The interview data were read repeatedly to deeply understand the content information; code recurring, meaningful statements; form a categorized coded view; write a detailed description; have sublimation view as the theme; and then to return the written text to the interviewee for verification. The 2 researchers were fully immersed in the interview content, independently reading and coding in detail. It was summarized after completion, and if any objection was raised, they were discussed and determined within the team (ZKKT, DNL, XC, and WZT). During this process, the research team adopted triangulation, randomly selected 20% transcripts and codes, and then submitted them to the noninterviewers for reviewing and improving the codes [20]. Then, regular meetings were held within the team to generate initial themes (ZKKT, DNL, XC, and WZT).

Ethical Considerations

This study was approved by the Ethics Committee of the First Affiliated Hospital of Guangxi Medical University (2024-E055-01). Before the interview, the interviewer introduced the purpose, significance, and content of the research to the subjects. All data were used only for research purposes. All participants signed informed consent forms after expressing their willingness to participate. During the interview, participants were free to interrupt the experiment if they chose to do so. Immediately following data collection, the interviewer engaged all participants in a standardized debriefing process to disclose the sham trial. Participants were not provided compensation for participation. All personal identifiers of the participants were removed before analysis to ensure privacy. This study strictly adheres to Beauchamp and Childress's Four Principles of Biomedical Ethics [21] to establish the theoretical framework for our ethical approach, recognizing that decision-making during a patient's surgical procedure inherently precludes the preservation of their decision-making capacity.

Results

Patient and Surrogate Decision-Maker Characteristics

The analysis sample for data saturation included 15 patients and their surrogate decision-makers. All participants were on average 39.8 (SD 13.29, range 20-68) years of age at the time of interview. The majority were male (11/15, 73%), and 27% (4/15) were female. The relationship to the patient was distributed as follows: 33% (5/15) spouses, 60% (9/15) children, and 6% (1/15) other relatives. All patients were on average 56.7 (SD 10.78, range 36-74) years of age at the time of interview. The demographic and clinical characteristics of these participants and patients are presented in Table 1.

Table 1. Characteristics of participants.

Number	Surrogate decision-maker					Patient					
	Gender	Age (years)	Education	Occupation	Relationship with patients	Gender	Age (years)	Medical insurance	HIPEC[a], n	Stage	Chemotherapeutics drugs
1	Male	43	Middle school	Farmer	Husband	Female	46	Medical insurance for residents	3	III[b]	Lobaplatin
2	Female	36	Junior college	Office clerk	Wife	Male	36	Medical insurance for residents	3	III	Docetaxel
3	Male	20	College	Student	Son	Male	53	No medical insurance	5	IV[c]	Lobaplatin
4	Male	55	Middle school	Farmer	Husband	Female	51	Medical insurance for residents	3	III	Oxaliplatin
5	Male	45	Master	Construction industry manager	Son	Female	67	Medical insurance for residents	3	IV	Lobaplatin
6	Male	32	College	Office clerk	Son	Male	60	Medical insurance for residents	3	IV	Docetaxel
7	Male	33	College	Civil servant	Son	Male	60	Medical insurance for residents	2	III	Oxaliplatin
8	Female	45	Primary school	Farmer	Wife	Male	47	Medical insurance for residents	3	IV	Docetaxel
9	Male	26	Junior college	Office clerk	Son	Male	54	Medical insurance for residents	1	III	Docetaxel
10	Female	49	College	Civil servant	Daughter	Male	74	Medical insurance for urban employees	3	III	Docetaxel
11	Male	51	High school	Worker	Son	Male	73	Medical insurance for residents	3	III	Docetaxel
12	Male	45	Junior college	Individual	Full brother	Male	51	Medical insurance for residents	3	III	Lobaplatin
13	Male	26	High school	Farmer	Son	Male	58	Medical insurance for residents	1	IV	Oxaliplatin
14	Female	24	Junior college	Individual	Daughter	Male	51	Medical insurance for residents	3	III	Oxaliplatin
15	Male	68	Junior college	Retiree	Husband	Female	70	Medical insurance for urban employees	1	III	Docetaxel

[a]HIPEC: hyperthermic intraperitoneal chemotherapy.

[b]III: stage III gastric cancer is categorized as locally advanced disease. In this stage, the primary tumor has invaded deeply through the gastric wall (potentially involving the serosa) and has extensively metastasized to the regional lymph nodes.

[c]IV: stage IV represents the most advanced phase of gastric cancer. It is defined by the presence of distant metastasis (M1), regardless of the extent of the primary tumor (Any T) or the involvement of regional lymph nodes (Any N).

Topic

The researchers identified four themes through their analysis: (1) shared decision-making participation mode, (2) decision-information sources, (3) challenges in the decision-making process, and (4) facilitators in the decision-making process. The themes and subthemes derived from the analysis are shown in Table 2.

Table 2. Themes and subthemes.

Themes	Subthemes
1. Shared decision-making participation mode	- Doctor-led passive decision-making - Doctor-family sharing decision-making
1. Decision-information sources	- Decision-making information comes from the medical-care personnel - Decision-making information comes from the internet - Decision-making information comes from acquaintances
1. Challenges in the decision-making process	- The financial burden - Anticipated therapeutic efficacy
1. Facilitator in the decision-making process	- Positive health beliefs - Cultural dimensions of perceived responsibility: a Confucian perspective

Theme 1: Shared Decision-Making Participation Mode

Overview

The way of shared decision-making was primarily based on the level of information mastery and education of decision-makers.

Doctor-Led Passive Decision-Making

Nine surrogate decision-makers expressed a preference for physician-dominated decision-making, indicating that their role was primarily to adhere to the physician's recommended treatment course.

The adoption of this decision-making approach demonstrates a significant correlation with educational attainment. Surrogates with limited formal education exhibited a substantial knowledge gap regarding HIPEC compared to clinical professionals, while simultaneously expressing stronger deference to hierarchical medical authority.

> *All of us live in rural areas. I, my wife, my younger brother and my younger sister all have only a middle school education. They seldom go to the hospital for medical treatment. I had never heard of HIPEC and had to rely on the doctor to make the decision. I'm at a loss right now.* [Number 4, aged 55 years, farmer, husband of patient]

> *I never considered challenging the doctor's decision. Since the treatment method they proposed was effective, I followed the expert's advice. After all, he was respected authorities whose opinions are widely accepted.* [Number 13, aged 26 years, farmer, son of patient]

From a cognitive perspective, many surrogates reported experiencing significant feelings of inadequacy and information overload. When participants acquired information but demonstrated either an unwillingness to engage in multisource verification or an inability to synthesize information from disparate channels, they consistently reverted to physician-dependent decision-making as a default strategy.

> *Several doctors came and told me a lot of information. I managed to understand a little bit, but it was too complicated. Without knowledge of HIPEC, the patient was lying on the bed, unable to move, unable to make decisions. We do what the doctor*

> *recommends completely at this time.* [Number 11, aged 50 years, worker, son of patient]

> *Although the doctor is obligated to inform us of this information, I don't think I can fully understand it. I don't worry about whether I can understand it or not. All I need to know is that the doctor's decision is correct, and I just need to follow his decision.* [Number 1, aged 43 years, farmer, husband of patient]

Doctor-Family Shared Decision-Making

Six surrogate decision-makers combined information obtained from various sources. Family caregivers who engaged in doctor-family shared decision-making typically possessed higher educational attainment, demonstrating not only comprehension of complex HIPEC information but also the capacity to critically evaluate disparate information sources, including both physician-provided guidance and internet-acquired content.

> *At the beginning, after being informed of HIPEC by the clinical doctor, first checked the Internet, but also asked acquaintances, to understand the thermal perfusion technology can prevent metastasis, avoid risk effect, we decided to carry out HIPEC.* [Number 5, aged 45 years, construction-industry manager, son of patient]

> *On the premise of knowing a lot about the principle, knowledge and effect of thermoperfusion, I took the initiative to choose the best hospital recognized for surgery and HIPEC.* [Number 6, aged 32 years, office clerk, son of patient]

These surrogate decision-makers did not passively await information but rather demonstrated a proactive communication stance, exemplified by actively seeking clarifications during consultations and engaging in iterative questioning with physicians. They perceived clinicians as collaborative partners in problem-solving rather than unidirectional authorities.

> *After consulting with acquaintances, I repeatedly confirmed with the doctor whether changing the treatment plan could cure gastric cancer and also determined whether the quality of life would change in the future.* [Number 5, aged 45 years, construction-industry manager, son of patient]

After I came to this hospital now, I will also ask the doctor to check the information I found online. Even though they urged me, I couldn't make up my mind easily. [Number 6, aged 32 years, office clerk, son of patient]

Theme 2: Decision-Information Sources

Decision-Making Information Came From Medical Care Personnel

All participants indicated that medical personnel were the initial source of information for their HIPEC decision-making. As a new therapeutic modality, HIPEC has a low popularity among the public, with less access, and obtaining relevant information initially in daily life was difficult for patients and their families.

I've never heard of HIPEC, and I don't know how it works. The first time I heard HIPEC, it was introduced by the surgeon. [Number 2, aged 36 years, office clerk, wife of patient]

I usually read disease-related information on social platforms, but rarely mention HIPEC, and only know it from doctors. [Number 10, aged 49 years, civil servant, daughter of patient]

The main source of HIPEC information for 10 (10/15, 66.6%) surrogate decision-makers of patients was medical staff. A total of 6 surrogate decision-makers did not subsequently seek information in other ways, so this became their only access to information. In particular, older decision-makers living in rural areas lack the competence and access to information.

We rural people do not know this, only through the doctor's recommendation, and do not look up other information. [Number 1, aged 43 years, farmer, husband of patient]

Born in a rural area and an elderly person, I rarely use a smartphone, so I only know about it from my doctor. [Number 4, aged 55 years, farmer, husband of patient]

Decision-Making Information Came From the Internet

Some surrogate decision-makers indicated that they actively sought information and confirmation through internet channels, these being by those with higher education or high internet usage. The primary information sought by participants concerned 3 key areas: the mechanism of HIPEC treatment, its efficacy in GC, and potential adverse effects.

After the doctor first told me HIPEC, I searched on the Internet myself to simply understand what therapeutic effect it has on GC. I looked it up through wechat public account and Baidu. [Number 2, aged 36 years, office clerk, wife of patient]

I searched for side effects (of HIPEC) through Baidu. There are other doctors on Baidu, they might give me different advice. [Number 7, aged 33 years, civil servant, son of patient]

Furthermore, the field of HIPEC is highly specialized, and some of the family caregivers of patients have difficulties understanding it.

But I have no knowledge reserve, even if I find relevant information, I cannot understand. [Number 7, aged 33 years, civil servant, son of patient]

Decision-Making Information Came From Acquaintances

In addition to seeking information through the internet, 3 decision-makers consulted expert acquaintances. For unknown professional treatment information, patients' families tended to consult other doctors through trusted relatives and friends. Surrogate decision-makers find it easier to hear the truth from close friends, to obtain better judgment, and ensure information credibility.

I have relatives and friends who are doctors, they asked someone who is an expert in the field of stomach cancer to know if HIPEC can help my mother's condition. [Number 5, aged 45 years, construction-industry manager, son of patient]

I asked the doctor at our local hospital about the effect of HIPEC and whether it was harmful to the patient's health. After all, it was the first time I heard about this treatment, and I was still a little afraid. [Number 6, aged 32 years, office clerk, son of patient]

Theme 3: Challenges in the Decision-Making Process

Financial Burden

An overarching theme from the interviews was that the significant economic pressure associated with postoperative HIPEC presented a major decisional impediment for nearly all participants. This financial strain was frequently cited as a direct barrier to completing the full course of recommended therapy.

As ordinary people, the economic pressure is relatively large, the thermoperfusion drainage tube is completely self-funded with thousands of yuan each time. I hope the society can be helpful in this respect. [Number 11, aged 51 years, worker, son of patient]

The price is very expensive and the medical insurance is not reimbursed, our average family salary is not high. what if the treatment results are not proportional to our efforts? [Number 9, aged 26 years, office clerk, son of patient]

Anticipated Therapeutic Efficacy

First, a notable uncertainty was noted among some participants concerning the expected benefits of HIPEC, particularly pertaining to the therapeutic protocol and its effectiveness in preventing metastasis and recurrence. This ambiguity was rooted in their nonprofessional background, which consequently hindered their comprehension of the proposed HIPEC regimen and led to profound decisional uncertainty.

The doctor and I have discussed whether to do it three times or four times before, but we still don't know what effect the number of times has on the efficacy, and we are not sure whether the patient can complete the radical cure or prevent metastasis after completing HIPEC, This makes me quite unsure

whether I really need it. [Number 2, aged 36 years, office clerk, wife of patient]

I mainly want to know what effect can be achieved by doing three times, although the doctor always said that the effect is not guaranteed, I hope you can take the initiative to give us a clear answer. [Number 5, aged 45 years, construction-industry manager, son of patient]

Second, some participants, after an in-depth understanding of HIPEC, were concerned that the new technology in chemotherapy had unknown risks of damaging health or aggravating conditions.

HIPEC is also a form of chemotherapy that kills cancer cells and seems to kill healthy cells, raising concerns that patients may suffer weakened immunity and other after-effects. [Number 2, aged 36 years, office clerk, wife of patient]

I'm still worried about any adverse reactions or accidents with this new technology. [Number 10, aged 49 years, civil servant, daughter of patient]

Theme 4: Facilitator in the Decision-Making Process

Positive Health Beliefs

The participants showed a desire to assist patients in their recovery and were the most important facilitators in decision-making. Such participants indicated that they would be more willing to consent to HIPEC, particularly for patients with GC at high risk of PM. They perceived the procedure as offering a promising therapeutic approach, citing its potential to prevent and treat metastatic dissemination, improve survival outcomes, and maintain a few side effects profile. Surrogate decision-makers considered that health was more important than wealth.

I know that the patient is not in good condition now. As long as the curative effect is good, the treatment should be treated, do not think about the problem of money, health is the most important. [Number 14, aged 24 years, individual, daughter of patient]

Health is the most important thing. I understand that HIPEC as early as possible after surgery can more thoroughly identify cancer cells, and then prolong life. As long as there is a effective treatment, we must actively coordinate. [Number 6, aged 32 years, office clerk, son of patient]

Cultural Dimensions of Perceived Responsibility: Confucian Perspective

A total of 60% (9/15) of surrogate decision-makers were children of patients who had the Chinese Confucian cultural values that maintained the integrity of the family and honored their parents. Having a parent with cancer triggered feelings of guilt, and participants felt it was their responsibility to help patients choose the best treatment. They were concerned that making the decision to forgo HIPEC would lead to adverse health outcomes for their parent.

My dad's situation of cancer was bad, but my parents have worked so hard for us since childhood, and as long as there is any hope, I want to try. [Number 10, aged 49 years, civil servant, daughter of patient]

My father knew that the cost of HIPEC was very expensive in a huff, and he wanted to give up the treatment. But he had worked hard all his life, and I, as a son, certainly would not give up the treatment easily. Now we comfort him every day and advise him to actively cooperate. [Number 9, aged 26 years, office clerk, son of patient]

Discussion

Principal Findings

In this qualitative study, 15 family caregivers of patients with GC as surrogate decision-makers were preliminarily studied in China. Applying thematic analysis to those that met our study inclusion criteria, we identified 4 themes, including the mode, facilitators, challenges, and decision-information sources of surrogate HIPEC decision-making.

Our findings identified 2 predominant modes of shared decision-making among HIPEC surrogate decision-makers. Those with lower educational attainment demonstrated reduced health literacy and stronger deference to hierarchical medical authority, making them more likely to rely on a health care provider for decision-making. This appears rooted in their limited capacity to comprehend medical concepts, compounded by inherent information asymmetry that predisposes clinical dominance. Lacking the ability and confidence to navigate this entrenched power structure, they often transferred final decision-making authority to clinicians, thereby mitigating the burden of decisional conflict [22]. Additionally, these decision-makers lack the foundational cognitive skills to assess information reliability and weigh risks against benefits—a finding consistent with Robertson et al [23]. This deficit impedes their ability to process highly specialized information. When confronted with unfamiliar and complex decisions, they frequently experience cognitive and informational overload. Such overload precipitates decisional conflict, characterized by internal contradiction and profound uncertainty, ultimately precluding meaningful participation in either independent or shared decision-making.

Surrogate decision-makers who used diverse information sources were more likely to engage in doctor-family shared decision-making, a finding consistent with Bakke et al [24]. From a personal capacity perspective, their cognitive and educational foundations translated into superior health literacy, enabling them to evaluate the credibility of web-based information and synthesize disparate sources into a coherent cognitive framework. This capacity fostered greater autonomy in assessing treatment efficacy and survival rates through independent verification [25]. Notably, during our interviews, these individuals voluntarily demonstrated their understanding of HIPEC specifics. Regarding behavioral strategies, these surrogates proactively managed information flow to ensure comprehensive understanding and approached decision-making as a process requiring their ultimate accountability. When

physicians and patients communicated effectively, they collectively arrived at treatment decisions [26].

The participation of patients and their families in decision-making conformed to the ethical principle of autonomy and should not play a passive decision-making role in this process [27]. Our findings underscore that facilitating effective shared decision-making requires the integrated provision of essential information alongside careful consideration of patient and family values throughout the decision-making continuum. Patient decision AIDS (PDAs) are popular tools in recent years that help patients make the best choices in health care options based on their personal values and goals, based on evidence-based medicine [28]. Online PDA provides treatment options according to the preferences of patients and their families, including related benefits, risks, and diagrams [29]. PDA can realize centralized information and effectively reduce decision-making conflicts in patients with cancer. From the health care team's perspective, we recommend establishing a dedicated HIPEC decision-support team comprising surgeons and specialized oncology nurses to provide structured decision guidance. This team would be responsible for implementing and systematically evaluating surrogate decision-makers' comprehension and use of decision aid materials [30]. Whole-process and dynamic decision-making support was provided to improve the health literacy of patients and their families and thus reduce decision-making difficulties and conflicts.

We found that participants lacked the basic knowledge of HIPEC and the ability to identify and understand information. Consistent with the result of Hart et al [31], surrogate decision-makers spent more time understanding decision information, with less information, they often misinterpret and undermine decisions. We found that participants with low education indicated that they were not interested in researching decision information. Xie et al [32] similarly found that caregivers' desire for information was lower than for decision-making participation. When the family caregivers, as nonprofessionals, were faced with highly specialized information such as HIPEC, they had difficulty understanding it. This inability even destroyed the positive degree of surrogate decision-makers who obtain further information, especially among the less educated [33]. These findings underscore that health care providers must prioritize the dissemination of HIPEC knowledge and enhance health education for patients with GC and their families, as this constitutes a fundamental prerequisite for facilitating informed decision-making. First, implementation should begin by advancing health care providers' understanding of current HIPEC evidence, enabling them to coherently translate and disseminate updated research insights to surrogates during decision-making consultations. Second, a supportive environment should be created. We recommend that health care institutions implement PDAs containing structured educational modules, which should provide an overview of GC natural history for HIPEC, comparative outcomes of treatment options, and so on. As demonstrated by Jayakumar et al [34], PDAs with professional guidance yield superior decision quality compared to merely distributing educational materials passively. With guidance from health care providers, these tools help laypersons

establish fundamental disease and treatment knowledge, creating essential cognitive foundations for decision-making. Furthermore, providing educational videos at hospital admission significantly enhances engagement and health literacy among patients and their families, thereby improving both the decision-making experience and overall satisfaction with care [35].

The participants expressed diverse challenges facing HIPEC decisions. Financial burden emerged as the primary and most formidable challenge during the decision-making process. Consistent with the result of Graves et al [36], the lower-income patients and caregivers with HIPEC were associated with higher rates of decision regret. Some participants said that the single-use perfusion catheters required for HIPEC were a substantial out-of-pocket expense. During initial discussions of HIPEC, clinicians informed patients of the treatment costs but did not sufficiently underscore the substantial financial implications. As a result, families proceeded with the procedure only to discover—after 1 or 2 cycles—that the cumulative expenses far exceeded their anticipated financial burden. Consistent with reports from Western health systems [37], it was compounded in China as HIPEC was currently not reimbursable through national health insurance, representing a significant financial burden borne directly by families. Consequently, most treatment costs must be borne directly by families rather than through social insurance mechanisms. This financial burden compromises the ability of surrogate decision-makers to pursue clinically optimal decisions and develop treatment plans aligned with optimal clinical guidelines [38]. Uninsured patients with PM will be less likely to consider HIPEC or adjuvant chemotherapy, resulting in people with low economic and social status still at a disadvantage in terms of health [37]. Hamilton et al [39] proved that although the cost of HIPEC for patients was higher than that of systemic chemotherapy, the quality and the overall cost-effectiveness are better. Therefore, according to China's medical conditions, the medical security system should be improved, and the compensation ratio related to HIPEC should be refined to accurately solve the economic burden of patients with GC.

Moreover, the unpredictability of treatment outcomes significantly contributes to this complex decision-making situation. First, most significantly, while the combination of cytoreductive surgery and HIPEC demonstrates efficacy in both treating and preventing peritoneal metastases in advanced GC, this approach remains controversial and continues to evolve within the oncology community [40]. Based on their concern for the patient, participants were concerned about whether a previously unknown treatment can actually improve the cancer situation and inflict new damage to the patient. A joint multicenter study from the United Kingdom and Australia demonstrated significant variations in post-HIPEC survival outcomes and length of hospital stay across different geographic populations [41]. As highlighted by Marano et al [42], even within high-volume specialized institutions, the application of cytoreductive surgery with HIPEC varies substantially in terms of indication, technical execution, and outcome expectations, underscoring the need for clearer communication strategies with patients and their families. Second, our findings indicate that

participants who engaged with multiple information channels and possessed some prior understanding of HIPEC experienced particularly pronounced uncertainty, often stemming from encountering conflicting or inconsistent information across these sources. Different from the results of Crijns et al [26], higher health literacy and satisfaction with the decision of decision-makers were associated with sufficient information support for them. We analyzed that the possible cause was cancer information overload, which can be defined as feeling overwhelmed by the amount of cancer-related material in the information environment. Shi et al [43] show that cancer information overload is associated with perceived perception of illness and treatment uncertainty can lead to anxiety, depression, and emotional fatigue, and, in turn, impaired decision-making ability [30,44]. Effective clinician-family communication serves as a fundamental prerequisite for mitigating therapeutic uncertainty among decision-makers, aiming to support their psychological well-being and maintain alignment with treatment goals. In this context, physicians should engage in transparent dialogue with surrogate decision-makers, recognizing that artificial intelligence-based decision aids cannot substitute for essential human interaction [45].

Regarding the facilitator underlying the surrogate decision-making process for HIPEC, participants indicated their choices were informed by positive health perceptions as well as socioculturally informed perceived responsibilities. First, a participant believed that the "hope" brought by HIPEC can restore a healthy life status. Consistent with the results of Boegle et al [46], when decision-makers perceive that HIPEC is meeting their needs, evoked hope and trust, it benefits the adherence to their treatment. To be precise, they are decision-makers who may care more about longer survival and relapse in the future [45]. Second, consistent with Nissen et al [47], family functionality support is also conducive to improving the disease pressure of patients with cancer and their families and to reducing the physical and psychological burden on caregivers. Furthermore, within traditional Chinese cultural norms, adult children serving as surrogate decision-makers typically adhere to the Confucian virtue of filial piety. This ethical framework mandates comprehensive care for elderly parents, and such filial behavior has been associated with mitigated caregiver burden among adult children [48,49]. Seeking aggressive treatment modalities is often viewed as an expression of loyalty and familial responsibility. However, as demonstrated by Wu et al [50], children with strong filial values may feel compelled to pursue intensive treatment options even when facing substantial financial costs, which can paradoxically lead to decision-making conflicts and psychological distress. In summary, we recommend implementing family centric support protocols for individuals considering HIPEC, delivered through multidisciplinary shared decision-making teams that integrate specialized psychotherapists and oncology nurses to provide sustained psychosocial support. This structured approach enhances decision-making quality by systematically leveraging family caregivers' capacity for optimism as a constructive psychological resource [30,44]. Given the significant role of filial piety in surrogate decision-making, health care providers should cultivate a balanced understanding of Confucian cultural

values among adult children and proactively identify decision-making conflicts during clinical consultations.

Strengths and Limitations

Strengths and limitations of our study warrant discussion. First, our study focuses on the decision-making process of family caregivers of patients with GC, considering HIPEC, an understudied population (to the best of our knowledge). By adopting a qualitative approach, we delve into their lived experiences, addressing a frequently overlooked dimension of patient-centered care. Second, the systematic methodology used enhances the methodological rigor of the inquiry.

Our study has several limitations that should be considered when interpreting the findings. First, our application of a purposive sampling strategy, recruiting participants from a single health care institution in Southern China, means our findings may not be fully representative of all family caregivers of patients with GC considering HIPEC. Second, our cohort consisted predominantly of male participants, reflecting the sociocultural context in China where male family caregivers often assume the role of primary decision-maker. Yet, the framework of culture could also be a strength: this research is contextualized within the framework of Chinese culture, examining the underlying logic and sensitivities of relevant sociocultural norms for the understanding of decision-making processes. Finally, this study was limited by its exclusive focus on the perspectives of surrogate decision-makers. The findings do not incorporate the views of treating clinicians, the patients themselves, or direct observation of clinical interactions, which represent critical avenues for future research to triangulate and enrich our understanding of the decision-making dynamics.

Future Directions

Regarding future research, we propose several directions. Subsequent studies should aim to disentangle the specific factors involved in both information acquisition and the decision-making process for HIPEC. This includes investigating how individuals receive and process information from various channels and how they navigate psychosocial challenges during decision-making. We further propose large-scale, multicenter studies that use a mixed methods approach engaging multiple stakeholders—including surgeons, oncologists, and patients—to develop an integrated model of HIPEC decision-making. Finally, we recommend that future research intentionally enroll more female surrogate decision-makers to facilitate a gender-based analysis and elucidate its influence on decision-making outcomes.

Conclusions

This qualitative study explored the real experiences of GC patients' family caregivers in making decisions about surrogate HIPEC treatment, including the participation mode, decision-making information sources, facilitators, and challenges. Our findings suggested that providing necessary and sufficient information support with regard to HIPEC was the key to achieving shared decision-making by surrogate decision-makers and improving the decision-making experience. Our findings highlighted areas that have not been previously addressed. Health care providers must intensify their efforts to

refine the shared decision-making framework for HIPEC and develop culturally sensitive PDA tailored to the sociocultural and health care context. Such instruments are essential to support GC families in achieving optimal surrogate decision-making aligned with patient values and clinical evidence.

Funding

Conflicts of Interest

None declared.

Multimedia Appendix 1
Tables of a qualitative interview guide, participant characteristics, and themes and subthemes.
[DOCX File , 20 KB - cancer_v12i1e80471_app1.docx]

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Abbreviations

GC: gastric cancer
HIPEC: hyperthermic intraperitoneal chemotherapy
PDA: patient decision AIDS
PM: peritoneal metastasis

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Using Latent Dirichlet Allocation Topic Modeling to Uncover Latent Research Topics and Trends in Renal Cell Carcinoma: Bibliometric Review

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Abstract

Background: Renal cell carcinoma (RCC) is a common, often lethal kidney cancer that originates in the renal cortex. Its incidence is rising, and major factors include smoking, obesity, and hypertension, though its etiology is uncertain. While surgery is effective for localized RCC, treatments for metastatic RCC have advanced significantly due to better diagnostic, prognostic, and predictive tools. Despite this progress, challenges remain, including long-term drug resistance and the complexity of RCC as a diverse group of diseases rather than a single entity.

Objective: The aim of this bibliometric review was a comprehensive analysis of the topics and trends in RCC research, offering a foundation for future investigations.

Methods: We used R "Bibliometrix" to conduct a bibliographic search in Scopus and PubMed covering publications from 1975 to 2023 to statistically assess the distribution of publications associated with RCC by year, journal, and country. Topic modeling of RCC research was conducted using latent Dirichlet allocation, a Bayesian network-based probabilistic algorithm that identifies unobserved thematic clusters in a collection of text documents. Trends in the retrieved themes were then characterized by using regression slopes over time, across countries, and in different journals. These trends were visualized as a heatmap, which was then used for hierarchical clustering to group similar topics based on their correlation strengths.

Results: A total of 35,228 documents from 3070 sources were found, with a steady yearly growth of 9.86% and 118 participating countries. Thirty topics with the best coherence score were found in 8 crucial domains: treatment and therapies, biomolecular and genetic characteristics, disease characteristics and progression, diagnosis and evaluation, metastasis and dissemination, epidemiology and risk factors, related conditions, and pathological features. The pertinent clustergrams that resulted from the heatmaps mirrored the latent Dirichlet allocation's algorithm identification of major RCC research subjects.

Conclusions: Over 50 years, RCC research's focus has shifted from diagnosis and assessment to a more thorough understanding of disease characteristics and progression. Because many patients are diagnosed with abdominal imaging studies, an emerging topic in RCC is diagnostic imaging and radiological evolution. The advances in omics technologies and the function of microRNA signature in the progression, diagnosis, therapy targeting, and prognosis of RCC have garnered a lot of attention. The discovery of the genetic background has enhanced our understanding of the growth of RCC. Drug resistance, local RCC ablation, and postoperative surveillance of RCC recurrence following nephrectomy are key future research avenues. The next generation of drug-targeted therapy and immunotherapy will make it possible to successfully treat metastatic RCC following nephrectomy. Neglected topics include the association between ferroptosis and RCC, the long-term assessment of novel treatments, and the application of artificial intelligence on RCC. Our bibliographic review delivered pertinent data for clinical decision-making and the planning of future RCC research.

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KEYWORDS

bibliometrics; carcinoma renal cell; knowledge discovery; machine learning; research

Introduction

Renal cell carcinoma (RCC) is the term coined to describe the malignant transformation of proximal renal tubular epithelium within the renal cortex [1]. RCC accounts for approximately 90% of all renal malignancies [2] and for approximately 2% of all cancer diagnoses and cancer deaths worldwide [3]. With a 2:1 ratio of new diagnoses, men are more likely than women to be affected by RCC, whose incidence rises significantly with age. RCC is a serious health problem since it is often a lethal kidney cancer with an increasing incidence worldwide. Its relevance is also tied to challenges in early diagnosis and the development of aggressive subtypes like those involving tumor thrombus. RCC's etiology is uncertain. The 3 main risk factors for RCC include being overweight, having hypertension, and smoking cigarettes [3]. Medical disorders such as chronic kidney disease, hemodialysis, kidney transplantation, polycystic kidney disease, and renal stones are additional risk factors for RCC. Numerous dietary, occupational, environmental, and lifestyle factors have also been linked to the development of RCC [4]. Even though the majority of RCCs are sporadic, 3%‐5% of all RCC diagnoses occur in patients younger than 46 years, which suggests an underlying RCC form that is inherited [5].

In terms of treatment, surgery is a successful strategy for managing localized RCC, but conventional chemotherapy is ineffective for treating metastatic RCC. Thankfully, during the past 10 years, amazing progress has been made in treating metastatic RCC, resulting in a significant drop in the cancer's death rates despite a continuous rise in the number of individuals receiving a diagnosis. The main factor for the improvement in RCC survival over the past few decades has been the wide diagnostic, prognostic, and predictive methodologies that are currently available [6,7]. Despite these advancements, long-term RCC drug resistance is still a problem [8]. While accelerating RCC cures is critically needed, research on RCC faces various obstacles. Prior to the discovery of the *VHL* gene, kidney cancer was regarded as a single disease [9]. In fact, kidney cancer is a multitude of diverse diseases, each with its own genetic makeup [10]. This has delayed the search for a cure by impeding reproducibility across studies and appropriate interpretation of the research [11].

RCC offers an intricate and challenging research landscape that hinders scientific progress. The goal of this study was to conduct a comprehensive and up-to-date summary of the topic structure, novel research avenues, study trends, and knowledge gaps in RCC research. Conventional bibliometric methods, scientific mappings, and network visualization studies fall short in offering this kind of text analysis [12], since they frequently necessitate manual categorization or extensive, subjective human intervention [13-16]. Instead, we sought a corpus of text-based data for research trends and topics by using a topic algorithm model called latent Dirichlet allocation (LDA) [17]. We intended for RCC research documents "to tell the story themselves" and for topics to emerge on their own, without human intervention, and only based on their statistical characteristics.

Methods

Search Strategy and Data Collection

This study was based on data obtained from PubMed [18] and Scopus [19] as of April 6, 2023. We chose Scopus over other databases because of its superior coverage in the health sciences field, accurate indexing, and "federated search interface" (ie, functionality), which enables us to query the content found across its sources using a common or standardized search form. The authoritative and comprehensive PubMed is the top choice for searching medical and health sciences literature. Medical Subject Headings (MeSH) terms were used for the PubMed search to improve comprehensiveness. Raw data were stored in *TXT* and *CSV* files, respectively. The R "Bibliometrix" tool of the R Statistical software [20] was used to clean data and integrate the 2 databases' unique publications into a combined dataset (with and without assigned DOI) [18,19,21-23]. At this point, duplicate documents with an assigned DOI (1809 in total) were eliminated. The inclusion criteria for the outcome were all the research documents, written in English in peer-reviewed journals, that were published between 1974 (the earliest article we found) and 2023, and that dealt with RCC. Books, book chapters, gray literature, and reports were not included to avoid noise. The search strings, which used a Boolean computation, are indicated in Table 1. Only those articles with the term "renal cell carcinoma" in their title or abstract were selected. The leader and the other authors reviewed the complete list of all possible acceptable publications. Their reliability and value to the field were based on criteria like the journal's impact factor, author affiliations, and citation count.

Table . Enhanced information retrieval for research on renal cell carcinoma.

Database	Search data	Search string	Results, n
PubMed	April 6, 2024	"renal cell carcinoma"[Title/Abstract] AND "english"[Language] AND "journal article"[Publication Type] AND 1974/01/01:2023/12/31[Date - Publication]	38,577
Scopus	April 6, 2024	TITLE-ABS ("renal cell carcinoma") AND PUBYEAR>1973 AND PUBYEAR<2024 AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re")) AND (LIMIT-TO (SRCTYPE , "j")) AND (LIMIT-TO (LANGUAGE , "English"))	40,479

Bibliometrix Analysis

Our bibliometric review procedure adhered to best practice guidance published elsewhere [24] (Checklist 1). A preliminary descriptive analysis of the retrieved information was carried out using the R package bibliometrix [22]. This open-source application analyzes publication and citation metrics using mathematical and statistical methods to obtain a broad picture of the scientific output that was within the purview of the study. The questions answered were as follows: (Q1) What are the primary research topics in RCC? (Q2) How have RCC research questions changed over time? (Q3) How are these research topics distributed across countries and scientific journals? Three levels of analysis—countries, sources, and authors—were included at this stage to answer the above questions.

The annual growth rate of publications was calculated using the Bibliometrix package in R, which computes the compound annual growth rate (CAGR) using the following equation:

$$(1) \quad CAGR = (V_f / V_i)^{\frac{1}{n}} - 1,$$

where V_f is the number of publications in the final year of the study period, V_i is the number of publications in the initial year of the study period, and n is the number of years between the initial and final year.

Latent Dirichlet Allocation

The unsupervised machine learning algorithm LDA [17] was applied to identify topics. Considered an extension of the probabilistic latent semantic analysis, it has its roots in Bayesian models [17,25]. Topics in LDA are thought of as multinomial distributions of vocabulary terms, in which each word has a given probability of occurring in a topic. This leads to the prominence of words that are more frequently used in a topic, creating clusters that reflect specific underlying themes. LDA does not require prior knowledge of the topics or the way they are presented in the texts. Rather, topics merely flow from the statistical properties of the data and the model's underlying assumptions. For thematic analysis, it was decided to use abstracts rather than entire texts because topics are more coherent and ranked higher in large document collections. Inaccurate or noisy terms have less impact on topic word distribution [26].

The LDA model was validated using the Cv metric, which is grounded in the distributional hypothesis stating that words with similar meanings tend to coexist in similar contexts [27]. In other words, Cv rates the semantic similarity of words within a topic (ie, topic interpretability). The Cv score was calculated by looking at word co-occurrence statistics in a reference corpus and their conformity to human-like semantic interpretation. The package textmineR was used for such analysis, which made it easier to determine the ideal number of topics (k) for the study. Because higher scores indicate better interpretability, a model with the highest coherence score among those in the study rank (from k=4 to 50) was selected to reach a balance between granularity and thematic clarity.

Identifying Research Topics

The procedure for identifying topics through LDA was divided into 3 stages: (1) preprocessing, (2) construction of the LDA model, and (3) assigning labels to topics. LDAShiny [28], an open-source R package that uses Bayesian inference for LDA and machine learning algorithms to improve the analytical process, was selected for the first 2 stages.

Preprocessing

Converting all documents into a standardized format for ease of handling was the objective of the stage known as "Text refining" [29]. Initially, textual data consisted solely of character sets. To enhance topic coherence, each abstract underwent tokenization using bigrams, which are consecutive unigram combinations. This process involves converting text to lowercase and removing punctuation marks, dashes, brackets, numbers, spaces, and "stop words." The list of stop words was extracted from standard libraries such as Natural Language ToolKit and Snowball and was modified to include unrelated terms unique to the medical and technical domains.

The preprocessed data result in the creation of a document-term matrix in which each document is represented as a vector containing an unordered collection of words. If the corpus contains a total of V words, each document becomes a V-dimensional vector, with the value of each element representing the frequency of the corresponding word in the document.

Construction of the LDA Model

LDA assumes that topics are shared by all documents in the collection, while subject proportions vary stochastically between documents, as they are randomly extracted from a Dirichlet distribution [30]. Establishing the expected number of topics was done a priori, making it a nontrivial task to choose the right number of topics (*k*) for a given collection of items. Since the optimal number of topics was unknown beforehand, we generated different models ranging from 4 to 40 topics. We ran 1000 iterations for Gibbs sampling [31] and utilized the default values of the LDAShiny package for Dirichlet parameters α and β. We used Cv as the topic coherence measure of the topics generated by LDA models [32].

Assigning Labels to Topics

The LDA model generates topics without semantic labels. Given that algorithmic analyses are not always able to fully capture the implicit meanings of human language, manual labeling is widely recognized as a normal practice in topic modeling [32]. The manual topic labeling involved a diverse team of 7 experts, including the authors and independent scholars with backgrounds in oncology research and bibliometric analysis. Team members were provided with 2 sources of information: the lists of most frequently occurring words (presumably) provided by the model and a sample of 3 document titles with their corresponding summaries classified by the algorithm. They were asked to independently validate and summarize the identified topics and investigate existing literature to identify research trends, gaps, and influential works. Discrepancies between team members were resolved through remote communications to minimize bias, improve rigor, and ensure the theme structures and semantic interpretation were aligned with the research objective. Reference [32] provides a guide to the procedures used to ensure the trustworthiness of the labels issued, with the difference that we used up to 16 annotators rating candidate labels.

By providing the most relevant and thematically aligned examples within each topic, these articles guaranteed readability and clarity. The 2 articles chosen allowed for a concise and efficient summary of each topic's key ideas without overwhelming the analysis and the reader. This approach strikes a balance between realistic representation and practical interpretability. These articles were then condensed into succinct summaries that encapsulated the essence of each topic. This manual approach not only provided a gold-standard reference [32] but also ensured interpretability and utility in the context of the study.

Quantitative Indices

For each topic, additional characteristics were revealed, especially at the journal and country levels, through statistical description based on the probability distributions of document-topic and topic-word acquired through LDA. To make results and findings more evident, we used certain quantitative indices suggested by Xiong and colleagues [33], which were obtained by adding document-topic and topic-word distributions. The indexes were described as follows:

The distribution of topics over time was obtained by the following equation:

$$(2) \theta ky = \sum m \in y \theta mk / ny,$$

where $m\,j$ represents articles published each year, θ_{mk} is the proportion of the *k*th topic in each item, and n^y is the total number of articles published in the year.

Topic distribution across journals was defined as the ratio of the *k*th topic in the journal *j*: θkj as indicated in the following equation:

$$(3) \theta kj = \sum m \in j \theta mk / nj,$$

where $m\,j$ represents the articles in a particular journal, θ_{mk} is the proportion of the *k*th topic on each item, and n^j is the total number of articles published in the journal *j*.

Topic distribution across countries was defined as the ratio of the *k*th topic in the country *c*, as in the following equation:

$$(4) \theta kc = \sum m \in c \theta mk / nc,$$

where $m\,c$ represents the articles in a particular country, θ_{mk} is the proportion of the *k*th topic on each item, and n^c is the total number of articles published in the country *c*.

Statistics

With the purpose of facilitating the characterization of the topics in terms of their tendency, topic datasets were also submitted to simple regression slopes where the year, country, and journal were the dependent variables, while the proportion of the topics in the corresponding year, country, and journal was the response variable [34]. From the regression slopes, we determined the directionality of these trends and set a significance threshold of $P<.01$ (Eq2). Topics that showed statistically significant positive slopes were identified as having upward trends, while those with statistically significant negative slopes were in decline. Tendencies were finally visualized using the *ggcorrplot* library of R to represent correlation strengths as a heatmap matrix. The color-mapped matrix was subjected to advanced hierarchical clustering analysis in order to investigate and compile correlation datasets, given its visual form like a tree-shaped dendrogram. The *Agnes* function with *Ward's* method showed the agglomerative hierarchical clustering of variables. Each leaf of the dendrogram corresponded to one observation (variable), and the fusion height showed the dissimilarity between 2 observations on the vertical axis. A cut height for cluster identification was calculated using the Average Silhouette method [35].

Results

Overview of the Dataset

The consolidated dataset was obtained by combining the results and removing duplicates, totaling 39,856 articles (Figure 1). After the relevant Excel file was created, 4628 articles lacking titles, abstracts, or affiliations were removed. Within this extensive dataset, 35,228 documents were assembled, demonstrating an annual growth rate of 9.86%. The extensive summary of the key descriptive characteristics pertaining to RCC from 1974 to 2023 can be found in Table 2. A substantial

number of information sources, 3070 in total, were revealed by the data. Given that the document's average age was 11.6 years (the time since the publication of the examined articles), it is likely that much of the research was carried out some time ago.

On average, however, each document received 32.35 citations, demonstrating their influence and recognition in the field (Table 2).

Figure 1. The workflow for article selection and bibliometric analysis in renal cell carcinoma using the PubMed and Scopus databases.
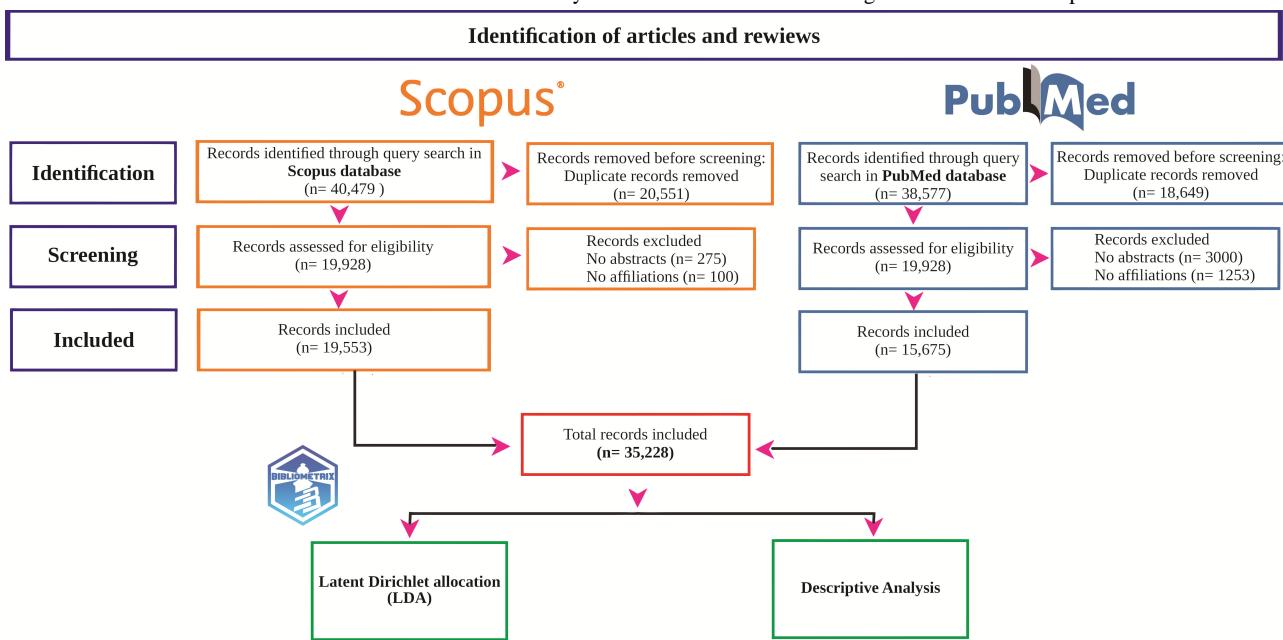
Table . Comprehensive overview of key descriptive characteristics and publication metrics on renal cell carcinoma from 1974 to 2023. Retrieved from the PubMed and Scopus databases.

Description	Results
Main information about data	
Timespan, range	1974 - 2023
Sources (journals, books, etc), n	3070
Total documents, n	35,228
Annual growth rate (%), mean	9.86
Document age (y), mean	11.6
Citations per document, mean	32.35
Document contents, n	
Keywords plus	52,792
Author's keywords	31,248
Authors, n	
Total authors	95,238
Authors of single-authored documents	608
Author collaboration	
Single-authored docs, n	769
Coauthors per doc, mean	7.55
Document types	
Original research	30,913
Review	4315

With respect to the yearly output of documents on RCC, Figure 2 provides an overview of increased production from 1974 (24 articles) to 2023 (2401 articles). Throughout the 1980s and 1990s, the document production grew modestly. However, the 2000s saw a significant increase in production, reaching a peak in 2017 (1832 articles) and indicating a solid trend in recent

years. Table 3 lists the top 30 scientific journals, while a global map (Figure 3) shows the 118 countries that were involved in RCC research. With 10,308 publications, the United States clearly was the top contributor.

Figure 2. Annual production of documents on renal cell carcinoma from 1974 to 2023.
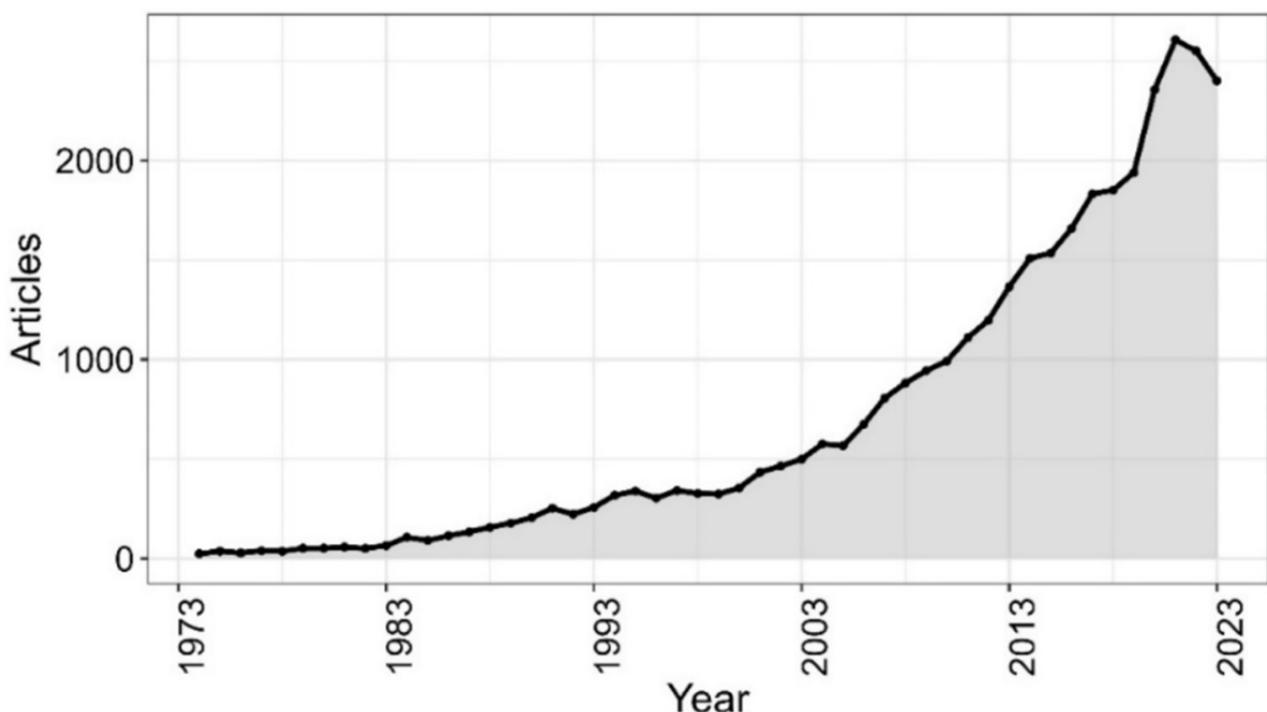
Table . Top 30 scientific journals for research on renal cell carcinoma based on articles published between 1974 and 2023.

Source	Abbreviation	Articles, n
Journal of Urology	*J Urol*	1161
Urology	*Urology*	839
Urologic Oncology: Seminars and Original Investigations	*Urol Oncol*	560
European Urology	*Eur Urol*	542
Frontiers in Oncology	*Front Oncol*	481
Cancer	*Cancer*	478
Clinical Genitourinary Cancer	*Clin Genitourin Cancer*	474
BJU International	*BJU Int*	451
International Journal of Urology	*Int J Urol*	422
Oncotarget	*Oncotarget*	363
PLOS One	*PLoS One*	362
Cancers	*Cancers*	350
Urologia Internationalis	*Urol Int*	316
International Journal of Cancer	*Int J Cancer*	311
Clinical Cancer Research	*Clin Cancer Res*	308
Oncology Letters	*Oncol Lett*	307
World Journal of Urology	*World J Urol*	297
British Journal of Cancer	*Brit J Cancer*	291
BMC Cancer	*BMC Cancer*	273
Scientific Reports	*Sci Rep*	248
American Journal of Surgical Pathology	*Am J Surg Pathol*	236
American Journal of Roentgenology	*Am J Roentgenol*	210
Journal of Clinical Oncology	*J Clin Oncol*	206
Cancer Research	*Cancer Res*	200
Human Pathology	*Hum Pathol*	196
Oncology Reports	*Oncol Rep*	189
International Urology and Nephrology	*Int Urol Nephrol*	188
International Journal of Molecular Sciences	*Int J Mol Sci*	186
Medicine (United States)	*Med (United States)*	172
Journal of Endourology	*J Endourol*	165

Figure 3. Distribution of geographical origins in the analysis of 35,228 published articles on renal cell carcinoma from 1974 to 2023. The table displays the top 30 countries with the highest research production.

Country	Articles	Country	Articles
USA	10308	Sweden	326
China	6084	Poland	325
Japan	3566	Austria	314
Germany	2029	Switzerland	253
Italy	1608	Brazil	219
United Kingdom	1079	Greece	197
South Korea	1057	Belgium	181
France	1056	Czech Republic	177
Canada	920	Israel	160
India	709	Denmark	155
Turkey	621	Iran	147
Netherlands	557	Finland	124
Spain	523	Portugal	119
Taiwan	390	Singapore	118
Australia	351	Russian Federation	114

Latent Dirichlet Allocation

The methodological rigor, reproducibility, and accuracy of LDA were ensured using advanced bibliometric tools such as Bibliometrix and Textminer. There were 30 topics with the best coherence score in the LDA model (Figure 4). The terms with the highest probabilities and semantically relevant labels for each latent topic are shown in Table 4.

Table . Topics discovered from 35,228 articles on renal cell carcinoma published between 1974 and 2023.

Terms	Article numbers, n	Top terms	Label	Themes	Prevalence (%)
t_1	1411	inhibitor, sunitinib, treatment, target, drug, kinas, vegf, growth, factor, tki, sorafenib, resist, agent, tyrosin, growth_factor	Inhibitors in treatment	Treatment and therapies	3.455
t_2	563	rcc, level, patient, serum, control, rcc_patient, increas, group, concentr, elev, blood, distribut, plasma, healthi, compar	Serum levels and patient control	Diagnosis and evaluation	2.414
t_3	1240	express, tissu, normal, protein, tumor, level, correl, mrna, sampl, kidnei, posit, compar, marker, normal_tissu, express_level	Protein expression in tissues and tumors	Biomolecular and genetic characteristics	3.866
t_4	1370	gene, mutat, tumor, chromosom, genet, dna, loss, alter, famili, sequenc, region, identifi, methyl, variant, r	Genetic mutations and chromosomal alterations	Biomolecular and genetic characteristics	3.067
t_5	2113	rcc, clear, tumor, papillari, type, case, subtyp, carcinoma, featur, clear_rcc, prcc, posit, chromophob, histolog, pattern	Histological features and subtypes	Disease characteristics and progression	4.537
t_6	1293	tumor, surgic, thrombu, complic, oper, nephrectomi, surgeri, resect, laparoscop, blood, vena, ivc, postop, perform, approach	Surgical approaches and complications	Pathological features	3.053
t_7	939	vhl, Î±, hif, factor, Î², hif_Î±, protein, hypoxia, activ, induc, von, lindau, hippel, hippel_lindau, von_hippel	Hypoxia factors and related proteins	Pathological features	2.654
t_8	575	effect, treatment, ablat, control, local, search, evid, review, includ, meta, radiat, perform, systemat, outcom, percutan	Treatment effects and local ablation	Treatment and therapies	2.281
t_9	770	immun, pd, respons, immunotherapi, combin, nivolumab, checkpoint, ici, inhibitor, immun_checkpoint, therapi, checkpoint_inhibitor, treatment, death, anti	Immunotherapy and immune responses	Treatment and therapies	2.416
t_10	544	model, predict, score, risk, base, valid, group, curv, clinic, perform, cohort, featur, characterist, set, auc	Risk prediction models and clinical assessment	Epidemiology and risk factors	2.782

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Terms	Article numbers, n	Top terms	Label	Themes	Prevalence (%)
t_11	1593	imag, ct, enhanc, lesion, mass, contrast, evalu, tomographi, mri, comput, detect, phase, comput_tomographi, scan, find	Diagnostic imaging and radiological evaluation	Diagnosis and evaluation	3.633
t_12	1794	patient, month, surviv, median, mrcc, progress, o, group, pf, treat, metastat, free, line, progress_free, receiv	Survival and disease progression	Disease characteristics and progression	4.504
t_13	125	tumor, node, lymph, lymph_node, invas, metastasi, distant, involv, stage, crcc, posit, distant_metastasi, presenc, patient, node_metastasi	Metastasis and lymph node involvement	Metastasis and dissemination	1.776
t_14	724	metastat, metastas, metastasi, primari, patient, bone, site, rcc, lung, lesion, brain, primari_tumor, resect, pet, diseas	Metastasis and lesions in other organs	Metastasis and dissemination	2.724
t_15	324	patient, syndrom, develop, symptom, diseas, clinic, common, earli, relat, occur, sever, adult, hypertens, infect, manifest	Syndromes and clinical manifestations	Pathological features	2.108
t_16	1969	tumor, activ, human, effect, induc, increas, mice, antibodi, antigen, anti, deriv, specif, growth, line, cytotox	Tumor activity and immune responses	Disease characteristics and progression	4.218
t_17	2190	patient, nephrectomi, year, recurr, group, surgeri, follow, rate, rang, underw, local, radic, month, partial, diseas	Nephrectomy and recurrence	Metastasis and dissemination	5.242
t_18	1147	rcc, risk, ci, increas, associ, ag, patient, incid, compar, ratio, popul, year, mortal, interv, data	Risk factors and epidemiology	Epidemiology and risk factors	3.858
t_19	2049	patient, respons, treatment, dose, toxic, dai, week, event, advers, receiv, diseas, progress, evalu, phase, efficaci	Toxicity and adverse events in treatments	Pathological features	4.779
t_20	102	bladder, prostat, urolog, urinari, health, urotheli, tsc, prostat_cancer, malign, kluwer, lippincott, wolter, wolter_kluwer, william, wilkin	Urological cancers and related conditions	Related conditions	1.628

Terms	Article numbers, n	Top terms	Label	Themes	Prevalence (%)
t_21	351	kidnei, diseas, long, term, transplant, function, long_term, develop, chronic, kidnei_diseas, egfr, diabet, dialysi, donor, recipi	Chronic kidney disease and transplant	Related conditions	1.967
t_22	1917	ccrcc, gene, clear, identifi, express, relat, prognosi, clear_ccrcc, ccrcc_patient, cancer, pathwai, biomark, potenti, data, genom	Gene expression and prognosis	Biomolecular and genetic characteristics	4.362
t_23	487	develop, molecular, potenti, recent, therapeut, provid, approach, clinic, understand, import, review, research, base, applic, strategi	Molecular advances and therapeutics	Pathological features	3.026
t_24	1388	surviv, patient, prognost, factor, independ, multivari, specif, cox, o, prognosi, free, prognost_factor, outcom, predictor, specif_surviv	Prognostic factors and survival	Disease characteristics and progression	4.137
t_25	202	cancer, type, lung, breast, kidnei_cancer, melanoma, cancer_patient, includ, lung_cancer, small, breast_cancer, research, acid, metabol, colorect	Nonrenal cancers and comparative analysis	Pathological features	2.354
t_26	555	malign, tumor, diagnosi, biopsi, benign, pancreat, neoplasm, thyroid, mass, case, diagnost, lesion, diagnos, carcinoma, small	Diagnosis and characterization of tumors	Diagnosis and evaluation	2.559
t_27	3022	rcc, mir, prolifer, inhibit, express, role, regul, assai, line, invas, effect, target, apoptosi, promot, migrat	Gene regulation and microRNA expression	Biomolecular and genetic characteristics	5.728
t_28	604	tumor, stage, grade, size, patholog, pt, tumor_size, low, nuclear, clinic, fuhrman, correl, necrosi, fuhrman_grade, tnm	Staging and pathological features	Pathological features	2.986
t_29	1168	therapi, treatment, clinic, target, improv, trial, advanc, system, review, manag, metastat, rcc, target_therapi, benefit, diseas	Advanced therapies and management of metastatic disease	Treatment and therapies	3.795
t_30	2699	case, report, year, present, rare, reveal, kidnei, left, mass, diagnosi, adren, report_case, examin, diagnos, literatur	Clinical presentation and diagnosis of rare cases	Diagnosis and evaluation	4.089

Figure 4. Evaluation of coherence scores for topic models in oncology across different numbers of topics (k). Coherence: measures the semantic quality of topics. Higher values indicate stronger word relationships. Topic models: identify thematic patterns in texts; in oncology, they reveal key research areas; k represents the number of topics in the model. Helps determine the optimal value for thematic analysis.
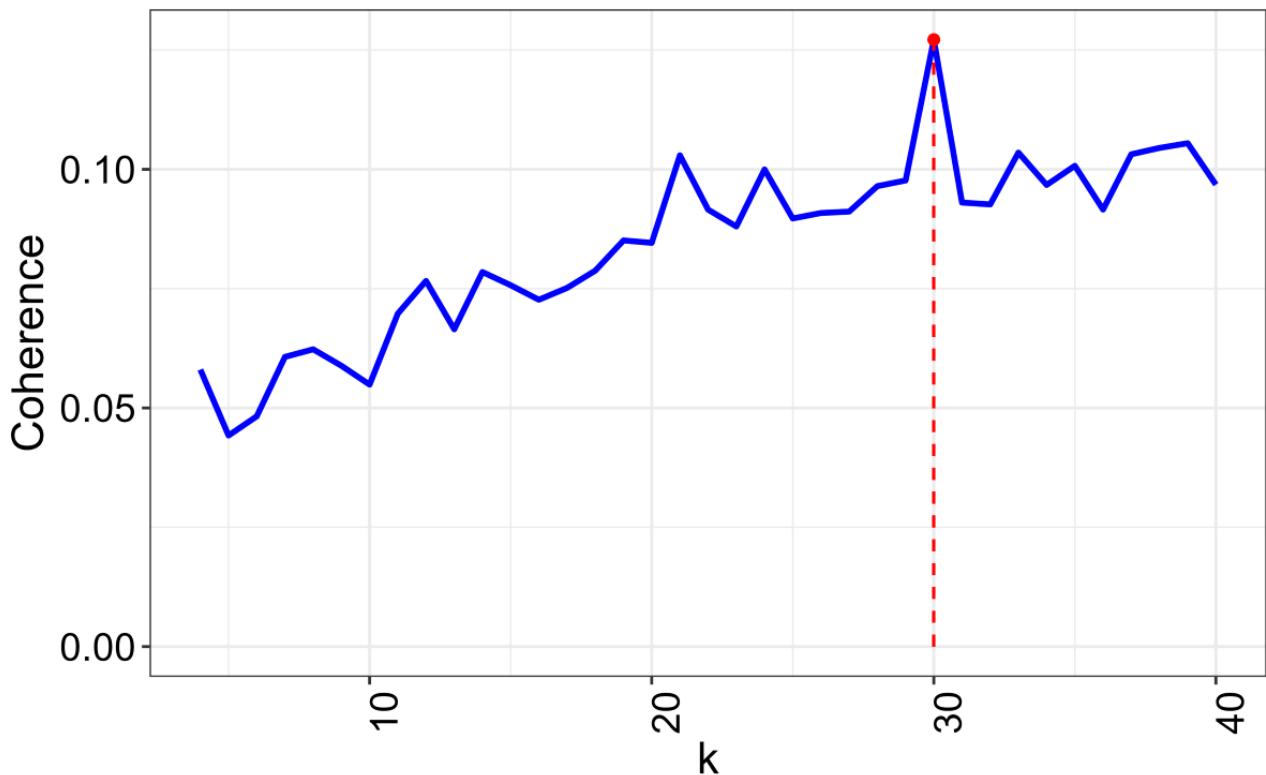
The 30 identified topics were in 8 crucial domains of RCC research:

- Treatment and Therapies: This category focused on different approaches to treating RCC, including targeted inhibitors (t_1), local ablation effects (t_8), immunotherapy responses (t_9), and advanced management of metastatic disease (t_29).
- Biomolecular and Genetic Characteristics: Here, the emphasis was on understanding the molecular and genetic makeup of RCC, covering topics like protein expression in tissues and tumors (t_3, t_22, and t_27) and genetic mutations and chromosomal alterations (t_4).
- Disease Characteristics and Progression: This category delved into the histological features and subtypes of RCC (t_5), as well as the dynamics of tumor activity and immune responses (t_16), and survival rates and disease progression (t_12 and t_24) and pathological features (t_28).
- Diagnosis and Evaluation: Topics in this category included diagnostic imaging and radiological evaluation (t_2 and t_11) for RCC detection and the characterization of tumors (t_26 and t_30) for accurate diagnosis.
- Metastasis and Dissemination: Here, the focus was on understanding how RCC spreads, including its involvement

with lymph nodes (t_13), lesions in other organs (t_14), and the recurrence of the disease post nephrectomy (t_17).
- Epidemiology and Risk Factors: This category examined the risk prediction models and clinical assessment tools (t_10) used to evaluate RCC risk, as well as the epidemiological factors associated with the disease (t_18).
- Related Conditions: Topics here explored conditions related to RCC, such as urological cancers (t_20), chronic kidney disease, and transplant issues (t_21).
- Pathological Features: Finally, this category encompassed various pathological features of RCC, including surgical approaches and complications (t_6), hypoxia factors and related proteins (t_7), syndromes and clinical manifestations (t_15), toxicity and adverse events in treatments (t_19), molecular advances and therapeutics (t_23), and comparisons with nonrenal cancers (t_25).

Topic Trends

The topic distribution by document θm was added to compute the average probability θky of all the articles published in a particular year to identify the trends (Figure 5). We found that the probabilities of some topics steadily increased over time (red). Black indicates topics with no discernible trend, whereas blue denotes topics with a decreasing behavior.

Figure 5. Trends of research topics in renal cell carcinoma between 1973 and 2023: increasing (red), decreasing (blue), and stable (black) topic dynamics over time.
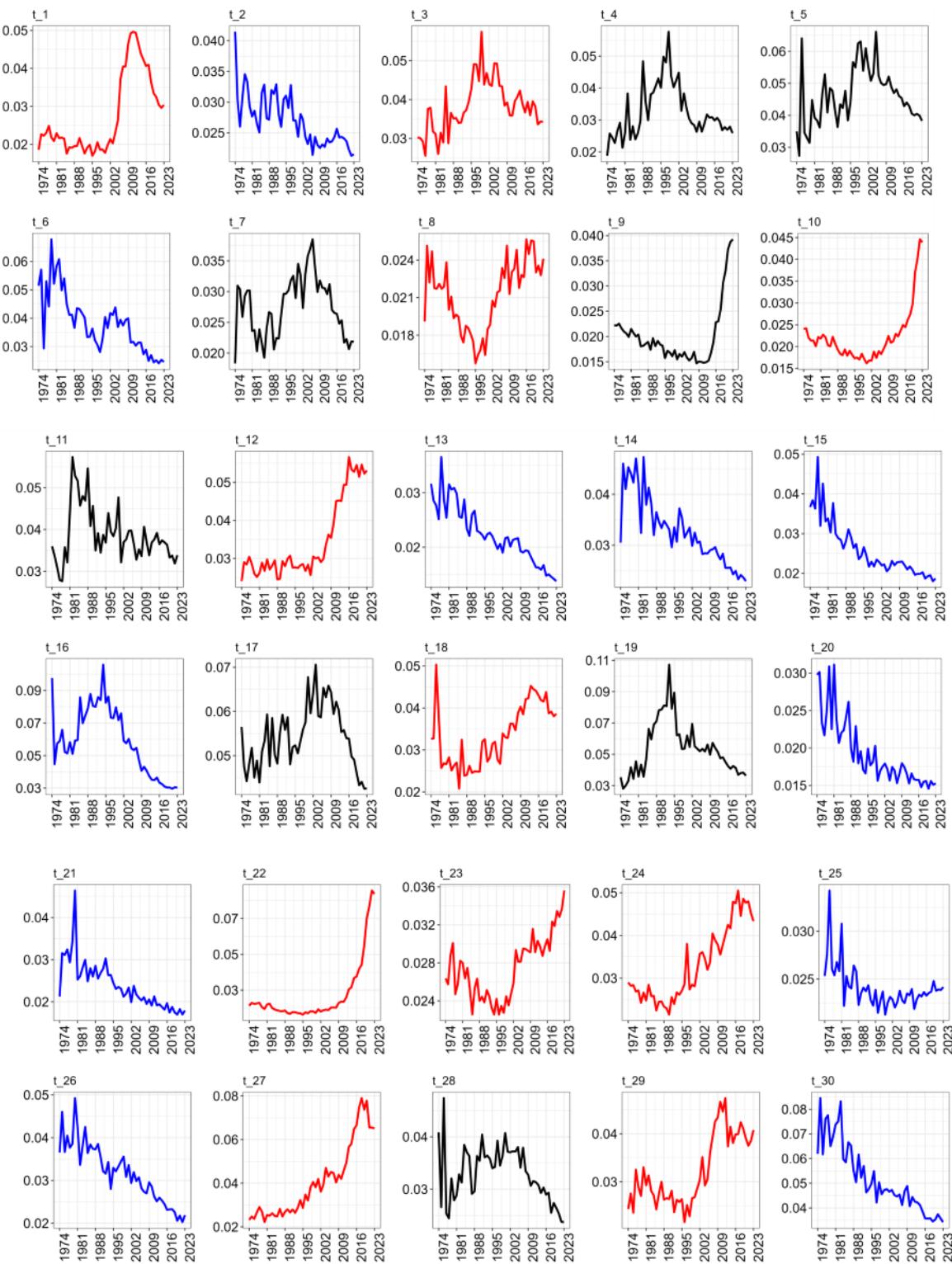
Heatmaps

Although the discovery of 30 unique themes with high coherence scores, a granular and nuanced analysis of the research landscape, was made possible by the LDA method, there was a need for validating the theme output by a form of visual data analytics. Heatmaps helped examine and understand how thematic patterns were related to variables like publication year,

country, and journal. Red highlighting indicates the strongest associations among variables, reflecting higher correlation levels.

Figure 6A illustrates correlations between specific topics and years. Red highlighting indicates the strongest associations among variables, reflecting higher correlation levels. For example, within Cluster 4, Topic 16 (t_16) "Tumor Activity and Immune Responses" is primarily associated with the years

1993, 1985, 1988, 1990, 1992, 1991, 1989, 1995, 1994, 1996, and 1999. Topic 17 (t_17) "Nephrectomy and Recurrence" exhibits stronger correlations with the years 1993, 1990, 1992, 1991, 1989, 1995, and 1994. In Cluster 3, Topic 22 (t_22) "Gene Expression and Prognosis" significantly correlates with the years 2020, 2021, 2022, and 2023, while Topic 27 (t_27), also addressing "Gene Regulation and microRNA Expression," shows significant associations with the years 2017, 2018, 2019, and 2020. Finally, in group 3, Topic Thirty30 (t_30) "Clinical Presentation and Diagnosis of Rare Cases" is linked with the years 1982, 1983, 1981, 1978, 1977, and 1975.

Figure 6. Heatmaps to correlate topics with year (A), country (B), and source (C).
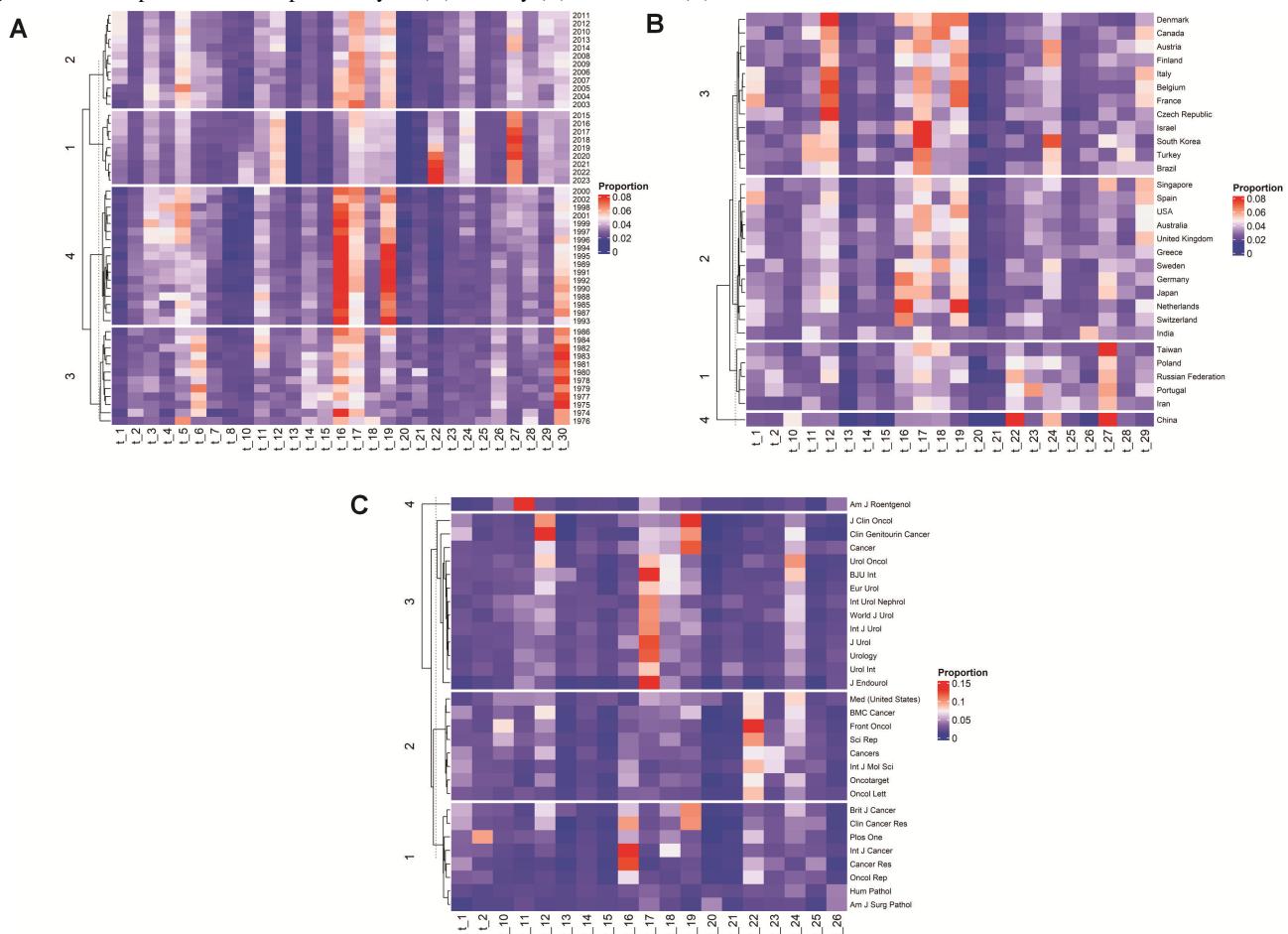
Figure 6B presents the interactions between countries and topics across different groups. In group 1, Topic 27 (t_27), "Gene Regulation and microRNA Expression," is predominantly correlated with Taiwan. Group 2's topics, "Tumor Activity and Immune Responses" and "Toxicity and Adverse Events in Treatments," are closely associated with the Netherlands. For group 3, "Survival and Disease Progression" shows significant correlations with the Czech Republic, Denmark, Belgium, France, and Italy, and "Nephrectomy and Recurrence" is notably linked with Israel and South Korea. Lastly, in group 4, "Gene Expression and Prognosis" and "Gene Regulation and microRNA Expression" are primarily connected with China.

Figure 6C outlines the dominant publication patterns for specific topics within various journals. In group 1, "Tumor Activity and Immune Responses" is predominantly linked with the *International Journal of Cancer* and *Cancer Research*. Group 2's topic, "Gene Expression and Prognosis," has a significant association with *Frontiers in Oncology*. In group 3, "Survival and Disease Progression" relates to *Clinical Genitourinary Cancer*, and "Nephrectomy and Recurrence" is associated with *BJU International*, *Journal of Endourology*, and *Urology*.

Lastly, in group 4, "Diagnostic Imaging and Radiological Evaluation" is prominently linked to the *American Journal of Roentgenology*. LDA algorithm's identification of the key RCC research themes was mirrored in the relevant clustergrams that emerged from the hierarchical cluster analysis of the heatmaps.

Discussion

Principal Findings

By displaying each topic as a group of related words, LDA was able to identify latent (hidden) topics within a corpus of documents and demonstrate how each document may be represented as a combination of these topics. According to this method, RCC research has evolved over the past 50 years from concentrating on surgery to comprehending its genetic underpinnings and the impact of new treatments like immune checkpoint inhibitors and targeted therapies, which have improved the prognosis of metastatic RCC.

The disease characterization, progression, and pathological features have dominated the RCC research landscape for the past 50 years (t_16 and t_19) [10]. Kidney cancer was regarded

as a single disease until the *VHL* gene was discovered [9]. Since then, scientists have realized that kidney cancer is a multitude of diverse diseases, each with its own genetic makeup. Although the characterization of genetic mutations and chromosomal alterations linked to the growth of RCC [36,37] has recently improved our knowledge of this kidney cancer (t_22), RCC research does emphasize the necessity of assessment of treatment effects' safety and efficacy, as well as surveillance of RCC recurrence following nephrectomy. Therefore, a better understanding of resistance mechanisms, molecular prognosis (t_22), and immunological responses (t_16) is essential.

The advances in omics technologies over the last 10 years constitute a promising area of personalized RCC cure [1,38,39]. In addition, the microRNA signature in RCC and its function in progression, diagnosis, therapy targeting, and prognosis of RCC (t_27) have also received particular attention [40,41]. Recent RCC research also moves toward earlier cancer detection through broad imaging and radiological evolution (t-11). RCC has a difficult pathological classification, since the histological analysis reveals three most recurrent sporadic types: clear-cell RCC (70%‑75%), papillary RCC (10%‑15%), and chromophobe RCC (5%) [42]. It is predicated on morphologies, architecture, underlying genetic abnormalities, and tumoral protein expression [43,44]. Pathologists can detect these malignancies more accurately and provide better treatment plans and patient outcomes if they are aware of the significance of these markers (t_12 and t_19).

A major cause for worry is the postoperative surveillance of RCC recurrence following nephrectomy (t_17) [45]. Research on local RCC ablation and assessment of treatment effects on safety and efficacy is still ongoing (t_12, t_16, and t_19). The discovery of tailored medication like tyrosine kinase inhibitors (also called TKIs), such as Sunitinib and Sorafenib, has been beneficial in treating metastatic RCC [46,47]. Another well-established component of RCC treatment is checkpoint inhibitor immunotherapy [48], which shows its superior therapeutic efficacy when combined with TKIs [49]. The next generation of TKIs and immunotherapy (t_16) [50] is being developed to overcome some unfavorable outcomes with kinase inhibitors [51,52] and immunotherapy (t_19) [53], as well as the emergence of drug resistance [54]. Only a small number of themes still earn little attention. The topics "Serum Levels and Patient Control" (t_2), "Hypoxia Factors and Related Proteins" (t_7), and "Risk Prediction Models and Clinical Assessment" (t_18) are overlooked and should require additional attention.

In line with the LDA analysis and our own scientific expectations and goals, it was also feasible to identify untapped topics that have not yet been covered by scholarly literature. Intriguing lines of inquiry are the prognostic value of vascular endothelial growth factor [55], endostatin [56], C-reactive protein [57], the hypoxia-induced pathway [58], and ferroptosis

[59]. The involvement of chronic inflammation [60] and gut and urinary microbiota in immune modulation of metastatic RCC [61] remains poorly investigated. Clinical judgments and patient stratification in RCC may be enhanced by the creation of new predictive models [62] based on, for instance, genetic biomarkers [63]. The application of artificial intelligence is another potential topic that could help physicians in identifying RCC subtypes by analyzing computed tomography scans, as well as in deconstructing complex epidemiological and environmental factors that influence RCC occurrence, like hypoxia [64].

In contrast to traditional bibliometric analysis, the LDA approach effectively extracted potential themes and inferred implicit information from a large collection of documents. The LDA approach and other topic modeling methods like co-citation and keyword co-occurrence cannot be compared with the same conceptual granularity or depth. LDA goes beyond who cites whom (ie, intellectual connection and research lineage) and uncovers the underlying conceptual themes that bind the literature, which may not be immediately apparent from citation patterns alone. Unlike a list of keywords, which reveals basic relationships, LDA organizes these co-occurring words into meaningful higher-order themes, offering a more detailed knowledge of topic relationships and structure. For this reason, the LDA analysis was not affected by the potential simplicity of the keywords chosen in the study.

The subjectivity involved in manually labeling LDA topics, the possibility of missing publications by using only 2 databases, the linguistic bias introduced by excluding articles written in languages other than English, the constraints of the "bag-of-words" model which disregards grammar and context, and the effects of excluding literature like book chapters are some limitations of the study. Despite the constraints, LDA can disclose "unknown unknowns" by revealing unarticulated or unacknowledged themes. It can also give an overview of the research landscape to identify new topics and interdisciplinary connections, as well as demonstrate how old themes are resurfacing in new ones. As a result, LDA remains the most often used natural language model [13,14,65].

Conclusions

This review offered a thorough summary of how research on RCC has changed over the previous 50 years. LDA helped identify important emerging trends in treatment development to address drug resistance and undesirable side effects, surgical techniques, and immunotherapy advancements, among other topics pertinent to clinical practice and medical research. In summary, this study presents a methodological synthesis of the development of RCC research and delivers pertinent data for clinical decision-making, early identification, and the planning of new biomedical research.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: JDLH-M, KM-E
Data curation: KM-E, JDLH-M
Formal analysis: JDLH-M, KM-E, CAS-M
Investigation: JDLH-M, KM-E, CAS-M, MF, SJB
Methodology: JDLH-M, KM-E, CAS-M
Supervision: MF, SJB
Validation: JDLH-M, KM-E, CAS-M, MF, SJB
Writing – original draft: KM-E, SJB
Writing – review & editing: MF, SJB
All the authors equally contributed to the writing of the final version of the manuscript and were responsible for its content.

Conflicts of Interest

None declared.

Checklist 1
Bibliometric analysis checklist.
[PDF File, 97 KB - cancer_v12i1e78797_app1.pdf]

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Abbreviations

LDA: latent Dirichlet allocation
MeSH: Medical Subject Headings
RCC: renal cell carcinoma

TKI: tyrosine kinase inhibitor

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Large Language Models for Supporting Clear Writing and Detecting Spin in Randomized Controlled Trials in Oncology: Comparative Analysis of GPT Models and Prompts

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Abstract

Background: Randomized controlled trials (RCTs) are the gold standard for evaluating interventions in oncology, but reporting can be subject to "spin"—presenting results in ways that mislead readers about true efficacy.

Objective: This study aimed to investigate whether large language models (LLMs) could provide a standardized approach to detect spin, particularly in the conclusions, where it most commonly occurs.

Methods: We randomly sampled 250 two-arm, single–primary end point oncology RCTs from 7 major medical journals published between 2005 and 2023. Two authors independently annotated trials as positive or negative based on whether they met their primary end point. Three commercial LLMs (GPT-3.5 Turbo, GPT-4o, and GPT-o1) were tasked with classifying trials as positive or negative when provided with (1) conclusions only; (2) methods and conclusions; (3) methods, results, and conclusions; or (4) title and full abstract. LLM performance was evaluated against human annotations. Afterward, trials incorrectly classified as positive when the model was provided only with the conclusions but correctly classified as negative when provided with the whole abstract were analyzed for patterns that may indicate the presence of spin. Model performance was assessed using accuracy, precision, recall, and F_1-score calculated from confusion matrices.

Results: Of the 250 trials, 146 (58.4%) were positive, and 104 (41.6%) were negative. The GPT-o1 model demonstrated the highest performance across all conditions, with F_1-scores of 0.932 (conclusions only; 95% CI 0.90-0.96), 0.96 (methods and conclusions; 95% CI 0.93-0.98), 0.98 (methods, results, and conclusions; 95% CI 0.96-0.99), and 0.97 (title and abstract; 95% CI 0.95-0.99). Analysis of trials incorrectly classified as positive when the model was provided only with the conclusions revealed shared patterns, including absence of primary end point results, emphasis on subgroup improvements, or unclear distinction between primary and secondary end points. These patterns were almost never found in trials correctly classified as negative.

Conclusions: LLMs can effectively detect potential spin in oncology RCT reporting by identifying discrepancies between how trials are presented in the conclusions vs the full abstracts. This approach could serve as a supplementary tool for improving transparency in scientific reporting, although further development is needed to address more complex trial designs beyond those examined in this feasibility study.

Introduction

Randomized controlled trials (RCTs) represent the gold standard for evaluating interventions in oncology [1]. However, the reporting and interpretation of trial results can be subject to inconsistency and "spin"—the presentation of results in a way that may mislead readers about the true efficacy of interventions [2]. This can, for example, be accomplished by emphasizing secondary end points or subgroup analyses when primary end points are not met. While most research that has looked at the topic has found a substantial prevalence of spin, the exact number varies as it is not always straightforward to differentiate between what constitutes a balanced and comprehensive presentation of the results and what may be an attempt to mislead the reader [3].

The presence of spin has important implications. Clinicians, policymakers, and even patients often rely heavily on abstracts and conclusions when interpreting trial findings, as full-text

analyses are time-consuming and not always accessible. Therefore, misrepresentation of results might contribute to overly optimistic perceptions of treatment benefits, potentially influencing clinical decision-making, guideline development, and even the allocation of research funding. Given the increasing complexity of cancer care and the rapidly expanding volume of clinical trials, ensuring clarity and accuracy in scientific reporting is crucial to avoid bias in evidence synthesis and translation into practice.

The growing capabilities of large language models (LLMs) could constitute a standardized way to determine the presence of spin. If an abstract is clearly written, a state-of-the-art LLM should be able to determine whether its primary end point was met. As multiple studies have identified the conclusions as the most frequent source of spin [4,5], we hypothesized that trials which are correctly classified as negative—defined as trials that did not meet their primary end point—by an LLM when provided with the title and abstract, but incorrectly classified as positive when provided with only the conclusions, would be likely to contain some form of spin. Therefore, the aim of this study was to evaluate whether LLMs can reliably classify oncology RCTs as positive or negative and whether discrepancies between conclusion-only and full-abstract classifications can help identify patterns consistent with spin.

Methods

Overview

Randomized controlled oncology trials from 7 major medical journals (*British Medical Journal*, *Journal of the American Medical Association*, *Journal of the American Medical Association Oncology*, *Journal of Clinical Oncology*, *The Lancet*, *The Lancet Oncology*, and *The New England Journal of Medicine*) published between 2005 and 2023 were randomly sampled by downloading the available abstracts for the time frame via PubMed in a text file and parsing the abstracts using regular expressions. These 7 journals were selected because they publish a large and consistent volume of oncology RCTs and are widely regarded as leading general or oncology-specific medical journals. The 2005 to 2023 range was chosen to capture contemporary trial reporting practices while ensuring sufficient volume across all selected journals. To avoid edge cases for this feasibility study, it was decided to limit the eligible trials to designs with exactly 2 arms and 1 primary end point.

We aimed to sample 250 trials as this number ensured a sufficiently large dataset for the feasibility analysis while remaining feasible for manual dual annotation. Trials were sampled by creating a randomized list of all retrieved abstracts. Two authors (CK and PW) then started the annotation from the top of the random list and stopped after 250 two-arm, single–primary end point oncology trials had been annotated. No journal-level quotas were applied.

The purpose of the annotation was to establish the ground-truth classification—whether the trial met its primary end point—against which model predictions could be evaluated. The annotation was conducted in a 2-step process. After annotating the first 20 trials, all samples were discussed to

recognize potential differences in the annotation criteria. The remaining trials were annotated separately, and discrepancies were discussed after all trials had been annotated. A third author (DRZ) would have been responsible for judging disagreements that persisted after discussion. However, this was not necessary. The annotation was performed using the Prodigy tool (version 1.13.1; Explosion), which only showed the extracted abstract as text without any additional information such as authors or institutions. Only in cases in which the abstract did not clearly state the primary end point and its results did we refer to the full publication or protocol. Three commercially available LLMs, namely, GPT-3.5 Turbo, GPT-4o, and GPT-o1 (OpenAI), were then tasked with classifying the trials as positive or negative. The 3 models were chosen to investigate whether the inherent capabilities of the models would impact their suitability for the classification task (eg, simpler models requiring more explicit language to correctly identify trials) and, thus, their performance when trying to leverage differences in classification accuracy to detect unclear writing and spin. The decision to use OpenAI models was based on the prevalent use of these models at the time as well as the convenience of application programming interface access and lack of privacy concerns regarding the study data. The respective model snapshots were gpt-3.5-turbo-0125, gpt-4o-2024-11-20, and o1-2024-12-17. The LLMs were called via the application programming interface, with the temperature parameter set to 1. We refrained from performing multiple classification runs as a previous study from the same research group had shown very consistent performance by LLMs for both classification and named-entity recognition tasks, as long as the temperature was kept at or below 1.50 [6].

Each model was evaluated in 4 different rounds. In round 1, the models were only provided with the conclusions of the abstract. In round 2, the models were provided with the methods and conclusions of the abstract. In round 3, the models were provided with the methods, results, and conclusions of the abstract. In round 4, the models were provided with the title and full abstract.

The following system prompt (ie, the fixed instruction provided to the model to define its task) was used: "You will be provided with the {section} of a randomized controlled oncology trial. Your task will be to classify if the trial was positive, i.e. if it met its primary endpoint, or negative, i.e. if it did not meet its primary endpoint. Your response should be either the word POSITIVE (in all caps) or NEGATIVE (in all caps)."

The "{section}" part was replaced with either "conclusion," "methods and conclusion," "methods, results, and conclusion," or "title and abstract." The user prompt (ie, the specific input text) was the corresponding title, abstract, or sections of the abstract.

The prompts were designed to be as explicit as possible regarding the definition of a positive trial to minimize ambiguity and ensure consistent model behavior across conditions. However, we did not conduct a systematic comparison of different prompts.

Statistical Analysis

Interannotator agreement was calculated as the percentage of agreement divided by the total number of annotated trials.

The results were evaluated against the ground truth (ie, the human-annotated classification of whether the trial met its primary end point) by creating confusion matrices and computing several performance metrics to obtain a holistic picture of model performance. These included accuracy (the proportion of correctly classified trials among all trials), precision (the proportion of predicted positive trials that were truly positive; equivalent to positive predictive value), recall (the proportion of truly positive trials that were correctly predicted as positive; equivalent to sensitivity), and F_1-score (the harmonic mean of precision and recall). For completeness, specificity (true negative rate), and negative predictive value can also be derived from the confusion matrix but were not separately reported. The 95% CIs were estimated using normal approximation intervals. For the best-performing model, we further analyzed and categorized the trials that were incorrectly predicted as positive when provided with the conclusions but were correctly predicted as negative when provided with the title and abstract. For these trials, a single author (PW) reviewed the full conclusions and abstracts to categorize the patterns leading to incorrect classification (eg, omission of primary end point, emphasis on subgroup findings, or unclear distinction between end points). To contextualize these findings, we additionally selected 10 randomly chosen trials correctly classified as negative by GPT-o1 and performed the same qualitative assessment. All programming was performed in Python (Python Software Foundation; version 3.13.2) using, among others, the *pandas* (version 2.2.3) and *openai* (version 1.67.0) packages.

Ethical Considerations

This study used publicly available abstracts from published clinical trials. All data were deidentified and contained no patient-level information; therefore, ethics approval was not required.

Results

Interannotator agreement was 97.2% (243/250). All of the disagreements were caused by simple mistakes and could be easily resolved during the discussion. Ultimately, 58.4% (146/250) of the trials were annotated as positive, and 41.6% (104/250) were annotated as negative.

The performances of the models when provided with different sections of the abstract are shown in Figure 1 and Table 1. GPT-o1 exhibited the best performance in each round, with F_1-scores of 0.932 (conclusions only), 0.96 (methods and conclusions), 0.98 (methods, results, and conclusions), and 0.97 (title and abstract). GPT-4o's F_1-scores across the 4 rounds were 0.89, 0.91, 0.94, and 0.94, respectively. GPT-3.5 Turbo exhibited F_1-scores of 0.89, 0.92, 0.91, and 0.91, respectively.

Figure 1. Confusion matrices. Classification performance of GPT-3.5 Turbo, GPT-4o, and GPT-o1 when predicting whether a trial was positive or negative based on different sections of the abstract.
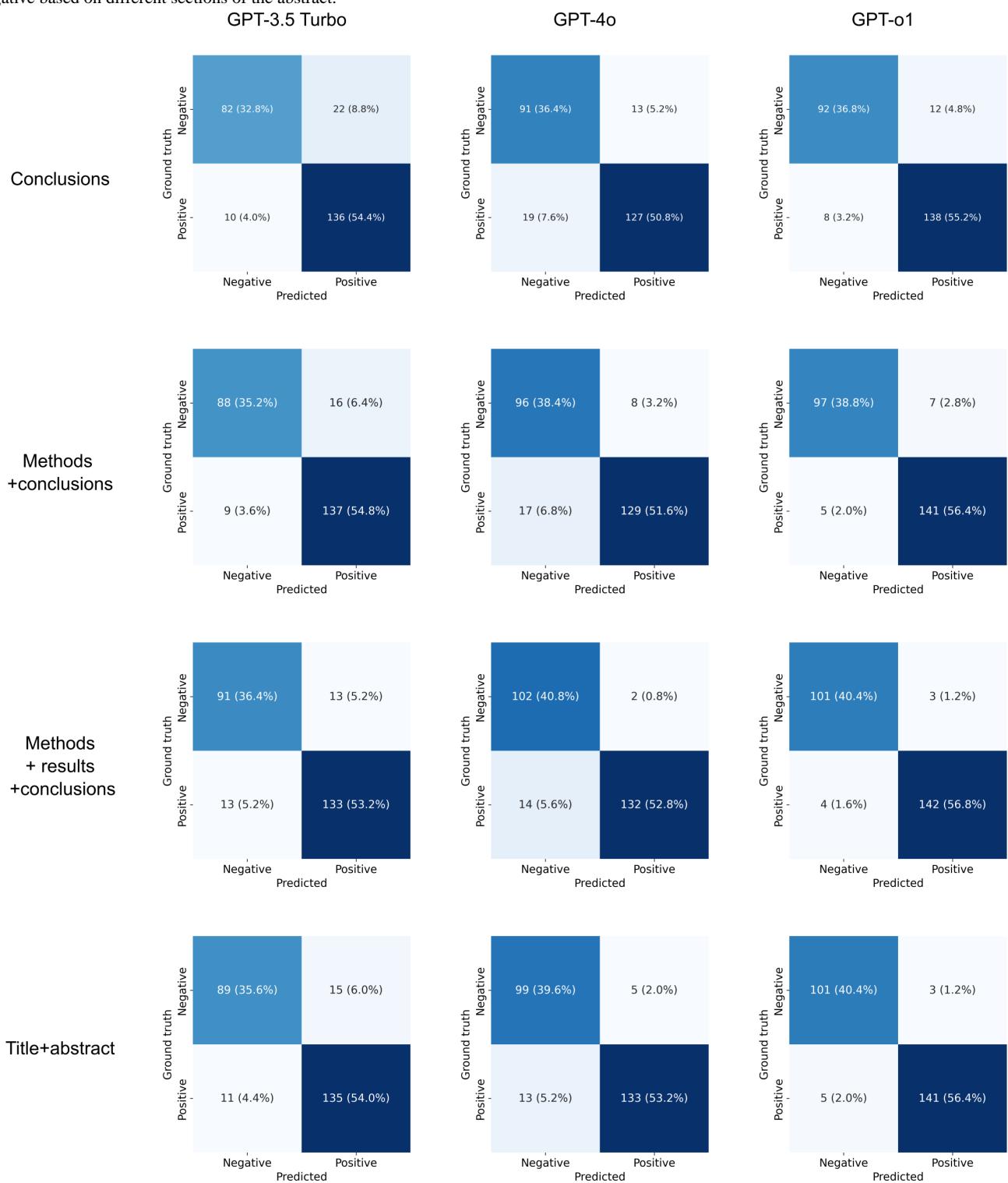
Table . Classification performance. Accuracy, precision, recall, and F_1-score for GPT-3.5 Turbo, GPT-4o, and GPT-o1 when predicting whether a trial was positive based on different sections of the abstract.

	Accuracy (95% CI)	Precision (95% CI)	Recall (95% CI)	F_1-score (95% CI)
Conclusions only				
GPT-3.5 Turbo	0.87 (0.83 ‐ 0.91)	0.86 (0.82 ‐ 0.90)	0.93 (0.90 ‐ 0.96)	0.89 (0.86 ‐ 0.93)
GPT-4o	0.87 (0.83 ‐ 0.91)	0.91 (0.87 ‐ 0.94)	0.87 (0.83 ‐ 0.91)	0.89 (0.85 ‐ 0.93)
GPT-o1	0.92 (0.89 ‐ 0.95)	0.92 (0.89 ‐ 0.95)	0.95 (0.92 ‐ 0.97)	0.93 (0.90 ‐ 0.96)
Methods+conclusions				
GPT-3.5 Turbo	0.90 (0.86 ‐ 0.94)	0.90 (0.86 ‐ 0.93)	0.94 (0.91 ‐ 0.97)	0.92 (0.88 ‐ 0.95)
GPT-4o	0.90 (0.86 ‐ 0.94)	0.94 (0.91 ‐ 0.97)	0.88 (0.84 ‐ 0.92)	0.91 (0.88 ‐ 0.95)
GPT-o1	0.95 (0.93 ‐ 0.98)	0.95 (0.93 ‐ 0.98)	0.97 (0.94 ‐ 0.99)	0.96 (0.93 ‐ 0.98)
Methods+results+conclusions				
GPT-3.5 Turbo	0.90 (0.86 ‐ 0.93)	0.91 (0.88 ‐ 0.95)	0.91 (0.88 ‐ 0.95)	0.91 (0.88 ‐ 0.95)
GPT-4o	0.94 (0.91 ‐ 0.97)	0.99 (0.97 ‐ 1.00)	0.90 (0.87 ‐ 0.94)	0.94 (0.91 ‐ 0.97)
GPT-o1	0.97 (0.95 ‐ 0.99)	0.98 (0.96 ‐ 1.00)	0.97 (0.95 ‐ 0.99)	0.98 (0.96 ‐ 0.99)
Title+abstract				
GPT-3.5 Turbo	0.90 (0.86 ‐ 0.93)	0.90 (0.86 ‐ 0.94)	0.92 (0.89 ‐ 0.96)	0.91 (0.88 ‐ 0.95)
GPT-4o	0.93 (0.90 ‐ 0.96)	0.96 (0.94 ‐ 0.99)	0.91 (0.88 ‐ 0.95)	0.94 (0.91 ‐ 0.97)
GPT-o1	0.97 (0.95 ‐ 0.99)	0.98 (0.96 ‐ 1.00)	0.97 (0.94 ‐ 0.99)	0.97 (0.95 ‐ 0.99)

We further analyzed trials that were incorrectly predicted as positive by GPT-o1 when the model was only provided with the conclusions but predicted correctly when provided with the title and abstract. Of these 10 trials, 6 (60%) did not mention the primary end point in the conclusions [7-12]. One mentioned an improvement in the primary end point in a subgroup [13].

One mentioned both improved secondary end points and the unimproved primary end point without specifying which was which [14]. The remaining 2 trials mentioned that one arm was superior to the other one without specifying that it was the control arm that showed improved results [15,16]. The list of trials is provided in Table 2.

Table . Trials that were incorrectly predicted as positive by GPT-o1 when the model was only provided with the conclusions but predicted correctly when provided with the title and abstract.

Title	Conclusions reported on primary end point	Possible reason for incorrect prediction
"Total Body Irradiation or Chemotherapy Conditioning in Childhood ALL: A Multinational, Randomized, Noninferiority Phase III Study" [15]	Yes	Conclusions mentioned that TBI[a] plus etoposide showed improved overall survival. Therefore, the model likely thought that TBI plus etoposide was the intervention that was tested, whereas it was actually the control.
"Volasertib Versus Chemotherapy in Platinum-Resistant or -Refractory Ovarian Cancer: A Randomized Phase II Groupe des Investigateurs Nationaux pour l'Etude des Cancers de l'Ovaire Study" [7]	No	Primary end point was not discussed in the conclusions.
"High-Dose Therapy and Autologous Blood Stem-Cell Transplantation Compared With Conventional Treatment in Myeloma Patients Aged 55 to 65 Years: Long-Term Results of a Randomized Control Trial From the Group Myelome-Autogreffe" [14]	Yes	Conclusions mentioned both improved secondary end points and the unimproved primary end point without specifying which was which.
"Results of a Randomized Trial of Chlorambucil Versus Fludarabine for Patients With Untreated Waldenström Macroglobulinemia, Marginal Zone Lymphoma, or Lymphoplasmacytic Lymphoma" [8]	No	Primary end point was not mentioned in the conclusions.
"Bortezomib-Dexamethasone, Rituximab, and Cyclophosphamide as First-Line Treatment for Waldenström's Macroglobulinemia: A Prospectively Randomized Trial of the European Consortium for Waldenström's Macroglobulinemia" [9]	No	Primary end point was not mentioned in the conclusions.
"Adjuvant tamoxifen and exemestane in early breast cancer (TEAM): a randomised phase 3 trial" [12]	No	Primary end point was not mentioned in the conclusions.
"Addition of Bevacizumab to Bolus Fluorouracil and Leucovorin in First-Line Metastatic Colorectal Cancer: Results of a Randomized Phase II Trial" [10]	No	Primary end point was not mentioned in the conclusions.
"Oral ibandronic acid versus intravenous zoledronic acid in treatment of bone metastases from breast cancer: a randomised, open label, non-inferiority phase 3 trial" [16]	Yes	Conclusions mentioned the superiority of zoledronic acid. Therefore, the model likely thought that zoledronic acid was the intervention, whereas it was the comparator in this noninferiority study.
"Bcl-2 Antisense (oblimersen sodium) Plus Dacarbazine in Patients With Advanced Melanoma: The Oblimersen Melanoma Study Group" [13]	Yes	Improvement in the primary end point in a subgroup was mentioned.
"Efficacy and Safety of Trabectedin or Dacarbazine for Metastatic Liposarcoma or Leiomyosarcoma After Failure of Conventional Chemotherapy: Results of a Phase III Randomized Multicenter Clinical Trial" [11]	No	Primary end point was not mentioned in the conclusions.

[a]TBI: total body irradiation.

To confirm that those writing patterns were not equally frequent in trials correctly classified as negative, we also analyzed 10 random trials predicted correctly as negative by GPT-o1 and have provided the analysis in Multimedia Appendix 1. Of these trials, only 10% (1/10) did not mention the primary end point for the whole trial population in its conclusions but, instead, reported the results of the primary end point in a positive subgroup [17]. In total, 70% (7/10) of the trials explicitly mentioned that the primary end point failed to meet statistical significance or that the trial as a whole was negative or only mentioned the negative primary end point in their conclusions [18-24]. A total of 20% (2/10) of the trials mentioned both the primary end point and secondary end points or subgroups [25,26].

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Discussion

Principal Findings

In this study, we evaluated the ability of 3 commercial LLMs to classify oncology RCTs as positive or negative based on different sections of trial abstracts. Our findings demonstrate that modern LLMs, particularly more advanced models, can achieve high classification accuracy even when provided with limited information. Our findings also support the hypothesis that trials that are correctly classified as negative by an LLM when provided with the title and abstract but incorrectly classified as positive when provided with only the conclusions are likely to contain patterns that may be interpreted as spin. While there is no ground truth of what constitutes spin, not mentioning the results for the primary end point at all in the conclusions, mentioning an improvement in the primary end point that only occurred in a subgroup, or mixed reporting of primary and secondary end points without clear distinction would be at least considered questionable by many readers [27]. Our findings also highlight that the LLM-based approach is not perfectly specific. In total, 20% (2/10) of the studies for which o1 was misled to believe they were positive when provided only with the conclusions had conclusions that clearly mentioned which arm had better outcomes. However, the LLM did not know which arm was the intervention and which arm was the control, so it assumed that the superior arm was the intervention arm. While this way of phrasing a conclusion may not be optimal for readability, it is certainly not an attempt at misleading the reader, who will still know which treatment yielded better results.

Therefore, our approach is likely not suitable as a fully automated solution. However, it demonstrated its potential to inform editors, reviewers, and authors alike of potential spin or unclear writing. The question of "Are the results for the primary endpoint clearly recognizable in the conclusion?" might serve as an alternative litmus test. Even though reviewers and journal editors are generally capable of recognizing questionable conclusions, we do believe that automated tools have value considering the ever-increasing list of items that have to be considered when conducting a careful review as they may, if implemented carefully, point toward parts of the manuscript that need increased attention. Another group of people who might benefit from a higher degree of automation are physicians who do not routinely read RCTs or have to do it in a situation in which they do not have time to fully digest all aspects of the research, such as in between patient consultations.

Comparison to Prior Work

While research on LLMs and spin is still in its infancy, Yun et al [28] evaluated 22 LLMs and found that they are actually more susceptible to spin than humans. As LLMs are being used increasingly for screening and synthesizing scientific literature, this highlights the importance of improved detection of spin, preferably at the prepublication stage. However, the approach demonstrated in this study could also be leveraged as part of a screening pipeline to detect spin when trying to systematically analyze the literature in an automated fashion.

Strengths and Limitations

This study has several strengths. The human annotation process was systematic, with independent dual review and consensus resolution, resulting in a reliable ground-truth dataset. Evaluating 3 LLMs of differing capability provided insights into how model complexity affects performance and sensitivity to unclear reporting. In addition, the structured comparison across 4 abstract conditions enabled us to isolate how specific sections of reporting contribute to misclassification.

This study has several limitations. First, the analysis was restricted to RCTs with 2 arms and a single primary end point. This constraint reduced complexity and helped ensure consistent interpretation but limits the applicability of our findings to trials with more complex designs, such as those involving multiple or co–primary end points. As noted in this paper, such designs introduce additional analytic considerations, for example, prespecified alpha splitting, that would have increased methodological heterogeneity and potentially confounded the evaluation [29]. Therefore, the restriction was deliberate, but it reduced generalizability.

Second, we did not include trials using analytical frameworks other than standard hypothesis testing, such as Bayesian designs [30]. Because these studies report results differently and may emphasize posterior probabilities rather than traditional statistical significance, the performance of LLMs in such contexts remains unknown. This limitation reflects the scope of the feasibility study rather than an inherent barrier of the method.

Third, it is uncertain whether the models had previously encountered some of the included abstracts during training. If so, prior exposure could have artificially increased performance, particularly when models were presented with only part of an abstract. Although this possibility cannot be fully eliminated for proprietary language models, our key analyses focused on discrepancies between conclusion-only and full-abstract predictions. These discrepancies are less susceptible to prior knowledge because recognizing internal inconsistencies requires examining the relationship between sections rather than retrieving memorized text. Nonetheless, this limitation may have influenced overall performance metrics.

Fourth, this study used a single, clearly defined prompt that specified what should be considered a positive or negative trial. While this approach ensured consistent instructions across models and conditions, it remains possible that different prompting strategies would yield different results. The choice of a single explicit prompt was intended to minimize variability, but it may limit insight into how models behave under alternative or less directive task formulations.

Future Directions

Future work could extend this approach to more complex trial designs, including studies with multiple or co–primary end points, adaptive designs, or Bayesian frameworks, to determine whether LLM-based assessments remain reliable under conditions in which end point interpretation is less straightforward. Evaluating models from different vendors and open-source architectures may also help clarify how

generalizable these findings are beyond the commercial systems examined in this study. In addition, refining prompting strategies or incorporating structured domain knowledge could improve model understanding of trial context, particularly in situations in which the distinction between intervention and control is not explicitly stated. Prospective integration of LLM-based screening tools into editorial workflows may help assess their practical utility in real-time manuscript evaluation. Finally, future studies may investigate whether LLMs can assist in promoting clearer reporting practices by providing automated feedback to authors during manuscript preparation.

Conclusions

In conclusion, this study demonstrates that LLMs can highlight potential spin in oncology trial reporting by identifying inconsistencies between conclusions and full abstracts. These findings suggest a possible role for LLMs as supportive tools that draw attention to areas in which reporting may be unclear or incomplete. While not a substitute for expert review, such tools may help promote clearer communication of trial results. Further evaluation in more complex trial settings will be needed to determine how broadly this approach can be applied.

Data Availability

The datasets generated or analyzed during this study are available in the GitHub repository [31].

Authors' Contributions

Conceptualization: CK, PW
Data curation: CK, PW
Formal analysis: CK, PW
Methodology: CK, PW
Project administration: DMA, DRZ
Supervision: DRZ
Writing – original draft: PW
Writing – review & editing: CK, FD, CS, DMA, RF, DRZ
All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Analysis of 10 random trials predicted correctly as negative by GPT-o1.
[PDF File, 64 KB - cancer_v12i1e78221_app1.pdf]

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Abbreviations

LLM: large language model
RCT: randomized controlled trial

Original Paper

Efficacy of Telehealth-Based Coaching to Improve Physical Activity and Overall Experience for Cancer Survivors: Secondary, Mixed Methods Analysis of a Randomized Controlled Trial

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Abstract

Background: Cancer survivors face significant challenges in maintaining adequate physical activity levels, which are essential for overall health and quality of life. Telehealth-based interventions offer promising opportunities to provide accessible support and promote healthier lifestyles throughout the cancer survivorship continuum. HealthScore is a telehealth coaching program designed to optimize the health of cancer survivors.

Objective: This study assessed the effectiveness of HealthScore in improving physical activity metrics among cancer survivors compared to controls. We also evaluated participants' qualitative experiences with the program to understand its impact on motivation, accountability, and overall health-related quality of life.

Methods: We performed a secondary analysis of a randomized controlled study of cancer survivors who participated in a comprehensive health coaching intervention called HealthScore. Participants in control and intervention groups received a Fitbit activity tracker that collected heart rate, step counts, active minutes, and calories burned. These metrics were analyzed using statistical methods to compare overall averages and temporal trends between intervention and control groups. Eleven exit interviews were conducted with intervention arm participants to ascertain their experiences with HealthScore. Inductive thematic analysis was performed to identify emerging themes. Data were collected between May 2020 and March 2022.

Results: Of the 32 participants enrolled, 20 (62%) were in the intervention group. Compared to the control group, intervention participants had significantly higher average daily steps (mean 3660, SD 3344; 95% CI 3557-3764 vs mean 3408, SD 3288; 95% CI 3299-3518; $P=.001$) and more moving average daily steps (mean 4813, SD 1723; 95% CI 4680-4946 vs mean 4581, SD 1224; 95% CI 4494-4669; $P=.003$). Moving average daily step counts in the intervention arm showed an increasing trend, which was significantly higher than that of the control group (regression slope=5.89 vs 2.80; $P<.001$). Compared to the control group, the intervention participants had significantly higher average daily walking distance (mean 2.6, SD 2.5; 95% CI 2.5-2.7 vs mean 2.4, SD 2.3; 95% CI 2.3-2.5; $P<.001$) and more moving average daily walking distance (mean 3.5, SD 1.3; 95% CI 3.4-3.6 vs mean 3.2, SD 0.8; 95% CI 3.1-3.3; $P<.001$). Moving average daily walking distances among intervention participants increased, which was also significantly higher than that of the control group (regression slope=0.0046 vs 0.0017; $P<.001$). Participants in the intervention group reported a growing sense of accountability and motivation. One barrier was completing weekly monitoring

of patient-reported outcome surveys, which focused on symptoms and physical function and did not always align with participants' goals.

Conclusions: The HealthScore telehealth coaching program improved physical activity levels among cancer survivors and enhanced motivation and accountability. These findings support the integration of telehealth-based health coaching into posttreatment care, promoting healthier lifestyles and improved quality of life for cancer survivors.

Trial Registration: ClinicalTrials.gov NCT04923997; https://clinicaltrials.gov/study/NCT04923997

Introduction

Maintaining adequate physical activity levels poses a significant challenge for cancer survivors [1]. The toxicity associated with cancer treatments often results in fatigue, pain, and decreased physical function, which can discourage individuals from participating in regular exercise [2,3]. Additionally, psychological symptoms, such as anxiety and depression, further impede motivation and adherence to physical activity regimens [4]. The lack of tailored programs for cancer survivors increases these challenges, making it harder for individuals to incorporate physical activity consistently into their routines [5].

Low physical activity levels among cancer survivors can have detrimental effects on their overall well-being and health care outcomes [1,6]. Inactivity has been associated with reduced health-related quality of life (HRQOL), increased fatigue, and higher anxiety and depression scores [7]. Additionally, a sedentary lifestyle is linked to higher risks of comorbidities, complicating the health status of cancer survivors [8]. Conversely, regular physical activity can alleviate treatment-related adverse effects, reduce cancer-specific and overall mortality, and improve HRQOL [9]. Furthermore, studies have demonstrated that telehealth exercise-based interventions can significantly enhance cardiorespiratory fitness, quality of life (QOL), and physical activity levels in cancer survivors [10,11]. Home-based physical activity interventions have been shown to be safe, with very low adverse event rates [12]. Finally, exercise has been recommended to cancer survivors since 2019 [13]. Therefore, promoting and maintaining adequate physical activity is essential for improving overall health among cancer survivors.

Research has shown that health coaching can be an effective method to promote physical activity among cancer survivors [14-16]. By definition, health coaching involves participant-led personalized support and guidance to help individuals set and achieve health-related goals [7]. In general, health coaching can lead to significant improvements in the frequency and intensity of physical activity, thereby improving overall physical activity levels [17,18]. However, to date, many health coaching programs have not shown improvements in physical activity among those with cancer, largely due to lower intervention intensity or low quality of coaching [19,20].

Telehealth-based health coaching has emerged as a promising solution to address these challenges by providing ongoing,

personalized support with remote convenience. Telehealth allows for higher accessibility for individuals who may not have access to in-person services [21]. Telehealth coaching combined with remote symptom monitoring can effectively increase patients' physical activity levels, improve biomarkers associated with diabetes, and reduce body weight [4,22]. Health coaching is distinct among behavioral interventions for cancer survivors for a number of reasons: (1) its emphasis on improving patient activation and motivation, (2) its ability to be delivered by trained and supervised lay health coaches, and (3) the extent to which participants drive the direction. Coaching is less scripted than other behavioral interventions in general, given the focus on encouraging participants to take ownership of their health. HealthScore places emphasis on improving motivation, mood, mindfulness, and movement (the 4M model) [23]. However, the effect of telehealth coaching on the physical activity levels of cancer survivors is unknown.

HealthScore is a telehealth coaching program that focuses on optimizing the overall health of cancer survivors (ie, from diagnosis through end-of-life) through (1) weekly, structured coaching sessions and (2) physiologically based patient-generated health data (PGHD) capture to enable comprehensive support to promote health. Preliminary work has demonstrated high levels of acceptability and feasibility of the HealthScore intervention [24]. The purpose of this study was to assess HealthScore's potential for improving physical activity and report on the experiences of intervention participants.

Methods

Overview

We conducted a secondary analysis of a randomized controlled pilot study [24] of cancer survivors who participated in a comprehensive health coaching intervention called HealthScore, using an explanatory sequential mixed methods approach [25]. This study was a registered clinical trial (NCT04923997). The pilot study assessed the feasibility and acceptability of the HealthScore program by measuring changes in physical function from baseline, evaluations conducted at 3 and 6 months, and patient-reported outcomes (PROs) as secondary outcomes. This secondary analysis assesses HealthScore's potential for improving physical activity by examining daily step count and walking distance, coupled with thematic analysis of participant exit interviews. For this study, we adopted the National Cancer

Institute (NCI) definition of cancer survivor: "An individual is considered a cancer survivor from the time of diagnosis through the balance of life" [26]. Data were collected between May 2020 and March 2022.

HealthScore's key components consist of weekly meetings with coaches to develop and clarify goals, the collection of PGHD from Fitbit activity tracking, and weekly participant-completed surveys centered on physical function, HRQOL, and symptom burden. Participants in the intervention group completed weekly sessions with a trained health coach who guided them in creating individualized SMART (Specific, Measurable, Achievable, Relevant, and Time-Bound) goals, reviewed their survey responses, including a graphic display of their self-reported physical function metrics over time (labeled their Health Score), and, when needed, connected them to additional supportive care resources [27]. Health coaches were a combination of 2 full-time cancer center staff and 12 volunteer health coaches. All coaches received training in motivational interviewing strategies, common symptoms affecting cancer survivors, and goal setting to facilitate focused, goal-oriented sessions. Coaches had participated in a series of didactic presentations surrounding the transtheoretical model of behavior change, coaching foundations, cancer center resources, and other health-related topics, including exercise, nutrition, and sleep. Training videos and manuals were developed by a board-certified health coach and maintained for reference [24].

The team was formally trained in conducting interviews and comprised of medical professionals and 12 interdisciplinary volunteer coaches. The majority of coaches were recruited through the National Board of Health and Wellness Coaches job board, had already completed an accredited program, and were planning to pursue the National Board examination for health and wellness coaching. Coaches were asked to complete a HealthScore-specific training, which included human participants protections, 5 hour-long HealthScore coaching trainings and associated assessments, and practice coaching sessions with the same board-certified staff coach. Having a singular coach trainer provided consistency across the multiple volunteer health coaches. Coaches were not permitted to work with patients who participated in HealthScore until the study team and the volunteer coach were confident that the volunteer had sufficient coaching skills and understanding of cancer center resources. Coaches were required to attend monthly team meetings to ensure they were up to date with study progress and to have a shared space where they could brainstorm participant-specific coaching challenges together. All volunteer coaches were supervised by a board-certified health coach.

The intervention group completed semistructured exit interviews after the intervention ended at 6 months. Exit interviews lasted 30-45 minutes and elicited participants' perspectives about the impact of the HealthScore intervention on their health goals and outcomes. The objective of the current analysis was to report findings from both the objective Fitbit physical activity data and intervention participant exit interview themes and to provide insight into HealthScore's mechanisms of action and refine the intervention for a future fully powered efficacy trial.

Study Design

To promote the autonomy and self-efficacy of participants and improve their long-term QOL, the HealthScore program is grounded on self-determination theory [28]. Additionally, the principles and the transtheoretical model of behavior change were supplemented by motivational interview techniques [29,30].

Patients were either referred to our program by clinical oncology teams, identified through screening of clinical visits, or self-referred to our program in response to the University of North Carolina (UNC) Research For Me listing. Patients across a variety of cancer types with advanced cancer staging were recruited. Once patients were identified, they were screened to ensure they met the inclusion criteria. Information, such as cancer type and treatment status, was collected; however, this information was used for evaluation of study eligibility and not used as exclusion criteria based on type and treatment status. If eligible, a study team member contacted them via phone to gauge interest, provide more information about the study. Once consented, patients completed the PROMIS (Patient-Reported Outcomes Measurement Information System) Physical Function 8b, [31] which evaluates limitations in physical activities (eg, mobility and extremity function). Responses were stratified into high or low physical function and then randomized into either the intervention or a waitlist control arm to study the impact of the intervention on the participants' physical function, HRQOL, and physical activities as measured by weekly averages of daily step counts. Participants were randomized by the research team and stratified at the median of baseline PROMIS physical function scores of (45+ and <45). The final number of participants included 20 in the intervention group and 12 in the control group, totaling 32 participants for the entire cohort. While there were 46 total participants in the parent trial, 14 participants were excluded from this secondary analysis due to missing or abnormal data. The TIDieR (Template for Intervention Description and Replication) and the CONSORT (Consolidated Standards of Reporting Trials) checklists were referenced to describe this study (Multimedia Appendices 1 and 2, respectively). Qualitative methods were guided and reported in compliance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) reporting guideline [32].

Measures

Quantitative Data Collection

Participants in control and intervention groups received a Fitbit activity tracker that collected metrics, such as heart rate, step counts, active minutes, and calories burned. The study team provided training and troubleshooting for participants, if needed. Data from each device were automatically sent via an intermediary application programming interface to the UNC Connected Health for Applications & Interventions (CHAI) Core, a UNC-developed secure data collection system used by the study team. CHAI Core created a HealthScore platform for coaches and participants to provide participant monitoring, generate reports, visualize data capture (including the PROMIS Physical Function measure, referred to as the HealthScore), and serve as a platform for collaborative goal setting. Survey

responses were collected and aggregated through another internal platform called PRO-Core.

Qualitative Data Collection

A semistructured interview guide (Multimedia Appendix 3) designed to synthesize themes of participants' perspectives of the HealthScore program was collaboratively developed by the study team and pilot tested during earlier phases of HealthScore. This guide structured questions around patients' perceived facilitators and barriers to participation, their interactions with their health coach, thoughts on the program's metrics, and caregiver involvement. Intervention group participants were asked about their perceptions after completing the one-time 6-month HealthScore program and its components, such as the Fitbit tracker, short- and long-term benefits, and recommendations for changes to HealthScore.

Study team members conducted interviews using web-based videoconferencing platforms or telephonically. The 30-minute interviews were audio recorded and transcribed, and representative quotes were identified. Field notes were captured during the sessions to amplify recordings. Transcripts were not shown or returned to participants for comment or correction.

Outcomes

This paper's analytical outcomes were (1) physical activity (daily step count and daily walking distance over the week) and (2) perceptions of participants in the intervention group elicited from exit interviews with intervention participants.

Data Analysis

Quantitative Analysis

Frequencies and means describing participant characteristics in both arms were calculated. A pragmatic methodological approach was undertaken for this mixed methods study [25].

For assessment of physical activity, we used the records of each participant's daily step count captured from participant-worn Fitbits. We calculated moving averages of daily step count for each participant using a window size of 7 days, as we inferred that the data collected from the participants tended to change over the course of the week, and this interval matched the frequency of weekly coach calls. The missing data and abnormal data (negative step counts) were removed (18%). The moving average of daily step count between participants in the intervention and control arms was compared, and t test was applied to detect the difference between them. Then, with the time change as the independent variable and the moving averages per participant as the dependent variable, linear regression models were fit to further analyze the trend of step counts per participant during this experimental phase, helping to understand how participants' adherence and motivation for physical activity changed over time. The same procedures were also applied to the analysis of walking distance. A P value less than .05 was considered significant.

Qualitative Analysis

For the participant perspectives of the intervention, an inductive qualitative research approach was used for analysis, with each unique participant serving as the unit of analysis [33]. The qualitative sample was limited to those participants for whom full interviews were available, totaling 11 participants overall. The interview sessions were automatically transcribed and then analyzed using Dedoose, a qualitative management web-based tool [34]. The research team followed a phased approach to ensure rigor and reproducibility in our analysis. Two coders (JG and KM) developed a codebook of 25 unique codes based on the initial readings of transcripts reviewed and standardized to code the interview transcripts [35]. Codes were focused on facilitators, barriers, and suggestions for improvement. We then reviewed codes to identify broader themes and refined them to ensure no key aspects of the data were overlooked. Finally, we captured direct quotes to provide meaningful insights that are aligned with our study's aim. Participants did not provide feedback on our findings.

Mixed Methods Integration

Following the explanatory sequential mixed methods design, quantitative and qualitative findings were integrated during the interpretation phase to provide a comprehensive understanding of HealthScore's intervention effectiveness. Integration involved comparing quantitative physical activity outcomes (eg, step counts) with qualitative themes. This integration aimed to explain how and why the intervention achieved its quantitative outcomes by examining participants' perspectives on program components, such as accountability and measurement tools. This integrated analysis facilitated a richer interpretation of the findings and leveraged the GRAMMS (Good Reporting of a Mixed Methods Study) checklist (Multimedia Appendix 4).

Ethical Considerations

The IRB (Institutional Review Board) of the UNC at Chapel Hill approved the study and its use of electronic consent (IRB number 20-0051). Consents were emailed and signed via UNC REDCap (Research Electronic Data Capture; Vanderbilt University). All study data complied with institutional guidelines and were deidentified. Participants provided written informed consent and received a US $20 gift card as compensation for returning questionnaires at each study milestone.

Results

Overview

There were 163 patients approached to participate in the HealthScore program (Figure 1). Of those, 53 consented, and 46 ultimately enrolled. Participants were randomized and stratified at the median of baseline PROMIS physical function scores of (45+ and <45). The final number of participants included 20 participants in the intervention group and 12 participants in the control group for a total of 32 participants (Figure 1). No adverse events related to exercise were noted.

Figure 1. CONSORT (Consolidated Criteria for Reporting Qualitative Research) flow diagram.
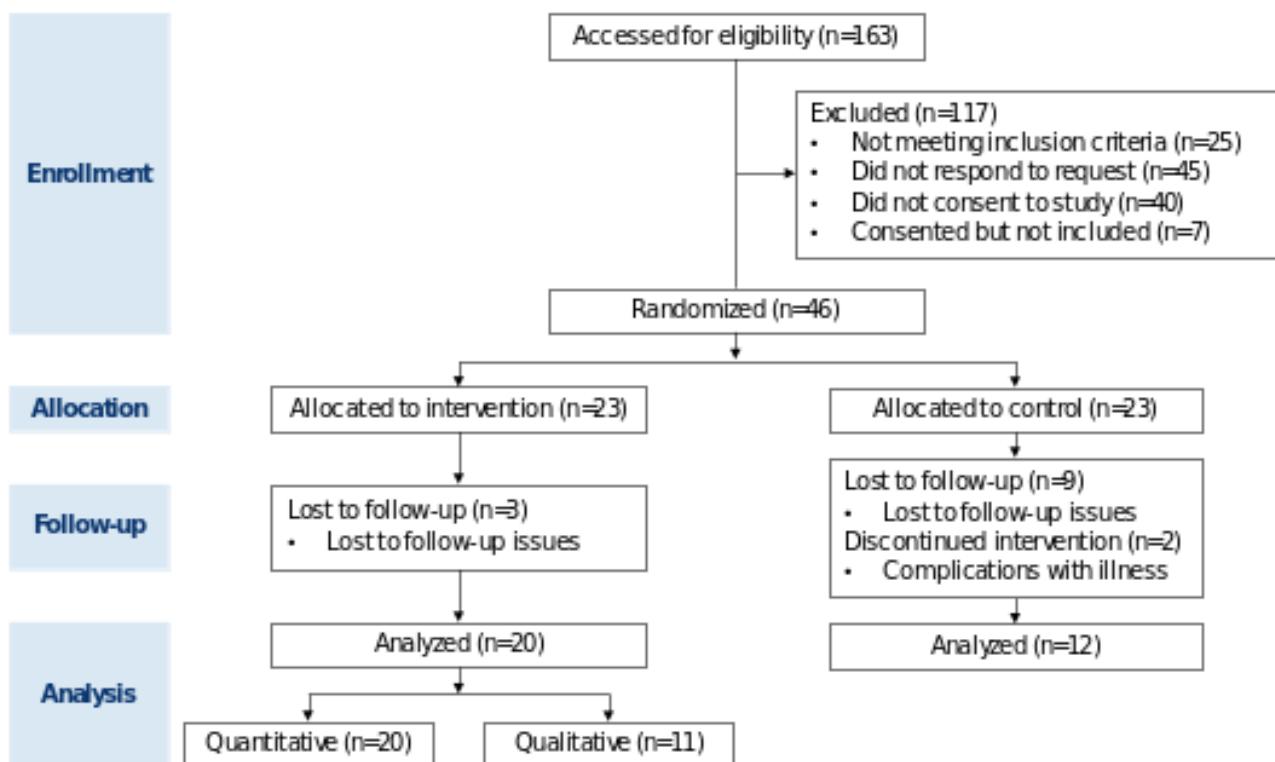
Table 1 provides participant demographics (N=32). Of the 20 intervention participants, 13 (65%) were female, 17 (85%) were Non-Hispanic White, and 11 (55%) were between 60 and 79 years old. Of 12 participants in the control group, 9 (75%) were female, 6 (50%) were White, 4 (33%) were between 40 and 59 years old, and 4 (33%) were between 60 and 79 years old. Baseline demographic data did not significantly differ between intervention and control participants (Table 1). Furthermore, within the intervention group, the participant demographics of the 11 interviewees were not significantly different from those of the other 9 intervention group participants. Multimedia Appendix 5 includes a demographics table specifically for the 11 interviewees.

Table 1. Demographics of the finally included participants.

Characteristic	Participants (N=32)	Intervention group (n=20)	Control group (n=12)	P value
Age (years)				.50
Mean (SD)	58.7 (12.5)	59.2 (10.8)	57.7 (16.3)	
Range	23-76	29-75	23-76	
Age group (years), n (%)				.35
20-39	2 (6)	1 (5)	1 (8)	
40-59	11 (34)	7 (35)	4 (33)	
60-79	15 (47)	11 (55)	4 (33)	
Not specified	4 (13)	1 (5)	3 (25)	
Sex , n (%)				.26
Female	22 (69)	13 (65)	9 (75)	
Male	9 (28)	7 (35)	2 (17)	
Not specified	1 (3)	0 (0)	1 (8)	
Race , n (%)				.16
Non-Hispanic White	24 (75)	17 (85)	6 (50)	
Non-Hispanic Black	4 (13)	2 (10)	3 (25)	
More than one race	2 (6)	0 (0)	2 (17)	
Not specified	2 (6)	1 (5)	1 (8)	
Ethnicity , n (%)				≥.99
Hispanic	2 (6)	1 (1)	1 (8)	
Non-Hispanic	30 (93)	19 (95)	11 (92)	
Education , n (%)				.51
9th-12th grade (no diploma)	1 (3)	0 (0)	1 (9)	
High school graduate or equivalent	2 (6)	1 (5)	1 (9)	
Some college (no degree)	5 (16)	4 (20)	1 (9)	
Vocational or associate's degree	7 (22)	4 (20)	3 (27)	
Bachelor's degree	10 (31)	8 (40)	2 (18)	
Higher than a bachelor's degree	6 (19)	3 (15)	3 (27)	
Employment, n (%)				.62
Employed full-time	4 (12)	2 (10)	2 (18)	
Unemployed, because of illness	5 (16)	3 (15)	2 (18)	
On disability	7 (23)	6 (30)	1 (9)	
Retired	14 (45)	8 (40)	6 (55)	
Other	1 (3)	1 (5)	0 (0)	
Marital status , n (%)				.71
Single, never married	2 (7)	1 (5)	1 (9)	
Married or partnered	20 (67)	12 (63)	8 (73)	
Separated	3 (10)	2 (11)	1 (9)	
Divorced	3 (10)	3 (16)	0 (0)	
Widowed	2 (7)	1 (5)	1 (9)	

Quantitative Results: Physical Activity

Participants in the intervention group had an overall average number of 3660 (SD 3344; 95% CI 3557-3764) daily steps, which was significantly more than participants in the control group, who had an overall average number of 3408 (SD 3288; 95% CI 3299-3518; t_{7476}=3.3; P=.001) daily steps. The comparison of weekly moving averages showed similar results. The weekly moving average step count of participants in the intervention group was 4813 (SD 1723; 95% CI 4680-4946), which was significantly more than that of the control group 4581 (SD 1224; 95% CI 4494-4669; t_{1400}=2.9; P=.003). Weekly moving average step counts in the intervention arm showed an increasing trend as the study progressed, with a regression slope parameter of 5.89 (P<.001). In contrast, the control weekly average step counts increased with a regression slope parameter of 2.80 (P<.001) but at a lower rate than the intervention arm. The slope of the line of best fit of the intervention group is steeper than that of the control group (Figure 2).

Figure 2. Linear regression of the weekly moving average steps over date per participant.
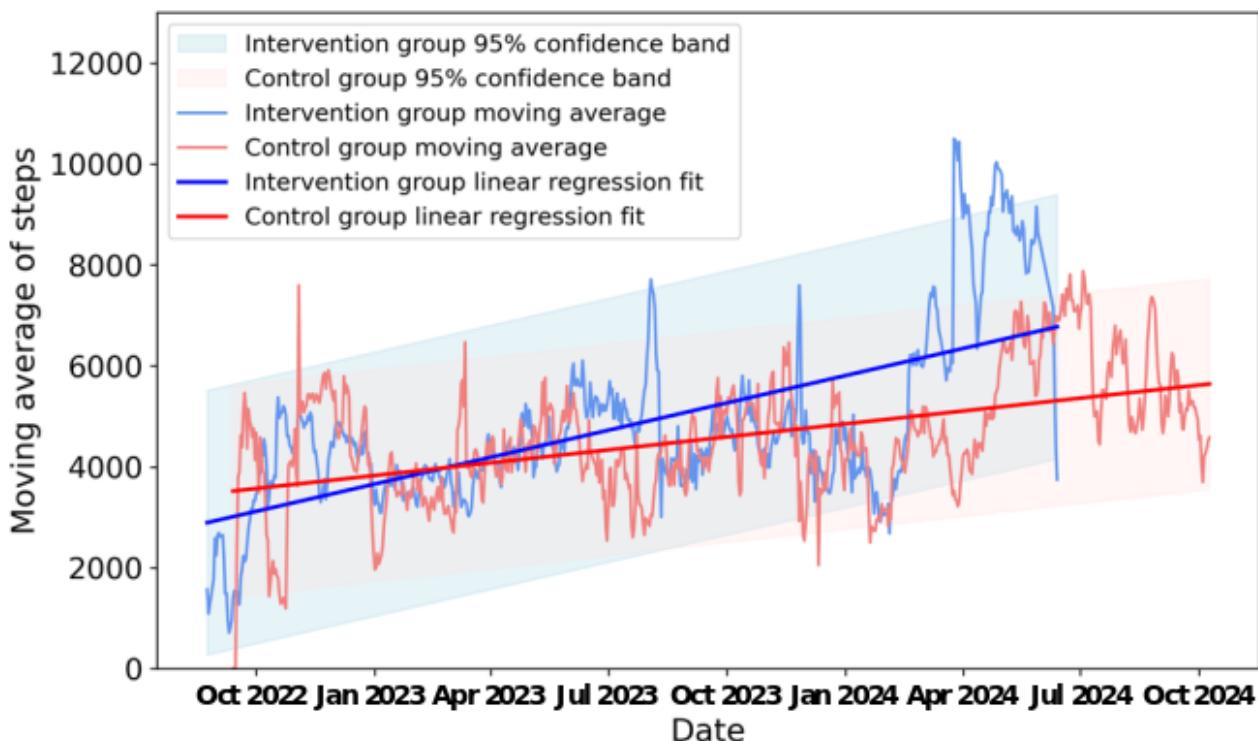
For the daily walking distance, intervention participants had an overall average daily walking distance of 2.6 (SD 2.5; 95% CI 2.5-2.7) miles, which was significantly more than control participants, who had a weekly average of daily walking distance of 2.4 (SD 2.3; 95% CI 2.3-2.5; t_{7476}=3.8; P<.001) miles. The comparison of the weekly moving average showed similar results. The weekly moving average walking distance of intervention participants was 3.5 (SD 1.3; 95% CI 3.4-3.6) miles, which was significantly more than that of control participants, 3.2 (SD 0.8; 95% CI 3.1-3.3; t_{1400}=4.6; P<.001) miles. Weekly moving average walking distances among intervention participants increased, with a regression slope parameter equal to 0.0046 (P<.001). In contrast, though the weekly average of daily walking distances also increased for controls, the regression slope parameter was smaller than that of the intervention group, less than half of that, at 0.0017 (P<.001). The slope of the line of best fit of the intervention group is steeper than that of the control group (Figure 3). Thus, walking distances of the intervention participants showed greater increases than those of the controls.

Figure 3. Linear regression of the weekly moving average of walking distance over date per participant.
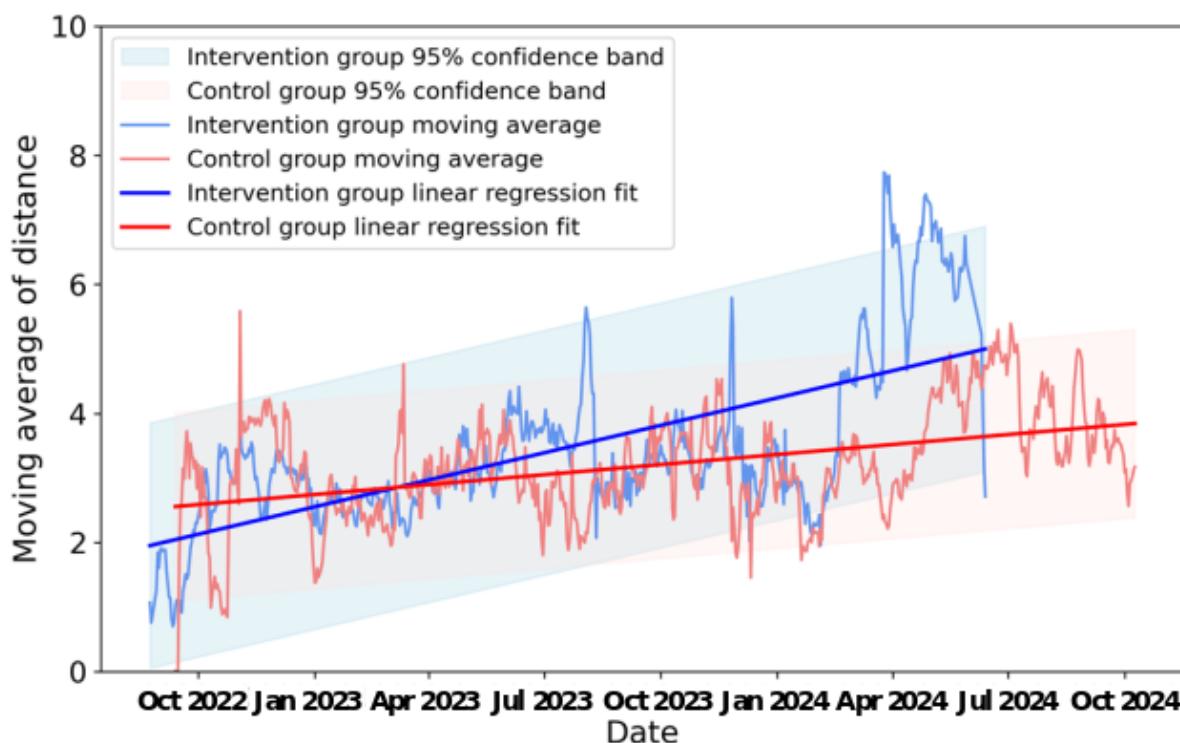
Qualitative Results

Participant Perspectives of the HealthScore Intervention

The inductive coding and analysis of 11 intervention participant interviews revealed 3 major thematic areas, including facilitators and barriers to participant engagement and program improvement. Each theme and subtheme was supported by multiple participant quotes, and thematic saturation was achieved after coding 6 interviews, as no new codes emerged in subsequent interviews (Table 2).

Table 2. Qualitative excerpts about the facilitators, barriers, and areas for improvement of the HealthScore from participants in the intervention group.

Major theme and subtheme	Representative quote
Facilitators	
Relationship with coach	• "[The health coach] and I talked a lot about my goals each week: what went well, what didn't go as well. And she would help me reflect on how I was doing which was really helpful. She helped me move forward." (F[a], 50-64)
Accountability via weekly calls	• "It's hard to feel motivated when you are sick, so having someone to talk to every week was really beneficial." (F, 50-64)
Increased physical function	• "It really helped me increase it. It was an inspiration to move, to get to the gym, to exercise. It definitely helped." (F, 65+)
Improved self-efficacy or QoL[b]	• "The more exercise you get, the more positive your attitude is, the more positive your attitude is the more chance you have to live longer." (F, 50-64) • "The cancer might get me, but at least I will die healthy!" (F, 65+)
Barriers	
Ineffective survey tool	• "Questions are always the same on the survey, which might not be great, and they are vague. 'In the last 7 days..' was hard to remember. Run 3 miles question is never going to happen." (M[c], 65+)
Lack of caregiver involvement	• "For them to learn to meet you where you are and to understand that more. Having caregivers learn how to release their expectations of what you need to do and not to push their own desires onto your experience." (F, 65+)
HealthScore metrics are not comprehensive	• "My symptoms were not addressed by the program- I talked to Bri (Health Coach) about my symptoms." (F, 50-64)
More attention on topics outside of physical activity	• "Diet- especially for diet with a compromised immune system. Being coached on nutrition- what is/isn't the best foods to eat, what helps your system regain immunity and strength." (F, 65+)
Areas for improvement	
Survey improvement	• "Some of the questions were redundant. The redundancy made me question my answers. Some of those questions could be removed." (F, 50-64) • "Let us tell you how we're feeling and what would help us, especially if we don't have a counselor. More of a mental component to the program might be helpful for some people who are struggling more with their cancer." (F, 50-64)
Caregiver support	• ".. husband could have used some mental support. Some caregivers might need physical and mental support. They will have different needs. Meet the caregiver where they are at and be able to answer questions for the caregiver because they are going to have a lot of questions..." (F, 50-64)
HealthScore metrics	• "Disappointed that I used the bike a lot and it didn't pick up a lot of steps." (M, 65+)

[a]F: female.

[b]QoL: quality of life.

[c]M: Male.

Facilitators

Patients reported that maintaining a strong positive relationship with the coaches and the weekly coaching calls were key facilitators that enabled them to establish accountability. Many patients expressed their appreciation for the encouragement and empathy they received from the coaches, which facilitated the patient-coach connections and openness. The rapport established enabled the coaches to guide participants to achieve success by reframing setbacks, shifting mindsets, and achieving SMART goals. Personal connection and trust enhanced patients' engagement more during the weekly check-ins, fostering accountability and contributing to overall success.

Patients voiced that Fitbit tracking and goal setting facilitated consistency of participation and adherence to health goals. Patients reported increased levels of physical activity, often making progress toward pretreatment levels and improved QOL. Many patients expressed eagerness to continue goal setting, exercise, and FitBit tracking beyond the conclusion of the study

period. This sustained interest reflects an improvement in their confidence to manage their own health and well-being without their coaches, indicating an improvement in self-efficacy.

Additionally, patients reported improved communication with their care teams, which enabled them to be more proactive in managing their symptoms. They felt more confident in expressing their concerns clearly and seeking help early.

Barriers

Some patients expressed that the survey tool, which primarily focused on symptoms and physical function, was ineffective in capturing the progress they observed through their Fitbits. Many participants reported frustration at having to complete weekly surveys, which they felt were tedious and repetitive. Some patients felt that specific survey questions provided led to the setting of unrealistic goals and feelings of discouragement. Completing the survey at the end of each week also posed a challenge, as some struggled to recall their weekly progress accurately. Since the surveys directly impacted the HealthScore metrics, patients felt that regularly displaying the HealthScore (physical function measure) during the study could have negatively affected their motivation. Additionally, participants expressed a preference for coaching with a focus on their personal needs, such as mental health, nutrition, and weight management.

One idea that some patients noted was that involving a family or friend caregiver in the coaching sessions could be an additional component to the program, with additional implications. Some noted that the program could be adapted to allow for shared goal-setting across patients and caregivers, which may benefit both members. Others expressed concern about placing an additional burden on their caregivers.

Areas for Improvement

Patients identified scope for improvement in the weekly surveys, HealthScore metrics, caregiver involvement, and customized coaching topics. They felt that the surveys needed to be revisited and adapted to better capture the progress they were making. They suggested the incorporation of the Fitbit data (step count, heart rate, and sleeping pattern) into the HealthScore Metric to provide a more accurate and comprehensive reflection of their progress.

Most patients perceived that there is a significant potential for this program to improve caregiver support by offering tailored resources, information, and services that address their caregiver responsibilities as well as their own physical and emotional well-being. Some patients believe that by providing the resources, tools, and services that alleviate caregiver burden, the program has the potential to improve caregiver HRQOL and ultimately the support they can provide to patients. Additionally, participants also perceived that caregiver support can be improved through the program by supporting the physical and mental well-being of their caregivers.

Some patients also identified ideas for personalizing the program by including additional health coaching topics, such as nutrition, sleep, weight management, and mental health. The program

could also be improved by enhancing the referral process to other community-based resources and services.

Integrated Mixed Methods Findings

The integration of quantitative physical activity data with qualitative interview themes revealed explanatory insights into the findings of the intervention group. Quantitatively, the findings demonstrated that intervention participants achieved significantly higher average daily step counts and daily walking distances compared to the control group, with steeper increases over time. Our qualitative analysis explained these improvements through specific program facilitators (eg, weekly coaching calls or growth in self-efficacy). However, this analysis also revealed a disparity in quantitative outcomes and participant experiences. While physical activity metrics improved overall, participants expressed frustration with the weekly PRO surveys, as they felt they were not aligned with their Fitbit-captured progress. Moreover, participants desired additional coaching in areas outside physical activity (eg, nutrition and sleep), topics not captured quantitatively but perceived as integral to their overall recovery and well-being.

Discussion

Principal Findings

We conducted a secondary analysis of a randomized controlled pilot study of cancer survivors who participated in a novel telehealth-based coaching program called HealthScore [24]. We found that participants in the intervention group had significantly higher physical activity than participants in the control group. Average daily step counts and average daily walking distance in the intervention participants were both significantly more than those of control participants and increased over the course of the 6-month intervention more than twice that of control participants. The integration of quantitative and qualitative findings revealed that these improvements were driven by enhanced accountability through weekly coaching relationships and increased self-efficacy, although the measurement tools themselves presented barriers that may have affected some participants' motivation. Our findings underscore the potential effectiveness of the HealthScore coaching program in enhancing physical activity levels among cancer survivors.

The combination of personalized coaching and physiologically based PGHD positions HealthScore as a robust approach to overcoming barriers associated with physical inactivity among cancer survivors. Our findings demonstrate patterns resonant with those in similarly designed health coaching interventions tested in cancer survivors [19,20], align with existing literature on the benefits of structured health coaching, and affirm that tailored interventions can significantly impact exercise adherence [36,37]. However, the sustained engagement via weekly sessions allowed participants to set realistic SMART goals and receive ongoing support, fostering an environment conducive to behavior change, which was praised by participants as an effective design for the coaching program. Moreover, the inclusion of motivational interviewing techniques proved beneficial in empowering participants, fostering autonomy, and addressing intrinsic barriers, such as anxiety and depression.

Qualitatively, participants indicated a growing sense of accountability and motivation throughout the program duration. Many expressed that the regular weekly check-ins with their health coaches provided essential encouragement and instilled a sense of connection, which is critical for cancer survivors who often experience feelings of isolation [38,39]. Participants recognized improvements in their physical capabilities and reported enhanced emotional well-being, highlighting the multifaceted benefits of the HealthScore program.

Key barriers identified by participants included aspects of the weekly monitoring PRO surveys, which were focused on symptoms and physical function. Participants felt that the surveys did not accurately capture their progress, which led to frustration with the tedious and repetitive nature of these assessments. This finding is congruent with prior literature showing survey fatigue as a common pain point in cancer health services research [1,40]. Additionally, challenges in recalling weekly progress and the potential negative impact of the displayed HealthScore on motivation were noted. Prior research reported similar findings that using self-monitoring tools can negatively impact participants' motivation [41,42]. Potential solutions include motivational messages accompanied by positive statistics showing improvement over time or comparing the participant's activity to the overall performance of participants.

The mixed methods integration illuminated meaningful insights. For example, participants attributed their increased activity to enhanced accountability through weekly coaching calls and the relationships they had built. Additionally, participants experienced growth in self-efficacy as they internalized goal-setting practices and saw tangible progress via their Fitbit devices. However, identified barriers, such as survey fatigue, may help explain the variability in quantitative outcomes. The participants' frustration with repetitive surveys that failed to capture their perceived progress suggests that while objective metrics improved overall, the measurement tools themselves may have dampened motivation for some. Therefore, it is important to align measurement approaches that optimize participant engagement throughout a sustained trial, such as HealthScore. Our convergence of quantitative improvements with qualitative insights strengthens the findings and can inform recommendations for refinement of similar programs.

Future iterations of HealthScore, or other similar programs, will integrate feedback from participants to further streamline the program for improved user experience. As identified by participants, the number and length of monitoring surveys should be reduced to avoid survey fatigue by considering biweekly or monthly surveys. In addition, incorporating Fitbit data into HealthScore metrics and providing personalized, evidence-based guidelines around nutrition, sleep, and mental health could improve the intervention. Emerging technologies, including artificial intelligence, have the power to collect, analyze, and synthesize PGHD and to provide real-time information from trusted sources.

Comparison to Prior Work

Prior research underscores the importance of high-quality, standardized coaching programs, as previous studies have shown that intervention intensity and participant engagement are critical for effective behavior change [43-45]. These limitations can be mitigated by implementing user-centered design principles through design thinking methods, expanding and incorporating objective measures alongside self-reports, and ensuring consistent training for all health coaches, all of which could enhance the effectiveness of future health interventions for cancer survivors.

This study contributes to prior literature by exploring the effectiveness of a telehealth-based coaching program, HealthScore, specifically designed to enhance physical activity among cancer survivors. It integrates PGHD from Fitbit devices for objective assessments, uses a mixed methods approach to combine quantitative and qualitative insights, and emphasizes the importance of structured, personalized coaching sessions aligned with SMART goals. The rigorous training of health coaches in motivational interviewing further distinguishes this study, highlighting the importance of interpersonal support in behavioral change, thereby offering a comprehensive and modern perspective on improving health outcomes in cancer survivors.

Limitations and Future Directions

Some limitations are worth noting. First, the sample size, while adequate for preliminary analysis, may not fully represent the diversity of the patients with cancer and cancer survivors. Future studies should consider larger, more diverse cohorts to better understand the generalizability of HealthScore's findings across the cancer continuum. Second, longer follow-up periods could help ascertain the sustainability of physical activity levels beyond the intervention, as well as the long-term effects on overall health outcomes. Third, there was a significant attrition imbalance between the control and intervention groups. While this is likely attributed to the fact that the intervention group entailed more time demand, there may also have been reluctance to the increased accountability of having a health coach. Importantly, the imbalance may have influenced both the qualitative and quantitative findings. Fourth, there are some limitations inherent in secondary data analysis. The original trial was not powered to detect the specific outcomes examined here, and the relatively small, demographically homogeneous sample, coupled with reliance on volunteer coaches, constrains both generalizability and scalability. Fifth, we acknowledge the potential for selection bias given that participation relied on self-referral and that a substantial number of individuals were lost between screening and analysis. As a result, those who remained in the study may represent a more motivated or otherwise distinct subset of the broader population, which may limit the generalizability of our findings. Future research should examine the long-term effects and applicability across diverse cancer populations and equally sized groups.

Conclusion

The HealthScore telehealth coaching program shows promise in enhancing physical activity and QOL for cancer survivors. Personalized coaching and PGHD foster sustained engagement in exercise, overcoming common barriers. Participants reported increased motivation and adherence to regimens, highlighting the importance of tailored support for psychological and physical

challenges. Qualitative feedback indicated that the program's holistic approach improved participants' confidence in managing their health after treatment. Integrating telehealth coaching into standard care for cancer survivors might be possible once these findings are replicated in larger and more diverse cohorts to promote active lifestyles and better health outcomes.

Data Availability

The datasets generated or analyzed during this study are not publicly available due to patient privacy issues, but are available from the corresponding author on reasonable request.

Authors' Contributions

Conceptualization: SK, EK, CB, WW
Data curation: JG, KM, ZZ, CB
Formal analysis: JG, KM, ZZ
Funding acquisition: WW
Investigation: SK, EK, CB, WW
Methodology: SK, EK, WW
Project administration: CB
Supervision: SK, EK, CB, WW
Validation: JG, KM, ZZ
Writing–original draft: SK, EK, JG, KM, ZZ, CB, WW
Writing–review & editing: SK, EK, JG, KM, ZZ, CB, WW

Conflicts of Interest

None declared

Multimedia Appendix 1
TIDieR Checklist.
[DOCX File , 37 KB - cancer_v12i1e78968_app1.docx]

Multimedia Appendix 2
CONSORT extension Pilot and Feasibility Trials Checklist.
[DOC File , 240 KB - cancer_v12i1e78968_app2.doc]

Multimedia Appendix 3
Participant exit interview questions.
[DOCX File , 26 KB - cancer_v12i1e78968_app3.docx]

Multimedia Appendix 4
GRAMMS Checklist.
[DOCX File , 46 KB - cancer_v12i1e78968_app4.docx]

Multimedia Appendix 5
Intervention Group Interviewee Characteristics.
[DOCX File , 20 KB - cancer_v12i1e78968_app5.docx]

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Abbreviations

CHAI: Connected Health for Applications and Interventions
CONSORT: Consolidated Standards of Reporting Trials
COREQ: Consolidated Criteria for Reporting Qualitative Research
GRAMMS: Good Reporting of a Mixed Methods Study
HRQOL: health-related quality of life
IRB: Institutional Review Board
NCI: National Cancer Institute
PGHD: patient-generated health data
PRO: patient-reported outcome
PROMIS: Patient-Reported Outcomes Measurement Information System
QOL: quality of life
REDCap: Research Electronic Data Capture
SMART: Specific, Measurable, Achievable, Relevant, and Time-Bound
TIDieR: Template for Intervention Description and Replication
UNC: University of North Carolina

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Original Paper

Reinforcement Learning–Based Digital Therapeutic Intervention for Postprostatectomy Incontinence: Development and Pilot Feasibility Study

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Abstract

Background: Postprostatectomy incontinence (PPI) is a common complication after robot-assisted radical prostatectomy and significantly impairs patients' quality of life. Although behavioral interventions such as pelvic floor muscle training and bladder diaries are evidence-based, their effectiveness is often limited by poor adherence and lack of personalization.

Objective: This study aimed to develop and evaluate a reinforcement learning (RL)–driven clinical behavioral intervention-supporting system (CBISs) for adaptive, personalized rehabilitation in patients with PPI.

Methods: The study comprised 2 sequential stages. First, the CBISs was developed through (1) construction of a medical record database from a prospective cohort of PPI patients using standardized 3-day bladder diaries, (2) design of functional modules and user interfaces based on clinical rehabilitation needs, and (3) development of an RL model using XGBoost (extreme gradient boosting) and Bayesian optimization to generate individualized training plans. Second, a separate cohort of 16 patients participated in a single-arm, pre-post pilot study to evaluate feasibility and preliminary outcome trends over a 3-month intervention period, with assessments based on bladder diary parameters and system usage metrics.

Results: The CBISs successfully implemented an adaptive, closed-loop behavioral rehabilitation framework that dynamically tailored training recommendations according to individual voiding patterns, fluid intake behaviors, and adherence signals. Feasibility outcomes were favorable, with high system engagement observed throughout the intervention (mean usage frequency 5.2, SD 1.1 times per day). In exploratory pre-post analyses (n=16), consistent directional improvements were observed across multiple outcomes. Mean daytime urinary frequency decreased from 5.74 (SD 1.21) episodes per day to 4.69 (SD 1.08) episodes per day, while median nighttime urinary frequency declined from 1.8 (IQR 1.6-2.2) episodes per night to 1.0 (IQR 1.0-1.6) episodes per night. Median incontinence episodes were reduced from 7.0 (IQR 6.0-11.0) episodes per day to 4.0 (IQR 2.0-6.0) episodes per day. Objective urine leakage measured by the 1-hour pad test decreased from a median of 8.5 (IQR 4.0-19.0) g to 3.5 (IQR 2.0-9.0) g. Patient-reported symptom burden, assessed using the International Consultation on Incontinence Questionnaire–Short Form (ICIQ-UI SF), showed a median reduction from 14.0 (IQR 12.0-20.0) points to 9.0 (IQR 6.0-16.0) points. Although several within-participant changes were statistically detectable, effect magnitudes varied across individuals. Given the single-arm design, small sample size, and lack of a control group, findings are presented as exploratory and hypothesis-generating rather than confirmatory of clinical efficacy.

Conclusions: The CBISs represents the first RL-powered digital therapeutic system for PPI, enabling adaptive, evidence-based behavioral optimization. By addressing limitations of static rehabilitation protocols and declining adherence, it offers a scalable approach for personalized PPI management. Future multicenter trials are needed to confirm its clinical effectiveness.

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Introduction

Prostate cancer (PCa) is one of the most prevalent malignant tumors in men and currently represents the second leading cause of cancer-related mortality worldwide [1]. It is estimated that by 2025, approximately 313,780 new cases of PCa will be diagnosed in the United States, accounting for 15.4% of all newly diagnosed cancers [2]. Over the past decade, robot-assisted radical prostatectomy has been increasingly recognized as a primary treatment for localized PCa [3]. Owing to the removal of the prostate, seminal vesicles, and surrounding tissues, as well as the reconstruction of the urinary tract during surgery, patients frequently experience varying degrees of postoperative bladder dysfunction. Among these complications, postprostatectomy incontinence (PPI) is the most common functional sequela, severely affecting patients' daily activities, sexual function, and overall quality of life (QoL) [4-6]. The reported incidence of PPI varies widely, ranging from approximately 4.2% to 87%, largely due to differences in definitions of urinary incontinence, follow-up duration, and assessment methodologies [7]. PPI symptoms typically persist for 3-12 months and, in some cases, may extend for up to 10 years, rendering urinary incontinence a major long-term concern during postoperative recovery [8,9]. Consequently, improving PPI and related QoL outcomes remains a central objective in the comprehensive management of survivors of PCa [10].

Behavioral therapies, including pelvic floor muscle training (PFMT), bladder retraining, urge suppression techniques, and lifestyle modification, constitute the cornerstone of conservative management for urinary incontinence. High-quality evidence from systematic reviews and meta-analyses, including Cochrane reviews, has consistently demonstrated that behavioral therapy–based interventions can reduce incontinence episodes and improve patient-reported QoL across diverse populations [11,12]. These interventions are widely recommended as first-line or adjunctive strategies in clinical practice, reflecting their favorable safety profiles and broad applicability. Nevertheless, the effectiveness of behavioral rehabilitation in real-world settings is frequently compromised by inadequate adherence, limited access to professional supervision, and insufficient patient understanding of correct training techniques.

Advancing from this foundation, digital therapeutics (DTx) have emerged as a promising modality for delivering structured rehabilitation programs remotely, thereby improving accessibility and continuity of care for patients following postprostatectomy. DTx are interventions delivered via digital platforms [13], which have the potential to mitigate the challenges posed by chronic diseases, such as enhancing patient adherence and improving patient self-management [14]. By enabling real-time monitoring, personalized feedback, and flexible scheduling, digital platforms may help address many of the practical limitations inherent in traditional rehabilitation

models [15]. However, many existing digital interventions for urinary incontinence remain largely static, relying on predefined rules or uniform training protocols that do not adequately account for individual variability in symptoms, adherence patterns, or recovery trajectories.

In this context, reinforcement learning (RL) represents a promising methodological framework for advancing personalization within digital therapeutic systems. RL is a machine learning approach whereby intelligent agents iteratively optimize decision-making models through cycles of action, feedback, and strategy adjustment [16]. Unlike traditional supervised learning methods, RL is particularly well suited to sequential decision-making problems where the effects of an action may be delayed, outcomes are uncertain, and the optimal strategy depends on the evolving state of the individual. In digital health applications, RL has been used to personalize "just-in-time" interventions—for example, adapting the timing, content, or intensity of behavioral prompts—based on each patient's history, context, and response pattern, thereby improving engagement and clinical outcomes compared with static or rule-based approaches [17]. Moreover, RL models are capable of processing sparse or noisy reward signals arising from heterogeneous patient behaviors and complex intervention-response relationships, making them especially suitable for individualized rehabilitation scenarios [18]. Applying it to DTx may facilitate individualized patient rehabilitation training.

In this study, to address the need for personalized rehabilitation, a Clinical Behavioral Intervention-Supporting System (CBISs) was developed. Using RL, the CBISs provides adaptive, individualized training guidance to patients with urinary incontinence following robot-assisted radical prostatectomy, aiming to accelerate functional recovery and improve QoL through data-driven support.

Therefore, the objectives of this study were to develop and preliminarily evaluate an RL–based CBISs integrated into a digital therapeutic platform to provide individualized pelvic floor and behavioral training for men with PPI after robot-assisted radical prostatectomy. The study was designed to examine whether an RL-driven CBISs could (1) demonstrate feasibility and acceptability, with favorable trends in urinary continence recovery and patient-reported QoL; and (2) enhance adherence to and engagement with the prescribed training over time.

Methods

Overview

The study was structured in two sequential phases, (1) the development of the CBISs, and (2) a feasibility and preliminary efficacy pilot test of the CBISs conducted with a separate cohort of 16 patients. The development of the CBISs consisted of three

main stages, (1) construction of a clinical behavioral database, (2) design of system functionalities and user interfaces based on rehabilitation needs, and (3) development and integration of RL models to support individualized training.

Recruitment of Participants

All patients were recruited during the follow-up visit of the Outpatient Department of Urology at Sun Yat-sen Memorial Hospital, Sun Yat-sen University. Patients were eligible if they were aged 18-75 years, had a confirmed diagnosis of urinary incontinence following radical prostatectomy, and could accurately maintain a voiding diary (recording fluid intake, urination, and leakage). Exclusion criteria comprised serious neurological diseases, concurrent conditions such as urinary tract infection or bladder stones, significant voiding dysfunction, and an inability to comply with the study protocol. During the CBISs construction phase, we recruited a total of 150 patients to participate.

Database Construction

This section details the complete workflow for building the analytical database, including the statistical procedures and tests for data curation and feature engineering, which collectively form the essential foundation for the subsequent development of the prediction model. Bladder diaries were prospectively collected from patients diagnosed with PPI at the urology department of a tertiary care academic hospital. To ensure data robustness, a minimum diary period of 3 days was required based on International Continence Society standards for reliable symptom capture [19].

Sample size determination addressed two dimensions. At the patient level, sample size considerations focused on ensuring sufficient coverage of behavioral variability for model development rather than hypothesis testing. A cohort of 150 patients was deemed adequate to support feature engineering, model training, and internal validation while minimizing the risk of overfitting. At the behavioral event level, more than 10,000 voiding events were targeted to ensure model generalizability, accounting for expected intrapatient variability (mean, 8 voids per day per patient). Sample size considerations therefore accounted not only for the number of patients but also for the volume of behavioral data, with a 3-day behavioral log per patient ensuring minimum model generalizability. Ethical approval for the collection of data required for system construction was obtained from the Medical Ethics Committee of Sun Yat-sen Memorial Hospital, Sun Yat-sen University (approval number: SYSKY -2023-925-01). Data collection was conducted between March 2022 and December 2023.

Determination of Key Features and System Functionalities

The research team conducted a systematic literature review and held 2 rounds of expert meetings to develop a checklist for the rehabilitation needs of patients with PPI. Based on this, researchers and software engineers collaborated to define the functional module division and design the human–computer interaction interface. The CBISs comprises 3 portals: patient portal, a health care team portal, and an administrator portal. The patient portal contains 4 modules: rehabilitation training, bladder diary, incontinence care, and assessment tool. The health care team portal displays the patient's bladder diary details and training completion status.

Reinforcement Learning Model Construction

The research team developed the conceptual plan and proposed the functional requirements of the model; algorithm engineers then constructed and validated the training model, which was subsequently embedded into the CBISs to complete the design and development. Individualized rehabilitation training models for patients with PPI include urination training, fluid intake training, and PFMT. To realize these features, the algorithm engineers used a preconstructed database and performed feature screening and dimensionality reduction through an exhaustive feature engineering step.

Data Preprocessing and Quality Control

Prior to model training, all raw bladder diary records and behavioral logs underwent a structured preprocessing pipeline. Missing values in continuous variables (eg, voided volume and urination interval) were imputed using patient-level mean strategy, while discrete variables (eg, fluid type and urgency score) adopted mode imputation. Abnormal values were detected through IQR filtering and time-series consistency checks. All timestamps were normalized to standard 24-hour format, and temporal alignment of drinking and voiding events was ensured using sliding-window techniques with a 60-minute threshold. Records from patients with <80% diary completion rate or >20% anomalous entries were excluded from analysis to guarantee robust data quality and integrity.

Feature Selection and Model Training Strategy

From the initial 29 behavioral and physiological features, recursive feature elimination and XGBoost's (extreme gradient boosting's) intrinsic gain-based importance ranking were jointly applied to refine input dimensions. Highly collinear features (Pearson $r>0.9$) were removed to prevent multicollinearity. Model development was performed using a stratified 70/15/15 train/validation/test split, preserving the distribution of leakage severity and adherence levels. Bayesian optimization was used to fine-tune hyperparameters (eg, learning rate, max_depth, and subsample) with the goal of maximizing prediction accuracy and minimizing overfitting. Model performance was evaluated using a composite metric, including area under the receiver operating characteristic curve (AUC), F_1-score, and mean absolute error (MAE). A 5-fold cross-validation strategy was used during the training phase to ensure model generalizability and robustness.

Reinforcement Learning Framework and Deployment

The customized offline RL architecture is adopted in the CBISs to support adaptive behavioral rehabilitation while clinical safety is maintained. The RL component is designed to function as a decision-support layer rather than as an autonomous optimizer of clinical outcomes, reflecting the exploratory nature of this pilot study.

Clinical state representations are constructed from multiday behavioral snapshots encompassing key metrics such as PFMT adherence, voiding intervals, fluid intake ratios, and

patient-reported outcomes. These inputs closely correspond to the information typically evaluated by clinicians when adjusting rehabilitation strategies, thereby ensuring that the RL state definition remains clinically interpretable and grounded in routine practice.

At each decision point t, the system observes a behavioral state s_t and selects an action a_t from a predefined discrete action space. Actions correspond to clinically admissible behavioral interventions; for example, when a patient demonstrates stable adherence to the prescribed training program but reports repeated episodes of urinary leakage, the system may recommend a modest extension of PFMT duration (eg, +15 minutes) while maintaining the current training intensity. Subsequent adjustments to PFMT intensity are then guided by changes in the frequency of reported leakage, allowing the intervention to progress in a gradual and clinically responsive manner. All actions are constrained within predefined safety ranges to avoid abrupt or excessive changes.

Reward Function Formulation

The reward function is designed to reflect clinically meaningful behavioral changes rather than to directly optimize long-term clinical outcomes. At each decision point t, the reward r_t is computed as a weighted composite function:

where A_t represents short-term adherence to prescribed training tasks, C_t reflects task completion and user engagement, Δ_t captures the magnitude of abrupt behavioral changes between consecutive recommendations, and P_t denotes penalty terms applied when predefined safety thresholds are approached (eg, overly frequent voiding prompts or rapid escalation of training schedules). All components are normalized to bounded ranges prior to aggregation to ensure numerical stability and interpretability.

In practical clinical terms, this formulation supports gradual and responsive rehabilitation adjustments. For instance, when a patient reports an increase in urinary leakage episodes, the system may recommend extending PFMT duration by 15 minutes, representing a moderate increase in task demand. If the patient demonstrates high adherence and engagement following this adjustment and a subsequent reduction in leakage frequency is observed, penalty terms decrease and the revised training plan is maintained. Conversely, if task completion or engagement declines and leakage frequency fails to improve, penalty values increase, indicating that the adjustment may be poorly tolerated. In such cases, the system may revise the recommendation by reducing the training extension (eg, to an additional 5 minutes) and continue monitoring adherence, engagement, and leakage trends before further modification. This iterative process mirrors routine clinical reasoning, emphasizing tolerability, patient response, and safety rather than rigid optimization.

Q Value Estimation and Policy Learning

Based on the defined reward, action values are estimated using standard Q-learning principles. The Q value represents the

expected cumulative future reward of selecting action a_t under state   and is updated offline according to:

where α is the learning rate and γ is the discount factor. Q values are learned entirely from historical behavioral data using offline batch updates, without real-time exploration in patients.

Conceptually, Q values estimate how beneficial a specific behavioral adjustment is expected to be over time. Actions associated with higher Q values are more likely to be recommended, as they have historically led to stable adherence and acceptable behavioral patterns.

To handle variability in patient engagement and avoid overreliance on historical patterns, an ε-greedy action selection strategy is used. In most situations, the system selects the action with the highest estimated Q value; however, with a small probability ε, alternative actions are explored. In simple terms, the model usually follows what has worked best before, but occasionally tests other reasonable options to prevent overly rigid behavior, particularly for patients with inconsistent adherence.

System Usability and Technical Validation

Usability testing was conducted with a pilot group of 30 patients drawn from the database construction cohort, recruited from September to November 2023, who participated in a 4-week trial from December 2023 to January 2024. Task completion rates, interaction time, feedback scores, and daily user feedback during usage were systematically recorded. The mean training plan navigation time was 56 seconds (SD 12 seconds), with a >92% completion rate of daily bladder diaries. The CBISs demonstrated full functional compatibility with both Android (v8.0+) and iOS (v13+) platforms. Backend performance stress testing indicated stable response under 1000 concurrent users with <500 ms latency. The final release version underwent security penetration testing to ensure robustness against common cybersecurity threats, such as injection attacks, data breaches, and unauthorized data access attempts.

Integration of Human–Artificial Intelligence Shared Decision-Making

To reinforce clinical safety and ensure alignment with real-world care standards, a "human–artificial intelligence (AI) shared decision-making" mechanism is integrated into the CBISs. This module operates as a safety net for low-confidence or guideline-sensitive scenarios, complementing the core RL model.

Specifically, when the model generates a recommendation with low predictive certainty or when the patient presents high behavioral variability or complex comorbidities, the CBISs triggers clinician review. Health care professionals evaluate the suggestion in a semiautomated interface, which also displays relevant confidence scores and patient history snapshots.

In addition, a rule-based expert constraint layer is provided, allowing clinicians to embed patient-specific limitations such as contraindications, comorbidity exclusions, or institutional

guidelines (eg, American Urological Association 2024 and International Continence Society). All final behavior plans are generated through an iterative approval flow that synthesizes algorithmic output, patient feedback, and clinician judgment.

This human–AI collaboration mechanism improves accountability, enhances clinical trustworthiness, and ensures DTx remain aligned with evidence-based care pathways.

Pilot Test of Clinical Behavioral Intervention-Supporting System

This pilot study was designed as an exploratory, single-arm, self-controlled evaluation to assess feasibility, adherence, and outcome trends rather than to establish definitive clinical efficacy. A separate cohort of 16 patients with PPI was recruited, distinct from the 150 participants was enrolled in the database construction phase. Participant recruitment and CBISs implementation occurred between January 2024 to March 2024. Participants eligibility criteria were consistent with the formal research protocol. Patient age and time since surgery were recorded. Voiding characteristics, including timing, intervals, and nocturia episodes (both frequency and total volume) were systematically collected. Patient compliance was evaluated based on completion of prescribed CBISs diary entries, with actual usage frequency tracked as the adherence metric. All participants were enrolled to use only the CBISs for postoperative rehabilitation for 3 months.

Both baseline data collection and postintervention outcome assessment were conducted over 5-day periods, with the mean values of these 5-day measurements used as pre- and postintervention results for comparison. The following parameters were recorded: daily voided volume (mL), daily fluid intake (mL), daytime urinary frequency, nighttime urinary frequency, incontinence episodes, urine leakage measured by the 1-hour pad test (g), total score of the ICIQ-UI SF (range 0-21), daily occurrence of urinary urgency, sensation of incomplete bladder emptying, postvoid dribbling, and dysuria (recorded as present or absent).

For each participant, the mean preintervention value was calculated as the arithmetic average of the baseline observations (the first 5 days of recording), yielding the preintervention daily average. The mean postintervention value was derived similarly from the final 5 days of recording. For symptom data recorded as binary outcomes (present=1, absent=0), symptom frequencies were calculated as continuous variables. Preintervention symptom frequency was defined as (number of days the symptom was present during the 5-day baseline period) / 5 × 100%. Postintervention symptom frequency was defined as (number of days the symptom was present during the final 5-day intervention period) / 5 × 100%. For all measured parameters, the change score (Δ) for each participant was computed as: Δ = postintervention value – preintervention value.

All statistical analyses were conducted using R software (version 4.4.2; R Foundation for Statistical Computing). Given the exploratory nature of this pilot study, analyses were performed to describe within-participant change patterns and estimate effect magnitude rather than to test confirmatory hypotheses.

A 2-tailed α level of .05 was adopted for descriptive purposes only.

The distribution of individual change scores (Δ) was assessed using the Shapiro-Wilk test. Paired-sample 2-tailed t tests or Wilcoxon signed-rank tests were applied as appropriate based on distributional assumptions. Binary symptom variables were converted to symptom frequency percentages and analyzed as continuous outcomes when normality assumptions were met.

Spearman rank correlation coefficient was used to explore associations between changes in selected outcomes. No adjustment for multiple comparisons was performed due to the pilot design and limited sample size, and statistical findings should be interpreted cautiously.

Ethical Considerations

Ethical approval for data collection required for system construction was obtained from the Medical Ethics Committee of Sun Yat-sen Memorial Hospital, Sun Yat-sen University (approval number: SYSKY-2023-925-01). All participants provided electronic informed consent approved by the Medical Ethics Committee (SYSKY-2023-925-01), explicitly detailing (1) bladder diary and behavioral data collection for RL model training to generate personalized recommendations, (2) anonymized data use for system-wide model improvement, (3) right to withdraw data or consent at any time without impact on care, (4) potential implications of AI-driven personalization (eg, adaptive vs static guidance). Consent forms used plain language with examples and were available in Chinese and English.

To mitigate bias from incomplete or anomalous data, preprocessing excluded records with <80% diary completion or >20% anomalies (IQR filtering and time-series checks). Stratified sampling (70/15/15 train/validation/test) preserved leakage severity and adherence distributions. Model fairness was monitored through subgroup performance (age and time since surgery) during 5-fold cross-validation, with clinician override for low-confidence predictions ensuring equity.

For data security, uploaded records were protected using ShangMi 3 (SM3; a cryptographic hash algorithm for integrity verification) and ShangMi 4 (SM4; a symmetric block encryption algorithm for secure data storage and transmission), in accordance with national cryptographic standards. Data handling adhered to China's Personal Information Protection Law and the General Data Protection Regulation–equivalent standards for health data. Health care professionals accessed aggregated views through the CBISs using an authorization key. Additionally, patient-side interfaces integrated real-time alerts for suspicious login attempts or data anomalies, ensuring prompt intervention and maintaining data integrity and patient privacy.

Results

Demographic and Disease-Related Characteristics of Participants

In the first phase of this study, a total of 150 participants were included who provided data for system development, model construction, and demographic characterization. From this

cohort, a subset of 30 additional participants was selected to participate in the focused usability testing phase of CBISs.

The full modeling cohort (N=150) had an age range of 43-82 years, with a mean age of 54.32 (SD 7.51) years. Participants included in the usability testing subsample (n=30) showed a comparable age distribution, ranging from 43-81 (mean 53.70, SD 7.30) years.

Regarding educational attainment, the modeling cohort was predominantly composed of 46 (30.67%) individuals with junior high school education, followed by 35 (23.33%) participants with vocational school education, 28 (18.67%) individuals with undergraduate education, 22 (14.67%) with senior high school education, 12 (8.00%) with primary school education, 6 (4.00%) with postgraduate education, and 1 (0.67%) with no formal education.

In the usability testing subsample, junior high school education was the most prevalent, reported by 13 (43.33%) participants, followed by junior college education with 6 (20%) participants. Senior high school and primary school education were each represented by 4 (13.33%) participants, while vocational school education accounted for 2 (6.67%) participants, and undergraduate education for 1 (3.33%) participants. No participants reported postgraduate education or no formal schooling.

With respect to physical characteristics, the mean BMI of the modeling cohort was 23.44 (SD 3.11) kg/m^2. The usability testing subsample demonstrated a similar BMI distribution, with a mean value of 24.01 (SD 3.18) kg/m^2. Overall, participants included in the usability testing phase were broadly comparable to the full modeling cohort in terms of age and BMI, while exhibiting modest differences in educational composition.

In the pilot test of CBISs, participants used the CBISs an average of 5.2 (SD 1.1) times per day. A total of 11 (68.75%) participants met or exceeded the preset usage target, while 5 (31.25%) participants fell below the target, with a minimum usage of 3 times per day. This indicates generally high engagement with the system during the intervention period. All participants, being older adults, ranged in age from 61-74 years and had a mean age of 67.6 (SD 4.3) years. Among them, 11 (68.75%) participants were within 1-3 months after PCa surgery, and 5 (31.25%) participants were within 3-6 months postoperatively.

The Model of Clinical Behavioral Intervention-Supporting System: Feature Engineering

Based on the patient bladder diary and behavioral monitoring data, a total of 29 features in 6 categories were constructed in this study (Table 1), with the feature construction methods detailed in Table 2. Following data cleaning, the dataset was partitioned via stratified sampling. Model construction was performed based on XGBoost, incorporating Bayesian optimization for model and parameter tuning.

Table 1. Patient data collection form for clinical behavioral intervention-supporting system (CIBSs).

Data category	Instruction
Basic information	
Gender	Discrete variables (male/female)
Age	Continuous variable (years)
BMI	Continuous variable (kg/m^2); associated with symptom typing, behavioral competence, and training intensity appropriateness
Time of onset	Continuous variable; determines symptom chronicity
Urinary flow rate parameter (Q_{max})	Continuous variable; identifies storage, voiding disorders, or bladder hypo-compliance, etc
Urinary flow rate parameter (Q_{ave})	Continuous variable
Residual urine volume test records	Continuous variable
Urinary behavior	
Time of urination	Continuous variable (min); establishment of a 24-hour urinary rhythm
Urinary output	Continuous variable (mL); partially collected automatically by portable urine flow rate instrumentation
Urinary flow rate	Continuous variable (mL/min); automatically collected by portable urinary flow rate instruments
Urination interval	Continuous variable (min); imputed from voiding time difference
Nocturnal urination	Continuous variable (times/mL); includes nocturnal urine frequency and volume
Urinary urgency event	Continuous variable (grade); graded 0-5, subjectively scored by the patient
Symptoms associated with urination	Discrete variables, for example, presence of "urine odor," "slow urine flow," "painful urination," "burning sensation," "divergent urinary stream," "feeling of not emptying," "dribbling after urination," and so on
Drinking behavior	
Drinking time	Continuous variable (specific time); establish temporal linkage with urination time
Drinking volume	Continuous variable (mL)
Drinking type	Discrete type variable, for example, water, tea, coffee, functional drinks, etc
Daily activity and sleep behavior	
Activity intensity (steps and body movement)	Continuous variable (steps/kcal); from wearable device or mobile health app
Activity period	Discrete variable (daytime/nighttime);
Sleeping time/number of night arousals	Continuous variable (min/times); basis for determining the rhythm between nocturia and nighttime arousal
Specialty scales and subjective scoring data	
Overactive Bladder Syndrome Score	Continuous variable; quantitative grading of symptoms to identify overactive bladder
International Prostate Symptom Score	Continuous variable; determination of symptom severity during storage/voiding phase
International Consultative Committee on Incontinence Questionnaire Short Form	Continuous variable; incontinence symptoms and quality of life implications
Self-assessment Scale for Anxiety and Depression	Continuous variable; assess anxiety and depressive states
Pittsburgh Sleep Quality Index–Sleep Quality Score	Continuous variable; determine the extent to which nocturia affects sleep
System interaction and training feedback data	
Record of training completion	Whether bladder training, water intake program, relaxation training, pelvic floor muscle training, etc, are completed as planned
Patient feedback score	Daily record of perceived efficacy, difficulty, and compliance
Abnormal events	Such as symptom exacerbation or incomplete training prompts

Data category	Instruction
Frequency of use, number of times of punching clock	Judge adherence and compliance level

Table 2. Feature engineering methodology for clinical behavioral intervention-supporting system (CIBSs).

Feature category and name	Source data items	Construction method	Clinical significance
Temporal features[a]			
Daytime mean voiding interval	Urination time, day/night encoding	Mean time difference between voids during 9 AM to 9 PM	Evaluates bladder storage stability
Nocturnal polyuria ratio	Nocturnal urine volume, 24-hour total volume	$\sum$ (nocturnal urine volume) / $\sum$ (24-hour urine volume) × 100%	Core diagnostic indicator for nocturnal polyuria
Urgency event frequency	Urgency event markers	Voids with urgency (7 days) / total voids (7 days)	Quantifies overactive bladder severity
Ratio features[b]			
Nocturia-arousal association index	Nocturnal voids, sleep interruptions	(Voided volume) / (voided volume + postvoid residual) × 100%	Differentiates pure nocturia from sleep disorders
Effective voiding rate	Voided volume, postvoid residual	Nocturia episodes / sleep interruptions	Reflects bladder emptying efficiency
Irritant beverage intake ratio	Fluid type, intake volume	Coffee + tea intake (mL) / total intake (mL) × 100%	Assesses bladder irritant exposure
Time-period features[c]			
Workday-weekend voiding pattern difference	Voiding time, date type	Mean weekend voiding interval – mean workday voiding interval	Detects stress-related voiding behavior changes
Postexercise urgency marker	Activity period, urgency markers	Binary indicator: urgency within 30 minutes after vigorous exercise	Identifies exercise-induced urgency
Contextual features[d]			
Fluid-void temporal association index	Intake time, voiding time	Voids within 60 minutes post intake / total voids	Evaluates bladder hypersensitivity
PFMT[e] adherence decay rate	Exercise logs, time	Adherence rate (last 3 days) / adherence rate (week 1)	Quantifies decline in behavioral intervention compliance

[a]Based on mean, extreme, and periodic variations within a fixed time window.

[b]Used for reflecting structural relationships.

[c]Used for behavioral pattern recognition.

[d]Describes behavioral markers triggered by specific conditions.

[e]PFMT: pelvic floor muscle training.

Model Training and Validation

The preconstructed database was used to support feature matching and behavioral pattern recognition, which informed the generation of personalized training recommendations. The RL component subsequently updated these recommendations over time based on patient interaction and behavioral feedback, completing the adaptive model construction process (Figure 1).

In the current implementation, the RL framework did not incorporate explicit clinical outcome measures (eg, reduction in leakage episodes or symptom score improvement) as direct reward signals. Instead, reward signals were defined using conservative, behavior-centered proxy indicators, including task completion, adherence stability over time, and avoidance of abrupt behavioral changes potentially associated with symptom aggravation. This design choice was intentionally adopted to ensure clinical safety and model stability in this exploratory pilot setting, where outcome responses are delayed, heterogeneous, and not suitable for short-horizon optimization.

Clinical outcome measures were therefore reserved exclusively for post hoc exploratory evaluation rather than real-time reward optimization. Model evaluation metrics (eg, AUC, F_1-score, and MAE) were used internally during development and tuning to support system calibration but were not reported as final performance outcomes, as this study was not designed as a standalone predictive model validation.

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Rather than optimizing a single mathematically fixed reward function, the RL component operated within a clinician-supervised decision-support framework, integrating multiple behavior-related feedback signals under predefined safety constraints. Accordingly, the RL module was designed to support adaptive behavioral guidance within a clinically supervised system rather than to function as an autonomous predictive model intended for direct performance benchmarking.

Figure 1. Patient flow diagram for clinical behavioral intervention-supporting system (CBISs) development and pilot feasibility evaluation. PPI: postprostatectomy incontinence; RARP: robot-assisted radical prostatectomy.
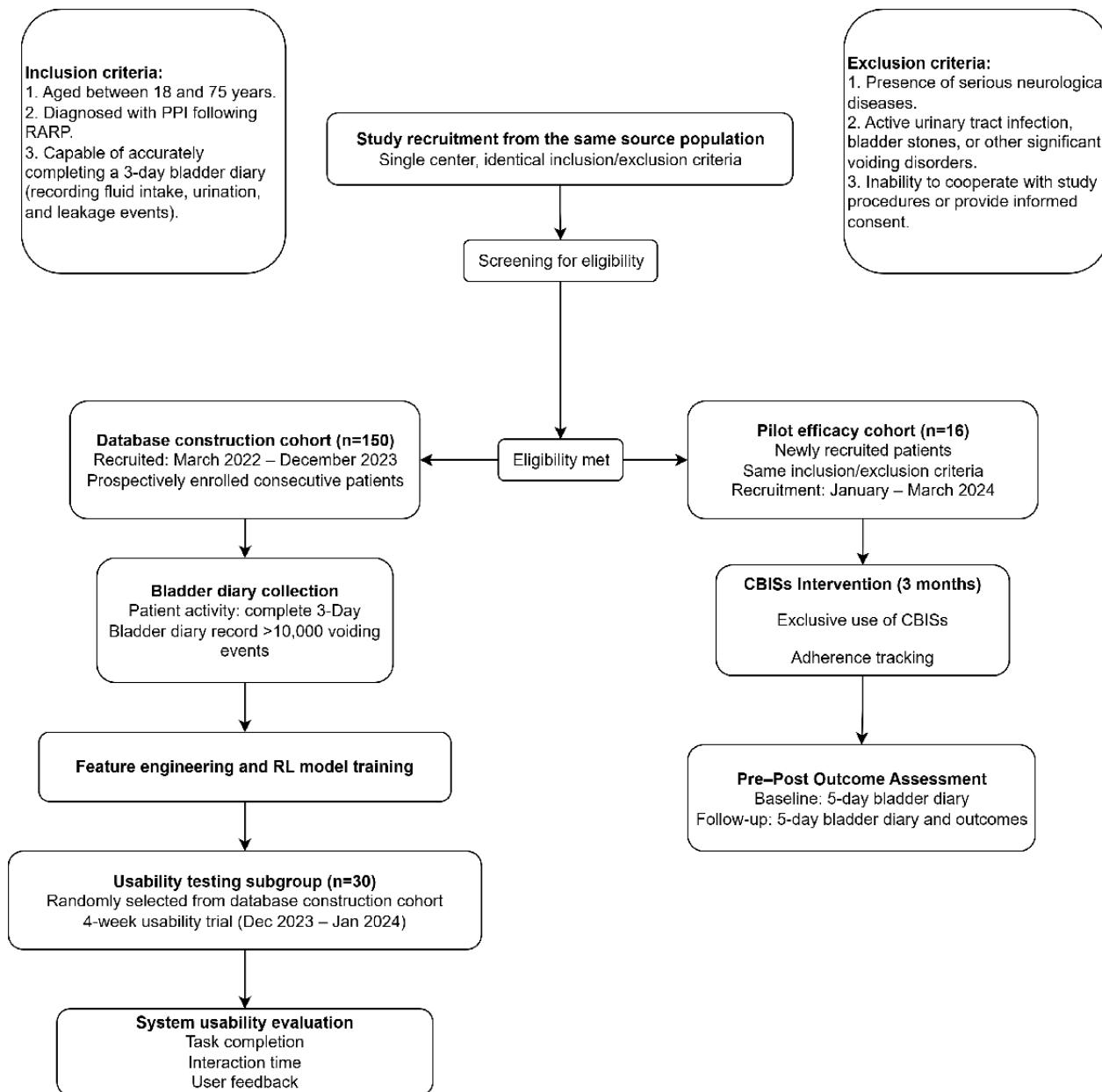
The Clinical Behavioral Intervention-Supporting System Mobile App

Overview

Based on the literature review and research team meetings, the main functional modules of the CBISs were identified (Figure 1). The CBISs provide patients with personalized voiding schedules, dietary and fluid intake plans, and pelvic floor muscle contraction training to enhance bladder function. A distinctive feature of the CBISs is its consideration of skin-related symptoms potentially caused by incontinence, offering patients guidance on incontinence-related nursing interventions, that is,

the incontinence skin care function. Based on their evaluation of perineal skin condition and severity, the CBISs recommends tasks such as daily cleansing, application of skin-protective dressings, and use of incontinence products. The health care team and administrator portals also receive early warning notifications regarding the occurrence of incontinence dermatitis in patients.

Key Features and Capabilities

The functional sections of the app and its user interface were identified. The app has 2 interfaces: the home page and the personal center. The home page is divided into 4 sections:

"Training Sections," "Bladder Diary," "Assessment Tools," and "Incontinence Care." The "Personal Center" page provides the user's basic information, contact options for doctors or nurses, and counseling services (Figure 2). Users are required to register an account upon first login and can access the app after using their account number and password. Patients can access the training program after registering their behavioral logs for 3 days.

In the training section, the app provides training programs based on the aforementioned RL models. The initial training program is based on the raw data provided by the patient, and the training content specifically includes voiding interval time, drinking time schedules, rising urine training (bladder capacity training), and pelvic floor muscle contraction and relaxation training. Patient's data are regularly evaluated to assess rehabilitation progress and adjust the training program accordingly. The learning model iteratively adjusts the program, while the health care team may also adjust the program manually. The "Contact Doctor/Nurse" module offers patients support and training guidance throughout the course of their illness to ensure that they maintain good habits after discharge (Figure 3).

Figure 2. Key functional modules of clinical behavioral intervention-supporting system (CBISs).

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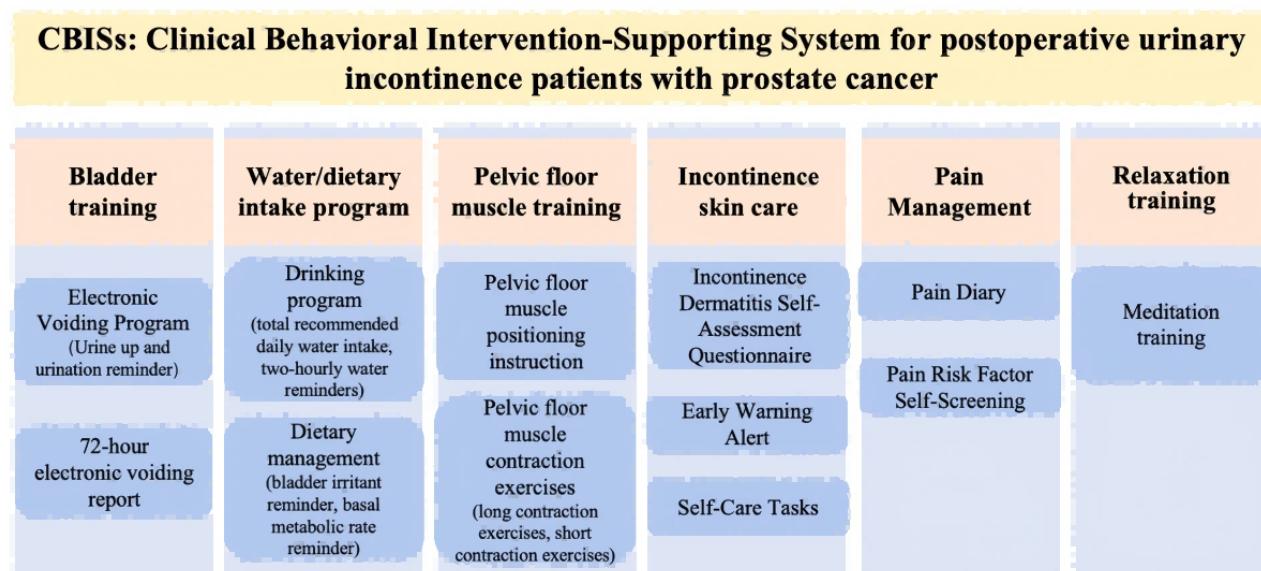
Figure 3. Clinical behavioral intervention-supporting system (CBISs) user interface. (A) Initial app screen—outpatient; (B) initial app screen—inpatient (patient clinical and demographic characteristics); (C) personal homepage (top to bottom: patient overview—Illness severity, demographics, disease details, and responsible medical personnel; records and support—health and user records, alongside user assistance; rehabilitation log—tracks rehabilitation activities and outcomes; service purchase—handles the acquisition of additional services); (D) bladder ultrasound monitoring; (E) urinary pad test; and (F) questionnaire entry screen.
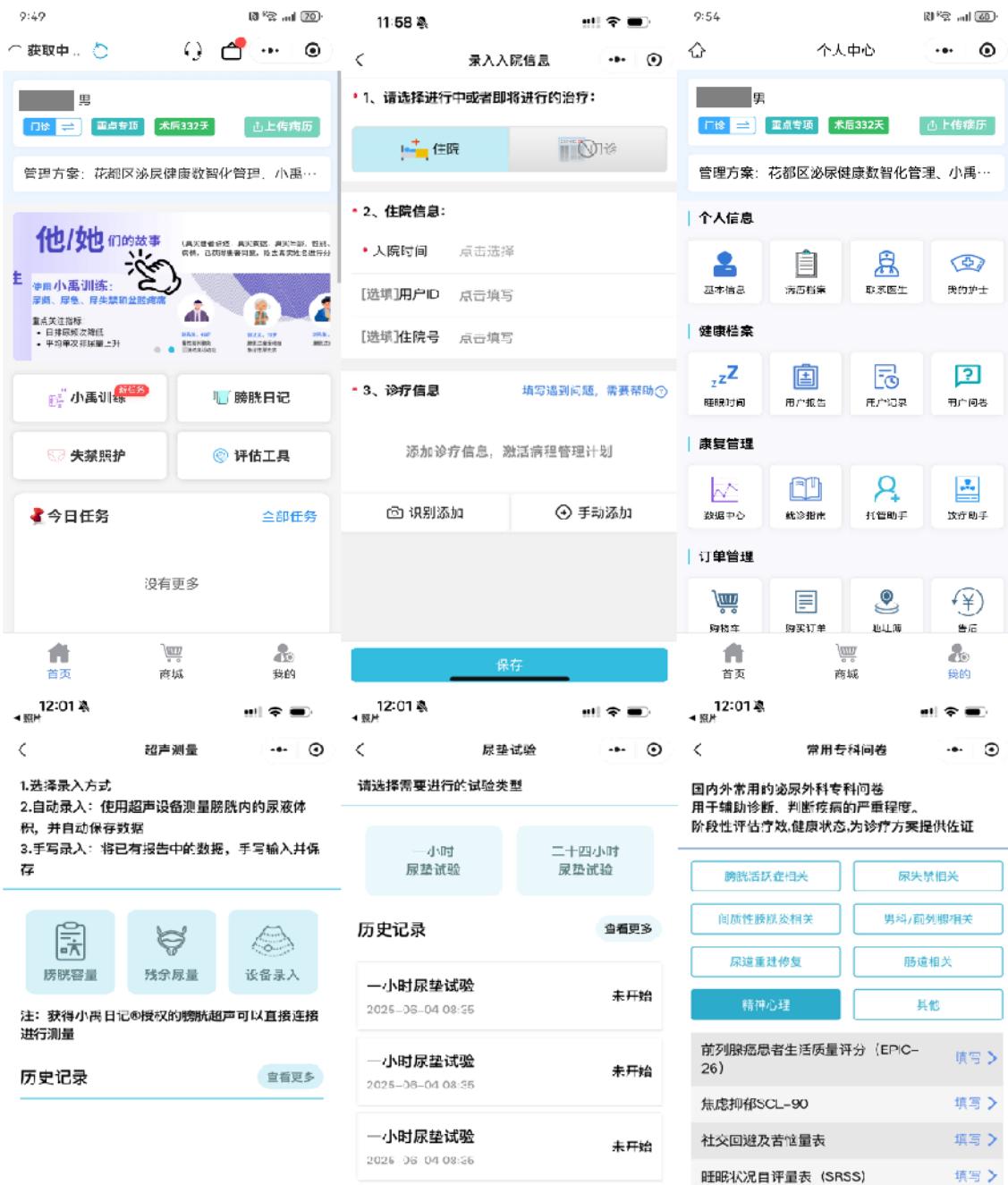
Safety and Feasibility

Regarding digital confidentiality, patients upload data by completing their own records as well as using wearable devices. Because the data are time series in nature, the app assigns timestamps to each data point and incorporates preprocessing interfaces to filter missing values and outliers. The study follows SM3 and SM4 encryption algorithms for desensitized and encrypted storage of data, alongside hierarchical management of data permissions, facilitating separate review processes for health care professionals and patients. Data privacy complies with the Personal Information Protection Act.

Pilot Evaluation of Clinical Behavioral Intervention-Supporting System Feasibility and Outcome Trends

Participants used the CBISs an average of 5.2 (SD 1.1) times per day. Following implementation of the CBISs-guided bladder function training program, directional changes were observed across multiple bladder diary parameters, incontinence-related outcomes, and patient-reported symptom measures (Tables 3 and 4). Given the exploratory nature of this pilot study and the limited sample size, results are presented to describe change patterns rather than to support confirmatory inference.

Mean voided volume increased from 984.6 (SD 132.7) mL at baseline to 1128.4 (SD 148.2) mL post intervention. Fluid intake also increased over the intervention period, suggesting changes in hydration and voiding behaviors consistent with the individualized training guidance delivered by the system.

Daytime urinary frequency showed a reduction from 5.74 (SD 1.21) episodes per day to 4.69 (SD 1.08) episodes per day. Nighttime urinary frequency similarly declined, with median values decreasing from 1.8 (IQR 1.6-2.2) episodes per night to 1.0 (IQR 1.0-1.6) episodes per night. Total urinary frequency demonstrated a comparable downward trend over the intervention period, reflecting changes in urinary storage and voiding patterns.

Incontinence episodes declined from a median of 7.0 (IQR 6.0-11.0) episodes per day at baseline to 4.0 (IQR 2.0-6.0) episodes per day after the intervention. Pad test measurements indicated lower postintervention urine leakage values compared with baseline, with a shift toward milder leakage severity categories observed among participants. Specifically, the number of patients classified as having severe or greater leakage decreased, while the number of patients classified as having mild leakage increased.

Patient-reported outcomes showed parallel trends. ICIQ-UI SF scores were lower after the intervention compared with baseline, indicating a reduction in perceived symptom burden. Exploratory correlation analysis suggested alignment between changes in patient-reported symptom scores and reductions in objective urine leakage measures; however, these associations should be interpreted cautiously given the small sample size and exploratory design.

The proportion of patients reporting urinary urgency and sensation of incomplete bladder emptying was lower following the intervention period. Dysuria incidence also declined, whereas changes in postvoid dribbling were less pronounced and more variable across individuals.

Effect size estimates were calculated to describe the magnitude of observed changes across outcomes. Several parameters demonstrated moderate to large effect size values; however, these estimates are provided for descriptive and hypothesis-generating purposes only and should not be interpreted as evidence of definitive clinical benefit in the absence of a concurrent control group.

Overall, the pilot results indicate that the CBISs can be feasibly implemented in postprostatectomy patients and is associated with consistent directional changes across multiple objective and subjective outcome domains. No causal conclusions regarding clinical efficacy can be drawn from this exploratory analysis.

Table 3. Exploratory changes in bladder diary parameters before and after the clinical behavioral intervention-supporting system (CBISs)–guided training program. Statistical comparisons are exploratory and intended to describe within-participant change patterns rather than to support confirmatory inference. Effect sizes are reported for descriptive purposes only.

Variable	Preintervention, mean (SD)	Postintervention, mean (SD)	Mean difference, 95% CI	2-tailed t test (df)	P value	Cohen d
Voided volume (mL)	984.6 (132.7)	1128.4 (148.2)	143.8 (69.2 to 218.4)	4.32 (15)	<.001	1.08
Fluid intake (mL)	1246.8 (181.4)	1428.2 (198.6)	181.4 (95.6 to 267.2)	5.12 (15)	<.001	1.28
Daytime urinary frequency	5.74 (1.21)	4.69 (1.08)	–1.05 (–1.68 to –0.42)	–3.56 (15)	.003	0.89
Total urinary frequency	7.86 (1.90)	5.96 (1.24)	–1.90 (–2.56 to –1.24)	–6.12 (15)	<.001	1.53
Urinary urgency frequency, %	68.8 (18.2)	31.3 (16.8)	–37.5 (–47.5 to –27.5)	–8.23 (15)	<.001	1.08
Incomplete emptying sensation frequency, %	58.8 (19.5)	28.8 (15.6)	–30.0 (–40.6 to –19.4)	–6.15 (15)	<.001	1.28
Postvoid dribbling frequency, %	25.0 (15.8)	18.8 (12.4)	–6.2 (–14.8 to 2.4)	–1.56 (15)	0.139	0.89

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Table 4. Exploratory changes in incontinence-related outcomes and patient-reported symptoms before and after the clinical behavioral intervention-supporting system (CBISs)–guided training program. Statistical analyses were conducted to characterize the direction and magnitude of changes in this pilot study. *P* values and effect sizes should be interpreted cautiously due to the small sample size and lack of a control group. For dysuria, the value represents percentage change.

Variable	Preintervention, median (IQR)	Postintervention, median (IQR)	Median difference	*z* value	*P* value	Effect size[a], *r*
Nighttime urinary frequency, n	1.8 (1.6-2.2)	1.0 (1.0-1.6)	–0.8	–3.82	<.001	0.68
Incontinence episodes, n	7.0 (6.0-11.0)	4.0 (2.0-6.0)	–3.0	–5.56	<.001	0.99
Urine leakage, g	8.5 (4.0-19.0)	3.5 (2.0-9.0)	–5.0	–5.56	<.001	0.99
ICIQ-UI SF[b] score	14.0 (12.0-20.0)	9.0 (6.0-16.0)	–5.0	–5.32	<.001	0.95
Dysuria incidence, %	43.8	25.0	–18.8*	–3.41	.001	0.61

[a]Effect size interpretation: Cohen *d*: small (0.2), medium (0.5), large (0.8); r effect size: small (0.1), medium (0.3), large (0.5).

[b]ICIQ-UI SF: International Consultation on Incontinence Questionnaire–Short Form.

Discussion

Overview

The pilot study provided preliminary evidence of improvements in urinary control and patient-reported symptoms, with the CBISs simulating professional supervision by dynamically adjusting behavioral prescriptions based on adherence patterns, symptom trajectories, and real-time data. Pilot results indicated enhanced urinary control and improved subjective symptom experiences among patients with PPI.

PPI etiology remains incompletely understood, with risk factors including age, BMI, prostate size, oncologic and surgical factors, and shorter membranous urethral length [20-23]. Despite refined surgical techniques and preoperative precautions, PPI persists, severely impacting QoL, finances, and psychology. Conservative treatment—lifestyle modifications, bladder diaries, and PFMT—is first-line for mild PPI, yet a significant implementation gap exists due to poor adherence influenced by fatigue, transportation, time constraints [24-27], inadequate PFMT technique comprehension, and lower cognitive ability [28]. Supervised rehabilitation outperforms unsupervised approaches [29,30].

Traditional in-person care faces geographical, resource, and adherence limitations. Digital health interventions extend support beyond clinics [31]. This study developed CBISs, which collects multidimensional data (diet, urination, activities, adherence, and perceived severity) to generate individualized RL-driven recommendations through XGBoost with rule-engine integration, continuously optimizing through cross-validation while preventing overfitting.

Several digital therapeutic approaches for PPI have been reported, including cognitive-behavioral therapy–based telehealth interventions for urinary incontinence control and QoL [31,32], mobile health apps combining bladder diary logging with PFMT prompts [33], perioperative telehealth programs with remote monitoring calls [28], WeChat-based health education and extended care services [34,35], social media platforms for patient education and community support [36], and proactive digital health interventions aimed at symptom reduction [37]. These platforms primarily focus on delivering educational content, standardized exercise instructions, symptom tracking, and periodic feedback through telehealth communication, messaging apps, or social media engagement. While such approaches improve accessibility and patient awareness, their rehabilitation protocols are generally static, relying on rule-based prompts, fixed schedules, or clinician-mediated adjustments. Consequently, they have limited capacity to adapt training intensity, content, or timing in response to individual patient trajectories, fluctuating adherence, or delayed and heterogeneous treatment responses.

In contrast, the CBISs introduces an RL–driven, closed-loop behavioral intervention framework that emphasizes continuous personalization rather than predefined content delivery, consistent with recent applications of RL in noncommunicable disease management and personalized medicine [38,39]. By iteratively integrating multidimensional patient data—including voiding behaviors, fluid intake patterns, and training adherence—the CBISs dynamically adjusts rehabilitation guidance in response to individual progress and engagement over time. This adaptive design is particularly suited to behavioral rehabilitation contexts, where patient responses evolve gradually and vary substantially across individuals, representing a key limitation of conventional static or rule-based digital platforms.

From a usability and scalability perspective, the CBISs is designed to translate complex behavioral information into actionable, individualized recommendations while reducing reliance on continuous clinician involvement. Clinicians primarily function as supervisors supported by automated monitoring and alert mechanisms, which may help mitigate workforce constraints in real-world clinical settings. Although this pilot study was not designed to establish definitive efficacy, the observed favorable trends in urinary symptom–related outcomes suggest that RL-driven adaptability may help address common challenges of existing digital rehabilitation approaches, including declining adherence and variable response patterns.

Collectively, these features distinguish the CBISs from existing digital therapeutic platforms by shifting the focus from content-centered delivery to behavior-centered, data-driven optimization. This paradigm more closely reflects the dynamic nature of rehabilitation processes and provides a plausible

pathway for improving long-term engagement and personalization in PPI management.

Several limitations warrant consideration. First, transparency and interpretability remain inherent challenges of machine learning–based systems. Although clinician oversight was incorporated into the CBISs workflow, the "black box" nature of RL algorithms necessitates ongoing monitoring to ensure the clinical appropriateness and reliability of generated recommendations. For example, the model may recommend aggressive voiding interval reductions (±15 min) for patients with irregular adherence decay without clearly explaining feature interactions (eg, fluid intake influencing urgency events). In pilot testing, 3 of 16 (18.8%) cases triggered low-confidence alerts routed to clinician override due to unexplained Q value shifts during nocturia spikes, highlighting the need for explainable AI techniques like Shapley additive explanations analysis in future iterations. CBISs relies on patient-reported bladder diaries and potential wearable integration, introducing variability from self-reporting inaccuracies (eg, underreported leakage) or device nonuse (12% dropout in usability testing). Participation may have induced Hawthorne effects, with improvements potentially attributable to heightened attention from research involvement rather than CBISs alone. Additionally, while pilot (n=16) and modeling (n=150) cohorts shared consistent inclusion and exclusion criteria, all participants were motivated outpatients from routine clinical settings, potentially overrepresenting compliant, tech-savvy patients and limiting generalizability to broader PPI populations with lower motivation or compliance challenges. In addition, the system processes large volumes of sensitive patient-level data, underscoring the importance of robust data security, privacy protection, and governance mechanisms for real-world implementation.

The pilot evaluation used a prospective self-controlled pre-post design, which is appropriate for early-stage investigation of interventions requiring high patient engagement and ethical sensitivity. By using patients as their own controls, this design reduced interindividual variability and improved statistical efficiency under small-sample conditions, supporting preliminary exploration of feasibility and potential effect sizes. The concurrent use of objective measures (pad test) and validated patient-reported outcomes (ICIQ-UI SF) further strengthened result interpretation.

Nevertheless, the absence of a concurrent control group limits causal inference, and the observed changes may be partially attributable to nonspecific factors such as time effects, repeated measurement, or expectancy-related bias. The relatively short follow-up period also precludes assessment of long-term effectiveness, sustainability of behavioral change, and delayed adverse effects.

Future studies incorporating appropriate control groups, blinded outcome assessment, and extended follow-up are warranted to establish the definitive clinical value of this intervention. In addition, future work will explore the integration of validated and delayed clinical outcome signals into the RL framework once sufficient longitudinal and controlled trial data become available.

Future studies with complete longitudinal labeling and independent test cohorts will enable formal reporting of model performance metrics such as AUC, F_1-score, and MAE. The lack of a fully formalized mathematical reward function reflects an intentional design choice in this exploratory phase and will be addressed in future work when sufficient validated outcome data become available. Comparative evaluation against simpler baseline models was beyond the scope of this feasibility-focused study and will be addressed in future controlled investigations.

Conclusions

This study describes the development and preliminary evaluation of a behavioral therapy–based CBISs designed to support personalized rehabilitation for PPI. By integrating multidimensional patient data—including voiding behaviors, fluid intake patterns, PFMT adherence, and patient-reported outcomes—the CBISs applies an RL framework to deliver adaptive, individualized behavioral guidance beyond static information delivery.

Rather than replacing clinician decision-making, the CBISs functions as a digital extension of guideline-based care, with the potential to enhance continuity, personalization, and accessibility of rehabilitation support outside traditional clinical settings. The findings from this early-stage study suggest feasibility and favorable trends, supporting further investigation of this approach.

Future multicenter randomized controlled trials are warranted to address several key research questions including whether (1) RL-driven personalization improves continence recovery, QoL, and adherence compared with standard or nonpersonalized digital rehabilitation; (2) observed benefits are sustained over longer follow-up periods; (3) the system performs across diverse patient populations, clinical environments, and levels of baseline motivation; and (4) adaptive, closed-loop interventions confer incremental value over conventional rule-based digital platforms. Addressing these questions will be essential for defining the clinical effectiveness, generalizability, and implementation potential of the CBISs.

As DTx continue to evolve, systems such as the CBISs may offer a scalable pathway toward precision rehabilitation, supporting individualized recovery trajectories for patients navigating functional challenges following prostate cancer surgery.

Funding

Data Availability

The data that support the findings of this study are available from the corresponding authors upon reasonable request.

Authors' Contributions

FF contributed to conceptualization, data curation, formal analysis, methodology, project administration, funding acquisition, and writing of the original draft. Hao H contributed to conceptualization, data curation, formal analysis, methodology, and writing of the original draft. CYX contributed to data curation, formal analysis, methodology, and writing of the original draft. XW contributed to formal analysis and writing—review and editing. CZ contributed to formal analysis, methodology, and writing—review and editing. DW contributed to resources, conceptualization, methodology, and writing—review and editing. JY and YQ contributed to project administration, resources, supervision, conceptualization, methodology, and writing—review and editing. JY contributed to resources, software, methodology, and writing of the original draft. Hai H contributed to resources, supervision, conceptualization, methodology, and writing—review and editing.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
AUC: area under the receiver operating characteristic curve
CBIS: clinical behavioral intervention-supporting system
DTx: digital therapeutics
ICIQ-UI SF: International Consultation on Incontinence Questionnaire–Short Form
MAE: mean absolute error
PCa: prostate cancer
PFMT: pelvic floor muscle training
PPI: postprostatectomy incontinence
QoL: quality of life
RL: reinforcement learning
SM3: ShangMi 3
SM4: ShangMi 4
XGBoost: extreme gradient boosting

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Acceptability of Sharing Internet Browsing History for Cancer Research: Think-Aloud and Interview Study

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Abstract

Background: Growing interest surrounds how internet search behaviors might provide digital signals of disease prior to diagnosis, for example, when people search symptoms online. Internet browsing data offer novel opportunities for understanding response to symptoms, public health surveillance, and early intervention in conditions such as cancer. However, the acceptability of using such sensitive data in medical research remains unclear, particularly among individuals at higher risk of health and digital exclusion, such as older adults and those from minority ethnic groups or with a lower socioeconomic status.

Objective: This study aims to explore the feasibility and acceptability of using internet browsing history data for health research.

Methods: Participants were purposively sampled to ensure representation from groups at risk of digital and health inequalities via community organizations and charities. We conducted semistructured and think-aloud interviews allowing participants to reflect on hypothetical research involving sharing their internet browsing data. The adapted theoretical framework of acceptability guided the interview structure and coding. The interviews were transcribed, coded in NVivo, and thematically analyzed. Patient and public involvement informed the study approach, participant-facing documents, and the interpretation of the findings.

Results: Twenty participants (10 with a history of cancer and 10 without) were included in the study representing a range of age, gender, and ethnic and socioeconomic groups. Key themes focused on factors necessary for acceptability, including trust, transparency, and control and on perceived feasibility and individual willingness. Trust and transparency were fundamental to participants' willingness to share data. Trust in researchers would have to be earned through clear communication, ethical data handling, and familiarity with a named research team. Privacy concerns were prominent, with participants wanting control over what was shared, particularly regarding nonhealth-related information (such as details related to banking) or activity related to others (such as their children). Potential use or misuse of data beyond the original research purpose caused more concern than the nature of the shared data itself. Digital literacy varied; many expressed concerns over the technical aspects of sharing data. Participants also doubted the value of their individual internet browsing history, for example, as they chose not to search for health information due to the prevalence of misinformation. However, they described wider benefits arising from internet browsing history research, such as potential advancements in early detection and opportunities to promote credible online sources.

Conclusions: Participant recommendations balanced privacy concerns against the potential of internet history data for early diagnosis and health research. The study highlights ethical and inclusive approaches to health research using internet browsing history. Future researchers should consider defining the scope of health-specific data filters, providing user-friendly information and guidance for study participants, and ensuring that participants are able to contact research team members to build trust and facilitate data sharing.

Introduction

For many medical conditions, good prognosis and effective treatment rely on timely diagnosis [1,2]. There is also a large economic burden of delayed diagnosis when disease becomes advanced or requires more invasive treatment, longer hospital stays, and greater impact on quality of life [3,4]. In particular, early detection of cancer is a national priority in England, with the National Health Service (NHS) Long-Term Plan aiming to diagnose 75% of cancers at an early stage by 2028 [5-7]. A patient's pathway to diagnosis of cancer may begin weeks or months before they seek help from a health care provider, when

they first notice changes in their body and make decisions about the next steps, including doing nothing, monitoring, self-managing (eg, through medication or rest), seeking external information, or consulting a health care provider [8]. Misinterpreting symptoms as not needing health care appears to be the most important reason for diagnostic delays, constituting approximately 60% of the overall time from first symptoms to diagnosis in cancer [9].

There is growing interest in exploring how the internet is used in response to symptoms and the decision to seek help. Accessing health information online prior to appointments can empower patients and enable more informed conversations with health care providers [10]. Individuals typically search for specific symptoms rather than diagnoses before visiting a health care professional [11,12], although over 40% of individuals opt against seeing a doctor after researching their symptoms [10,13,14]. Recent research has suggested that internet search activity history may provide valuable early digital signals of disease at an individual level. For example, there has been pilot work into the predictive utility of internet searches in relation to gynecological malignancies [15]. The researchers found differences in online search data between malignant and benign gynecological conditions, up to a year before general practitioner referral. Similar findings have been reported in lung cancer [16] and pancreatic adenocarcinoma [17]. However, studies have found variable opinions on sharing internet browsing history data [18-20], and there is a lack of diversity in studied populations. This has the potential to compound existing inequalities [21]. It is known that older adults, those from minority ethnic groups, and those with the lowest levels of socioeconomic status have differences in linguistics, disease rates, digital literacy, and help-seeking behaviors [21-23]; are less likely to use the internet for health information [24-26]; face barriers to internet access [22,27]; and are more likely to experience inequalities in cancer care and outcomes [28]. Disadvantaged groups are also less likely to be willing to share health information more generally [29,30].

Crucial to successful research into internet browsing history is ensuring this research is acceptable to research participants and achieves representative participation. There is currently a lack of knowledge about public and patients' perceptions of acceptability of using individual level internet search data for medical research or the criteria that would enhance engagement. This is important as low or biased engagement could limit the potential of these studies. In this study, we define acceptability as a multifaceted construct, which reflects how potential research participants consider the proposed research to be appropriate [31]. We apply the adapted theoretical framework of acceptability [32], which highlights 8 constructs relevant to establishing acceptability, to explore the feasibility and acceptability of sharing internet browsing history data for health research among individuals with and without a history of cancer, including those from disadvantaged groups.

Methods

Participants and Recruitment

Recruitment took place through in-person engagement and recruitment posters (with a study email and phone number) at community organizations, local networks, and charities using a purposive sampling strategy to ensure representation of groups at higher risk of poorer health and digital exclusion, such as individuals experiencing higher levels of deprivation, older adults, individuals with lower educational attainment, and ethnic minority groups. Participants were adults of any gender, had access to a portable web-browsing–enabled device; were able to read and speak in English; and self-reported either no history of cancer or a history of cancer as an adult (excluding nonmelanoma skin cancer) to explore whether previous experience of cancer influenced willingness to share (see Multimedia Appendix 1 and Checklist 1 for full recruitment details). Individuals interested in taking part were screened in person or by phone for eligibility and sampling by MR, provided with study materials, and a date for the interview booked in pending consent. Interviews were conducted by MR or SA and took place between September 2024 and January 2025 at the university, community organization (London), or online (any location, England), whichever was preferred by the participant. Recruitment was ceased when we had captured a broad range of experiences and attitudes across a diverse group and achieved sufficient information power [33].

Study Design

This research was led by an experienced health services research team, supported by a research assistant and a medical student. The team has expertise in psychology, anthropology, digital health, inequalities, clinical practice, and policy and was supported by patient and public involvement (PPI) contributors from diverse backgrounds (see the *Patient and Public Involvement* section), allowing us to bring together different perspectives during the study design, data collection, and analysis.

Taking a critical realist position, a mixed "reactive" and "reflective" "think-aloud" interview approach was used [34,35], in which participants were invited to speak their thoughts aloud in response to material prompted by the interviewers. After a "warm-up" think-aloud activity, participants were asked to think aloud while reading sections of a participant information sheet for a hypothetical future study, which asked people to share internet browsing data for health research (either prospective or retrospective data sharing). A second think-aloud activity involved participants viewing information on "Google Takeout" (a Google service that allows users to export data from other Google products, which has been used in previous studies to allow participants to share their internet history). To visualize this, participants were also shown an example image of internet search history and encouraged to view their own internet search history via their personal devices, if available. Participants were then asked broad questions on their attitudes to data sharing and the feasibility of taking part in internet sharing research projects. Interviews lasted approximately 60 minutes and were conducted by MR or SA.

Data Analysis

Interviews were audio-recorded and professionally transcribed verbatim, and notes were made by the interviewer as a memory aid during the think-aloud portion of the interview. A framework analysis approach was employed, guided by the adapted theoretical framework of acceptability [32]. Familiarization and initial inductive and deductive coding were conducted by NCG using NVivo (version 1.6; Lumivero). To ensure consistency in the coding and thematic framework development, MR reviewed a subset of transcripts. Code definitions, grouping, and theme development were led by NCG and refined through discussion with MR, SS, and CD via a series of consensus meetings and validated with patient and public contributors. These discussions were informed by field notes kept by SA and MR, and analysis notes were kept by NG. Microsoft Excel was used to chart codes, develop a framework matrix, and compare responses between participants with and without a history of cancer.

Ethical Considerations

Ethical approval was granted from Queen Mary University of London (QMUL) Research Ethics Committee (reference QME24.0548). The study protocol is available on OSF [36], and there were no deviations from this protocol. Informed consent was obtained from participants through a written consent form that was explained by the researcher following a detailed participant information sheet. Participation was voluntary, and participants could withdraw at any point of the study. Participants' identifying information has not been included in this study. Participants were reimbursed £25 (US $33.50) for their time.

Patient and Public Involvement

Three patient and public involvement contributors were recruited from the Centre for Cancer Screening, Prevention and Early Diagnosis (Queen Mary University of London) PPI pool. This is a working database of over 150 people who have expressed an interest in contributing to research. We requested engagement particularly from people aged 55 years or older and from a Black, Asian, or other minority ethnic background. PPI contributors discussed the overall study approach; reviewed the study documents, such as participant information sheets and interview guides; and validated the interpretation of the results and the study recommendations. Recommended changes that were implemented included improved wording on the study recruitment posters and clarification of the study purpose in the participant information sheets. PPI reporting is included in Checklist 2.

Results

Participant Characteristics

In total, 22 interviews were conducted. Two transcripts were excluded from the final analysis following team discussion. In both interviews, there was little engagement, the participants repeated information included within the question and were unable to provide details about their own experiences. As a result of this, the relevance and reliability of the data were insufficient for meaningful analysis. Half (n=10, 50%) of the participants had no history of cancer and half (n=10, 50%) had a history of cancer, representing a range of age, gender, and ethnic groups. Half of those with no history of cancer (n=5) and one third of those with a history of cancer (n=3) lived in areas described as high deprivation (ie, local postcode scores 1 or 2 according to the English Indices of Deprivation), where 1 represents the highest level of deprivation and 10 represents the lowest level of deprivation [37]. The full details of participant demographics are included in Table 1.

Table . Demographics of interview participants.

Demographic characteristic	Those with history of cancer (n=10), n	Those without history of cancer (n=10), n
Gender		
Male	2	5
Female	8	5
Ethnicity		
White/White British/White—Other	7	5
Black British/Black Caribbean	1	2
Asian British or Asian Other	2	3
Age range (y)		
19‐34	0	1
35‐44	1	2
45‐54	1	2
55‐64	6	2
65‐74	0	1
75‐84	2	2
Indices of deprivation		
1‐2 (highest deprivation)	3	5
3‐4	2	4
5‐6	3	1
7‐8	1	0
9‐10 (lowest deprivation)	1	0
Highest level of education		
Primary	0	0
Secondary	3	5
Tertiary (including professional qualifications)	6	3
No qualifications	1	1
Not provided	0	1

Interview Results

The key themes focused on factors necessary for acceptability, including trust, transparency, personal control, and setting digital boundaries and on the perceived feasibility and individual willingness of participants to share internet browsing history for health research. Finally, participants offered recommendations on how future studies using this approach could facilitate trust and encourage participation.

Trust and Transparency as Foundations for Acceptability

Trust and transparency emerged as central factors influencing participants' willingness to share their browsing history data. Trust was not automatic but needed to be actively earned through clear communication, familiarity with the research team, transparency about who would access the data, and integrity in data handling. Direct interaction with researchers, a clear understanding of the study's purpose, and reassurance about data access enhanced participants' sense of security and credibility.

I'd feel comfortable because I've met you guys and you've explained clearly what your research is about, if it was a third party, then that's kind of weird because I've never met that person. [P02, 35-39 years, female, no history of cancer]

Participants consistently articulated that their trust in the research team was closely tied to the perceived transparency of the team's actions and intentions. Providing clear information about the researchers' identities, data use, and opportunities to ask questions would foster reassurance and informed participation. Transparency also entailed setting clear boundaries around what data would be accessed and outlining the safeguards in place to protect privacy. Participants were generally willing to share information provided researchers strictly adhered to stated objectives, maintained ethical standards, and implemented robust data handling protocols, such as anonymization and secure deletion.

It is always reassuring to see that you are following all the right things and that you delete information

once you've collected it for your analysis. [P43, 75-79 years, female, history of cancer]

Because of the sensitivity of that nature, I need to be 100% sure that this data are being used in the right way, are stored, accessed by a limited number of people for the purpose that is being clearly described and given consent for. [P54, 35-39 years, male, history of cancer]

Importantly, participants noted that it was not the nature of their data that caused concern but rather the apprehension that would arise if researchers deviated from the agreed scope of use. Such actions would raise doubts about the researchers' intentions and significantly undermine trust. Thus, trust and transparency were seen as mutually reinforcing, whereby transparency was essential to the development and maintenance of trust throughout the research process.

Providing that the researchers are open about what they're doing and only do what they say they're going to do, then that's fine. If they start going beyond that then it would concern me ... because it makes you question why they're wanting to look for other things. [P47, 60-64 years, female, history of cancer]

As long as it's for research ... If they are properly trained researchers, they'll be ethical and respectful and will observe people's confidentiality and privacy. [P43, 75-79 years, female, history of cancer]

Several participants highlighted the importance of having choice and autonomy, including the ability to opt out or withdraw consent at any time. These features reassured participants that their involvement remained voluntary and under their control.

It's quite good that it's got an opt-out clause ... you don't have to take part if you don't want to and that it won't affect you in any way. [P26, 55-59 years, female, history of cancer, responding to the PIS]

Trust in the organizations managing search data was a fundamental factor in acceptability, with participants clearly differentiating between trusted public bodies and commercial companies. Institutional affiliations with reputable entities, such as the NHS (United Kingdom) and universities, were seen as markers of legitimacy, with logos, branding, and clear consent processes being mentioned as ways of reinforcing this trust. Commercial companies were often not trusted due to their profit-driven motives and concerns about data misuse, such as selling personal information to health insurance companies leading to potential discrimination.

I'm not sure I saw a university or NHS trust logo ... Just to give me that added confidence. [P43, 75-79 years, female, history of cancer, responding to the PIS]

I think with the NHS it's okay, but if it's a private corporation or some commercial that engages with marketing stuff, then I'd be quite apprehensive about that. [P02, 35-39 years, female, no history of cancer]

If it is for other reasons like health insurance, then they can target you and make you pay a higher premium, then I don't think that is fair. And then I'm not happy with it. [P17, 60-64 years, female, no history of cancer]

Personal Control, Privacy Concerns, and Setting Digital Boundaries

Privacy and data security emerged as critical concerns for participants, reflecting broader mistrust in digital systems. The foundations of trust in data management were heavily dependent on participants' perceptions of how their personal information would be treated. While some participants were open to sharing their data for medical research, many expressed reservations about the potential misuse of their personal information or information of other individuals using their devices, as well as data breaches. They highlighted the importance of maintaining control over their personal data.

The only thing I'd worry is if certain things have been hacked. [P09, 20-24 years, male, no history of cancer]

It's that right to say yes or no, I have the right to keep my private things private. [P49, 60-64 years, female, history of cancer]

The concept of privacy was also viewed as inherently linked to transparency, with many participants seeking clear assurances about how their data would be used. Individuals described their internet history as deeply personal, a window into their habits, interests, and private moments and therefore a reflection of their day-to-day lives. Participants expressed strong concerns about the intrusiveness of using this type of data, emphasizing that it could feel like a violation of privacy if there was a risk of others accessing their data, making its use in research a potentially sensitive issue without clear ethical safeguards in place.

I need to be convinced about this and get some reassurances that privacy issues will be dealt with accordingly. Otherwise, I find it intrusive. [P54, 35-39 years, male, history of cancer]

Interestingly, 6 out of the 20 participants, all those without a history of cancer, reported using incognito mode for reasons such as accessing restricted websites, watching YouTube, avoiding cookies or pop-ups, and conducting private searches related to health or banking.

Some participants expressed a strong desire to maintain autonomy over their personal information. While many would feel comfortable sharing health-related information, they were clear that they did not want to disclose any other personal or sensitive details, frequently citing financial information, political views, or family matters as examples.

I like to have this agency over my digital data ... I wouldn't like such sensitive data to sneak in my internet use history and shared with irrelevant people. [P54, 35-39 years, male, history of cancer]

To overcome this, several participants emphasized the importance of having a filtering system that would allow them to share only health-related data, reassuring them that irrelevant or sensitive information, such as bank details or private communications, would not be accessed. This idea of a "health filter" was repeatedly mentioned as something that would make

people feel more comfortable and in control of what was being shared.

> *I do personally think that if this research is medical, then there has to be a way that all you are taking are medical notes.* [P49, 60-64 years, female, history of cancer]

> *I mean obviously no computer programme is 100% going to sift out everything that's medical, but I think it would probably come close to answering my concerns.* [P26, 55-59 years, female, history of cancer]

Participants did not state a preference for prospective or retrospective data collection. When prompted to reflect on whether knowing they would share their data with researchers would change their behavior, only 1 participant felt that they would be on "good behavior" and potentially delete personal activities. Other participants stated they were not concerned as they "had nothing to hide," felt that "everything's big brother as it is," or that they would "forget."

> *I don't believe people would necessarily be mindful about what they look, what they search, knowing that somebody else is checking on it.* [P17, 60-64 years, female, no history of cancer]

Perceived Feasibility and Willingness to Participate in Health Research

Burden of Effort and Digital Literacy

Willingness to share internet browsing history was influenced by perceptions of effort and confidence with digital tools. While many participants were open to the idea, concerns emerged about the time and technical knowledge required to download and share these data. The process was seen by some as potentially tedious or confusing, particularly over a year-long period. One participant joked, "you'd be there all day with mine" [P40, F, 60‑64, history of cancer], reflecting anxieties about data volume and complexity.

Digital literacy varied considerably. While some participants felt comfortable navigating online platforms, others described themselves as "not expert" or relied on others for support. Tools such as Google Takeout were unfamiliar to many, and concerns were raised about storage, filtering content, and whether the process could be made simple and secure. For those less confident, the technical aspects posed as a potential barrier to engagement. These concerns were more commonly expressed by older participants, particularly those aged over 70 years, often unfamiliar with basic terms such as "browser" and relying on others for support; for example, 1 person told us: "I say I'm too old to learn" [P19, 75‑79, F, no history of cancer]. However, confidence did not always coincide with age, as some younger participants also expressed uncertainty.

> *It's too new to me, I didn't know about Google Takeout and I didn't know there was such a thing as a Google account.* [P01, 70-74 years, male, no history of cancer]

> *I don't mind sharing it as long as it's easy for me to actually share it.* [P48, 55-59 years, female, history of cancer]

Personal Experience and Online Health Information

Participants with a history of cancer expressed notably higher levels of privacy concern, emphasizing the sensitive nature of their health data and the need for strict anonymity, whereas participants without a history of cancer, while still valuing privacy, were generally more pragmatic and less emotionally driven in their concerns. These differences suggest that a cancer diagnosis may intensify apprehensions about data sharing and potential identification. Some participants with cancer also highlighted that their main interaction with online health information came after their diagnosis, limiting the utility of their browsing history for early diagnosis ("… for me, … I don't go looking for stuff on-on the internet until it's happened").

Innovation and Societal Impact

Participants recognized the potential for using internet browsing history data to improve individual health outcomes and also contribute to broader societal benefits. During the think-aloud interviews, many participants spoke more broadly about health, cancer, and internet search behavior, with some focusing on how people search for symptoms before diagnosis, while others mentioned improvements in accessing trustworthy information. Many commented on the culture of online health information, expressing frustration over "fake news" and the negative tone of many search results. There was hope that the research could help promote credible sources and bring trustworthy sources such as NHS websites to the forefront.

> *I think it's a really interesting premise, looking at if people are Googling their symptoms before they seek medical help … because intervening earlier might lead to earlier diagnosis and this would be very positive.* [P26, 55-59 years, female, history of cancer]

> *Google search symptoms can be a little bit doom and gloom … it would be great if people actually get more access [to] information … that [is] practical.* [P02, 35-39 years, female, no history of cancer]

Participants expressed strong support for the use of digital tools and online behaviors in health contexts, particularly if related to improving early diagnosis and accessing trustworthy advice.

> *If people can be helped earlier and better, then yes, I support it.* [P17, 60-64 years, female, no history of cancer]

> *Technology can really help people with health stuff.* [P02, 35-39 years, female, no history of cancer]

> *People like to be involved and want to know what effect it might lead to.* [P43, 75-79 years, female, history of cancer]

> *Only by sharing our data can progress be made in medical research.* [P47, 60-64 years, female, history of cancer]

Early diagnosis emerged as a powerful motivator for data sharing and health research participation, with several

participants emphasizing the importance of online data to prompt earlier help-seeking and therefore improve health outcomes. Participants' experiences of cancer shaped their perspectives on the potential value of the research.

> *I always feel really happy if I can help with a study that is going to absolutely make someone move forward with an early diagnosis.* [P49, 60-64 years, female, history of cancer]

> *We shouldn't be going to stage three in cancer. I think we should be able to fix it at stage one.* [P46, 45-49 years, female, history of cancer]

However, while people felt the research was worthwhile for early diagnosis, some questioned the usefulness of their own browsing history, describing it as "low value" or highlighting that they did not frequently use the internet to look up health questions.

Discussion

Principal Findings

This study explored the acceptability of using individual-level internet browsing history data for health research focusing on earlier cancer diagnosis. To our knowledge, no previous study has assessed the acceptability of using such data with respect to health inequalities and cancer.

In this study, participants placed greater confidence in public institutions such as the NHS and universities rather than commercial companies with fear of data misuse, discrimination, and profit motives being predominant reasons, similar to other studies [29,38,39]. Transparency played a foundational role in fostering trust, and this could be built and sustained through clearly communicating study aims, respecting participant boundaries, and keeping participants informed throughout the process.

Participants expressed ongoing concerns about the potential for their data to be hacked or misused once shared, reflecting broader mistrust in digital systems and the sensitive and private nature of internet browsing data. This sentiment was particularly strong among those with a history of cancer who linked their online searches to periods of emotional vulnerability and distress, particularly around diagnosis and treatment phases, similar to previous studies [40,41]. Younger participants took steps toward digital privacy, using "incognito mode" or alternative browsers or search providers seen as more secure, presenting a potential barrier for future research which relies on search history data.

To overcome these concerns of data intrusiveness, a key recommendation across interviews was the implementation of a robust filtering mechanism to isolate health-related data from other forms of personal information. Not only did this offer reassurance that sensitive or irrelevant information would not be accessed, but it also served as a practical mechanism to enhance participation by directly addressing concerns around data intrusion and potential misuse. Previous studies have applied health filters using a list of symptoms, diseases, and medications and their synonyms [15,42]. However, patient descriptions of symptoms may vary according to sociodemographic, linguistic, cultural, regional, and other factors [43,44], which may not be taken into account in lists developed from clinical lexicons. The definition of health-relevant information may also vary according to the condition a study focuses on: for example, negatively valenced web pages in individuals with depression [45], or typing speed and error rate in the presence of cognitive changes, such as in multiple sclerosis [46]. Future research approaches using browsing data will need to clearly define and communicate the limitations of any such filtering to participants.

Additionally, the study revealed wide variation in digital literacy, with both older adults and some younger participants expressing confusion around basic digital terms and concerns about making mistakes during the data-sharing process. This uncertainty about the technical aspects of using unfamiliar tools to download internet browsing data (such as Google Takeout) posed as a barrier, especially for those with limited digital confidence, highlighting the need for simple, user-friendly processes and tailored, individual support. Table 2 outlines key recommendations to enhance participation for future studies.

Table . Recommendations for research involving individual-level internet browsing history, as suggested by participants, linked to the study's themes and the adapted theoretical framework of acceptability (ATFA) [32].

Area (ATFA construct)	Recommendations for research involving individual-level internet browsing history
Trust and transparency (ethicality, intervention coherence)	- Provide clear and accessible information about the study and data use - Use NHS[a] or university branding to build trust where possible - Ensure participants have control, including opt-out options - Maintain open communication with participants - Ensure each participant has a point of contact to direct queries - Include clear information on the research team members including name and credentials
Privacy, data control, and digital boundaries (ethicality, trust)	- Implement a robust filtering system to isolate health-related data and exclude nonhealth-related content (eg, finances, politics, schools); potentially including the option to remove browsing activity related to, or on behalf of, others such as friends and family - Reassurance regarding anonymity, data storage, data protection, and confidentiality
Burden of effort and digital literacy (burden, self-efficacy)	- Offer simple, step-by-step guidance on how to share search history - Include visual aids or videos to support less digitally confident users - Provide technical assistance when needed
Innovation and societal impact (affective attitude, perceived effectiveness)	- Emphasize the societal benefits, such as improving early diagnosis - Highlight how the research could help others - Reassure participants that their contribution is meaningful and valued

[a]NHS: National Health Service (United Kingdom).

Comparison With Prior Work

A recent review of harnessing internet search data as a potential tool for medical diagnosis identified ethical, bias, technical, and policy challenges [47]. In our study, several key factors emerged as influencing participants' willingness to share their internet browsing data, consistent with previous research, which broadly categorized these into four key themes: (1) the relationship between the participants and the researchers, (2) fears and harms of data sharing, (3) purposes, and (4) benefits [48]. Similar recommendations were made in studies to share other digital data, such as loyalty card (purchase history) for academic research [49,50].

Across our study and other work, trust and transparency are integral components and prerequisites for willingness to share data. Trust is not a singular concept but multi-layered, operating at 3 distinct levels: interpersonal (trust in individual researchers), institutional (trust in health care or academic organizations), and systemic (trust in the digital infrastructure more broadly) [51]. Key "enablers" and "impediments" within these trust levels include sociodemographic factors and the reputation of the institution fitting into both categories [39]. Understanding these intersecting factors is key to ensuring research utilizing internet browsing history data for health research is equitable: for example, 1 study suggested that internet and social media data may be viewed by the public as more sensitive than electronic health record data [20]; another found that medical records were seen as the most sensitive type of data, but this was willingly shared with health researchers, while sharing banking data (seen as the second most sensitive) raised more concerns [50]. Attitudes to data protection and sharing may also vary by

demographic group: for example, younger people and people with more education were more likely to choose an option to pay for a service to keep their data private, regardless of income level [52]. Additionally, people with long-term health conditions and those from ethnic minority backgrounds express higher concern about sharing data in general [53], and trust in researchers may vary by ethnic group [54]. Smart Data Research UK's recent public engagement also found that while information about the purpose and benefits of the research positively influenced willingness for their data to be used in research, there was low trust in government and public institutions for these findings to impact policy [55]. This highlights the need to build trust at all levels to ensure that research using digital data targets those who would benefit the most from the earlier detection of cancer and to prevent the risk of exacerbating inequalities. Participants stressed the personal nature of establishing trust ("I've met you guys"), and prospective studies must consider the practical and resource implications of maintaining these relationships over the course of a study to support sustained participant engagement.

Our study also highlighted potential issues of feasibility related to sharing internet browsing history. Previous research has utilized "Google Takeout" as a method for data porting in this type of research. This study identified potential limitations to this approach: for example, participants used other browsers (eg, did not use Android devices); did not have a Google account or were not logged in. Further fragmentation of the digital ecosystem occurs through social media channels, in-app data access, and the impact of generative artificial intelligence on how people seek and review health information—such as only reading the in-browser artificial intelligence summary or asking

ChatGPT [56]. A review of the use of internet search data in diagnosis research found no studies that integrated data from across different platforms and noted the complexity of standardizing such data for analysis and a need for supporting infrastructure and guidance on best practice.

Participants' individual behavior also impacted feasibility; for example, they avoided "cyberchondria" by not using internet searches for health, used incognito mode to hide searches, and searched for health-related data for others (leading to potentially "messy" data). One study recruiting women with gynecological symptoms reported that one quarter of potential participants did not have a Google account and nearly 30% did not have relevant data or faced technical issues with sharing their data [15]. While the median age was similar in those included and excluded in the study, other potential demographic differences were not discussed. Other studies have identified similar issues, including participants consenting to take part in the study but deciding they did not want to share their Google searches [57]. One study that focused on internet use in older age groups (mean age 81 years) found that even among individuals who used computers, 22/76 (29%) did not conduct any searches during the duration of the study, and a further 12 did not conduct any searches in a particular 3-month period [58]. Some studies have only included individuals with a Google account [59-61], but this may impact the utility of this type of research approach in sociodemographically diverse populations.

This study found that in most domains, participants with and without a history of cancer shared similar perspectives. It is possible that the differences in the use of incognito mode between the participants with and without a history of cancer may relate to individual variability in digital literacy, as other participants were not aware of this function. This was not necessarily limited by age or education level, as those who used it were within age brackets from 20 to 64 years. In contrast, participants with a history of cancer expressed notably higher levels of privacy concern, although they were similarly willing to share their data given adequate safeguards. We speculate that this may be due to their closer experiences with the health system, potentially identifying the nature of rare cancers and their focus on their browsing activity postdiagnosis. Qualitative studies in cancer survivor populations have found similar willingness to share and made similar recommendations for building trust [62], and comparisons of individuals with and without a history of cancer found similar willingness to share information and a higher willingness in those with a history of cancer to share sensitive information (such as genetic information) [63]. This suggests an opportunity to examine in more detail how individual health experiences may impact willingness to share data for research related to specific health risks.

Studies that have involved sharing of internet search logs and health data with researchers have typically been retrospective, and there is limited evidence regarding differences in search patterns in study participants who donate data prospectively [47]. A study of the observer effect on social media use did find differences in posting behavior including frequency and topics [64]. Participants were prompted to discuss this during the interview and reported that it would not impact their (long-term)

browsing activities. Nevertheless, this remains an important area to explore.

Strengths and Limitations

This study aimed to explore the acceptability of sharing internet browsing history for research, ensuring representation from groups more at risk of experiencing digital and cancer inequalities. We know that 3% of the population of the United Kingdom do not use the internet, facing barriers such as cost, poor connectivity, and lack of digital skills and that people in this group are more likely to be older and/or earning less [65]. Any future research of this kind would require individuals to use the internet; this required us to find a balance when recruiting and designing the methods. Offering both online and face-to-face interviews (at a convenient location) improved accessibility and allowed those who only use the internet on their phone or on shared devices (eg, library computers) to participate. Additionally, we purposively sampled groups affected by health and digital inequalities, enhancing the relevance of the findings across diverse populations. The participants with a history of cancer were more likely to have a tertiary level of education and showed more variability in whether they lived in more or less deprived areas. However, as limited comparisons were made between the groups, we feel this sample shows sufficient variability across different groups affected by health and digital inequalities. The interviews were restricted to English to support the think-aloud exercises, and as current internet history research has focused on single-language searches. However, future approaches should consider how the internet activity of more diverse populations can be included, particularly as diaspora populations may choose to seek and act on health information from their country of origin [66]. While self-selection bias is possible as participants may have had a preexisting interest in health research or felt comfortable discussing digital data, the diversity and depth of responses suggest that a broad range of perspectives was captured. This was an exploratory study (n=20), and future studies may wish to explore specific barriers and solutions in populations at different risks of exclusion.

Conclusion

This study highlights the steps required to improve the viability of internet browsing data to support earlier diagnosis and enhance public health outcomes. While concerns around privacy, data use, and institutional trust persist, they were not seen as insurmountable. Participants generally expressed positive attitudes toward this innovation, when use is clearly linked to tangible health benefits, provided there are ethical safeguards, simple guidance, and opportunities for consent. The integration of internet browsing data with a patient's medical records may present an opportunity for identifying early signals of disease and holds promise for future research.

Importantly, this research approach offers unique opportunities to reach individuals who may face barriers to accessing traditional health care services, potentially reducing health inequalities and promoting more inclusive approaches to early diagnosis. However, the implementation of this approach requires careful attention to issues of accessibility, digital literacy, and infrastructure; otherwise, the same approach is at

risk of inadvertently exacerbating existing sociodemographic disparities.

To fully harness the benefits of internet search data in health care, systems must become more integrated, secure, and person-centered. As global health pressures grow, such as the rising incidence of cancer, leveraging digital data responsibly offers a path toward more preventative and sustainable health care strategies.

Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Authors' Contributions

SES acquired funding. SES and MR contributed to conceptualization and were responsible for project administration. MR and SA undertook the data collection, and NCG and MR undertook the analysis, with input from SES and CD. NCG and MR drafted the original manuscript. All authors contributed to writing – review and editing.
MM and RP are not affiliated with an organization but contributed as patient and public contributors.

Conflicts of Interest

The Data Liberation Front (based at Google) was a collaborator on the study and advised on accurate description about Google Takeout. They had no other input on the study design or conduct. The research team (SES, MR) was the sole decision-makers on research design and outputs.

Multimedia Appendix 1
Participant recruitment, interview guide, and sample participant information sheet.
[DOCX File, 120 KB - cancer_v12i1e82009_app1.docx]

Checklist 1
COREQ checklist.
[PDF File, 440 KB - cancer_v12i1e82009_app2.pdf]

Checklist 2
GRIPP checklist.
[DOCX File, 14 KB - cancer_v12i1e82009_app3.docx]

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Abbreviations

NHS: National Health Service
PPI: patient and public involvement

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Hashimoto Thyroiditis and Progression of Papillary Thyroid Cancer: 10-Year Retrospective Cohort Study

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Abstract

Background: In recent years, the global incidence of thyroid cancer has been increasing.

Objective: This study aimed to examine the association between Hashimoto thyroiditis (HT) and papillary thyroid cancer (PTC) progression under active surveillance (AS).

Methods: Our retrospective study was conducted at Peking University Third Hospital and included 203 patients with PTC who underwent AS for ≥6 months before surgery. Patients were first categorized into 2 groups: the HT group (n=90) and the non-HT group (n=113). Cox proportional hazards models were then used to evaluate the association between HT and PTC progression during AS, adjusting for age, sex, baseline tumor size, BMI, pregnancy status, number of tumor foci, and thyroid-stimulating hormone level. Subgroup analyses stratified by the 6 covariates mentioned above were also applied to explore the potential effect modification.

Results: No significant difference was observed between the HT and non-HT groups in PTC progression-free survival (hazard ratio [HR] 1.11, 95% CI 0.61‐1.99; *P*=.74), tumor enlargement-free survival (HR 1.02, 95% CI 0.56‐1.86; *P*=.95), or lymph node metastasis-free survival (HR 1.76, 95% CI 0.31‐10.12; *P*=.52). Subgroup analyses revealed a potential interaction between HT and BMI. Among patients who were overweight or obese (BMI >24 kg/m²), HT was significantly associated with an increased risk of disease progression (HR 6.32, 95% CI 1.84‐21.69; *P*=.003), while among patients with BMI ≤24 kg/m^2, no association between HT and progression risk was observed (*P*=.01).

Conclusions: We found no evidence of association between HT and PTC progression during AS. However, the relationship between HT and PTC progression may be modified by overweight or obesity status.

Introduction

Thyroid cancer is not only the most common malignant tumor of the head and neck but also the most prevalent endocrine malignancy. In recent years, the global incidence of thyroid cancer has been steadily increasing. Between 1990 and 2020, the number of newly diagnosed cases worldwide rose from 95,000 to 586,000 [1-3]. In China, the age-standardized incidence rate increased from 3.21 per 100,000 in 2005 to 24.64 per 100,000 in 2022 [4,5]. Clinically, papillary thyroid cancer (PTC) is the most frequently encountered, representing approximately 80% of all thyroid cancer cases worldwide [6].

As understanding of PTC has evolved, active surveillance (AS) has been increasingly adopted by Japan and Korea as part of a comprehensive management approach for low-risk PTC [7,8]. The US and Chinese guidelines also consider AS an acceptable treatment approach [9,10]. AS is an emerging management strategy that offers a more conservative alternative to immediate

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surgery [9]. It involves active monitoring of the patient's condition without initiating surgical treatment unless there is evidence of tumor progression [11]. Active monitoring primarily refers to performing neck ultrasound every 6 months for the first 1 to 2 years, followed by annual examinations. Despite growing interest in AS for low-risk PTC, there is still no clear consensus on which patients should undergo immediate surgery and which are appropriate candidates for AS.

Hashimoto thyroiditis (HT) is an autoimmune disorder characterized by immune-mediated destruction of thyroid cells through both cellular and humoral mechanisms [12]. The incidence of HT has been increasing steadily over the years, and its coexistence with PTC is relatively common [13-15]. Some studies have suggested that HT may be a risk factor for the development of PTC, while others have indicated that HT could be a protective factor against postoperative recurrence of PTC [13,14,16].

Nevertheless, the vast majority of existing research has focused solely on the postoperative recurrence, overlooking the increasingly prevalent management strategy of AS in recent years. Currently, there is limited evidence on the association between HT and PTC progression during AS. Importantly, the risk factors for postoperative recurrence and those for disease progression under AS may differ substantially [9,17]. Identifying the risk factors for tumor progression during AS is crucial for selecting appropriate candidates, helping to avoid both undertreatment and overtreatment [9]. Moreover, patients with HT tend to be younger and more likely to be female compared to those without HT [14]; both sex and age have been independently associated with disease progression [18,19]. Therefore, it is essential to investigate the role of HT in PTC progression while carefully accounting for potential confounders.

Two reviews have investigated the role of HT in PTC progression [3,13]; however, they have several notable limitations:

1. Lack of stringent inclusion and exclusion criteria: most of the included studies focused on patients who underwent surgery, providing limited insight into the role of HT during AS.
2. Failure to account for confounding factors: key confounders such as sex and age were not adequately considered. For example, the observed association between HT and favorable prognosis in some studies may be attributed to the higher proportion of female patients in the HT group.
3. Unclear definition of outcome measures: these reviews did not clearly distinguish between the role of HT in tumor progression during AS and its effect on recurrence after surgery. This distinction is important, as the extent of surgery may differ for patients with HT and may itself act as a confounding factor in recurrence outcomes.
4. Lack of quantitative synthesis: one of the reviews did not include a quantitative meta-analysis, limiting the ability to draw robust conclusions [3].

Therefore, we investigated the relationship between HT and progression-free survival of PTC under AS—including tumor enlargement and lymph node metastasis (LNM)—while controlling for multiple potential confounding factors.

Methods

Ethical Considerations

The study was approved by the Medical Ethics Committee of Peking University Third Hospital (ethical project number: IRB00006761-M2022721). The requirement for informed consent was waived by the Ethics Committee due to the retrospective nature of the study. All patient data were deidentified and anonymized prior to analysis to ensure the privacy of individuals.

Study Population

The Electronic Medical Record system of Peking University Third Hospital was searched to retrieve cases of thyroid surgery with a subsequent diagnosis of PTC, covering the period from January 2012 to September 2022.

The AS strategy was routinely implemented at our institution beginning in 2015. Since then, all patients diagnosed with low-risk PTC have been introduced to the AS option during outpatient consultations. Following comprehensive counseling by clinicians regarding the risks associated with thyroid surgery, the potential need for thyroid hormone replacement therapy, and the possibility of disease progression during AS, patients make their decision based on individual circumstances—such as pregnancy plans and overall health status—on whether to pursue AS. Patients independently decided whether to undergo AS at our center.

Based on previous studies [20-23] and domain knowledge, the inclusion criteria for the study population were as follows: (1) patients with a pathological diagnosis of PTC in surgical paraffin-embedded specimens; this criterion was feasible because the specimen acquisition method is consistently documented in all pathology reports; (2) patients who underwent at least two thyroid ultrasound examinations prior to surgery at our center; and (3) patients who underwent ≥6 months of preoperative surveillance; (4) patients without surgical contraindications. Patients who presented with LNM or extrathyroidal extension (ETE) at baseline were excluded, as AS is generally not recommended for individuals with evidence of metastasis. For patients with multifocal PTC, only the lesion with the largest mean tumor diameter was considered for analysis [24]. Ultimately, based on the presence or absence of HT, the study population was divided into the HT group and the non-HT group.

Following relevant guidelines and previous studies [14,25], the criteria for diagnosing HT were defined as meeting at least one of the following conditions: (1) pathological evidence of HT in the peritumoral thyroid tissue on the postoperative pathology report or (2) thyroid function test results within 30 days before surgery showing thyroglobulin antibody ≥60 U/mL or ≥4.5 IU/mL, or thyroid peroxidase antibody ≥60 U/mL or ≥34 IU/mL.

Progression During Surveillance

The primary outcome of this study was progression-free survival, defined as the time from baseline to the progression

of PTC. Tumor progression was determined based on either of the following criteria [26] : (1) tumor enlargement, defined as an increase of ≥3 mm in any tumor diameter or (2) newly detected LNM during surveillance. In cases of suspected progression, original pathological, ultrasonographic, and surgical records were independently reviewed by senior clinicians and investigators to ensure accurate determination of disease progression.

Data Extraction

All authors involved in data entry for this study received standardized and targeted training to ensure consistency and comparability of the collected data. The demographic characteristics, imaging examinations, laboratory results, and pathological data extracted from the Electronic Medical Record system were entered and consolidated using Epidata software. To minimize subjective bias during data extraction, patient information was anonymized. Quality control was implemented at multiple stages. Initial and midterm audits were independently conducted by investigators: for each data entry personnel, 20 records were randomly selected and cross-checked against the original source documents to verify accuracy. After data entry was completed, a final spot-check review was performed by a senior physician to ensure the overall accuracy and reliability of the dataset. Data filtering was implemented in R (R Core Team) language according to the predetermined enrollment criteria.

Statistical Analyses

First, we compared baseline characteristics between the HT group and the non-HT group. For categorical variables, frequencies and percentages were reported, and differences between groups were assessed using the Pearson chi-square test or the Fisher exact test when the expected cell count was ≤5. For continuous variables, normality was tested using the Shapiro-Wilk test. Since the data did not follow a normal distribution, group differences were analyzed using the Mann-Whitney U test.

Next, to examine the association between HT and progression-free survival, we first tested the proportional hazards assumption using Schoenfeld residuals. We then constructed a multivariable Cox proportional hazards regression model, adjusting for potential confounders, including age, sex, baseline maximal tumor diameter, BMI, pregnancy status, number of tumor foci, and thyroid-stimulating hormone (TSH) level [27,28]. To visually illustrate the survival differences between the HT and non-HT groups, adjusted Kaplan-Meier PTC progression-free survival curves were plotted.

Further subgroup analyses were conducted based on median age (≥36 or <36 y), median TSH level (>1.72 or ≤1.72 µIU/mL), sex (male or female), baseline tumor size (the maximum diameter >1 or ≤1 cm), number of tumor foci (single or multiple), BMI (>24.0 or ≤24.0 kg/m^2), and pregnancy status (pregnant or not). We evaluated the modifying effects of these variables on the association between HT and progression-free survival using interaction terms (subgroup variable × HT/non-HT group) within the Cox regression model. In the subgroup analyses, covariates other than the stratifying variable were adjusted for accordingly. For example, when stratifying by sex, adjustments were made for age, TSH level, baseline tumor size, number of tumor foci, BMI, and pregnancy status. Similarly, when stratifying by age, adjustments were made for sex, TSH level, baseline tumor size, number of tumor foci, BMI, and pregnancy status.

All statistical analyses were performed using R software (version 4.4.3; R Foundation for Statistical Computing). A 2-sided P value of <.05 was considered statistically significant.

Results

Characteristics of the Study Population

A total of 203 patients with PTC under AS were included in the study. The median age was 36 (IQR 30-42) years, and 187 (92%) patients were female. The median preoperative surveillance duration was 1.45 (IQR 0.89-2.60) years. Patients were categorized into the HT group (n=90) and the non-HT group (n=113). The study flow diagram is presented in Figure 1, and the baseline characteristics of both groups are summarized in Table 1. Significant differences in age and sex were observed between the 2 groups (both P<.001). Table 2 shows the progression status of the study population.

Figure 1. Study flow diagram of the inclusion. HT: Hashimoto thyroiditis; PTC: papillary thyroid carcinoma.
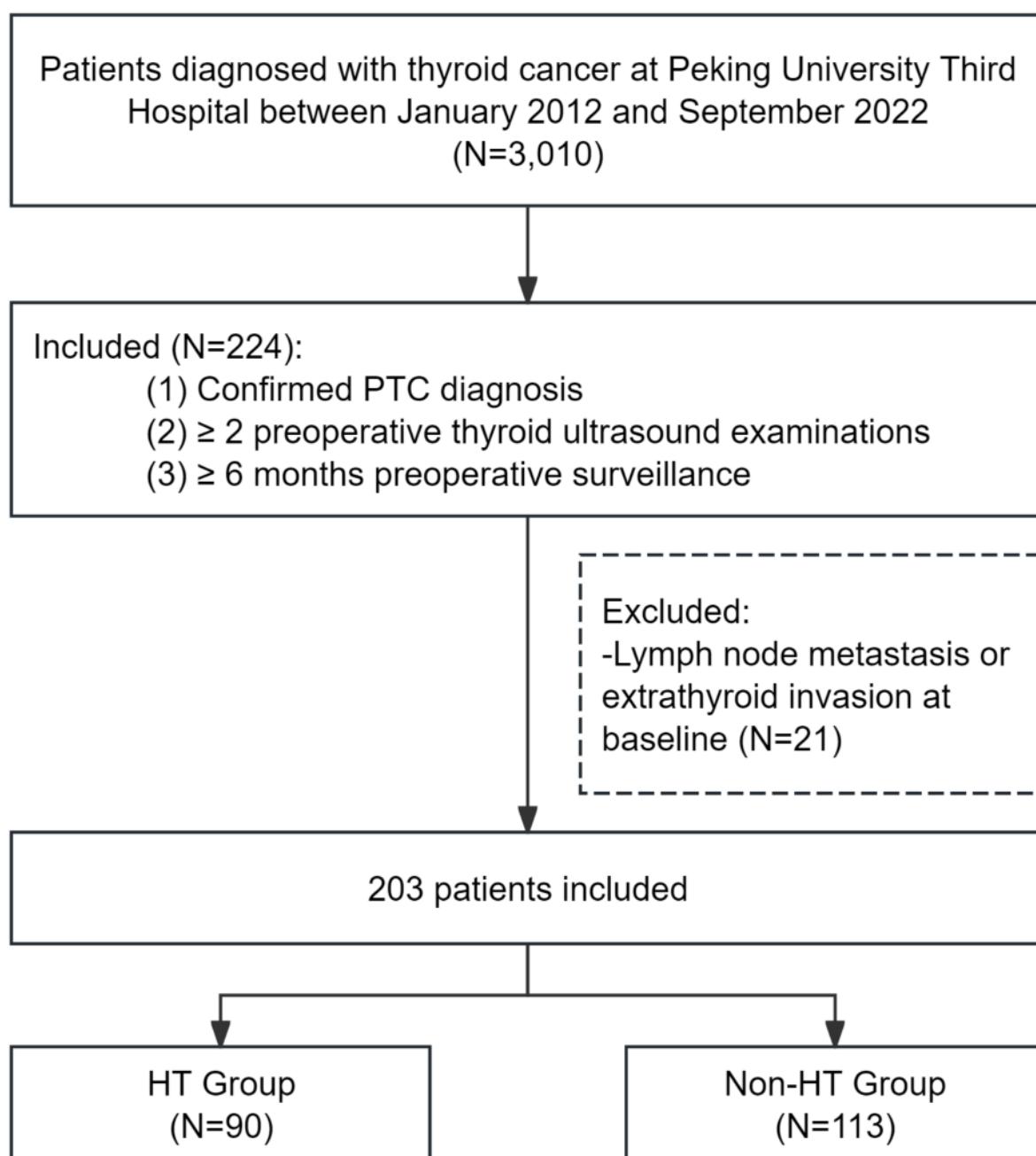
Table . Baseline characteristics of the study population.

Characteristics	HT[a] group (n=90)	Non-HT group (n=113)	P value
Age (y), median (IQR)	34.5 (30.0-39.8)	39.0 (31.0-45.0)	<.001[b]
Baseline maximal tumor diameter (cm), median (IQR)	0.7 (0.6-1.1)	0.8 (0.6-1.2)	.41[b]
Surveillance duration (y), median (IQR)	1.53 (0.83-2.74)	1.44 (0.93-2.49)	.86[b]
Sex, n (%)			<.001[c]
Female	89 (98.9)	98 (86.7)	
BMI (kg/m^2), median (IQR)	23.4 (21.1-25.4)	23.4 (21.5-26.9)	.42[b]
Pregnancy status, n (%)			.47[d]
Yes	8 (8.9)	6 (5.3)	
Number of tumor foci, n (%)			.06[d]
Single	53 (58.9)	82 (72.6)	
Multiple	37 (41.1)	31 (27.4)	
Thyroid-stimulating hormone (TSH) level (μIU/mL), median (IQR)[e]	1.83 (1.12-2.56)	1.64 (1.26-2.18)	.29[b]

[a]HT: Hashimoto thyroiditis.

[b]Mann-Whitney *U* test.

[c]Fisher exact test.

[d]Pearson χ^2 test with Yates' continuity correction.

[e]TSH levels were missing in 93 patients during the observation period.

Table . Progression status of the study population.

Progression type	HT[a] group (n=90)	Non-HT group (n=113)	P value
PTC[b] progression, n (%)			
Yes	30 (33.3)	32 (28.3)	.54[c]
Tumor enlargement, n (%)			
Yes	28 (31.1)	31 (27.4)	.68[c]
Lymph node metastasis, n (%)			
Yes	6 (6.7)	3 (2.7)	.19[d]

[a]HT: Hashimoto thyroiditis.

[b]PTC: papillary thyroid carcinoma.

[c]Pearson χ^2 test with Yates' continuity correction.

[d]Fisher exact test.

Association Between HT and Progression-Free Survival

The Schoenfeld residuals test indicated that our data met the proportional hazards assumption (*P*>.05). During the surveillance period, 63 (31.0%) patients experienced progression, with 30 (33.3%) patients in the HT group and 33 (29.2%) patients in the non-HT group. Among the 63 patients who progressed, 6 experienced both tumor enlargement and LNM, 54 had tumor enlargement only, and 3 had LNM only.

In the multivariable Cox regression analysis, after adjusting for age, sex, and baseline mean tumor diameter, no significant difference in PTC progression-free survival was observed between the HT and non-HT groups (hazard ratio [HR] 1.11, 95% CI 0.61‐1.99; *P*=.74). Similarly, no significant differences were found in tumor enlargement-free survival (HR 1.02, 95% CI 0.56‐1.86; *P*=.95) or LNM-free survival (HR 1.76, 95% CI 0.31‐10.12; *P*=.52; Table 3).

The Kaplan-Meier curves for PTC progression-free survival revealed that the survival curves of the HT and non-HT groups were nearly identical, indicating no significant difference between the 2 groups (Figure 2).

Table . Association between HT[a] and progression-free survival.

Outcomes	HR[b, c] (95% CI)	P value
PTC[d] progression	1.11 (0.61-1.99)	.74
Tumor enlargement	1.02 (0.56-1.86)	.95
Lymph node metastasis	1.76 (0.31-10.12)	.52

[a]HT: Hashimoto thyroiditis.

[b]HR: hazard ratio.

[c]Adjust for age, sex, baseline maximal tumor diameter, BMI, pregnancy status, number of tumor foci, and thyroid-stimulating hormone level.

[d]PTC: papillary thyroid carcinoma.

Figure 2. Kaplan-Meier papillary thyroid carcinoma progression-free survival curves. Adjust for age, sex, baseline maximal tumor diameter, BMI, pregnancy status, number of tumor foci, and thyroid-stimulating hormone level. HT: Hashimoto thyroiditis.
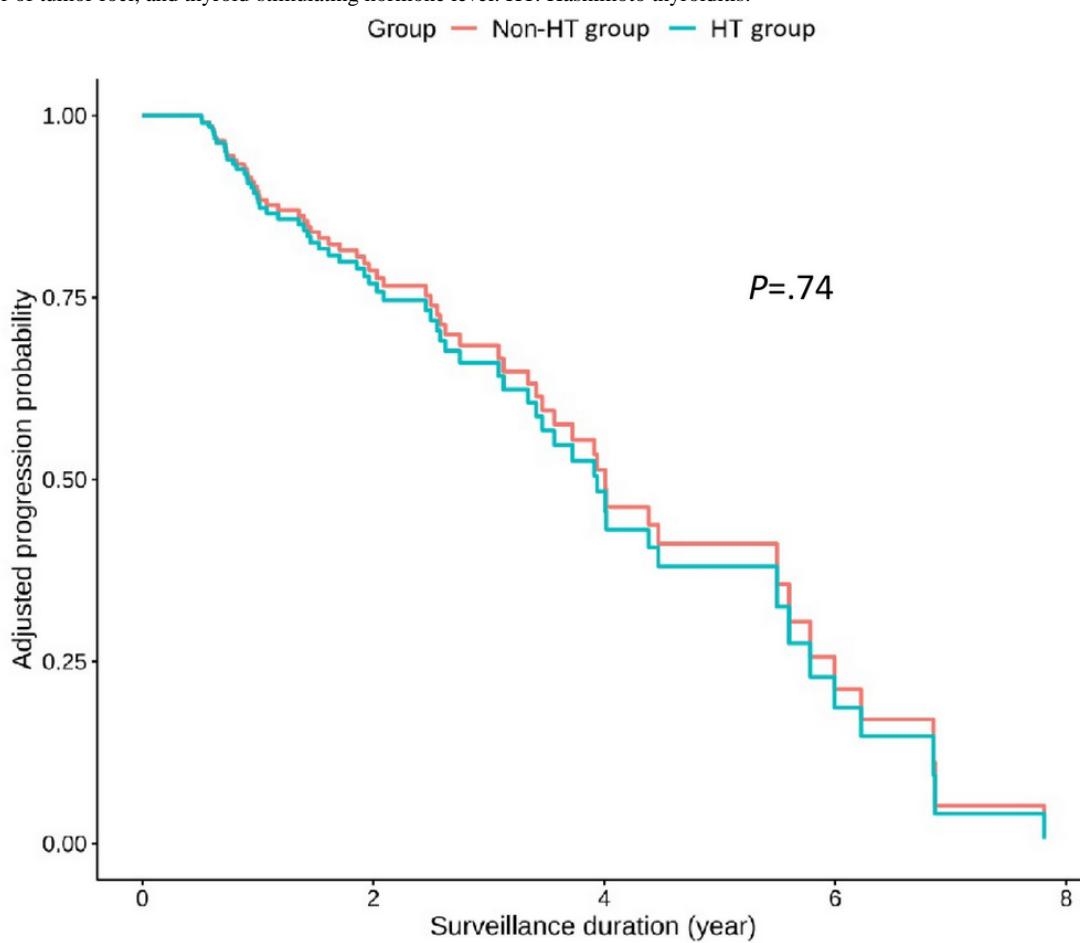
Sensitivity Analyses

In the sensitivity analyses, no significant difference in PTC progression-free survival was observed between the HT and non-HT groups (HR 1.23, 95% CI 0.60‐2.53; P=.58). Similarly, no significant differences were found in tumor enlargement–free survival (HR 1.08, 95% CI 0.51‐2.28; P=.84) or LNM-free survival (HR 2.44, 95% CI 0.23‐25.23; P=.46). The findings from the sensitivity analyses were consistent with those of the primary analyses, suggesting the robustness of the results.

Subgroup Analyses

Figure 3 shows the forest plot of subgroup analyses. There was no significant difference in the association between HT and progression-free survival across subgroups classified by median age (36 y), median TSH level (1.72 μIU/mL), sex, baseline tumor size (the maximum diameter >1 or ≤1 cm), number of

tumor foci, or pregnancy status ($P_{\text{interaction}}$>.05). Notably, we found a potential interaction between HT and BMI ($P_{\text{interaction}}$<.01). Among patients who were overweight or obese (BMI >24 kg/m^2), HT was associated with a significantly higher risk of progression (HR 6.32, 95% CI 1.84‑21.69; P=.003). In contrast, no association between HT and progression risk was observed in patients with BMI ≤24 kg/m^2 (P=.10).

Figure 3. Subgroup analysis of the association between Hashimoto thyroiditis (HT) and progression-free survival. TSH levels were missing in 93 patients during the observation period. In the male subgroup, only 1 patient had HT, and no progression was observed in this case; therefore, an estimate could not be provided. TSH: thyroid-stimulating hormone.

Subgroup	Number of cases	Hazard ratio (95% CI)	P value	P for interaction
Age				.92
≥36 years old	100	1.06 (0.33-3.42)	.92	
<36 years old	103	0.89 (0.43-1.81)	.74	
TSH				.37
>1.72 uIU/mL	55	2.87 (0.593-13.99)	.19	
≤ 1.72 uIU/mL	55	0.99 (0.36-2.68)	.97	
Sex				≥.99
Male	16	-		
Female	187	1.21 (0.65-2.25)	.55	
Tumor size at baseline				.45
>1cm	55	0.76 (0.27-2.16)	.61	
≤ 1cm	148	1.87 (0.86-4.06)	.11	
Number of tumor foci				.67
Single	135	1.23 (0.60-2.53)	.58	
Multiple	68	1.21 (0.31-4.66)	.78	
BMI				.001
>24.0 kg/m^2	85	6.32 (1.84-21.69)	.003	
≤ 24.0 kg/m^2	118	0.53 (0.25-1.12)	.10	
Pregnant				.95
Yes	14	1.08 (0.57-2.04)	.82	
No	189	0.33 (0.03-3.47)	.36	
Overall	203	1.11 (0.61-1.99)	.74	

Discussion

Summary of the Findings

Over a median surveillance period of 1.45 years, our analysis demonstrated no significant association between HT and PTC progression under AS. This finding was consistent for both tumor enlargement and LNM. The results remained consistent in the sensitivity analysis. In the subgroup analyses, no significant association between HT and progression-free survival was found across strata defined by age, TSH level, sex, baseline tumor size, number of tumor foci, or pregnancy status. However, a potential interaction between HT and BMI was identified. Among patients who were overweight or obese (BMI >24 kg/m²), HT was significantly associated with an increased risk of progression.

These results suggest that HT is not independently associated with PTC progression during AS in the general population. However, our subgroup analysis revealed a potential interaction between HT and BMI, suggesting that the association between HT and PTC progression may be modified by overweight or obesity status. Overweight is an increasingly recognized clinical condition. The association between obesity and ETE, tumor multifocality, larger tumor size, as well as LNM remains controversial. However, it has been established that a positive correlation exists between elevated BMI and the presence of the BRAFV600E mutation [29]. Although HT has been proven to be a factor for a better prognosis, this study confirms that, compared to other clinical indicators, an association between HT and PTC progression can be observed specifically within the overweight subgroup in this study. Although the current understanding of the mechanisms underlying the interaction between obesity and HT in PTC progression remains unclear, we speculate that their association may involve the following aspects: (1) HT is associated with a lower BRAF V600E mutation rate [14], while obesity is associated with a higher BRAF V600E mutation rate [30,31]. When both conditions coexist, their opposing effects on gene mutation might offset each other. (2) HT is characterized by lymphocytic infiltration in thyroid tissue. Patients with HT and PTC have been observed to have reduced Tregs and increased interleukin 10 secretion [32]. Conversely, obesity induces Treg expansion and elevated interleukin 10 [33], which may indirectly promote tumor immune escape by suppressing the cytotoxic functions of CD8$^+$ T cells and natural killer cells, thereby counteracting the influence of HT on PTC. (3) Regarding metabolism, in the state of obesity, increased levels of free fatty acids provide more energy for tumor cells.

Further studies with larger cohorts and mechanistic investigations were warranted to validate and elucidate this interaction.

Comparison With Previous Studies

Previous studies have provided substantial evidence supporting a potential association between HT and PTC prognosis. For example, Marotta et al [34] conducted a multicenter retrospective cohort study in Italy involving 301 patients with PTC, of whom 42.5% had coexisting HT and reported significantly longer recurrence-free survival in those with HT. Similarly, Xu et al [14] performed a single-center retrospective cohort study in China involving 9210 patients with PTC, with a 19% prevalence of coexistent HT. Xu et al also suggested that HT was associated with better PTC prognosis.

Nevertheless, the association between HT and postoperative recurrence may differ substantially from its relationship with disease progression under AS. Yet, this distinction has been largely overlooked, as few studies have specifically investigated the impact of HT on PTC progression during AS. In a Korean cohort of 699 patients with PTC managed with AS, Lee et al [17] reported that tumor progression was associated with diffuse thyroid disease (DTD) as detected by ultrasound, with a 2.3-fold increased risk of progression in patients with HT compared to those without. Interestingly, although our study did not find a statistically significant association between HT and PTC progression under AS in the general population, we observed a 6.32-fold increased risk of progression associated with HT in patients who were overweight or obese. It is important to highlight that our study design differs from that of Lee et al [17]. First, HT represents only one type of DTD, which also includes other conditions such as Graves' disease and simple goiter. Second, according to Lee et al [17], DTD was diagnosed based on preoperative ultrasound examinations, while in our study, the diagnosis of HT was primarily based on postoperative pathological confirmation and preoperative serum antibody levels measured within 30 days before surgery.

Limitations and Strengths

Our study has several strengths. First, we applied strict eligibility criteria, including only patients who had undergone AS for more than 6 months preoperatively, to ensure that sufficient follow-up time was available for detecting clinically meaningful changes. The relatively low enrollment proportion is attributable to 2 main factors: (1) AS has only been widely adopted in recent years, and many preoperative cases did not undergo this protocol. (2) Some nonlocal patients or those seeking examinations at other hospitals underwent only a single ultrasound at our institution prior to surgery, making them largely ineligible. We also excluded patients with baseline LNM or ETE to reduce confounding by indication. Second, we employed Cox proportional hazards models to fully utilize time-to-event data, providing more robust estimates. Third, all outcome events were individually reviewed by experienced

clinicians to ensure the accuracy of progression assessment. Fourth, beyond the overall analysis, we examined the association between HT and specific types of progression (including tumor enlargement and LNM) and conducted sensitivity analyses to assess the robustness of our findings. Furthermore, we investigated potential interactions and associations across various patient subgroups.

Nevertheless, our results should be interpreted with caution. First, this was a retrospective study based on data extracted from electronic medical records. We plan to conduct a well-designed, prospectively followed cohort study with standardized data collection to validate our findings. Second, in clinical practice, the decision to undergo AS is influenced not only by the biological risk of tumor progression but also by patient preferences. For instance, patients with significant anxiety may opt for surgery even if their clinical condition qualifies for observation. Such preference-based decisions could introduce selection bias in our study population. Third, as a single-center study, the generalizability of our findings may be limited. Fourth, the limited sample size restricted our adjustment to only a constrained set of confounders. Future studies with larger cohorts are needed to control for a broader range of potential confounding factors. Fifth, the relatively short follow-up period may have limited our ability to detect long-term disease progression dynamics. In several instances, surgical intervention occurred before tumor progression could be observed, which could introduce observational time bias and potentially affect the accuracy of outcome assessments.

These findings should be regarded as hypothesis-generating and may help inform the design of future prospective studies with longer surveillance and more comprehensive data collection.

Clinical Implications

Given the intensive resources required to conduct prospective cohort studies on AS, there are currently very few studies addressing this issue globally. Our study provides a foundation for future research and has important implications for clinical practice. With a methodologically sound design, we contribute relatively high-quality evidence suggesting that, in general, patients with PTC with coexisting HT who meet clinical criteria for AS do not face an increased risk of disease progression. However, among patients with HT who are overweight or obese (BMI >24 kg/m²), particular attention should be paid to a potentially elevated risk of PTC progression.

Conclusion

The findings of our retrospective cohort study implied that for patients with PTC, the presence of HT alone might not be a major factor in determining eligibility for AS versus immediate surgery, except in cases where the patients were overweight or obese. We advocate for future prospective cohort studies on AS to validate these findings before they are applied to clinical decision-making.

Acknowledgments

Funding

Data Availability

The datasets generated and analyzed during this study are available from the corresponding author upon reasonable request via email.

Authors' Contributions

Conceptualization: ZL (lead)
Data curation: BS (supporting), CY (supporting), FM (equal), SS (supporting)
Formal analysis: RS (equal), XL (equal)
Review and editing: BS (supporting), CY (supporting), FM (supporting), SS (supporting)
Writing – original draft: XL (equal), XY (equal)
Writing – review & editing: RS (supporting), XL (equal), XY (equal), ZL (lead)

Conflicts of Interest

None declared.

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Abbreviations

AS: active surveillance
DTD: diffuse thyroid disease
ETE: extrathyroidal extension
HR: hazard ratio
HT: Hashimoto thyroiditis
LNM: lymph node metastasis
PTC: papillary thyroid cancer
TSH: thyroid-stimulating hormone

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Original Paper

Health Care Providers' Perceptions of Unmet Needs Among African American Cancer Caregivers: Qualitative Investigation Among US Medical Professionals

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Abstract

Background: African American caregivers are more likely to be sole unpaid caregivers, spend more hours on caregiving tasks, and receive less external support compared to White caregivers; yet, limited research focuses on their specific needs. Even less attention has been paid to health care provider perspectives on how to better support this population, despite providers' critical role in connecting caregivers to resources and implementing systems-level changes.

Objective: This study aimed to understand health care providers' experiences supporting African American cancer caregivers and to identify actionable recommendations for improving care. Specific objectives were to (1) identify unmet needs that providers observe among African American cancer caregivers, (2) explore barriers preventing these needs from being met, and (3) elicit provider recommendations for interventions to enhance caregiver support.

Methods: Between January and May 2023, we conducted semistructured online interviews with 12 health care providers across 7 US states. Providers were purposively sampled from facilities serving patient populations with ≥20% African American representation. Participants included physicians (n=7), social workers (n=2), nurses (n=2), and other providers (n=1), with 58% identifying as Black or African American and 83% having more than 15 years of clinical experience. Interviews lasted ~60 minutes and were conducted via Zoom (Zoom Video Communications, Inc) with audio recording. Data were analyzed using condensed thematic analysis guided by the McKillip needs assessment framework and socioecological model.

Results: Thematic analysis revealed 2 overarching categories of findings. First, providers identified three types of unmet needs among African American cancer caregivers (1) practical needs, including transportation, financial constraints, and competing family obligations; (2) social-emotional needs, including stress, burnout, and fear; and (3) cultural barriers, including medical mistrust rooted in historical trauma, "superhero Black woman" expectations, tensions between faith and medical treatment, and stigma around mental health. Second, providers offered four themes of recommendations for transformational change: (1) formal acknowledgment and compensation of caregiving as essential work; (2) integration of caregivers as equal members of multidisciplinary care teams; (3) recognition and leveraging of cultural assets, including strong family networks, community values, and faith-based support; and (4) strengthening providers' roles as hubs for individual-level support and systems-level advocacy.

Conclusions: Health care providers readily identify substantial unmet needs among African American cancer caregivers and offer practice-based recommendations that extend beyond individual-level support to emphasize structural and systems transformation. Findings suggest that meaningful improvement requires multilevel intervention. This includes policy changes to formalize and compensate caregiving work, organizational restructuring to integrate caregivers into care teams, provider training in cultural humility and asset-based approaches, and institutional commitment to addressing historical trauma and rebuilding trust with African American communities. This novel provider-focused approach offers actionable pathways for clinical settings to reduce disparities and improve outcomes for African American cancer caregivers and the patients they support.

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Introduction

Cancer Caregiving

As cancer survivorship increases in the United States due to medical advances, the burden of long-term caregiving has grown substantially [1-5]. This burden falls disproportionately on communities of color, who face higher rates of chronic disease, greater caregiving responsibilities, and significant structural barriers, including limited health care access, lower socioeconomic status, and systemic medical mistrust rooted in historical trauma [6-8].

Caregivers play a crucial role in addressing the health and social needs of individuals with chronic conditions, providing essential support that significantly impacts patient outcomes [5]. For instance, cancer caregivers dedicate an average of 32.9 hours per week to caregiving tasks, with 32% reporting more than 40 hours of caregiving weekly [6]. Informal caregiving, which involves providing care without formal employment or financial compensation, is particularly common [4]. However, the burden of informal caregiving falls disproportionately on communities of color [7,8].

Systematic reviews and meta-analyses focused on caregiving within communities of color consistently reveal negative effects on caregivers' physical and mental health [9-11]. One meta-analysis identified a significant association between caregiving and increased levels of self-reported depression and stress, along with reduced general well-being [10]. Additionally, caregivers were found to have lower odds of engaging in preventive health services and personal wellness activities compared to noncaregivers, often prioritizing the needs of those they care for over their own health [12,13].

Studies of access to medical support also show significant gaps. For instance, 54% of caregivers reported having no contact with a health care team in the past year [14]. Among cancer caregivers, many performed complex medical tasks without prior training, and few addressed their own self-care needs during medical visits [6].

Prior Work on African American Caregivers

The prevalence of caregiving is higher among African American (28.1%) and Hispanic (21.9%) populations compared to White populations (19.8%) [7]. However, these groups often face greater health disparities, including higher rates of negative health outcomes, limited access to health care, lower health literacy, and lower income and education levels than White populations [15]. Furthermore, caregivers from diverse backgrounds frequently receive less empathetic communication from health care providers, obtain less medical information, are less involved in medical decision-making, and feel less confident in requesting training or social assistance from health care professionals [16,17].

African Americans are more likely to be the sole informal and unpaid caregivers compared to White caregivers (55% vs 44%), more likely to live full-time with the individuals they care for (45% vs 36%), and more frequently report receiving no external support for their caregiving duties (41% vs 30%) [7]. Additionally, they tend to spend more hours per week on caregiving tasks and are more likely to assist with both activities of daily living, such as managing incontinence and bathing, and instrumental activities of daily living, including medication and financial management. Despite these increased responsibilities, African American caregivers are only half as likely to receive respite services compared to their White counterparts [7].

Caregiving can negatively impact caregivers' health, with only 34% of African American caregivers rating their health as excellent or very good, compared to 45% of White caregivers [7]. African American caregivers also face greater financial challenges, reporting lower household incomes and higher levels of financial strain than their White counterparts [18-21]. Among African American caregivers, 74% have had to modify their employment status due to difficulties balancing work and caregiving responsibilities [19]. Social values, such as familyism—which emphasizes prioritizing family needs over individual needs—are prevalent in African American and other communities of color, adding further strain and contributing to poorer health outcomes for caregivers [12,19]. Additional complexities can arise from the fact that only 3% of oncologists in the United States are Black [22], limiting the potential positive effects of racial concordance on patient-provider (and caregiver-provider) interactions during care visits [23,24].

The Critical Role of Provider Perspectives in Understanding Caregiver Needs

Health care provider perspectives on African American cancer caregiver needs remain understudied. This represents a critical gap given providers' roles as gatekeepers to resources, care coordinators, and drivers of institutional change. Providers like physicians, nurses, and social workers occupy a unique structural position at the intersection of individual patient and caregiver needs and institutional resources and policies [25]. Unlike caregivers who experience their own individual challenges, providers are in a unique position to observe patterns across multiple patients and caregivers, allowing them to identify common issues, effective strategies, and systemic gaps that may not be apparent from individual caregiver accounts.

Provider awareness, attitudes, and behaviors directly influence whether and how caregivers receive support during clinical encounters [26]. Providers who recognize caregiver burden and prioritize caregiver needs are more likely to initiate conversations about support services, make appropriate referrals, and engage caregivers as partners in care planning. Conversely, when providers lack awareness of caregiver challenges or hold implicit biases about caregiver capacity based on race or

socioeconomic status, caregivers may be overlooked in care processes despite having substantial unmet needs [27].

Providers also serve as the primary conduit through which caregivers access formal support services, including social work, care navigation, palliative care, respite services, and community resources [28]. One of the strongest predictors of patients and caregivers accessing support services is provider recommendation. Understanding what providers observe about caregiver needs and what improvement recommendations they offer directly informs how to optimize referral pathways, given their position to influence institutional and systems-level change [29]. They often hold positional authority that allows them to champion policy changes, implement new care models, secure resources, and influence organizational priorities.

Further, understanding provider perspectives can identify discrepancies between caregiver-reported needs and provider perceptions, revealing potential blind spots in current health care delivery across specialties and well beyond oncology [28,30]. When providers underestimate caregiver burden, misunderstand cultural factors shaping caregiver experiences, or fail to recognize specific issues faced by African American caregivers, these gaps in awareness translate directly into inadequate support. No studies, to our knowledge, have specifically examined provider perspectives on the unique challenges and support needs of African American cancer caregivers, despite well-documented disparities in both cancer outcomes and caregiving experiences within this population [31].

Goals of This Study

Existing research addresses caregivers' general needs, but there is a gap regarding African American cancer caregivers' specific needs and even more so considering how providers might play a supportive and constructive role in improving the caregiving experience. This study aims to engage with this understudied area by describing the unique challenges faced by these caregivers in three key ways: (1) within the context of cancer caregiving, (2) specific to the experiences of African American caregivers, and (3) from the provider's viewpoint, rather than solely from the caregiver's perspective. This study seeks to offer valuable insights into how health care professionals can better assist and work alongside African American cancer caregivers, guided by the following research questions:

1. What are health care providers' experiences in supporting the needs of African American cancer caregivers?
2. What unmet needs do health care providers observe among African American cancer caregivers, and what barriers prevent African American cancer caregivers from having their needs met?
3. What recommendations do providers offer for improving support for African American cancer caregivers at individual, organizational, and systems levels?

This provider-focused approach offers unique insights into systemic barriers and solutions that can inform practice improvements and policy changes to better support African American cancer caregivers.

Innovation and Implications for Participatory Cancer Care

This study offers methodological and conceptual innovations aligned with advancing participatory, patient-centered cancer care. Methodologically, we apply a needs assessment framework through the provider lens to explicitly link identified needs to actionable, multilevel solutions [32]. Unlike traditional needs assessments that document gaps without pathways to change, our approach positions providers as both informants about needs and architects of solutions, recognizing their capacity to translate insights into implementable interventions.

Conceptually, this research advances participatory care models by identifying mechanisms to formally integrate caregivers as essential members of multidisciplinary care teams rather than peripheral figures. By centering provider perspectives on caregiver integration, we identify specific strategies for operationalizing truly collaborative care that includes patients, caregivers, and health care professionals as partners.

Our findings also have direct implications for designing technology-enabled interventions responsive to African American caregiver needs. Provider recommendations regarding accessibility, communication, and cultural responsiveness can inform the development of telehealth platforms, mobile health (mHealth) apps, patient and caregiver portals, and digital care coordination tools that address rather than perpetuate existing disparities.

Finally, this work directly addresses health equity priorities in cancer care by focusing on an underserved population and identifying concrete, systems-level strategies for improvement, providing actionable pathways for health care organizations committed to reducing disparities in cancer survivorship.

Methods

Study Context and Background: Research Context and Rationale

This research emerged from identified gaps in understanding the specific needs and experiences of African American cancer caregivers within US cancer care systems. Provider perspectives are essential for several reasons. First, providers are positioned at the intersection of individual patient and caregiver needs and institutional resources, making them uniquely situated to identify both clinical-level and systems-level barriers and potential solutions. Second, provider awareness and prioritization of caregiver needs directly influences whether and how caregivers receive support during clinical encounters. Third, providers observe patterns across multiple patients and caregivers that individual caregivers may not recognize, offering a broader view of common challenges and effective strategies. Finally, understanding provider perspectives illuminates opportunities for professional education, clinical practice improvement, and institutional policy change that can create more supportive environments for African American cancer caregivers.

Institutional and Geographic Context

Participants in this study represented diverse cancer care settings, including academic medical centers, community

hospitals, comprehensive cancer centers, and outpatient oncology clinics, representing the range of settings where cancer care is delivered. This diversity of institutional contexts provides insights into how different care delivery models and resource environments shape both the challenges caregivers face and the support providers can offer.

Temporal and Sociopolitical Context

Data collection occurred between January and May 2023, a period marked by heightened national attention to health equity and racial disparities in health care. This timeframe followed widespread recognition during the COVID-19 pandemic of the disproportionate health impacts on African American and other marginalized communities, as well as growing public discourse about systemic racism in health care institutions. National initiatives from organizations including the American Cancer Society, the National Cancer Institute, and the Centers for Disease Control and Prevention were emphasizing the urgent need to address cancer disparities affecting African American populations. Professional medical organizations were increasingly calling for cultural humility training, diversification of the health care workforce, and structural changes to reduce disparities.

This sociopolitical context is relevant to understanding provider perspectives captured in this study. Providers interviewed during this period were practicing within an environment of increased awareness, institutional pressure, and professional discourse around health equity. Their insights may reflect not only their direct experiences but also evolving consciousness about systemic factors contributing to disparities and the imperative for change. This context may have made providers more willing to engage in critical reflection about shortcomings in current care delivery and more open to discussing unmet needs, structural barriers, and potential solutions. Throughout this paper, we use "unmet needs" to describe gaps in support or resources required by caregivers and "barriers" to describe specific obstacles preventing those needs from being met.

Funding and Study Development Context

This study represents a secondary analysis of interview data originally collected under funding from EMD Serono to Gryt Health, a patient and caregiver support organization. The original data collection was designed to inform the development of culturally responsive support programs and resources for African American cancer caregivers. The partnership between a pharmaceutical company (EMD Serono), a patient advocacy organization (Gryt Health), and academic researchers (University of Texas at Austin) reflects a collaborative model increasingly common in patient-centered outcomes research, wherein industry funding supports community-focused research with academic rigor and independence.

The current manuscript represents an independent academic analysis conducted by the research team coordinated at the University of Texas at Austin under appropriate institutional review board approval and data use agreement (though not all authors are affiliated with the university). While the original project produced internal reports to guide program development at Gryt Health, the current analysis employs different theoretical frameworks, such as the McKillip needs assessment model [32] and social-ecological theory [15]. Also, this analysis uses analytical approaches such as condensed thematic analysis with multilevel intervention classification [33] to generate novel insights for academic dissemination and broader health care system application. This secondary analysis allows extraction of maximum knowledge value from rich qualitative data while adhering to ethical principles of research efficiency by avoiding redundant data collection that would place additional burden on health care providers already stretched thin by clinical demands.

The research team maintained complete independence in conducting analysis, interpreting findings, and preparing this manuscript for publication. EMD Serono and Gryt Health had no role in the design of the secondary analysis, interpretation of findings reported here, manuscript preparation, or the decision to submit for publication.

Recruitment and Data Collection

Semistructured interviews were selected as the optimal method to explore provider experiences and elicit detailed, contextually rich insights that cannot be captured through quantitative approaches. Qualitative methods are particularly appropriate for this study because they enable exploration of under-researched topics where validated measurement instruments do not yet exist, allow investigation of the "how" and "why" questions underlying observed patterns, and generate rich contextual understanding needed to inform culturally responsive interventions [33-35]. Also, the semistructured interview format allowed providers to share experiences in their own words while ensuring core topics were consistently addressed across interviews. Twelve health care providers participated in online key informant interviews conducted via Zoom (Zoom Video Communications, Inc) between January and May 2023. Participants represented a range of professional roles with diverse experiences and firsthand knowledge of supporting African American cancer caregivers in their clinical practice.

Sampling Strategy and Inclusion Criteria

Participants were recruited via purposive sampling with snowball recruitment according to explicit inclusion criteria. To be eligible, participants had to be 18 years of age or older and self-identify as health care providers who support African American cancer caregivers in their professional role. Additionally, providers had to work in facilities serving patient populations with at least 20% African American representation. This threshold was established to ensure that providers had substantial, sustained experience working with African American patients and caregivers rather than relying on limited or anecdotal encounters. The 20% threshold exceeds the overall US African American population proportion (approximately 13%), ensuring recruitment of providers with above-average exposure to these communities and deeper understanding of the specific challenges and strengths characteristic of African American cancer caregiving experiences. We acknowledge this threshold is somewhat arbitrary and represents a pragmatic research decision rather than an empirically derived cutoff.

The research team engaged in directed outreach through systematic review of LinkedIn (LinkedIn Corporation) profiles and affiliated faculty websites of providers who met the inclusion criteria. This directed outreach focused on facilities providing cancer care with significant African American patient populations and, when possible, providers with lived experiences as people of color themselves. After each interview, participants were invited to refer others in their professional networks to the study in a snowball sampling approach. In total, 25 providers were contacted for participation and 12 completed interviews (48% response rate).

The sample size of 12 was established a priori based on qualitative research guidelines indicating that samples of 6-15 participants are sufficient for focused research questions [36,37]. This sample size was deemed appropriate given the study's high "information power" (the richness of data from knowledgeable participants) [37] stemming from the narrow study aim (provider experiences with a specific caregiver population), sample specificity (participants with substantial experience supporting African American cancer caregivers), established theoretical framework [32], quality of dialogue (in-depth interviews), and systematic analysis strategy [36]. Data saturation was observed beginning at approximately the ninth interview, with no fundamentally new themes emerging in the final 3 interviews. The sample size was further constrained by the limited pool of eligible providers; fewer than 12% of oncologists in the United States are from underrepresented minorities, and fewer than 3% are Black, limiting the available recruitment pool [22].

Positionality Statement

Qualitative research is inherently shaped by the perspectives and experiences of researchers. To promote transparency, we acknowledge how our research team's characteristics may have influenced this study. The research team included BL, PhD (health communication researcher with 20 years of experience in cancer caregiving research and personal experience as a cancer caregiver); AS, MA (anthropology background focused on marginalized groups, 10 years amplifying patient voices); GD (doctoral student in community health with personal caregiving experience and diverse urban upbringing); and SU, PhD (health communication professor with 10+ years of qualitative research at a university cancer center).

Our team's racial and professional diversity provided multiple perspectives during data collection and analysis. Team members brought both insider perspectives (shared racial and ethnic identities with many participants and caregivers, personal caregiving experiences) and outsider perspectives (different racial backgrounds, academic positions) that shaped our interpretations. We acknowledge this study involved layered interpretation; providers interpreted caregiver experiences, and we then interpreted provider accounts. This twice-removed relationship to caregivers' lived experiences means both provider perspectives and our interpretations are filtered through our own frameworks and potential blind spots.

Our research was informed by commitments to health equity, asset-based rather than deficit-based framing of communities, and the belief that providers can play active roles in addressing systemic inequities. Two team members' affiliation with Gryt

Health reflected engagement with patient and caregiver communities while potentially biasing us toward pragmatically feasible solutions. To mitigate bias, we employed multiple independent coders, maintained reflexive memos throughout analysis, actively sought contradictory evidence, and grounded findings in direct quotations that allow readers to assess our interpretations. We recognize our positionalities likely influenced which themes drew our attention and how we interpreted provider statements, particularly regarding structural solutions and cultural assets.

Interview Procedures and Data Collection

All interviews were conducted online via Zoom video conferencing software. The online format was selected to remove geographic limits to participation and allow recruitment of providers from diverse locations across the United States.

Interviews were conducted by 2 members of the research team. BL, PhD (Associate Professor of Health Communication and Chief Research Officer at Gryt Health), conducted 75% (9/12) of interviews, and AS, MA (Senior Vice President for Outcomes and Impact at Gryt Health), conducted the remaining 25% (4/12) of interviews. Both interviewers have extensive training in qualitative research methods through their graduate education and substantial experience with cancer caregiver research (see Positionality Statement for detailed backgrounds).

Interviews were scheduled at various times throughout the week and day to accommodate the complex and variable schedules of health care providers. Interview duration ranged from 45 to 60 minutes (mean 54 minutes, SD 4). This timeframe was selected to respect providers' time constraints while allowing sufficient depth of exploration. The shorter duration compared to many qualitative interviews (often 60-90 minutes) was a deliberate accommodation to the realities of provider availability and was deemed appropriate given the focused nature of the research questions and the providers' ability to offer rich, experience-based insights efficiently.

Interview Guide Development and Pilot Testing

The semistructured interview guide (Multimedia Appendix 1) was developed collaboratively by the research team through an iterative process. Development was informed by the McKillip needs assessment framework [32], which emphasizes identifying community needs, available resources, and gaps requiring intervention, as well as by a comprehensive literature review on caregiver experiences, African American health disparities, and provider perspectives in cancer care. The guide was designed to balance structure, coverage of key topics, and flexibility to allow providers to share unexpected insights and follow emergent themes.

To ensure clarity, cultural sensitivity, and appropriateness of language, the interview guide underwent rigorous review and pilot testing before full implementation. The guide was first reviewed by 2 community stakeholders, a cancer survivor and a community health manager, both with lived experience relevant to cancer caregiving in underserved communities. Their feedback informed refinements to question wording, sequencing, and cultural framing. Following this review, the guide was pilot tested with 2 health care providers who met the study inclusion

criteria but were not part of the final sample. Pilot testing revealed that some questions required refinement to reduce interview length and that certain prompts could be reworded to encourage more open-ended, expansive responses rather than brief confirmatory answers. Based on pilot feedback, the research team made minor adjustments to shorten the overall guide while maintaining coverage of essential topics and revised question phrasing to enhance elicitation of detailed narratives. No major structural changes were required, as pilot testers confirmed the guide was effective in exploring the intended topics.

Audio Recording and Data Capture

All interviews were audio recorded using Zoom's recording function with participants' informed consent (as described in Ethical Considerations). To enhance data quality and capture nuances that might not be fully represented in automated transcription, each interview was accompanied by a dedicated note taker who documented detailed observations in real time. The note taker recorded not only the content of responses but also observed emphases, emotional tone, pauses, and other contextual elements that provide interpretive depth.

Following each interview, Zoom's automated transcription feature was used to generate initial transcripts of the audio recordings. These automated transcripts, along with the detailed notes taken during interviews, were then systematically verified for accuracy against the original audio recordings by research team members, who corrected transcription errors, verified observations, and began considering emerging themes to ensure comprehensive and accurate data capture. This dual approach of combining Zoom automated transcription with human-verified contextual notes provided both efficiency and rigor in data documentation.

Data Analysis Procedures

Interview data were stored and coded using Atlas.ti software (ATLAS.ti Scientific Software Development GmbH) for Mac (RRID:SCR_022920). A condensed thematic analytic approach was used to identify key themes. The methods of this analysis were guided by the McKillip model of needs assessment [32], which emphasizes identifying specific community needs, available resources, unmet needs, and linking each topic to community-driven solutions. The analysis also employed a socioecological framework [38,39] to categorize themes at micro (individual), meso (organizational or community), or macro (structural or policy) levels of intervention.

A socioecological framework allows for conceptualization of health determinants and interventions across multiple interconnected levels (1) micro level (individual-level factors affecting individual caregivers and their immediate support systems), (2) meso level (organizational and community-level factors including health care systems, community organizations, and social networks), and (3) macro level (structural and policy-level factors including health care policy, reimbursement structures, and societal norms). This multilevel framework recognizes that comprehensive solutions require coordinated change across individual, organizational, and structural domains.

This classification helps identify which stakeholders and systems must be engaged to address each category of unmet needs.

Preliminary analysis was completed by a PhD-level graduate research assistant and a member of the publication team, who together created a coding scheme through reading 3 interview transcripts independently and then using an open coding technique to identify themes within the transcripts following a modified thematic analysis informed by Strauss and Corbin [40]. The analysis included both inductive and deductive reasoning that followed open coding, axial coding, and then selective coding. Emerging themes related to the research questions were established.

Provider experiences with African American cancer caregivers were coded using the thematic analysis approach to better understand the lived experiences of providers in supporting the unique needs of these caregivers. Notes taken by the research team during the interview process were reviewed for each interview, and memos were included with the data for the initial development of a codebook. Codes were developed into a themed codebook starting with the "thickest" file and then building upon the initial codebook with every subsequent transcript and note analysis. Subcodes were created and evidence through cited quotations of interviewees was placed within the matrix.

Trustworthiness and Rigor

To promote scientific rigor, we used multiple strategies aligned with Lincoln and Guba's criteria for qualitative research trustworthiness: credibility, transferability, dependability, and confirmability [41].

Credibility was established through purposive sampling of experienced providers with substantial exposure to African American cancer caregivers (facilities with ≥20% African American patient populations), detailed field notes documenting content and contextual elements during interviews, dual data capture combining Zoom transcription with human verification against audio recordings, and probing follow-up questions to deepen understanding and verify interpretation of participants' meanings in real time.

Transferability was enhanced through description enabling readers to assess applicability to their own contexts, including comprehensive participant characterization (provider types, racial or ethnic backgrounds, years of experience, and geographic locations), explicit articulation of sampling procedures and inclusion criteria rationale, description of temporal and sociopolitical context, and transparent reporting of all procedures from recruitment through analysis.

Dependability was addressed through systematic documentation of all research procedures and maintenance of an audit trail, including recruitment contacts and response rates, interviewer assignments, data verification procedures, dated codebook versions, coding decisions and rationale, team meeting notes, and reflexive memos. Atlas.ti software provided systematic, transparent organization of coded data. The semistructured interview guide ensured consistency across interviews while allowing flexibility for emergent themes.

Confirmability was enhanced through independent coding by 2 team members who compared codes, discussed discrepancies, and developed the codebook iteratively through regular team meetings until consensus was reached. Atlas.ti provided transparency in coding decisions, allowing verification by other team members. Reflexive memos documented interpretive decisions, assumptions, and potential biases, which were discussed in team meetings to make implicit processes explicit and subject to critical examination. Both inductive and deductive coding approaches balanced exploratory discovery with theoretical structure, reducing the risk of purely subjective interpretation. Extensive use of direct quotations in reporting allows readers to assess whether interpretations are well-grounded in participant language.

Data saturation, as noted in the recruitment and data collection section, was observed beginning at approximately the ninth interview, with core themes clearly emerging and subsequent interviews reinforcing rather than expanding these themes. No fundamentally new themes emerged in the final 3 interviews. While sample size was constrained by the limited pool of eligible providers (fewer than 12% of US oncologists are from underrepresented minorities, and <5% are Black), the observation of saturation combined with focused research questions and high "information power" of experienced, knowledgeable participants provides confidence that findings meaningfully capture provider perspectives.

Ethical Considerations

This study received exempt determination from the Institutional Review Board at the University of Texas at Austin (Protocol #STUDY00005543). The research met criteria for exemption under 45 CFR 46.104(d)(2), as it involved interviews with health care professionals about their professional experiences and observations in their roles as providers, rather than direct research involving vulnerable populations or sensitive personal information about the participants themselves. Although the study involved discussion of patient and caregiver populations, participants (providers) were asked to reflect on their professional practices and aggregate experiences without sharing identifiable information about specific patients or caregivers under their care.

The data used in this manuscript were originally collected by Gryt Health under funding from EMD Serono. The current analysis represents a secondary analysis of these interview data, conducted under an independent research protocol at the University of Texas at Austin. Data sharing between institutions is governed by the Nondisclosure Data Use License Agreement UTAUS-DUA00001286, which establishes terms for appropriate use, storage, and reporting of the data in accordance with research ethics standards and participant protections established during the original data collection.

All participants provided verbal informed consent before interview participation. Given the online nature of the interviews conducted via Zoom, verbal consent was deemed appropriate and was audio recorded as documentation. Prior to beginning each interview, the interviewer reviewed the following elements with each participant the purpose of the study (to understand health care providers' experiences supporting African American

cancer caregivers and to identify recommendations for improved support), study procedures (participation would involve a single 45-60 minutes semistructured interview conducted via Zoom), voluntary nature of participation (participants could decline to answer any question and could withdraw from the study at any time without penalty), recording practices (the interview would be audio recorded using Zoom's recording function for transcription and analysis purposes), data use (deidentified interview data would be used for research analysis, academic publications, and to inform development of caregiver support resources), right to ask questions (participants were invited to ask questions before, during, or after the interview), and contact information (participants were provided with contact information for the research team and the institutional review board).

Participants verbally confirmed their understanding of these elements and their willingness to participate before interviews commenced. For this secondary analysis, the original informed consent obtained during data collection explicitly allowed for analysis and publication of deidentified data for research purposes. The University of Texas at Austin Institutional Review Board reviewed the scope of the original consent and confirmed that it was sufficient to permit the secondary analysis reported in this manuscript without requiring additional consent from participants.

Multiple measures were implemented to protect participant privacy and maintain confidentiality of research data. All interview data were deidentified, with participants assigned numeric codes used in analysis files. Any potentially identifying information mentioned during interviews was redacted. During interviews, participants were explicitly instructed not to share identifying information about patients, caregivers, or colleagues. All audio recordings and analysis files are stored on password-protected, encrypted servers maintained by Box (Box, Inc), with access limited exclusively to research team members who completed human subject research training and signed confidentiality agreements. Following verification of data accuracy and quality, all audio recordings were permanently deleted from Zoom's cloud storage and from local research team devices. Only deidentified data and analysis files are retained for the duration of the research project and the required institutional retention period.

Data sharing between Gryt Health (original data collector) and the University of Texas at Austin research team is governed by the nondisclosure agreement mentioned above, specifying appropriate data use, establishing data security requirements, limiting who may access the data, and prohibiting reidentification efforts or sharing of data with unauthorized parties. In reporting results, illustrative quotations from provider interviews are presented without attribution to specific participants to prevent potential identification based on distinctive speech patterns, roles, or institutional characteristics. Given the relatively small sample size (n=12) and the specialized nature of providers who work extensively with African American cancer populations, additional care was taken to avoid presenting combinations of demographic characteristics that might enable deductive identification.

Participants did not receive financial compensation for their participation in this study. The decision not to provide compensation was based on several considerations. First, participation involved health care professionals sharing insights from their professional practice, which is commonly considered part of professional development and service to the field rather than an activity requiring payment. Second, the interview duration (45-60 minutes) was relatively brief and scheduled at participants' convenience to minimize disruption to their work schedules. Third, many participants expressed intrinsic motivation to contribute to research aimed at improving support for underserved caregiver populations, indicating that the opportunity to shape future interventions served as a meaningful nonfinancial incentive. Finally, the absence of financial compensation helped ensure that participants' decision to participate was based on genuine interest in the research topic rather than external inducement, which may enhance the authenticity and thoughtfulness of responses.

Results

Participant Characteristics

Participants included physicians (7/12, 58.3%), social workers (2/12, 16.7%), nurses (2/12, 16.7%), and other providers (1/12, 8.3%). More than half of providers (7/12, 58.3%) identified as Black or African American, with additional representation from Latinx and Hispanic (3/12, 25%) and White (2/12, 16.7%) providers. Most participants (10/12, 83.3%) had more than 15 years of experience in their field. Providers practiced across 7 US states: California, Florida, Georgia, North Carolina, Ohio, Pennsylvania, and Tennessee. Detailed participant characteristics are presented in Table 1.

Table 1. Participant characteristics (N=12).

Category and subcategory	Values, n (%)
Provider type	
Social worker	2 (16.7)
Nurse	2 (16.7)
Provider or Physician	7 (58.3)
Other	1 (8.3)
Race and ethnicity	
White	2 (16.7)
African American or Black	7 (58.3)
Latinx or Hispanic	3 (25)
Gender identity	
Male	5 (41.7)
Female	7 (58.3)
Years of experience, (years)	
0-5	0 (0)
6-10	1 (8.3)
11-15	1 (8.3)
16-20	5 (41.7)
21-25	4 (33.3)
26-30	1 (8.3)
Geographic location	
California	2 (16.7)
Florida	1 (8.3)
Georgia	2 (16.7)
North Carolina	3 (25)
Ohio	1 (8.3)
Pennsylvania	2 (16.7)
Tennessee	1 (8.3)

Evaluation Outcomes

Thematic analysis revealed two overarching categories of findings: (1) unmet needs and barriers faced by African American cancer caregivers, and (2) opportunities and recommendations for improving caregiver support. The first category, unmet needs and barriers, comprises 3 subthemes practical barriers (transportation, financial constraints, housing insecurity, and competing obligations); social-emotional barriers (stress, guilt, burnout, fear, and unexpressed emotions); and cultural barriers (medical mistrust, superhero expectations, faith or spirituality tensions, and stigma around mental health and medications).

The second category, opportunities and recommendations, comprises four subthemes representing providers' suggestions for transformational change: (1) acknowledgment and formal compensation of caregiving work, (2) integration of caregivers into multidisciplinary care teams, (3) recognition and leveraging of cultural assets, and (4) strengthening the provider's role as a hub for change. These themes and subthemes are discussed below with supporting quotations from provider interviews.

The first theme of unmet needs and barriers covers 3 major categories practical, social-emotional, and cultural. Practical needs included lack of transportation, lack of food, lack of childcare, lack of available sick time for the caregiver, housing insecurity, and competing family obligations of partners and children. Additionally, several providers noted that African American cancer caregivers they have encountered cannot afford to sustain the caregiving role over the long term, as they lose income from the time they are performing their caregiving roles. Social-emotional challenges discussed included providers observing feelings of guilt or shame for not being able to be there for the family member as much as they would like. Also, providers discussed the range of unique emotions of African American cancer caregivers that they have observed, including anger, fear, grief, and sadness; both the ones that they express and other emotions that are not outwardly expressed but still noticed.

The third and most influential theme discussed relates to the cultural barriers unique to African American cancer caregivers. Providers frequently observed overwhelming stress among African American cancer caregivers. This stress stemmed both from the demands of caregiving and from previous negative experiences with the health care system, which contributed to medical mistrust and reluctance to participate in care decisions. Providers also discussed the cultural expectations of the "superhero Black woman" who takes on multiple roles in the family beyond cancer caregiving. Several providers discussed unspoken norms in African American communities that cancer caregiving is a family responsibility and that responsibility is often expected to occur in the home where there is limited support. Providers also discussed the role of faith and spirituality with African American communities, which is often complex when trying to provide care in a manner that is also responsive to a commonly held view of putting care "in God's hands." Finally, providers discussed cultural stigma at length, focusing on how African American communities can view caregiving, medications, and emotional labor. These thematic categories with illustrative quotes are listed in Table 2.

The second thematic category, opportunities and recommendations, comprises four subthemes representing providers' suggestions for transformational change and centers around (1) acknowledgment and compensation of the caregiver role, (2) incorporation of the caregiver into an expanded caregiving team, (3) reliance on the use of cultural assets as protective factors, and (4) the active role of the provider in providing support and facilitating systems change. Themes and selected illustrative quotes are listed in Table 3 and then discussed below in the context of their social-ecological placement to contextualize the findings as nested opportunities for change.

Table 2. Thematic barriers of African American cancer caregivers.

Theme	Example	Illustrative Quote
Practical barriers	Money, paid family sick leave, transportation, food, housing, competing obligations	• "If I call out means I don't get paid. Who's gonna watch the kids? How long is this gonna take? Is this a half day of work? Is this a full day of work? You see them doin' the calculations and you're understandin' because people need to take care of themself as well." • "It's essential they need to work to pay their bills, to survive. You understand the struggle." • "They understand that it's important. They want to be there and part of their care and their treatment plans, but they also have to do what they need to do to survive." • "Housing and then followed by transportation, followed by food, those seem to be the big three, but in that, I think transportation just gets the most, because that's the one we see quickly when someone doesn't show up for their appointment. I think underlying that, there seems to be a larger challenge with housing." • "That's a great need for a lot of, um, our minority patients, you know, African American patients, where you're having to take care of different generations. So it's not just that you have maybe a spouse or you have a parent, but you also have younger generations for whom you're caring for, and so you are torn." • "The wife was not only responsible for caring for her husband who was in the terminal process, but she had grandchildren in the home who she was caring for. She was trying to use the income that she did have to support adult children in the home." • "They've been tryin' to pay these bills. They've been tryin' to find daycare. They've been tryin' to find transportation. They're at the point where they have to go to work. They have to pick up a extra shift. They have to work two jobs. Now they can't be that caregiver because they have to do what they need to do for themselves."
Social emotional barriers	Stress, guilt, burnout, anxiety, fear, sadness, anger	• "They wanna protect their loved one and that they're not trusting. They may also pour that on to their loved one, the patient that have those reservations and fear. I think medical mistrust is just a huge blanket of an issue that should be addressed across African American community as a whole." • "That lead caregiver, begins to just take the rings and starts making really hard concrete decisions much to a loss to themselves because they forget, or they have to shelve their own emotion so that they take care of everyone else." • "That guilt and that anger, they're angry. Like, hey, I've put so many things on the backburner. I've sacrificed. That thought of still losing their family member even all that they've sacrificed is heartbreaking. They do get angry." • "A lot of the times they're not vocal. They kinda just deal with it. They're like, oh, I'm just used to doin' what we have to do. A lotta the times when they meet their breakin' point when they can't come anymore, they can't drop 'em off, they can't do this. Lots of times it's we're at that point where it's just so much that it's a lot too late where we don't have the grants or resources to help them through because they've been tryin' to get past it." • "There's definitely this duty, and I'm not quite sure if there's a lot of coping. The duty to get more information, the duty to be there, even if it means hurting themselves and not caring for themselves."

Theme	Example	Illustrative Quote
Cultural barriers	Mistrust or distrust, stigma and discrimination in health care, limited reflective providers, historical trauma, feels of exclusion or isolation, norms of caregiving expectations, cultural stigma of medications, stigma or taboo of mental health concerns or emotional needs, feeling of inferiority	• "This superhero Black woman thing is incredibly burdensome on caregivers because not only does she have to be the one for her father—and she loves it. She loves her father and will do it, But I'm sure she's the one who is the pillar of her kids and her husband, and at work she's taking on many roles. I think people put all these things on themselves." • "In the African American community, um, you know, family support is such a great thing. Um, and sometimes when we think about those patients that are hospitalized and have to go home or they need to go to, like, a rehab, sometimes they may not want their loved one to go to rehab or a skilled nursing facility. They would rather have them home. But when they're home, um, there may not be available equipment." • "In the African-American…the thought of going on hospice means that they are giving up, and they are not doing everything they can to live." • "Typically, in my experience in African American families, faith is very strong. When you're dealing with trauma or turmoil, the common notion is to put it in God's hands. God's got this, I put it in God's hands, and if I claim this disease, that means I'm going against the word of God." • "We have to look at the historical trauma and the mistrust that's developed over many, many, many years because of the disparities in care, the health inequities, the poor treatment that African Americans have and consistently still do experience. We're overcoming maybe a situation that we never had anything to do with, but we still have to recognize and honor it in the place that it is." • "When it comes to things like medications, there can be a stigma against pain medication, for example, I've had scenarios where there maybe was substance abuse in the family so there's this avoidance of, we're not gonna take anything but an aspirin for stage four metastatic cancer to the bones." • "My experience in the Black community is that it's uncommon or not a comfort space to admit that you're feeling vulnerable or to admit that you're struggling with anxiety or depression or fear, sadness, grief, any of those things because an acknowledgment of that can be seen as either weak or there's a lot of stigma associated with mental health and mental health illness. I think what that does is leave some really glaring gaps for our caregivers." • "My experience with African Americans looks different, from my experience with African Americans in the South. Some of what, like I brought up earlier, I think some of that might be colored by systemic racism that's pervasive in regions, that may not have anything to do with cultural challenges." • "What I've seen in the past is that, particularly among minorities and African Americans, they would come with very limited expectations, so whatever the doctor said was fine. They didn't ask questions among all of my other cultural components of patients. They didn't ask as many questions, because they assumed whatever was given was enough." • "If we think about mental health, and traditionally that's been a very taboo thing to address in the African American community. It's been very taboo for us to even admit, 'Hey, I need help. I think something's wrong.' It's not something that traditionally African Americans seek services for." • "'Just pray about your cancer, God don't hear you have your cancer.' Sometimes there's a disconnect with a person being seen as spiritually weak if they are seeking man for clinical services."

Table 3. Opportunities and aspirations for African American cancer caregivers.

Theme	Level of intervention	Quotes
Theme 1: acknowledgment of African American cancer caregiving as formal work with adequate compensation and support	Macro (structural)	"We don't really think of what the caregivers go through and talk about the grief and everything. They always focus on the patients, all the emotions they go through, but the caregivers go through so much as well as far as all the emotions. Understand when they're angry it's valid because they don't get to voice that a lot of the times. We have so many mental health resources for our patients, but we don't really have a lot as far as the caregivers when it comes to oncology clinics." "African Americans, I think more than any other community, because of the historical mistrust, should allow us first to start with being able to embrace their voices. Everybody's voice, they've gotta be able to own it." "We've got social workers, we've got psychotherapists, we've got caregiver support groups, we've got art classes, we have tai chi, we have healing touch, we have all of what people call the soft and fuzzy stuff, but it's open to not just the individual with the diagnosis, but the caregiver too, knowing that the caregiver is also feeling the pain and the suffering, and is also walking through the journey and also carrying the extra weight of being in charge of the care, that's a herculean task." "They're trying to hold the entire ocean in their hands. Just acknowledging, man, this is a lot. You're going through so many things, you're doing and pointing out the things that are going really well like you handled that beautifully. I don't know that I could have done so well."
Theme 2: acknowledgment and integration of African American cancer caregiving in a core multidisciplinary care team alongside providers and navigators.	Macro (structural)	"I believe that it's absolutely, um, important to engage caregivers, for them to be part of the care team, so that this is not just, um, the providers and the patient, um, but allowing caregivers to be part of decision-making." "The social worker will say, this caregiver is burned out, this caregiver needs this, and I'm always so happy because that's usually the perspective that the social worker can find quickly. I would say, I don't know that providers always have the best perspective on that, but I think having another person on the team see that, is probably even more useful." "You know, caregivers expect that not only are we going to be, um, a team that provides the best care available to our patients, um, but also availing all the resources to make that successful." "I think everyone needs to be listened to very closely, the provider and the patient. I think that caregivers are that link that translate the patient to us. They add information that we may not get." "I think it's very important with just educating caregivers as well that you're an integral part of this journey as well. I want to empower them to ask questions, to question things because they need to understand what's goin' on with the patient as well so that they can help better take care of them." "Yeah, it's important for—I think my way of doctoring is one that is very much—I'm gonna use this word—it's collaborative, in the sense that—or inclusive, or it is important that we're on the same team, that we have the same—that we're working together toward this."

Theme	Level of intervention	Quotes
Theme 3: recognition of African American diverse cultural and social assets as key outcomes to success.	Meso (community)	• "Sometimes, the best supportive care is providing hospice, and a lotta times, in the African-American community, they (don't) wanna do that either. They feel that they either have very good networks in their church, their religious communities that may be able to provide things." • "I think the first thing is trying to develop trust and trying to show that you care about them as a person, them as a believer in their faith and in what they actually feel is strong in their own persona and trying to not appear to be trying to coerce them or push them into one thing or the other and allow them as many options as possible." • "I think fortunately in the African-American community, usually that bond of family is very strong, and I think that helps." • "Churches in the African-American community are oftentimes a very central player in the lives of patients and the caregivers, and a huge source of strength and the support of being able to go to a church as well as knowing that everyone's praying for them, prayer circles, different things like that, that I feel are almost more specific to African Americans than some of our other groups." • "You only survive if there's a family network. There's no housing. There's no health care. There's no services. But if you have a family that is tight-knit that takes care of the elderly and the young, they take care of the addicted and the not addicted, people do well." • "If the pastor says to do it, people do it. Again, oftentimes women are very strong in their households. The matriarch of the family, if she says do it if grand-mama says do it, everybody's gonna do it. It's understanding the dynamics of what the relationships are in those families but resources like the faith nurse ministry, wonderful resource, because they're often embedded within their own community and providing not just health education, but the empathy side of things as well." • "Someone comes and someone else is there, and if the patient doesn't ask, a caregiver is asking, and that doesn't have to be a traditional caregiver, and I like that." • "They're bringing a niece, they're bringing a neighbor, they're bringing somebody a part of the faith that was big in the south, a minister or someone from church. I think that that's huge, and I think that's where the shift has been. I think where we are making strides." • "There's a large church just a few miles from my home that offers health ministry. People and their families can come to those and get some support and have a community of people who understand what they're going through."
Theme 4: solidifying the role of the provider as the hub for both individual level and transformational systems level change to better meet African American cancer caregiving needs.	Micro, Meso, Macro (individual, community, structural)	

Theme	Level of intervention	Quotes
		• "I play connect the dots every day, and sometimes I collect dots of names and organizations and resources because I may not need 'em today, but at some point, I'm gonna encounter someone that needs me to connect that next dot. I'm a professional dot collector, also known as a junk drawer because I keep all those things knowing that someone at some point may reach out and I wanna be able to help them to weave their way through the tsunami that's not only a health diagnosis but the system itself." • "She was so focused on the assessment papers that she had as her task and her duty and her job that she was missing that golden opportunity to just sit alongside this family and embrace where they are and listen to what they needed to share and express. I think there's so much we can learn from people's stories if we as providers leave our agenda behind." • "I realized in my case that thinking about, particularly when African Americans and Latinos, that the adherence to treatments depends upon us showing the commitment to the patient…I learned that if I give my cellphone to my patients, even though they don't call me, they show up to clinic. If I don't, they don't show up to clinic. I was able to increase adherence to the treatment just by giving my cellphone." • "I think that we need to make ourselves available to caregivers to make their job easier. We need to make more telemedicine available. We have to make ourselves more available. We have to answer questions more readily. We have to have that, but we also probably need to reach out and see what they need. I don't think we're asking enough." • "I feel like there's not a lot offered for caregivers in the clinical setting that I'm working in." • "I feel like we have a brief intervention during the clinic visit where we may turn attention to a caregiver's concern, but just acknowledging and really supporting that caregiver and having anything to offer them at all, I don't feel like that's something that I'm aware of or that I was trained to do during all of these years of medical practice and training. I don't feel like that's something that has ever been magnified or highlighted or focused on." • "I think that we need to make ourselves available to caregivers to make their job easier. We need to make more telemedicine available. We have to make ourselves more available. We have to answer questions more readily. We have to have that, but we also probably need to reach out and see what they need. I don't think we're asking enough." • "In the same way that we have thermometers of stress in patients, we should have thermometers of stress on caregivers. That would be very easy to deliver. It could be an after-visit survey that you can give out, then the institution can then appoint services to that." • "I think also understanding even the caregivers may feel overwhelmed, and they may not feel like they have the right to ask so they themselves may not be straightforward. I think that we go so fast that we just—okay. It's all a monologue, 'I'm telling you X, X, X, X. Okay. Bye.' Next. It's really a conversation. This was lovely. Do you need anything else in the future, or if you wanted to talk to caregivers, I could find some."

Theme 1. Acknowledgment of Cancer Caregiving as Formal Work With Adequate Compensation and Support (Macro)

All providers interviewed acknowledged cancer caregiving as work. Providers discussed the need for formal acknowledgment and compensation for African American cancer caregivers, with changes being made at a structural or governmental level. Providers discussed that caregivers need to be compensated at appropriate levels or minimum "living wages." Providers stressed that this formal employment should include benefits that acknowledge workplace hazards and stress and provide resources to support social and emotional health. This formal acknowledgment, compensation, and support are particularly salient for African American cancer caregivers who face unique practical, social-emotional, and cultural barriers to cancer caregiving.

Theme 2. Acknowledgment and Integration of African American Cancer Caregivers in a Core Multidisciplinary Care Team Alongside Providers and Navigators (Macro)

Providers overwhelmingly discussed the need to integrate caregivers as part of the cancer care team, along with the primary care provider, navigator, and social worker. This care team should be collectively trained, oriented, and prepared to meet the needs of the patient. African American cancer caregivers should play an essential and equal role in the care team as they serve as "transformational interpreters" for the patient with cancer. This newly realized care team should include open communication and mutual respect to transform the health outcomes of patients. The thematic analysis highlights

key attributes that would be necessary for the provider role, including having providers that are reflective of the community with shared lived experiences. Therefore, initiatives that seek to diversify providers are necessary. Many interviewed participants also highlighted the essential role of the navigator, especially when serving African American communities. Navigators can provide value to the patient and facilitate better outcomes for the entire team. This defined care team has the potential to be especially effective, as data show that supported African American caregivers show less stress in their caregiving role than other races and ethnicities and are well equipped to respond as part of the care team.

Theme 3. Recognition of African American Diverse Cultural and Social Assets as Key Outcomes to Success (Meso)

Participants noted that African American cancer caregivers have unique assets within their families, communities, and culture that can drive transformational change. Participants noted the diverse support systems and assets among African American communities, such as the cultural norm of taking pride in the caregiving roles and valuing a strong family support network. Participants also observed the African American community having a unique advantage of having a collectivist culture where community caregiving is the norm and often performed by a variety of people, including partners, children, friends, neighbors, pastors, and faith leaders. Religion and spirituality serve a unique and influential role in having the potential to positively affect the emotional health, well-being, and health outcomes of both the patient and the caregiver.

Theme 4. Solidifying the Role of the Provider as the Hub for Both Individual-Level and Transformational Systems–Level Change to Better Meet African American Cancer Caregivers' Needs (Micro, Macro)

Participants who were interviewed also acknowledged the contributing and transformative role that providers could and should play in supporting African American cancer caregivers and their networks. Participants noted that providers are intentionally situated as an intermediary between individual (micro) and organizational and managerial (macro) influence to make these suggested changes to better care for caregivers. Due to this level of influence, participants emphasized that it is essential for providers to be trustworthy, humble, sincere, authentic, caring, and empathetic throughout this process. The provider serves as a central hub for "resource capture" and ensures the functioning of the system at all levels. Participants noted that to be successful, providers must listen, support, and communicate effectively. A key attribute to this success is being available both in appointments and by providing cues of being open and available. Participants shared personal successes of sharing emails or phone numbers that signaled availability and care to caregivers, showing, "I am here. I care. You can reach me."

Discussion

Principal Findings

This study reveals how providers identify and support the needs of African American cancer caregivers, highlighting both the unique challenges these caregivers face and opportunities for improvement. Within health practice settings, this research presents an opportunity for care providers to work with African American cancer caregivers to meet their needs and improve the health outcomes for both themselves and those they care for.

Findings from this study highlight issues faced by African American cancer caregivers, as reported by health care professionals experienced working with these populations. The insights offered cover practical and social-emotional topics as well as culturally specific challenges unique to the African American cancer caregiving experience. The data offered by providers highlight the increasing need for the acknowledgment and support for the caregiving role, especially among African American communities. Further, the findings support structural interventions, including the establishment of the caregiving role as one that is respected, compensated, and formally included in the care team system.

Providers interviewed for this study identified multiple cultural assets unique to African American communities that they observed serving as protective factors for both caregivers and patients. As detailed in Theme 3 and Table 3, providers described witnessing the pride and dedication African American caregivers demonstrated in their caregiving roles, the centrality of family networks in mobilizing support, the influential role of religion and faith communities in providing emotional support and practical assistance, the collectivist orientation where caregiving was shared among extended family and community members rather than falling to one individual, and the strength derived from these interconnected support systems.

These observations represent providers' interpretations of cultural strengths they witnessed in their clinical practices and offer important insights into community resources that health care systems might better recognize and leverage in supporting African American caregivers, particularly drawing from extensive quotations tied to Theme 3. Finally, providers identified their influential and important role that they need to take to support African American cancer caregivers and transform systems to better meet needs. Health care providers have the opportunity to work directly with caregivers to ensure their needs are met and their status is elevated in the caregiving role, though doing so would reasonably need additional administrative and organizational support.

Implications for Innovation in Participatory Cancer Care

This research offers important implications for innovation in cancer care delivery, particularly regarding participatory care models, technology implementation, and health equity initiatives.

Advancing Participatory Care Models

Our findings provide a roadmap for operationalizing participatory cancer care. Provider recommendations for formally integrating caregivers into multidisciplinary care teams (Theme 2) offer specific mechanisms defining caregivers as official team members with designated roles, including caregivers in care planning meetings, providing training and resources, and creating communication channels that position caregivers as partners. Health care organizations committed to patient- and family-centered care can use these provider-generated recommendations to redesign care delivery models and team structures.

The emphasis on formal acknowledgment and compensation of caregiving work (Theme 1) has implications for health care policy and payment models. As value-based care increasingly recognizes the importance of care coordination and outcomes beyond acute treatment, there are opportunities to reimagine how caregiving contributions are valued and supported. Provider recommendations point toward policy innovations such as caregiver stipends, paid family leave expansions, and coverage for family caregiver training and support.

Informing Technology and Digital Health Innovation

Provider insights have significant implications for designing digital health tools responsive to African American caregiver needs. Providers emphasized accessibility, cultural responsiveness, and addressing practical barriers such as time constraints and competing obligations. These insights can inform the development of telehealth platforms designed with African American caregiver needs in mind (addressing medical mistrust through culturally concordant providers, flexible scheduling, and technical support); mHealth apps addressing practical needs while providing emotional support and culturally relevant resources; patient and caregiver portals that recognize caregivers as partners with appropriate information access and care coordination tools; and remote monitoring systems that engage both patients and caregivers sustainably.

Critically, providers highlighted the importance of recognizing and leveraging cultural assets such as faith communities, extended family networks, and collectivist values (Theme 3). Digital innovations that facilitate rather than replace these existing support systems—for example, by enabling coordination among multiple family caregivers or connecting caregivers with faith-based resources—may be more culturally acceptable and effective.

Reducing Disparities Through Systems Innovation

Providers' emphasis on systems-level change (Theme 4) points toward structural innovations, including workforce diversification initiatives to increase representation of underrepresented minority providers and navigators, institutional policies requiring caregiver assessment and support planning with specific attention to barriers affecting communities of color, care navigator programs specifically designed to address barriers faced by African American caregivers, provider training incorporating cultural humility and asset-based approaches, and quality metrics including caregiver support as a measured component of cancer care quality.

Translation to Practice and Policy

The multilevel nature of our findings provides several entry points for intervention. Health care organizations can begin with feasible changes such as provider training and caregiver assessment tools while advocating for policy changes like caregiver compensation and employment protections. Importantly, our asset-based findings (Theme 3) offer a counter-narrative to deficit-focused approaches, providing a foundation for interventions that leverage community strengths while addressing systems-level barriers, an important shift toward equity-oriented innovation.

Limitations

Limitations of this research include the fact that it employs a purposive sample of 12 participants. This sample was established a priori due to the limited number of qualifying providers in the United States. The research represents the lived experiences of a group of providers reporting interactions with African American cancer caregivers and may not be fully reflective of the caregiving experience. Further, this data does not represent the lived experiences of African American cancer caregivers but provides some external insights into the health care experiences of this population and how participants in systems interact with these caregivers. Our purposive sampling strategy, while methodologically appropriate for exploratory qualitative research [40,42], introduces potential selection bias that limits generalizability. Providers who responded to recruitment outreach and agreed to participate may differ systematically from nonresponders in important ways, including greater awareness of or commitment to health equity issues, more positive experiences working with African American caregivers, higher comfort discussing issues of race and health care disparities, or more flexible schedules allowing research participation. Additionally, recruitment via LinkedIn profiles and institutional websites may have skewed toward more digitally engaged or academically oriented providers working at larger institutions. These selection effects mean our findings may not fully represent the perspectives of providers who work in smaller community practices, have less experience or comfort working with African American populations, hold views less aligned with patient-centered care models, or face greater time constraints that prevented participation. Readers should interpret findings as representing the perspectives of a motivated, experienced subset of providers rather than all providers caring for African American patients and caregivers with cancer. Despite these limitations, the rich, detailed insights from experienced providers provide valuable direction for intervention development even if not necessarily generalizable. Significant accessibility limitations must also be noted. Recruitment and data collection were completed online. Potential participants without a significant online presence or less familiar with Zoom may not have participated. These limitations may result in a younger, more technologically savvy, and more urban sample. Following best practices of qualitative research, the interview guide was flexible but not substantially adapted during the iterative process of data analysis. Many culturally sensitive and stigmatized topics were discussed in the research. Participants may not have fully shared experiences related to prejudices or medical experiences due to distrust or social desirability.

Comparison With Prior Work

Our findings confirm and extend prior research on African American caregiver experiences while offering novel insights from the provider perspective. Previous literature documented that African American caregivers are disproportionately burdened as sole caregivers, often receiving no external support [7]. Our provider interviews corroborated these disparities, with participants observing the "superhero Black woman" phenomenon, where caregivers assume multiple family roles beyond cancer care, often without adequate support systems.

Additionally, our provider observations aligned with prior research identifying that only a few African American caregivers rate their health as excellent or very good [7]. Our findings here note significant social-emotional barriers, including stress, guilt, and burnout among African American caregivers (Table 2).

Existing literature highlighted that African American caregivers face greater financial strain, with 74% modifying employment status due to caregiving demands [19]. Our provider participants confirmed these practical barriers, emphasizing transportation, housing, and competing family obligations as primary challenges. Importantly, providers observed how financial pressures create impossible choices: "They have to pick up an extra shift...Now they can't be that caregiver because they have to do what they need to do for themselves."

Previous studies noted limited provider diversity, with only 3% of oncologists being Black [22], potentially limiting racial concordance benefits. Our findings suggest this deficit profoundly impacts care delivery, with providers emphasizing the need for workforce diversification as essential for building trust and improving communication.

Novel Contributions

While prior research documented caregiver challenges through direct caregiver accounts, our study uniquely reveals provider perspectives on these same issues, offering novel insights. First, we identified cultural assets that providers observe as protective factors, including strong family networks, faith communities, and collectivist caregiving approaches, each of which has been underexplored in deficit-focused caregiver literature. Second, our findings reveal specific recommendations from providers for systems-level change, including formal caregiver compensation and integration into care teams, which existing literature has not addressed. Third, we document how medical mistrust, previously identified as a barrier [15,16], manifests in provider-caregiver interactions and affects care delivery from the provider perspective.

These provider insights complement existing caregiver-focused research by identifying actionable intervention points within health care systems and revealing potential misalignments between caregiver experiences and provider perceptions that could inform targeted improvements in care delivery. Our study also extends the understanding of caregiving by revealing that providers often witness caregivers suppressing emotions ("a lot of the times they're not vocal, they kinda just deal with it"), suggesting the health impacts may be even more severe than self-reported measures indicate.

Conclusions

This research lays a foundation for understanding and responding to the needs unique to African American cancer caregivers. It provides key data from providers to support the need for health care transformation and better meet the needs of African American cancer caregivers. With increases in the number of cancer caregivers within the African American population, it is essential to understand mechanisms of support in a culturally responsive manner.

Caregiver support is always and everywhere a systems phenomenon; individual interventions cannot address structural inequities that require institutional transformation. Data shows that this population faces significant health disparities coupled with numerous barriers within the physical, social, cultural, and political environments. This research can positively contribute to the long-term goals of addressing unmet needs and their practical barriers, supporting an assets-based approach to meeting the needs of this population through transformational systems change.

Also, this research will contribute to a better understanding of how providers can specifically help to meet the unique needs of the African American cancer caregiver population. Caregivers cannot be peripheral to care teams when they are central to patient outcomes, as providers note in this project. Future work should seek to provide evidence-informed guidelines for the implementation of these suggested strategies in addition to adding the perspectives of caregivers themselves so more of the care team is included in the dialogue. Full implementation of these strategies will require substantial organizational commitment and resources, which may pose challenges.

Additional research is needed that (1) provides an evidence-informed guide to organizational transformation to better meet the needs of African American cancer caregivers, (2) explores the readiness and resources of health care organizations and their staff to implement such changes, (3) explores the readiness of African American cancer caregivers to be more formally acknowledged and included in the caregiving process, and (4) evaluates the effectiveness of the suggested transformation.

support social and emotional health. This formal acknowledgment, compensation, and support are particularly salient for African American cancer caregivers who face unique practical, social-emotional, and cultural barriers to cancer caregiving.

Funding

Data Availability

The data generated in this study are available upon request from the corresponding author. Interested researchers may contact the corresponding author to discuss access arrangements that maintain ethical obligations to participants while supporting research transparency. Interview transcripts contain potentially identifying information about participants and the health care settings in which they work, so any arrangement would need to respect participant anonymity, also recognizing the need for the depth of the qualitative data.

Authors' Contributions

Author contributions are reported according to the Contributor Roles Taxonomy (CRediT).
Conceptualization: BL (lead), AS (equal)
Data curation: AS (lead), GD (equal)
Formal analysis: GD (lead), BL (equal), SU (supporting)
Funding acquisition: AS (lead), BL (supporting)
Investigation: BL (lead), AS (equal)
Methodology: BL (lead), AS (equal)
Project administration: AS (lead), BL (equal), GD (supporting)
Resources: GD (lead), AS (supporting)
Supervision: BL (lead)
Validation: SU (lead), BL (supporting)
Writing – original draft: BL (lead), GD (equal), AS (supporting), SU (supporting)
Writing – review & editing:BL (lead), GD (supporting), AS (supporting), SU (supporting)

Conflicts of Interest

BL is a co-founder at Gryt Health, where he is a member of the governing board and serves as chief research officer. AS was senior vice president for outcomes and impact at Gryt Health at the time of this work. Both have equity shares in Gryt Health.

Multimedia Appendix 1
Interview guide.
[DOCX File , 12 KB - cancer_v12i1e76266_app1.docx]

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Abbreviations

mHealth: mobile health

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Navigating the Complexity of Lung Cancer Surveillance Practices: Qualitative Pilot Study on Provider Perspectives

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Abstract

Background: Surveillance is noted to be an important part of survivorship to detect recurrence and/or second primary lung cancer (SPLC) at a curable stage. However, current surveillance guidelines remain controversial, and the factors providers consider in clinical decision-making are neither well-defined nor consistently applied.

Objective: In order to inform the qualitative protocol for a larger national study, this pilot study aimed to understand the factors that influence lung cancer surveillance and how providers view risk stratification as a potential tool to inform surveillance practices.

Methods: Semistructured interviews were conducted between October 2023 and July 2024 with purposively sampled providers involved in treating and surveilling patients with lung cancer from the US-based Palo Alto Veterans Affairs Medical Center and Stanford Medicine and its affiliate clinics. Providers were recruited through both email outreach and in-person invitations. Interviews were transcribed by an external transcription service and analyzed through a qualitative inductive content analysis approach to identify themes.

Results: In total, 11 physicians and 2 advanced practice providers (N=13) participated in interviews. The majority were from medical specialties (n=8, 61.5%), and the average number of years of practice as a provider was 9 years. A total of 3 themes were identified that describe the clinicians' sentiments about current surveillance practices and how a risk stratification tool could be used in screening for recurrence and/or SPLC. Clinicians consider a variety of clinical and nonclinical factors (category 1: factors that influence clinical decision making) and highlighted limits of a risk stratification tool, including concerns about generalizability, accuracy, and validity (category 2: sentiments toward a hypothetical risk stratification tool). Finally, concerns were raised about how delivering risk stratification data might impact patient anxiety, misinterpretation, and adherence to surveillance plans (category 3: delivery of risk stratification data to patients).

Conclusions: This qualitative analysis highlights the complexity of lung cancer surveillance decision-making and provider concerns about tool accuracy and delivery. While risk stratification tools may support surveillance decisions, their further development must address data quality, accuracy across diverse clinical and nonclinical risk factors, and effective patient-level data delivery. Doing so will facilitate the practical implementation of risk stratification tools to improve surveillance of SPLC and recurrence.

Introduction

Surveillance is widely accepted to be an important part of lung cancer survivorship to help early detection of local recurrence and second primary lung cancer (SPLC) at a more curable stage.

Guidelines by the American Society of Clinical Oncology, the National Comprehensive Cancer Network, and the European Society of Medical Oncology recommend surveillance imaging every 6 months for the first 2 years and then annually after those 2 years [1-3]. Despite these universal guidelines around

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surveillance, not all survivors receive surveillance imaging. One study found that two-thirds of 1288 patients did not receive recommended surveillance imaging [4], while another study reported that less than 1 in 5 patients out of 1537 at Veterans Health Administration received recommended surveillance imaging [5].

Current variability in imaging receipt may be due to a complex mix of factors, including uncertainty about the optimal frequency of surveillance, duration of surveillance, which findings warrant continued surveillance, or who would be a good candidate for surveillance, considering other comorbidities. Although surveillance imaging is a widely accepted and guideline-recommended practice, there is limited clinical trial evidence that increased surveillance improved survival, especially for patients with advanced non-small cell lung cancer (NSCLC) [6]. Moreover, patients' comorbidities and overall life expectancy compel providers to balance the potential benefits of surveillance against its harms, including complications from biopsies of false positives and reduced quality of life from anxiety around scans [7,8]. How clinicians navigate these competing considerations remains unclear and may vary inconsistently across patients.

Tailored approaches to surveillance may benefit low-risk patients by reducing the frequency of surveillance, while focusing surveillance efforts on high-risk patients [6]. Risk calculators, developed using factors considered in retrospective evidence, can guide clinical judgment when current guidelines lack clear recommendations. For example, risk stratification based on malignancy risk is already used in primary lung cancer screening to identify high-risk patients and improve adherence to screening [9]. Applying a similar strategy to surveillance decision-making in survivors of lung cancer could help reduce variability and promote more consistent clinical practices.

Our study objective was to explore clinicians' clinical decision-making practices around surveillance and to assess the acceptability of risk stratification tools to guide surveillance.

Methods

Study Design

This pilot qualitative interview study was designed to gather insights and perspectives from providers who treat lung cancer. The aim of this study was to identify the array of factors that providers consider for risk of recurrence and/or SPLC and to explore provider perceptions of a hypothetical risk stratification tool that would evaluate the risk of recurrence and/or SPLC.

To contextualize clinician feedback, the hypothetical risk stratification tool referenced in interviews was modeled after the validated Second Primary Lung Cancer–Risk Assessment Tool (SPLC-RAT) developed by Stanford Medicine [10]. SPLC-RAT generates a 5-year SPLC risk estimate using regression-based modeling of clinical and smoking history inputs (eg, age at diagnosis, cancer stage, histology, surgical resection, smoking status, pack-years, and time since cessation). In practice, such a tool could integrate with the electronic health record to automatically pull structured data (eg, age, gender, and race) and combine it with manually entered variables, similar to the integration of analogous tools for primary lung cancer screening [11]. While modeled after SPLC-RAT, the hypothetical risk stratification tool was unnamed to study participants to collect their broader perceptions of risk stratification tools.

Recruitment

Providers were purposively identified and recruited from the Palo Alto Veterans Affairs (VA) medical center and Stanford Medicine and its affiliate clinics, all located within the United States. Eligibility criteria included licensed providers who are involved in treating and surveilling patients with lung cancer at these 2 health care systems. Eligible clinicians were invited to participate in the study through both email and in-person outreach. Initially, 1 provider from a thoracic oncology department was contacted, who then introduced the researcher (JMW) to other oncology providers in that department who were invited to be interviewed in person. The remaining providers were introduced by the study principal investigator (PI) (a thoracic oncologist; JTW) and were invited to participate via email.

Interview Process

The interview guide was modeled on a previous study on machine learning prognostic algorithms and adapted to fit the research questions for this study [12]. The interview guide contained 9 questions surrounding provider surveillance practices in evaluating risk of recurrence and perspectives on a hypothetical risk stratification tool (Textbox 1). Mock interviews were conducted among the research team (JMW, JTW, and SC), and the interview guide was subsequently adjusted for clarity. Research questions asked to providers aimed to explore their clinical decision-making practices around lung cancer surveillance and to assess their perspectives on a hypothetical risk stratification tool to guide surveillance.

Textbox 1. Interview questions.

1. When considering stopping surveillance for a lung cancer survivor, some clinicians stop once a certain timeframe has passed (ie, five y), while others may prefer to continue surveillance indefinitely. When do you think clinicians should consider stopping surveillance indefinitely? When do you think clinicians should consider stopping surveillance imaging for a survivor?

   a. If they do not mention, ask: What are the reasons behind your opinion?

   b. Follow up: What events or circumstances prompt you to order a surveillance scan?

   c. If prompted for clarification or if the subject only discusses the time of diagnosis, mention that some clinicians are prompted by certain events or circumstances, such as multiple negative surveillance scans or declining functional status due to non-cancer-related causes.

2. How do you define risk of recurrence? Numerical risk? Or context of relative risk?

   a. Do you think about risk in concrete terms, as in quantitative numbers or relative terms (ie, this pt is higher risk than someone else)?

3. What factors do you use in assessing the risk of recurrence and/or second malignancy in the context of the patient's overall health?

   a. I understand guidelines say to screen regularly, but in practice, there are other co-morbidities that can change your decision. Does this come to mind apart from the guidelines regarding quantitative risk assessment?

      i. Do you use clinical intuition to modify guidelines?

4. What information about risk of recurrence and/or second malignancy do you usually share with a patient? [Do you have a discussion with a lung cancer survivor about whether or not to continue surveillance imaging?]

   a. If they do not describe this, ask: Some clinicians frame surveillance in terms of general risk, such as the high risk of recurrence for lung cancer. Others specifically tailor it to patient-specific factors, such as ongoing smoking and advanced stage at diagnosis. Where along that spectrum do you fall?

5. We are developing a computer program that can use a patient's medical record data to estimate the patient's risk of developing a second primary lung cancer. If you had access to a score that accurately estimated a 5-year risk of each of your patients -- for example, a 0.1% risk of cancer or a 6% risk of cancer -- how would you use this information in the care of the patient, if at all?

   a. If prompted for clarification of specific scenarios, specify: For example, a 60y patient diagnosed with early stage resected lung adenocarcinoma with a history of prior cancer before lung cancer and a 20 pk-yr smoking history has ~6% 5-year risk of SPLC. If that same patient did not receive resection and does not have a prior history of cancer, the risk reduces to 1.3%.

   b. If they do not mention, ask: Do you think it would prompt a discussion about surveillance practices?

6. Who on the care team should be the primary recipient of this information and how should it be incorporated into the clinical workflow? [Are you comfortable with the primary recipient of this information being a designated screening coordinator?]

   a. If prompted for clarification, mention that lung cancer screening has dedicated coordinators who triage patients based on risk assessment of lung nodule findings and that surveillance follow-up could follow a similar model

7. No prediction model will ever be perfect. A model could have many false positives, which in this case would be patients who are erroneously flagged as having a high risk of cancer. Alternatively, a model could have many false negatives, which in this case would be patients who are high risk of cancer but not flagged by the model. With that in mind, would you prefer to have a model that has more false negatives or more false positives? Why?

   a. If prompted to define "high risk of cancer," it is whatever the clinician would consider high risk.

8. What concerns, if any, do you have about using computer-generated cancer risk predictions in the clinical care of your patients?

9. Do you have any current or prior experience using computer-generated models or cancer risk prediction tools to inform clinical decision-making?

   a. If the person answers "Yes," ask: How does your experience impact the way you view the utility of computer-generated cancer risk predictions in clinical care?

After the main interview questions, demographic information including their years practicing in their specialty, specialty, age, gender, and race were collected.

Semistructured interviews with providers were conducted on Microsoft Teams by 2 trained female researchers (JMW and SC) and the female study PI (JTW). At each interview, verbal consent was obtained before the audio recording. Some study participants knew the PI before interviews, given her role as a thoracic oncology clinician at the health care systems participants were based. Some participants also had previous exposure to a previously developed SPLC risk stratification tool (SPLC-RAT) from Stanford Medicine, including as coauthors on the model development publication, which may have informed their responses to the hypothetical tool described in the interview guide. Interviews were conducted between October 2023 and July 2024, and audio files were transcribed by an external transcription service. The interviewers reviewed all

transcriptions to verify accuracy. Participants were not contacted following the initial interview.

Our research team consists of oncology and surgical clinicians, along with health services researchers, including experts in qualitative methods and oncology. We value a comprehensive understanding of current health system landscapes and the importance of engaging with providers directly involved in patient care before developing future interventions and tools to enhance the quality of health services.

Data Collection and Analysis

The research team aimed to interview at least 12 providers to support preliminary pilot findings; this has similarly been found sufficient for reaching a general level of saturation, or repetition of basic themes or findings [13]. When creating our participant sample, we also considered the concept of information power, which is defined as the capacity of a study's sample size to effectively capture the unique experiences and insights of participants, particularly when the sample is specifically aligned with the research objectives [14]. Since the eligibility criteria created a smaller, well-defined sample of eligible participants, a smaller sample size was sufficient to provide exploratory pilot data that addressed our research questions. Moreover, since interview questions were highly specific, with multiple follow-up probes, and there was depth to the answers, a wide array of insights was captured despite a smaller sample.

Interview transcripts were uploaded to Microsoft Excel. Data analysis was completed through an inductive content analysis approach. First, familiarization with the data was conducted by 2 researchers (JMW and JTW), after which a list of initial codes was identified. During this process, the researchers met weekly to discuss and determine consensus, creating the initial codebook, which contained preliminary codes and definitions, and to adapt the codebook as needed. The finalized codebook was further reviewed externally by the qualitative methods methodologist (CG), providing expert validation and addressing

potential biases that may have arisen from the internal coding team. Once the codebook was agreed upon, the rest of the interviews were coded (JMW and SC). Finally, codes were analyzed and organized into groups to identify overarching themes. Themes were defined, and supporting data that were already analyzed were summarized into these larger themes.

Ethical Considerations

The study was approved by the Stanford University Institutional Review Board (IRB #67922) as an expedited review with a waiver of documentation of informed consent. VA Local Union Notification was obtained for VA employees. Oral information about the study was given before verbal informed consent. This included details about the study's purpose, risk, and benefits of participation, confidentiality protections, and participants' rights to withdraw at any time. All participants provided verbal consent for participation before audio recording. All data were deidentified before transcription using a coding system. Only the interviewers (JMW, SC, and JTW) had access to the code key. Transcriptions and audio recordings were stored in a secure and access-restricted folder on a server behind the VA firewall, accessible only to the research team. Participants did not receive any compensation for their participation.

Results

Participants

Of the 29 eligible providers recruited to participate, 11 physicians and 2 advanced practice providers (N=13) who were specifically involved in treating and surveilling patients with lung cancer were interviewed. The interviews ranged from 14 to 30 minutes. The average number of years the participants have been practitioners was 9 (SD 5.52, range 3‐20) years. The majority of participants were medical specialists (n=8, 61.5%), while the remaining 38.4% (n=5) were interventional specialists. Additional demographic information is provided in Table 1.

Table . Demographic characteristics of providers (N=13).

Characteristics	Value
Age (y), mean (SD; range)	42.5 (5.75; 34-50)
Sex, n (%)	
Female	9 (69.2)
Male	4 (30.8)
Race, n (%)	
White	6 (46.1)
African American	1 (7.8)
Asian	6 (46.1)
Ethnicity, n (%)	
Hispanic, Latino/a/x, or Spanish Origin	0 (0)
Specialty, n (%)	
Interventional	5 (38.4)
Medical	8 (61.5)
Average time as a practitioner (y), mean (SD; range)	9 (5.52; 3-20)

Themes

Findings clustered around three main themes: (1) factors that influence clinical decision making, (2) sentiments toward a hypothetical risk stratification tool, and (3) delivery of risk stratification data to patients. Themes and illustrative quotes are displayed in Table 2.

Table . Themes and representative quotes.

| Overarching theme and subcategory	Definition	Representative quotes
Factors that influence clinical decision-making (for surveillance)		
Clinical risk factors	Clinical risk factors providers consider for surveillance, including cancer-specific and non–cancer-specific factors.	• "I would probably consider smoking history in addition to the patient's medical history. Maybe other medical illnesses we need to consider, different types of cancers and pathologies" [Interventional Specialty, practicing for 10 y] • "What the patient's overall life expectancy is in respective to the diagnosis" [Medical Specialty, practicing for 1.5 y] • "With older people over the age of 75, they have competing risks. Not just their lung cancer recurrence but also dying from other causes so we certainly take that in account and a patient's ability to continue coming in. It's really a shared decision making with the patient" [Medical Specialty, practicing for 12 y]
Nonclinical risk factors	Nonclinical risk factors that providers consider such as patients' social circumstances and sentiments toward surveillance. Some social circumstances include differing emotional capacities, financial situations, and insurance coverage.	• "[There's] still a lot of anxiety result[ing] from living as a cancer survivor" [Medical Specialty, practicing for 21 y]
Sentiments toward a hypothetical risk stratification tool		
Positive sentiments	Providers' positive sentiments toward a hypothetical risk stratification tool	• "I think these risk calculators could be very helpful because it gives us concrete idea of the risk level and if it tells us of a very low risk level, it can give us some confidence in doing less surveillance imaging" [Medical Specialty, practicing for 8 y]
Provider concerns	Concerns providers have toward a hypothetical risk stratification tool. This includes concerns about the tool's generalizability, accuracy, and validity.	• "I'd have to trust the model and have to trust the data that is going into it to make sure I would be convinced that the information would be helpful to me" [Medical Specialty, practicing for 15 y] • "I think a computer-generated model will certainly have more pitfalls in poor and less fortified areas. You're going to have a lot of data for the rich folks and not so much data on the poor folks. This might be a serious social justice element to that – who gets screened for cancer, people who can afford a house in Palo Alto? If you live in Nevada, maybe not so." [Interventional Specialty, practicing for 10 y]
Views on false positives versus false negatives	Provider views on which error (type I or type II) they would choose between in a model setting.	• "The repercussions of missed opportunity to diagnose recurrence earlier is worse than the risk of overtreating" [Interventional Specialty, practicing for 14 y] • "Could do some Markov modeling to see ideal threshold. There could be downsides to over biopsying benign things. I would err on the side of flagging people" [Medical Specialty, practicing for 4 y]

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Overarching theme and subcategory	Definition	Representative quotes
Provider concerns about delivery of risk stratification data to patients	Providers' concerns about how patients would receive the risk stratification data.	• "Making sure that they understand the importance of coming back for their scans regularly" [Interventional Specialty, practicing for 5 y] • "I think it would be valuable to speak to that patient about the risk of radiation, risk of recurrence of cancer, and really put the numbers in front of them" [Interventional Specialty, practicing for 10 y]

Factors That Influence Clinical Decision Making

There are a multitude of factors that providers consider that can influence their clinical decision making, falling into 2 categories, clinical factors (patient risk factors and guidelines) and nonclinical factors (patients' social factors; Figure 1).

Figure 1. Factors that influence provider decisions on surveillance. This figure describes a summary of the factors mentioned that influence provider decisions on lung cancer surveillance. The first row of headings is different overarching groups of factors. Following each heading ("patient risk factors," "guidelines," and "patient social factors") are arrows pointing to further specific categories under the respective headings. For the "patient risk factors" and "patient social factors" sections, there is a second set of arrows that are pointing to specific examples of factors that were noted by the participants.
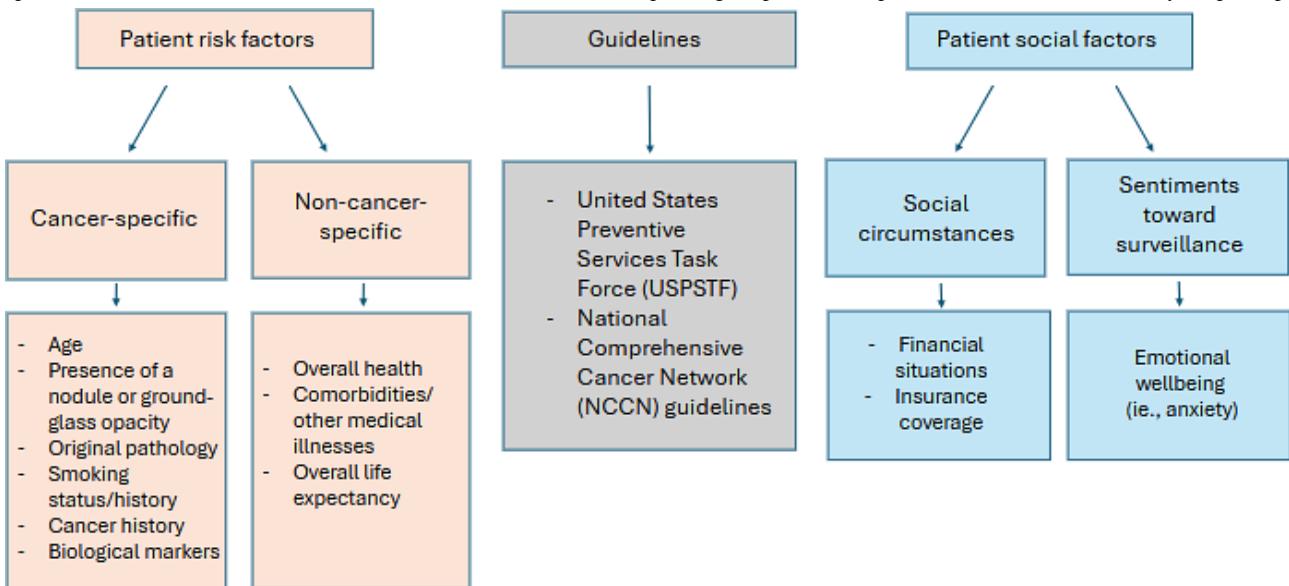
Clinical Factors (Patient Risk Factors and Guidelines)

When providers were asked about what factors they consider for surveillance, they first mentioned cancer-specific factors (patient's age, presence of a nodule or ground-glass opacity, original pathology, smoking status and history, and medical history). They also explained that they consider cancer history (stage of cancer, history of lung cancer, family history of cancer, and time from treatment) as well as biological markers (presence of mutations, molecular markers, and lymph node status) when considering surveillance for a specific patient.

Besides these factors, they also described how they consider guidelines and published data. Many providers mention a 5-year cutoff for surveillance unless there is a presence of a nodule, while others stated they screen every year indefinitely. The United States Preventive Services Task Force and National Comprehensive Cancer Network guidelines were mentioned as resources they use as well. When asked if they currently use a risk stratification tool for risk of recurrence and/or SPLC, the providers denied using one.

Beyond the guidelines and published data, providers listed other non–cancer-specific clinical factors, such as the patient's overall health, comorbidities, other medical illnesses, and overall life expectancy. One provider expressed how:

> ...with older people over the age of 75, they have competing risks. Not just their lung cancer recurrence but also dying from other causes so we certainly take that in account and a patient's ability to continue coming in. It's really a shared decision making with the patient. [P04]

One provider mentioned how they look at life expectancy tables to help decide if focusing on lung cancer surveillance is in the patient's best interest.

Nonclinical Factors (Socioeconomic and Patient Sentiments)

Factors such as patient social circumstances and patient sentiments toward surveillance were highlighted. One provider stated,

People have a certain bandwidth for their healthcare, and I think they should be able to put their energy on what specific condition they should focus on [ie, heart condition or diabetes]. [P01]

They explained that patients' factors, such as differing emotional capacities, financial situations, and insurance coverage, all play a role in their clinical judgment on whether surveillance is beneficial. For instance, it was mentioned,

I also tell them things like I don't know if their insurance will cover surveillance after five years and things like that and then generally if they want to, then I'll order the scan. [P08]

The provider explains that financial capability is also a part of the shared decision-making process in considering surveillance. Another provider described how they consider "healthcare spending [and] patients' bank accounts" (P10) as well.

Emotional well-being, particularly patient anxiety, was stated a few times. One provider explained how there's "still a lot of anxiety result[ing] from living as a cancer survivor" (P07). They noted there are significant emotional challenges that patients face as survivors of lung cancer and expressed great caution with how they bring up the topic of risk of recurrence and/or SPLC with their patients. One provider shared how "...many of them have anxieties, of course, some of them won't want the scans sooner and then some people don't want to know" (P11).

Another provider brought up a similar sentiment, stating:

There is a lot of anxiety about just having nodules knowing that one of them turned into a lung cancer group [in the past]. [P08]

The providers explained how this is a shared decision-making process with their patients, acknowledging patients' socioeconomic and emotional bandwidths. One provider acknowledged that at times, they'll need to follow how the patient feels and stated:

If the patient decides that they don't want to do surveillance anymore then it is a discussion and then we will stop. [P11]

Sentiments Toward a Hypothetical Risk Stratification Tool

When asked about a hypothetical risk stratification tool that can use a patient's medical record to estimate a 5-year risk of recurrence and/or SPLC, providers were generally positive, but did express concerns surrounding a risk stratification tool (Figure 2).

Figure 2. Provider sentiments on a risk stratification tool. This figure describes a summary of the provider sentiments on a hypothetical risk stratification tool. The first row of headings is different overarching groups of sentiments. Following each heading ("positive sentiments," "concerns," and "delivery of risk stratification data") are arrows pointing to further explanations and examples of sentiments that were noted by the participants. For the "delivery of risk stratification data," the arrows are pointing to outcomes providers expressed concerns of in relation to how the risk stratification data is delivered to patients.
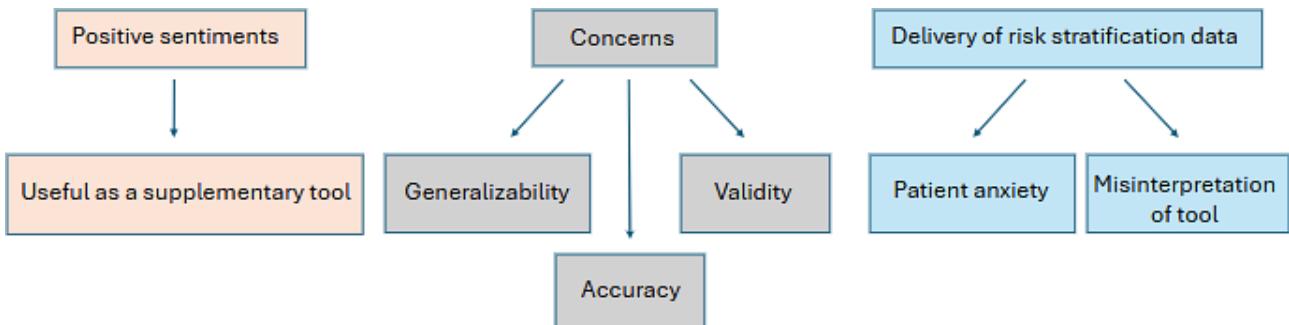
Positive Sentiments

Many providers expressed interest in the hypothetical risk stratification tool, especially its role in surveillance practices past the 5-year mark, which they consider the cutoff for surveillance in survivors of lung cancer without a nodule as it would be "useful for determining whether [they] should keep surveying after 5 years" (P08). Having a risk stratification tool could be beneficial for providers,

...because it gives [a] concrete idea of the risk level and if it tells of a very low risk level, it can give some confidence in doing less surveillance imaging. [P10]

While these providers expressed positive attitudes toward this hypothetical risk stratification tool, the majority stated that although it could be useful as a supplementary tool to clinical decision making, they would not rely solely on it due to various concerns outlined below.

Provider Concerns

Many providers expressed concerns about the generalizability, accuracy, and validity of the tool. They questioned the data the model would be using, with 1 provider suggesting:

...[they would] have to trust the data that is going into it to make sure [they] could be convinced that the information would be helpful. [P13]

They expressed hesitancies if a tool could consider all the factors they consider and how representative of the patient population the data would be.

Regarding generalizability, 1 provider mentioned the potential shortcoming in the data surrounding socioeconomic status, stating:

...[the] model will certainly have more pitfalls in poor and less fortified areas. You're going to have a lot of data for the rich folks and not so much data for poor folks. That might be a serious social justice element

to that – who gets screened for cancer, people who can afford a house in Palo Alto? If you live in Nevada, maybe not so. [P02]

Not only that, underrepresentation of racial and gender disparities was also highlighted as a concern, with 1 provider expressing that,

...[they] worry a bit about racial or gender disparities in terms of information that models are given and whether that will actually apply to all patients. [P08]

Due to the concerns that the data may not be representative and comprehensive enough, the providers suggested that the model may not be generalizable to their patients and thus may not be a tool they can fully rely on in their clinical decision-making.

Concerns with the accuracy and validity of the input data for the tool were also shared. A participant explained,

...as you do this [with] large amounts of data, things that might not be apparent otherwise can come forward. That's where we have the challenge of, is it really there or is it not really there, but you know you're not going to have most people though there will be some who ask about all those little details. [P07]

Other concerns providers highlighted were the limitations of relying on data from electronic medical records. A provider stated that "there is lots of variability in the patient data like the dates of diagnoses" (P09) and how "the date of diagnosis is not discrete and consistent" (P09). One provider illustrated that,

...many patients have incomplete follow-up and survival data which could bias your observed outcomes and could result in an inaccurate model. [P10]

Therefore, instead of being a primary tool to depend on, the providers emphasized that this tool should have a "disclaimer that of course [is] not predictive" (P12) of whether a patient has a recurrence and/or SPLC and should be used as a supplementary check.

Views on False Positives Versus False Negatives

Providers also discussed their perspectives on false positives and false negatives in a tool, with most providers preferring a model threshold that errs on the side of more false positives. One provider explained,

The repercussions of missed opportunity to diagnose recurrence earlier is worse than the risk of overtreating. [P03]

Other providers, while still agreeing that false positives were better than false negatives, shared that there should be "some Markov modeling to see [an] ideal threshold" (P06) to help minimize the difference. Many providers illustrated that this approach of more false positives would be useful in flagging patients and then verifying if the finding is accurate, but false positives would falsely worry patients who did not have lung cancer, and that "there could be downsides to over biopsying benign things" (P06).

Delivery of Risk Stratification Data to Patients

When asked whether patients should directly receive the risk stratification tool data, most of the providers emphasized that patients should not directly receive it due to the potential for misinterpreting the numbers and developing anxiety about their health status. Many of the providers explained that they generally do not give quantitative values involving risk prediction as they want to avoid worrying their patients. They also worry that if they gave specific numbers, it would not truly resonate with the patient, as they would not understand the numbers in depth. One provider puts it as sharing enough in "making sure that they understand the importance of coming back for their scans regularly" (P08). There were a few providers who stated that they would share exact numbers to patients if the patients pushed for those numbers or used the numbers "...to speak to that patient about the risk of radiation, risk of recurrence of cancer, and really put the numbers in front of them" (P02).

Discussion

Principal Findings

This qualitative pilot study interviewed specialists from 2 medical systems about their current practices surrounding surveillance for risk of recurrence and/or SPLC, their attitudes toward a hypothetical risk stratification tool, and how they would deliver risk stratification data to their patients. Surveillance decisions were found to incorporate diverse clinical and nonclinical factors beyond current guidelines, which may explain variability in imaging receipt observed in population-based studies [15]. While participants showed interest in risk stratification tools to systematize decision-making, they raised concerns about the tool's generalizability, accuracy, validity, and content delivery. These concerns highlight key areas for future tool and intervention development. These pilot findings will also inform the development of a future national survey study of physician attitudes and perspectives of an adapted risk stratification tool for SPLC and lung cancer surveillance.

Providers emphasized how their surveillance plans go beyond following current guidelines, incorporating both clinical and nonclinical risk factors. They consider patients' overall well-being, comorbidities, and sentiments toward surveillance, tailoring efforts to reduce adverse outcomes, such as complications or reduced quality of life [7,8]. Most participants highlighted the importance of shared decision-making, which has been shown to improve knowledge surrounding lung cancer screening and be positively associated with intentions to go through screening again [16]. This personalized approach allows providers to create comprehensive patient-centered surveillance plans.

With innovations, such as computer models and artificial intelligence (AI) in cancer care, understanding provider acceptance and opinions toward a computer-generated risk stratification tool is important [17]. This feedback provides risk stratification tool developers with the necessary elements and concerns clinicians are likely to have. Given the complexity of factors in lung cancer recurrence and SPLC, such models could

guide and standardize surveillance by identifying high-risk patients while reducing unnecessary low-dose computed tomography scans for low-risk individuals.

Providers expressed interest in a hypothetical risk stratification tool for improving clinical care, but stated it was not robust enough to be used independently and emphasized they trust their clinical intuition above all. They viewed it as a supplemental tool that could provide additional validation to their clinical decision-making, citing limitations such as the data quality and model accuracy. Providers emphasized the importance of inclusive input data, particularly for underrepresented groups based on income, race, and gender. This has been shown to be a significant barrier to the widespread adoption of AI models in cancer care [18]. Accuracy concerns were also raised, such as overestimating risk in low-risk individuals or failing to identify high-risk patients. Given these limitations, most providers viewed such tools as secondary to clinical intuition. They stressed that the tool's output should not drive decisions independently, and that providers should understand the input factors and rely on their expertise to override the tool if inaccuracies arise.

Delivery of risk information was another key concern. Most providers indicated that they would avoid sharing exact risk stratification numbers with their patients, citing concerns about potential misinterpretation and anxiety. Studies have shown that patients with cancer already have scan-associated anxiety, and adding to this underlying anxiety could negatively influence their adherence to getting necessary surveillance scans [19,20]. Instead, providers have suggested that they could use the risk stratification tool to initiate conversations about risk without focusing on specific numbers. These sentiments from providers shed light on the importance of considering how patients will receive risk stratification tool information before sharing it, and in response, sharing enough information to ensure that the patient can continue to pursue the best care in a well-informed manner. Although providers viewed this tool as supplementary, they agreed that it could be a helpful double-check for their own clinical judgment and prompt alternative surveillance strategies, such as adjusting scan frequency. Ultimately, providers emphasized that with a tool or not, their goal for patients is to adhere to the most clinically accurate and effective plan to prevent recurrence and/or SPLC.

Limitations

First, the small sample size limits the transferability of findings to lung cancer survivorship specialists nationwide. However, as a pilot study, it gathered perspectives across various settings, including academia, the VA, and satellite clinics, which may have broadened the findings beyond a single clinic or hospital. Nonetheless, these results will inform our planned national study, which will produce more transferable findings. Second, participants were from an affluent, research-focused region, and providers may be more receptive to technology and innovation than those at other locations. This initial pilot study was also limited by recruitment reach. Future work would benefit from the inclusion of a more diverse group of lung cancer providers from various geographic locations, institutions, and hospital settings across the United States, particularly those in rural areas where access to new technology and innovation may be limited or less emphasized. Third, some participants knew the PI before interviews, given her role as a thoracic oncologist, and some participants had previous exposure to SPLC risk stratification tools. Due to narrow eligibility criteria and the interconnectedness of these 2 health care systems, this was inevitable and had the potential to impact study participants' responses. Future work will gather perspectives from a national sample of providers to broaden findings and make them more transferable. Fourth, providers' perceptions were reported based on a hypothetical tool, rather than one they have used or trialed, limiting the applicability of findings. While the hypothetical risk stratification tool concept was explained to providers and some had previous knowledge of risk stratification tools, participants were still inferring what the tool could or could not do. Future work should provide a detailed explanation of a developed risk stratification tool, outlining its exact functionality within surveillance.

Conclusions

This study illustrates the complexity of lung cancer surveillance decision-making, which may contribute to variability in surveillance imaging among survivors. While risk stratification offers a systematic approach to guide decisions, uptake is limited by concerns about data quality, tool accuracy, and delivery and applicability to individual patients. Addressing these issues can inform the development and implementation of more acceptable and effective risk stratification tools.

Data Availability

The full dataset cannot be made publicly available due to privacy concerns and restrictions imposed by our local institutional review board. For investigators with the appropriate authorizations within the Department of Veterans Affairs, requests for data access can be made to the corresponding author.

Authors' Contributions

Conceptualization: JMW, JTW
Data curation: JMW, JTW, SC
Formal analysis: JMW, JTW, SC, CG
Funding acquisition: JTW, SA
Investigation: JMW, JTW, SC
Methodology: JMW, JTW
Project administration: JMW, JTW, SC
Resources: JTW, SA
Supervision: JTW, CG, SA
Visualization: JMW, SC, JTW
Writing – original draft: JMW, JTW, SC
Writing – review & editing: All authors.

Conflicts of Interest

SA is a consultant for Gore Medical and Novartis. All other authors have no potential conflicts of interest to disclose.

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Abbreviations:

AI: artificial intelligence
SPLC: second primary lung cancer
SPLC-RAT: Second Primary Lung Cancer–Risk Assessment Tool
VA: Veterans Affairs

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Letter to the Editor

Adapting Interventions for Home Hospice Caregivers Using Digital Health Innovation

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The recent meta-synthesis by Deng et al [1] on the experiences of family caregivers in home-based cancer hospice care was read with great interest. The authors presented a precise summary of their needs and perceptions and, in doing so, highlighted a critical gap in tailored interventions for supporting this vulnerable group. This is a gap that warrants further consideration.

This gap, while concerning, is understandable. The time and physical confinement inherent in home hospice care limit caregivers' ability to participate in research or access traditional in-person support. Deng et al's [1] review emphasized the dual challenges of this role: the immense burden of being "physically and emotionally present" and the critical need for "sharing responsibility" with palliative care teams, community partners, and family. While this shared support makes caregivers feel less isolated, the home hospice care setting creates logistical barriers to effective collaboration. To make this sharing of responsibility more accessible for home hospice caregivers, we should leverage innovative technology to connect the caregivers with their external support network. This is where we can adopt proven therapies like mindfulness-based stress reduction, delivering them through flexible digital methods that fit the specific constraints of the home hospice setting.

Encouragingly, some recent studies have validated this approach. For example, a pilot study using virtual reality demonstrated that technology can provide homebound caregivers with much-needed individual psychological respite through immersive nature scenes [2]. On a larger scale, a randomized controlled trial of the "Symptom Care at Home" intervention proved that an automated digital coaching system could significantly reduce caregiver burden by connecting them to their care team when symptoms escalated [3]. These studies illustrate the potential of novel ways of delivering support to overcome the practical barriers of home hospice care.

The work of Deng et al [1] should be a catalyst for action. To translate these promising findings into real-world practice, robust collaboration is essential for adapting and testing such interventions. An ideal model would involve researchers and developers co-designing digital tools with caregivers, an approach shown to improve the usability and adoption of digital health interventions [4]. This also calls for a partnership between hospice providers and community organizations to bring these tools into routine care, creating hybrid support models that combine scalable technology for both individual coping and shared care. Through such collaborative efforts, we can deliver interventions that truly empower caregivers to navigate one of life's most profound challenges.

Conflicts of Interest

None declared.

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Editorial Notice

The corresponding author of "Family Experiences, Needs, and Perceptions in Home-Based Hospice Care for Patients With Terminal Cancer: Meta-Synthesis and Systematic Review" declined to respond to this letter.

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Patient and Clinician Perspectives on Expanding Telehealth Use for Older Adults Across the Cancer Control Continuum: Mixed Methods Study

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Abstract

Background: Reliance on telehealth increased dramatically during the COVID-19 pandemic, introducing new opportunities to consider the use of telehealth across the cancer control continuum. However, patient, clinician, and staff perspectives about the types of cancer care appointments that are considered appropriate and the clinical care needs to support expanded remote care services are limited. Understanding older adults' diverse technology needs and perspectives is especially important given that they comprise a large and growing proportion of patients with cancer.

Objective: This study aimed to describe the perceptions and experiences of older patients with cancer and their clinical care team members regarding the expansion of telehealth use across the cancer control continuum and to solicit suggestions about how to support telehealth use for cancer care delivery.

Methods: Using a convergent mixed methods design, we surveyed and interviewed patients aged ≥60 years, clinicians, and staff at a comprehensive cancer center in the southern United States between December 2020 and November 2021. Interview questions were rooted in the sociotechnical model, which proposes 8 interrelated dimensions representing factors influencing the design, use, and outcomes associated with health information technologies. Patient survey domains included telehealth experience and satisfaction and factors affecting telehealth perceptions and use; clinician survey domains included contexts of telehealth appropriateness, training, and barriers and facilitators to telehealth service provision. Survey data were analyzed using descriptive statistics. Qualitative data were thematically analyzed using a combined deductive and inductive approach.

Results: We received completed surveys from 128 patients (567 invited) and 106 clinicians and staff (146 invited). We completed 14 patient (29 invited) and 20 clinician and staff (22 invited) interviews. Across all participants, most agreed or strongly agreed that multiple cancer care appointment types should be offered via telehealth, including discussing treatment side effects (75/102, 73.5% of patients and 66/94, 70.2% of clinicians and staff), results communication (71/102, 69.6% of patients and 65/94, 69.1% of clinicians and staff), and treatment follow-up (67/102, 65.7% of patients and 52/93, 55.9% of clinicians and staff). In interviews, participants elaborated on factors influencing the appropriateness of telehealth versus in-person appointments, including symptom severity, type of cancer, and purpose of the appointment. Many patient and staff suggestions focused on ways to address digital literacy gaps, while clinicians recommended improving clinic workflows, infrastructure, and training.

Conclusions: Overall, clinicians, staff, and older patients with cancer all responded positively toward expanding telehealth use across multiple cancer and appointment types across the cancer control continuum. Older adults with cancer are generally interested in telehealth for cancer care, especially if strategies to address digital literacy gaps are incorporated. Clinicians and staff members expressed specialized training and infrastructure needs to optimize telehealth uptake and service delivery.

KEYWORDS

telemedicine; video visits; remote technology; older adults; remote cancer care; cancer prevention; cancer treatment

Introduction

Synchronous video visits, or telehealth, have transformed the way cancer care is delivered, accelerated in large part due to the COVID-19 pandemic [1-4]. Avoiding infection due to COVID-19 was particularly important for patients with cancer, who were twice as likely to contract the SARS-CoV-2 virus and 8 times as likely to die from it compared to individuals without cancer [5,6]. In the pre-COVID era, telehealth services for patients with cancer primarily focused on the survivorship phase of the cancer control continuum [7-10] (see Figure 1), addressing issues like long-term monitoring and rehabilitation [11,12]. Among cancer survivors, telehealth had been shown to increase independence, convenience, quality of life, and patient satisfaction with care [13-16]. However, patient and clinician attitudes toward broader implementation of telehealth across other phases of the cancer control continuum, detection, diagnosis, and treatment, for example [17,18] are limited.

Figure 1. Cancer control continuum, adapted from the National Cancer Institute [17].
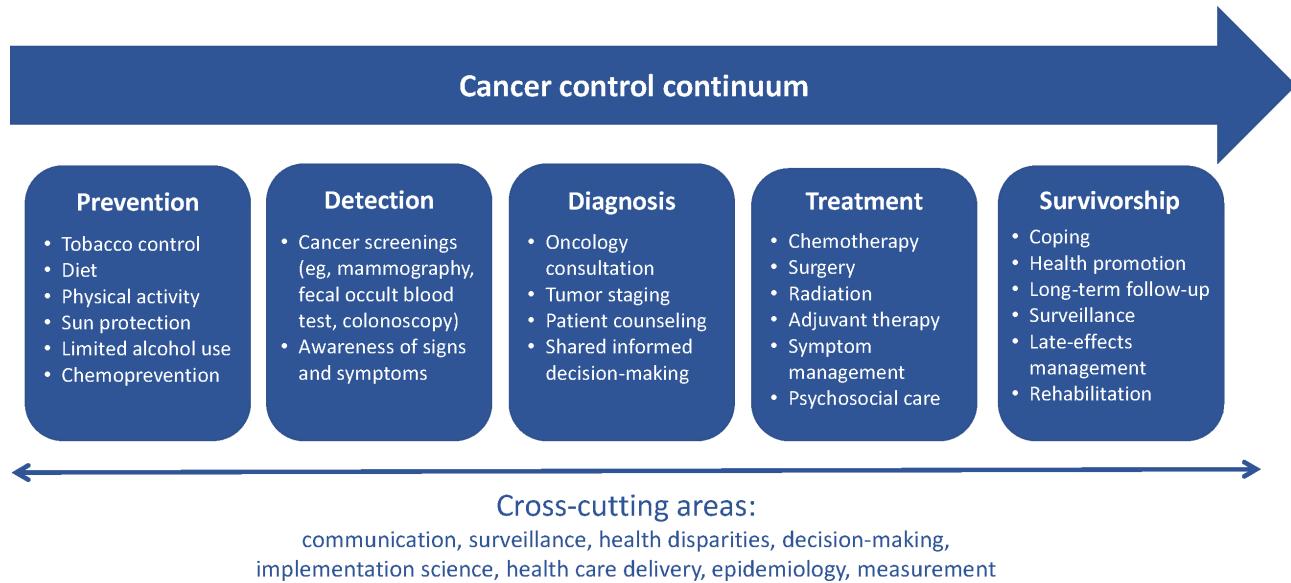
During the COVID pandemic, health care systems rapidly developed and deployed new remote care protocols and processes for patients across the cancer control continuum, with little time to assess patient and clinician needs and preferences. Cancer centers reported between 33% and 50% of patient visits occurring via telehealth, compared to rates formerly in the single digits [19]. Given that approximately 65% of cancer cases occur in patients aged 65 years and older [20,21], as well as the potential for this age demographic to face disparities in technology use, we had anticipated the need to examine the impact of the rapid expansion of telehealth on older patients specifically. Before the pandemic, a growing body of literature had begun to assess digital health literacy and technology preferences among older adults. Attitudes were diverse and multiple factors affected inequities in health literacy in addition to age, including socioeconomic status, level of education, and rural residence, particularly in the delivery of health care services [22-27]. The transition to telehealth use beyond the survivorship phase created an opportunity to understand shareholder perspectives on both the types of appointments and clinical needs that would be appropriate for remote care, and what could be done to bridge the digital health disparities facing older adults.

The objective of this study was to explore patients' and clinicians' pandemic-era experiences and perceptions of the appropriateness of telehealth expansion for different encounter types across the cancer control continuum. We also solicited suggestions for enhancing access to telehealth in the current era of increasing remote cancer care delivery.

Methods

Study Design

Using a convergent mixed methods design [28], we conducted surveys and semistructured interviews with patients, clinicians, and staff at a National Cancer Institute-designated comprehensive cancer center ("Cancer Center") located at a large academic medical center in the southern United States. We conducted a small number of interviews as a preliminary step to inform the question items and domains included on subsequent survey instruments and to capture participant perceptions and experiences in more depth than could be captured through surveys alone. Concurrently, we used surveys to measure the robustness of experiences and perceptions with a larger sample than could be accomplished in interviews.

Instrument Design

We selected survey domains by drawing on the literature and the sociotechnical model [29], which proposes 8 interrelated dimensions that represent the range of factors that can influence the design, use, and outcomes associated with health information technologies. The patient survey addressed a range of domains relevant to perceptions of and experiences with telehealth, including access and use, challenges encountered, perceived usefulness, and satisfaction. The clinician and staff survey similarly addressed a range of domains, including extent of experience with telehealth, perceived appropriateness of telehealth in different clinical contexts, training, and barriers and facilitators to use. In all, the patient survey comprised 89 unique questions and the clinician staff survey 124 unique questions, including Likert scale ratings, categorical items, and open-ended responses. We pilot tested the survey and interview guides with clients, caregivers of patients with cancer, and staff members of a local community-based organization for seniors in 4 focus groups prior to launching data collection. Their insights helped us optimize the content, wording, and length of instruments.

In addition to exploring some of the survey domains in greater depth, interview guides for clinicians and staff reflected their unique roles (eg, patient care, administrative leadership, and front-line clinical and administrative staff). Additionally, interviews with patients, clinicians, and staff included questions soliciting suggestions about how to improve telehealth services and the role of telehealth in cancer care in the future.

Sampling

Surveys

We sampled patients for surveys from the Adult Cancer Patient Registry at the Cancer Center (n=4037) (Multimedia Appendix 1). Eligible patients were ≥60 years of age, had completed at least one telehealth encounter since March 15, 2020 (approximately the start of the COVID-19 pandemic), were English- or Spanish-speaking, were open to contact for research through the portal, and were diagnosed and received treatment for breast, prostate, colorectal, and/or hematological cancer (in order to achieve a diverse sample by cancer type; n=2464). Of these individuals, we identified n=580 patients for survey recruitment, first stratified by cancer organ site in proportion with the Adult Cancer Patient Registry, then randomly selected within each organ category by date of telehealth appointment, age, gender, and race and ethnicity to achieve a diverse sample. We invited all employees across the Cancer Center to participate in the electronic survey.

Interviews

Patients recruited for semistructured interviews followed the same eligibility criteria as those for the survey but additionally were identified as being in active cancer treatment (defined as receiving chemotherapy, radiation, or being within 6 months postsurgery) at the time of recruitment. We also purposefully recruited 3 patients for interviews who met all criteria except that they had not completed a telehealth encounter in an effort to understand possible reasons for nonengagement or barriers to telehealth.

The primary investigators (RTH and TPH), who are nonphysicians with expertise in qualitative methods, worked with Cancer Center leaders and clinical co-investigators (SC and JM) to create a purposive sample of clinicians and staff given the diversity of cancer care services available. We jointly identified individuals with expertise across various organ sites (breast, colorectal, prostate, and heme), roles (medical oncologists, surgical oncologists, radiation oncologists, clinical staff, and administrative staff), and levels of telehealth proficiency.

Recruitment

Surveys

Because our objective was to survey patients who had completed telehealth appointments, and because telehealth appointments require the use of a patient portal account at the Cancer Center where we conducted our work, we first contacted patients through a messaging function within the patient portal with an invitation to complete the survey. Patients who did not respond to the portal message within one week were sent the same message to their personal email on file in the electronic health record. Those who did not respond to the first email inviting them to complete the survey, or who did not decline to participate, were sent a reminder email one week later, and those who did not respond to both emails within 2 weeks were sent an opt-out invitation letter by postal mail before they were called twice and offered the option to complete the survey by telephone, online through REDCap (Research Electronic Data Capture; Vanderbilt University; RRID:SCR_003445), or on paper via postal mail.

We recruited Cancer Center clinicians and staff via email for both surveys and interviews. The survey invitation included a link to take the survey in REDCap [30]. Clinicians and staff invited to participate in interviews were provided the option to schedule the interview via video conferencing or telephone. Two additional emails were sent if a survey response was not logged or if no reply was received to the interview invitation.

Interviews

Patients who completed a survey and who indicated in the survey a willingness to be contacted for interview participation were in turn recruited for interviews. We conducted semistructured telephone interviews with 14 patients, 11 of whom completed at least one telehealth appointment since March 15, 2020; we also purposefully recruited 3 patients who had never completed a telehealth appointment to provide contrasting perspectives. Patients who had completed telehealth appointments were recruited the same way as survey participants. The 3 patients who did not complete a telehealth appointment were mailed an opt-out letter, then contacted by phone. Up to two attempts were made to contact each of these participants.

Data Collection

Surveys

We conducted patient surveys between July and October 2021 and clinician and staff surveys between April and June 2021. Patient surveys took approximately 20 minutes to complete,

while clinician and staff surveys took approximately 10 minutes to complete.

Interviews

We conducted patient interviews between August and November 2021 and clinician and staff interviews between December 2020 and September 2021. Patient interviews lasted 24‐78 minutes (average 51 minutes) and were conducted via telephone in English or Spanish by bilingual, qualitatively trained nonphysician research staff (RTH and Ana Belen Conrado). Clinician and staff interviews lasted 29‐54 minutes (average 41 minutes) and were conducted via telephone or videoconferencing per individual preference by nonphysician investigators (RTH and TPH). Interviewers recorded brief field notes following each interview, which were reviewed and discussed in weekly meetings with members of the research team to determine when thematic saturation had been reached and thus data collection ended.

Data Analysis

Survey data were analyzed using descriptive statistics. Audio-recorded interviews were transcribed by a professional vendor and data were managed using NVivo 12.0 (QSR International; RRID:SCR_014802). Interviews were analyzed using a thematic content analysis approach. Two qualitatively trained researchers (RTH) first developed an initial, deductively driven codebook corresponding to the semistructured interview guide domains and sociotechnical model. They jointly coded the first 20% of transcripts, sampling from a diverse set of clinician and staff roles to refine codebook definitions and add and define codes as needed based on emergent findings. The codebook was then finalized, and researchers independently coded the remaining 80% of transcripts, meeting weekly to resolve discrepancies. The lead qualitative analyst (RTH) then reviewed thematic code reports and selected representative quotes and findings for discussion and interpretation with the research team. In line with our mixed methods design, to assess areas of convergence between the survey and interview findings, the team used a joint display approach [31] to systematically integrate findings from the interviews corresponding to survey questions that we had chosen to explore in greater depth (eg, preferences for appointment type, perceptions of the telehealth implementation process, and training or preparedness for telehealth use).

We engaged the Cancer Center leaders and clinical co-investigators in 2 small group meetings to review the data and discuss their interpretations of the findings.

Ethical Considerations

This study was approved by the Institutional Review Board at the University of Texas Southwestern Medical Center. All participants provided verbal informed consent to participate in interviews in accordance with the approved protocol (STU 2020‐0919). Participants who completed the survey received a $10 gift card. All patients who completed an interview received a $20 gift card. Clinicians and staff did not receive remuneration per institutional policy. Consent included recognition that identifiable information about participants would not be included in any publications or reports resulting from the research.

Results

Overview

Of 567 patients and 146 clinicians and staff invited to participate in the survey, 128 patients (23% recruitment rate) and 106 clinicians and staff (73% recruitment rate) completed the survey. For interviews, we contacted 29 patients who completed the survey and had indicated they were willing to be contacted for interviews; 3 people were unavailable after the maximum 3 attempted calls, 12 declined to participate ("not interested after all"), and 14 patients consented and were interviewed. We invited 22 clinicians and staff to participate in interviews; 2 did not respond, and 20 consented and participated in an interview. Demographic characteristics of survey and interview participants are shown in Table 1.

The qualitative and quantitative findings converged across multiple domains. In this analysis, we focus on two principal thematic findings: (1) agreement in patients' and clinicians' openness toward expanding cancer care via telehealth beyond the survivorship phase of the cancer control continuum, and (2) comparison between patients' and clinicians' recommendations about how to enhance telehealth in the future. Representative quotes from semistructured interviews are documented by theme in Multimedia Appendix 2.

Table . Demographics of patient and clinician and staff survey and interview participants.

Total	Patient surveys (n=131), n (%)	Clinician and staff surveys (n=106), n (%)	Patient interviews (n=14), n (%)	Clinician and staff interviews (n=20), n (%)
Gender				
Women	55 (42)	57 (54)	7 (50)	10 (50)
Men	61 (47)	14 (13)	7 (50)	10 (50)
No response	15 (11)	35 (33)	0 (0)	0 (0)
Age (years)				
60‑69	55 (42)	__[a]	__[b]	__[a]
70‑79	50 (38)	__[a]	__[b]	__[a]
≥80	12 (9)	__[a]	__[b]	__[a]
≤35	__[a]	23 (22)	__[b]	2 (10)
36‑45	__[a]	25 (24)	__[b]	7 (35)
46‑55	__[a]	11 (10)	__[b]	4 (20)
56‑65	__[a]	11 (10)	__[b]	3 (15)
≥66	__[a]	2 (2)	__[b]	3 (15)
No response	14 (11)	34 (32)	__[b]	1 (5)
Race or ethnicity				
Asian	3 (2)	8 (8)	0 (0)	4 (20)
Black	10 (8)	4 (4)	2 (14)	1 (5)
Hispanic	9 (7)	11 (10)	0 (0)	2 (10)
White	93 (71)	43 (41)	12 (86)	12 (60)
Two or more race or ethnicity	2 (2)	3 (3)	0 (0)	1 (5)
Other	0 (0)	1 (1)	0 (0)	0 (0)
No response	14 (11)	36 (34)	0 (0)	0 (0)
Language				
English	117 (89)	106 (100)	14 (100)	20 (100)
Spanish	1 (1)	0 (0)	0 (0)	0 (0)
No response	13 (10)	0 (0)	0 (0)	0 (0)
Driving time from home to Cancer Center				
<15 minutes	4 (3)	__[a]	__[a]	__[a]
15‑30 minutes	38 (29)	__[a]	__[a]	__[a]
31‑59 minutes	49 (37)	__[a]	__[a]	__[a]
1‑2 hours	18 (14)	__[a]	__[a]	__[a]
>2 hours	8 (6)	__[a]	__[a]	__[a]
No response	14 (11)	__[a]	__[a]	__[a]
Role				
Administrative managers	__[a]	3 (3)	__[a]	3 (15)
Administrative staff (eg, Medical Office Assistant)	__[a]	8 (8)	__[a]	2 (10)

Total	Patient surveys (n=131), n (%)	Clinician and staff surveys (n=106), n (%)	Patient interviews (n=14), n (%)	Clinician and staff interviews (n=20), n (%)
Clinical staff (eg, Clinical Staff Assistant, Dietician)	__[a]	6 (6)	__[a]	1 (5)
Clinicians (eg, MD, NP, PA, Psychologist)	__[a]	26 (25)	__[a]	13 (65)
Nurse (RN, LVN)	__[a]	32 (30)	__[a]	1 (5)
No response	__[a]	31 (29)	__[a]	0 (0)

[a]Not applicable.

[b]Not available.

Theme #1: Perceptions Toward Expanding Telehealth to Other Phases of the Cancer Control Continuum

Patients

Both patient and clinician and staff participants responded positively toward questions about the future use of telehealth during other phases of the cancer control continuum. A majority of surveyed patients indicated they would be "willing to have a video visit with a member of their cancer care team" for discussing treatment side effects (75/102, 73.5%), results communication (71/102, 69.6%), and treatment follow-up (67/102, 65.7%), as shown in Table 2. Of note, less than 6% (6/102) of our sample indicated that telehealth should not be used for any types of cancer care appointments.

Table . Patient perceptions regarding appointment types for which telehealth should be offered (n=102).

Appointment type (check all that apply)	Value, n (%)
Discussing treatment side effects	75 (73.5)
Results communication	71 (69.6)
Treatment follow-up	67 (65.7)
New treatment planning	48 (47.1)
Routine check-up	32 (31.4)
Planning the end of cancer treatment	32 (31.4)
Postoperative surgical follow-up	28 (27.5)
Genetic counseling	26 (25.5)
Physical evaluation	13 (12.7)
None	6 (5.9)
Other appointments	3 (2.9)
Total	102 (100)

In semistructured interviews, patients cited various reasons why they would feel comfortable having certain types of appointments via telehealth versus in-person, including how they were feeling physically, whether the appointment was routine, whether they had extensive questions, or whether the appointment was with a new clinician. Patients also mentioned that, regardless of appointment type, telehealth was often a convenient option for purely logistical reasons. Some had small children, others had mobility impairments, and still others noted that an easy public transportation system was unavailable to them.

Clinicians and Staff

Clinician and staff survey findings mostly mirrored patients', but there was recognition of the potential role for telehealth in an even greater range of appointment types. A majority of clinicians and staff felt telehealth should "definitely" be offered for discussing treatment side effects (66/94, 70.2%), results communication (65/94, 69.1%), genetic counseling (63/94, 66.7%), routine check-ups (61/94, 64.9%), and treatment follow-up (52/93, 55.9%), as shown in Figure 2.

In semistructured interviews, clinicians elaborated on the multiple considerations that would determine whether they would offer a telehealth versus in-person appointment. One clinician felt that appointments scheduled to discuss laboratory results were an appropriate opportunity to use telehealth because the primary purpose of such appointments is to support conversation as opposed to gathering more laboratory data or providing other treatment. Similarly, another clinician felt that patients on infusion could be followed adequately via telehealth appointments, provided they are in a stable place with their treatment.

Some clinicians indicated that the appropriateness of telehealth depended on the type of cancer the patient has. A urology oncologist commented that telehealth was appropriate for his patients with prostate cancer, whose treatment comprised only hormone shots every 6 months. A hematologist noted there were varying circumstances in which patients with leukemia required in-person visits; lymph node checks required a physical exam, whereas discussing lab results did not.

Other factors included the complexity of a patient's care, with one clinician noting that the immediate perioperative period for surgical patients could influence the appropriateness of the modality of care delivery. Further, the stage of a patient's disease was also an important consideration in the eyes of some clinicians, with advanced-stage disease requiring more aggressive monitoring and treatment. Not surprisingly, a majority of clinicians felt physical exams still required in-person visits. One clinician, for example, noted that an in-person exam would be crucial when determining what type of breast surgery was most appropriate for a patient with breast cancer because the breast size, shape, tumor size, and tumor location all factored into her surgical strategy.

Figure 2. Clinician and staff perceptions regarding appointment types for which telehealth should be offered.
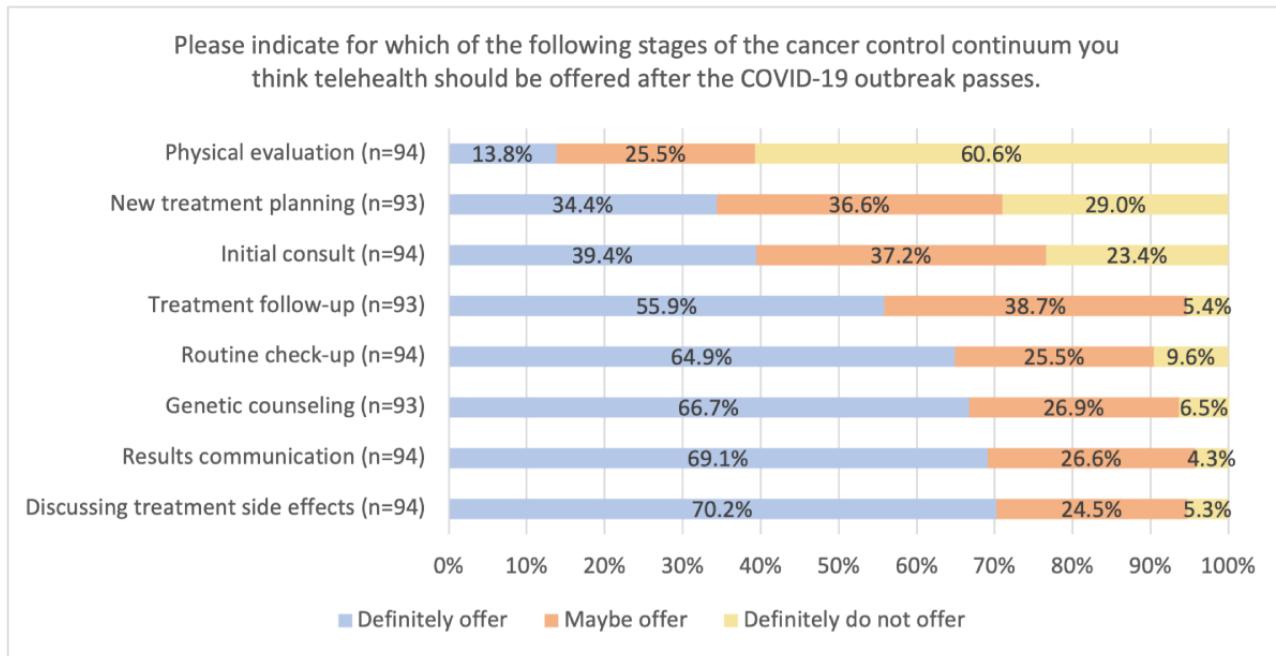
Theme #2: Suggestions to Enhance Remote Cancer Care in the Future

Patients

The Cancer Center dedicated significant resources to patient education and technical assistance during the COVID-19 pandemic to facilitate rapid conversion of patient appointments to telehealth. Surveyed approximately one year after the height of the pandemic, fewer than 20% of patients reported experiencing specific challenges with initiating or preparing for telehealth appointments. Specifically, 18% did not understand the video visit setup process, 19% did not feel it was easy to join the video visit session, and 17% did not have enough technical support. But while the vast majority (88%) of the surveyed patients felt sufficiently prepared for their telehealth appointment, less than a third (31%) of surveyed clinicians and staff agreed or strongly agreed that the Cancer Center did a good job of preparing patients for their first telehealth encounter.

Importantly, in semistructured interviews, patients still offered various suggestions about how telehealth care could be enhanced in the future. One participant recommended improving the quality of educational materials pertaining to telehealth, noting they often assume patients have better digital literacy than they actually do. Another patient felt that in-person education for older patients, particularly when initiating or preparing to use telehealth, would be helpful. One individual, who was initially opposed to having telehealth appointments before the pandemic but became a strong supporter of the technology after completing telehealth appointments during the pandemic, suggested offering testimonials to convince patients who may be apprehensive about trying telehealth.

Other patients indicated that telehealth appointments needed to be offered to patients on a more regular basis, acknowledging that they sometimes ask if telehealth is possible when scheduling.

Clinicians and Staff

Administrative leaders, clinicians, and front-line staff offered various suggestions based on the different challenges they faced and the telehealth workarounds they devised. During the early part of the pandemic, clinical and administrative staff were assigned to assist patients with initiating their telehealth appointments. This process involved first logging on through a patient's portal account, and during this step, some patients discovered problems with their portal login credentials. In such cases, knowing what level of familiarity patients already had with the portal was key to triaging a high volume of technical assistance requests. Other staff suggestions to assist patients with limited digital literacy included establishing "fake

appointments" for patients to practice online connections and hiring a dedicated employee like a digital health navigator to provide on-call technical assistance and setup of the online portal.

Whereas front-line staff suggestions tended to focus on digital literacy assistance for patients, clinician, and administrator suggestions tended to focus on the need to enhance workflows and infrastructure to improve privacy, efficiency, and clinician training. Multiple clinicians expressed the need for dedicated physical spaces with sufficient privacy for them to conduct telehealth appointments. From a technical standpoint, some clinicians noted that it would also greatly improve efficiency to implement consenting for surgical procedures and clinical trials via telehealth. Some clinicians felt that additional training was needed, for example, to show patients images over telehealth using the "share screen" function.

Despite the challenges they experienced, a majority of both patients (65.7%) and clinician and staff (76.9%) survey respondents reported that they intended to continue using telehealth in the postpandemic era.

Discussion

Principal Findings

In this mixed methods study, patients, clinicians, and staff reported an openness toward expanding telehealth-based cancer care across the cancer control continuum. Participants recognized that some situations still favored in-person visits, including appointments in which a physical exam would be necessary and appointments for patients who required more aggressive surveillance due to the stage of their disease. However, both patients and clinicians agreed that telehealth would be convenient and efficient for appointments to discuss treatment side effects, lab results, and treatment follow-up. Clinicians also noted that genetic counseling and consenting patients for surgery or clinical trials could be effectively performed over telehealth. Participants also offered multiple recommendations for health care systems to establish the infrastructure to support these specific opportunities for telehealth-based cancer care delivery.

Comparison to Prior Work

Despite the reported willingness of older patients to engage in telehealth, literature indicates that older adults are often offered telehealth appointments and patient portal registration at lower rates than younger patients, partly due to health care clinicians' assumptions that older patients may be less interested in or capable of using digital health tools [32-34]. Such assumptions can inadvertently limit older patients' access to telehealth, even though many are both willing and able to engage with these technologies when provided adequate support. Such ageist biases highlight the need for intentional strategies to encourage telehealth use among older adults, ensuring that they are not inadvertently excluded from the potential benefits of the technology. Further, given that approximately 65% of cancer cases occur among patients aged 65 years and older [20,21], addressing such inequities among older patients could expand the role of telehealth in cancer care.

Several strategies to improve digital engagement for older adults may serve to address inequities in telehealth service delivery and outcomes for older adults [22-24]. These include technical modifications in portal interfaces to simplify the sign-in process, changes to size or color of text or icons, and incorporation of more pictures as opposed to text, which may improve user experience and capability [35,36]. Other recommendations include patient portal adoption campaigns targeting older adults, task-specific training, support for proxy users, challenging assumptions about older adults and technology, and alternative workflows to allow for communication between patients and personnel to review personal health information within patient portals [22,37]. Clinical and administrative staff may benefit from having policies and procedural guidance detailing when and for whom telehealth appointments should be offered.

Our findings contribute evidence that educational materials must be tailored to older adults or other patients with lower digital health literacy, such as through in-person educational sessions and testimonials from those who have benefited from telehealth. Clinicians and staff on our study also suggested the idea of establishing "fake appointments" for patients to practice using telehealth interfaces and hiring a dedicated employee such as a digital health navigator for technical assistance. The use of digital navigators—trained individuals who assist patients in accessing and using digital health resources—has been found to be effective in enhancing digital literacy and reducing barriers to telehealth access, especially for socioeconomically disadvantaged populations [38-41]. These programs could be particularly beneficial for older adults with cancer, who may face additional challenges due to their complex care needs.

Increasing the use of telehealth for older adults with cancer has the potential to increase independence, patient satisfaction, and quality of life [13-16,42-44]. Studies have found that older adults who learned to use new technology were over twice as likely to adopt telehealth during the pandemic compared to those who did not [45]. In light of the "gray tsunami" phenomenon, where an increasing number of older adults are anticipated to require health care services, and the overwhelming burden of cancer among patients aged 65 years and older [20,21], it is important to recognize the urgency of addressing digital health literacy to minimize health disparities.

Strength and Limitations

This study has several limitations that impact the potential transferability of our findings to other settings. First, the sample was drawn from a single Cancer Center, with most participants being White and English-speaking, thereby limiting applicability to more diverse populations. Second, data collection for this study occurred during the latter half of 2021, and as such, should be considered within the context of the COVID-19 pandemic. Third, attitudes toward patient portals and telehealth use were evolving during the pandemic, and remote cancer care delivery was a necessity for some patients with cancer during this time. Fourth, by recruiting participants through the portal to sample patients who could adequately comment on telehealth experiences, we may have introduced a bias toward patients who are already more technologically proficient or feel positively about telehealth. This may have limited insights into

the experiences of older adults with lower digital literacy, potentially underrepresenting the experiences of those with significant barriers or negative perceptions. Anticipating this limitation, we purposefully recruited 3 individuals without telehealth experience to participate in an interview; however, the small overall patient sample size may also be a limiting factor. Similarly, by recruiting our patient interview sample from our survey sample, we may have introduced a potential response bias toward the inclusion of individuals who felt strongly toward telehealth (positively or negatively). Our recruitment for clinician and staff interviews could also have introduced bias given our reliance on suggestions by our clinician co-investigators. Strengths of this study include its use of the sociotechnical model as a guiding framework for the instrument design and analysis plan, and our inclusion of both patients and clinicians and staff. Finally, our approach of conducting a small number of targeted, preliminary clinician and staff interviews enabled us to assess the appropriateness and representativeness of our survey question items prior to launching our full surveys with patients and other clinicians and staff.

Future Directions

If telehealth expands across the cancer control continuum, it will be critical that health care organizations prioritize digital equity and inclusion of populations with lower digital literacy. This includes racial and ethnic minorities and older adults and their care partners, to ensure that the needs of these growing populations are adequately met and to provide a more balanced view of the challenges they may face. Future research would benefit from exploring the relative impacts of various interventions, such as digital navigator programs and tailored educational materials, on telehealth engagement and health outcomes.

Conclusions

This study contributes new evidence that older patients and their clinical care members welcome the expansion of telehealth use across the cancer control continuum. This is an important finding given the fact that digital health technologies, including but not limited to synchronous telehealth visits, are already integral components of health care delivery. It suggests that, as the population ages, health care systems will have the potential to reach a greater share of their patients by enhancing access to cancer services through telehealth and other digital health technologies.

Data Availability

Data are presented in the main manuscript; additional data may be available upon reasonable request from the authors.

Authors' Contributions

RTH and TPH contributed to conceptualization and methodology. RTH, BE, SC, JCM, and TPH conducted the investigation. RTH, JL, and AZ drafted the original manuscript. All authors contributed to manuscript review and editing. RTH and TPH were responsible for funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey recruitment consort diagram.
[PDF File, 94 KB - cancer_v12i1e73058_app1.pdf]

Multimedia Appendix 2
Illustrative quotes from patients, clinicians, and staff.
[DOCX File, 18 KB - cancer_v12i1e73058_app2.docx]

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Checklist 1
GRAMMS checklist.
[DOCX File, 13 KB - cancer_v12i1e73058_app3.docx]

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Abbreviations

NCATS: National Center for Advancing Translational Sciences
REDCap: Research Electronic Data Capture

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Financial Toxicity of Hematologic Malignancy Therapies, Including Cellular Therapy and Its Impact on Access to Care: Prospective Pilot Study

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Abstract

Background: Patients with cancer often face significant financial challenges, known as financial toxicity (FT), which is associated with reduced quality of life. Patients with hematologic malignancies (HMs) are especially vulnerable due to intensive and prolonged treatments, frequent hospital visits, and a high risk of complications. While FT affects many in the general population, it is particularly severe among racial and ethnic minorities, especially those below the poverty line. To our knowledge, no studies have specifically examined FT in this vulnerable group in the United States.

Objective: This study aimed to evaluate the severity of FT in patients receiving treatment for HMs in a socioeconomically underserved population, explore sociodemographic factors that may predict the severity of FT, and evaluate the subjective experiences of these patients as they relate to FT.

Methods: We conducted a prospective, observational, longitudinal study at the Montefiore Cancer Center's outpatient department in the Bronx, New York, from October 1, 2022, to October 30, 2023. Participants included either adult patients newly diagnosed (ND) with HMs or those already diagnosed, undergoing cellular therapy (CT). The severity of FT was assessed using the validated Comprehensive Score for Financial Toxicity–Functional Assessment of Chronic Illness Therapy (COST-FACIT) questionnaire. Additionally, an investigator-designed questionnaire was developed to gather sociodemographic data and evaluate the subjective effects of financial burden on patient care. Patients in both the ND and CT groups were followed for 90 days. Data collection occurred at their initial presentation, as well as on days 30 and 90.

Results: Ninety patients participated in the study (ND=52 and CT=38). The median age was 59 (IQR 44-66) years, with 27% (n=24) African American and 55% (n=48) Hispanic. Overall, 75% (n=67) of participants experienced some degree of FT, most with mild FT at baseline (day 0, median COST-FACIT score=19.4). In the CT group, FT worsened significantly over time, with a decline in median COST-FACIT scores from 19.9 at day 0 to 15.5 on day 90 (P=.02). In a multivariable linear regression model, race and ethnicity were a significant predictor of FT burden: identifying as African American or Hispanic was associated with a significantly lower COST-FACIT score (ie, higher FT) compared to non-Hispanic White participants (B=−3.08, P=.04, 95% CI −6.05 to −0.12). Additionally, over half of ND and CT participants reported difficulty affording basic necessities (ND: 28/52, 54%; CT: 23/38, 61%) and concerns regarding transportation access and costs (ND: 26/50, 52%; CT: n=18/38, 47%).

Conclusions: FT is prevalent among patients with HMs receiving care in underserved populations, and the burden is significantly higher among African American and Hispanic populations.

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Introduction

Cancer continues to be a significant public health concern in the United States. According to the American Cancer Society, in 2022, there were nearly 2 million new cancer cases and over 600,000 cancer-related deaths in the United States [1]. Receiving a new cancer diagnosis brings untold physical, emotional, and psychological distress to the patient and their caregivers. Although survival rates of patients with cancer have improved over the years due to advances in diagnosis and treatment, the rising cost of cancer care has become a significant challenge for patients and their providers in the US health care system. Financial toxicity (FT) has emerged in oncologic care to describe the psychological, material, and behavioral hardships arising from the economic burden of cancer [2].

Indeed, several studies have reported a close association between FT and reduced quality of life, delays in seeking medical care, nonadherence with treatment, emotional and psychological distress, and reduced overall survival in patients with cancer [3-5]. The impact of FT is particularly pronounced in patients with hematologic malignancies (HMs) as they must deal with the high cost of therapy, especially with the shift from conventional chemotherapy to immunotherapy, multiple infusion visits, prolonged hospitalizations due to life-threatening presentations, long duration of intensive treatment, and treatment-related complications [6,7]. In 2014, the average cumulative costs of hematologic cancer care in the United States ranged from approximately US $200,000 for chronic leukemias to greater than US $800,000 for acute leukemias within the first 3 years of treatment. In comparison, the cost for lung cancer was around US $250,000 and that for colorectal cancer was approximately US $150,000 [8].

The severity of FT is also determined by the patient's sociodemographic and socioeconomic factors. Extremes of age, Black race, lower income level, limited ability to provide basic household needs, unemployment, and insurance status are associated with worse FT [2,9-11]. The factors associated with worse FT are predominant in households living below the federal poverty line. This population primarily comprises Native American, Black, and Hispanic individuals [11].

Despite growing attention to FT, most studies were conducted predominantly on the White population, who are often insured. To the best of our knowledge, no similar studies in the United States have specifically targeted racial and ethnic minorities with HM in underserved areas in the United States. This study aims to assess the severity of FT, examine relevant sociodemographic factors influencing FT, and explore the subjective experience of FT among patients with HMs.

This study was conducted in a large academic hospital in the Bronx, where more than 25% of the population lives below the federal poverty line [12].

Methods

Study Design and Setting

This prospective observational study was conducted over 12 months, from October 1, 2022, to October 30, 2023, at Montefiore Medical Center in Bronx, New York. The study took place in both outpatient and inpatient hematologic oncologic units of the Montefiore Cancer Center, a quaternary academic center serving a predominantly low-income, racially and ethnically diverse population.

Participant Eligibility and Recruitment

Eligible participants included adults over 18 years old with a HM (ie, acute or chronic leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, or multiple myeloma) who either received a new diagnosis or were being evaluated for cellular therapy (CT), such as autologous or allogeneic stem cell transplantation (SCT) or chimeric antigen receptor T-cell (CAR-T) therapy.

Patients were excluded if (1) they were being seen for conditions other than HMs, (2) they were seeking a second opinion after treatment at a different institution, (3) they presented after recurrence ineligible for autologous or allogeneic SCT and CAR-T therapy, (4) they were being evaluated for a second autologous SCT as part of tandem autologous transplantation or for recurrent myeloma, or (5) they lacked capacity or were non-English or non-Spanish speakers.

Recruitment took place during routine clinical visits and on the oncology floors. Eligible patients were identified by treating providers or study personnel and were invited to participate on a rolling basis. Participants were divided into two cohorts: (1) newly diagnosed (ND) and (2) undergoing CT (SCT or CAR-T).

Data Collection and Measurements

Data were collected in person at three time points: baseline (day 0), day 30, and day 90. At each time point, the participants completed two instruments:

1. Sociodemographic and Subjective Impact Questionnaire: The research team developed an investigator-designed, bilingual (English and Spanish) questionnaire to gather information on demographics (age, sex, race and ethnicity, income, education, employment, and insurance), cancer type, and subjective experience of financial burden, including effects on basic needs and access to care.
2. Comprehensive Score for Financial Toxicity–Functional Assessment of Chronic Illness Therapy: FT was assessed using the validated Comprehensive Score for Financial

Toxicity–Functional Assessment of Chronic Illness Therapy (COST-FACIT) tool [13]. It is categorized into grades 0 to 4, based on the level of FT severity, with scores ranging from 0 to 44. A score of 0 represents grade 0 or *severe toxicity*; 1‐13, grade 2 or *moderate toxicity*; 14‐25, grade 3 or *mild toxicity*; and >25, grade 4 or *no toxicity*. Hence, higher scores indicated less severe FT. The patients were assessed at three different time points: day 0, the initial visit time, day 30, and day 90.

Statistical Analysis

Data analysis was performed using SPSS version 29 (IBM Corp). Descriptive statistics summarized demographic characteristics and COST-FACIT scores. Frequencies and percentages were calculated for categorical variables, while medians and IQRs were used for continuous variables. Comparison of the severity of FT across the timelines was determined using the Friedman test. The Mann-Whitney *U* test and Kruskal-Wallis *H* test were used to examine significant differences in FT with respect to sociodemographic groups. Linear regression analysis identified sociodemographic predictors of FT. A two-tailed *P* value of <.05 was considered statistically significant. No adjustment for multiple comparisons was made due to the exploratory nature of the study.

Ethical Considerations

Study Approval

This study was conducted in accordance with ethical standards and received approval from the IRB at Albert Einstein College of Medicine and Montefiore Medical Center (approval number: IRB 2022‐13798, approval date: 09/13/2022). The research involved human participants and adhered to the principles outlined in the Declaration of Helsinki.

Informed Consent

The provider (MD or nursing practitioner) or study personnel obtained informed consent during the initial visit at the HM clinic or for auto/allo SCT and CAR-T evaluation. All participants gave written informed consent before enrollment. The consent process included explaining the study's objectives, procedures, risks, and benefits and the fact that participation is voluntary. For patients unable to give written consent, verbal consent was obtained in the presence of a trained research coordinator, per institutional policy.

Privacy and Confidentiality

All collected data were deidentified prior to analysis to protect participant confidentiality. Study data were stored in secure, password-protected databases accessible only to authorized personnel. No identifiable personal health information was used in any publication or presentation.

Compensation

Participants were not financially compensated for their involvement in this study.

Results

Sociodemographic Characteristics

Over a period of 12 months, we recruited 90 patients who met eligibility criteria and consented to the study. The sociodemographic characteristics of these participants are shown in Table 1. Fifty-two of 90 (57%) patients were ND, whereas the rest (n=38, 43%) were either currently receiving or preparing to receive CT. The median age was 59 (IQR 44-66) years. There were more male patients (n=56, 62%), 24 (27%) patients were African American, and more than half (n=48, 55%) were Hispanic. Over 60% (n=55, 63%) of the participants were not employed, and over a third (n=33, 37.1%) were on Medicaid. Regarding HMs, most patients had plasma cell dyscrasias (n=33, 37%) compared to other HMs.

Table . Sociodemographic characteristics.

Sociodemographic characteristics	Newly diagnosed group (n=52)	Cellular therapy group (n=38)	Total (n=90)
Age, median (IQR)	59 (42.5‐66.0)	58 (50.0‐67.0)	59 (43.5‐66.0)
Sex, n (%)			
Male	31 (60)	25 (66)	56 (62)
Female	21 (40)	13 (34)	34 (38)
Race, n (%)			
African American	15 (29)	8 (22)	24 (27)
Non-Hispanic White	6 (11)	8 (22)	14 (16)
Others	31 (60)	22 (56)	51 (57)
Ethnicity, n (%)			
Hispanic	28 (54)	20 (57)	48 (55)
Non-Hispanic	24 (46)	15 (43)	40 (45)
Employment status, n (%)			
Employed	21 (41)	11 (31)	32 (37)
Retired	13 (25)	9 (25)	22 (25)
On disability	9 (18)	8 (22)	17 (20)
Unemployed	8 (16)	8 (22)	16 (18)
Health insurance, n (%)			
Private	22 (43)	16 (42)	38 (43)
Medicare	10 (20)	8 (21)	18 (20)
Medicaid	19 (37)	14 (37)	33 (37)
Type of hematologic malignancy, n (%)			
Leukemias	21 (41)	10 (27)	31 (34)
Lymphomas	16 (31)	9 (24)	26 (29)
Plasma cell dyscrasias	14 (28)	18 (49)	33 (37)

Severity of Financial Toxicity Across Time

Overview

Table 2 and Figure 1 depict the median FT scores at various periods. Over 75% (n=67) of patients experienced some degree of FT, with a median COST score of 19.4 at baseline (day 0).

While the median COST score indicates mild FT, many patients experienced moderate FT at the individual level. The CT group demonstrated significant changes in FT scores over time (day 0: 19.9; day 30: 19.0; day 90: 15.5; *P*=.02). When comparing FT severity between the ND and CT groups, as shown in Table 3, no statistically significant differences were observed at any period (day 0: *P*=.88; day 30: *P*=.54; day 90: *P*=.75).

Table . Financial toxicity at days 0, 30, and 90.

Financial toxicity	Day 0	Day 30	Day 90	P value
Newly diagnosed group				
Number of patients, n	50	39	32	
Median FT[a] (IQR)	16.5 (8.9-27.5)	17.0 (9.5-21.0)	17.5 (9.0-27.0)	.85
Grade category n (%)				
No toxicity	11 (22)	7 (18)	9 (28)	
Mild toxicity	17 (34)	18 (46)	10 (31)	
Moderate toxicity	21 (42)	14 (36)	13 (41)	
Severe toxicity	1 (2)	0 (0)	0 (0)	
Cellular therapy group				
Number of patients, n	36	29	16	
Median FT (IQR)	19.9 (9.0-27.0)	19.0 (13.8-28.0)	15.5 (12.3-32.3)	.02
Grade category n (%)				
No toxicity	10 (28)	8 (28)	5 (31)	
Mild toxicity	11 (31)	14 (48)	4 (25)	
Moderate toxicity	15 (42)	7 (24)	5 (31)	
Severe toxicity	0 (0)	0 (0)	0 (0)	
Total population				
Number of patients, n	88	69	48	
Median FT (IQR)	19.4 (8.9-27.0)	18 (10.0-25.0)	17 (10.0-17.5)	.31
Grade category n (%)				
No toxicity	21 (24)	15 (22)	14 (30)	
Mild toxicity	29 (33)	33 (48)	14 (30)	
Moderate toxicity	36 (41)	21 (30)	18 (39)	
Severe toxicity	2 (2)	0 (0)	0 (0)	

[a]FT: financial toxicity.

Table . Comparison of financial toxicity between newly diagnosed and cellular therapy groups on days 0, 30, and 90.

Days	ND[a]	CT[b]	P value
Day 0			
Number of patients, n	50	37	
Median FT[c] (IQR)	16.5 (8.9-27.5)	19.9 (9.0-27.0)	.88
Day 30			
Number of patients	36	32	
Median FT (IQR)	17.0 (9.5-21.0)	19.0 (13.8-28.0)	.54
Day 90			
Number of patients	31	15	
Median FT (IQR)	17.5 (9.0-27.0)	15.5 (12.3-32.3)	.75

[a]ND: newly diagnosed.

[b]CT: cellular therapy.

[c]FT: financial toxicity.

Figure 1. Box-plot graph comparing COST-FACIT scores across the timelines for both groups. COST-FACIT: Comprehensive Score for Financial Toxicity–Functional Assessment of Chronic Illness Therapy; CT: cellular therapy; FT: financial toxicity; FT 0: FT score day 0; FT 30: FT score day 30; FT 90: FT score day 90; ND: newly diagnosed.
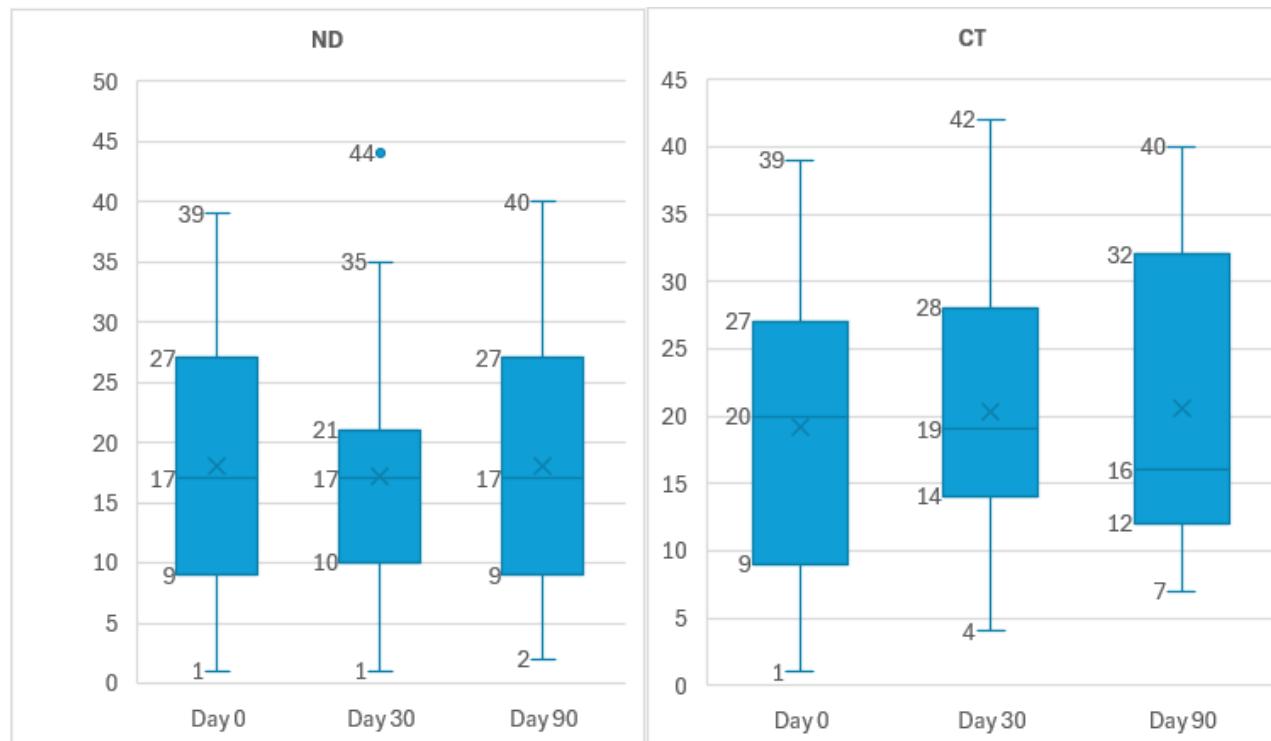
Financial Toxicity and Sociodemographic Factors

Table 4 summarizes the difference in FT by race and ethnicity, diagnosis, and employment status at day 0, day 30, and day 90. We examined the association between FT and sociodemographic factors such as race, ethnicity, type of HM, and employment status (employment status was recategorized as employed vs unemployed for ease of analysis). Differences in FT across racial groups were marginally significant, with White patients experiencing relatively milder FT at day 0 (median FT: 27.0 for White patients, 16.5 for African American patients, and 14.0 for other racial groups; P=.08) and at day 90 (median FT: 37.0 for White patients, 13.5 for African American patients, and 15.0 for other racial groups; P=.06).

Table . Difference in financial toxicity on days 0, 30, and 90.

Sociodemographics	Financial toxicity, median (IQR)		
	Day 0	Day 30	Day 90
Total cohort			
Race			
African American	16.5 (8.8-25.2)	18.0 (10.0-25.8)	13.5 (6.0-26.0)
White	27.0 (22.0-36.0)	20.6 (17.0-30.8)	37.0 (19.0-41.0)
Other	14.0 (8.9-24.1)	16.8 (10.5-21.2)	15.0 (10.0-27.5)
P value	.08	.38	.06
Ethnicity			
Hispanic	13.5 (8.9-24.8)	15.5 (8.9-21.2)	14.5 (9.8-28.0)
Non-Hispanic	20.0 (8.5-27.5)	18.0 (14.0-26.5)	19.0 (7.8-31.5)
P value	.45	.17	.49
Diagnosis			
Leukemia	19.4 (10.3-24.5)	18.0 (17.0-22.0)	17.0 (8.8-25.8)
Lymphoma	10.0 (8.0-28.0)	14.4 (8.4-17.6)	15.0 (4.5-27.8)
Plasma cell dyscrasias	20.0 (8.8-28.0)	19.5 (9.8-28.2)	18.0 (10.0-30.0)
P value	.75	.11	.77
Employment status			
Employed	12.0 (8.0-24.0)	19.0 (17.0-22.0)	17.0 (8.0-23.0)
Unemployed	15.0 (10.0-28.0)	18.0 (10.0-28.0)	15.0 (9.0-28.0)
P value	.13	.67	.94
Newly diagnosed cohort			
Race			
African American	15.4 (8.2-20.4)	18.0 (9.0-22.5)	13.5 (6.0-22.0)
White	33.5 (26.7-36.0)	19.8 (18.4-31.9)	22.0 (16.0-40.0)
Other	14.0 (8.8-24.2)	16.5 (9.0-20.0)	19.0 (10.0-28.0)
P value	.04	.46	.16
Ethnicity			
Hispanic	14.0 (9.0-28.0)	15.0 (9.0-20.0)	21.5 (10.0-28.0)
Non-Hispanic	16.5 (7.9-25.5)	18.0 (15.5-23.8)	18.0 (9.0-24.0)
P value	>.99	.29	.38
Diagnosis			
Leukemia	17.0 (8.0-23.0)	18.0 (15.8-20.0)	19.5 (8.5-27.3)
Lymphoma	9.8 (9.0-27.5)	12.0 (8.9-17.3)	11.0 (4.0-27.0)
Plasma cell dyscrasias	22.0 (9.1-28.0)	19.4 (8.0-28.8)	19.0 (10.0-28.0)
P value	.92	.29	.48
Employment status			
Employed	11.0 (7.25-26.0)	18.0 (13.3-20.5)	18.0 (9.0-22.3)
Unemployed	15.0 (9.0-15.0)	12.0 (8.0-28.0)	12.0 (6.0-28.0)
P value	.41	.95	.71
Cellular therapy cohort			
Race			
African American	19.5 (8.8-28.3)	24.0 (14.5-29.2)	33.0 (7.0-44.0)

	Financial toxicity, median (IQR)		
Sociodemographics	Day 0	Day 30	Day 90
White	22.0 (13.8-29.5)	22.8 (10.9-29.4)	39.5 (37.0-42)
Other	19.9 (10.0-24.0)	18.0 (13.9-1.5)	13.0 (8.75-16.25)
P value	.77	.55	<.001
Ethnicity			
Hispanic	16.0 (8.9-22.5)	16.0 (11.3-21.5)	13.0 (8.75-16.3)
Non-Hispanic	24.5 (9.5-31.0)	22.5 (14.5-30.9)	37.0 (20.0-43.0)
P value	.29	.24	.05
Diagnosis			
Leukemia	20.0 (13.0-25.0)	22.0 (19.5-29.5)	13.5 (8.75-25.5)
Lymphoma	13.0 (8.0-28.0)	15.0 (10.7-17.0)	N/A
Plasma cell dyscrasias	19.9 (8.7-27.8)	20.0 (13.5-26.8)	14.0 (8.25-32.25)
P value	.94	.21	.95
Employment status			
Employed	20.0 (5.0-20.0)	22.0 (12.0-29.5)	12.0 (7.5-31.5)
Unemployed	16.5 (10.3-34.0)	20.5 (15.0-29.0)	15.5 (13.3-32.8)
P value	.25	.45	.66

Within the ND cohort, White patients had significantly less severe FT than other racial groups at day 0 (median FT: 33.5 for White patients, 15.4 for African American patients, and 14.0 for other racial groups; P=.04). However, the significance was not maintained at day 30 or day 90.

A similar trend was observed in the CT group at day 90 (median FT: 39.5 for White patients, 33.0 for African American patients, and 13.0 for other racial groups; P<.001).

Predictors of Financial Toxicity

A linear regression analysis was performed (Table 5) to identify potential predictors of FT, as measured by the continuous COST-FACIT score. The model incorporated sex, race and ethnicity, insurance status, employment, and type of malignancy as independent variables. Among individual predictors, race and ethnicity were the only statistically significant predictors, which were associated with a 3.08-point lower COST-FACIT score, indicating higher FT in this group (B=−3.08, P=.04, 95% CI −6.047 to −0.121). The other variables—sex, insurance status, employment, and malignancy type—were not significantly correlated with FT.

Table . Linear regression predicting financial toxicity using the COST-FACIT[a] score.

Predictor	B (95% CI)	SE	β	t	P value
Sex	3.521 (−1.136 to 8.177)	2.337	.169	1.507	.14
Race/ethnicity	−3.084 (−6.047 to −0.121)	1.487	−.232	−2.074	.04
Health insurance	0.357 (−2.697 to 3.411)	1.533	.027	0.233	.82
Type of malignancy	0.185 (−2.711 to 3.080)	1.453	.014	0.127	.90
Employment	3.724 (−2.711 to 3.080)	2.511	.173	0.127	.90
Intercept	14.317 (−1.272 to 29.906)	7.824	—	1.830	.07

[a]COST-FACIT: Comprehensive Score for Financial Toxicity–Functional Assessment of Chronic Illness Therapy.

Subjective Experience of Financial Toxicity

Our social workers evaluated more than 75% of the patients in our survey at the time of diagnosis. Over a third (n=32, 37%) of our patients were employed, while more than 60% were retired, disabled, or unemployed (Table 1). Table 6 and Figure 2 show the results of our investigator-based questionnaire. Most patients reported financial difficulties in carrying out their daily activities, such as paying for food, heating/air-conditioning, or warm clothes over the past 6 months (ND group: n=28, 54%; CT group: n=23, 61%). Additionally, over half of the patients experienced some degree of emotional distress in their daily

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lives (ND group: n=29, 57%; CT group: n=18, 48%). About 15% in the ND group and 26% in the CT group delayed seeking medical care due to financial constraints, and only about 10% missed appointments due to caregiver issues.

Table . Subjective experience of financial toxicity on patient's well-being and access to care.

Economic data	Day 0 Newly diagnosed (n=52)	Cellular therapy (n=38)
Have you felt financially constrained, such as paying for food, heating/cooling in the last 6 months? n (%)		
Never	24 (46)	15 (39)
Sometimes	13 (25)	14 (37)
Often	5 (10)	4 (11)
Most of the time	10 (19)	5 (13)
During the past 4 wk, have you had any problems with your work or daily life due to any emotional problems, such as feeling depressed, sad, or anxious? n (%)		
Never	22 (43)	20 (52)
Sometimes	22 (43)	11 (29)
Often	3 (6)	1 (3)
Most of the time	4 (8)	6 (16)
Over the last 6 months, have you felt particularly low for more than 2 wk? n (%)		
Yes	14 (27)	10 (26)
No	38 (73)	28 (74)
Are you worried about access and cost of transportation for medical appointments? n (%)		
Yes	26 (52)	18 (47)
No	24 (48)	20 (53)
Have you missed an oncology appointment due to lack of transportation? n (%)		
Never	44 (86)	32 (84)
Sometimes	6 (12)	5 (13)
Often	1 (2)	1 (3)
Have you delayed seeking medical care due to financial toxicities? n (%)		
Yes	7 (15)	10 (26)
No	39 (85)	28 (74)
Which mode of transportation do you use to come to medical appointments? n (%)		
Personal	25 (53)	19 (53)
Self-paid transportation	5 (11)	5 (14)
Insurance transportation	6 (13)	6 (17)
Public transportation	11 (23)	6 (17)
Distance from treatment clinic (miles)		
Median (range)	5.8 (0‐131)	5.8 (0‐217.1)
How do you feel about telephone or video visits in addition to in-person visits? n (%)		
I feel comfortable with phone/video visits	27 (53)	14 (40)
I prefer phone visits to video visits due to technological challenges	3 (6)	2 (3)

Economic data	Day 0	
	Newly diagnosed (n=52)	Cellular therapy (n=38)
I always prefer in-person visits	21 (41)	22 (57)
Have you missed doses or delayed treatments due to not being able to pay for medications? n (%)		
Yes	6 (12)	5 (14)
No	45 (88)	32 (86)
Have you missed an oncology appointment due to caregiver issues? n (%)		
Never	47 (92)	34 (89)
Sometimes	2 (4)	3 (8)
Often	2 (4)	1 (3)
Evaluated by a social worker, n (%)		
Yes	40 (78)	38 (100)
No	11 (22)	0 (0)

Figure 2. Box-plot graph showing frequencies of parameters assessing subjective experience from financial toxicity by treatment group. CT: cellular therapy; ND: newly diagnosed.
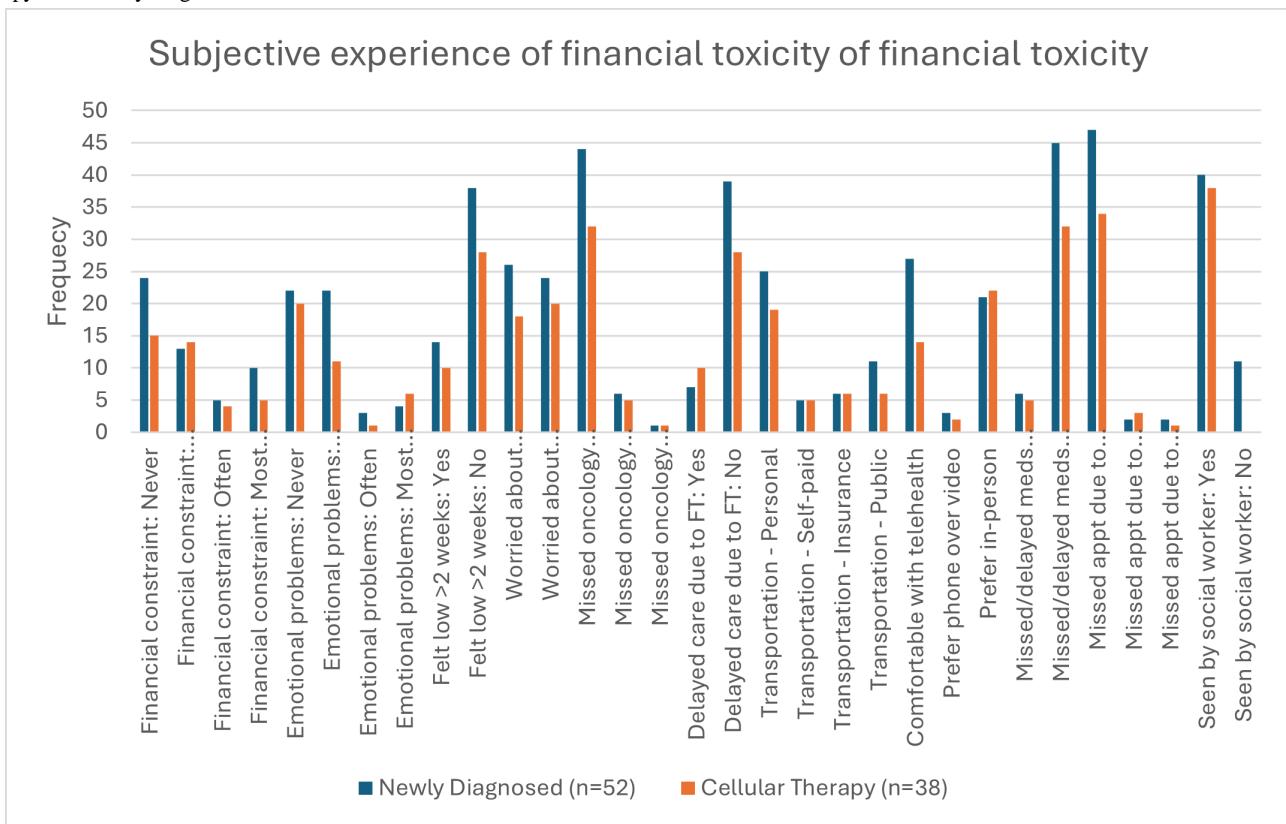
Regarding transportation, the median distance from patients' homes to the treatment center was 5.8 km in both groups. Although fewer than 20% missed appointments due to lack of transportation, many expressed concerns about the cost and accessibility of transportation to their medical appointments (ND group: 52% on day 0; CT group: 47% on day 0). Interestingly, many patients showed interest in telemedicine alongside in-person visits (ND group: 53% and CT group: 40% at day 0). We examined differences in social factors and subjective experiences of FT by ethnicity, and no statistical difference was found at day 0 in either cohort.

Discussion

Principal Findings

Our pilot study highlights a high prevalence of FT within the study population, affecting over 70% of participants. While no significant differences in FT were observed between patients

ND and those undergoing CT, those in the CT group had significantly worse FT at day 90 compared to baseline (day 0). Race and ethnicity emerged as significant predictors of FT, with African American and Hispanic patients experiencing greater FT compared to non-Hispanic White counterparts. Although most patients could attend their oncology appointments and receive treatment, over one-third expressed concerns regarding access to transportation and associated costs.

Comparison to Prior Work

Our findings are consistent with a growing body of literature that identifies FT as a persistent and complex challenge in cancer care [14]. Our patients in the CT group experienced worse FT over time, similar to a previously published study on CAR-T therapy [15]. The study by Maziarz et al [16] on health care costs in patients receiving allogeneic transplants reported that the median cost of health care for a patient receiving a transplant was over US $300,000. Apart from the high cost of SCT and CAR-T, prolonged hospital stays and multiple hospitalizations from treatment-related toxicities add to the burden of FT in these patients [17,18].

In addition to direct medical costs, indirect expenses—such as transportation, loss of employment from poor productivity due to illness, or switching to low-income jobs because they are less physically demanding—also add to the burden of FT [19,20]. Our study confirms these findings. In our study, although most patients made their oncology appointments, over a third were worried about access and the cost of transportation to attend them. Patients undergoing scheduled chemotherapy infusions need to make multiple visits to the clinic, which can be burdensome, especially for those in the CT group who must travel long distances to a FACT (Foundation for Accreditation of Cellular Therapy)-accredited center. This increases gas and public transportation costs, ultimately increasing the overall treatment cost burden [21,22]. Insurance coverage, while protective, may be insufficient to offset the rising costs. Increased deductibles, co-payments, and coinsurance have shifted much of the burden to patients, leading to substantial out-of-pocket expenses for their cancer care. Our study did not assess these out-of-pocket costs directly, nor did it quantify medical debt, areas that merit further investigation.

We found that race and ethnicity are significant predictors of FT, with African American and Hispanic patients experiencing worse FT than non-Hispanic White patients. Our results do not differ from studies on race and cancer-related FT in the literature [23-25]. Most of our patients are essentially racial and ethnic minorities and immigrants, and some are undocumented. They are likely to have lower incomes compared to their White counterparts, to be in the lowest socioeconomic tier, and have access only to public health insurance with limited coverage or even be uninsured [26-28]. Additionally, these patients are likely to have lower health literacy, leading to late disease presentation, increasing the intensity and cost of treatment. These findings underscore the structural inequities that contribute to FT among racial and ethnic minorities and immigrant populations. The convergence of social, economic, and health care–related factors amplifies financial strain and perpetuates disparities in outcomes. Addressing FT in these populations will require more than individual-level solutions; it demands systems-level change.

Beyond the direct effects of FT, it also encompasses the subjective financial distress—the emotional and psychological toll of economic strain [2,29]. This includes the depletion of household wealth and nonmedical budgets, as well as worries about the effectiveness of coping strategies [30]. In our study, over half of the patients experienced financial difficulty in paying for basic needs such as food, and more than 50% experienced emotional distress in their daily life, aligning with findings from Yu et al [31]. Although our results indicate a substantial emotional burden, further research is needed to determine whether this stems from receiving devastating news of a cancer diagnosis, the financial burden of treatment, or a combination of both. In our study, where over 50% of patients are unemployed, most of them will likely have to adjust their monthly budget and spend less on basic needs to pay for their cancer treatment. As their cancer treatment progresses, which is often prolonged in HM, they may face increasing financial burdens, leading them to adopt coping strategies such as relying on retirement savings, selling valuables, or borrowing from friends, family, or financial institutions [32]. In some cases, patients may resort to maladaptive strategies such as missing hospital appointments, medication nonadherence, or even stopping treatment entirely [33]. In our study, though a few patients missed or delayed treatments due to financial constraints, we see a decrease in the number of patients when followed up on day 30 and day 90. Although only a few patients in our study reported missing or delaying treatment due to financial constraints, we observed a decline in patient follow-up at 30 and 90 days. While the reasons for this attrition are not fully elucidated, the inability to afford ongoing treatment remains a plausible factor. These strategies may temporarily mitigate the financial impact of cancer care but ultimately lead to reduced quality of life, emotional distress, and devastating clinical outcomes.

Limitations

Our study certainly has limitations. First, we had a low sample size, especially at the 90-day time point, as many of our patients were lost to follow-up, deceased, or chose not to continue with the study. Second, although our study was observational, the follow-up period may not have been long enough to detect a significant change in FT across time. Third, we did not collect data on the participants' monthly income and the number of cycles of chemotherapy received at each survey time. This may have provided additional insights into assessing the severity of FT in our patient population. With our pilot study, we aimed to capture some of the barriers to cancer care in a unique patient population.

Potential Solutions and Future Directions

Mitigating the burden of FT will involve developing and implementing intervention strategies at multiple levels, from the state/national level to the health insurance/payer, hospital, and provider levels [34]. In our study, many patients were worried about the transportation cost to their oncology appointments but were open to telemedicine visits. Therefore, incorporating telemedicine visits as an option in the care of our

patient population could offer more flexibility for patients, reducing the travel burden and lost income from missed work [35]. Most of our patients were assessed by a social worker. While they play a role in identifying patients at high risk of financial distress, their assistance may not be sufficient, and they may not have the expertise to provide solutions to mitigate the severity of FT. A dedicated financial navigator, especially in a quaternary academic medical center, is required to help patients understand the economic aspects of their cancer care, budget appropriately, and maximize their employment and disability benefits in the context of ongoing financial commitment [36]. A larger cancer center–wide study is underway to evaluate the social determinants of health and better understand their implications on patient outcomes.

Conclusions

This study highlights the significant and far-reaching impact of FT experienced by patients with cancer, particularly those from socioeconomically disadvantaged and ethnic and racial minority backgrounds. Our findings underscore the need for early FT screening and multilevel interventions to protect vulnerable populations from economic harm during cancer care.

Data Availability

The datasets underpinning this study are securely stored on a restricted institutional server and are not publicly accessible, safeguarding participant confidentiality. Access may be granted upon formal request to the corresponding author, contingent upon ethical and legal approvals.

Authors' Contributions

Conceptualization: KF, NS, AS, KW
Data curation: LA, LL, KF, AS, DL, RM
Formal analysis: CZ, M Kim
Writing-original draft: LA, NS.
Writing -review and editing: DC, MG, IM, RAS, KG, M Konopleva, RG, NK, AV, BR, AS.

Conflicts of Interest

None declared.

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Abbreviations

CAR-T: chimeric antigen receptor T-cell therapy
COST-FACIT: Comprehensive Score for Financial Toxicity–Functional Assessment of Chronic Illness Therapy
CT: cellular therapy
FACT: Foundation for Accreditation of Cellular Therapy
FT: financial toxicity
HM: hematologic malignancies
ND: newly diagnosed
SCT: stem cell transplantation

Prognostic Value of Dynamic Lactate Dehydrogenase Trends in Immunotherapy for Advanced Esophageal Squamous Cell Carcinoma: Retrospective Cohort Study

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Abstract

Background: Immune checkpoint inhibitors (ICIs) have emerged as a pivotal treatment for advanced esophageal squamous cell carcinoma (ESCC). However, their efficacy can significantly differ among patients, highlighting the need for reliable prognostic markers to enhance treatment outcomes. Lactate dehydrogenase (LDH) plays a key regulatory role in the complex relationship between cancer metabolism and the immune system, suggesting that monitoring LDH levels may provide valuable insights into treatment efficacy and inform personalized therapeutic strategies for advanced ESCC.

Objective: This study aimed to explore the prognostic significance of dynamic changes in LDH levels during ICI therapy in predicting treatment outcomes.

Methods: We retrospectively analyzed the clinical data of 126 patients with advanced ESCC who received first-line ICI therapy at the Department of Radiation Oncology, Cancer Center, Shandong Provincial Hospital, between April 2018 and November 2022. Serum LDH levels were measured after every 3 cycles of combined immunotherapy and chemotherapy. Receiver operating characteristic curve analysis determined the optimal LDH reduction threshold. Kaplan-Meier survival curves and Cox regression models assessed progression-free survival (PFS) and overall survival.

Results: Among the 126 patients, 55 (43.6%) were classified into the LDH-increased group, while 71 (56.4%) belonged to the LDH-decreased group. Within the LDH-increased group, 78.2% (43/55) of the patients were male, compared to 90.1% (64/71) in the LDH-decreased group. The median age of patients in the LDH-increased group was 59 (range 55‐68) years, whereas the median age in the LDH-decreased group was 65 (range 58‐65) years. LDH decrease following first-line ICI therapy was associated with improved outcomes compared to LDH increases (median PFS 13.4, IQR 8.1‐24.3 mo vs median 10.8, IQR 4.8‐20.6 mo; *P*=.03). Patients with a posttreatment LDH decrease of more than 14.4% had a median PFS of 11.1 (IQR 7.2‐24.3) months, whereas those with an LDH decrease between 0% and 14.4% had a median PFS of 21.7 (IQR 9.4‐34.5) months. Conversely, an increase in LDH resulted in a median PFS of 10.8 (IQR 4.8‐20.6) months. Patients with tumor reduction exhibited a significantly greater decrease in LDH levels compared with those without tumor reduction (*P*<.001). Multivariate analysis identified LDH decrease as an independent predictor of a 41% lower mortality risk (hazard ratio 0.59, 95% CI 0.36‐0.96; *P*=.04).

Conclusions: In patients with advanced ESCC, a decrease in serum LDH levels ranging from 0% to 14.4% after treatment initiation was significantly associated with prolonged PFS. Notably, an early decrease in LDH levels observed after 3 cycles of immunotherapy further correlated with improved clinical outcomes. These results highlight the potential of LDH as a valuable biomarker for risk stratification and personalized treatment optimization in advanced ESCC.

KEYWORDS

XSL•FO
RenderX

Introduction

Background

Esophageal squamous cell carcinoma (ESCC) is a globally prevalent oncological challenge marked by high incidence and mortality rates, particularly in regions such as Asia, Eastern Europe, and Africa [1]. The typically asymptomatic nature of early-stage ESCC often results in late-stage diagnoses, which limit therapeutic options and contribute to high mortality rates [2]. Current management strategies for ESCC include a combination of surgery, radiation, and chemotherapy. However, the 5-year survival rate remains dismally low at approximately 20%, emphasizing the aggressive nature of this malignancy and the complexities surrounding its treatment [3].

Recent advancements in immunotherapy, particularly immune checkpoint inhibitors (ICIs) targeting the programmed death-1 (PD-1) and programmed death-ligand 1 (PD-L1) axis, such as nivolumab and pembrolizumab, have revolutionized the treatment landscape for advanced ESCC. Evidence from pivotal studies such as KEYNOTE-181 and ATTRACTION-3 has demonstrated the superior efficacy of ICIs compared to conventional chemotherapy [4]. Despite these breakthroughs, not all patients with advanced ESCC derive significant benefits from ICIs [5], highlighting the critical need for reliable, accessible, and cost-effective biomarkers to predict treatment response and patient prognosis more effectively.

Lactate dehydrogenase (LDH), a key enzyme in cancer cell metabolism, has gained attention as a potential prognostic biomarker in oncology due to its role in metabolic reprogramming and tumor adaptation to hypoxic microenvironments [6]. Elevated LDH levels have been linked to increased tumor aggressiveness, metabolic stress, and poor clinical outcomes across various malignancies, including melanoma, lung cancer, and breast cancer, underscoring its potential as a universal biomarker of malignancy [7,8]. Emerging research highlights the intricate relationship between cancer metabolism and the immune system, with LDH functioning as a critical mediator of this interplay [9]. LDH plays a pivotal role in metabolic reprogramming, enabling tumor survival in hypoxic conditions by facilitating anaerobic glycolysis and lactate production. These processes not only support tumor growth but also contribute to the creation of an immunosuppressive tumor microenvironment. This suggests that dynamic changes in LDH levels could significantly influence the efficacy of immunotherapeutic approaches in ESCC [10]. Preliminary studies have shown that variations in LDH levels following ICI treatment correlate with improved survival outcomes, pointing to the potential of LDH as a valuable prognostic tool in ESCC immunotherapy [11].

Objectives

To identify a more accessible and precise prognostic marker for advanced ESCC, this study enrolled patients receiving first-line immunotherapy combined with chemotherapy. The primary objective was to investigate the prognostic value of dynamic changes in LDH by assessing LDH kinetics. This research aims to provide new insights into the potential of LDH as a cost-effective and practical biomarker for guiding personalized treatment strategies and improving outcomes in patients with advanced ESCC.

Methods

Ethical Considerations

This study was approved by the Ethics Committee of Biomedical Research at Shandong Provincial Hospital (SWYX NO 2023‐595). Given the retrospective nature of the study, which involved secondary analysis of existing electronic health records, no prospective informed consent specific to this research was required. At the time of admission or outpatient registration, all patients provided a general consent permitting the use of their medical records for research purposes, in accordance with institutional policy. All data in this study were deidentified to ensure participant anonymity and protect confidentiality. This was a retrospective study based on the analysis of pre-existing patient medical records. As such, no participants were actively recruited for this research, and therefore, no compensation was involved.

Patient Selection

This retrospective cohort study was conducted at Shandong Provincial Hospital between April 2018 and November 2022. The study included patients diagnosed with stage IV ESCC based on the Tumor-Node-Metastasis classification system. Eligible patients were those who received ICIs in combination with chemotherapy and who had a Karnofsky Performance Status score greater than 80.

The exclusion criteria were as follows: history of other malignancies, presence of autoimmune disorders, previous immunotherapy with agents such as Carrelizumab or Tislelizumab, and incomplete clinical or laboratory data.

The follow-up period ended in September 2023. The medical records were retrieved from the Shandong Provincial Hospital database. Data collected included patient age, sex, comorbidities, tumor location, treatment response evaluations, TNM stages, stage at initial diagnosis, baseline LDH levels, posttreatment LDH levels, and dynamic changes in LDH levels.

Treatment and Evaluation Criteria

All participants in the study received a treatment regimen consisting of PD-1 inhibitors combined with chemotherapy agents, such as 5-fluorouracil, cisplatin, taxanes, and irinotecan, administered either as monotherapy or as part of polychemotherapy protocols. The PD-1 inhibitors were administered intravenously at a standard dose of 200 mg, with infusions performed every 2 to 3 weeks for a total of 4 to 6 cycles, or until disease progression, unacceptable toxicity, or death.

Serum LDH levels were measured at 2 key time points: at baseline (before the initiation of immunotherapy) and after the final immunotherapy cycle. LDH quantification was performed by the Department of Laboratory Medicine at Shandong Provincial Hospital. The study evaluated treatment efficacy longitudinally, with key end points including progression-free survival (PFS) and overall survival (OS). Progressive disease was defined as a ≥20% increase in the sum of the longest

diameters of target lesions from the nadir, the appearance of new measurable disease foci, or other substantial indicators of disease progression, according to the Response Evaluation Criteria in Solid Tumors (version 1.1) [12]. PFS was measured from the initiation of anti–PD-1 therapy to the point of documented disease progression or death from any cause, while OS was defined as the time from the initiation of immunotherapy to death from any cause.

Statistical Analysis

Overview

Descriptive statistics were used to summarize baseline characteristics, using means (SD) for normally distributed variables, medians (IQR) for non–normally distributed variables (as assessed by the Shapiro-Wilk test), and frequencies (%) for categorical variables. Serum LDH levels were measured both before treatment and after immunotherapy (median of 3 cycles). The LDH reduction rate was calculated as follows:

$$[\frac{Baseline\ LDH - Post\text{-}treatment\ LDH}{Baseline\ LDH}] \times 100\%$$

Critical Methodological Note on Cutoff Selection

The initial receiver operating characteristic analysis for OS prediction yielded suboptimal performance (area under the curve=0.602; data not shown), likely due to the heterogeneity inherent in retrospective cohorts. Consequently, we adopted a distribution-driven approach, selecting the 25th percentile of observed LDH reduction values (−14.4%) as the primary cutoff. This threshold, representing a substantial decline in LDH, demonstrated significant discriminative power for PFS in subsequent analyses.

Kaplan-Meier curves, analyzed using log-rank tests, were used to compare survival between different LDH trajectory groups.

Cox regression analysis was used to identify prognostic factors, with a two-step process: (1) univariate screening with a *P*<.10 entry threshold and (2) multivariate adjustment for age, Karnofsky Performance Status, and TNM stage. Results were reported as adjusted hazard ratios (HRs) with 95% CIs. Missing data were minimal (<1% for LDH, PFS, and OS) and were handled using complete-case analysis, confirmed to be missing completely at random; sensitivity analyses with multiple imputation yielded consistent results. The sample size (n=126) provided 80% power (α=.05) to detect an HR of 0.60 for PFS improvement in LDH reducers versus nonreducers, based on KEYNOTE-181 data with a 15% attrition adjustment. Analyses were conducted using SPSS (version 25.0; IBM Corp), with statistical significance set at *P*<.05 (2-tailed).

Results

Patient Characteristics

As shown in Figure 1, from an initial cohort of 2635 patients diagnosed with ESCC, 446 (16.9%) patients with non-ESCC diagnoses, 1402 (53.2%) patients at non-IV stages of ESCC, 326 (12.4%) patients who did not receive PD-L1 and PD-1 treatment, 51 (1.94%) patients with incomplete medical records, 176 (6.68%) patients lacking LDH data during first-line treatment, and 108 (4.1%) patients diagnosed with other cancers were excluded. The final study cohort consisted of 126 patients.

The follow-up period concluded with a median follow-up duration of 13.8 (range 8.00‐18.75) months. From the 126 patients, 9 (7.14%) were alive at the time of follow-up. The median PFS for all patients was 11.8 (95% CI 6.1‐22.9) months, while the median OS was 28 (95% CI 14.6‐43.9) months.

Figure 1. Patient selection criteria and process. ESCC: esophageal squamous cell carcinoma; LDH: lactate dehydrogenase; PD-1: programmed death-1; PD-L1: programmed death-ligand 1.
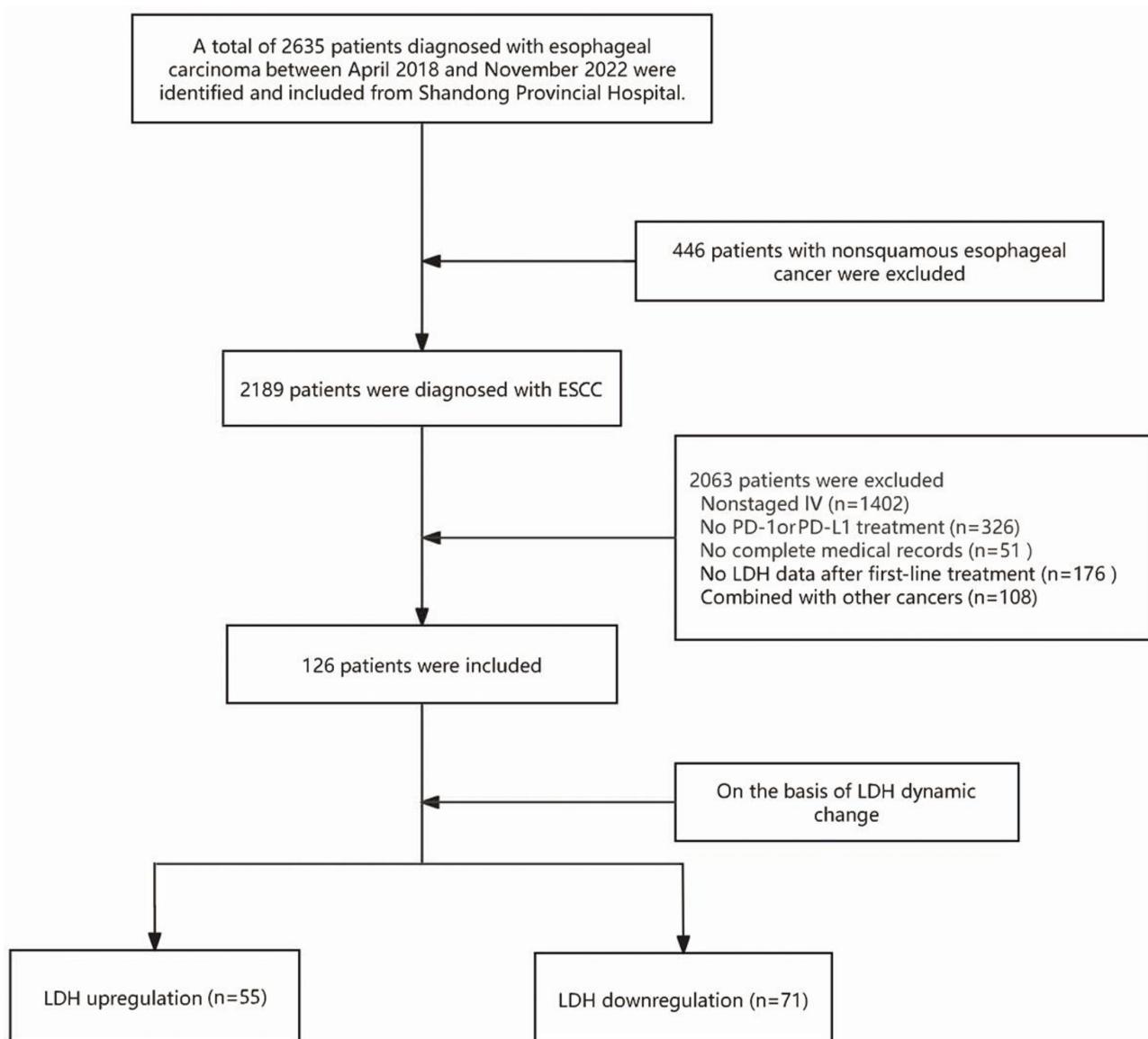
Patient characteristics are summarized in Table 1. Among the 126 patients, 55 (43.6%) were classified into the LDH-increased group, while 71 (56.4%) belonged to the LDH-decreased group. Within the LDH-increased group, 78.2% (43/55) of the patients were male, compared to 90.1% (64/71) in the LDH-decreased group. The median age of patients in the LDH-increased group was 59 (range 55‐68) years, whereas the median age in the LDH-decreased group was 65 (range 58‐65) years. In addition, in the LDH-increased group, 38.2% (21/55) of patients had other comorbidities, whereas in the LDH-decreased group, the proportion was 43.7% (31/71).

The LDH ratio was calculated by comparing the posttreatment LDH levels to the baseline LDH levels. On the basis of this ratio, patients were subsequently classified into 2 categories: those with elevated LDH levels and those with decreased LDH levels.

Table . Patient characteristics—comparison of lactate dehydrogenase (LDH) levels after treatment and at baseline.

	LDH upregulation (n=55), n (%)	LDH downregulation (n=71), n (%)	P value
Age (years), median (IQR)	59 (55‐68)	65 (58‐65)	—[a]
Age (years), n (%)			.07
≤63	33 (60.0)	30 (42.3)	
>63	22 (40.0)	41 (57.7)	
Gender, n (%)			.08
Male	43 (78.2)	64 (90.1)	
Female	12 (21.8)	7 (9.9)	
Tumor location, n (%)			.81
Upper	5 (9.1)	5 (7.0)	
Middle	28 (50.9)	40 (56.3)	
Lower	22 (40.0)	26 (36.6)	
T stage, n (%)			.59
T1-3	25 (45.4)	28 (39.4)	
T4	30 (54.6)	43 (60.6)	
N stage, n (%)			.24
N0-1	8 (14.5)	5 (7.0)	
N2-3	47 (85.5)	66 (93.0)	
Clinical stage, n (%)			.57
IVA	16 (29.1)	25 (35.2)	
IVB	39 (70.9)	46 (64.8)	
Comorbidity, n (%)			.07
Yes	21 (38.2)	31 (43.7)	
No	34 (61.8)	40 (56.3)	

[a]Not applicable.

Kaplan-Meier Survival Analysis

To assess dynamic changes in LDH levels, collection points were established at intervals of every 3 cycles of chemotherapy combined with immunotherapy. Dichotomous analysis revealed that patients exhibiting downregulated LDH levels showed a significant improvement in PFS (P=.03; Figure 2A). However, no statistically significant difference was observed in OS (P=.36; Figure 2B).

Figure 2. Kaplan-Meier curves for (A) progression-free survival and (B) overall survival based on lactate dehydrogenase (LDH) dichotomization (downregulation vs upregulation). Patients with downregulated LDH levels exhibited a significantly better prognosis.
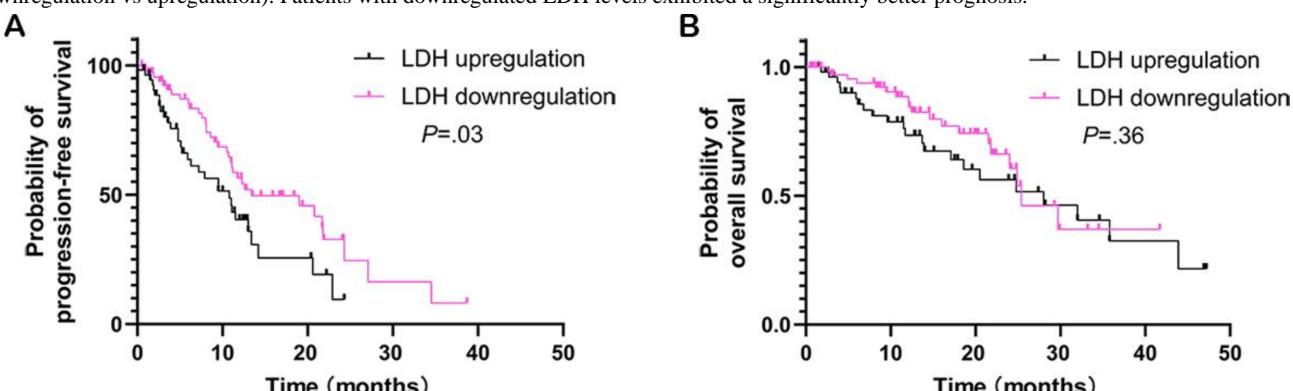
It was noted that a reduction in LDH levels may also reflect a decline in the patient's physical condition or nutritional status, necessitating further stratified analysis. Receiver operating characteristic curve methodology was applied, with OS used as the end point criterion for analysis. On the basis of this methodology, an appropriate threshold for LDH reduction was

identified as greater than −14%, closely approximating the −14.4% mark, which represents the boundary at the 25th percentile of the data distribution. At the threshold of −14.4%, a significant difference in PFS was observed (Figure 3A), while no significant difference was detected for OS (Figure 3B).

Figure 3. Kaplan-Meier curves of (A) progression-free survival and (B) overall survival stratified by lactate dehydrogenase (LDH) change into 3 groups: an increase (LDH≥0%), a moderate decrease (−14.4%≤LDH<0%), and a marked decrease (LDH<−14.4%) following treatment. A decrease in LDH levels exceeding 14.4% after treatment was associated with a significantly improved prognosis.
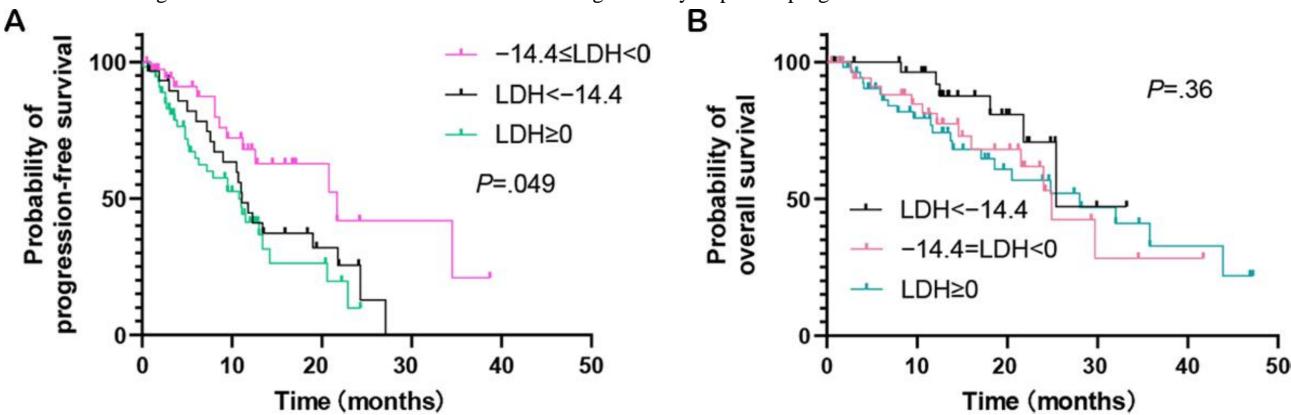
Further we analyzed the relationship between LDH dynamics and radiological tumor response. As shown in Figure 4, patients in the tumor reduction group experienced a significantly greater decline in LDH levels than those in the non-reduction group ($P<.001$; Figure 4). This indicates that a decrease in LDH levels is consistent with tumor shrinkage.

Figure 4. Comparison of LDH change rates between the tumor reduction group and the non-reduction group after 3 cycles of treatment. The tumor reduction group exhibited a significantly greater decrease in LDH levels compared with the non-reduction group ($P < 0.05$). ($P<.001$). "Relieve" indicates radiological evidence of reduction in the size of the primary tumor or affected lymph nodes after treatment, as assessed by the radiology department. "Not relieve" indicates no measurable reduction on follow-up imaging.
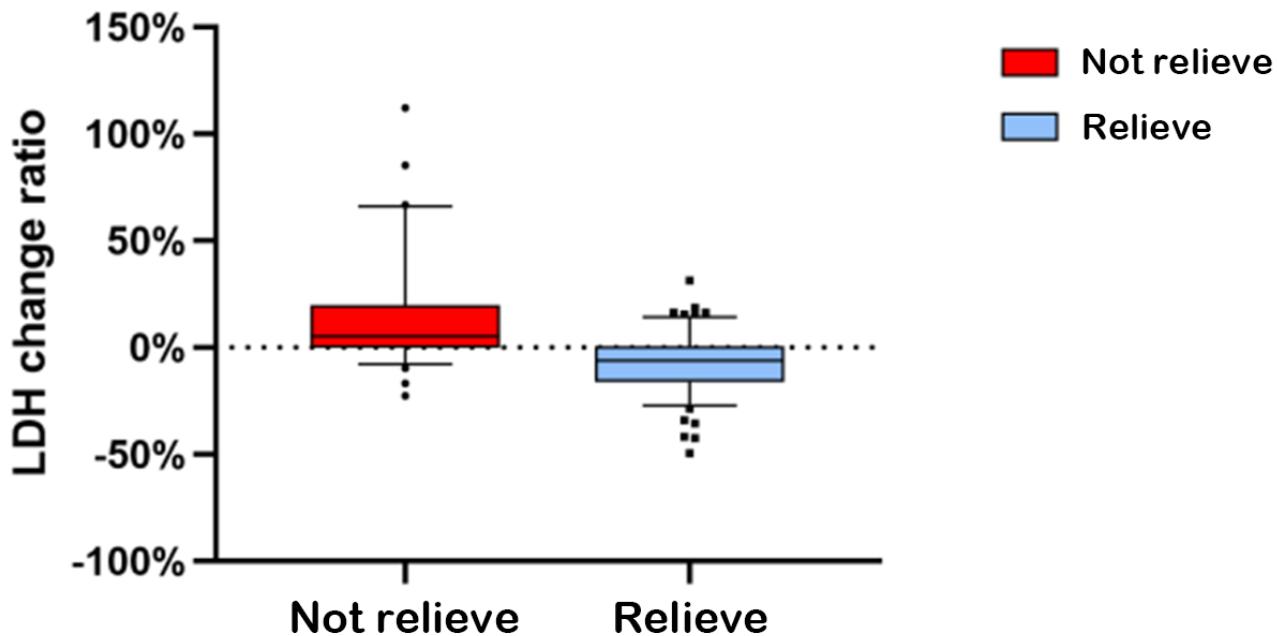
Multivariate and Univariate Analyses

In the univariate analysis performed using the Cox proportional hazards model (Table 2), it was observed that patients with decreased LDH levels (threshold=200 U/L) following treatment demonstrated a 41% reduction in the risk of death compared with those exhibiting increased LDH levels (HR 0.59, 95% CI 0.37‐0.98; P=.04).

In addition to LDH changes, given that other clinical factors, including age, tumor length, tumor stage, tumor location, and the presence of comorbidities, were associated with PFS, we included these factors in our multivariate analysis (Table 2). The results of the multivariate analysis identified a reduction in LDH levels as an independent prognostic factor for improved outcomes (HR 0.59, 95% CI 0.36‐0.96; P=.04; Table 2).

Compared with patients with elevated LDH levels, LDH downregulation was an independent prognostic factor for a 41% reduction in the risk of death (HR 0.59, 95% CI 0.36‐0.96; P=.04).

Table . Univariate and multivariate analyses of factors influencing progression-free survival in all patients.

Variables	Univariate analysis		Multivariate analysis	
	HR[a] (95% CI)	*P* value	HR (95% CI)	*P* value
Gender (male vs female)	0.73 (0.37‐1.43)	.35	__[b]	—
Age (years; <63 vs >63)	1.10 (0.67‐1.80)	.70	—	—
Comorbidity (yes vs no)	1.08 (0.65‐1.82)	.76	—	—
T stage (1‐3 vs 4)	0.6 (0.37‐0.97)	.04	0.67 (0.38‐1.20)	.18
N stage (0‐1 vs 2‐3)	0.78 (0.33‐1.80)	.56	—	—
Clinical stage (IVA[c] vs IVB[d])	0.60 (0.34‐1.08)	.09	0.75 (0.37‐1.48)	.40
Tumor length (<5 cm vs >5 cm)	0.98 (0.58-1.65)	.93	—	—
Tumor location				
Upper	Reference	—	—	—
Middle	0.69 (0.29‐1.65)	.40	—	—
Lower	0.74 (0.30‐1.82)	.51	—	—
LDH[e] change (down vs up)	0.59 (0.37‐0.98)	.04	0.59 (0.36‐0.96)	.04

[a]HR: hazard ratio.

[b]Not available.

[c]IVA: cancer stage IVA.

[d]IVB: cancer stage IVB.

[e]LDH: lactate dehydrogenase.

Discussion

Principal Findings

This study provides valuable insights into the prognostic significance of dynamic changes in LDH levels among patients with ESCC undergoing ICI therapy. The findings demonstrate that a reduction in LDH levels is associated with improved PFS. Specifically, patients with a moderate LDH decrease (0% to 14.4%) exhibited a median PFS of 21.7 months, compared to 10.8 months in those with increased LDH. Multivariate analysis further confirmed that an LDH decrease independently predicted a 41% reduction in mortality risk. These results underscore the potential utility of dynamic LDH monitoring as an accessible, cost-effective, and valuable prognostic tool for informing individualized treatment strategies in advanced ESCC.

Comparison to Previous Work

LDH, a key enzyme involved in cellular metabolism, facilitates the interconversion of lactate and pyruvate, which are critical to both aerobic and anaerobic metabolic pathways [13]. Elevated LDH levels have long been recognized as a prognostic marker in various malignancies, reflecting increased tumor burden and metabolic stress [14,15]. However, this study expands on existing knowledge by focusing on the dynamic changes in LDH levels during treatment rather than static measurements.

This novel approach enables a more precise evaluation of treatment efficacy by capturing real-time fluctuations in tumor metabolism and therapeutic response. While traditional biomarkers for ICI therapy, such as PD-L1 expression, tumor mutational burden, and immune cell infiltration, provide valuable prognostic information, they often require complex, resource-intensive assessments [16-18]. In contrast, dynamic LDH monitoring offers a similarly predictive yet simpler and more cost-effective alternative. This is particularly advantageous in resource-limited settings, where such a practical tool can guide clinical decisions and optimize treatment strategies.

Role of LDH in Tumor Metabolism and Therapeutic Implications

Elevated LDH activity in cancer cells reflects reliance on anaerobic glycolysis, leading to increased lactate production [19]. Accumulation of lactate acidifies the tumor microenvironment, disrupts immune cell function, promotes tumor progression, and creates conditions favorable for immune evasion [20,21]. Dynamic monitoring of LDH levels provides crucial insights into these metabolic shifts, illustrating the impact of therapy on tumor biology. Specifically, elevated lactate levels impair T-cell function, reduce immune cell cytotoxicity, and promote an immunosuppressive phenotype in tumor-associated macrophages [22,23]. Conversely, a reduction in LDH levels, indicative of decreased lactate production, may alleviate these

immunosuppressive effects and enhance the efficacy of immune therapies. ICIs are specifically designed to counteract immune suppression in the tumor microenvironment [24]. Monitoring dynamic changes in LDH levels can therefore provide valuable insights into the evolving tumor state and its microenvironment during therapy. A decrease in LDH levels may signal effective tumor cell apoptosis or reduced glycolytic activity, both of which can relieve metabolic stress, enhance immune cell function, and ultimately improve therapeutic outcomes [25].

Clinical Utility

Dynamic monitoring of LDH facilitates personalized treatment strategies by allowing real-time assessment of therapeutic efficacy and metabolic changes. Patients with significant reductions in LDH levels are more likely to benefit from continued ICI therapy, while those with stable or increasing LDH levels may require alternative therapeutic approaches [26]. This approach allows clinicians to optimize treatment strategies tailored to individual patient responses, enhancing treatment efficacy and patient outcomes. However, integrating LDH monitoring into routine clinical practice necessitates the establishment of standardized testing protocols and data interpretation guidelines to ensure consistency and reliability across clinical settings [27]. Regular LDH assessments should be incorporated into treatment plans to provide ongoing feedback on therapeutic response. Furthermore, combining LDH data with other biomarkers could enhance the predictive accuracy of treatment outcomes, supporting individualized decision-making and more precise treatment strategies [28].

Limitations

Despite its potential, the retrospective design of this study introduces certain limitations, including selection bias and inconsistencies in data recording, which may impact the generalizability of the findings. Although efforts were made to minimize these biases through standardized procedures and data validation, the inherent limitations of retrospective analyses remain. In addition, the relatively small sample size may have influenced the statistical power and generalizability of the results. Moreover, variations in chemotherapy regimens could influence treatment outcomes, thereby affecting the conclusions of this study. In the future, additional samples should be collected to conduct more detailed subgroup analyses of various highly specific chemotherapy regimens, and prospective studies are needed to validate these findings and confirm the reliability of dynamic LDH monitoring as a prognostic marker. The applicability of these results to diverse populations and clinical settings also requires further exploration. Large-scale, multicenter studies are essential to evaluate the consistency and generalizability of LDH dynamics as a prognostic tool across diverse patient cohorts. Furthermore, variations across ethnicities, genders, and regions should be investigated to ensure broader applicability and relevance.

Future Directions

Future research should include prospective cohort studies and randomized controlled trials to validate the prognostic value of dynamic LDH changes and identify optimal monitoring strategies for enhancing treatment efficacy. Exploring the combination of LDH with other biomarkers, such as genomic features and immune cell subsets, could further refine prognostic accuracy. Integrating multiple biomarkers may offer a more comprehensive assessment of patient status, informing more precise treatment strategies. Moreover, studies should investigate how to tailor immune therapies based on dynamic LDH changes, including potential treatment modifications and individualized approaches. Evaluating the impact of these strategies on long-term patient outcomes through clinical trials will be critical. The integration of LDH monitoring with other clinical data could lead to the development of comprehensive treatment plans, ultimately improving patient prognosis and quality of life.

Conclusions

Dynamic changes in LDH levels, specifically a reduction within the 0% to 14.4% range, represent novel and significant predictors of PFS in patients with advanced ESCC. After 2 cycles of immunotherapy, patients with decreased LDH dynamic ratios demonstrated significantly better prognoses. These findings highlight the potential of LDH as a metabolic biomarker that reflects tumor biology and therapeutic response in real time. Future investigations are warranted to validate the utility of this specific LDH dynamic threshold as a prognostic tool. Such efforts could enhance personalized treatment strategies, ultimately improving clinical outcomes in patients with advanced ESCC.

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

BZ was responsible for the study design, data analysis, and manuscript writing and revision. ZK contributed to experimental implementation, data collection, and manuscript writing and revision. YD, WJ, AF, RZ, JL, and YZ were responsible for experimental implementation and data collection. LS and ZY contributed to the study design and revised the manuscript. All authors reviewed and approved the final manuscript.

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Conflicts of Interest

None declared.

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Abbreviations

ESCC: esophageal squamous cell carcinoma
HR: hazard ratio
ICI: immune checkpoint inhibitor
LDH: lactate dehydrogenase
OS: overall survival
PD-1: programmed death-1
PD-L1: programmed death-ligand 1
PFS: progression-free survival

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<u>Original Paper</u>

Explainable AI for Predicting Mortality Risk in Metastatic Cancer: Retrospective Cohort Study Using the Memorial Sloan Kettering-Metastatic Dataset

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Abstract

Background: Metastatic cancer remains one of the leading causes of cancer-related mortality worldwide. Yet, the prediction of survivability in this population remains limited by heterogeneous clinical presentations and high-dimensional molecular features. Advances in machine learning (ML) provide an opportunity to integrate diverse patient- and tumor-level factors into explainable predictive ML models. Leveraging large real-world datasets and modern ML techniques can enable improved risk stratification and precision oncology.

Objective: This study aimed to develop and interpret ML models for predicting overall survival in patients with metastatic cancer using the Memorial Sloan Kettering-Metastatic (MSK-MET) dataset and to identify key prognostic biomarkers through explainable artificial intelligence techniques.

Methods: We performed a retrospective analysis of the MSK-MET cohort, comprising 25,775 patients across 27 tumor types. After data cleaning and balancing, 20,338 patients were included. Overall survival was defined as deceased versus living at last follow-up. Five classifiers (extreme gradient boosting [XGBoost], logistic regression, random forest, decision tree, and naive Bayes) were trained using an 80/20 stratified split and optimized via grid search with 5-fold cross-validation. Model performance was assessed using accuracy, area under the curve (AUC), precision, recall, and F_1-score. Model explainability was achieved using Shapley additive explanations (SHAP). Survival analyses included Kaplan-Meier estimates, Cox proportional hazards models, and an XGBoost-Cox model for time-to-event prediction. The positive predictive value and negative predictive value were calculated at the Youden index–optimal threshold.

Results: XGBoost achieved the highest performance (accuracy=0.74; AUC=0.82), outperforming other classifiers. In survival analyses, the XGBoost-Cox model with a concordance index (C-index) of 0.70 exceeded the traditional Cox model (C-index=0.66). SHAP analysis and Cox models consistently identified metastatic site count, tumor mutational burden, fraction of genome altered, and the presence of distant liver and bone metastases as among the strongest prognostic factors, a pattern that held at both the pan-cancer level and recurrently across cancer-specific models. At the cancer-specific level, performance varied; prostate cancer achieved the highest predictive accuracy (AUC=0.88), while pancreatic cancer was notably more challenging (AUC=0.68). Kaplan-Meier analyses demonstrated marked survival separation between patients with and without metastases (80-month survival: approximately 0.80 vs 0.30). At the Youden-optimal threshold, positive predictive value and negative predictive value were approximately 70% and 80%, respectively, supporting clinical use for risk stratification.

Conclusions: Explainable ML models, particularly XGBoost combined with SHAP, can strongly predict survivability in metastatic cancers while highlighting clinically meaningful features. These findings support the use of ML-based tools for patient counseling, treatment planning, and integration into precision oncology workflows. Future work should include external validation on independent cohorts, integration with electronic health records via Fast Healthcare Interoperability Resources–based dashboards, and prospective clinician-in-the-loop evaluation to assess real-world use.

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Introduction

Cancer remains one of the foremost global health challenges, with 611,720 deaths projected in the United States alone for 2024, and metastatic disease accounting for the overwhelming majority of these fatalities [1]. Metastasis is particularly vexing because disseminated tumor cells frequently acquire distinct genomic and phenotypic profiles that render them resistant to standard therapies. Contemporary oncology research, therefore, acknowledges intra- and intertumor heterogeneity as fundamental obstacles to curative treatment, therapeutic resistance, and accurate prognosis [2,3]. Reliable, early-stage prediction of patient survivability is pivotal not merely for counseling patients but also for tailoring aggressive interventions, prioritizing scarce health care resources, and designing adaptive clinical trials aimed at improving long-term outcomes.

Historically, clinicians have relied on the tumor-node-metastasis staging system, Kaplan-Meier life tables, and the Cox proportional hazards (CPH) regression model to stratify survival risk. Although statistically rigorous, these techniques impose proportional hazards and linearity assumptions that rarely hold across the dynamic, nonlinear biology of metastatic cancers. When violated, CPH models can yield biased hazard ratios, suffer from time-dependent covariate effects, and perform poorly on censored or highly imbalanced datasets [4].

The emergence of artificial intelligence (AI) and machine learning (ML) has enabled the development of sophisticated models that can uncover previously hidden patterns in heterogeneous clinical and multiomics datasets, thereby providing new insights into cancer biology, diagnosis, prognosis, and treatment outcomes. Over the past decade, ML models have repeatedly outperformed traditional statistical approaches. A deep-learning algorithm developed by Esteva et al [5] achieved a sensitivity of 97% and a specificity of 78% in classifying skin lesions as benign or malignant, while Liu et al [6] reported an area under the receiver operating characteristic curve (AUROC) of 0.94 for lung cancer risk prediction using computed tomography images. Similar gains have been demonstrated for breast cancer survival [7], lymph node metastasis [8], colorectal and soft tissue sarcoma outcomes [9], lung cancer survival [10], and prostate cancer prognosis [11,12].

Among contemporary ML pipelines, gradient-boosted decision trees, particularly extreme gradient boosting (XGBoost) [13], have emerged as a workhorse because they natively handle missing data, nonlinear feature interactions, and mixed data types. Recent examples include a non–small cell lung cancer microwave-ablation study where XGBoost achieved an area under the curve (AUC) of 0.89 [14]; a 2025 *Scientific Reports* analysis integrating survival models for breast cancer recurrence (concordance index [C-index]=0.82) [15]; a large colorectal cancer cohort where boosted trees yielded the highest 5-year survival accuracy [16]; and a thyroid cancer study that constructed a 10-year overall survival nomogram using Surveillance, Epidemiology, and End Results data [17].

Biomarkers are critical for early detection, diagnosis, prognosis, and monitoring. Traditional biomarker-discovery approaches often suffer from low sensitivity, limited reproducibility, and dependence on prior biological hypotheses. ML circumvents many of these limitations by integrating diverse data types and identifying complex nonlinear relationships. Algorithms such as random forests [18], support vector machines [19], and neural networks [20] have successfully identified biomarkers from gene expression [21-23], microRNA expression [24-27], DNA methylation [28,29], and imaging modalities [30-33].

Despite this progress, significant gaps persist at the intersection of scale, interpretability, and clinical use. First, while large datasets like the Memorial Sloan Kettering-Metastatic (MSK-MET) cohort [34] provide unprecedented scale, their analysis has largely relied on traditional statistics, failing to harness state-of-the-art ML for predictive modeling. Second, most ML survival-prediction studies focus on single tumor types, use modest sample sizes, or omit high-dimensional genomic features, limiting their generalizability to the pan-cancer reality of metastatic disease. Third, and most critically, interpretability remains a bottleneck; oncologists are understandably reluctant to incorporate opaque "black box" risk scores into clinical workflows. Explainable AI methods like Shapley additive explanations (SHAP) provide a mechanism for transparency. For instance, SHAP has revealed previously unknown drivers of prostate cancer mortality [35]. Although explainable AI frameworks offer a solution, large-scale, pan-cancer implementations that jointly optimize predictive performance and model explainability remain scarce. Consequently, the field lacks an interpretable, cross-tumor framework capable of ranking metastasis-specific risk factors at a scale that reflects real-world heterogeneity.

To address these critical gaps, we designed a methodological framework that moves beyond standard, single-model architectures. We leverage the MSK-MET dataset, a pan-cancer cohort of genomic and clinical data from 25,775 patients spanning 27 tumor types, as an ideal test bed for this purpose due to its scale and diversity. Our approach is conceived as a hierarchical and explainable pipeline specifically to tackle the challenges of data heterogeneity, the need for clinical trust, and biological discovery. It integrates rigorous pan-cancer benchmarking with targeted, tumor-specific submodels and crucially unifies ML classification with traditional survival analysis. This ensures that the predictive performance of our models is directly coupled with transparent, clinically actionable insights.

Driven by this methodology, our work addresses persistent gaps at the intersection of scale, interpretability, and clinical use in metastatic cancer prognosis. Leveraging a large pan-cancer cohort that captures real-world heterogeneity, we focus on whether explainable ML approaches can yield clinically useful

survivability predictions while providing transparent, biologically and clinically coherent insights across tumor types.

The primary aim of this study is to develop and validate an interpretable ML framework for predicting overall survival in patients with metastatic cancer. We hypothesize that (1) ML models will achieve clinically useful discrimination and calibration for survivability prediction, (2) explainable AI techniques will identify a core set of prognostic biomarkers that are consistently important across diverse tumor types, and (3) integrating ML predictions with established survival analysis techniques will yield a transparent and clinically actionable tool for risk stratification.

Methods

Overview

Figure 1 illustrates the steps followed to predict cancer survivability using explainable AI. Raw data were used to initially train the ML models, followed by SHAP analysis. Top features identified by SHAP were then further used in the survival analysis. The subsequent steps below detail how this was implemented. All analysis and visualization were carried out in Python (version 3.12; Python Software Foundation) with relevant packages and libraries such as *pandas*, *numpy*, *scikit-learn*, *shap,* etc.

Figure 1. Overview of the explainable machine learning (ML) pipeline for metastatic cancer survivability prediction. The Memorial Sloan Kettering-Metastatic (MSK-MET) cohort is preprocessed and balanced, then split into stratified training and test sets before training and tuning 5 candidate classifiers (extreme gradient boosting [XGBoost], random forest, logistic regression, decision tree, and naive Bayes). The best-performing XGBoost model is subsequently interrogated with Shapley additive explanations (SHAP) to identify key prognostic clinical and genomic features, which are then carried forward into downstream survival analyses (Kaplan-Meier curves, Cox proportional hazards models, and XGBoost-Cox) to generate time-to-event estimates and clinically interpretable risk stratification.
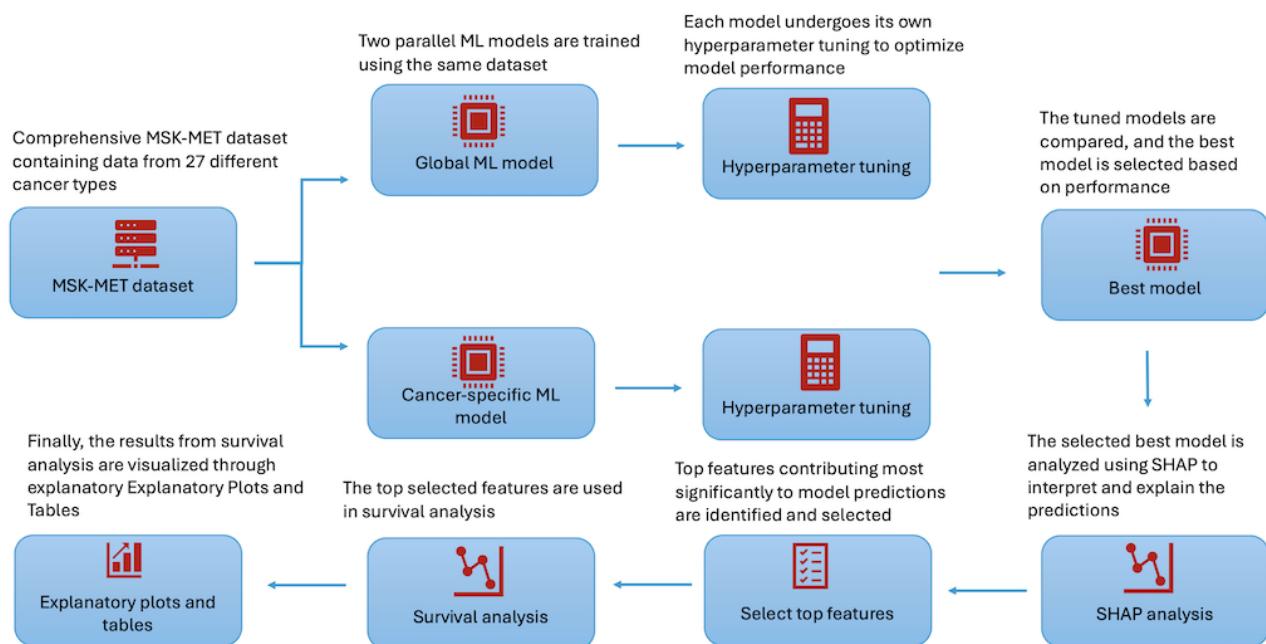
Data Preprocessing

We first performed a thorough exploratory data analysis on MSK-MET that contained information from 25,775 patients with cancer. Our exploratory data analysis process began with a comprehensive analysis of the dataset, including the distribution of different cancer types, stages, and other relevant features. This helped us gain a deeper understanding of the underlying patterns and structures, which informed subsequent preprocessing steps. We preprocessed the input dataset and dropped columns (such as patient ID) and rows having large proportions of missing data. The target variable had 2 classes, that is, living (positive class, coded as 1) and deceased (negative class, coded as 0). In the final stage of preprocessing, the data were balanced using the target classes. Using resampling, we down-sampled the minority class (0). The final set contained 20,338 patients (10,169 living and 10,169 deceased) with 39 variables for each patient. In total, there were 27 cancer types (Table 1). The overall survival status was the target variable for prediction. Categorical variables were encoded using label encoding, and features were scaled using minimum-maximum scaling to ensure that variables with larger magnitudes did not unduly influence model outcomes. The resulting preprocessed data were then split into training and testing sets for further analysis.

Table 1. Distribution of primary cancer types in the Memorial Sloan Kettering-Metastatic cohort. Frequency counts are reported for all cancer types represented in the dataset; the 5 largest groups (non–small cell lung, colorectal, breast, pancreatic, and prostate cancer) provided the primary strata for cancer-specific extreme gradient boosting models and downstream survival analyses.

Cancer type	Frequency count, n
Non–small cell lung cancer	3790
Colorectal cancer	2696
Breast cancer	2043
Pancreatic cancer	1738
Prostate cancer	1596
Endometrial cancer	988
Ovarian cancer	923
Melanoma	882
Bladder cancer	870
Hepatobiliary cancer	790
Esophagogastric cancer	738
Soft tissue sarcoma	420
Head and neck cancer	362
Thyroid cancer	319
Renal cell carcinoma	318
Gastrointestinal stromal tumor	286
Small cell lung cancer	277
Germ cell tumor	241
Mesothelioma	219
Appendiceal cancer	160
Uterine sarcoma	133
Salivary gland cancer	123
Gastrointestinal neuroendocrine tumor	115
Skin cancer (nonmelanoma)	87
Cervical cancer	80
Small bowel cancer	76
Anal cancer	68

Stratified Random Sampling of Training and Testing Sets

We used a stratified random sampling approach to create the training and test sets. First, we randomized the complete dataset to eliminate any inherent order or sequence. Then, we implemented stratification to ensure that the distribution of specific cancer types or stages in our training and testing sets mirrored that of the entire dataset. This is paramount to avoid potential biases and to ensure that our models have a representative sample of the different cancer types and stages present in the entire dataset. Following stratification, we allocated 80% of the data (16,270 patient records) to the training set while reserving the remaining 20% (4068 patient records) for the test set. This approach provides a robust foundation for model development and validation, ensuring both broad and deep representation of the dataset in our training and testing phases.

Selection and Screening of ML Models for Cancer Survival Prediction

This study used 5 ML algorithms—XGBoost, naive Bayes, decision tree, logistic regression, and random forest—to predict cancer survival rates using the MSK-MET dataset. XGBoost was selected for its efficiency in handling sparse data and combining models to improve accuracy through ensemble learning. Naive Bayes, a simple classifier applying Bayes theorem, was chosen for its efficiency in high-dimensional datasets. The decision tree, known for its easy visualization and handling of nonlinear relationships, was included for its interpretability. Logistic regression was used for binary classification, predicting survival probabilities, while random forest, an ensemble method using multiple decision trees, was

chosen for its accuracy and control over overfitting in large datasets.

Hyperparameter Optimization Via Grid Search and Model Training

Grid search with hyperparameter tuning was applied to all 5 ML models. For XGBoost, parameters "n_estimators" (50-1000), "max_depth" (1-10), and "learning_rate" (0.01-0.3) were adjusted to optimize the number of trees, tree depth, and learning speed. Naive Bayes was tuned by varying "alpha" (0.01-10.0), "binarize" (0.0, 0.5, 1.0), and "fit_prior" (True/False). The decision tree's grid search adjusted "max_depth" (None-10), "min_samples_split" (2, 5, 10), "min_samples_leaf" (1, 2, 4), and "criterion" ("gini" or "entropy"). Logistic regression was optimized with "C" (0.001-1000), "penalty" ("l1," "l2," "elasticnet," "none"), and "solver" ("newton-cg," "lbfgs," "liblinear," "sag," "saga"). Random forest explored "n_estimators" (50, 100, 200) and "max_features" ("auto," "sqrt").

Using 5-fold cross-validation on the MSK-MET dataset, we trained the 5 classifiers to identify a robust, interpretable predictor and to derive a cohort-wide view of metastatic patterns.

Model Evaluation

After training and testing the ML models on the MSK-MET dataset, we assessed their performance using 2 key metrics: the classification report (Table S2 in Multimedia Appendix 1) and AUROC (Figure 2). The AUROC measures the model's ability to distinguish between classes, with higher AUC indicating better prediction. A score of 1 represents perfect predictions, 0.5 indicates random guessing, and below 0.5 suggests worse than random predictions. These metrics provide a comprehensive evaluation, ensuring the models not only predict accurately but also effectively identify positive cancer cases. This approach helps in selecting the best model for predicting cancer survival, balancing the need to detect true cases while minimizing false diagnoses.

Figure 2. Receiver operating characteristic (ROC) curves for the 5 tuned classifiers on the held-out Memorial Sloan Kettering-Metastatic test set. Each curve shows the trade-off between sensitivity and 1 – specificity across decision thresholds, with corresponding area under the curve values summarized in Table 2. The extreme gradient boosting (XGBoost) model achieves the steepest ROC trajectory and highest area under the receiver operating characteristic curve (AUROC=0.82), indicating the strongest discrimination between surviving and deceased patients, while random forest and logistic regression (LogisticReg) form an intermediate tier, and decision tree and Bernoulli naive Bayes (BernoulliNB) exhibit comparatively weaker performance.

To characterize operating-point behavior, we computed threshold-dependent trade-offs of true positive (TP), false positive (FP), true negative (TN), and false negative (FN);

sensitivity, specificity, precision, negative predictive value (NPV), F_1-score, balanced accuracy, Matthews correlation coefficient (MCC), Cohen κ, and accuracy at 3 decision

thresholds: a fixed 0.50, the Youden J optimum, and a clinically constrained point targeting sensitivity ≥0.85. Scalar metrics were accompanied by 95% CI obtained via a 1000-sample stratified bootstrap.

To obtain unbiased estimates and avoid tuning leakage, we used nested repeated cross-validation on the training data. The outer loop applied RepeatedStratifiedKFold (5 folds × 10 repeats); within each outer training split, an inner 5-fold GridSearchCV tuned hyperparameters per model. Inner-tuned models were then scored on their corresponding outer validation splits, yielding a matrix of outer cross-validation (CV) results. The model with the highest mean outer-CV performance was refit on the full training set using the selected hyperparameters and evaluated once on the held-out test set (reporting accuracy, AUROC, and a confusion matrix).

For statistical comparison across the 5 models, we ran a Friedman omnibus test on the outer-CV score matrix. As a prespecified confirmatory analysis, we tested the directional hypothesis that random forest ≥ each baseline using 1-sided Wilcoxon signed-rank tests with Holm correction; we also reported effect sizes (mean and median paired differences) with 95% paired bootstrap CI. For rank-based visualization and exploratory post hoc inference, we computed average ranks with a Nemenyi critical-difference diagram and performed 1-sided Wilcoxon tests comparing the top-ranked model to the remaining models (Holm-adjusted). Where paired per-example test predictions were available, we used the McNemar test to compare error patterns between 2 models.

Cancer Survival Prediction With XGBoost

XGBoost was therefore chosen for the rest of the analyses, involving both pan-cancer and cancer-specific models, metastatic cancer survival prediction, and survival analysis. To enhance transparency and clinical interpretability, we adopted a 2-tier XGBoost design. First, a unified XGBoost model was trained without the "Cancer Type" variable, leveraging clinical and demographic features to capture signals that generalize across diseases. Second, we trained cancer-specific XGBoost models for the 5 largest cancer groups identified in the cohort to capture within-disease interactions that can be diluted in a single global model. This combination provides both a cross-cancer perspective and disease-tailored insights that reflect differences in metastatic behavior and treatment context. In the final evaluation for both global and cancer-specific analysis, we focused only on measuring accuracy and AUC score.

Model Interpretation and Explanation

To enhance the understandability and transparency of our predictions, we used XGBoost and SHAP for model explainability. SHAP, based on game theory, provides a detailed and consistent measure of feature importance by computing each feature's contribution to the prediction. SHA*P* values represent a feature's responsibility for a change in the model output, ensuring local accuracy, missingness, and consistency. This method quantifies the impact of each feature on predictions and explains how the presence or absence of a feature affects the outcome. In our SHAP analysis, survival is the positive class. Beeswarm plots are particularly useful for visualizing

SHA*P* values, showing features' influence and variability in a nuanced manner.

Survival Analysis

Following the training of the XGBoost ML model and SHAP analysis, the most important features, such as metastatic site count, tumor mutational burden (TMB), and specific organ metastases (eg, liver, bone, and lung) influencing patient survival, were identified and used in the survival analysis. The primary goal was to examine the duration from cancer diagnosis to patient death, assessing how clinical and genomic variables impact survival times. We used Kaplan-Meier survival analysis, CPH modeling, log-rank tests for comparing survival distributions, and XGBoost survival analysis to deepen our understanding of patient outcomes. All of the original data was used in the survival analysis.

Kaplan-Meier Survival Analysis

The Kaplan-Meier estimator was used to evaluate survival probabilities over time across different patient subgroups. Patients were stratified based on key features identified from SHAP analysis. Survival curves were compared using the log-rank test to assess statistically significant differences between groups. A P value of <.05 was considered statistically significant. The analysis was first performed on all the data to assess survival of patients with metastatic versus nonmetastatic disease and then on subgroups of the top 5 cancer types including non–small cell lung cancer, colorectal cancer, breast cancer, pancreatic cancer, and prostate cancer.

CPH Model

The CPH model was applied to assess the influence of multiple covariates on patient survival while controlling for potential confounders. Key covariates included metastatic site count, fraction of genome altered, TMB, and distant metastases in specific organs. The proportional hazards assumption was evaluated using Schoenfeld residuals, and any violations were addressed through stratification or inclusion of time-varying covariates. Hazard ratios with corresponding 95% CI were reported to quantify risk associations.

Log-Rank Test

To further compare survival distributions between different patient cohorts, the log-rank test was applied. This test was used to determine whether survival differences observed between patient subgroups (eg, metastatic vs nonmetastatic) were statistically significant. The resulting P values guided the identification of meaningful clinical predictors. Furthermore, a plot was generated for the Kaplan-Meier survival curves with the overall survival (months) on the x-axis and survival probability on the y-axis.

XGBoost Survival Analysis

To capture complex, nonlinear relationships and interactions among variables, XGBoost survival analysis was implemented. This adaptation of XGBoost used a Cox-based loss function to accommodate censored survival data. Hyperparameter tuning was conducted using grid search, optimizing parameters such as "n_estimators," "max_depth," and "learning_rate." The model's C-index was used to evaluate predictive performance.

SHA*P* values were also applied to the survival model to interpret feature importance and explore individual risk predictions.

Ethical Considerations

This study analyzed secondary, noninterventional data from the MSK-MET cohort obtained via a publicly accessible repository (cBioPortal for Cancer Genomics). All records used for modeling and statistical analysis were anonymous and deidentified prior to access; no direct identifiers (eg, names, street addresses, full dates of birth, medical record numbers) or indirect reidentification keys were available to the research team. Because only deidentified data were used and no contact with human participants occurred, the work was considered non–human participants research and did not require informed consent or additional institutional review.

Data handling procedures followed best-practice privacy safeguards. Working datasets were stored on access-controlled systems. We did not attempt any record linkage or reidentification. To support responsible AI, model development incorporated transparent methods (eg, SHAP explanations) and prespecified subgroup evaluations to screen for potential performance disparities. All code and evaluation protocols are shared to enable reproducibility without exposing any protected information.

Results

Model Performance

The evaluation of the 5 distinct models on the MSK-MET dataset yielded a spectrum of performances. The overall classification performance for the 5 classifiers is summarized in Table 2. Receiver operating characteristic (ROC) curves are shown in Figure 2, and precision-recall curves are shown in Figure S2A, calibration in Figure S2B, decision-curve analysis in Figure S2C, and threshold-dependent metrics in Figure S2D in Multimedia Appendix 1.

Table 2. Discrimination and calibration of tuned classifiers on the same test set. Reported are area under the curve (AUC), area under the precision-recall curve (AUPRC), and Brier score, each with 95% CIs; the outcome prevalence was 0.50. Extreme gradient boosting (XGBoost; lr=0.01; depth=5; n=500) showed the strongest overall performance, with the highest AUC and AUPRC and the lowest Brier score, followed by random forest, while logistic regression, decision tree, and naive Bayes exhibited progressively lower discrimination and less favorable calibration.

Model	AUC (95% CI)	AUPRC (95% CI)	Brier score (95% CI)
XGBoost (lr=0.01; depth=5; n=500)	0.82 (0.81-0.84)	0.83 (0.81-0.85)	0.17 (0.16-0.18)
Random forest (n_estimators=200; max_features=auto)	0.80 (0.78-0.81)	0.81 (0.79-0.82)	0.18 (0.18-0.19)
Logistic regression (C=10; l2; liblinear)	0.79 (0.78-0.81)	0.79 (0.77-0.81)	0.19 (0.18-0.19)
Decision tree (gini; depth=8; min_leaf=1; min_split=10)	0.78 (0.77-0.80)	0.78 (0.76-0.80)	0.19 (0.18-0.20)
Naive Bayes (α=10.0; binarize=0.5; fit_prior=False)	0.78 (0.77-0.80)	0.77 (0.75-0.79)	0.21 (0.20-0.22)

XGBoost demonstrated the strongest discrimination and probability quality. It achieved an AUC of 0.82 (95% bootstrap CI 0.81-0.84) and the highest area under the precision-recall curve (AUPRC) at approximately 0.83 against a baseline precision equal to the prevalence (0.50; Table 2 and Table S2 in Multimedia Appendix 1). In accuracy terms, XGBoost reached 0.74 (3010/4068) and, for our summary counts, corresponded to 3335 out of 4068 test patients correctly stratified at the chosen operating point. Random forest (AUC=0.80; AUPRC=0.81) and logistic regression (AUC=0.79; AUPRC=0.79; accuracy=0.72; 2929/4068) formed a consistent middle tier, while decision tree and Bernoulli naive Bayes trailed slightly (both AUC=0.78; accuracy=0.72; 2929/4068; correctly stratified=3173/4068 for AUC-aligned counts; see Table 3 and Table S3 in Multimedia Appendix 1 for detailed counts and metrics). These rankings were concordant across ROC and precision-recall analyses and remained stable across threshold-dependent operating points (fixed threshold=0.50, Youden J optimum, and a clinically constrained sensitivity ≥0.85; Figure 2; Figures S2A and S2D and Tables S2 and S3 in Multimedia Appendix 1).

Calibration analyses reinforced this ordering. XGBoost produced the lowest Brier score (approximately 0.17; Table 2; Table S2 and Figure S2B in Multimedia Appendix 1) and a reliability curve that closely tracked the 45° line, with logistic regression comparably well-calibrated, whereas Bernoulli naive Bayes deviated most at the extremes (Table 2; Table S2 and Figure S2B in Multimedia Appendix 1).

Table 3. Compact comparison of 5 classifiers across 3 operating points, that is, default probability cutoff (0.50), Youden J (threshold maximizing sensitivity + specificity − 1), and a high-sensitivity setting (constrained to sensitivity ≥0.85). For each model-threshold pair, we report sensitivity, specificity, Matthews correlation coefficient (MCC), and accuracy; thresholds are applied to the predicted positive-class probability. This summary emphasizes decision-relevant trade-offs: balanced performance at Youden J and the specificity cost of prioritizing high sensitivity. In this cohort, extreme gradient boosting (XGBoost) yields the strongest balanced performance (highest MCC and accuracy) at Youden J while retaining the best specificity among the high-sensitivity operating points.

Model and operating point	Threshold	Sensitivity	Specificity	MCC	Accuracy
Naive Bayes					
Probability cutoff 0.5	0.50	0.66	0.78	0.44	0.72
Youden J	0.50	0.65	0.78	0.44	0.72
Sensitivity ≥0.85	0.15	0.85	0.52	0.39	0.69
Decision tree					
Probability cutoff 0.5	0.50	0.72	0.71	0.43	0.72
Youden J	0.56	0.64	0.80	0.45	0.72
Sensitivity ≥0.85	0.32	0.86	0.49	0.37	0.67
Logistic regression					
Probability cutoff 0.5	0.50	0.73	0.73	0.45	0.73
Youden J	0.53	0.69	0.77	0.46	0.73
Sensitivity ≥0.85	0.38	0.85	0.54	0.41	0.69
Random forest					
Probability cutoff 0.5	0.50	0.69	0.76	0.45	0.72
Youden J	0.49	0.70	0.75	0.46	0.73
Sensitivity ≥0.85	0.32	0.85	0.54	0.41	0.69
XGBoost					
Probability cutoff 0.5	0.50	0.72	0.78	0.50	0.75
Youden J	0.50	0.72	0.78	0.50	0.75
Sensitivity ≥0.85	0.33	0.85	0.58	0.45	0.72

Threshold-dependent performance, summarized from confusion matrix–derived metrics at 3 operating points, made the error trade-offs explicit (Table 2; Table S3 and Figure S2D in Multimedia Appendix 1). At a fixed 0.50 threshold essentially indistinguishable from the Youden J optimum on this balanced test set, XGBoost balanced sensitivity and specificity most effectively (sensitivity=0.72; specificity=0.78; positive predictive value (PPV)=0.77; NPV=0.74; F_1-score=0.74; MCC=0.50; accuracy=0.75). Under a clinically constrained operating point prioritizing case-finding (sensitivity ≥0.85), XGBoost required a threshold of approximately 0.33 and achieved a sensitivity of 0.85 (specificity=0.58; PPV=0.67; NPV=0.80; F_1-score=0.75; MCC=0.45; accuracy=0.72). The corresponding counts at this setting were TP=1731, FP=846, TN=1188, and FN=303 (n=4068). Comparator models met the same sensitivity target with lower specificity and weaker composite indices; for example, random forest and logistic regression both settled near a specificity of 0.54 with MCC=0.41, while decision tree and Bernoulli naive Bayes lost additional specificity and MCC. These results indicate that, when sensitivity is held high, XGBoost preserves more TNs

and maintains stronger global agreement (MCC, balanced accuracy).

Decision-curve analysis supported the same ordering of clinical use across a broad range of threshold probabilities (approximately 0.15-0.70), with XGBoost yielding the highest net benefit, random forest next, and logistic regression close behind (Figure S2C and Table S2 in Multimedia Appendix 1). Together with the calibration findings, these analyses suggest that XGBoost not only separates cases from controls most effectively but also produces usable risk estimates for thresholding and shared decision-making.

Furthermore, when the global XGBoost model was compared to cancer-specific XGBoost models for the top 5 cancer types (non–small cell lung, colorectal, breast, pancreatic, and prostate cancer; Tables 4 and 5), the prostate cancer model emerged as the most accurate, with an AUC of 0.88 and an accuracy of 0.84. (268/319 test patients) and an AUC of 0.88 (281/319 test patients correctly stratified). Meanwhile, pancreatic cancer posted a lower AUC of 0.68 (236/348 test patients correctly stratified), reflecting greater challenges in classification for that subgroup.

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Table 4. Condensed Cox proportional hazards model for overall survival in the Memorial Sloan Kettering-Metastatic cohort. Hazard ratios (HRs), 95% CIs, and *P* values are reported for the most influential covariates identified in the global model, showing that metastatic status, higher metastatic site count, increased tumor mutational burden (TMB), greater fraction of genome altered, and distant metastases to liver, bone, and lung are all associated with significantly elevated mortality risk, whereas primary sample type is modestly protective.

Risk factor	HR (95% CI)	*P* value
Patient with metastatic disease	2.18 (1.97-2.42)	<.001
Metastatic site count	1.03 (1.02-1.04)	<.001
TMB (nonsynonymous)	1.00 (0.99-1.00)	<.001
Fraction of genome altered	1.32 (1.19-1.46)	<.001
Sample type (primary=ref)	0.87 (0.83-0.90)	<.001
Distant metastasis: liver	1.81 (1.73-1.90)	<.001
Distant metastasis: bone	1.43 (1.37-1.50)	<.001
Distant metastasis: lung	1.16 (1.11-1.22)	<.001

Table 5. Comparison of classification performance between the unified or global extreme gradient boosting (XGBoost) model and cancer-specific XGBoost models. Overall accuracy and area under the curve (AUC) are reported for each classifier, showing that while the global model achieves strong baseline discrimination (accuracy=0.74; AUC=0.82), several cancer-specific models, particularly prostate and breast cancer, attain even higher AUCs (0.88 and 0.85, respectively), whereas the pancreatic cancer model lags behind, reflecting underlying heterogeneity in predictability across tumor types.

Classifier	Accuracy score	AUC score
Unified or global model	0.74	0.82
Non–small cell lung model	0.71	0.79
Colorectal cancer model	0.73	0.81
Breast cancer model	0.76	0.85
Pancreatic cancer model	0.72	0.68
Prostate cancer model	0.84	0.88

Model Explainability

The SHAP analysis of the global XGBoost model established a clear hierarchy of feature importance, identifying metastatic site count, TMB, fraction of genome altered, and distant metastases to the liver and bone as the predominant prognostic factors (Figure 3 and Table S6 in Multimedia Appendix 1). The beeswarm plots for these top features demonstrated a robust predictive power, with high and low feature values cleanly separating along the SHA*P* value axis, indicating a consistent and strong directional impact on model output (Figures S3A-S3E in Multimedia Appendix 1).

Figure 3. Shapley additive explanations (SHAP) beeswarm plot for the global extreme gradient boosting (XGBoost) mortality classifier in the Memorial Sloan Kettering-Metastatic cohort. Features are ordered by mean absolute SHAP value, highlighting metastatic (Met) site count, tumor mutational burden (TMB), fraction of genome altered (FGA), and distant metastases to the liver and bone as the strongest drivers of model predictions. Each point represents a patient, with horizontal position indicating the direction and magnitude of impact on predicted mortality risk and color denoting low (blue) to high (red) feature values, illustrating how extreme values systematically shift risk estimates. Central nervous system is denoted by CNS.
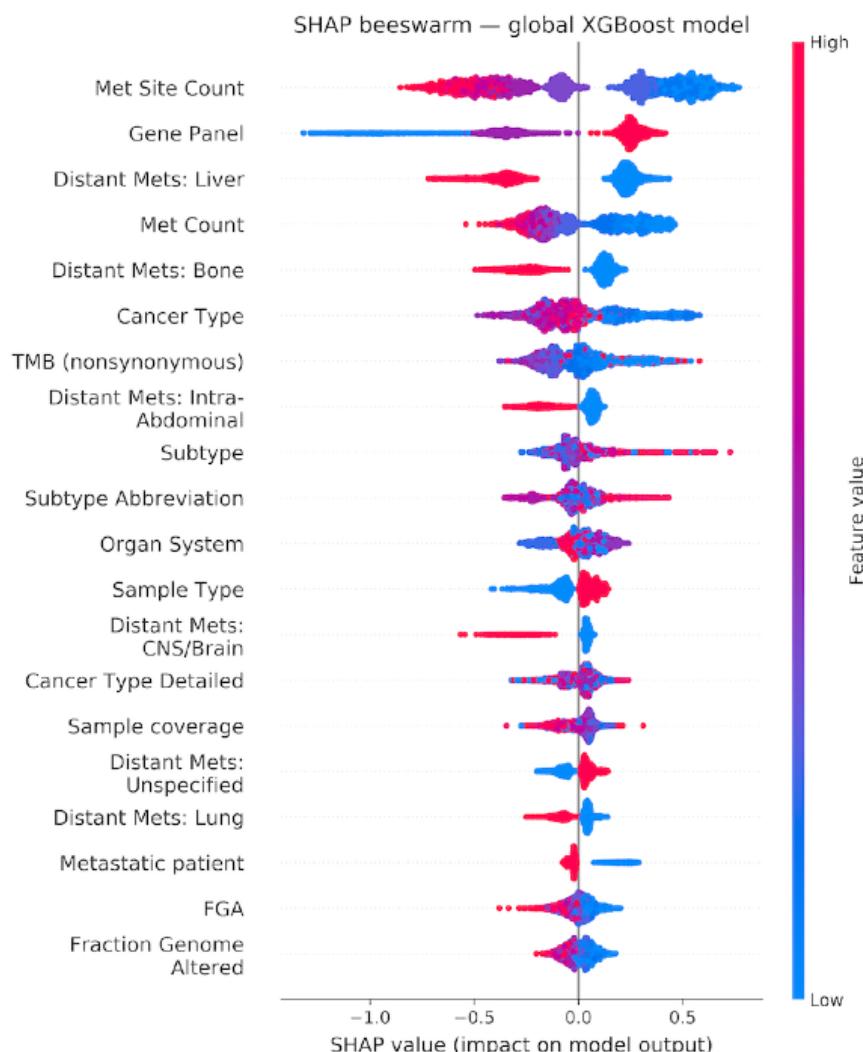
This analysis was extended to cancer-specific models, revealing a critical dual perspective, that is, the core features identified in the global model recurrently ranked among the most important across individual cancer types, while disease-specific features also emerged. For instance (Table S6 and Figures S3A-S3E in Multimedia Appendix 1), the global top features like metastatic burden and liver metastases remained highly influential in specific models such as colorectal and prostate cancer. Concurrently, the models identified context-specific predictors, such as distant metastasis in the lung for non–small cell lung cancer, sample type for breast cancer, and distant metastasis in the male genital for prostate cancer (Figure 3; Figures S3D and S3E in Multimedia Appendix 1). This underscores that while a common set of pan-cancer drivers exists, the models successfully capture nuanced, disease-specific metastatic behaviors.

The consistent importance of features like metastatic site count was further validated by the SHAP force plot (Figure 4), which visually confirmed that an increasing number of metastatic sites directly correlated with a higher model output for mortality risk, reinforcing the clinical and biological plausibility of the model's predictions.

Figure 4. Shapley additive explanations force plot illustrating the impact of metastatic (Met) site count on predicted mortality risk for the first 1000 patients in the Memorial Sloan Kettering-Metastatic test set. Each horizontal bar represents an individual patient, with the baseline prediction shown at the center and shifts toward higher (right, red) or lower (left, blue) mortality risk driven by the number of metastatic sites. The consistent rightward push associated with increasing metastatic site count visually confirms its strong, monotonic contribution to higher predicted risk, reinforcing the biological and clinical plausibility of the extreme gradient boosting model's behavior.
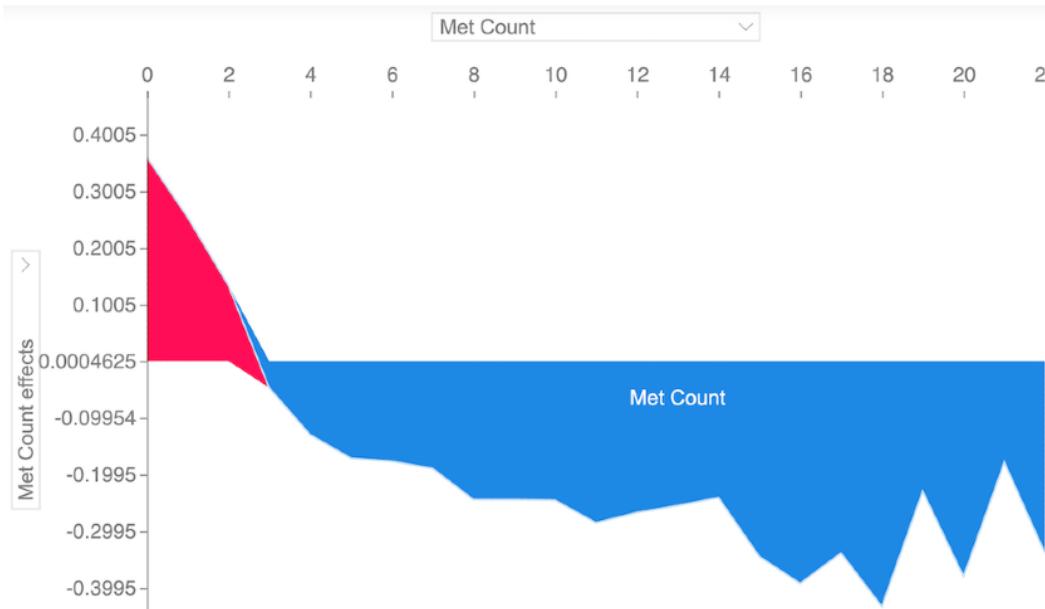
Survival Analysis

In the Kaplan-Meier analysis (Figure 5 and Table S7 in Multimedia Appendix 1), patients were stratified into "metastatic" and "nonmetastatic" groups to compare differences in overall survival. The survival probability of patients in the metastatic group was notably lower than that of the nonmetastatic group, as seen in the pronounced separation of their survival curves. By approximately 80 months, patients with metastatic disease exhibited a survival probability of 0.30 (3041/10,169 patients with metastatic disease) versus 0.80 (8135/10,169 patients without metastatic disease), underscoring the substantial impact of metastatic status on long-term survival outcomes.

Figure 5. Kaplan-Meier survival curves comparing overall survival in patients with vs without metastatic disease in the Memorial Sloan Kettering-Metastatic cohort. Patients with metastases demonstrate markedly lower survival probabilities and earlier median survival times than patients without metastases, underscoring the substantial impact of metastatic status on long-term outcomes.
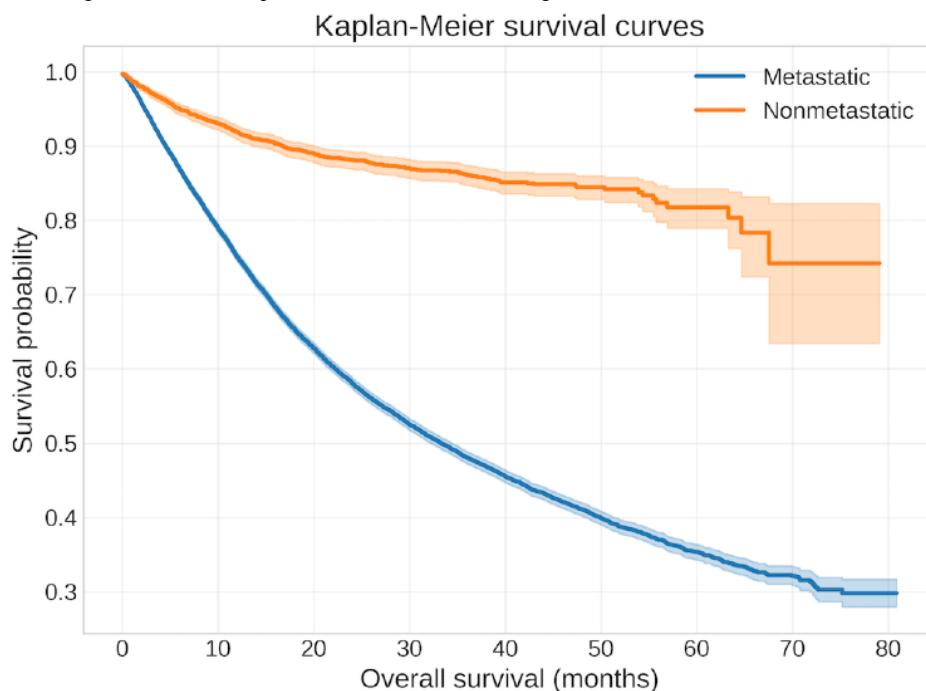
Subgroup survival results for the top 5 cancer types were as follows: in non–small cell lung cancer (n=4686), 43.75% (n=2050) of patients experienced an event and 82.5% (n=3866) presented with metastatic disease; the median overall survival

was 17.7 (IQR 8.4-33.2) months. In colorectal cancer (n=3541), the event rate was 33.52% (n=1187), the metastatic proportion was 90.82% (n=3216), and the median survival was 17.5 (IQR 10-30) months.

In breast cancer (n=2601), 35.64% (n=927) experienced an event and 76.47% (n=1989) had metastatic disease, with a median survival of 33 (IQR 14.4-43.4) months. In pancreatic cancer (n=1981), the event rate was 60.27% (n=1194), the metastatic proportion was 93.54% (n=1853), and the median survival was 11.6 (IQR 4.2-21.8) months. Finally, in prostate cancer (n=2166), 26.45% (n=573) experienced an event and 81.12% (n=1757) had metastatic disease, with a median survival of 21.6 (IQR 11.6-38.2) months (Figure S5A-S5E in Multimedia Appendix 1).

In the CPH model (Table 4), factors like metastatic site count, TMB, fraction of genome altered, and distant metastases displayed hazard ratios above 1.0, indicating an increased risk of mortality. These relationships attained statistical significance, with P values under the established threshold. The proportional hazards assumption was checked through Schoenfeld residuals, and only minor deviations were noted, which did not substantially affect the covariate estimates. The model's C-index reached approximately 0.66, reflecting moderate predictive power in distinguishing survival outcomes among different patient subgroups.

An XGBoost survival model, fitted with a Cox-based loss function, achieved a higher C-index (0.7) than the standard Cox model. In Table S7 in Multimedia Appendix 1, the model's important features are displayed, with distant metastasis, TMB, and fraction of genome altered, among others, listed as the most important features that influence the prediction.

Discussion

Principal Findings

Using a large, multitumor metastatic cohort (MSK-MET), we developed explainable ML models for survivability prediction and complemented them with time-to-event modeling. Among conventional classifiers, XGBoost delivered the best overall performance, achieving an accuracy of 0.74 and AUC=0.82 on the held-out test set. In parallel, an XGBoost-Cox variant improved time-to-event concordance over a standard Cox model (C-index=0.70 vs 0.66, with key hazard ratios from the Cox model). Model explanations (SHAP) and hazard-based analyses converged on clinically recognizable prognostic factors: the number of metastatic sites, TMB, fraction of genome altered, and the presence of liver and bone metastases, while cancer-specific performance varied in biologically plausible ways (eg, higher AUC in prostate and lower in pancreatic). At the Youden-optimal threshold, PPV was approximately 70% and NPV approximately 80%, indicating practical use for risk stratification in balanced decision contexts. We expand the discussion of these findings in the following subsections.

Model Performance, Robustness, and Benchmarking

Our evaluation moved beyond accuracy to provide a comprehensive assessment across discrimination, calibration, operating-point trade-offs, and clinical use. XGBoost consistently emerged as the most dependable model, with its incremental gains in AUC and AUPRC translating into more favorable confusion-matrix profiles at clinically relevant thresholds. For instance, when sensitivity is constrained to be high, XGBoost retains more specificity and a higher MCC, reducing FPs without sacrificing case finding. Its well-calibrated probability estimates are crucial for decision support, enabling rational threshold selection and clear communication of absolute risk.

The model's practical use is further evidenced by its performance across different decision contexts. For balanced decision-making, a default threshold near 0.50 (coinciding with the Youden J optimum) provides a sensible starting point. In triage-like scenarios demanding high sensitivity, a lower threshold around 0.33 yields sensitivity near 0.85 with tolerable specificity losses and an NPV around 0.80. Decision-curve analysis confirmed that XGBoost provides a larger net benefit across a wide band of threshold probabilities, suggesting robustness to varying clinical preferences.

These performance results harmonize with model explanations and survival evidence. SHAP analyses validate that predictions are driven by biologically sensible covariates, while survival curves and hazard ratios show coherent, directionally consistent effects. This triangulation across discrimination, calibration, interpretability, and survival analysis adds credibility that the learned signal reflects underlying disease biology rather than being an artifact of the classifier or data split.

Parameter Sensitivity and Model Robustness

During extensive grid-search tuning, we found that XGBoost hyperparameters, especially tree depth, learning rate, and number of estimators, greatly influenced AUC and classification accuracy. Shallow trees underfit, while deeper ones improved performance but risked overfitting in smaller cancer-specific cohorts. Learning rates below 0.05 caused slow convergence, while overly high rates destabilized training. Despite this variability, certain predictive features, particularly metastatic burden and genomic alterations, remained consistently impactful, underscoring the robustness of our model. Future research could explore adaptive optimization techniques such as Bayesian optimization or reinforcement learning for enhanced generalizability.

Is the Performance "Good Enough"?

The discriminatory performance of prognostic models is central to their clinical use. In oncology, C-index or AUC of at least 0.70 is generally regarded as the minimum threshold for clinical usefulness, while values exceeding 0.80 are considered strong and often necessary for clinical translation [36,37]. These interpretive standards are rooted in established methodological work on ROC analysis, where AUC values between 0.7 and 0.8 are typically described as "acceptable" and those above 0.8 as "excellent" [36,37].

Evidence from systematic reviews of head and neck cancer prognostic models demonstrates how these thresholds translate into practice. Philip et al [38] reported that most radiomics-based prognostic models achieved C-indices below 0.70, underscoring their weak discriminatory power and limited clinical

applicability. In contrast, externally validated models that approached or exceeded the 0.80 mark, as summarized by Dretzke et al [39], were identified as more robust and clinically relevant, supporting their potential integration into patient management. These findings emphasize that models below the 0.70 threshold may remain academically interesting but lack sufficient reliability for routine use, whereas those meeting or surpassing 0.80 provide stronger grounds for clinical adoption.

Comparisons with deep learning approaches further reinforce this interpretation. Gouthamchand et al [40] found that the most competitive deep learning models in head and neck oncology consistently achieved AUCs of 0.80 or higher, placing them above many handcrafted radiomics models. This pattern suggests that 0.80 represents not merely an aspirational benchmark but an increasingly practical requirement for prognostic tools aiming to match or surpass the performance of advanced ML methods already being piloted in clinical contexts.

Regulatory precedents also align with this threshold. Analyses of Food and Drug Administration (FDA)–cleared AI- and ML-enabled medical devices, such as the LumineticsCore software, indicate that most systems demonstrate discriminatory performance in the high 0.7 to 0.9 range, with pivotal studies for devices such as IDx-DR reporting AUCs above 0.80. Joshi et al [41] provide a comprehensive overview of this landscape, confirming that AUCs in this range are characteristic of AI systems deemed safe and effective for clinical use. FDA guidance similarly emphasizes the importance of demonstrating robust discriminatory performance in supporting claims of clinical effectiveness [42].

However, the thresholds discussed here should not be treated as rigid cutoffs. Clinical acceptability is not defined by a single number but by the context of the decision, the potential harms and benefits, and the baseline risk of the population. In high-stakes oncology decisions such as treatment intensification that carries significant morbidity, a well-calibrated model with an AUC of 0.78 but demonstrable net benefit at clinically relevant thresholds may be more valuable than a model with an AUC of 0.84 that is poorly calibrated or unstable. Thus, performance thresholds should be interpreted as contextual benchmarks rather than universal standards.

It is also important to recognize that discrimination does not equal usefulness. AUC or C-index quantifies a model's ability to rank patients by risk, but it does not measure whether the absolute risk estimates are accurate. For clinical practice, calibration is equally critical whether a patient predicted to have a 30% risk actually experiences that outcome about 30% of the time. Calibration-in-the-large, calibration slope, Brier score, and visual calibration plots provide this essential information. Moreover, calibration at clinically meaningful cut points (eg, deciles of predicted risk) is necessary to ensure predictions are trustworthy for patient counseling and decision-making.

Finally, prognostic end points in oncology are often time-to-event outcomes. In such settings, the C-index is commonly used, but time-dependent AUCs provide more clinically interpretable information by specifying the prediction horizon (eg, 12-month or 36-month survival). This allows clinicians to understand how well the model performs over the actual time frames relevant to follow-up and treatment decisions. Where applicable, handling of censoring and competing risks should also be reported, particularly if the terminal outcome is mortality.

Taken together, these considerations emphasize that while an AUC ≥0.80 is encouraging and aligns with many published benchmarks, true clinical use depends on calibration, decision-curve analysis, and performance at specific decision thresholds relevant to patient care.

Clinically Actionable Metrics, Implications, and Use

The performance metrics of our optimal XGBoost model are translated into clinically actionable insights through decision-curve analysis. At the threshold maximizing the Youden index, the model achieves a PPV of 70.3% and an NPV of 79.8%. This indicates that a high-risk prediction from the model would correspond to an actual terminal outcome in approximately 7 out of 10 cases, supporting its use in justifying intensified monitoring or treatment. Conversely, the high NPV means 8 out of 10 low-risk predictions correctly identify patients with a more favorable prognosis, providing a quantitative basis for discussions about de-escalating care and reducing treatment-related morbidity.

Critically, the decision-curve analysis confirms the model's practical use across a spectrum of clinical decision-making preferences. The analysis demonstrates that the XGBoost model provides a superior net benefit compared to both alternative models and the default strategies of treating all or no patients across a wide range of threshold probabilities. This indicates that using the model to guide decisions is clinically advantageous regardless of whether the clinician prioritizes avoiding FPs (overtreatment) or FNs (missed interventions). The point at which the net benefit of the model crosses the "treat all" strategy is particularly important, as it defines the minimum probability at which the model's prediction becomes more useful than intervening in every case. The sustained positive net benefit of our model underscores its robustness and potential to improve patient outcomes by aligning interventions with individualized risk.

The combination of strong predictive performance and model explainability supports several immediate clinical use cases: (1) patient triage and counseling via individualized risk summaries, (2) treatment planning and shared decision-making aided by feature-level rationales, and (3) integration into electronic health record (EHR)–embedded dashboards for longitudinal monitoring. The top predictive features are routinely available in most cancer centers, facilitating adoption with minimal workflow disruption.

Model Explainability and Biological Plausibility

Our model selection was guided by metrics that reflect clinical reality, prioritizing both accuracy and AUROC. The AUROC is especially critical in medical settings, as it captures the essential balance between TPs and FPs, where the cost of FNs (missed cases) is high [43]. This evaluation consistently identified XGBoost as the top performer. Its superior ability to capture complex, nonlinear relationships within high-dimensional clinical and genomic data, as evidenced by

its significant lead over other models, aligns with established literature on gradient boosting for cancer predictions [44,45]. The model's discriminative power is substantial, with an AUC of 0.82 representing an excess over chance of 0.32. This can be intuitively communicated as a "number needed to screen" of approximately 3-4 patients to identify 1 additional correct classification relative to chance, providing a tangible sense of clinical yield. This strong performance is operationalized at the Youden-optimal threshold, where PPV of approximately 70% and NPV of approximately 80% offer concrete use for risk stratification, effectively ruling in or ruling out high-risk status to guide downstream clinical actions.

Crucially, this high performance is rendered transparent and trustworthy through SHAP-based interpretation. The model's decisions are not black box outputs but are demonstrably driven by biologically plausible features that align with oncological principles. SHAP analysis consistently identified metastatic site count, liver and bone metastases, TMB, and fraction of genome altered as the top predictors; moreover, these findings are well-supported in the literature [46]. This biological plausibility was further refined and validated in our cancer-specific models. For example, the prominence of lung metastases in non–small cell lung cancer and prostate cancer models, and the major role of sample type in the breast cancer model, demonstrate a nuanced understanding of disease-specific pathophysiology as pointed out in other studies [47]. The distinct, right-skewed SHAP distribution for "metastatic count" and its direct correlation with risk in force plots further reinforced the importance of total lesion burden in driving high-risk predictions. This coherence between model explanations and established clinical knowledge across both pan-cancer and disease-specific contexts is fundamental for building clinician trust and facilitating the integration of this tool into point-of-care decision support.

Survival Modeling and Risk Stratification

Time-to-Event Insights

Survival analysis confirmed classification results. Kaplan-Meier curves revealed steep survival drops in patients with versus without metastatic disease (0.3 vs 0.8 at 80 months). Traditional Cox models identified high hazard ratios for metastatic site count, TMB, and fraction of genome altered but struggled with their linearity assumptions (C-index=0.66). In contrast, XGBoost-based survival modeling better captured nonlinearity, achieving a higher C-index of 0.70.

Subgroup Survival Analysis

The 5 disease-specific results highlight substantial heterogeneity in survival outcomes across cancer types within the same analytic framework. Pancreatic cancer exhibited the shortest median survival alongside the highest event rate and metastatic proportion, underscoring its aggressive clinical course even within a predominantly metastatic cohort. By contrast, breast cancer showed the longest median survival (as visualized in the respective Kaplan-Meier curves) despite a sizable metastatic share, suggesting comparatively slower disease trajectories and greater effectiveness of available therapies in this subgroup. Non–small cell lung cancer and colorectal cancer shared similar

median survivals near 17-18 months, though colorectal cancer carried the highest metastatic proportion among the five. This juxtaposition implies that crude metastatic prevalence alone does not fully account for survival differences, motivating disease-specific modeling of covariates and sites of spread. Prostate cancer combined the lowest event rate with a midrange metastatic proportion and an intermediate median survival, indicating a slower accumulation of events over time relative to the other cancers. Together, these patterns justify presenting separate Kaplan-Meier curves and parsimonious Cox summaries per cancer type, while enabling a consistent cross-cancer narrative that focuses on differences in event rates, metastatic burden, and median survival.

Novelty and Comparison to Prior Work

Although significant studies [48-52] (Table S8 in Multimedia Appendix 1) have been conducted in the realm of predicting cancer survivability, our work stands out by bringing new enhancements that significantly contribute to better prediction of cancer survivability, particularly by the thorough comparison of ML models, the strategic use of both global and cancer-specific models, in-depth model explainability using SHAP values, and detailed survival analysis.

First, we begin by comparing 5 different ML models (XGBoost, naive Bayes, decision tree, logistic regression, and random forest), each rigorously tuned using exhaustive grid search for hyperparameters. This approach ensures that each model is thoroughly tested for the task of predicting cancer survivability, a detail that is often overlooked in existing literature. Many studies tend to focus on one or two models, without ensuring that the models are fully evaluated for comparison. For example, prior work done by Zhao et al [48], Tapak et al [49], and Nicolò et al [50] evaluate models but lack the thoroughness in hyperparameter tuning that our study provides. We believe that this rigorous approach enhances the reliability of our findings and provides a more comprehensive understanding of which model performs best under specific conditions.

Moreover, we use a methodology that is designed to first use a global model to gain a general overview of the most important patterns and predictors for metastatic cancer survivability, followed by a deeper dive into cancer-specific models. This 2-tiered approach is critical because it allows us to identify broad patterns while also uncovering nuances that might be missed or misinterpreted in a global model. Many published studies, such as Kourou et al [51] and Zhao et al [48], predominantly dwell on global accuracy metrics without taking this crucial next step to explore more specific patterns within subgroups of the data. By contrast, our approach provides a dual perspective, that is, broad insights from the global model and detailed, cancer-specific insights that we believe are essential for advancing personalized medicine.

The use of SHAP values in our study is particularly noteworthy. We did not just stop at model performance but delved deep into explainability, first for the global model and then for the cancer-specific models. This process allowed us to generate refined explainability that highlights not just which features are important, but how their importance varies across different types of cancer. The use of SHAP in both global and specific contexts

is a novel approach that we believe adds substantial value to the study. While many studies, such as Maouche et al [52], use SHAP or similar methods, they often do so at a surface level, without the comprehensive, model-specific analysis that we provide. This depth of analysis is crucial for understanding the true implications of the model's predictions and for making informed clinical decisions.

Finally, we conduct survival analysis after predicting cancer survival with explainable ML to translate model predictions into clinically meaningful insights about patient outcomes over time. While ML classifiers can distinguish between patients likely to survive or not, survival analysis provides a time-to-event perspective, capturing not just "if" but "when" an event such as death occurs. This temporal dimension allows researchers and clinicians to estimate hazard rates, median survival times, and differences between risk groups. Coupled with explainable ML (eg, SHAP values), survival analysis also helps validate whether the features driving predictions correspond to biologically and clinically relevant risk factors. Together, this integration strengthens both the predictive performance and interpretability of the model, supporting its potential use as a trustworthy decision-support tool in oncology practice.

Limitations and Biases

We acknowledge several limitations that must be considered alongside the model's strong performance. First, generalizability may be constrained by inherent biases in the MSK-MET dataset, which is a single-institution cohort from a tertiary care center. The sample underrepresents socioeconomically disadvantaged and racially diverse populations, with non-White ethnicities comprising less than 15%, and genomic profiling was preferentially performed in advanced-stage cases, potentially inflating the importance of features like TMB. These biases may partly explain the performance disparities observed across cancer types. Furthermore, technical limitations exist; for instance, linear and naive Bayes baselines may have been disadvantaged by the use of label encoding for categorical variables.

These factors underscore the necessity for several future steps before clinical deployment. External validation using diverse,

multicenter cohorts with stratified sampling is crucial to improve equity, fairness, and generalizability. Prospective calibration should be rechecked under local prevalence shifts, with techniques like Platt scaling or isotonic regression applied, if necessary. Additionally, prospective benchmarking against oncologist-estimated prognoses and real-world deployment outcomes will be critical to establish clinical noninferiority or superiority. Finally, while this study provides a comprehensive classification and survival analysis, future work should focus on integrating these outputs; for example, by generating risk-stratified Kaplan-Meier curves at chosen thresholds to unify the decision framework across binary and time-to-event end points.

Future Directions and Deployment Considerations

Improving Rare Cancer Predictions

Model performance was limited for rare cancers (eg, anal cancer: n=68; AUC=0.61), due to data scarcity. To address this, we suggest (1) using transfer learning to initialize models with global XGBoost weights, (2) using synthetic oversampling (eg, synthetic minority oversampling technique, adaptive synthetic sampling) during training, and (3) leveraging federated learning to aggregate data across institutions while preserving privacy. These techniques can bolster performance in underrepresented malignancies.

EHR Integration and Clinical Deployment

While the primary aim of this study was informatics-driven discovery, the robustness of our model supports a clear pathway for clinical translation through EHR integration. We envision a real-time, standards-based system where automated risk alerts are seamlessly integrated into clinical workflows, particularly within tumor-board discussions (Figure 6). By leveraging Fast Healthcare Interoperability Resources Representational State Transfer hook events, patient risk scores could be dynamically updated and surfaced directly within the EHR as cases are reviewed. To ensure both privacy and computational efficiency, the XGBoost model would be deployed as a containerized service within the hospital's secure analytics infrastructure (eg, Epic Cogito), keeping protected health information on premises while using available hardware acceleration.

Figure 6. Electronic health record (EHR) integration and clinical deployment. Framework illustrating how patient risk scores and Shapley additive explanations (SHAP)–based explanations are integrated into the EHR and surfaced during tumor-board discussions to enable transparent, real-time clinical decision support. FHIR: Fast Healthcare Interoperability Resources; REST: Representational State Transfer; XGBoost: extreme gradient boosting.
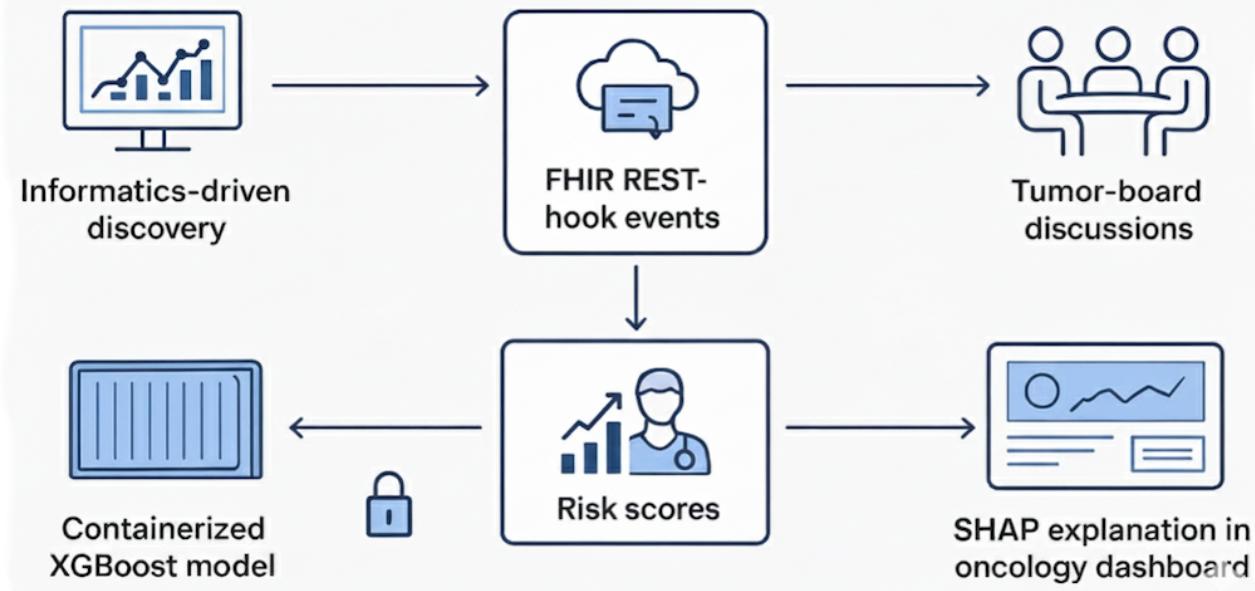
A critical differentiator of this approach is the coupling of each risk alert with a SHAP-based explanation embedded directly into the oncology dashboard. This transforms the model from a "black box" into an "explain-and-act" tool, providing clinicians with immediate, interpretable rationale by highlighting the top clinical and genomic features contributing to an individual's risk score. Alert protocols would be tiered and threshold-aware, directly translating the model's predictive values into actionable clinical guidance. For instance, a low-risk classification (supported by an NPV of 79.8%) could justify lengthening follow-up intervals, while a high-risk flag (PPV of 70.3%) would prompt rapid biomarker reassessment and discussion of treatment intensification.

An initial rollout would prioritize safety and reliability through a prospective pilot study, continuous performance monitoring for model drift, and an implementation that minimally disrupts existing workflows. The validation evidence and explainable framework presented in this study provide a solid foundation for a potential regulatory submission as a Class II clinical decision support tool, paving the way for a new generation of transparent, AI-augmented oncology care.

Conclusion

In this large-scale, pan-cancer study, we developed and validated an interpretable ML framework for predicting survivability in patients with metastatic cancer. By leveraging the comprehensive MSK-MET cohort, we demonstrated that an XGBoost classifier robustly predicts overall survival (AUC=0.82, accuracy=0.74), outperforming other conventional ML models. Crucially, the integration of SHAP explainability illuminated the model's decision-making process, consistently identifying metastatic site count, TMB, fraction of genome altered, and the presence of liver and bone metastases as major prognostic features across diverse tumor types. This biological plausibility is fundamental for building clinical trust.

Our 2-tiered modeling approach, combining a unified pan-cancer perspective with targeted, cancer-specific submodels, provided both broad generalizability and nuanced, disease-tailored insights. This was evidenced by the varying performance across cancer types, such as the high predictive accuracy for prostate cancer (AUC=0.88) contrasted with the greater challenges in pancreatic cancer (AUC=0.68). Furthermore, the survival analysis corroborated the classification findings, with the XGBoost-Cox model (C-index=0.70) capturing nonlinear relationships more effectively than the traditional Cox model (C-index=0.66), and Kaplan-Meier curves starkly illustrating the significant survival disadvantage associated with metastatic disease.

The clinical use of our model is underscored by its strong predictive values (PPV=70% and NPV=80% at the Youden-optimal threshold) and its demonstrated net benefit across a range of decision thresholds. By reconciling high performance with transparent, actionable explanations, this work provides a foundational framework for the next generation of clinical decision-support tools in oncology. Future efforts should focus on external validation in multicenter cohorts, prospective evaluation integrated within EHR systems, and addressing performance gaps in rare cancer subtypes to ensure equitable and widespread clinical adoption.

There was no generative artificial intelligence tool used. Responsibility for the final manuscript lies entirely with the authors.

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Data Availability

The datasets used in this study are available in the Memorial Sloan Kettering-Metastatic repository at cBioPortal [54]. The code is available at GitHub [55].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional tables and figures.
[DOCX File , 2147 KB - cancer_v12i1e74196_app1.docx]

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Abbreviations

AI: artificial intelligence
AUC: area under the curve
AUPRC: area under the precision-recall curve
AUROC: area under the receiver operating characteristic curve
C-index: concordance index
CPH: Cox proportional hazards
CV: cross validation
EHR: electronic health record
FDA: US Food and Drug Administration
FN: false negative
FP: false positive
MCC: Matthews correlation coefficient
ML: machine learning
MSK-MET: Memorial Sloan Kettering-Metastatic
NPV: negative predictive value
PPV: positive predictive value
ROC: receiver operating characteristic

SHAP: Shapley additive explanations
TMB: tumor mutational burden
TN: true negative
TP: true positive
XGBoost: extreme gradient boosting

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Development of a Web-Based Experiential Learning Intervention for the Public to Reduce Cancer Stigma: Tutorial on the Application of Intervention Mapping

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Abstract

Background: Stigma may negatively impact individuals throughout the continuum of cancer care and survivorship. Multitheory and multilevel intervention programs are necessary to reduce stigma but remain globally limited.

Objective: This tutorial aims to illustrate the development of a web-based experiential learning intervention, "Friend Supporter," designed for the public, which simulates scenarios to foster empathy and helping intentions. We applied the intervention mapping (IM) approach, which is rooted in the socioecological model, using the first four steps.

Methods: In step 1, key issues faced by cancer survivors and influential factors were identified through empirical evidence and literature reviews on cancer stigmas and psychological theories. A multidisciplinary planning team assessed issue-related logic. In step 2, a logic model of change was created based on step 1 findings. In step 3, we designed program themes and a structure using systematic reviews and needs surveys among the public (n=1076) and cancer survivors (n=473), while applying theoretical change methods and practical strategies. Step 4 integrated prior findings. Inputs from an expert panel (n=5) and the public (n=13) using the think-aloud approach were used to refine the materials and functions, with educational resources for program providers also developed.

Results: Step 1 revealed that public misconceptions and attitudes worsened the quality of life of cancer survivors. Step 2 identified 3 long-term outcomes: reduced public bias, improved responses to disclosure via acquired skills, and support aligned with survivors' aspirations. The short-term primary outcome was helping intention. Personal factors (knowledge, skills, and self-efficacy) were also expected to improve helping intention as mediators. In step 3, the literature review showed that multicomponent online interventions effectively reduced stigma. The survey indicated the public most needed information on "how to interact with friends diagnosed with cancer" (317/1076, 29.5%), regardless of whether they had a friend diagnosed with cancer (χ^2_1=0.98; P=.32). Participants with no friends diagnosed with cancer were more likely to require information concerning "survival rates of all types of cancer" (χ^2_1=7.3; P=.007). Preferred delivery modes were booklets or leaflets (529/1076, 49.2%) and the internet (texts and figures: 460/1076, 42.8%). Cancer survivors wanted their friends to understand "the possibility of a cure as a result of early detection and treatment" (193/473, 40.8%). To produce program materials, we applied stigma and discrimination, protection motivation, social cognitive, and learning theories. The 5-module program included self-learning, role-plays, worksheets, and written feedback from clinical psychologists. Step 4 confirmed the feasibility of the program with minor refinement. We then developed a practical guide for program providers' future implementation.

Conclusions: IM is useful for systematically developing web-based multitheory and multilevel interventions. "Friend Supporter" offers a promising approach to enhance supportive behaviors and reduce cancer stigma. Quantitative evaluation is underway using the final 2 IM steps (implementation and evaluation) to determine real-world effectiveness.

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Introduction

Background

Cancer stigma is a global public health concern, contributing to poor health and social inequality among survivors [1]. Stigma, which can be categorized as involving both public stigma and internalized stigma, is produced through complex societal processes [2]. The term "cancer" may automatically evoke fears of death (negative stereotypes or ignorance) or emotional discomfort (prejudice), which then may lead to discrimination toward cancer survivors. Survivors who are aware of this public stigma, in turn, may experience diminished self-esteem, intense self-blame, and shame [3], reflecting internalized stigma.

Public stigma undermines the cancer care continuum by reducing screening uptake, delaying diagnosis, and lowering treatment adherence, which can contribute to poor survival outcomes [1,4,5]. The literature further demonstrates that stigma negatively affects survivorship through impaired mental health [6-8], weakened social relationships [9], and reduced social participation [8,10]. Survivors of breast, cervical, prostate, and lung cancer are particularly vulnerable; the associations reported between these survivors and sexuality or risk-related behaviors (eg, smoking) may intensify both public and internalized stigma [3,7,9,11,12], further hinder timely access to care [4,8,13], and worsen quality of life (QoL) [3,14,15].

In Japan, however, policy interventions are not primarily aimed at reducing mortality through stigma mitigation. Instead, as articulated in the Fourth Basic Plan for Cancer Control [16], the national focus is on cancer survivorship through promoting coexistence with cancer by reducing stigma, enhancing public understanding, and fostering a supportive environment for survivors. This approach emphasizes citizen engagement and social inclusion to improve survivors' QoL and to remove stigma-related barriers to social participation.

To reduce stigma, multitheory and multilevel interventions are recommended [13,17-20]. These approaches are grounded in the socioecological model, which emphasizes the dynamic interactions between intrapersonal factors and broader environmental contexts, such as interpersonal relationships, organizational structures, community settings, and policy frameworks [21]. Most illness-related stigma reduction programs focus on HIV/AIDS, leprosy, tuberculosis, mental illness or substance use disorders, and epilepsy [17-19,22], with limited numbers of cancer-specific intervention programs [1,23]. In Japan, 1 intervention dealing with romantic relationships among Japanese youngsters has been reported [24]. Most interventions rely on education and/or intergroup contact [17-19,21,24]. Sustaining intergroup contact poses challenges due to infectious risks (eg, COVID-19) and the burden on patients with cancer. Thus, interventions that minimize in-person contact while maintaining efficacy are needed.

Intervention content and delivery must also reflect relationships that survivors have (eg, with friends, colleagues, employers, teachers, caregivers, neighbors, and even those with no prior connection), survivors' cancer types, and available provider resources (eg, human and infrastructure). However, developing multiple intervention versions for each context is impractical [25]. Instead, adapting core components may be a more feasible approach. We focused on friendships, which are vital to survivors' well-being across the lifespan [26,27]. According to stigma research, engaging with hypothetical friends has been shown to help reduce psychological distance and foster empathetic understanding of an individual's experience of stigma [28].

Brief Description of the Intervention

We developed a 5-week web-based experiential learning program named "Friend Supporter" that was designed for the adult public with no history of cancer diagnosis (hereafter, the public). In this program, experiential learning is defined as a method that allows the program participants to learn the contents of the program and deepen their understanding of practical conduct through simulation. The program centers on a hypothetical scenario: "What if your friend were diagnosed with cancer?" This framing enables broad participation regardless of prior connection to cancer survivors as friends. The primary outcome of the program was helping intentions, assessed immediately after program completion. In addition, the program was designed to foster long-term outcomes, including supportive interactions with adult cancer survivors, increased support provision, and stigma reduction.

The intervention was conceptually designed for broad applicability across cancer types in adulthood, with a theoretical foundation that addressed common relational challenges and support needs identified in diverse contexts [29]. Through text-based role-play, program participants practice empathetic listening and supportive responses across diverse scenarios. These scenarios vary by cancer type, age, gender, occupation, disclosure context, and conversational content. These varied scenarios are intended to help participants adapt to different contexts. By applying core interpersonal skills learned through the program, they can respond more effectively across various situations. The program is grounded in the socioecological model and primarily focuses on intrapersonal and interpersonal levels, but with further potential effects at organizational and community levels.

Objective

This paper aimed to illustrate the developmental processes of the 5-week web-based experiential learning program "Friend Supporter," using the first 4 steps of the intervention mapping (IM) approach [30].

Methods

The IM Approach

Overview

IM, rooted in the socioecological model, is a systematic method for developing, intervening, and implementing health promotion programs by integrating theories, empirical evidence, and practical input [30]. IM emphasizes that interventions operate within dynamic systems, where their impact is influenced by interaction across environmental levels [30]. Thus, IM has been widely recommended for designing multilevel interventions

[31]. This framework has been applied in diverse digital interventions; for example, pain self-management apps [32] and mobile-based self-compassion programs for patients with cancer [33], and web-based exercise interventions for patients with diabetes [34].

IM comprises 6 steps. Step 1 involves the identification of issues and factors, step 2 involves the establishment of program outcomes, step 3 involves program design, step 4 involves the production of materials, step 5 involves implementation planning, and step 6 involves implementation plan evaluation. Each step includes the completion of several tasks that form the basis for the subsequent step; however, the procedure is not always performed in a linear manner [30].

Step 1: Identification of Issues and Factors

In step 1, we identified issues in cancer survivors' QoL and associated personal, behavioral, and environmental factors [30]. To do this, we conducted needs assessments focusing on breast cancer survivors [35,36]. This initial focus was chosen due to the availability of relevant Japan-based datasets and the stigma literature documenting relational challenges associated with breast cancer globally. We also investigated the public perceptions of cancer [37,38], existing literature reviews on cancer stigma [39], and relevant stigma and psychological theories [40-42]. This allowed us to provide a conceptual foundation for designing an intervention with broader applicability.

A multidisciplinary planning team was established that included a health psychologist, a clinical psychologist, a nurse, and an oncologist (another clinical psychologist and another nurse subsequently joined the planning team). Three members had the experience of information website development. All members discussed the logic model of the problem to reach a consensus.

Step 2: Establishment of the Program Outcomes

In step 2, we created a logic model of change that was intended to illustrate how the intervention program could modify or reduce the factors directly and indirectly associated with cancer survivors' QoL, as identified in step 1; this model served as a theoretical framework rather than a definitive causal pathway [30]. As the logic model of the problem (Figure 1) shows, there were 2 possible populations for which the intervention program could be developed.

Figure 1. A logic model of the problem.
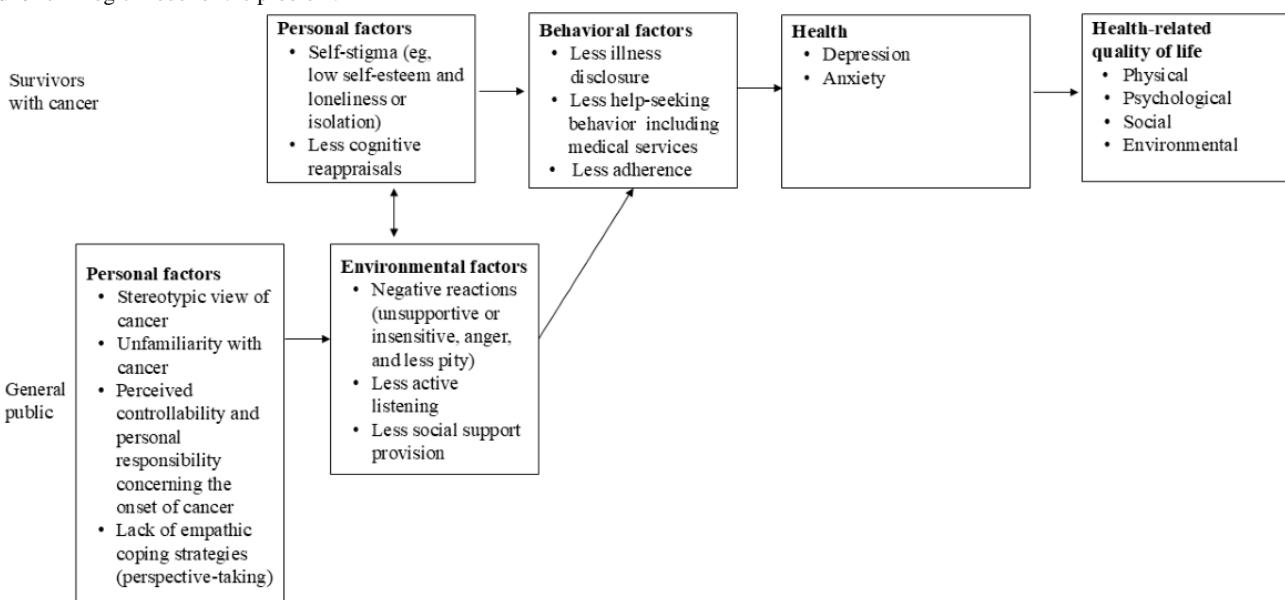
The multidisciplinary planning team discussed which populations needed to have interventions and what needed to be changed to improve the QoL of cancer survivors, in accordance with the national policy in Japan. Based on these discussions, the planning team decided to develop an intervention program designed for the public. This decision was grounded in the reality that many cancer survivors resume their usual lives and reintegrate into their communities after discharge. If a new intervention program could reduce stigma and discrimination among program participants, they might become advocates for cancer survivors. This, in turn, could empower cancer survivors and promote a society where living with cancer is more widely accepted.

A logic model of change was drafted to guide the intervention design. Behavioral and environmental impact, performance objectives (long-term outcomes), and change objectives (short-term outcomes) were established through a stepwise logic modeling process. Change objectives were mapped to personal determinants and organized in a matrix. These were theorized to support individual behavioral and interpersonal changes.

Step 3: Program Design

Overview

Step 3 involved generating themes, components, and sequences of components for the intervention program [30]. Theory-, evidence-, and practice-based change methods should be determined to optimize the effectiveness and adaptability of an intervention [30]. We reviewed existing systematic reviews and conducted 2 surveys (one among the public and another among cancer survivors) in Japan. This approach was adopted because

customization based on user preferences facilitates smoother implementation [43]. To design the program, various theoretical and practical change methods were discussed among the planning team.

Existing Systematic Review of Literature

To identify existing effective interventions that could achieve the performance objectives established in step 2, the Cochrane Database of Systematic Reviews (CDSR) was searched. To gain insight into the intervention design and components, we reviewed interventions that were indicated in the findings of a meta-analysis as having significant effects.

Needs Survey Among the Public

To investigate the necessary content and preferable modes of intervention delivery, a cross-sectional online survey was conducted among the adult public (≥20 y) in Japan.

The detailed survey procedures have been previously reported in a study concerning a cancer-related scale development process among the public [44]. Potential adult Japanese participants were conveniently recruited from the panels of a research company. The company developed and tested the survey website for this study. Participants voluntarily accessed the closed survey and read the information sheets before participating. Each participant ticked the statement "I agree to participate in this study" before responding to the questionnaire. Question items were randomly presented to minimize order bias. The researchers created all the study materials except for the survey website and had no direct contact with the participants. The response rate was reported in a previously published article based on the same survey dataset [44]. As the recruitment and data collection were conducted by the research company, the investigators did not have access to individual-level invitation procedures and response tracking.

Data concerning demographics, willingness to disclose their cancer to surrounding people (families, friends, colleagues, and neighbors) if the participants were diagnosed with cancer, and whether they had friends with cancer were obtained. The participants were instructed to read a scenario describing a situation where a hypothetical friend talked about a cancer diagnosis, after which the participants were asked to respond to the following question: "Reflecting on your reactions to have better relationships with the friend with cancer, please tell us what you want to know?" There were 24 items with dichotomous responses. Additionally, a detail concerning preferred modes of delivery when the participants received the relevant information was requested.

The study variables were summarized using descriptive statistics (mean and SD or frequencies and percentages). Chi-square tests were conducted to examine differences in information needs and preferred modes of delivery between the participants whose friends had been diagnosed with cancer and those who had not in real life. Information needs were categorized into the relevant change objectives identified in step 2.

Needs Survey Among Cancer Survivors

To investigate the necessary content for the public, a cross-sectional online survey was conducted among adult cancer survivors in Japan. The detailed survey procedures have been previously reported in a study concerning cancer survivors' psychological distress with cancer disclosure [45]. Potential adult Japanese participants were recruited from the panels of a research company, which were independent of those involved in the public survey. The recruitment process, consent process, survey design, and data collection methods were identical to those used in the public survey.

Demographic and cancer-related information was collected. The participants, including those who had been diagnosed with cancer 5 years previously and those who had already disclosed their cancer diagnosis to friends, were asked to respond to the following question: "To have better relationships, what information would you want your friends to know when you tell them of your cancer diagnosis?" There were 20 items with dichotomous responses.

The study variables were summarized using descriptive statistics (mean and SD or frequencies and percentages). Information needs were categorized into the relevant change objectives identified in step 2.

Setting Up the Theoretical and Practical Change Methods

Considering the findings from the CDSR search and the 2 surveys, the planning team discussed the appropriate mode of delivery and themes and sequences of the components of the intervention program. In parallel, theoretical change methods for each change objective were selected by referring to a taxonomy of behavior change methods in IM [46] where applicable. The planning team discussed various practical change methods to reach a consensus.

Step 4: Program Materials

Overview

Step 4 involved drafting, pilot testing, refining, and finalizing the program material [30]. The planning team drafted and reviewed the initial content. While the evaluation framework was initially conceptualized during step 2 through the logic model of change, the relevant behavioral and environmental impact was further structured during step 4, as part of the intervention logic model. A multidisciplinary expert panel evaluated the conceptual and practical validity of the materials. The IT team deployed materials for pilot testing. The adult public participants engaged in think-aloud sessions and individual interviews. Based on these findings, we refined the materials, finalized the intervention logic model, and produced accompanying educational resources.

Internal Material Production

The planning team reviewed the theoretical and practical change methods identified in step 3 and proposed that the program consist of 5 modules corresponding to the themes and sequences established in step 3. Prior to the development of the module materials, the planning team established formatting and stylistic guidelines to ensure consistency and accessibility. These included: standardized font type and size across all modules; use of concise and short sentences written in polite Japanese; and active use of visual elements such as images, charts, and diagrams to support comprehension. These guidelines were

applied throughout the material development process to ensure a coherent learning experience across modules.

The planning team was divided into subgroups according to their expertise (eg, medicine and nursing, and psychology). Each subgroup created specific component materials, using credible sources and empirical findings, where applicable. To facilitate the design and review process, materials were initially created in slide format (Microsoft PowerPoint), allowing for visual structuring and annotation. The fourth component of the program, which features role-playing scenarios, required a distinctive approach in relation to the other components. The program participants could choose from multiple cases and progress through them interactively. This component was visually prototyped to ensure clarity, usability, and flexibility. First-person narratives were used in role-play case stories, based on evidence from a systematic review showing their effectiveness in reducing mental health prejudice [47]. In the role-play case stories, a character (a cancer survivor) shares a personal experience via text on a screen (eg, "I've been diagnosed with cancer—take care of yourself too"). The program participants, acting as the character's friend, are prompted to respond through text-based interactions, simulating a supportive conversation. Finally, the planning team independently reviewed all the initial materials, and their feedback was incorporated through iterative refinements.

Multidisciplinary Expert Inputs

A multidisciplinary expert panel (n=5), including a medical oncologist, a psychiatrist, an oncology nurse, and researchers in pedagogy and sociology, independently evaluated the intervention logic model and paper-based materials. Electronic versions with voice recordings in role-play components were also provided. Regarding the evaluation of the intervention logic model, 16 questions were developed and assessed using a 5-point Likert scale (completely agree/agree/neither agree nor disagree/disagree/completely disagree), referring to relevant logic model guides [48,49]. To evaluate the materials, 29 questions were similarly assessed using the same scale. Open-ended questions were also included to gather qualitative feedback. Responses to the Likert scale were summarized by frequency. To guide subsequent refinements, particular attention was given to comments associated with "disagree" and "completely disagree" responses.

Pilot Testing

After refinement reflecting the expert panel's concerns, an IT team deployed "Friend Supporter" on the Internet. The planning team provided the IT team with detailed instructions regarding slide navigation and hyperlinking (in both PowerPoint presentation and PDF formats) to ensure that the materials could be deployed effectively. Revisions were conducted collaboratively through embedded comments within the slides, enabling iterative refinement. The program participants would be expected to complete one module per week using the internet, and modules they had already completed could not be reviewed.

To investigate the feasibility, usability, and acceptability of this web-based program, we conducted a pilot study using a think-aloud approach among the public in Japan (this study has already been published [50]). Participants were recruited using snowball sampling. Participant characteristics were summarized using frequency, and the interview transcripts were analyzed using content analysis. Based on the findings, the program was further refined, the intervention logic model was finalized, and educational materials for implementation were developed.

Ethical Considerations

Ethical approval for the survey conducted among the public was obtained from the institutional research board of the National Cancer Center (2017‐378). Ethical approval for the survey among cancer survivors was obtained separately from the institutional research board of the National Cancer Center (2017‐134). For the 2 surveys, appropriate electronic informed consent was obtained from all participants. The surveys were anonymous. Participants in the public survey received a 2,000-yen gift voucher (approximately 17 USD at the time of study).Ethical approval for pilot testing was obtained from the institutional research board of the National Cancer Center (2021‐020). Electronic informed consent was obtained from all participants. Participants in the interviews received a 2,000-yen QUO card (a prepaid purchasing card), which was approximately 15 USD. No personally identifiable information, including initials, was included in the transcripts and the published results. All procedures were conducted in accordance with the ethical standards of the institutional research board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Results

Step 1: Identification of Issues and Factors

The relevant literature shows that some members of the public have negative reactions toward cancer survivors due to beliefs about cancer (eg, "cancer equals death" and "incurable disease" [37]), lack of familiarity with survivors, and perceptions of the risk factors [37-39]. These interactions can adversely affect survivors' self-concepts, cognitive reappraisals, social disclosure [35,36], help-seeking behaviors (eg, less medical use), treatment adherence [39], mental health status [39], and QoL [36]. Psychological theories such as stigma attribution theory [40,41] and empathetic coping theory [42] have been used to elaborate on the links between the general public's attitudes and the impact of such attitudes on cancer survivors. The findings underscore the need to address cancer stigma across the cancer experience, including coexistence, early detection, and clinical care. Figure 1 illustrates the relationship among health problems, QoL, and associated factors. The multidisciplinary planning team agreed to this logic model of the problem.

Step 2: Establishment of the Program Outcomes

The logic model of change was structured around three key components: performance objectives, change objectives, and personal determinants. This stepwise structure enabled a systematic evaluation of how targeted changes in personal determinants may lead to behavioral shifts, ultimately contributing to a more supportive environment for cancer survivors. While improved QoL of cancer survivors was the ultimate goal, this was not directly measured in this model.

To clarify the logic of change, the primary outcome was defined as strengthening the public's intention to support hypothetical friends with cancer, representing the short-term learning effect of the program. This proximal change was considered a key indicator of immediate program success. To achieve the primary outcome, the intervention targeted intrapersonal mediators of change, such as increased knowledge about cancer and cancer survivors and greater self-efficacy, as well as interpersonal skills such as empathetic coping skills. Change objectives for each performance objective were presented together with personal determinants (knowledge, skills, self-efficacy, and attitudes) in a matrix; for example, regarding change objectives aimed at reducing stereotypes and prejudice about cancer and cancer survivors, personal determinants associated with knowledge focused on "increasing accurate knowledge of cancer and cancer survivors" (Multimedia Appendix 1). These short-term shifts were theorized to contribute to the long-term goals outlined in the three performance objectives and were expected to emerge over a span of 2 to 3 years.

Step 3: Program Design

Existing Systematic Review of Literature

The CDSR search found that there were no systematic reviews about cancer stigma reduction interventions for the public. However, there was 1 article about mental illness stigma reduction interventions [47], which reported that mass media intervention, first-person narratives, and multiple-component interventions were effective in reducing prejudice about mental illness. Additionally, a meta-analysis revealed that 2 reviewed interventions [51,52] significantly decreased prejudice and increased knowledge of mental illness and of affected patients. These interventions included information about mental illnesses and relevant patients, addressing negative reactions toward such patients and providing practical guides to help these patients using patient-related stories. However, these interventions did not address communication issues shown in Multimedia Appendix 1 or the established outcome. The planning team decided not to adapt these existing programs in the cancer context.

Needs Survey Among the Public

A total of 1076 people participated in the survey. The descriptive statistics showed that the mean age was 47.2 (SD 11.4) years, 35.4% (381/1076) were women, and 17.5% (188/1076) had friends with cancer [44]. The participants reported that if they were diagnosed with cancer, they would "strongly agree/agree" to disclose their cancer diagnoses to their families (920/1076, 85.5%), friends (474/1076, 44.1%), colleagues (480/1076, 44.6%), and neighbors (104/1076, 9.7%).

After reading scenarios depicting hypothetical friends with cancer, the participants identified the following 5 most sought types of information: "how to interact with friends diagnosed with cancer" (317/1076, 29.5%), "types of cancer treatment" (288/1076, 26.8%), "side-effects of cancer treatment" (249/1076, 23.1%), "survivors' desire for relationships with their friends" (212/1076, 19.7%), and "what cancer survivors do not want friends to say" (202/1076, 18.8%). These information needs were ranked and mapped to the relevant change objectives

identified in step 2 (Multimedia Appendix 2). Chi-square tests revealed that the participants whose friends had not been diagnosed with cancer were more likely to require information concerning "survival rates of all types of cancer" ($\chi^2_1 = 7.3$; $P=.007$) compared with those whose friends had been diagnosed (Multimedia Appendix 3).

Preferable modes of delivery were booklets or leaflets (529/1076, 49.2%), the Internet (texts and figures: 460/1076, 42.8%; text only: 297/1076, 27.6%; text and video: 155/1076, 14.4%), apps (75/1076, 7%), DVDs (46/1076, 4%), and other (24/1076, 2%). There were no differences in these preferences between those participants whose friends had not been diagnosed with cancer and those whose friends had been diagnosed (Multimedia Appendix 4).

Needs Survey Among the Cancer Survivors

A total of 473 cancer survivors participated in the survey. The descriptive statistics showed that the ages ranged from 25 to 85 years, and that 49.7% (235/473) were men. The participants had primarily developed breast cancer (118/473, 24.9%), colorectal cancer (68/473, 14%), and prostate cancer (51/473, 11%), with most at the early stage (grades 0/I/II) of cancer (311/473, 65.8%) [45].

The 5 most important types of information that the cancer survivors wanted their friends to know included: "the possibility of a cure as a result of early detection and treatment" (193/473, 40.8%), "types of cancer treatment" (154/473, 32.6%), "survivors continuing their social life during/after cancer treatment" (130/473, 27.5%), "outpatient cancer treatment" (116/473, 24.5%), and "risk factors of cancer" (114/473, 24.1%). These information needs were categorized into the relevant change objectives identified in step 2 (Multimedia Appendix 5).

Setting Up the Theoretical and Practical Change Methods

According to the CDSR findings and the 2 surveys, the planning team decided to develop a multiple-component and web-based (texts and figures) intervention program. The contents of the program were to include information about interpersonal skills, cancer and its treatments, and cancer survivors' social life, which would meet the needs of both the public and cancer survivors. Referring to the two reviewed interventions in the CDSR search [51,52], the structure and sequences would have 5 thematic components, in the following order: (1) cancer, treatment, and survivors; (2) emotional and cognitive reactions to hypothetical friends with cancer; (3) reasons for cancer survivors' illness disclosure to friends and expected responses from them; (4) guiding principles and role-plays on how to listen to make survivors feel safe; and (5) survivors' desire for relationships with and support from their friends.

Several behavioral change methods that matched the determinants and change objectives were selected. Regarding knowledge (increasing accurate knowledge of cancer and cancer survivors), details on stereotype-inconsistent information were derived from stigma and discrimination theory [53], and details on framing were derived from protection motivation theory

[54,55]. Regarding skills (acquiring empathetic coping strategies to use when told about hypothetical friends' cancer diagnosis), details on empathy training were derived from stigma and discrimination theory [56], details on modeling from social cognitive theory [57], and details on feedback from learning theories [58]. To facilitate understanding of how theoretical and practical change methods were selected and translated into the program components, a comprehensive table is presented in Multimedia Appendix 6. The planning team agreed to these practical change methods.

Step 4: Program Materials

Internal Material Production and Refinements

After individually reviewing all the draft materials, the planning team observed notable variation in both the quantity and presentation styles across the 5 modules. Through discussions, the planning team decided to standardize the duration of each module to within 30 minutes and to clearly state the learning objectives at the beginning of each module to help program participants understand the intended goals.

Multidisciplinary Experts' Inputs and Refinements

The multidisciplinary expert panel reported some disagreements concerning the validity of the intervention logic model and program materials. Regarding the logic model, disagreements were reported on "concrete descriptions of the activities" (n=1), "the impact does not deviate from the scope of the stated outcome of the activity" (n=1), "the approximate time is clearly stated in which program participants would complete each module of the activity" (n=3), and "the time until all the activities would be completed is clearly stated" (n=3). We added the estimated time to complete each module and the total duration required to complete the program.

Regarding the materials, disagreements were reported on the "appropriateness of content" (n=3), "appropriateness of sentence expression" (n=2), "cost effectiveness" (n=5), "usefulness for short-term outcomes" (n=2), "appropriateness of audio recording with case stories" (n=1), "appropriateness of the use of worksheets" (n=2), and "appropriateness of feedback for worksheets" (n=2).

Most disagreements of the expert panel concerned participant burden in relation to the program. The planning team prioritized the expert panel's suggestions concerning addressing matters that might adversely affect the program participants' learning motivation and understanding. Consequently, the volume of materials was reduced by deleting unnecessary quizzes and worksheets, and voice recordings of the case stories. Terminology (eg, the 5-y survival rate) was clarified by adding explanations, and layouts were refined by separating the contents into 2 slides. The planning team discussed the refined materials and reached a consensus.

Pilot Testing and Refinements

A total of 13 adults participated in the think-aloud session. The descriptive statistics showed that the ages ranged from 20 to 63 years. The program's visualization, content, quantity, and written feedback on worksheets were well received among the program participants. However, some older participants expressed a preference for printed or PDF materials to review in advance [50].

The interview data (n=8) [50] showed that some participants preferred to revisit previously studied modules freely and requested access to external links to the case stories to explore a wider range of survivors' experiences and situational contexts. Based on these findings, both printed and PDF materials were developed. The IT team added functions to allow program participants to freely browse complete modules. The planning team finalized the intervention logic model (the final version is shown in Figures 2 and 3) and developed a practical guide for program providers to support future implementation.

Figure 2. Intervention logic model: from input to output. PR: public relations.

Input	Activities	Outputs
• Web-based intervention program	**Participant background** • Collecting data about gender, age, marital and employment status, had friends with cancer (relationships), health literacy, and route to participation	• Participants' background gender, age, marital and employment status, had known friends with cancer (relationships), and health literacy
• Participants (internet users and adults with no cancer experiences)	**Step 1: self-learning** (1st wk; 25 min) Learning about • Patients' emotional fluctuation since cancer diagnosis • Characteristics of cancer, cancer treatment, and side effects • Social life of survivors with cancer and importance of support provision	• Route to participation (what media was used to find out about the web intervention program or whether past participants referred to this program)
• Program operation staff: psychologists, nurses, physician, IT specialist (7 staff in total)	**Step 2: self-learning** (2nd wk; 15 min) Learning about • Basic psychology in mind • How survivors with cancer tell their cancer diagnosis to their friends • Possible emotional and cognitive responses to a friend's cancer disclosure • To allow participants to accept their own negative feelings towards a friend's cancer disclosure	
• Resources: operating costs, labor costs, and system maintenance costs	**Step 3: self-learning** (3rd wk; 15 min) Learning about • Patients' feelings and timing and desired reactions when they talk to their friends about cancer	Number of participants and participation rate
	Step 4: self-learning and role play (4th wk; 30 min) Learning about • Fictional case presentation and short quizzes • The ways of listening to stories that put people with cancer at ease • Fictional case presentation and writing responses toward the case user selected, using worksheets and submission	Time required to complete the web program
• Equipment: PC, server, internet, and web-based intervention software		Complete reading rate for each step
		Number of times going back and forth for each step
• PR on the web-based intervention program	**Step 5: self-learning** (5th wk; 30 min) Learning about • The desired ways of supporting friends with cancer, presenting survivors' discourse • Reading scenarios and web-based practice using worksheets and submission (Obtaining perspective taking of friends with cancer and another, on ways to respond to the friend with cancer, on how the friend with cancer feel about the response; what participants have noticed through the program, what could be applied to their own lives, [if applicable] how to apply it to their own daily life?)	Readability and difficulty of each step
		Participants' satisfaction with each module and overall program
		Dropout rate

5-week program in total

Feedback from psychologists

Continue in Figure 3 (short-time outcomes)

XSL•FO

RenderX

Figure 3. Intervention logic model: from outcomes to impact.

Furthermore, the interview data showed that the intervention program was found to reduce participants' distancing attitudes and increase their intention to support hypothetical friends [50]. These promising results suggest the program's potential to enhance helping behaviors toward cancer survivors (the snapshot of the "Friend Support" is shown in Multimedia Appendix 7).

Discussion

Principal Findings

This study is the first to apply the IM approach to develop a web-based experiential learning program aimed at reducing cancer stigma among the public.

We set out and described the first four steps of the IM approach [30]. While adapting existing evidence-based intervention programs can be more efficient than creating new ones, there remains a notable lack of programs aiming to reduce cancer stigma [1,23]. Therefore, it was considered worthwhile to undertake and report on a step-by-step developmental process that integrates empirical findings, behavioral change theories, and practical input. The incorporation of expert panel input and user feedback through a think-aloud approach significantly enhanced content refinement, as well as the relevance and feasibility of the final product.

The intervention logic model allowed for the development of the hypothesis that the primary goal of this proposed intervention

program would be achieved, namely, to increase helping intentions toward hypothetical friends with cancer. We set up multiple mediators: increasing knowledge, empathetic skills, and self-efficacy. Individuals with heightened helping intentions are more likely to respond supportively when someone discloses a cancer diagnosis. Over time, such attitudinal changes may contribute to the three specified long-term outcomes: improved interpersonal responsiveness, increased support provision, and reduced stigma. If supportive behaviors become widespread across interpersonal, organizational, and community levels, the subsequent effects are more likely to foster a culture of inclusion, one that accepts cancer without prejudice and reduces discrimination against cancer survivors. While QoL was not explicitly defined as a direct outcome in the logic model, it serves as a foundational construct that underpins the broader objectives of the program. By fostering supportive environments and reducing stigma, the program is expected to indirectly contribute to enhancing the QoL of cancer survivors.

Comparison With Prior Work

Prior studies have shown that public stigma contributes to internalized stigma among cancer survivors [6-14,59]. This dynamic aligns with the socio-ecological framework, which recognizes the interplay between societal attitudes and individual experiences. Whereas most digital interventions using IM have focused on intrapersonal factors to support individuals with cancer [32,33], our program uniquely targets the public, situated

in the outer layer of the socio-ecological model, to promote broader cultural and relational change. Similar logic has been applied in intervention development targeting parental behavior, with the intention of indirectly influencing children's physical activity levels by modifying relational dynamics [60].

Previous stigma reduction efforts have largely emphasized knowledge acquisition, including exposure to patient narratives [18-22,24]. However, social cognitive theory [61] suggests that knowledge alone may be insufficient to drive behavioral change; attitudes toward behavioral intentions are also essential components in predicting supportive actions toward individuals with cancer. Our experiential learning integrates empathy training together with cancer-related knowledge to foster emotional and cognitive empathy, and to enhance self-efficacy and helping intentions toward cancer survivors.

Unlike prior stigma studies that focused on specific cancer types [4,6,8,9,11-13,15,59], our program addresses stigma toward cancer survivors more broadly and is applicable to any kind of relationship. Centering on relational challenges and support needs common to diverse cancer contexts [29], the materials were intentionally designed for wide applicability. In addition to fostering transferable interpersonal skills, the program also equips participants with foundational knowledge about cancer, treatment processes, and the social lives of patients, namely survivorship. The program's modular design allows for the inclusion of supplementary materials tailored to specific cancer types, enhancing its adaptability across diverse contexts.

Strength and Limitations

This project demonstrates several key strengths in relation to the development of a web-based experiential learning intervention for cancer stigma reduction. First, the use of the IM framework enabled a systematic integration of theory, empirical evidence, and practical input. A multidisciplinary planning team guided the process through structured consensus-building, ensuring that diverse perspectives were reflected and that certain professional opinions were not overly influential. Second, the logic model helped identify and target essential mediators—knowledge, skills, and self-efficacy—within the program materials. The public survey data further informed the content and delivery preferences, aligning the intervention with the needs of both the public and cancer survivors. Appropriate reflection on the public's needs, together with cancer survivors' needs, may help motivate participation, implementation, and dissemination [43]. Third, the inclusion of communication-focused components and empathy training was undertaken in response to stigma-related challenges identified in prior research [56]. Various techniques, such as modeling, feedback, and first-person narratives [47], were incorporated to enhance self-efficacy and promote prosocial attitudes. The clinical psychologists' written feedback on worksheets may provide further assurance and facilitate prosocial attitudes. Finally, expert reviews and end user feedback contributed to the credibility, feasibility, and relevance of the program, increasing the likelihood of achieving its performance objectives and supporting future implementation.

Regarding limitations, the investigation of the research on cancer stigma was limited to creating a logic model of the problem.

However, recent findings suggest that public stigma may intersect with structural factors such as education and employment [10,62-64]. Future studies should address structural dimensions of stigma, which were not explicitly targeted in the current program. Further, we used the end user approach. However, while we did not invite cancer survivors into the expert panel, we compensated for this limitation by using the findings of the needs survey among cancer survivors. Finally, we did not establish a specific performance objective or change objectives for the environmental impact. In the future, appropriate change methods and practical applications should be identified and combined.

Practical Implications

We plan to assess the effectiveness of this web-based intervention program, "Friend Support," quantitatively, using randomized clinical trials among the public. If its effectiveness is confirmed, implementation studies could be performed in the future using steps 5 and 6 of the IM approach. To facilitate dissemination, intervention packages, including materials for users, a practical guide for program providers, and feedback training workshops for researchers and clinicians, have been prepared. A developed practical guide would be helpful for staff training, not only in terms of providing feedback on worksheets but also for understanding how to deliver the intervention program effectively.

For future implementation, collaboration with schools, companies, and community-based organizations, such as nongovernmental organizations or civil groups, could support localization and sustainable delivery. While the current program is framed around the role of a friend, extending this application to other social roles, such as workplace colleagues or teachers, may enhance its relevance. Core components of the program, particularly those related to interpersonal empathy and supportive communication, can be retained while adapting delivery methods to suit different contexts. For instance, incorporating reflective exercises that prompt program participants to consider how they might respond if a coworker or student were diagnosed with cancer could deepen empathy and foster supportive engagement in professional or institutional settings. These adaptations may also help address stigma in environments where social dynamics are shaped by hierarchical or role-based interactions.

The intervention has the potential to serve as a long-term resource for the public, promoting supportive attitudes and behaviors toward cancer survivors. Although the program was developed in response to Japan's legal emphasis on stigma reduction in cancer survivorship, future research may explore whether stigma reduction can also encourage preventive behaviors, such as cancer screening and health care-seeking attitudes and behaviors [4,5,8,13].

Conclusions

IM is a useful framework for integrating theory, evidence, and practical inputs to develop a web-based experiential learning intervention program designed for the public to reduce cancer stigma. A qualitative pilot test demonstrated the program's feasibility, but further evaluation involving the public is required

before implementation can be considered. We hope this tutorial paper will help researchers and educators systematically develop similar web-based experiential learning interventions, particularly those using simulation to address stigma and promote an inclusive and supportive community.

Data Availability

The data are not available as they are not held in a public archive owing to participant privacy reasons.

Authors' Contributions

Conceptualization: MT (lead), KA (supporting), KK (supporting), AK (supporting)
Data curation: MT (lead), AK (supporting)
Formal analysis: MT (lead), KA (supporting), AK (supporting), KK (supporting)
Investigation: MT (lead), AK (supporting), KA (supporting), KK (supporting)
Methodology: MT (lead), KA (supporting), AK (supporting), KK (supporting)
Visualization: MT (lead), AK (supporting), KK (supporting), KA (supporting)
Writing – original draft: MT (lead), KA (supporting), AK (supporting), KK (supporting)
Writing – review & editing: MT (lead), all authors (supporting)
Supervision: MT (lead), KA (lead)

Conflicts of Interest

None declared.

Multimedia Appendix 1
Matrix of the performance objectives and change objectives by personal determinants.
[PDF File, 117 KB - cancer_v12i1e71166_app1.pdf]

Multimedia Appendix 2
Information priorities in the public and corresponding change objectives (n=1076).
[PDF File, 77 KB - cancer_v12i1e71166_app2.pdf]

Multimedia Appendix 3
Information needs of the public in relation to having friends with cancer (n=1076).
[PDF File, 92 KB - cancer_v12i1e71166_app3.pdf]

Multimedia Appendix 4
Preferred mode of information delivery among the public in relation to having friends with cancer (n=1076).
[PDF File, 109 KB - cancer_v12i1e71166_app4.pdf]

Multimedia Appendix 5
Survivors' knowledge priorities for friends and corresponding change objectives (n=473).
[PDF File, 107 KB - cancer_v12i1e71166_app5.pdf]

Multimedia Appendix 6
Theoretical methods and practical applications for change objectives and program components.
[PDF File, 120 KB - cancer_v12i1e71166_app6.pdf]

Multimedia Appendix 7
Snapshot of "Friends Supporter."
[PDF File, 961 KB - cancer_v12i1e71166_app7.pdf]

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Abbreviations

CDSR: The Cochrane Database of Systematic Reviews
IM: intervention mapping
QoL: quality of life

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