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Contents

Original Papers

Reviews

Original Paper

Email Patient-Provider Communication and Cancer Screenings Among US Adults: Cross-sectional Study

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Abstract

Background: The growth of electronic medical records and use of patient portals have allowed for patients and health care providers to communicate via email and direct messaging between health care visits. Email patient-provider communication (PPC) may enhance traditional face-to-face PPC by allowing patients to ask questions, receive clear explanations, engage in shared decision-making, and confirm their understanding between in-person visits. Despite increasing trends in the use of email PPC since the early 2000s, few studies have evaluated associations between email PPC and the uptake of preventive services.

Objective: The objective of this study was to determine associations between the use of email PPC and the likelihood of undergoing breast, cervical, and colon cancer screenings among adults who have received health care in the past 12 months.

Methods: Secondary, cross-sectional data from the 2011-2015 National Health Interview Survey were combined and analyzed. For each cancer screening, inclusion criteria were based on the age of screening recommendations and prior history of cancer diagnosis (n=35,912 for breast, n=48,512 for cervical, and n=45,884 for colon). The independent variable was whether adults used email PPC in the past 12 months (yes or no). The dependent variables were whether (1) women (aged ≥40 years) received a mammogram in the past 12 months; (2) women (aged 21-65 years) received a Pap test in the past 12 months; and (3) individuals (aged ≥50 years) received a colon cancer screening in the past 12 months. Bivariate and multivariable logistic regression analyses were conducted.

Results: Adults who reported receiving all three cancer screenings in the past 12 months were more likely to be non-Hispanic White; be married or living with a partner; have a bachelor’s degree or higher education level; have health insurance coverage; and perceive their health as excellent, very good, or good (all $P<.001$). Men were more likely to receive colon cancer screenings than women ($P<.001$). Multivariable logistic regression models showed women who used email to communicate with their health care providers had greater odds of receiving breast (odds ratio [OR] 1.32, 95% CI 1.20-1.44) and cervical (OR 1.11, 95% CI 1.02-1.20) cancer screenings than women who did not use email PPC. Adults who used email to communicate with their health care providers had 1.55 times greater odds (95% CI 1.42-1.69) of receiving a colon cancer screening than those who did not use email PPC.

Conclusions: Our results demonstrate that email PPC is a marker of increased likelihood of adults completing age-appropriate cancer screenings, particularly breast, cervical, and colon cancer screenings. More research is needed to examine other factors related to the reasons for and quality of email PPC between patients and health care providers and determine avenues for health education and intervention to further explore this association.

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KEYWORDS

email; patient-provider communication; online, patient portals; mammogram; Pap test; colon cancer screening; cancer screenings; National Health Interview Survey

Introduction

Email patient-provider communication (PPC) is broadly defined to include computer-based PPC "within a contractual relationship in which the health care provider has taken an active measure of responsibility for the clients" [1]. Email PPC includes messages sent through electronic personal health management tools and patient portals, which can enhance traditional face-to-face communication between health care providers and patients. Email PPC has been used by patients for asynchronous inquiries about nonacute issues, medication information, administration questions, and lab results [2]. Adults who used email PPC reported it was most useful for managing appointments, asking administrative questions, reviewing test results, requesting prescriptive refills, and asking health-related questions [2,3]. Individuals have also reported benefits of email PPC for communicating sensitive issues that patients may be too embarrassed to discuss during face-to-face encounters and follow-up visits for chronic diseases [4]. Although some studies have demonstrated that email PPC can increase the quality and efficiency of health care delivery [5], others have found that the use of electronic and email PPC, and the use of "e-visits," may lead to more office visits and limit health care providers' abilities to treat new patients [6]. Despite patients expressing interest in communicating with their provider via email, the uptake remains low [2]. In 2003, only 4% of adults reported using email to communicate with their health care provider. By 2018, the prevalence of email PPC had increased to 36% [7]. Among older adults, its prevalence rose from 2.7% in 2009 to 14.2% in 2018 [8]. Regardless of increasing trends, email PPC remains underutilized, and disparities exist based on demographic, socioeconomic, and health-related characteristics [7,9-12]. Previous studies have found that adults who engage in email PPC are more likely to be female and younger aged; living in urban areas; have higher levels of education and income; and have a history of chronic disease [7,9-11]. Several studies have found that non-Hispanic White adults are more likely to use email PPC than non-Hispanic Black and Hispanic adults [4], yet the usage of email PCC among Hispanic adults varies by US- and foreign-born subgroups [12]. These differences may be due to structural barriers that exist with broadband internet access, which may be more limited in poor neighborhoods [13]. Individuals with diabetes, cardiovascular disease, hypertension, a history of cancer, and multiple chronic conditions are more likely to use email PPC than adults with no chronic diseases [10,11]. Other studies have demonstrated that gay and bisexual men are more likely to use email PPC than heterosexual men [14].

Although previous research has demonstrated that quality face-to-face PPC during traditional visits is a marker of an increased likelihood of adults receiving cancer screenings and immunizations [15-20], few studies have evaluated the impact of email PPC between visits on the individual's use of preventive services. Interventions using electronic patient health records and patient portals that engage patients in taking an active role in their health care through electronic means have been effective at improving delivery of recommended cancer screenings [21]. However, less is known about how this engagement through electronic modes of communication with providers between visits can improve cancer screening outcomes. Huang and colleagues [22] demonstrated that adults who used patient portals to schedule appointments, request referrals or prescription refills, share medical records, or communicate with health care professionals by email were more likely to receive a blood pressure check, lipid level check, influenza vaccination, or colon cancer screening than those who did not use patient portals. Totzkay and colleagues [23] found that women who used electronic medical records were more likely to receive breast cancer screenings. Despite positive findings, these studies did not directly evaluate associations between email PPC and likelihood of adults receiving immunizations and cancer screenings.

To begin to fill this gap in our understanding of how email PPC may be a marker of increased likelihood of cancer screenings, this study is part of a program of research that utilizes national health surveys to examine how predisposing and enabling factors are associated with morbidity, mortality, and use of health services. Patient experiences, including the use of face-to-face, email, and other electronic communications with health care providers, are examined as enabling factors of health services use as an extension of Anderson's Behavioral Model of Health Services [24]. Two preliminary studies were conducted to determine whether email PPC is a marker of increased likelihood of vaccinations and cancer screenings. Using cross-sectional data from the National Health Interview Survey (NHIS), we found that adults who used email PPC had greater odds of reporting receipt of an influenza vaccine [25]. Using cross-sectional data from the Health Information National Trends Survey (HINTS), we found no difference in the odds of reporting receipt of breast, cervical, or colon cancer screening among adults who used email PPC compared to those who did not use email PPC [15]. Although nationally representative, the HINTS sample is much smaller (ie, N=3865 adults in HINTS 5 Cycle 3) than the NHIS sample (ie, N= 31,997 adults in 2019), and the focus of the survey content is geared toward cancer risk communication [26,27]. More research is needed to confirm these findings by using larger nationally representative samples focused on broader topics of morbidity, mortality, and the use of preventive services. To further explore this relation, this study aimed to determine the association between email PPC use and the likelihood of adults receiving breast, cervical, and colon cancer screenings before and after controlling for potential covariates.

Methods

Data Source

We analyzed secondary, cross-sectional data from the 2011-2015 NHIS. Since 1957, the NHIS has collected information on demographics, socioeconomics, and a wide range of health topics among the civilian noninstitutionalized US population [28]. During 2011-2015, the NHIS used a multistage sampling design to monitor national trends in health, illness, and disability while tracking progress toward national goals by using a computer-assisted personal interviewing system during face-to-face interviews [28]. The sampling design oversampled Hispanic, Asian, and non-Hispanic Black persons to increase the precision of estimates among racial and ethnic minorities [28]. Information about health information technology use and cancer screening behaviors have been measured annually since 2011 [29-31]. Further details of the NHIS sampling design and data collection methods have been reported previously [28].

Participants

We limited our sample to individuals who received primary health care in the past 12 months and were within the recommended age groups for each cancer screening of interest. For breast cancer screening, for instance, our sample was limited to women aged 40 years and above without any prior history of breast cancer based on American College of Obstetricians and Gynecologists (ACOG) screening recommendations (n=35,912) [32]. For cervical cancer screenings, our sample was limited to women aged 21-65 years without any prior history of cervical cancer based on the American Cancer Society (ACS), ACOG, and the United States Preventive Services Task Force (USPSTF) screening recommendations (n=48,512) [33-35]. For colon cancer screenings, our sample was limited to adults aged 50 years and older without any prior history of colon cancer based on the ACS screening recommendations (n=45,884) [33]. Individuals who reported that they do not use the internet were excluded.

Variables

Independent Variable

The NHIS measured email PPC by asking individuals, “During the past 12 months, have you ever used computers for any of the following,” specifically to “…communicate with a health care provider by email” (yes or no question) [28].

Dependent Variables

For breast cancer screenings, the NHIS asked women aged 30 years and older, “Have you had a mammogram during the past 12 months?” For cervical cancer screenings, women aged 18 years and older were asked, “Have you had a pap smear or pap test during the past 12 months?” Adults aged 40 years and older were asked, “During the past 12 months, have you had any test done for colon cancer [28]?” Dichotomous variables (yes or no) were created for each screening measure based on the abovementioned inclusion criteria for age.

Covariates

We evaluated the following covariates based on previous studies [15,25]: age (ie, 21-29 years and 30-39 years for cervical cancer screenings only, 40-49 years for breast and cervical cancer screenings only, 50-59 years, 60-70 years [60-65 years for cervical cancer screenings], or 70 years and older); sex (ie, female or male); race or ethnicity (ie, non-Hispanic White, Hispanic, non-Hispanic Black, or non-Hispanic “other” race); nativity status (born in the United States or not born in the United States); marital status (ie, never married; married or living as married; divorced, widowed, or separated); highest level of education achieved (ie, no degree, high school degree or General Educational Development tests, some college or associate degree, or bachelor’s degree or higher); insurance coverage (ie, insured or uninsured); perceived health status (ie, excellent, very good, or good vs fair or poor); and survey year.

Statistical Analysis

Bivariate analyses were used to describe the association between demographic, socioeconomic, health-related characteristics, use of email PPC, and receipt of each cancer screening in the past 12 months (chi-square test; =.05). We calculated age-adjusted prevalence estimates of receiving breast, cervical, and colon cancer screenings among adults who reported using email PPC by using estimated marginal (least-squares) means. Crude and multivariable logistic regression procedures were used to test for associations between email PPC (independent variable) and whether they received breast, cervical, and colon cancer screenings (dependent variable) before and after controlling for covariates. Purposeful selection methods were used for building fitted multivariable logistic regression models [36]. Our multivariable models were adjusted for age (reference: youngest age group, 40-49 years for breast cancer screenings, 21-30 years for cervical cancer screenings, and 50-59 years for colon cancer screenings); race or ethnicity (reference: non-Hispanic White); marital status (reference: never married); education (reference: bachelor’s degree or higher); health insurance (reference: covered); and perceived health status (reference: fair or poor). For colon cancer screenings only, multivariable models were adjusted for sex (reference: men).

Sensitivity Analysis

Sensitivity analyses were conducted to align with different age cutoffs for screening recommendations from other agencies based on previous research [37]. For breast cancer and colon cancer screenings, we limited the sample to women aged 50-75 years based on USPSTF recommendations [37,38]. No sensitivity analyses were conducted for cervical cancer screenings.

Data were analyzed using SAS software (version 9.4) survey procedures to account for primary sampling units, clustering, and the sophisticated weighting in the sampling design. The annual sample adult weight was divided by five to account for combining 5 years of data based on NHIS analytic recommendations [39].

This study was deemed exempt from human subjects review by the Committee for the Protection of Human Subjects at the University of Texas Health Science Center at Houston.

Results

Selected Characteristics

The mean ages of women who received breast and cervical cancer screenings in the past 12 months were 56.90 years (95% CI 56.71-57.08) and 41.2 (95% CI 41.00-41.40) years, respectively. The mean age of adults who received a colon cancer screening the past 12 months was 62.1 (95% CI 61.94-62.35) years. Women who reported having a breast cancer screening in the past 12 months were more likely to be non-Hispanic White; be married or living with a partner; have a bachelor’s degree or higher level of education; have health insurance coverage; and perceive their health as excellent, very good, or good (all *P*<.05). Similar results were observed for cervical cancer screenings. Additionally, US-born women (27,006/31,977, 85.5% weighted) were more likely to receive a cervical cancer screening than foreign-born women (4971/31,977, 14.5% weighted; *P*<.001). Furthermore, over half (5587/11,713, 50.9% weighted) of the adults who received a colon cancer screening were male (*P*<.001). Results were similar to those for breast and cervical cancer screenings for race or ethnicity, marital status, education, and health insurance coverage (all *P*<.001). Further details of the bivariate analyses (unweighted frequencies and weighted percentages) are reported in Table 1.

Age-adjusted prevalence estimates of receiving a breast, cervical, or colon cancer screening based on email PPC use are reported in Table 2. Among adults who received primary health care in the last 12 months, the age-adjusted prevalence of receiving a colon cancer screening was the lowest (34.4%) among those who used email PPC compared to women who underwent breast (70.5%) and cervical (70.6%) cancer screenings.

Table 1. Selected characteristics by receiving a breast, cervical and colon cancer screening in the last 12 months, National Health Interview Survey 2011-2015.

Characteristic	Breast cancer screening (n=35,912), n (weighted %)			Cervical cancer screening (n=48,512), n (weighted %)			Colon cancer screening (n=45,884), n (weighted %)		
	No (n=13,557)	Yes (n=22,355)	*P* value	No (n=16,530)	Yes (n=31,982)	*P* value	No (n=34,171)	Yes (n=11,713)	*P* value
Race or ethnicity			.005			<.001			<.001
Non-Hispanic White	9659 (76.3)	15,865 (76.4)		11,087 (72.0)	19,598 (68.7)		26,330 (81.6)	8476 (78.5)	
Hispanic	1367 (8.4)	2200 (7.9)		2175 (11.3)	4801 (11.9)		2494 (6.1)	950 (6.4)	
Non-Hispanic Black	1752 (9.6)	3121 (10.6)		2013 (9.5)	5493 (13.6)		3646 (7.6)	1698 (10.5)	
Non-Hispanic Asian or Other	779 (5.7)	1169 (5.0)		1255 (7.1)	2090 (5.8)		1701 (4.7)	589 (4.6)	
Nativity status			.46			.001			0.03
Foreign-born	1856 (13.9)	3089 (13.5)		2649 (15.9)	4971 (14.5)		3895 (11.5)	1431 (12.6)	
US-born	11,697 (86.1)	19,263 (86.5)		13,875 (84.1)	27,006 (85.5)		30,269 (88.5)	10,279 (87.4)	
Marital status			<.001			<.001			<.001
Never married	1502 (8.1)	2165 (6.6)		3498 (18.2)	7557 (18.5)		2963 (5.9)	949 (5.5)	
Married or living with partner	6340 (61.1)	12,227 (69.2)		8752 (63.6)	17,838 (67.5)		18,594 (69.3)	6792 (72.5)	
Divorced, widowed, or separated	5664 (30.8)	7899 (24.2)		4232 (18.2)	6507 (14.1)		12,522 (24.8)	3947 (22.0)	
Education			<.001			<.001			<.001
Less than high-school graduate	1426 (9.1)	1515 (5.6)		1352 (7.5)	2076 (5.4)		2989 (7.3)	955 (6.8)	
High-school graduate	3360 (25.2)	4857 (22.2)		3598 (22.5)	5724 (18.1)		8134 (24.0)	2468 (20.9)	
Some college	4758 (34.7)	7325 (31.8)		6136 (36.9)	11,050 (33.8)		10,822 (30.9)	3808 (31.7)	
Bachelor’s degree or higher	3966 (31.0)	8600 (40.3)		5400 (33.2)	13,081 (42.8)		12,127 (37.8)	4447 (40.6)	
Health insurance			<.001			<.001			<.001
Not covered	1506 (11.0)	865 (3.5)		2391 (13.7)	2989 (8.0)		1882 (5.1)	302 (2.4)	
Covered	12,016 (89.0)	21,446 (96.5)		14,078 (86.3)	28,915 (92.0)		32,223 (94.9)	11,396 (97.6)	
Perceived health status			<.001			<.001			.08
Fair or poor	2760 (18.5)	2736 (11.0)		2694 (15.0)	2806 (7.7)		5765 (15.3)	2105 (16.1)	
Excellent, very good, or good	10,792 (81.5)	19,606 (89.0)		13,831 (85.0)	29,162 (92.3)		28,385 (84.7)	9606 (83.9)	
Survey year			<.001			<.001			0.02
2011	3875 (27.9)	5414 (23.8)		3493 (21.2)	7455 (23.0)		9299 (26.6)	3139 (25.8)	
2012	1991 (15.2)	3872 (17.7)		2683 (16.3)	6222 (18.9)		5259 (16.0)	1889 (16.3)	
2013	2323 (17.5)	4168 (19.1)		3175 (19.4)	6219 (19.6)		5899 (17.8)	2159 (19.5)	
2014	2675 (18.9)	4554 (19.4)		3645 (21.0)	6319 (18.9)		6901 (19.3)	2260 (18.3)	
2015	2693 (20.4)	4347 (19.9)		3534 (22.1)	5767 (19.5)		6813 (20.4)	2266 (20.1)	

Table 2. Age-adjusted prevalence of screenings by email patient-provider communication (PPC), National Health Interview Survey 2011-2015.

Email PPC	Breast cancer screening, OR[a] (95% CI)	Cervical cancer screening, OR (95% CI)	Colorectal cancer screening, OR (95% CI)
No	62 (61-63)	67 (66-67)	25 (24-26)
Yes	71 (69-72)	71 (69-72)	34 (33-36)

[a] OR: odds ratio.

Logistic Regression Analysis

Crude and adjusted logistic regression results are reported in Table 3. In adjusted models, women who used email to communicate with their health care providers had 1.32 times greater odds (95% CI 1.20-1.44) of receiving a breast cancer screening and 1.11 times greater odds (95% CI 1.02-1.20) of receiving a cervical cancer screening than women who did not use email PPC. Adults who used email to communicate with their health care providers had 1.55 times greater odds (95% CI 1.42-1.69) of receiving a colon cancer screening than those who did not use email PPC. Specific estimates for covariates included in our logistic regression models are provided in Table S1 of Multimedia Appendix 1

Table 3. Crude and adjusted logistic regression models, National Health Interview Survey 2011-2015.

Email PPC[a]	Breast cancer screening[b], OR[c] (95% CI)		Cervical cancer screening[b], OR (95% CI)		Colorectal cancer screening[b], OR (95% CI)	
	Crude	Adjusted	Crude	Adjusted	Crude	Adjusted
No	1.00	1.00	1.00	1.00	1.00	1.00
Yes	1.50 (1.38, 1.62)	1.32 (1.20, 1.44)	1.17 (1.08, 1.27)	1.11 (1.02, 1.20)	1.58 (1.44, 1.73)	1.55 (1.42, 1.69)

[a] PPC: patient-provider communication.

[b] For each cancer screening, multivariable models adjusted for age (reference: youngest age group, 40-49 years for breast cancer screening, 21-30 years for cervical cancer screening, 50-59 years for colon cancer screening); race or ethnicity (reference: non-Hispanic White); marital status (reference: never married); education (reference: bachelor's degree or higher); health insurance (reference: covered); and perceived health status (reference: fair or poor). For colon cancer screening only, multivariable models adjusted for sex (reference: men).

[c] OR: odds ratio.

Sensitivity Analysis

Crude and adjusted logistic regression results from our sensitivity analysis are reported in Table S2 of Multimedia Appendix 1. The results were similar to our analytical sample. All 95% CIs overlapped with our initial findings.

Discussion

Principal Findings

We aimed to determine the association between email PPC and whether adults received breast, cervical, and colon cancer screenings. Overall, we found that adults who used email to communicate with their health care providers between visits had greater odds of receiving each of the three types of screenings. These findings go beyond our previous research that used other nationally representative data sources (Medical Expenditure Panel Survey and HINTS), which demonstrated that quality face-to-face PPC increased the likelihood of adults receiving cancer screenings [15,16]. Nevertheless, there was no difference in breast, cervical, or colon cancer screening uptake among adults who did and those who did not use email PPC.

Using the NHIS, we were able to further explore the role of email PPC as a marker of the likelihood of adults receiving cancer screening using a nationally representative sample larger than that used in previous studies. For breast cancer screening, we found that women who used email PPC had 32% increased odds of receiving a mammogram compared to women who did not use email PPC. Other studies exploring whether online PPC and general health information technology use were associated with breast cancer screening found that electronic medical record and patient portal use increased women's likelihood of receiving mammograms [23,40-42]. Moreover, we found that email PPC increased women's odds of receiving a Pap test by 11%. This finding result differs from our study using HINTS data, which did not find any association between email PPC and cervical cancer screenings [15]. To our knowledge, only one other study has demonstrated that general electronic medical record use can increase cervical cancer screenings [41]. Finally, we found that the use of email PPC increased the likelihood of adults receiving a colon cancer screening by 55%. Our previous study using HINTS data indicated that adults had 39% higher odds of receiving a colon cancer screening; however, the results did not reach statistical significance (95% CI 0.99-1.95). Similar to studies evaluating breast cancer screening, previous research has demonstrated that adults who used patient portals to schedule appointments, request referrals or prescription refills, view decision aids, share medical records, or communicate with health care professionals by email were more likely to receive colon cancer screenings than those who did not use patient portals [22,42]. For all cancer screenings, the lack of research providing direct comparisons to our results may be due to limitations of examining email PPC only, which excludes other online communicative functions such as text messaging, mobile apps, and social media [43].

For all cancer screenings, several factors may have contributed to obtaining results different from our previous study using HINTS data [15]. The greatest factor may be the way email PPC was measured. The NHIS measured whether adults used computers or the internet to communicate with their health care provider by email [28]. A similar measure was used in the HINTS 4 survey during Cycles 1 and 3 [44]. Adults who responded “yes” on either survey may have regarded automatic emails for appointment reminders or diagnostic test results as email PPC versus directly emailing their health care provider about specific health concerns. During HINTS Cycle 3 and 4, this question was revised to directly assess whether adults exchanged health information with their health care provider via email [44]. The reasoning for and quality of communication remained unmeasured by both surveys. Future iterations of these data sources should be revised to fully capture communication behaviors to further explore the implications of email PPC on the uptake of preventive services.

Strengths and Limitations

A strength of this study was the use of survey data from multiple years of the NHIS, a nationally representative survey that has consistently measured health behaviors, preventive health services, and a wide array of other health-related characteristics to meet national health objectives for over 60 years [28]. The depth and breadth of demographic, socioeconomic, and health-related characteristics measured by the NHIS on an annual basis allowed us to explore and control for multiple covariates in our logistic regression models. However, the NHIS does not collect characteristics on patient engagement in health care outside from assessing adults’ use of health information technology to look up health information, refill prescriptions, schedule appointments, use online chat groups, and communicate with health care providers via email that may result in unresolved confounding. Previous research has demonstrated that adults who use electronic methods of communication with their health care providers and adults who follow recommended cancer screening guidelines are more engaged in their health care than those who do not [5]. In our study, email PPC and cancer screening behaviors were both measured in the past 12 months based on how the questions were asked by the NHIS. Our results may suffer from temporality biases, as we were unable to determine whether email PPC occurred before or after receiving any cancer screening. By limiting our cancer screening outcome to the past 12 months instead of based on adherence (eg, past 2 years for mammogram, past 3 years for Pap testing, and past 10 years for colonoscopy), we minimized this potential bias. A limitation to our measurement of email PPC was that we were unable to determine the direction of the email (ie, patient to provider vs provider to patient) and whether the content of the communication was screening related or pertaining to any medical information. The clinical significance of our results may be limited due to reporting odds ratios and marginal means. The use of other marginal effects may have improved our study’s practical relevance [45]. Our cancer screening measures were self-reported. Some studies have cautioned that results from self-reported nationally representative studies may overestimate cancer screening uptake [46], whereas others have found that self-reported responses are consistent with findings from hospital records [47,48]. It is also important to note that the NHIS is a cross-sectional survey, so our results only represent associations instead of causal relations.

Conclusions

This study begins to fill the gap in our understanding of how email PPC and direct electronic messaging between appointments may be a marker of the increased likelihood of adults receiving preventive health services, in particular, cancer screening uptake. More research is needed to determine the need for and effectiveness of targeted strategies for promoting appropriately timed cancer screenings by using web-based PPC tools such as email and direct messaging. Furthermore, there is a need for more research to examine reasons for and quality of email PPC for making preventive health care decisions.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables presenting results from logistic regression models.
[DOCX File , 36 KB - cancer_v7i3e23790_app1.docx]

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Abbreviations

ACS: American Cancer Society
ACOG: American College of Obstetricians and Gynecologists
HINTS: Health Information National Trends Survey
NHIS: National Health Interview Survey
OR: odds ratio
PPC: patient-provider communication

USPSTF: United States Preventive Services Task Force

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Original Paper

Search Behavior Regarding Cancer Susceptibility Genes Using a Clinical Decision Support Tool for Gene-Specific Penetrance: Content Analysis

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Abstract

Background: Genetic testing for germline cancer susceptibility genes is widely available. The Ask2Me.org (All Syndromes Known to Man Evaluator) tool is a clinical decision support tool that provides evidence-based risk predictions for individuals with pathogenic variants in cancer susceptibility genes.

Objective: The aim of this study was to understand the search behavior of the Ask2Me.org tool users, identify the patterns of queries entered, and discuss how to further improve the tool.

Methods: We analyzed the Ask2Me.org user-generated queries collected between December 12, 2018, and October 8, 2019. The gene frequencies of the user-generated queries were compared with previously published panel testing data to assess the correspondence between usage and prevalence of pathogenic variants. The frequencies of prior cancer in the user-generated queries were compared with the most recent US population–based cancer incidence.

Results: A total of 10,085 search queries were evaluated. The average age submitted in the queries was 48.8 (SD 16.5) years, and 84.1% (8478/10,085) of the submitted queries were for females. *BRCA2* (1671/10,085, 16.6%), *BRCA1* (1627/10,085, 16.1%), *CHEK2* (994/10,085, 9.9%), *ATM* (662/10,085, 6.6%), and *APC* (492/10,085, 4.9%) were the top 5 genes searched by users. There was a strong linear correlation between genes queried by users and the frequency of pathogenic variants reported in published panel testing data (r=0.95, r^2=0.90, P<.001). Over half of the queries (5343/10,085, 53.0%) included a prior personal history of cancer. The frequencies of prior cancers in the queries on females were strongly correlated with US cancer incidences (r=0.97, r^2=0.95, P<.001), while the same correlation was weaker among the queries on males (r=0.69, r^2=0.47, P=.02).

Conclusions: The patients entered in the Ask2Me.org tool are a representative cohort of patients with pathogenic variants in cancer susceptibility genes in the United States. While a majority of the queries were on breast cancer susceptibility genes, users also queried susceptibility genes with lower prevalence, which may represent a transformation from single gene testing to multigene panel testing. Owing to these changing tides, more efforts are needed to improve evidence-based clinical decision support tools to better aid clinicians and their practice.

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KEYWORDS

genetic testing; pathogenic variant; germline; risk communication; online health; digital health; cancer data; genetics; online tool; bioinformatics; web tool; cancer

Introduction

Since the commercialization of *BRCA1* and *BRCA2* testing in 1996, the costs of DNA sequencing and genetic testing have dropped rapidly [1]. Today, germline multigene panel testing is widely used to assist cancer prevention and management. Based on genetic testing results, management strategies such as screening, surveillance, and risk-reducing surgery are now common in clinical guidelines and widely accepted by health care providers [2]. A recent study has shown that in managing patients with identified pathogenic variants, approximately 80% of the providers recommended clinical management aligned with the guidelines, and nearly all patients adhered to their providers' recommendations [3]. Unfortunately, only 10%-15% of patients with breast and ovarian cancer in the United States who are eligible for genetic testing are actually tested [4], suggesting that there are still considerable gaps in the implementation of genetic testing.

One major challenge for clinicians in dealing with positive genetic testing results is to provide patients with accurate cancer risk estimates. Following genetic testing, patients usually rely on their providers to interpret results and assess cancer risk. However, literature regarding the magnitude of cancer risk for specific pathogenic variants (ie, penetrance) often varies in quality and study design. It is almost impossible for busy providers to keep up with the rapidly growing literature, carefully evaluate each study, and select the most reliable risk estimate [5,6]. In addition, despite the rapidly growing need, the availability of genetic counseling is still limited. In the United States, the estimated number of genetic counselors in 2018 was 4400, of whom only 48% practiced cancer genetics [7]. Patients, especially in rural areas, often have to wait weeks or months before seeing a genetic counselor. Therefore, an evidence-based, easily accessible, and regularly updated cancer risk prediction tool is needed to address these challenges.

The Ask2Me.org (All Syndromes Known to Man Evaluator) tool is a clinical decision support tool used for providing a summary of the major cancer susceptibility genes and the associated absolute cancer risk predictions [5,8]. Braun et al [5] describe the overall design and statistical basis of this tool, and it has been recommended as a resource in the American Society of Breast Surgeons hereditary breast cancer guidelines [9]. In this study, we aimed to understand the search behavior of Ask2Me.org users, identify the patterns of queries entered, and discuss how to further improve the tool.

Methods

User-Generated Queries

The Ask2Me.org tool allows users to enter patient information that includes their age and sex, prior surgical (bilateral mastectomy, hysterectomy, and oophorectomy) and cancer history, and select a gene with a pathogenic variant. In return, this tool provides a summary of that gene along with the patient's future risk for each type of cancer associated with a pathogenic variant in the selected gene. A total of 35 genes can be queried in the Ask2Me.org tool, which covers most of the commonly tested cancer susceptibility genes such as *APC*, *ATM*, *BRCA1/2*, *CDH1*, *CHEK2*, *PTEN*, *STK11*, and *TP53*. Personal health information such as name, date of birth, home address, and email address is not collected when using this tool. For this study, we collected user-generated queries from the Ask2Me.org tool between December 12, 2018, and October 8, 2019. Queries correspond to test cases, research use, and real patients. From each query, we collected the age, sex, genes with the pathogenic variant, prior cancer, and surgical history (bilateral mastectomy, hysterectomy, and oophorectomy).

Reference Groups

To assess the correlation between the frequency of genes entered by users in the Ask2Me.org tool and the frequency of pathogenic variants among patients who undergo panel testing (ie, the targeted user group of this tool), we used a large multigene cancer panel cohort reported by LaDuca et al [10] as the reference group. Based on 165,000 patients undergoing hereditary cancer predisposition testing between 2012 and 2016 at a single diagnostic laboratory, LaDuca et al's study reported the frequency of pathogenic variants across 32 cancer susceptibility genes. Their cohort's median age was 52 (IQR 43-62) years, which was similar to that in this study (median 49 [IQR 37-61] years). The majority of the included patients were females (94.2%), Caucasian (64.0%), and had a personal history of cancer (72.5%) or a history of family history of cancer among first-degree and second-degree relatives (90.1%) [10]. To access the correlation between the frequency of prior cancer in the Ask2Me.org user–generated queries and the cancer incidence at the population level, we used the most recent US population–based cancer incidence estimated by the American Cancer Society [11].

Statistical Analysis

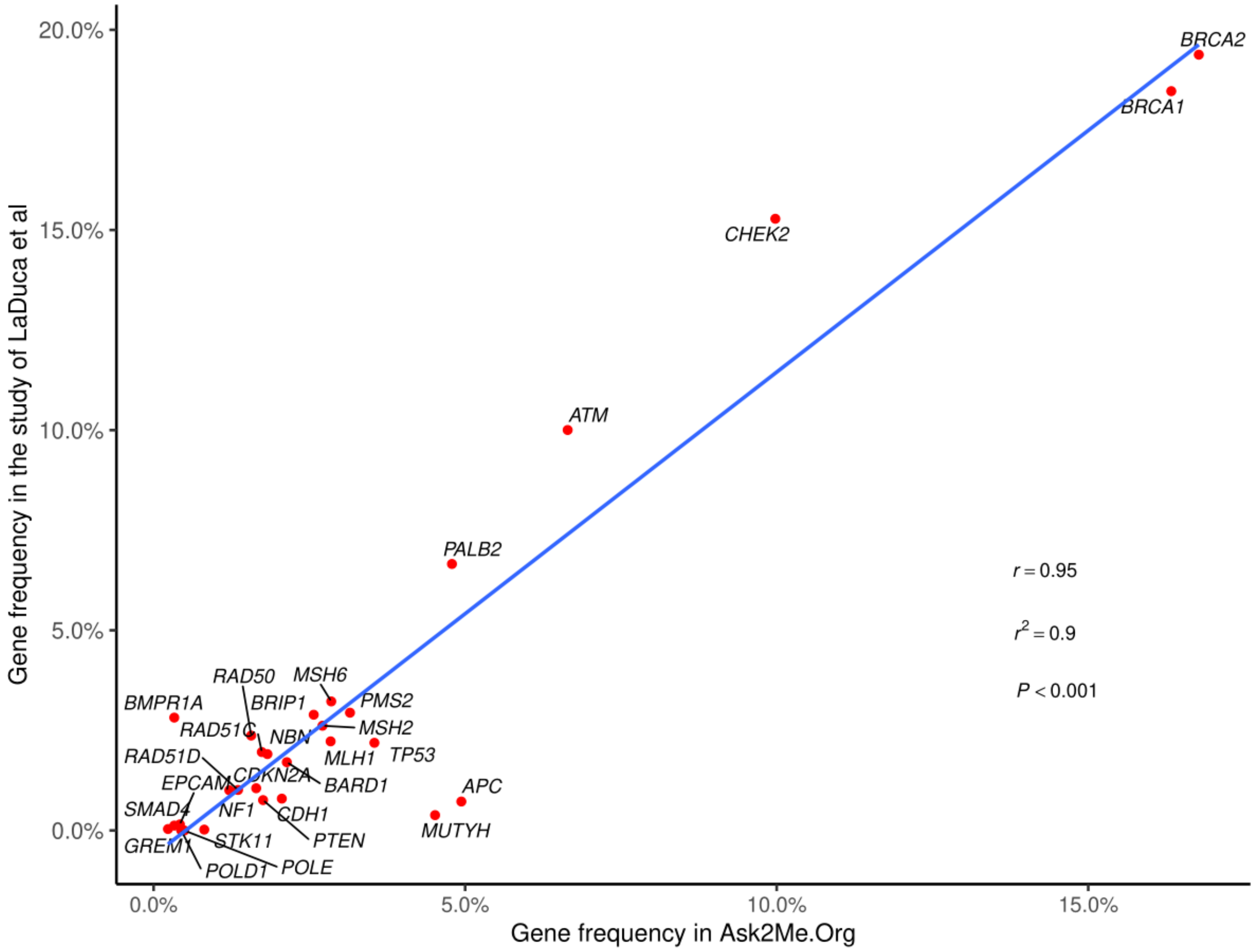
Continuous data were expressed as mean (SD) and median (IQR). Categorical data were expressed as percentages. Pearson correlation coefficients were used to evaluate the degree of correlation between both user-generated queries and published gene frequencies and user-generated queries and population-based cancer incidence. A linear regression model was fitted to visualize the results. As the default setting of the Ask2Me.org tool—a 25-year-old female with no cancer or surgical history as a likely test case—a sensitivity analysis was performed by excluding these entries and re-evaluating the correlations. *P* values less than .05 were considered statistically significant. All analyses were performed using the R language statistical software (version 4.0.3; R Foundation for Statistical Computing).

Results

Queried Susceptibility Genes

From December 12, 2018 to October 8, 2019 (300 days), 10,085 queries were submitted to the Ask2Me.org tool. The average age submitted in the query was 48.8 (SD 16.5) years (median 49 [IQR 37-61] years), and 84.1% (8478/10,085) of the submitted queries were for females. *BRCA2* (1671/10,085, 16.6%), *BRCA1* (1627/10,085, 16.1%), *CHEK2* (994/10,085, 9.9%), *ATM* (662/10,085, 6.6%), and *APC* (492/10,085, 4.9%) were the 5 most common genes searched by users. Lynch syndrome–associated genes such as *PMS2* (314/10,085, 3.1%), *MSH6* (284/10,085, 2.8%), *MLH1* (283/10,085, 2.8%), *MSH2* (270/10,085, 2.7%), and *EPCAM* (42/10,085, 0.04%) were queried less frequently. Seven out of the ten most commonly searched genes were breast cancer susceptibility genes. For queries on females (8478/10,085, 84.1%; mean age 49.2 [SD 16.1] years; median age 50 [IQR 38-61] years), 79.7% (6757/8478) of the queries were of breast cancer susceptibility genes, and the top 5 genes were *BRCA1* (1467/8478, 17.3%), *BRCA2* (1449/8478, 17.1%), *CHEK2* (895/8478, 10.6%), *ATM* (548/8478, 6.5%), and *PALB2* (402/8478, 4.7%). For queries on males (1607/10,085, 15.9%; mean age 46.4 [SD 18.4] years; median age 47 [IQR 32-61] years), the top 5 genes queried were *BRCA2* (222/1607, 13.8%), *BRCA1* (160/1607, 10.0%), *ATM* (114/1607, 7.1%), *APC* (105/1607, 6.5%), and *CHEK2* (99/1607, 6.2%). Comparing the top 10 genes queried on females and males, we found 8 of them overlapped, namely, *APC*, *ATM*, *BRCA1*, *BRCA2*, *CHEK2*, *MUTYH*, *PALB2*, and *TP53*. *BRIP2* and *PMS2* were only listed in the top 10 queries on females, and *MLH1* and *MSH2* were only listed in the top 10 queries on males. After excluding 3 individual queries without age information, we found that there were 2979 (29.5%), 4422 (43.9%), and 2681 (26.6%) queries in the <40 years, 40-60 years, and >60 years age groups, respectively. In the <40 years age groups, the top 5 queried genes were *BRCA1* (479/2979, 16.1%), *BRCA2* (383/2979, 12.9%), *CHEK2* (215/2979, 7.2%), *APC* (215/2979, 7.2%), and *ATM* (173/2979, 5.8%). In the 40-60 years age group, the top 5 queried genes were *BRCA2* (757/4422, 17.1%), *BRCA1* (683/4422, 15.4%), *CHEK2* (469/4422, 10.6%), *ATM* (265/4422, 6.0%), and *PALB2* (208/4422, 4.7%). Similarly, in the >60 years age group, the top 5 queried genes were still *BRCA2* (530/2681, 19.8%), *BRCA1* (464/2681, 17.3%), *CHEK2* (310/2681, 11.6%), *ATM* (224/2681, 8.4%), and *PALB2* (141/2681, 5.3%). There was a strong linear correlation between the frequencies of genes entered by users in the Ask2Me.org tool and the frequencies of pathogenic variants reported by LaDuca et al (r=0.95, r^2=0.90, P<.001; Figure 1) [10]. By excluding the queries with the default setting (ie, 25-year-old female, no prior cancer, and no history of surgery), the strong linear correlation was still maintained (r=0.95, r^2=0.91, P<.001).

Figure 1. Correlation between frequencies of genes entered by the Ask2Me.org tool users and frequencies of pathogenic variants in panel testing results reported by LaDuca et al [10]. The blue line represents the results from the regression model.



Prior History of Cancers

Of the 10,085 queries, 5343 queries (52.9%) entered a prior history of cancer, comprising 56.3% (4771/8478) of the queries on females and 35.6% (572/1607) of the queries on males. The frequencies of the type of prior cancer in the queries on females have a strong linear correlation with the corresponding US cancer incidences (r=0.97, r^2=0.95, P<.001; Figure 2), while the same correlation was weaker in the queries on males (r=0.69, r^2=0.47, P=.02, Figure 3). Sensitivity analysis revealed that the above linear correlation in queries on females did not change significantly after excluding the queries with the default setting (females: r=0.97, r^2=0.95, P<.001; the correlation in males was not affected by removing the queries with the default setting). There were 634 queries (11.9% of all queries with cancer history) who selected multiple prior cancers. Among the 521 queries on females with multiple cancers, breast and ovarian cancers (78/521, 15.0%) and breast cancer and melanoma (70/521, 13.4%) were the 2 most common combinations. Among the 113 queries on males with multiple cancers, prostate and colorectal cancers were the most common combination (42/113, 37.2%). In addition, 23.0% (1947/8478) of queries were on females who had an oophorectomy, 22.4% (1899/8478) of queries were on females who had a hysterectomy, and 17.2% (1462/8478) of queries were on females who had a bilateral mastectomy.

Figure 2. Correlation between frequencies of prior cancers in the Ask2Me.org user queries on females and corresponding US cancer incidences. The blue line represents the results from the regression model.

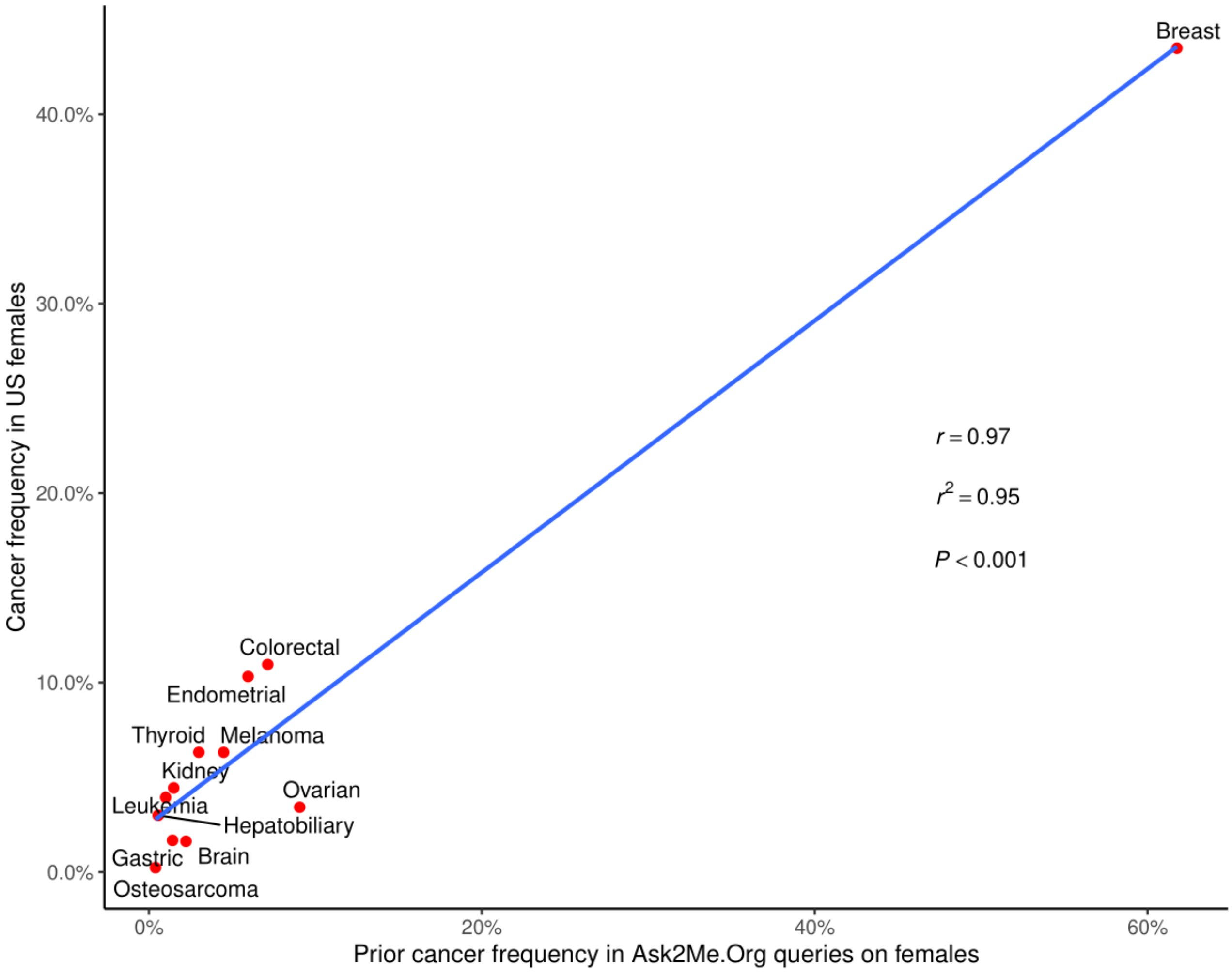
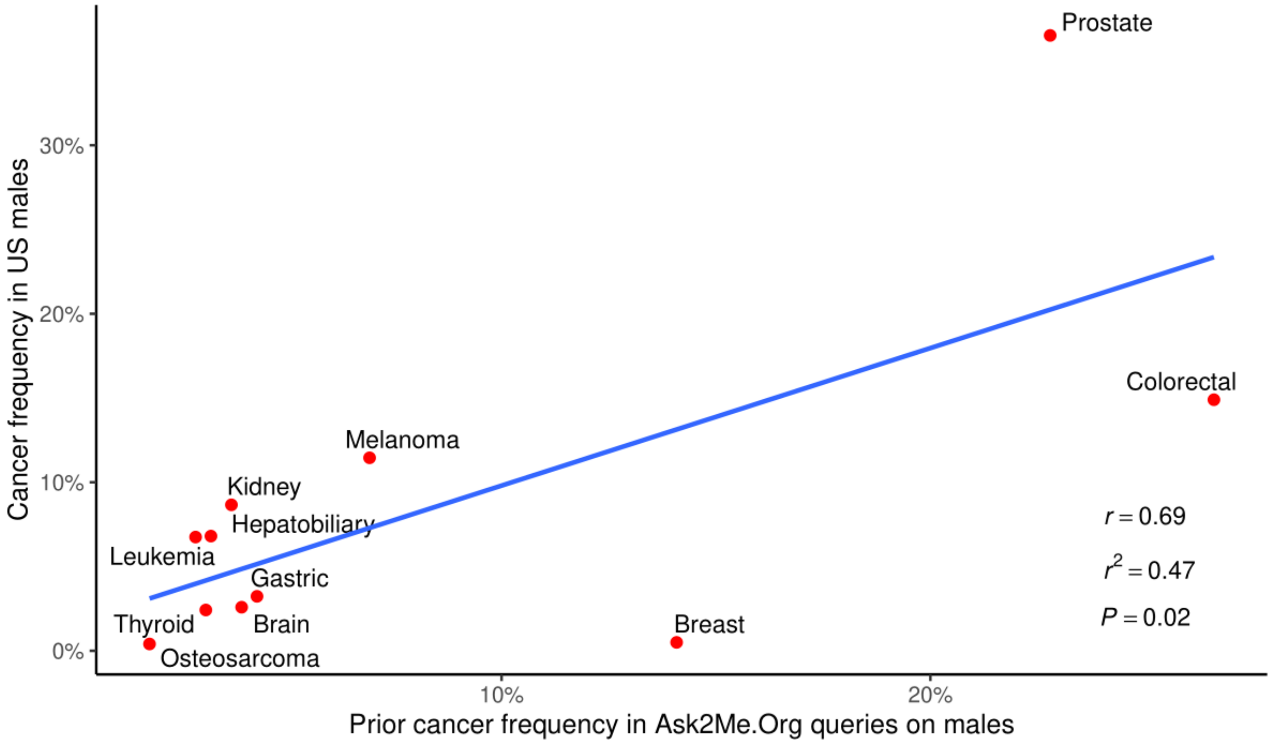


Figure 3. Correlation between frequencies of prior cancers in the Ask2Me.org user queries on males and corresponding US cancer incidences. The blue line represents the results from the regression model.



Discussion

In this study, by analyzing over 10,000 user queries, we characterized the search behaviors of Ask2Me.org tool users and identified the patterns of pathogenic variants and cancer history among the queries. We found that breast cancer susceptibility genes were the most commonly searched genes in both males and females. There was a strong linear correlation between the frequencies of genes entered by Ask2Me.org users and the prevalence of pathogenic variants in panel testing results recently reported by LaDuca et al [10]. Over half of the queries included a prior cancer history. The frequencies of prior cancers in the queries on females had a strong correlation with US cancer incidences, while the same correlation was weaker among the queries on males. Overall, these findings suggest that the patients entered into the Ask2Me.org tool are a representative cohort of patients with pathogenic variants in the United States. We found that the majority of the commonly searched genes are breast cancer susceptibility genes. In current practice, most germline genetic test takers are individuals who have a high suspicion of hereditary cancer predisposition. Among all types of cancers, breast cancer's inherited component is one of the most intensively studied and appreciated. Several breast cancer risk assessment models have been developed to identify individuals with a high risk of being pathogenic variant carriers [12] and they are widely implemented in clinical practice. Taking all this together, plus the high incidence of breast cancer (30% of all newly diagnosed cancers in US women) [11], it is not surprising to see the majority of the commonly searched genes are related to breast cancer. In contrast, we found that genes associated with colorectal cancer were searched less frequently, with none of the 6 Lynch syndrome–associated genes accounting for more than 3.9% (400/10,085) of the total searches. This may be due to the less frequent use of multigene panel testing in patients with colorectal cancer and their families. With the inclusion of more newly identified genes in the National Comprehensive Cancer Network colorectal cancer genetic/familial high-risk assessment guidelines [13] and more wide use of panel testing in clinical practice, we expect to see an increasing search of colorectal cancer susceptibility genes in the Ask2Me.org tool in the future.

Hart et al [14] recently reported the pathogenic variant prevalence among nearly 148,000 individuals referred for hereditary cancer genetic testing. The most prevalent mutated genes in this high-risk population share a similar pattern as we identified in the Ask2Me.org tool: 8 out of the top 10 most frequently mutated genes found in these 148,000 individuals are among the top 10 most commonly searched genes in the Ask2Me.org tool. In addition, there was a strong linear relationship between the frequencies of genes entered by users in the Ask2Me.org tool and the frequencies of pathogenic variants in the panel testing results reported by LaDuca et al [10]. These findings suggest that the rates of queries in the Ask2Me.org tool may be proportional to their prevalence. Users not only queried commonly tested genes such as *BRCA1* and *BRCA2* but also queried lower prevalence genes, which may represent the shift from single gene testing to multigene panel testing.

Over half of queries entered in the Ask2Me.org tool included a personal history of cancer, with around 10% of them having multiple cancers. These results show that queries with prior cancers accounted for a considerable portion of the Ask2Me.org tool user queries. Similarly, in LaDuca et al's 165,000-patient cohort, 72.5% of patients had a personal history of cancer [10]. This is likely in part because most patients tested already have cancer [15]. As Dr. Mary-Claire King stated at her Lasker Award speech, this represents "a failure of cancer prevention" [16]. These findings suggest that we need to increase genetic testing in people who do not yet have cancer and implement appropriate interventions before cancer develops. We also observed a strong linear association between the frequencies of queries with prior cancers entered and the US cancer incidences in queries on females, further demonstrating that queries on females were not only limited to one or several cancer types but distributed proportionally to the population-level cancer incidence. The same correlation in queries on males was weaker, which may be explained by the relatively young age entered in these male queries (median age 47 years). Since approximately 60% of prostate cancer cases are diagnosed in men older than 65 years [17], the young age in Ask2Me.org male queries may result in a lower proportion of prostate cancers queried compared to the US population–based incidence of prostate cancers.

The indications for germline genetic testing have been expanded in recent decades. In addition to testing for hereditary breast and ovarian cancer, germline genetic testing has also been recommended to manage other cancers such as colorectal cancer, pancreatic cancer, and prostate cancer. It is essential to incorporate high-quality, evidence-based, and easy-to-access clinical decision support tools into the interpretation of testing results and the personalization of disease prevention and clinical management plans. One purpose of studying search behavior is to understand user needs and further improve the Ask2Me.org tool. Since this tool became available in 2016, efforts have been made to optimize and improve this clinical decision support tool. A natural language processing algorithm was developed to classify medical literature on cancer susceptibility genes [18]. Based on this algorithm, a semiautomated natural language processing–based procedure was developed to identify the penetrance studies in the medical literature, which has proven to reduce 84% of the abstract review workload and cover 99% of penetrance studies [6,19]. In addition, we have reviewed over 10,000 cancer genetic papers identified over 700 penetrance studies and provided the absolute risk curves for at least 154 gene-cancer combinations. In addition, a framework of the systematic review and verification of gene-disease associations has been developed [20]. Using this framework, we have examined all genes listed in the Ask2Me.org tool, verified over 500 gene-disease associations, and reported the disease spectra for breast, thyroid, and gastric cancer susceptibility genes [20-23]. Since users are not only interested in the commonly tested genes such as *BRCA1/2*, we plan to expand the Ask2Me.org tool to cover a broader range of genes, especially those with relatively low prevalence. Further, as over half of the queries included a prior personal history of cancer, we hope in the future that cascade testing will allow patients with no cancer to benefit from increased surveillance. Moreover, additional cancer-related features such as infection status (eg, HPV, HIV) and cancer status (eg, remission, recurrence) may also be incorporated into this tool.

This study has several limitations. First, search queries are likely to correspond to not only real patients but also test cases or research purposes. Although we performed sensitivity analyses by removing the queries with default settings, there is still no way to explicitly distinguish them. Second, the frequencies of genes and prior cancers were only reflective of the search queries of the Ask2Me.org tool but may not represent the actual prevalence of the pathogenic variants and cancers at the population level. Third, as the vast majority of users are in the United States, the current findings in the searching behavior may not be generalized to users from other countries. The Ask2Me.org tool has become an increasingly recognized clinical decision tool that provides risk predictions for patients with pathogenic variants in cancer susceptibility genes. There is a strong linear relationship between the frequencies of genes entered by the Ask2Me.org tool users and the frequencies of pathogenic variants in panel testing results reported by LaDuca et al [10]. The frequencies of prior cancers in the queries on females have a strong correlation with US cancer incidences, while the same correlation was weaker among the queries on males. Our data suggest that clinicians seek information on almost all genes identified and not just the less recognized or more recently identified genes.

Authors' Contributions

DB and KSH conceived and designed the research; KY collected and analyzed the data; KY, JZ, PS, JW, and DB interpreted the results; KY and JZ drafted the manuscript; and DB and KSH made critical revisions of the manuscript. Data are available upon reasonable request. All authors approved the submission of the final manuscript.

Conflicts of Interest

KSH receives Honoraria from Hologic (surgical implant for radiation planning with breast conservation and wire-free breast biopsy) and Myriad Genetics and is a founder of and has a financial interest in CRA Health (Formerly Hughes RiskApps, cancer risk assessment software), which was recently acquired by Volpara (breast density and cancer risk assessment company). KSH is the cocreator of Ask2Me.org (a genetic risk KnowledgeBase), which Mass General Brigham licenses to MedNeon (a cancer risk assessment company). KSH's interests were reviewed and are managed by Massachusetts General Hospital and Mass General Brigham Healthcare in accordance with their conflict of interest policies. DB coleads the BayesMendel laboratory, which licenses software for the computation of risk prediction models. She does not currently derive any personal income from these licenses. All revenues are assigned to the laboratory for software maintenance and upgrades. The other authors declare that they have no conflict of interest.

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Abbreviations

Ask2Me: All Syndromes Known to Man Evaluator

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Original Paper

Improving Electronic Survey Response Rates Among Cancer Center Patients During the COVID-19 Pandemic: Mixed Methods Pilot Study

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Abstract

Background: Surveys play a vital role in cancer research. During the COVID-19 pandemic, the use of electronic surveys is crucial to improve understanding of the patient experience. However, response rates to electronic surveys are often lower compared with those of paper surveys.

Objective: The aim of this study was to determine the best approach to improve response rates for an electronic survey administered to patients at a cancer center during the COVID-19 pandemic.

Methods: We contacted 2750 patients seen at Moffitt Cancer Center in the prior 5 years via email to complete a survey regarding their experience during the COVID-19 pandemic, with patients randomly assigned to a series of variations of prenotifications (ie, postcard, letter) or incentives (ie, small gift, modest gift card). In total, eight combinations were evaluated. Qualitative interviews were conducted to understand the level of patient understanding and burden with the survey, and quantitative analysis was used to evaluate the response rates between conditions.

Results: A total of 262 (9.5%) patients completed the survey and 9 participated in a qualitative interview. Interviews revealed minimal barriers in understanding or burden, which resulted in minor survey design changes. Compared to sending an email only, sending a postcard or letter prior to the email improved response rates from 3.7% to 9.8%. Similarly, inclusion of an incentive significantly increased the response rate from 5.4% to 16.7%, especially among racial (3.0% to 12.2%) and ethnic (6.4% to 21.0%) minorities, as well as among patients with low socioeconomic status (3.1% to 14.9%).

Conclusions: Strategies to promote effective response rates include prenotification postcards or letters as well as monetary incentives. This work can inform future survey development to increase response rates for electronic surveys, particularly among hard-to-reach populations.

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KEYWORDS

response rates; electronic survey; cancer; COVID-19; pandemic; surveillance; cancer patients; health promotion; digital health; patient experience; health outcomes

Introduction

Surveys are a critical aspect of many research studies, and electronic surveys are increasingly being used in research. Benefits of electronic compared to paper surveys include greater reach, higher survey completeness, lower costs, flexibility in survey design, real-time data access, and increased willingness of participants to share information [1-4]. Prior work has demonstrated that the vast majority of research participants, including cancer patients, prefer a computer-assisted survey compared to a paper-based survey [2,5,6].

Nevertheless, compared with mailed or in-person paper surveys, electronic surveys tend to have lower response rates and decreasing response rates over time [7-10], although most studies using paper surveys also experience attrition with follow-up [11-15]. Response rates, regardless of survey type, are usually lower in minority racial and ethnic groups, as well as among those with poorer health status, lower incomes, and lower education [16]. A study among breast cancer patients found that those who were older, had lower education levels, and had worse quality of life were more likely to prefer paper-based surveys to collect health data, indicating a potential barrier to electronic surveys in these populations [17].

As a consequence of the COVID-19 pandemic, there is reduced face-to-face interaction with research participants, increasing the need to reach study participants using remote approaches [18,19]. Thus, it is critical to evaluate potential approaches to engage participants and enhance the response to electronic surveys. For example, shortening the length of the survey and improving the clarity of questions can reduce the burden and improve understanding, leading to higher response rates [10,20-23]. Additionally, monetary and nonmonetary incentives, a notification prior to administering the survey, including an image in the email, and follow-up contact may also enhance participation [4,10,21,22]. To address the growing need to enhance response rates for electronic surveys, we used a mixed methods approach to (1) assess participant burden and understanding through qualitative interviews, and (2) quantitatively evaluate the impact of prenotifications and incentives on response rates of an electronic survey during the COVID-19 pandemic among individuals who were seen at a cancer center.

Methods

Study Population

This study included patients at Moffitt Cancer Center who were seen between January 1, 2015 and September 13, 2020; had English as a preferred language; were between 40 and 89 years old; lived in the cancer center catchment area; had a valid email address; and a last known vital status of alive. Half of the patients in this study had previously consented to an institutional biobanking study (Total Cancer Care: MCC14690, Advarra IRB Pro00014441; Moffitt Cancer Center Screening and Prevention Study: MCC14453, USF IRB 103792). We randomly selected patients for each pilot condition with oversampling of Hispanic and Black/African American patients. Similar to the general Moffitt Cancer Center population, the participants included in this study were those diagnosed with invasive and in situ cancer, benign diseases, and patients who were screened without a cancer diagnosis. The survey contained questions regarding COVID-19–specific behaviors, testing, symptoms and treatment, demographics, medical history, health behaviors, and psychosocial well-being (143 total items across 26 web pages). Participants were able to change their answers through a “back” button if desired. The survey was tested with staff members before sending to participants to check for usability, technical functionality, and appropriate wording. After surveys were submitted, they were reviewed by study staff for completeness.

Ethical Statement

This study was approved by Advarra Inc (MCC 20629, Pro00043372). Emails invited eligible patients to the study and included a unique link to an information and consent page. This page included a description of the study goals, the approximate length of the survey, a Health Insurance Portability and Accountability Act authorization if they were not consented to a biobanking study or information about the biobanking study they had consented to previously, and the Institutional Review Board contact information. At the bottom of this web page was a unique link, based on the patient’s email address, to start the voluntary survey.

Pilot Conditions

We evaluated eight different conditions with an email sent with a survey link for each condition, and various methods of prenotifications and incentives were tested based on findings from prior literature [10,20-23]. Although prior studies have shown that prenotifications and incentives improve response rates, there has been little work performed in this regard with cancer center patients, especially during the pandemic; therefore, we considered multiple methods and their combinations. Participants in the first condition (n=1000) received a lengthy (380-528 words) text-only email discussing the aim of the study, study procedures, and links for more information about the COVID-19 pandemic and the cancer center’s response. Due to cost and time constraints, the subsequent conditions included 250 patients each. Participants in conditions 2-8 received a condensed version of the email sent in condition 1, containing only a few sentences (119-142 words), with the cancer center’s logo and an image of the principal investigators’ signatures. Participants in condition 2 received only the condensed email, those in condition 3 received a mailed letter from the principal investigators of the study and the center’s Associate Center

Director of Clinical Science, which discussed the importance of the work and noted that an email with the survey link would be sent shortly; this was followed by a condensed email 3 to 4 days after mailing the letter. Condition 4 was the same as condition 3 but with the addition of a small gift (Moffitt-branded adhesive phone wallet) in the envelope. Participants in condition 5 received a postcard about the study and asked patients to look for an email with a survey link, which was sent 3 to 4 days later. Participants in condition 6 received only the condensed email with an additional note stating that an electronic US $10 gift card would be sent via email within 5 days of completion of the survey. Participants in condition 7 received the same letter as sent in condition 3, further noting a US $10 gift card incentive upon survey completion. Participants in the final condition received a postcard noting that an email will be sent with a US $10 gift card after completing the survey. For all conditions, up to two reminder emails were sent in 4-day intervals.

Covariates

We collected information on current age (continuous), years since their most recent visit to the cancer center (<2 years, 2-5 years), gender (male, female), race (White, non-White), ethnicity (non-Hispanic, Hispanic), cancer status (invasive cancer, benign, in situ, or no cancer diagnosis), and zip code to assess the area deprivation index (ADI) decile rank for the state of Florida, which ranges from 1 to 10. The ADI ranks neighborhoods based on socioeconomic factors, including income, education, employment, and housing quality, with a higher ADI rank indicating a greater socioeconomic disadvantage [24,25]. All variables were obtained through medical records and Cancer Registry data; missing information was supplemented with self-reported data from the survey where possible (eg, self-reported race and ethnicity). Data collected on the survey were linked to medical record data. All data were stored on a secured, password-protected server.

Qualitative Interviews

Individual qualitative interviews were conducted with survey participants to better understand their motivations to participate in the survey, and to assess understanding of the survey questions and participant burden. Upon completion of the survey, participants within condition 1 (long email only) were asked if they would like to volunteer for an interview to provide feedback about their survey experience. A research coordinator contacted participants who volunteered and obtained verbal consent via telephone. Videoconference interviews (n=9) were scheduled an average of 4 weeks after participants completed the survey and were conducted by two trained interviewers (MC and MK). A semistructured interview guide was used with two primary domains: understanding and burden, informed by health literacy models and the perceived research burden literature [26-28]. The interviews were conducted over a period of 2 weeks using Zoom [29,30]. The interviews lasted an average of 21 minutes and were audio-recorded with participant consent. Data saturation was reached after nine interviews with participants in the first condition; therefore, we did not conduct interviews with the other pilot conditions.

Qualitative Data Analysis

Interview transcripts were analyzed using rapid ethnographic methods [31,32] and constant comparison analysis [33], an integrative process of cumulative and concurrent data generation and analysis, to identify emergent themes that informed continuing data collection [34]. These methods were adopted to accommodate the time-sensitive nature of the research, since the survey was ongoing during analysis. Emergent themes were identified and agreed upon by the researchers, and when available, specific quotes that were representative of each theme were selected and segmented. Data saturation was reached after nine interviews (ie, no new themes emerged), consistent with other qualitative studies [35,36].

Statistical Analysis

We calculated response rates for each pilot condition and compared groups of conditions (eg, pre-email notification vs none, incentive vs none) by calculating overall response rates as well as response rates within key sociodemographic groups. We used χ^2 tests to assess statistical differences in response rates and logistic regression was used to estimate the odds of completing the survey between groups of conditions. We also used logistic regression analysis to assess the odds of response for each condition (compared to condition 2 with only the condensed email) adjusting for sociodemographic factors that were found to be significantly associated with response rates in univariable logistic regression. All P values were two-sided and analytic results were considered statistically significant if $P<.05$. Study data were collected and managed using REDCap electronic data capture tools hosted at Moffitt Cancer Center [37,38]. Analyses were performed using SAS version 9.4 (SAS Institute Inc).

Results

Population Characteristics

Among the 2750 patients contacted, a total of 262 patients (9.5%) completed the survey. Compared to the total invited population, those who completed the survey were slightly older, more likely to be female, less likely to be Black, and more likely to be Hispanic (Table 1). Those with higher measures of socioeconomic status (ie, a lower ADI rank) were also more likely to complete the survey (mean decile rank of 4.5 vs 5.0 among the invited population). Most patients had a cancer diagnosis (75%), approximately 7% of those contacted had a benign or in situ diagnosis, and 18% had no reported cancer diagnosis. The survey took an average of 18.4 minutes to complete. Demographic information for each pilot condition is shown in Multimedia Appendix 1.

Table 1. Demographic characteristics of participants who completed the survey and those who were invited to participate.

Characteristics	Completed survey (n=262)	Invited to survey (n=2750)
Time to complete survey (minutes), mean (SD)	18.4 (14.3)	N/A[a]
Age (years), mean (SD)	65.6 (10.9)	64.5 (11.6)
Years since last Moffitt visit, mean (SD)	1.0 (1.3)	1.5 (1.6)
Area Deprivation Index State Decile Rank, mean (SD)[b]	4.5 (2.6)	5.0 (2.7)
Gender, n (%)		
Male	118 (45.0)	1339 (48.7)
Female	144 (55.0)	1411 (51.3)
Race, n (%)		
American Indian	0 (0)	4 (0.2)
Asian/Pacific Islander	1 (0.4)	41 (1.5)
Black	26 (9.9)	379 (13.8)
Other	4 (1.5)	69 (2.5)
White	231 (88.2)	2192 (79.7)
Unknown	0 (0)	65 (2.4)
Ethnicity, n (%)		
Hispanic	38 (14.5)	378 (13.8)
Non-Hispanic	224 (85.5)	2312 (84.1)
Unknown	0 (0)	60 (2.2)
Cancer status, n (%)		
Invasive	212 (80.9)	2058 (74.8)
Benign or in situ	9 (3.4)	193 (7.0)
No cancer	41 (15.7)	499 (18.2)
Stage at first diagnosis[c], n (%)		
0	9 (4.3)	77 (3.7)
1	64 (30.2)	476 (23.1)
2	28 (13.2)	280 (13.6)
3	16 (7.6)	183 (8.9)
4	17 (8.0)	157 (7.6)
Unknown	78 (36.8)	885 (43.0)
Recruitment method, n (%)		
Long email only	26 (9.9)	1000 (36.4)
Condensed email only	20 (7.6)	250 (9.1)
Condensed email + letter	28 (10.7)	250 (9.1)
Condensed email + letter + gift[d]	39 (14.9)	250 (9.1)
Condensed email + postcard	21 (8.0)	250 (9.1)
Condensed email + gift card	36 (13.7)	250 (9.1)
Condensed email + letter + gift card	46 (17.6)	250 (9.1)
Condensed email + postcard + gift card	46 (17.6)	250 (9.1)

[a] N/A: not applicable.

[b] Missing: n=11 completed survey, n=100 invited to survey.

[b] Among those diagnosed with invasive or metastatic cancer.

[c] The gift included a Moffitt-branded adhesive phone wallet inside the envelope.

Qualitative Interviews

The qualitative interview responses were summarized using a priori determined themes (ie, understanding, burden) and emergent themes (ie, access, question-specific feedback). All participants reported being able to understand and comprehend most survey questions; however, participants also reported that if they did not understand the question, they skipped it. If participants were unable to answer the question accurately with the answers provided, they answered the best they could. When available, participants clarified their answers in a free-text field at the end of the survey and suggested adding free-text fields to some questions to allow participants to clarify their responses, which were then added to the survey for subsequent conditions.

Participants did not report experiencing stress due to the survey; however, some participants commented that the survey was too long. One participant who was not undergoing treatment said, “If I wasn’t feeling well, I’ll tell you this [survey] is the last thing I’d do.” Other participants mentioned the extra effort required to answer questions about their cancer history, such as recalling specific dates, diagnosis (ie, first, recurrence), treatments, and medications. Other burden-related comments included high levels of stress participants were experiencing in their lives (ie, due to cancer, COVID-19 pandemic) and feeling isolated. Given this initial feedback, several questions were removed or reworded in the survey to reduce participant burden.

Participants did not report difficulty accessing the survey, although interviewed participants were among those who successfully completed the survey and agreed to provide feedback. They felt that the email was clear and the links were easy to find. However, participants did provide specific suggestions related to improving access, including the use of text messages or the patient portal to notify participants that a survey was emailed. Most participants did not have feedback or recommendations to improve access to the survey.

Condition Response Rates

Table 2 presents response rates for the overall sample and sociodemographic subgroups. The pilot condition with the lowest response rate was the long email only and the highest responses were for the conditions with a prenotification (either letter or postcard) and receiving a US $10 gift card for completing the survey. Further, differences in response rates were observed for the pilot conditions based on sociodemographic factors. For example, those receiving an email, postcard, and gift card had the highest response rates among non-White individuals and those with lower socioeconomic status, and participants of Hispanic ethnicity responded more frequently when receiving an email, letter, and gift card. Women had a higher response when a letter and an incentive were included, showing similar results if the incentive was a gift or a gift card. Alternatively, men responded more frequently when there was a postcard and a gift card, although responses were only slightly lower for the letter-only or the letter+gift card conditions.

Multivariable logistic regression was used to evaluate the odds of survey completion by pilot condition and sociodemographic factors. Compared with receiving only the condensed email, adding a letter and gift, a gift card, a letter and gift card, or a postcard and gift card significantly increased the odds of survey response (Table 3). Further, having previously consented to a Moffitt biobanking study versus not was related to a higher odds of survey response. Having a worse socioeconomic disadvantage (ADI rank 6-10 vs 1-5) as well as the last visit to the cancer center being more than 2 years from the date of the email led to a decreased response. Results were similar in the univariable models (data not shown).

Table 2. Response rates for each condition overall and by sociodemographic factor.

Sociodemographic factor	Long email only (n=1000)	Email only (n=250)	Email+letter (n=250)	Email+letter+gift (n=250)	Email+postcard (n=250)	Email+gift card (n=250)	Email+letter+ gift card (n=250)	Email+postcard+gift card (n=250)
Minutes to complete survey, mean (SD)	20.4 (21.1)	14.6 (9.6)	15.6 (7.0)	18.3 (11.5)	21.7 (22.0)	22.0 (18.6)	16.6 (7.1)	18.4 (14.3)
Overall response rate	2.6%	8.0%	11.2%	15.6%	8.4%	14.4%	18.4%	18.4%
Race								
White	3.1%	9.0%	11.7%	18.1%	8.9%	15.9%	19.0%	18.7%
Non-White	0.0%	2.6%	9.1%	4.3%	6.4%	8.2%	16.0%	17.3%
Ethnicity								
Non-Hispanic	2.8%	8.1%	11.3%	16.8%	7.9%	15.6%	16.9%	17.0%
Hispanic	1.5%	7.4%	10.3%	8.3%	11.8%	7.9%	27.0%	25.0%
Gender								
Male	1.7%	8.8%	15.2%	11.8%	5.8%	12.2%	15.4%	18.1%
Female	3.3%	7.4%	7.2%	20.2%	10.8%	16.8%	21.9%	18.7%
Years since last visit								
<2	3.3%	8.1%	14.9%	17.3%	9.9%	17.4%	21.1%	20.4%
2-5	1.0%	6.9%	3.4%	12.2%	5.1%	7.7%	12.0%	13.0%
Age (years)								
<65	2.8%	4.1%	10.8%	11.2%	5.6%	14.2%	21.1%	19.2%
≥65	2.5%	11.7%	11.5%	18.9%	10.6%	14.6%	15.7%	17.7%
Cancer status								
Invasive cancer	3.0%	7.6%	14.0%	16.8%	9.8%	14.4%	17.8%	20.5%
Benign, in situ, or no cancer	1.2%	9.1%	5.1%	12.1%	4.5%	14.5%	20.8%	10.9%
ADI[a] decile								
1-5 (less disadvantaged)	2.9%	9.9%	13.8%	17.2%	12.0%	14.9%	19.2%	21.2%
6-10 (more disadvantaged)	1.9%	5.1%	6.5%	14.9%	3.1%	13.0%	19.1%	13.1%

[a] ADI: Area Deprivation Index.

Table 3. Odds of completing the survey for the different pilot conditions and various sociodemographic factors.

Variables in multivariate model	OR[a] (95%CI)	*P* value
Email + letter (vs short email only)	1.51 (0.81-2.82)	.20
Email + letter + gift (vs short email only)	2.29 (1.27-4.13)	.01
Email + postcard (vs short email only)	1.02 (0.53-1.99)	.95
Email + gift card (vs short email only)	2.03 (1.11-3.71)	.02
Email + letter + gift card (vs short email only)	2.83 (1.59-5.06)	<.001
Email + postcard + gift card (vs short email only)	2.55 (1.42-4.58)	.002
Previous consent to biobanking study (vs not consented)	2.15 (1.59-2.93)	.006
Area Deprivation Index decile (6-10 vs 1-5)	0.65 (0.48-0.88)	.01
Cancer status (invasive vs benign/in situ/no cancer)	1.04 (0.71-1.53)	.84
Age (per 10 years)	1.13 (0.99-1.29)	.08
Non-White (vs White/missing)	0.68 (0.45-1.04)	.08
Hispanic (vs non-Hispanic/missing)	1.11 (0.74-1.68)	.60
Years since last visit to Moffitt (2-5 vs <2)	0.52 (0.36-0.73)	<.001
Female (vs male)	1.33 (0.98-1.81)	.06

[a] OR: odds ratio.

Logistic regression analyses were performed to examine the impact of including a prenotification and/or incentive among sociodemographic subgroups. Compared with receiving only an email, response rates were significantly better among those receiving a prenotification letter or postcard (Table 4). A significant increase in response was observed with the prenotification for nearly every sociodemographic group examined, except those last seen at the cancer center more than 2 years ago, those without invasive cancer, and those with a worse socioeconomic disadvantage. The largest increase in response rates was observed for Hispanic and non-White patients. Further, when comparing no incentive to any incentive (gift card or gift), the response rate increased from 5.4% to 16.7% overall; every group had significantly improved response rates (Table 5). The largest increases in response rates were for non-White individuals, those with a greater socioeconomic disadvantage (ADI=6-10), and those without an invasive cancer diagnosis (Table 5). The condensed email also had significantly higher response rates; generally, there were no differences in response rates when comparing the two different prenotification modalities (letter vs postcard) or incentive types (gift vs gift card) (see Multimedia Appendix 2). Overall, 192 patients (7% of 2750) read the consent and answered at least one question but did not complete the survey. The noncompletion rate of the survey was the highest in conditions 1 and 2 (10.9% and 10.8%, respectively) and was the lowest for conditions 6, 7, and 8 (0.8%, 1.2%, and 0.8%, respectively) (data not shown).

Table 4. Response rates and odds of response when including a pre-email notification letter or postcard overall and by sociodemographic groups.

Socioeconomic group	Long or condensed email only (n=46/1250)		Condensed email + letter or postcard (n=49/500)		OR[a] (95% CI)
	Complete, n (%)	Incomplete, n (%)	Complete, n (%)	Incomplete, n (%)	
Overall	46 (3.7)	1204 (96.3)	49 (9.8)	451 (90.2)	2.84 (1.87-4.31)
White	45 (4.3)	1000 (95.7)	42 (10.3)	367 (89.7)	2.54 (1.64-3.94)
Non-White	1 (0.5)	204 (99.5)	7 (7.7)	84 (92.3)	17.00 (2.06-140.31)
Non-Hispanic	42 (3.9)	1048 (96.2)	42 (9.6)	395 (90.4)	2.65 (1.70-4.13)
Hispanic	4 (2.5)	156 (97.5)	7 (11.1)	56 (88.9)	4.88 (1.37-17.29)
Male	18 (3.1)	557 (96.9)	26 (10.6)	219 (89.4)	3.67 (1.97-6.84)
Female	28 (4.2)	647 (95.9)	23 (9.0)	232 (91.0)	2.29 (1.29-4.06)
<2 years since last visit	37 (4.3)	828 (95.7)	42 (12.5)	293 (87.5)	3.21 (2.02-5.09)
2-5 years since last visit	9 (2.3)	376 (97.7)	7 (4.2)	158 (95.8)	1.85 (0.68-5.06)
<65 years old	18 (3.0)	575 (97.0)	19 (8.3)	209 (91.7)	2.90 (1.50-5.64)
≥65 years old	28 (4.3)	629 (95.7)	30 (11.0)	242 (89.0)	2.78 (1.63-4.76)
Any cancer	37 (3.9)	902 (96.1)	42 (11.8)	313 (88.2)	3.27 (2.06-5.18)
Benign, in situ, or no cancer	9 (2.9)	302 (97.1)	7 (4.8)	138 (95.2)	1.70 (0.62-4.66)
ADI[b] rank 1-5	30 (4.3)	664 (95.7)	38 (12.9)	256 (87.1)	3.29 (1.99-5.42)
ADI rank 6-10	13 (2.5)	503 (97.5)	9 (4.7)	181 (95.3)	1.92 (0.81-4.58)

[a] OR: odds ratio.

[b] ADI: Area Deprivation Index.

Table 5. Response rates and odds of response when including a pre-email notification of an incentive upon completion overall and by sociodemographic groups.

Socioeconomic group	No incentive (n=95/1750)		Any incentive (n=167/1000)		OR[a] (95% CI)
	Complete, n (%)	Incomplete, n (%)	Complete, n (%)	Incomplete, n (%)	
Overall	95 (5.4)	1655 (94.6)	167 (16.7)	833 (83.3)	3.49 (2.68-4.55)
White	87 (6.0)	1367 (94.0)	144 (17.9)	659 (82.1)	3.43 (2.59-4.55)
Non-White	8 (2.7)	288 (97.3)	23 (11.7)	174 (88.3)	4.76 (2.08-10.87)
Non-Hispanic	84 (5.5)	1443 (94.5)	140 (16.6)	705 (83.4)	3.41 (2.57-4.54)
Hispanic	11 (4.9)	212 (95.1)	27 (17.4)	128 (82.6)	4.07 (1.95-8.47)
Male	44 (5.4)	776 (94.6)	74 (14.3)	445 (85.7)	2.93 (1.98-4.34)
Female	51 (5.5)	879 (94.5)	93 (19.3)	388 (80.7)	4.13 (2.88-5.93)
<2 years since last visit	79 (6.6)	1121 (93.4)	133 (19.1)	563 (80.9)	3.35 (2.49-4.51)
2-5 years since last visit	16 (2.9)	534 (97.1)	34 (11.2)	270 (88.8)	4.20 (2.28-7.75)
<65 years old	37 (4.5)	784 (95.5)	78 (16.6)	392 (83.4)	4.22 (2.80-6.35)
≥65 years old	58 (6.2)	871 (93.8)	89 (16.8)	441 (83.2)	3.03 (2.14-4.30)
Any cancer	79 (6.1)	1215 (93.9)	133 (17.4)	631 (82.6)	3.24 (2.41-4.35)
Benign, in situ, or no cancer	16 (3.5)	440 (96.5)	34 (14.4)	202 (85.6)	4.63 (2.50-8.58)
ADI[b] rank 1-5	68 (6.9)	920 (93.1)	104 (18.1)	470 (81.9)	2.99 (2.16-4.14)
ADI rank 6-10	22 (3.1)	684 (96.9)	57 (14.9)	325 (85.1)	5.45 (3.28-9.07)

[a] OR: odds ratio.

[b] ADI: Area Deprivation Index.

Discussion

Overview

In this study, patients seen at a cancer center who were sent a prenotification letter or postcard had higher response rates to an email invitation for an electronic survey than those not sent a prenotification, with much higher rates among those offered an incentive. Notably, both types of incentives—a small gift included with the prenotification letter or a gift card upon survey completion—improved response rates of electronic surveys for individuals who are often underrepresented in studies, including racial or ethnic minorities and those with low socioeconomic status. Further, prior engagement in biobanking studies and having been seen more recently at the cancer center were strong predictors of higher response rates. Finally, qualitative interviews identified that although the survey itself was not particularly burdensome, cancer patients are experiencing many external stressors due to the pandemic that may interfere with or deter from participation.

Conclusions

Our study is consistent with previous literature showing that prenotifications can increase response rates, particularly for electronic surveys [4,10,20-22,39]. We also observed higher response rates when including a gift or monetary incentive; however, prior studies only observed an increase with monetary incentives [39-42] and not with other incentives [43-46]. Interestingly, in cancer patients, both a small gift for all invited individuals or a gift card for those who completed the survey led to similar response rates. Above and beyond the cost of sending the letters, postcards, and emails, we spent US $378 on gifts sent to all 250 invited patients in condition 4 and US $1280 on gift cards sent to the 128 participants who completed surveys in conditions 6-8. This yielded a cost of US $9.69 per completed survey for those in condition 4 and US $10 for those in conditions 6-8. Because these conditions had similar response rates and similar cost per completed survey, each study should evaluate the feasibility and best method for their population.

This study builds on the literature by finding higher response rates in traditionally underrepresented groups when sent a prenotification and/or incentive, which has not been evaluated previously. Additionally, patients with prior involvement in research and who had more recently been seen at the study site were more likely to have a higher response overall, indicating that connection or engagement with the study site in advance of the invitation to research studies could be a critical modality to enhance response rates for remote studies, especially during a pandemic such as COVID-19. The salient nature of this survey may have increased our response rates, although we are unable to evaluate this as participants in all pilot conditions received the same survey.

Ensuring understanding and minimizing burden are important in the development and dissemination of effective surveys for research. Although participants noted that the survey was lengthy, those who completed the survey expressed that they did not feel the survey was overly burdensome. Nevertheless, the length of the survey (approximately 15-20 minutes) may have been a barrier to participation for nonrespondents. Participant suggestions of how to further improve understanding and minimize burden included: (1) reducing the use of medical terminology and incorporating lay terms; (2) adjusting the questions to make the language more specific and less confusing (eg, define what "physical contact" means in the question "How often have you had physical contact with individuals that do not live with you?"); and (3) more clearly communicating the expectations and purpose of the survey through the consent process or via email (eg, length of the survey, expected time commitment). When possible, the length of the survey should be reduced to include questions focused on answering the primary research questions, which may increase response rates [47]. We used adaptive questions such that some questions were only shown if participants self-reported a cancer diagnosis, thereby reducing the overall burden.

Strengths and Limitations

This study has many strengths, including the use of a mixed methods approach to improve the design of the survey and response rates. As a result of the qualitative interviews, adjustments were made to specific survey questions to improve understanding and the invitation email was substantially condensed to increase readability. We oversampled underrepresented groups to ensure adequate representation, allowing us to evaluate response rates within specific populations. However, due to low response rates with the first pilot condition (long email only), some analyses had limited power. Further, we only conducted qualitative interviews with those who completed the survey and answered the survey question asking whether they would be interested in participating in the interview, which limited our ability to understand why patients did not complete the survey. Our overall response rate was low (9.5%), which may be due to our population of older adults and the increased mortality rates among cancer patients, as well as barriers to accessing online surveys. However, 7% of those invited to participate started the study but did not finish. Future work should attempt to interview nonrespondents to understand the reason for nonparticipation and incomplete participation, which can help to determine strategies to address nonresponse.

Implications

As the COVID-19 pandemic forces research to evolve, use of electronic surveys is increasing in lieu of in-person interactions [48]. The use of incentives and prenotifications can increase the response rates overall and in vulnerable populations, leading to more diverse studies, increased generalizability, and the ability to assess critical research questions in underrepresented populations. Further, patients engaged in prior research studies appeared to improve response rates, highlighting the importance of the researcher-participant relationship. Our work provides support for use of prenotifications via mail as well as incentives as critical methods to improve electronic survey response rates, particularly in traditionally hard-to-reach populations.

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Conflicts of Interest

BDG is an advisory board member for Elly Health, Inc, a former paid consultant for KemPharm, and a paid consultant for SureMed Compliance, none of which is relevant to this manuscript. DER serves on the Board of Directors for NanoString Technologies, Inc., although this position does not relate to her contributions to this paper, and NanoString's business does not relate to the contents of the current manuscript. All other authors have no conflicts of interest to declare.

Multimedia Appendix 1
Demographic characteristics of pilot groups for respondents and all invited.
[DOCX File , 34 KB - cancer_v7i3e30265_app1.docx]

Multimedia Appendix 2
Response rates by specific pilot conditions, including a long versus condensed email, comparing prenotification approaches (letter versus postcard) and incentive types (gift to all individuals invited versus US $10 gift card for survey completion).
[DOCX File , 29 KB - cancer_v7i3e30265_app2.docx]

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Abbreviations

ADI: area deprivation index

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Original Paper

Understanding Communication in an Online Cancer Forum: Content Analysis Study

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Abstract

Background: Cancer affects individuals, their family members, and friends, and increasingly, some of these individuals are turning to online cancer forums to express their thoughts/feelings and seek support such as asking cancer-related questions. The thoughts/feelings expressed and the support needed from these online forums may differ depending on if (1) an individual has or had cancer or (2) an individual is a family member or friend of an individual who has or had cancer; the language used in posts in these forums may reflect these differences.

Objective: Using natural language processing methods, we aim to determine the differences in the support needs and concerns expressed in posts published on an online cancer forum by (1) users who self-declare to have or had cancer compared with (2) users who self-declare to be family members or friends of individuals with or that had cancer.

Methods: Using latent Dirichlet allocation (LDA), which is a natural language processing algorithm and Linguistic Inquiry and Word Count (LIWC), a psycholinguistic dictionary, we analyzed posts published on an online cancer forum with the aim to delineate the language features associated with users in these different groups.

Results: Users who self-declare to have or had cancer were more likely to post about LDA topics related to hospital visits (Cohen *d*=0.671) and use words associated with LIWC categories related to health (Cohen *d*=0.635) and anxiety (Cohen *d*=0.126). By contrast, users who declared to be family members or friends tend to post about LDA topics related to losing a family member (Cohen *d*=0.702) and LIWC categories focusing on the past (Cohen *d*=0.465) and death (Cohen *d*=0.181) were more associated with these users.

Conclusions: Using LDA and LIWC, we show that there are differences in the support needs and concerns expressed in posts published on an online cancer forum by users with cancer compared with family members or friends of those with cancer. Hence, responders to online cancer forums need to be cognizant of these differences in support needs and concerns and tailor their responses based on these findings.

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KEYWORDS

Cancer; Reddit; online forum; natural language processing; latent Dirichlet allocation; Linguistic Inquiry and Word Count; psycholinguistics; social media

Introduction

Background

Increasingly, individuals affected by cancer are seeking support on online cancer forums [1-4]. These forums function as a support group where individuals can seek and receive support around cancer from members of the forum, some of whom may (from their personal experience) be familiar with the support expressed.

Prior work determined that members of online cancer forums who self-declare to be diagnosed with cancer or going through cancer treatment tend to seek advice [5] and the more emotional support members of an online cancer forum received, the more likely they were to continue their membership in the forum [6].

The support needs and concerns expressed in online cancer forum posts may vary depending on who is accessing the forum; for example, the support needs expressed by individuals with cancer may vary from those of individuals who are family members or friends of individuals with cancer. In prior work, researchers have used language features from social media and online forum posts to determine whether users belong to different groups such as different age groups [7] and genders [8], to identify and characterize users who express loneliness from other users (who do not express loneliness) [9,10], and to predict patients risk for cardiovascular disease [11]. Similarly, in this paper, we analyze posts published on an online cancer forum on Reddit to determine the language features that delineate posts by users who self-declare to have or had cancer (we will refer to this group as the "has cancer" group) from posts by users who self-declare to be family members or friends of individuals with cancer (referred to as the "family or friend" group).

We hypothesize that these language features will reflect the differences in support needs and concerns expressed by users who belong to these different groups.

Related Work

Users join online health forums to seek and give support as it relates to their health and well-being and that of others. Prior work has shown that online health forums are an effective way for seeking and giving support around mental health [12], substance use recovery [13,14], and cancer [1-4].

Prior work analyzed posts and comments on an online cancer forum and determined that members expressed more negative personal information in public messages compared with private messages [4] and the more emotional support members received, the higher the chance they will continue their membership in the forum [6]. Members of an online cancer forum who were either diagnosed with cancer or going through cancer treatment tended to seek advice and survivors of cancer shared their cancer-related experiences [5].

Over the course of their membership, members of an online cancer forum take on various roles on the forum and for individuals who have been members of the forum for a long period, these roles tend to be more focused on encouraging other members compared with their roles when they first became members of the forum, which tended to be related to seeking information [3]. These forums provide significant peer-to-peer support to individuals seeking support; hence, it is important that members of the forum responding to posts have an accurate understanding of the types of support being sought.

Our work in this paper is different from prior work analyzing posts in online cancer forums as they did not delineate posts by members of the forum that have/had cancer from those who are family or friends.

Methods

Data

Our data comprise posts from an active online cancer forum on Reddit, */r/Cancer*, which is the cancer forum with the most number of users (37,000 members as of March 2021) on Reddit. */r/Cancer* is self-described as "This reddit is for the discussion of cancer, cancer related news, stories of survival, stories of loss and everything else associated with the disease." Using Google's BigQuery [15], which is a data store with publicly available Reddit data sets, we collected 29,533 posts published between December 2015 and August 2019 on */r/Cancer*. From these posts, we identified users who self-declared to have or had cancer by selecting the user names of authors of posts that explicitly mentioned that the author of the post either has or had cancer; specifically, we selected posts which contained the word "cancer" and a first-person singular pronoun (ie, "I" and "me"), for example, "Just got diagnosed with lung cancer, how do I cope". One of the coauthors (AA) reviewed these posts and took out the posts that were not indicating that a user has or had cancer. Similarly, we identified users who self-declared to be family members or friends of individuals with or that had cancer by selecting the user names of authors of posts that explicitly mentioned that a family member or friend has or had cancer; specifically, we selected posts which contained the word "cancer" and also contained the following keywords associated with family members and friends: "mother," "mom," "father," "dad," "parent," "grand mother," "grandmother," "grand mom," "grand ma," "grand father," "grandfather," "grand dad," "granddad," "grand pa," "husband," "wife," "spouse," "son," "daughter," "child," "aunty," "aunt," "uncle," "nephew," "niece," "sister," "brother," "family," "friend," for example, "My young child is battling cancer." One of the coauthors (AA) reviewed these posts and took out the posts that were not indicating that a user was a family member or friend of an individual with or that had cancer. Given the user names of users who either self-declared in posts to have or had cancer or were family members or friends of individuals with or that had cancer, we collected all their posts published in the forum (ie, */r/Cancer*). Table 1 shows a summary of our data set.

Table 1. Summary of our data set. This shows the number of posts by (1) users who self-declared to have or had cancer (the “has cancer” group) and (2) users who self-declared to be family members or friends (the “family or friend” group) of individuals with cancer.

Category	Number of posts	Number of users
The “has cancer” group	4414	2938
The “family or friend” group	3483	2456

Differences in Language Use

We used 2 approaches to determine the differences in language use in posts by users who belong to either the “has cancer” group or the “family or friend” group. Specifically, we used (1) an open vocabulary method and (2) a dictionary-based method. In all the analysis in this work, we report the effect size by using Cohen *d*, which is the standardized difference between means.

Open Vocabulary Method

In this section, we use a natural language processing topic modeling algorithm, latent Dirichlet allocation (LDA) [16], which is used to identify and group co-occurring words in documents (ie, Reddit posts in this work); these word groups are referred to as *topics*. LDA is a generative model which assumes that topics consist of a combination of words and tokens and Reddit posts consist of a mixture of topics. As words in Reddit posts are known, the latent variables of the topics can be estimated using Gibbs sampling [17]. Labels can be assigned to the various topics based on the content words associated with the topic. For example, LDA may cluster the words “Monday,” “Tuesday,” “Wednesday,” “Thursday,” and “Friday'” as days of the week. Using the DLATK package [18], we generated 20 LDA topics from the /r/Cancer posts by users that self-declared to have or had cancer (ie, the “has cancer” group) and users who self-declared to be family members or friends (ie, the “family or friend” group); we chose to generate 20 topics because we varied the number of LDA topics by using 10, 20, 30, and 40 topics, and one of the coauthors (AA) reviewed these topics and observed that the topic themes from 20 topics had the most coherent themes. Similar to prior works which used LDA to identify the topic themes from social media posts most associated with users who expressed loneliness from those who did not [9,10] and to delineate posts by individuals belonging to different age groups [7] and genders [8], we used the DLATK package [18] to identify the topic themes most associated with posts belonging to the “has cancer” group when compared with posts belonging to the “family or friend” group, and vice versa.

Dictionary-Based Method

In this section, we used Linguistic Inquiry and Word Count (LIWC) [19], which is a psycholinguistic dictionary with 73 categories (eg, positive and negative emotions, health, and personal pronouns) and a curated list of words associated with these categories. Specifically, using the DLATK package [18], we determined the frequency of occurrence of words associated with LIWC categories in posts belonging to the “has cancer” group compared with the “family or friend” group.

Ethics and Privacy

This study was deemed exempt by the Institutional Review Board guidelines of the authors institution. The data set used for this work is publicly available. The authors of this work did not contact any member or moderator of the forum */r/Cancer* nor did we contact any Reddit users. Besides, Reddit user profile information was not reviewed or used in this work.

Results

Open Vocabulary Method

Table 2 shows the effect sizes (using Cohen *d*) of the most significant LDA topics ($P<.001$ [Benjamini–Hochberg *P* correction]) associated with */r/Cancer* posts by users that belong to the “has cancer” group compared with posts by users belonging to the “family or friend” group. In addition, Table 3 shows the effect sizes (using Cohen *d*) of the most significant LDA topics associated with */r/Cancer* posts by users belonging to the “family or friend” group compared with posts by users that belong to the “has cancer” group. The authors of the paper independently labeled each topic theme and then met to discuss and agree on the labels for each topic theme.

Table 2. LDA topics associated with posts by users who self-declared to have or had cancer (ie, the “has cancer” group) compared with posts by users in the “family or friend” group.

LDA[a] topic themes	Highly correlated words in topics	Cohen *d*
Hospital visit	pain, hospital, back, days, blood, started, doctor, home, worse, ER	0.671
Questions/seeking advice	advice, good, wondering, experience, type, information, questions, survival, early, similar	0.537
Symptoms, risk, and cure of disease	cells, risk, cure, disease, symptoms, cancers, cervical, pancreatic, body, patients	0.474
Research/questions around cancer	research, patient, part, study, breast, questions, diagnosis, prostrate, find, survivor	0.432
Cancer surgery	surgery, colon, removed, tumor, thyroid, remove, lymph, kidney, nodes, stomach	0.349
Cost/payment for treatment	treatment, insurance, medical, money, health, clinical, working, options, pay, trials	0.345
Change in diet	eat, weight, food, stomach, throat, diet, healthy, tongue, taste, loss	0.293
Tests around cancer	scan, biopsy, back, doctor, results, CT, lymph, found, oncologist, tumor	0.290
Support from people/community	support, people, post, free, share, story, group, love, hope, great	0.245
Side effects of treatment	chemo, treatment, radiation, side, effects, week, hair, round, pretty, started	0.214

[a] LDA: latent Dirichlet allocation.

Table 3. LDA topics associated with posts by users who self-declared to be family members or friends of individuals with or that had cancer (ie, the “family or friend” group) compared with posts by users in the “has cancer” group.

LDA[a] topic themes	Highly correlated words in topics	Cohen *d*
Losing family member	mom, day, passed, lost, home, didn't, love, hospital, wanted, made	0.702
Caring for family member	sister, brother, family, wife, home, work, parents, mother, live, care	0.373
Diagnosis of family member	dad, he’s, father, diagnosed, stage, ago, found, lung, today, pancreatic	0.339
Diagnosis of family member	mom, stage, breast, diagnosed, advice, she's, friend, ovarian, grandma, lung	0.179
Talk around support	time, life, family, things, make, support, care, health, long, difficult	0.159

[a] LDA: latent Dirichlet allocation.

Dictionary-Based Method

Table 4 shows the effect sizes (using Cohen *d*) and LIWC categories that are more associated with posts belonging to the “has cancer” group when compared with the “family or friend” group. In addition, Table 5 shows the effect sizes (using Cohen *d*) and LIWC categories that are more associated with posts by the “family or friend” group when compared with posts by the “has cancer” group.

Table 4. LIWC categories most associated with posts belonging to the “has cancer” group when compared with the “family or friend” group. Effect size is reported as Cohen *d*.

LIWC[a] category	Cohen *d*
Health	0.635
Biological processes	0.607
Second-person pronouns	0.234
Anxiety	0.126

[a] LIWC: Linguistic Inquiry and Word Count.

Table 5. LIWC categories most associated with posts belonging to the “family or friend” group when compared with posts by the “has cancer” group. Effect size is reported as Cohen *d*.

LIWC[a] category	Cohen *d*
Third-person singular pronoun	1.168
Personal pronoun	0.977
Female references	0.964
Male references	0.746
First-person singular pronouns	0.543
Past focus	0.465
Affiliation	0.398
First-person plural pronouns	0.242
Sadness	0.224
Time	0.222
Present focus	0.221
Death	0.181
Friends	0.175

[a] LIWC: Linguistic Inquiry and Word Count.

Discussion

Principal Findings

In this work, using LDA and LIWC, we show that there are differences in the support needs and concerns expressed in online cancer forum posts by users who belong to the “has cancer” group compared with those belonging to the “family or friend” group. In the following section, we summarize the findings from this work.

In our analysis, we observed that users who self-declare to have or had cancer tend to post about topic themes such as their hospital visits and seeking advice and information as these relate to cancer; this finding is in line with previous work [5], which showed that individuals who self-declared (in an online cancer forum) to be diagnosed with cancer or undergoing treatment mostly sought advice from other members of the forum. We also observed that users who self-declared to have cancer tend to post about topics themes related to the cost/payments for their treatments, change in diet, and side effects of treatment, and use words associated with LIWC categories related to health and anxiety. These findings can aid in the design of processes for providing better support on online cancer forums. For example, the cost for cancer treatment can be expensive, and because users who self-declare to have or had cancer tend to post about topic themes related to cost/payment for their treatment, online cancer forums can partner with health care providers and relevant organizations to come up with and document detailed ways and tips in which patients with cancer can approach paying for their treatment; this information can be made easily available and accessible to users on the online forum. A similar thing can be done for other user concerns such as change in diet and side effects of treatments. Given that LIWC categories associated with anxiety are more associated with users who self-declared to have or had cancer, online cancer forums can provide/recommend professional mental health services to these users.

For users who self-declared to be family members or friends of individuals diagnosed with cancer, we observed that they tend to post about topic themes such as losing a family member, caring for a family member, and the diagnosis of a family member; also, these users tend to use words associated with LIWC categories focusing on the past/present, sadness, and death. Given that some of the topic themes users who self-declare to be family members or friends tend to post about are caring for a family member and the diagnosis of a family member, online cancer forums can partner with health care providers to document ways in which these users can provide support and care to their loved ones with cancer—this information can be made easily accessible on the forum. Besides, given that LIWC categories associated with past/present, sadness, and death are more associated with the “family or friends” group, this may imply that users belonging to this group express (in their posts) having a difficult time coping with either losing their loved one or their loved one being sick; hence, the cancer forum can provide professional mental health counselors who can provide help to these users on how to cope with a loved one being sick or losing a loved one.

Limitation

Prior work determined that the interests of members of online forums focused on similar topics may differ [20]; hence, a limitation of this work is that the language used on */r/Cancer* may differ from that used in other online cancer forums. In addition, the sample used in this work is composed of Reddit users who publish posts on the subreddit */r/Cancer* and is not representative of all users affected by cancer.

Conclusion

In this paper, using LDA and LIWC, we determined the LDA topics and LIWC categories associated with posts by (1) users who self-declared to have or had cancer and (2) users who self-declared to be family members or friends of individuals with cancer; also, we observed that these language use differences reflect the differences in support needs and concerns expressed in posts belonging to these groups.

Conflicts of Interest

None declared.

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Abbreviations

LDA: latent Dirichlet allocation
LIWC: Linguistic Inquiry and Word Count

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Original Paper

COVID-19 Communication From Seven Health Care Institutions in North Texas for English- and Spanish-Speaking Cancer Patients: Mixed Method Website Study

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Abstract

Background: The COVID-19 pandemic has created an urgent need to rapidly disseminate health information, especially to those with cancer, because they face higher morbidity and mortality rates. At the same time, the pandemic's disproportionate impact on Latinx populations underscores the need for information to reach Spanish speakers. However, the equity of COVID-19 information communicated through institutions' online media to Spanish-speaking cancer patients is unknown.

Objective: We conducted a multimodal, mixed method document review study to evaluate the equity of online information about COVID-19 and cancer available to English- and Spanish-speaking populations from seven health care institutions in North Texas, where one in five adults is Spanish-speaking. Our focus was less on the "digital divide," which conveys disparities in access to computers and the internet based on the race/ethnicity, education, and income of at-risk populations; rather, our study asks the following question: to what extent is online content useful and culturally appropriate in meeting Spanish speakers' information needs?

Methods: We reviewed 50 websites (33 English and 17 Spanish) over a period of 1 week in the middle of May 2020. We sampled seven institutions' main oncology and COVID web pages, and both internal (institutional) and external (noninstitutional) linked content. We conducted several analyses for each sampled page, including (1) thematic content analysis, (2) literacy level analysis using Readability Studio software, (3) coding using the Patient Education and Materials Assessment Tool (PEMAT), and (4) descriptive analysis of video and diversity content.

Results: The themes most frequently addressed on English and Spanish websites differed. While "resources/FAQs" were frequently cited themes on both websites, English websites more frequently addressed "news/updates" and "cancer+COVID," and Spanish websites addressed "protection" and "COVID data." Spanish websites had on average a lower literacy level (11th grade) than English websites (13th grade), although still far above the recommended guideline of 6th to 8th grade. The PEMAT's overall average accessibility score was the same for English (n=33 pages) and Spanish pages (n=17 pages) at 82%. Among the Dallas-Fort Worth organizations, the average accessibility of Spanish pages (n=7) was slightly lower than that of English pages (n=19) (77% vs 81%), due mostly to the discrepancy in English-only videos and visual aids. Of the 50 websites, 12 (24%) had embedded videos; however, 100% of videos were in English, including one on a Spanish website.

Conclusions: We identified an uneven response among the seven health care institutions for providing equitable information to Spanish-speaking Dallas-Fort Worth residents concerned about COVID and cancer. Spanish speakers lack equal access in both diversity of content about COVID-19 and access to other websites, leaving an already vulnerable cancer patient population at greater risk. We recommend several specific actions to enhance content and navigability for Spanish speakers.

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KEYWORDS

COVID-19; coronavirus; safety net; internet; communication

Introduction

The COVID-19 pandemic created an urgent need for information to reach people with cancer because they are twice as likely to contract COVID-19 [1] and eight times more likely to die from it [2]. Health care institutions' websites constitute a major communication mechanism with the public at large and often have subsections to specifically serve the needs of cancer patients. As health care consumers, patients rely on these websites to provide information about available health services, basic information about health problems, and access to additional resources [3]. For patients with cancer, websites may include information about multidisciplinary cancer care (ie, chemotherapy, surgery, and radiation), support services (eg, case management), and survivorship resources (eg, wellness education). During public health crises, timely and equivalent access to health information is critical for patients to adequately inform and protect themselves. However, the equity of information about COVID-19 to Spanish-speaking cancer patients, which is communicated through institutions' online media, is unknown.

The disproportionate impact of the pandemic on healthy Latinx populations [4,5] underscores the need for equally high-quality information to reach Spanish-speaking populations impacted by cancer and concerned about COVID. The Centers for Disease Control and Prevention (CDC) estimates that the risks of COVID-19 infection, hospitalization, and death among Latinx persons were 2.0, 3.0, and 2.3 times higher compared to those among non-Hispanic Whites [6]. Much of this was likely due to the fact that Latinx populations are at elevated risk for severe disease given their higher rates of comorbid conditions [4] and exposure due to living and working conditions [5]. A study in May 2020 on access to coronavirus testing in major Texas cities also suggested that lack of testing locations in heavily Latinx and African American neighborhoods may have hampered quarantine efforts, enabling the virus to spread unchecked and contributing to disproportionate rates of COVID-19 [7].

Health care institutions serving large Spanish-speaking populations have a professional and moral obligation to ensure that information reaches Spanish speakers. Moreover, the disproportionate impact of the pandemic on Black and Latinx populations [4,5] in general elevates the need for information to reach Spanish-speaking populations impacted by cancer and concerned about COVID. For example, the Dallas-Fort Worth (DFW) area is home to over 1.6 million Spanish speakers [8], that is, persons aged 5 years or older who speak Spanish at home. Spanish speakers, the largest non-English speaking group, comprise approximately 21% of the 7.5 million residents in the 13-county DFW catchment area [9]. Among Spanish-speaking adults aged 25 years or older, most have less than a high school education (42%), 26% are high school graduates, and 14% are college graduates or beyond [10].

Educational attainment notwithstanding, the delivery of health information at a low literacy level (between the 6th and 8th grades) is a recommended best practice to enhance comprehension of materials [11]. While the average American adult reads at about an 8th grade level, the American Medical Association recommends that the readability of patient-facing health materials be no higher than 6th grade [12]. In the United States, adults who prefer to communicate in Spanish are especially affected by negative health outcomes associated with low literacy, such as higher emergency department utilization, higher morbidity, and lower use of preventive services [13-15]. Therefore, with new disease outbreaks like COVID, it is particularly important for new information to be conveyed in Spanish at a low literacy level. Thus, it is critically important to monitor if online information meets the needs of populations with lower literacy.

In this paper, our focus was less on the "digital divide," which conveys disparities in access to computers and the internet based on the race/ethnicity, education, and income of at-risk populations [16-18]. We considered the following question: "Once Spanish-speaking consumers have physical access to technology, to what extent is the content of institutions' websites useful and culturally appropriate in meeting their needs?" [19]. By "culturally appropriate," we mean how language and messages are targeted to address the needs of the population. In this study, we examined several forms of cultural appropriateness, including availability of websites in Spanish, reading level, ease of locating information, and visual representations of racial/ethnic minorities [20,21].

We conducted a document review study to evaluate the equity of information about cancer and COVID-19 available online to English and Spanish speakers from large health care institutions in the DFW area. Document analysis is the ideal method to capture information at discrete periods of time as a historical record of the online information presented to health care consumers by each institution. It allows for thematic analysis using pattern recognition and fitness to the proposed purpose of the document. Here, we report the results of that evaluation, including a thematic analysis of institutional website content, measurement of literacy and accessibility, and analysis of links to external websites and representations of diversity.

Methods

Website Sampling

Rigorous document analysis involves a systematic sampling strategy grounded in the research problem and the purpose of the study [22]. In this exploratory study, our website sampling approach was guided by the goal of comparing what cancer- and COVID-related resources were available to English- and Spanish-speaking consumers in the DFW area. We sampled a total of 50 websites in a hierarchical sampling "block" strategy with the criteria outlined in Table 1.

Table 1. Website sampling by blocks, criteria, and number of pages.

Sampling block	Pages	Criteria	Number of pages (N=50)
A	Seven DFW[a] institutions' main cancer/oncology websites	We sampled all seven institutions' main cancer/oncology pages in English. Only one institution had a parallel[b] Spanish website, which we also sampled (ie, we did not sample Google translate versions of English websites).	8
B	Seven DFW institutions' main COVID websites	Same criteria as Block A (n=8). In addition, one academic medical center had two COVID websites to orient patients/families on health care services and inform the public about research and educational missions, so we sampled both in English.	9
C	Internal direct sublinks to English/Spanish parallel content	We sampled any internal[c] linked content in Spanish from the main cancer or COVID pages if (1) parallel English and Spanish contents were available for comparison; and (2) relevant[d] information was available.	10 (5 pairs)
D	External direct sublinks to English/Spanish parallel content	We sampled any external[e] linked parallel content in Spanish and English from the main cancer or COVID pages using the same criteria as in Block C.	12 (6 pairs)
E	External direct sublinks of English or Spanish nonparallel content	We sampled external nonparallel English (n=7) and Spanish (n=4) pages with relevant information linked from the main cancer or COVID pages.	11

[a] DFW: Dallas-Fort Worth.

[b] "Parallel" is defined as separate web pages that mirror each other in format and content.

[c] "Internal links" are links to other web pages authored by the institution.

[d] "Relevant" is defined as including information about COVID that would be pertinent specifically to a cancer patient, survivor, or someone participating in a cancer prevention service.

[e] "External links" are links to web pages not authored by the institution.

We focused first on the main oncology and COVID web pages of a purposive sample of seven prominent DFW area health care institutions (Blocks A and B) to assess the type and accessibility of COVID and cancer information available to consumers. As shown in Table 2, our purposive sample included the two safety-net institutions in the metropolitan area (Institutions 1 and 2), a nonprofit cancer specialty health provider network (Institution 3), and the four largest nonprofit health systems (Institutions 4-7a), including one academic health system, with "largest" defined by the number of hospital beds. These seven organizations represent all but one of the top 10 cancer care provider organizations in DFW (excluded one, a private health system) [23].

Table 2. Description of the seven institutions sampled.

Institution number	Description
1	Safety net
2	Safety net
3	Nonprofit cancer specialty health provider network
4	Nonprofit health system
5	Nonprofit health system
6	Nonprofit health system
7/7a	Nonprofit academic health system/Affiliated academic comprehensive cancer center

From there, we sampled these seven institutions' internal and external linked contents available in both languages to further assess the equity of information to English- and Spanish-speaking consumers (Blocks C, D, and E). By "internal links," we mean links to other web pages authored by the institution. As indicated in the sampling strategy, we assessed internal linked content if (1) parallel English and Spanish content was available for comparison and (2) content was relevant. By "parallel," we mean separate web pages in English and Spanish designed by the institution to convey the same information. We define "relevant" as including information about COVID that would be pertinent specifically to a cancer patient, survivor, or someone participating in a cancer prevention service. Using this strategy, we identified five pairs (n=10 websites) of internal English and Spanish content from two institutions' main COVID websites, and six pairs (n=12 pages) of parallel English and Spanish external linked websites. These are itemized as Blocks C and D in Table 1. Finally, we sampled external links to seven English and four Spanish nonpaired websites to assess potentially inequitable information available to consumers (Block E). The 50 total websites included 33 (66%) predominantly English and 17 (34%) Spanish websites.

Data Collection

To promote systematic and consistent data collection, the principal investigator (RTH) designed a data collection tool in

REDCap [24] that structured rules for evaluation and data entry of specific constructs informed by the literature [12,19,25-27]. The tool consisted of (1) topics for thematic analysis (eg, main headers, presence of embedded videos, internal and external links, and markers of cultural inclusiveness); (2) a literacy score, measured using *Readability Studio* (Oleander Solutions) software; and (3) a survey instrument consisting of 12 items measuring accessibility (using the Patient Education and Materials Assessment Tool [PEMAT] [28]). We also assessed websites with respect to markers of diversity and inclusivity in video and visual content. One research staff used the tool to collect data from each website, except for the PEMAT survey portion, which was completed by two staff members per website to enhance rigor.

All website data were collected during a 1-week period in the middle of May 2020. At that time, all 50 websites had been updated in 2020. Of the 50 websites, 31 were updated since March 1, 2020; 26 were updated since April 1, 2020; and 12 were updated since May 1, 2020. A few websites reported being updated daily.

The principal investigator performed a quality assessment check by reviewing 10% of the collected data to ensure completeness and adherence to the data collection tool during documentation.

Data Analyses

Once data were collected, several analyses were performed, including: thematic content analysis, literacy level analysis using Readability Studio software, coding of the PEMAT, and descriptive analysis of video and diversity content.

Thematic Content Analysis

We used website headers to approximate the thematic content of the main COVID and cancer websites in English and Spanish. First, data collection staff recorded the headers that corresponded to content related to cancer or COVID on each of the 50 selected websites. Next, the principal investigator reviewed these data and created a qualitative codebook consisting of 29 topics, such as “prevention,” “resources,” and “testing.” Three persons then double coded in an alternating matrix the free-text headers into codebook topics. Discrepancies between two coders were resolved by the principal investigator. A table of this conversion process is shown in Multimedia Appendix 1. We used the same approach to analyze the thematic content of linked internal and external pages from the institutions’ main COVID and cancer websites to assess health care consumers’ ease of navigating to additional information.

Literacy Level

A literacy level or readability score approximates the level of education a person may need to be able to read a piece of text easily. Scores are generally based on factors such as sentence length, syllable length, and syntax. Website content was scored using *Readability Studio*, which yielded a combined score from the Gilliam-Peña-Mountain and SOL (Spanish SMOG) readability scales [29,30]. For the purpose of this study, we defined “low literacy” as a reading level less than 9th grade.

PEMAT

The PEMAT instrument measures the overall clarity and accessibility of print materials, such as the simplicity of concepts, syntax, layout, and the availability of nontext communication tools [28]. Four coders were trained by the lead investigator in the use of the PEMAT instrument to promote consistency in coding. Then, two pairs of two coders each scored 25 websites (for a total of 50 websites). Coding agreement between paired individuals was high (k=0.77 and 0.82). Where discrepancies existed, coders reconvened, discussed, and decided upon one code to be used for the final PEMAT scoring.

Video Content

While most individuals learn visually (ie, what they see and read), others are auditory or kinesthetic learners, which means they prefer to learn by touch or manipulation like note-taking and role-playing. Given these different learning styles, videos can enhance the accessibility of websites by engaging audiences, reducing literacy burden, and quickly delivering important health messages [31]. We counted the number of websites that contained embedded videos and language videos, in which videos were presented.

Diversity and Inclusiveness

Communications of racial and ethnic diversity on websites can convey an institution’s core values and may serve to attract members of racial/ethnic minorities to web content [27,32]. Therefore, we counted the number of websites with pictures of persons of perceived non-White racial backgrounds, or statements of diversity (eg, “For interpreting services, please call: xxx-xxxx.”) as markers of cultural inclusiveness.

Results

Spanish Content Availability

Only Institution 1 from the seven institutions had parallel Spanish cancer and COVID websites. In 2015, the institution logged 75,000 encounters each month with non-English speakers, 92% of which were with Spanish-speakers [33]. Institutions 3, 4, and 7a had some Spanish content and/or links to external websites in Spanish. The remaining websites had no Spanish content and no links to external Spanish content.

Thematic Content

The top 10 themes of website headers are reported by language and number of times cited in Table 3. Examples of website headers are shown in Figures 1 and 2.

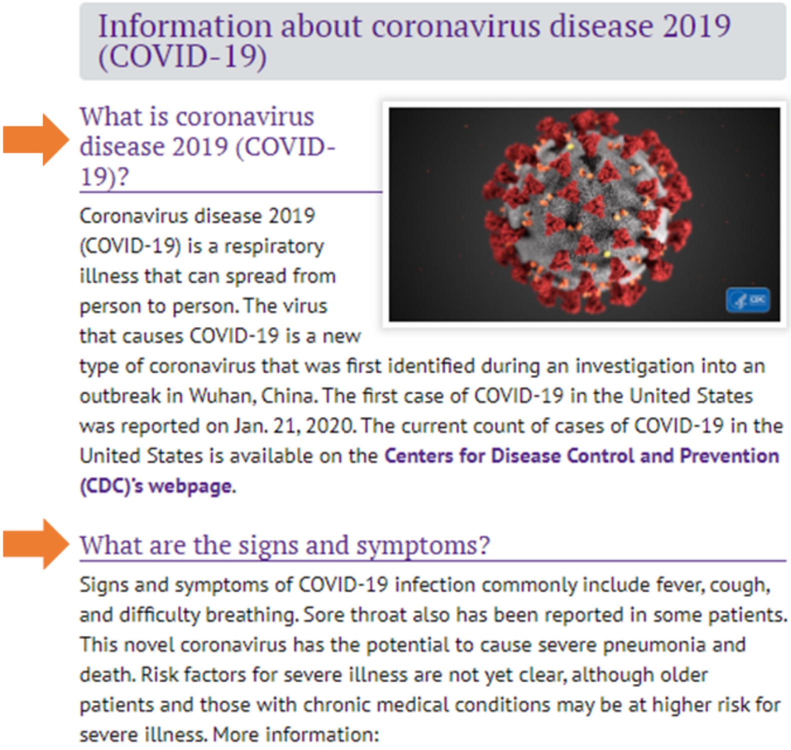
Table 3. Themes of website headers.

Website language and theme	Value, n (%)
English websites (n=33)	
Resources/more information/FAQ	25 (76)
Updates/news[a]	20 (61)
Cancer and COVID	19 (58)
Prevention/how it spreads	14 (42)
Protection/what you can do	13 (39)
Services/treatments available	13 (39)
Signs/symptoms[a]	13 (39)
Testing/screening[a]	11 (33)
What is X institution doing?[a]	10 (30)
What to do if you are sick or you think you have COVID	10 (30)
Spanish websites (n=17)	
Protection/what you can do	14 (82)
Resources/more information/FAQ	8 (47)
COVID data[b]	7 (41)
What to do if you are sick or you think you have COVID	7 (41)
Cancer and COVID	6 (35)
Hours/locations/info for patients and visitors[b]	5 (29)
Prevention/how it spreads	5 (29)
Risk factors/risk assessment/high risk populations[b]	5 (29)
Social distancing[b]	5 (29)
Specific population information[b]	5 (29)

[a] Themes in English that did not appear in the top 10 themes cited on Spanish websites.

[b] Themes in Spanish that did not appear in the top 10 themes cited on English websites.

Figure 1. Example of an English website header.



Information about coronavirus disease 2019 (COVID-19)

What is coronavirus disease 2019 (COVID-19)?

Coronavirus disease 2019 (COVID-19) is a respiratory illness that can spread from person to person. The virus that causes COVID-19 is a new type of coronavirus that was first identified during an investigation into an outbreak in Wuhan, China. The first case of COVID-19 in the United States was reported on Jan. 21, 2020. The current count of cases of COVID-19 in the United States is available on the **Centers for Disease Control and Prevention (CDC)'s webpage.**

What are the signs and symptoms?

Signs and symptoms of COVID-19 infection commonly include fever, cough, and difficulty breathing. Sore throat also has been reported in some patients. This novel coronavirus has the potential to cause severe pneumonia and death. Risk factors for severe illness are not yet clear, although older patients and those with chronic medical conditions may be at higher risk for severe illness. More information:

Figure 2. Example of a Spanish website heading.

Información sobre la enfermedad de coronavirus 2019 (COVID-19)

¿Qué es la enfermedad de coronavirus 2019 (COVID-19)

La enfermedad de coronavirus 2019 (COVID-19) es una enfermedad respiratoria que puede contagiarse de una persona a otra. El virus que ocasiona COVID-19 es un nuevo tipo de coronavirus que se identificó por primera vez durante una investigación en un brote en Wuhan, China. El primer caso de COVID-19 en los Estados Unidos se informó el 21 de enero de 2020. El conteo actual de casos de COVID-19 en los Estados Unidos está disponible en **la página web del Centro para el Control y Prevención de Enfermedades (CDC)**.

¿Cuáles son los signos y síntomas?

Los signos y síntomas de infección por COVID-19 habitualmente incluyen fiebre, tos y dificultad para respirar. También se ha informado dolor de garganta en algunos pacientes. Este coronavirus novedoso tiene el potencial de causar neumonía grave y la muerte. Los factores de riesgo de esta enfermedad grave aún no están claros, aunque los pacientes de mayor edad y con afecciones médicas crónicas pueden tener un mayor riesgo de enfermedad grave.

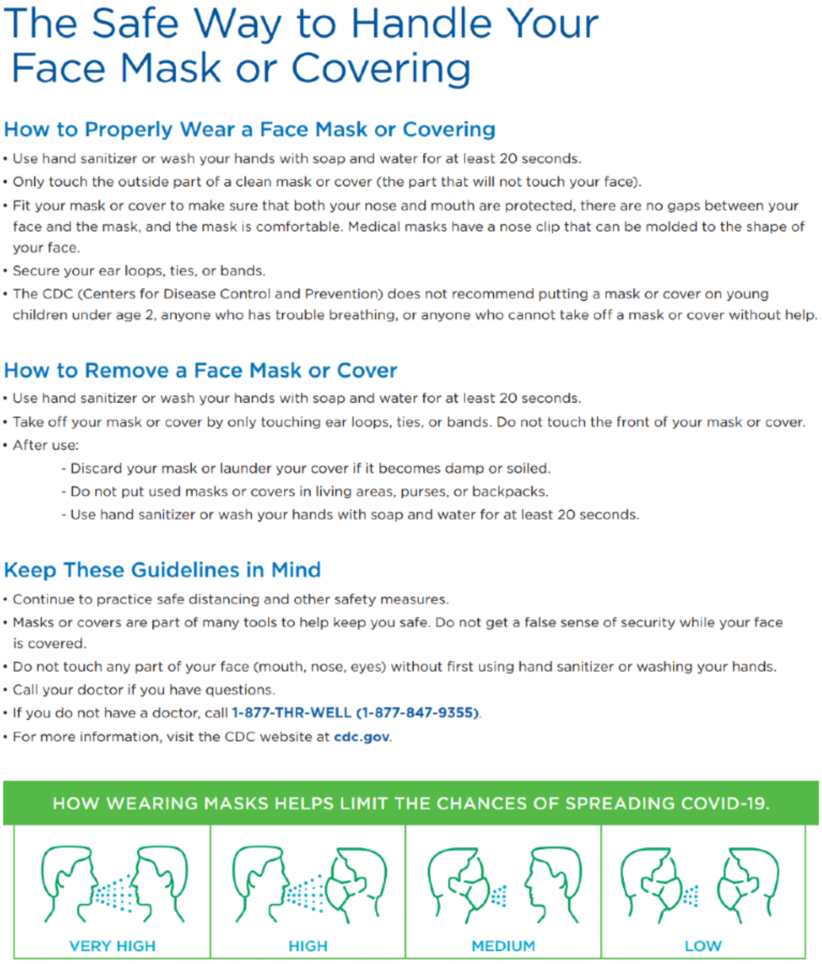
There were some similarities and several differences in the content of website information on English and Spanish websites. With respect to organizations' main COVID websites, for example, content related to the topic of how to obtain additional resources (eg, where to find more information, and responses to frequently asked questions) figured prominently on both English (#1) and Spanish (#2) websites, as did content related to COVID prevention and protection. However, while COVID news and updates constituted the second most frequently cited theme and testing constituted the eighth most frequently cited theme in English, neither theme ranked among the top 10 content areas in Spanish. In contrast, the Spanish websites contained several headers and subheaders that did not figure in the top 10 English content areas, including COVID data, hours and locations for patients and visitors, risk factors or information for high-risk populations, social distancing, and information for specific populations (eg, elderly persons or pregnant women).

With respect to information specifically about COVID and cancer, there was far more information available in English (9/16, 56%) than in Spanish (4/16, 25%) among the institutions' internal websites. Institutions 1, 2, and 3 had no information about COVID on their main cancer page; Institutions 4, 5, and 6 included a banner at the top of the page with a link to some form of COVID-19 information, such as "COVID-19 updates" and "Important information about COVID-19;" and Institution 7 had 21 instances of "COVID" mentioned on its cancer main page (represented as Institution 7a), indicating a substantial amount of detailed information for cancer patients. Examples of content headers included "Cancer and COVID-19: What You Need to Know," "Virtual Visits Available," and "Am I considered immunocompromised if I have had cancer treatment?" These headers linked consumers to content that, for example, explained safety measures for in-person care and informed patients of options for virtual care.

Internal Links

Institutions 3 and 4 had some internal content in English and Spanish, for example, a bulletin called "About Coronavirus" (Figure 3). A total of five pairs of English/Spanish links were identified (sampling Block C). Institutions 2, 5, 6, and 7 had no internal links or links to external Spanish content. However, for those familiar with how to access the function in the Chrome web browser, a "Google Translate" version of the website was available. An evaluation of the "Google Translate" versions of websites was beyond the scope of this study [34].

Figure 3. Example of an internally linked bulletin.



The Safe Way to Handle Your Face Mask or Covering

How to Properly Wear a Face Mask or Covering

- Use hand sanitizer or wash your hands with soap and water for at least 20 seconds.
- Only touch the outside part of a clean mask or cover (the part that will not touch your face).
- Fit your mask or cover to make sure that both your nose and mouth are protected, there are no gaps between your face and the mask, and the mask is comfortable. Medical masks have a nose clip that can be molded to the shape of your face.
- Secure your ear loops, ties, or bands.
- The CDC (Centers for Disease Control and Prevention) does not recommend putting a mask or cover on young children under age 2, anyone who has trouble breathing, or anyone who cannot take off a mask or cover without help.

How to Remove a Face Mask or Cover

- Use hand sanitizer or wash your hands with soap and water for at least 20 seconds.
- Take off your mask or cover by only touching ear loops, ties, or bands. Do not touch the front of your mask or cover.
- After use:
  - Discard your mask or launder your cover if it becomes damp or soiled.
  - Do not put used masks or covers in living areas, purses, or backpacks.
  - Use hand sanitizer or wash your hands with soap and water for at least 20 seconds.

Keep These Guidelines in Mind

- Continue to practice safe distancing and other safety measures.
- Masks or covers are part of many tools to help keep you safe. Do not get a false sense of security while your face is covered.
- Do not touch any part of your face (mouth, nose, eyes) without first using hand sanitizer or washing your hands.
- Call your doctor if you have questions.
- If you do not have a doctor, call **1-877-THR-WELL (1-877-847-9355)**.
- For more information, visit the CDC website at **cdc.gov**.

HOW WEARING MASKS HELPS LIMIT THE CHANCES OF SPREADING COVID-19.

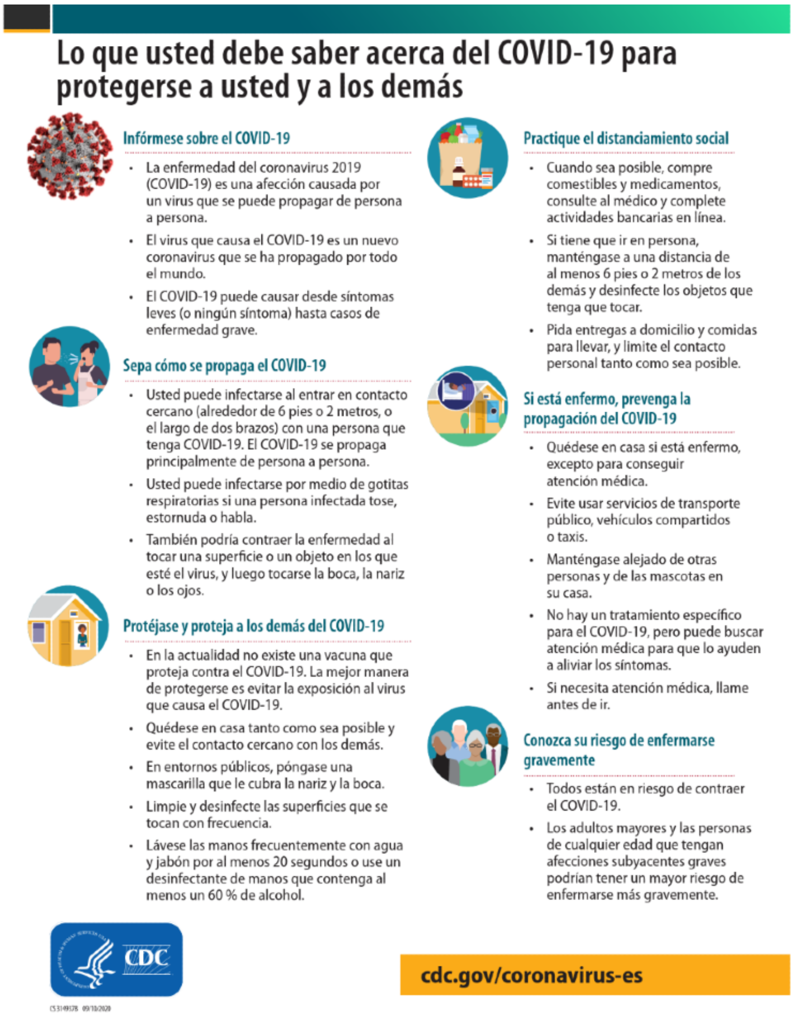
External Links

For Institutions 1, 3, and 4, the main COVID website also contained links to external websites in Spanish, either as English/Spanish pairs (sampling Block D) or individual Spanish links (sampling Block E).

Among all external links in Spanish (n=10), the main CDC coronavirus website was linked to twice, and 7 of 10 links were to CDC pages. However, 4 of 10 external links were to one-page static factsheets and not websites (Figure 4). Moreover, 4 of 5 links were to an English page (eg, [35]), where the user must locate a button to convert the page to Spanish, rather than linking directly to the Spanish website URL (eg, [36]). In other words, much of the available content in Spanish was abbreviated and did not lead to further opportunities to link to other websites, and of the available websites, many required users to navigate in English to arrive at Spanish text. Consumers with lower health literacy or digital literacy [37] may miss the opportunity to arrive at the Spanish website, or at best, may get frustrated in navigating there.

The external links from the cancer and COVID websites in English (n=24) from all seven DFW organizations demonstrated greater heterogeneity. In total, links included 10 different CDC websites, as well as local organizations (eg, Department of State Health Services, Komen Greater Fort Worth), academic organizations (eg, New England Journal of Medicine and American Society of Microbiology), and government entities (eg, National Institutes of Health, Occupational Safety and Health Administration). As was the case in Spanish, the main CDC coronavirus website was the most frequently linked-to page (four times); this was followed closely by the CDC's website about symptoms (three times). All organizations linked to at least one CDC page. However, the fact that different, that is, nonparallel, websites were offered as links on the English and Spanish main pages underscores the finding that inequitable information is available to English- and Spanish-speaking consumers.

Figure 4. Example of a static factsheet.



Lo que usted debe saber acerca del COVID-19 para protegerse a usted y a los demás

Infórmese sobre el COVID-19

- La enfermedad del coronavirus 2019 (COVID-19) es una afección causada por un virus que se puede propagar de persona a persona.
- El virus que causa el COVID-19 es un nuevo coronavirus que se ha propagado por todo el mundo.
- El COVID-19 puede causar desde síntomas leves (o ningún síntoma) hasta casos de enfermedad grave.

Sepa cómo se propaga el COVID-19

- Usted puede infectarse al entrar en contacto cercano (alrededor de 6 pies o 2 metros, o el largo de dos brazos) con una persona que tenga COVID-19. El COVID-19 se propaga principalmente de persona a persona.
- Usted puede infectarse por medio de gotitas respiratorias si una persona infectada tose, estornuda o habla.
- También podría contraer la enfermedad al tocar una superficie o un objeto en los que esté el virus, y luego tocarse la boca, la nariz o los ojos.

Protéjase y proteja a los demás del COVID-19

- En la actualidad no existe una vacuna que proteja contra el COVID-19. La mejor manera de protegerse es evitar la exposición al virus que causa el COVID-19.
- Quédese en casa tanto como sea posible y evite el contacto cercano con los demás.
- En entornos públicos, póngase una mascarilla que le cubra la nariz y la boca.
- Limpie y desinfecte las superficies que se tocan con frecuencia.
- Lávese las manos frecuentemente con agua y jabón por al menos 20 segundos o use un desinfectante de manos que contenga al menos un 60 % de alcohol.

Practique el distanciamiento social

- Cuando sea posible, compre comestibles y medicamentos, consulte al médico y complete actividades bancarias en línea.
- Si tiene que ir en persona, manténgase a una distancia de al menos 6 pies o 2 metros de los demás y desinfecte los objetos que tenga que tocar.
- Pida entregas a domicilio y comidas para llevar, y limite el contacto personal tanto como sea posible.

Si está enfermo, prevenga la propagación del COVID-19

- Quédese en casa si está enfermo, excepto para conseguir atención médica.
- Evite usar servicios de transporte público, vehículos compartidos o taxis.
- Manténgase alejado de otras personas y de las mascotas en su casa.
- No hay un tratamiento específico para el COVID-19, pero puede buscar atención médica para que lo ayuden a aliviar los síntomas.
- Si necesita atención médica, llame antes de ir.

Conozca su riesgo de enfermarse gravemente

- Todos están en riesgo de contraer el COVID-19.
- Los adultos mayores y las personas de cualquier edad que tengan afecciones subyacentes graves podrían tener un mayor riesgo de enfermarse más gravemente.

CDC

cdc.gov/coronavirus-es

Literacy Level

Among the 50 websites, the average literacy score for the English websites (n=33) was 13.2, while the average score for the Spanish websites (n=17) was lower at 11.7. Websites with parallel English and Spanish content scored exactly the same, at an overall average of 12.8. However, among the DFW area organizations' main cancer and COVID websites only, the average literacy score was higher at 15.4 (range 14.8-16.9) and 12.6 (range 8.3-15.5), respectively. Only Institution 1's main COVID page in Spanish had a low literacy level (score 8.3).

PEMAT

The overall average accessibility score using the PEMAT analysis was the same for English (n=33 pages) and Spanish pages (n=17 pages) at 82%. Among the DFW organizations, the average accessibility of the Spanish pages (n=7) was slightly lower than that of the English pages (n=19) (77% vs 81%), due mostly to the discrepancy in English-only videos and visual aids. Overall, the most common items on which websites scored negatively included the following (the first and third items likely accounted for the high overall literacy scores):

- "Medical terms are used only to familiarize the audience with terms. When used, medical terms are defined" (22/50 websites scored negatively). Nondefined higher literacy terms included "oncology," "SARS CoV-2," and "intravenous iron supplementation."
- "The material uses visual aids whenever they could make content more easily understood" (17/50 websites scored

negatively). Visual aids included, for example, the use of videos, icons, graphics, and GIFs.
- "The material uses common everyday language" (9/50 websites scored negatively). Higher literacy language typically included multiple sentences containing more than 23 words and multiple words with more than three syllables, e.g. infrastructure.

In contrast, among the external organizations' websites, the average accessibility score of the Spanish pages (n=10) was slightly higher than that of the English pages (n=13) (86% vs 83%). Overall, the scores indicate a moderately high level of accessibility. With relatively few total pages being scored, we could not state whether these differences were statistically significant.

Video Content

Of the 50 websites, 12 (24%) had embedded videos in them; however, 100% of the videos were in English, including one that was on a Spanish website. This indicates a missed opportunity to not only reach Spanish speakers, but also engage lower literacy audiences using nontextual information delivery.

Diversity and Inclusiveness

Just over half (n=26, 52%) of the 50 websites had pictures of people. Of those that had pictures, 69% (n=18/26) included people of non-White racial or ethnic backgrounds. Other markers of inclusivity included data stratified by race and ethnicity, patient stories told from the perspective of those from different racial backgrounds, and documents offered in several languages in a drop-down menu.

Missed opportunities were as follows: a button for a Spanish website was listed at the very bottom of an English web page, and the Spanish website about local cases was not updated in real time like the English equivalent (the Spanish website reported zero cases in the county as of March 2020, whereas the English website correctly reported the cases).

Lastly, there were a few instances where websites lacked equity or cultural sensitivity. By "cultural sensitivity," we mean cultural awareness and appreciation for the needs of Spanish-speaking persons. These included the following:

- A link from to a YouTube video from the Spanish text "Pasos simples para prevenir COVID" (English translation: Simple steps to prevent COVID) took the user to a video in English, even though the text and page was in Spanish.
- Charts available on the English website ("Cases by Race and Age" and "Cases by Ethnicity and Age") were not available on the Spanish parallel website.
- The English website was last updated the day before, whereas the Spanish parallel website was updated over a month ago. This resulted in significantly outdated and imbalanced content on the Spanish website.
- The English website used the phrase "Keep America Open," whereas the Spanish parallel website said "Keep the United States open." In this case, the English website lacks sensitivity because using the term "America" to refer to the United States implies a political and cultural dominance over a continental area.

Discussion

This document analysis of seven health care institutions' websites demonstrates that Spanish speakers lack equal access to information about COVID-19 compared with their English-speaking counterparts, leaving an already vulnerable cancer patient population at greater risk. In addition to a greater volume of information, English speakers had access to a wider variety of content via linked information on dynamic web pages rather than static fact sheets. Additionally, video content, which is recommended for low literacy audiences, was available only in English or on English websites. This is especially concerning given the finding of a recent study using nationally representative data that Hispanics were more likely to report watching health-related videos [38]. Moreover, findings noted postaccess disparities [19], such as ease of navigability, which could exacerbate deficits in content for Spanish-speaking consumers of online information. A summary of our main findings demonstrating the inequity of online information about cancer and COVID-19 available to English and Spanish speakers is shown in Table 4.

Our readability analysis demonstrated that overall Spanish websites had a lower average literacy level than English websites (11.7 vs 13.2). However, both literacy levels are unacceptably high given the recommended 6th to 8th grade reading level range for patient-facing health materials [12]. This indicates a significant need for institutional changes to make all websites more accessible to health care consumers in accordance with suggested guidelines [39].

According to the American Hospital Association's Code of Ethics, health care institutions have professional and moral obligations to provide communications that are "clear, accurate, and sufficiently complete," and "should be aimed primarily at better public understanding of health issues, the services available to prevent and treat illness, and patient rights and responsibilities to health care decisions" [40]. However, the guidelines are unclear regarding how health care institutions should best structure and deliver content during public health emergencies, such as the COVID-19 pandemic, when information is rapidly evolving and institutions may lack the resources for regular updates. The American Hospital Association guidelines also lack specificity about the scope and speed with which to inform the non-English-speaking public, which is critical in the DFW metroplex, where 21% of the population is Spanish-speaking. Indeed, findings from this study demonstrate an uneven response among the seven health care institutions to providing equitable information to Spanish-speaking DFW residents concerned about COVID and cancer. Variations in the proportion of Spanish-speaking patients served, institutional resources, organizational culture, and other factors may all play roles in these differences. Above all, however, there is a clear need for public health communication to reach vulnerable populations in real time. Our findings are consistent with the findings of a recent study by the National Cancer Institute (NCI) that found, during the early months of the COVID-19 pandemic, cancer survivors and caregivers were more likely to engage with NCI's Cancer Information Services resources than tobacco users or the general public. This pattern was consistent for English- and Spanish-speaking users accessing content via telephone, instant messaging, email, and social media [41].

This study is unique in assessing the equity of local health care institutions' cancer and COVID website content for English- and Spanish-speaking consumers. We are aware of only one other study that completed a limited examination of equity by noting accessibility of NCI comprehensive cancer centers' visitor policies; it determined that the majority (66%) of the cancer centers published their visitor policies only in English, even in areas of the country with large proportions of Hispanic/Latinx populations [42]. Other studies have inventoried online resources about COVID-19 in Spanish, but these were limited in investigating the educational activities of health care institutions, namely instructional videos [43,44].

Table 4. Summary of the findings.

Variable	Finding for English speakers	Finding for Spanish speakers
Health care institutions' website availability		
Main cancer website	7 institutions	1 institution
Main COVID website	7 institutions	1 institution
Additional information via internally linked pages	7 institutions	3 institutions
Additional information via externally linked pages	7 institutions	4 institutions
Thematic content frequency		
#1 cited theme	Resources/more information/FAQ (76% of websites)	Protection/what you can do (82% of websites)
#2 cited theme	Updates/news (61% of websites)	Resources/more information/FAQ (47% of websites)
#3 cited theme	Information about cancer and COVID (58% of websites)	COVID data (41% of websites)
Usability		
Ease of navigability	Direct links	Page links to English requiring the user to locate the Spanish version via a pull-down menu or page links to Spanish at the bottom of the page
Diversity of information	Links to 24 different pages	Links to six different pages
Completeness of information	All 24 links are to "live" pages with additional links to further information	Four of six links are to limited static pages (eg, a PDF)
Literacy level[a] and accessibility[b]		
Average literacy score overall	13.2 (n=33)	11.7 (n=17)
Average literacy score for institutions' main cancer and COVID pages	15.4 (n=17)	12.6 (n=2)
Average accessibility score overall (DFW[c] and external organization pages)	82% (n=33)	82% (n=17)
Average accessibility score among DFW institutions' pages	81% (n=19)	77% (n=7)
Average accessibility score among external organization pages	83% (n=13)	86% (n=10)
Video content		
Availability	12/50 (24%) websites	0/50 (0%) websites
Diversity and inclusion (images of people[d])		
Perceived non-White and White racial/ethnic groups	10/33 (30%) websites	8/17 (47%) websites
Only perceived White racial/ethnic groups	7/33 (21%) websites	1/17 (6%) websites

[a] Literacy level measured by Readability software (Oleander Solutions).

[b] Accessibility measured by the Patient Education and Materials Assessment Tool (PEMAT).

[c] DFW: Dallas-Fort Worth.

[d] Remaining websites had no images of individuals (49% of 33 English websites; 47% of Spanish websites).

We recommend several specific actions to enhance content and navigability for Spanish speakers. First, all health care institutions should feature at least the CDC's and their State Public Health Department's main coronavirus websites. For example, in this study, the CDC's main COVID websites were the English website [35] and Spanish website [36]; and the Texas Department of State Health Service's main coronavirus websites were the English website [45] and Spanish website [46]. In addition to having websites in English and Spanish, both organizations' main COVID websites link to many other COVID-related websites in English and Spanish. Second, they should label links to Spanish websites with text in Spanish, as shown in Figure 5. Third, we recommend lowering the readability of website text to the recommended 6th to 8th grade reading level. Fourth, linked content should be sent directly to the Spanish version of a page (eg, [36]), rather than to the English version (eg, [35]), where users would need to navigate in English to a button or pull-down menu to select the Spanish page. Lastly, English websites should display more markers of cultural inclusivity, such as images of people of non-White racial/ethnic backgrounds.

Figure 5. Example of linked content labeled in Spanish.

ESPAÑOL

Centros para el Control y Prevencion de Enfermedades (CDC)

Departmento de Servicios de Salud del Estado de Tejas (TX DSHS)

This study has several limitations. First, this study was conducted in Texas, a border state with a large Spanish-speaking population. The findings may not be as generalizable or relevant for other regions with small Spanish-speaking populations. Second, this analysis was performed during a single week in May 2020; we did not examine how information evolved. For example, by May 2020, the country had experienced only the first wave of the pandemic; a cursory review in April 2021 revealed a greater volume of Spanish content on some health care institutions' websites compared to when they were analyzed the year prior. Finally, this study, like all document review studies, is inherently limited in detail; intentionality cannot be clarified, as would be expected in an interview, for example [22]. For this reason, this analysis did not include an evaluation of translation accuracy and conceptual equivalence. However, document analysis studies like this one provide clear objective documentation of an institution's online record that can be reanalyzed by others. Given that a website's communication goal should be to meet the specific needs of local communities [47], further research using other qualitative methods could clarify whether there was an evidence-based rationale for differentiating content between English and Spanish websites.

The COVID-19 pandemic has presented significant challenges for health care institutions in meeting the informational needs of the public. This study is significant in being the first of its kind to demonstrate inequities in the online information available to English- and Spanish-speaking residents concerned about COVID and cancer in a large US metropolitan area. Future research should qualitatively assess where Spanish speakers go for information about COVID and cancer, and evaluate the implications of information-seeking from potentially nonreputable sources.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Coding of website headings.
[XLSX File (Microsoft Excel File), 32 KB - cancer_v7i3e30492_app1.xlsx]

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Abbreviations

CDC: Centers for Disease Control and Prevention

DFW: Dallas-Fort Worth
NCI: National Cancer Institute
PEMAT: Patient Education and Materials Assessment Tool

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Original Paper

Using Social Media for Peer-to-Peer Cancer Support: Interviews With Young Adults With Cancer

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Abstract

Background: Web-based social support can address social isolation and unmet support needs among young adults with cancer (aged 18-39 years). Given that 94% of young adults own and use smartphones, social media can offer personalized, accessible social support among peers with cancer.

Objective: This study aims to examine the specific benefits, downsides, and topics of social support via social media among young adults with cancer.

Methods: We conducted semistructured interviews with young adults with cancer, aged between 18 and 39 years, who were receiving treatment or had completed treatment for cancer.

Results: Most participants (N=45) used general audience platforms (eg, Facebook groups), and some cancer-specific social media (eg, Caring Bridge), to discuss relevant lived experiences for medical information (managing side effects and treatment uncertainty) and navigating life with cancer (parenting and financial issues). Participants valued socializing with other young adults with cancer, making connections outside their personal networks, and being able to validate their emotional and mental health experiences without time and physical constraints. However, using social media for peer support can be an emotional burden, especially when others post disheartening or harassing content, and can heighten privacy concerns, especially when navigating cancer-related stigma.

Conclusions: Social media allows young adults to connect with peers to share and feel validated about their treatment and life concerns. However, barriers exist for receiving support from social media; these could be reduced through content moderation and developing more customizable, potentially cancer-specific social media apps and platforms to enhance one’s ability to find peers and manage groups.

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KEYWORDS

cancer survivors; social support; peer groups; social media; young adults; pyscho-oncology; mobile phone

Introduction

Social media has the potential to provide critical social support for young adults with cancer [1,2]. Cancer has unique psychosocial impacts on young adults (aged 18-39 years), with unmet social support needs being a challenge for many [3-5]. Young adults with cancer struggle to find peers with their diagnoses and are often affected by social isolation, which is compounded by debilitating life disruptions such as extended absences from school and work [3,4,6,7]. Feelings of isolation may occur throughout their cancer experience and into survivorship [8,9]. Lack of social support among young adults with cancer is associated with poorer physiological and physical functioning, greater psychological distress, and reduced quality of life [10-12].

Many young adults with cancer report a need to meet peer survivors [3] and desires for peer connections via convenient, technology-based support options [13,14]. With 94% of young adults in the United States owning a smartphone [15], social media can leverage the power of networks and the ubiquity of smartphones for accessible, personalized social support [16]. Web-based social support can also uniquely contribute to well-being [17,18], especially among those unable or unwilling to receive face-to-face support [19]. Young adults may particularly benefit from peer support, defined as seeking or sharing emotional, informational, or instrumental support among other young adults with cancer via social media [20]. Young adults with cancer consistently express the need to connect with peers to feel less alone in their unique challenges, hear from others' experiences for what to expect, and maintain or form their identity [3,14,21]—the need for support is potentially alleviated through synchronous or asynchronous social media connections among youth [17,22,23].

Social media also appears to increase social connectedness among young adults with cancer [24,25]. Peer-to-peer sharing on social media may meet unique, age-specific needs [26-29]; however, many still recognize the need to better understand how young adults with cancer use social media for social support [30,31]. Social media engagement can involve complex relational processes where young adults with cancer benefit most from reciprocal and responsive disclosures [32]; however, few have addressed upstream experiences that facilitate (or hinder) cancer-related conversations on social media. In addition, although many have analyzed the content (eg, social media posts) of cancer conversations [28,33,34], less attention has been given to why young adults with cancer decide to engage before messages are sent (or not sent). There is also a need to identify the downsides of peer support among individuals with cancer to generate possible solutions, as social media use can negatively influence well-being among young adults [35]. Previous studies have often focused on the positive impacts of social media use, with a limited focus on potential downsides in these novel approaches [29,36]. If it is known that emotions drive social connections on the web, including negative mental experiences (eg, isolation and fear) [30], then there is a need to provide more balanced approaches to understand why young adults are motivated to organically share their stories and drawbacks of peer support. Thus, for this study, we seek to examine specific benefits and downsides, along with motivations for specific topics of peer-to-peer social support when using social media from the lived experiences of young adults with cancer.

Methods

Participants and Procedure

We conducted semistructured interviews with young adults with cancer between April and May 2020. Participants were recruited via email and social media posts (Facebook, Instagram, and Twitter) from *Stupid Cancer*, one of the largest adolescent and young adult cancer advocacy organization in the United States. Emails and social media posts had a brief description of the study and incentives, eligibility recruitments (aged between 18 and 39 years and those either currently receiving treatment or have completed treatment for cancer), and how to contact the team. Potential participants emailed to confirm eligibility by stating their age and whether they had a cancer diagnosis and scheduled an interview. We received 163 initial responses and scheduled the first 45 eligible respondents for 30-minute interviews for "our study to learn more about what young adults affected by cancer look for in online support" (recruitment description). We planned to schedule additional interviews if we did not reach saturation, but these were not needed.

All interviews were conducted via Zoom by 2 researchers (AJL and MKRC) to allow for virtual participation. The day before the interview, participants received a web-based Qualtrics survey with written consent and demographic items, including age, gender, diagnosis, and treatment status. Before the interview, the researcher confirmed their consent and permission to record. This study was part of a larger data collection to better understand web-based social support. For this study, participants were first asked about social media they were currently using or had previously used for support, how these apps or platforms were helpful for making connections and support, what issues or topics they connected with others about, and any downsides of web-based social support, with questions adapted from our cancer support app research [29]. Then, all interviewees were asked about initiation or any changes to how they used web-based support and who they connected with, which is reported elsewhere [37]. Despite the vast disruptions to life for months to come from COVID-19, these interviews were planned and conducted before the scope was known, and the impact of the pandemic was not an explicit focus in the interviews. Each participant received a US $40 Amazon gift card. The University of North Carolina Institutional Review Board approved all procedures (#19-2715); all team members completed human-subjects training before the study.

Data Analysis

Overview

Interviews were auto-transcribed using Zoom software and then cleaned for accuracy by 2 researchers listening to and manually correcting any errors in the transcripts (AH and TV). The same 2 researchers coded the transcripts with codes developed a priori for specific apps or platforms used and large *broad-brush* topics [38] about benefits, downsides or hesitations, and topics of support. Disagreements were reviewed, discussed by the research team, and then resolved independently by the first and last author (AJL and CB) [39,40]. All the members of the research team interpreted the individual codes into broader themes.

Statistical Methods

Descriptive statistics were conducted in SPSS 26 to analyze participant demographics.

Results

Overview

The participants (N=45) were mostly White (36/45, 80%) and female (33/45, 73%; Table 1). The average age was 31 (SD 5.56) years, and the average age at diagnosis was 26 (SD 6.95) years. One-third of the participants (15/45, 33%) reported breast cancer as their primary diagnosis. More than half of the participants (25/45, 56%) had completed treatment at the time of the interview. Participants resided in every geographic region of the United States.

The participants primarily reported the use of general audience platforms for cancer support. Almost all participants reported using Facebook, generally or through private groups, or Instagram at some point in their cancer timeline. Twitter use was organically mentioned by just over a tenth of young adults, and a few shared about using Snapchat, TikTok, or YouTube to seek out cancer stories. About a quarter of young adults referenced using cancer-specific social media (eg, Gryt Health and Caring Bridge) or web-based forums of national cancer advocacy organizations, such as Stupid Cancer or American Cancer Society. About 1 in 6 participants reported the use of video chat platforms, such as Zoom or Webex, which became popular in the COVID-19 pandemic. A few also highlighted texting cancer peers, sometimes via WhatsApp, and meeting through other means (eg, in-person meet-ups and support groups). Reported social media use was similar across age, gender, diagnoses, or treatment status; themes were also consistent unless noted below.

Table 1. Demographics of participants in this study (N=45).

Characteristics	Values
Current age (years), mean (SD)	31.00 (5.56)
Age at diagnosis (years), mean (SD)	26.39 (6.95)
Gender, n (%)	
Male	12 (27)
Female	33 (73)
Race, n (%)	
Asian	3 (7)
Black or African American	6 (13)
White	36 (80)
Ethnicity, n (%)	
Hispanic or Latino or Latina	3 (7)
Non-Hispanic or Latino or Latina	42 (93)
Diagnosis[a], n (%)	
Breast cancer	15 (33)
Hodgkin lymphoma	6 (13)
Leukemia	4 (9)
Sarcoma	3 (7)
Lung cancer	2 (4)
Brain tumor	2 (4)
Ovarian or uterine cancer	2 (4)
Colon or rectal cancer	2 (4)
Other cancer	9 (20)
Treatment status, n (%)	
In treatment	9 (20)
Ongoing therapies	10 (22)
Completed treatment	25 (56)
Region of residence in the United States, n (%)	
New England	1 (2)
Mid-Atlantic	12 (27)
South	9 (20)
Midwest	9 (20)
Southwest	5 (11)
West	9 (20)

[a] According to the American Cancer Society [41], the leading cancer types in adolescents and young adults are thyroid cancer, breast cancer, lymphomas, leukemia, testicular germ cell tumors, melanoma, soft tissue and bone sarcomas, colon and rectum cancer, and uterine cervix cancer, followed by cancers at other sites.

Topics of Web-Based Social Support

Overview

On social media, young adults commonly had conversations about medical information and navigating life with cancer when seeking or sharing support among peers. The participants noted the benefits and downsides of these conversations. Participants' responses were edited for grammar and clarity.

Medical Information

Young adults with cancer often turn to peers on social media for medical information because they feel uncertain about future chemotherapy, treatments, and operations; what side effects to expect; how to manage side effects; and what comes after their current treatment. Many are often unsure whether their side effects and symptoms are normal or warrant provider care.

Social media offers accessible ways to share and compare experiences, for example:

> *I think it's a nice way for people to sort of manage their anxiety around the uncertainty of what's to come. Because there's a lot of it when you're diagnosed.* [Female, 32 years, breast cancer, ongoing therapies]

Reading others' cancer posts helps alleviate the fear of the unknown.

Participants also received and shared personal *tips and tricks* for dealing with symptoms and side effects, such as using over-the-counter or alternative medicine to help with nausea, swelling, and pain. Connecting with others to receive diagnosis-specific information was especially important. Some online groups are organized by diagnosis or treatment to allow young adults to seek relevant or cancer-specific peer support from informal mentors:

> *You kind of adopt someone to sort of, like, mentor you, if that makes any sense. And it's not formal, it's just when you feel like, oh, I really kind of like that person. I feel like they're easy to talk to.* [Female, 38 years, breast cancer, ongoing therapies]

Other organizations facilitate mentorships between members with similar diagnoses that can lead to peer support:

> *I did start out with Imerman Angels, and since my mentor was on the West Coast and I'm at the East Coast, it was, you know, online. She introduced me to Twitter [cancer community].* [Female, 38 years, brain tumor, completed treatment]

Generally, participants found hashtags or search bars within private groups helpful for seeking out diagnosis-specific information.

Sometimes, advice-sharing with peers on the web extends to clinical information about drugs and treatments. Several participants used online groups or communities to *crowdsource* information, asking others about information from providers or web-based resources. One participant explained the following:

> *What I like from Facebook these days, especially, I use it as a crowdsourcing platform. So, when I have a question...I'll have 12,000 people potentially. 12,000 answers.* [Female, 38 years, brain tumor, completed treatment]

Participants value obtaining information from peers because they are usually jargon-free and often feel more complete than provider information. For example, one participant said the following:

> *Your oncologist you know, will tell you all the side effects, but it's very comforting and nice to hear actually come out of someone's mouth that's been on the medication...they tell you the raw deal of it, what it really is, or what they took for it, how long they've been on it, how long it's worked for them. So, I find it very informative. It's like a whole other side that like my oncologist doesn't reveal to me.* [Female, 33 years, breast cancer, ongoing therapy]

Participants also turned to social media or online groups to express dissatisfaction with their doctors and seek recommendations for other providers:

> *Another thing we talked a lot with everybody about is doctor recommendations. That's flying around a lot. Who you're happy with, who you're not happy with, who would you suggest people to stay away from.* [Female, 38 years, breast cancer, ongoing therapies]

Similarly, a breast cancer survivor shared how peer support influenced her choice of provider:

> *I didn't really like the way they wanted to do my reconstruction. It was what they wanted, not what I wanted...that's when the social media came into place where I could see what others had done and then you know what, what their outcomes look like from the doctors or the facilities. And so, I think it really helped me choose where I finally did go for my reconstruction....So, it wasn't like, that, you know, it wasn't like you were getting a doctored photo. It was like you're getting a real-life situation.* [Female, 38 years, breast cancer, completed treatment]

Navigating Life With Cancer

Participants sought social support for navigating the impact of cancer on life, including their professional lives and personal relationships. Peer support on social media was often mentioned as helpful for managing work and career goals. One young adult turned to social media when having *continued issues* and needing advice on how others have handled returning to work (male, 32 years, colon cancer, in treatment). Another shared the following:

> *I found that I follow some women who are vocal about their cancer process and cancer diagnosis on Twitter and that's been helpful because...I feel like [they are] in similar sort of professional situations as me...at a similar point in their career, which is important for me as someone who, you know, hopes to who knows eventually like enter [profession].* [Female, 32 years, breast cancer, ongoing therapies]

A small number of female participants used social media for peer support about dating and sex, including finding helpful mechanisms for coping:

> *One thing that I didn't realize...there's like a lot of funny cancer jokes...they really have helped me understand a lot of stuff and think, like, okay, I'm not the only one...they talk a lot about...different relationship stuff and dating.* [Female, 29 years, breast cancer, ongoing therapies]

The few parent participants shared about connecting for specific advice to talk to their children or support with parenting more broadly:

> *How do you explain it to them in a way that's, you know, it's not scary, but you're also not lying to them, you know?* [Female, 32 years, lung cancer, in treatment]

> *One of the groups I'm in is a stage four moms group [with young kids]....And sometimes...that page is a little more not centered on cancer so much. But then there'll be, "I hope I get to see them graduate," and stuff like that.* [Female, 29 years, breast cancer, ongoing therapies]

Participants also received advice about managing the impact of cancer on their bodies. A few female participants who had completed treatment shared about supporting those with hair loss:

A *lot of the times it's like, you don't have to shave your head right in the beginning, you can wait or when it feels right to you...we all give each other like supportive feedback on it.* [Female, 24 years, Hodgkin lymphoma, completed treatment]

Peers also shared fitness or exercise support, advice about eating—albeit not always evidence-based nutrition—and support for fertility or other debilitating effects of treatment:

> *A lot of people have said that yoga seems to help them because it's not a strenuous but it's you know, working their muscles.* [Female, 32 years, lung cancer, in treatment]
>
> *There's conflicting information out there...some say the keto diet...a plant-based diet...vegan style is the best...And then there's a lot of people selling supplements, which can be really expensive and maybe a bit dangerous to take without any guidance from a medical professional.* [Male, 29 years, sarcoma, completed treatment]
>
> *They have a lot of like different groups for different specific things. I found the general colon cancer group to be sort of overwhelming because there was a lot of people in a lot of different situations, but when you [are] specifically looking for help with, like, neuropathy or fertility issues or people in the local area, it was nice to be able to filter it down to those things.* [Male, 32 years, colon cancer, in treatment]

Young adults, primarily those in posttreatment, also reported frequently discussing mental health among peers as a group or for individual support:

They do like a mental health check post and everyone, they'll say like, "how are you doing today" and we just allcomment. [Female, 30 years, breast cancer, completed treatment]

> *I spoke to someone on Twitter because they had posted something about like, "is this normal, blah, blah?" And I, like, privately messaged them..."yes." I was like, "I was at my most anxious, my most depressed, like, a year after treatment."* [Female, 29 years, Hodgkin lymphoma, completed treatment]

Notably, in the initial months of a global pandemic, a few mentioned seeking advice for managing exposure to coronavirus while immunocompromised recommendations.

Both during and posttreatment, young adults turned to peers on social media for advice about the unique support needs introduced by cancer. Young adults sought out peers for navigating insurance or financial support:

> *They post things, they take polls on all different topics relating to cancer...like, you know, insurance "did your insurance cover this"* [Female, 31 years, ovarian cancer, completed treatment]
>
> *The big one for me is financial assistance...as far as the cancer that I have, I kind of know what it is, I kind of know if there's a cure or not...the big thing for me with the cancer was financial assistance. What help was out there for people like me, going through this.* [Male, 31 years, recurrent neuroblastoma, in treatment]

Young adults also seek and share about cancer-related stigma:

> *Whenever I get on the group, [pain medicine shaming]'s like the hugest topic. And, you know, and we're, you know, it's a thing that makes us really angry too because we can't help that we need pain medicine, you know?* [Female, 36 years, breast cancer]

Young adults rely on web-based social support to navigate their survivorship. Upon finishing treatments, young adults sought guidance by transitioning back to *normal* life. Describing feelings posttreatment, one participant said the following:

> *Oh my gosh, I am, like, broken, and traumatized. How am I supposed to go back [to life before cancer]? So that's when I just needed, I guess, just to hear from others, like "Holy crap, this is really hard."* [Female, 28 years, Hodgkin lymphoma, completed treatment]

Additional struggles include lasting impacts of *chemo brain*, facing survivor's guilt, and coping with the deaths of friends with cancer.

Some young adults also enjoyed sharing non–cancer-related topics with their peers on the web. One participant explained the following:

> *It would be overwhelming if we constantly talked about cancer, cancer, cancer.* [Female, 30 years, breast cancer, completed treatment]

Many of these participants talked about shared hobbies and local bars and restaurants, providing recommendations for people nearby or temporarily around for treatment. These conversations are especially enjoyable among age-similar peers and can foster lasting friendships. However, not all participants perceived conversations as steering away from cancer; one participant said the following:

> *We started talking about other stuff, you know, just our daily life...But it seems it all still revolves around cancer-based things just because, I guess it's such a big part of our life.* [Female, 29 years, breast cancer, ongoing therapies]

Benefits of Web-Based Social Support

Beyond receiving information from peers for desired topics, participants noted several other benefits of web-based social support, including connecting with others, mental health and emotional benefits, and web-specific benefits.

Connecting With Others

Web-based social support can reduce loneliness via alternate ways of socializing. With cancer, meeting in person can be difficult because of being immunocompromised to exhaustion or pain and wanting to keep diagnoses private. Sometimes, friends and family members are afraid or nervous to talk about cancer. Many of these challenges become nonissues in online cancer-focused groups, where young adults can comfortably *lean on* peers in similar situations any time of day. This was especially helpful when needing to talk while having pain, when receiving difficult news from the doctor, or when hearing about a friend's declining health. Many posttreatment participants use social media to *give back* and share support for those undergoing treatment—who join diagnosis-specific Facebook groups to find an informal mentor with a similar diagnosis. A few participants expressed how using web-based social support to combat loneliness became even more important during the COVID-19 pandemic, as many young adults with cancer were immunocompromised and needed to practice strict social isolation for their safety:

> *I mean, especially because I'm not leaving my house right now, so I like the Zoom being able to see people and being able to interact.* [Female, 37 years, lung cancer, completed treatment]

Some participants also mentioned how the pandemic created new opportunities for connecting with peers:

> *And I do like that during this time of COVID, my cancer center has been moving towards online activities that don't have anything necessarily to do with cancer...I wish that had been more [popular before] because, sometimes you're at home, recovering from a surgery and you'd like to be talking to other cancer patients, but you don't have the stamina or mental energy to hear other people talk about their surgeries or their chemotherapy, but you just want to be around people who understand.* [Female, 29 years, thyroid cancer, ongoing therapies]

Some have made lasting friendships within tightly knit online cancer communities, whereas others found that connecting with just a few people on the web helped combat isolation. Participants emphasized the importance of shared experiences; it is nice to vent to someone who understands. A young adult with breast cancer spoke about her *breasties* on the web:

> *Whatever is going on in your life, you feel like you can post there without judgment...Because I feel like a lot of times your friends and family don't quite understand everything that your cancer sisters or your breasties would understand.* [Female, 38 years, breast cancer, completed treatment]

Sometimes, participants enjoyed just being together (virtually) with peers who understand their experiences, for example, doing a shared craft or activity through a video chat. Others emphasized the importance of connecting with peers who lived nearby and seeking out social media accounts of local chapters of national cancer organizations to do so. Social media also allows young adults with cancer to create new groups to fulfill unmet needs for seeking or sharing peer support. One participant created her own web-based organization and the corresponding Facebook group for Black women to connect and discuss unique experiences.

Mental Health and Emotional Benefits

Many participants discussed the emotional benefits of web-based social support. Seeing others' self-disclosures about mental health or responses to their mental health challenges made their experiences feel more *normal*. Venting about fears and frustrations with peers was also helpful for decompressing and expressing themselves.

Seeing others' positive cancer milestones or success stories (ie, "five years out from remission" or "I had a baby in spite of chemo") helped some feel hopeful for their future. Gathering resources from online groups helped others feel in control of their cancer diagnosis. Humor can also be a helpful coping mechanism; young adults sought out funny, relatable posts from Instagram accounts such as @thecancerpatient, with the posts' numerous likes and comments, to help them feel less alone.

Furthermore, social media provides young adults with cancer with individualized encouragement. Participants made friends on the web who would occasionally reach out to check in on their well-being and they would do the same in return. One participant described a tight-knit online group that regularly posted *mental health checks* for updates from each member. One participant explained the following:

> *Whenever I'm have anything that I am like mentally or emotionally struggling with, physically struggling with, any things that I feel are successes or roadblocks, like there are literally dozens of people now I feel like I can throw out a question to or an emotion to or something like that. And I've received so much just encouragement through those platforms that it's really been a very healing factor for me...So I think it's been a godsend for me.* [Female, 32 years, sarcoma, completed treatment]

Web-Specific Benefits

Although some participants preferred in-person support, others noted the specific benefits of web-based social support. On social media, participants do not face scheduling conflicts, can share without interrupting others, are not restricted to a number of questions, and can receive support throughout the day (and often night). Social media also gives more control—young adults can choose when to connect, view others' profiles before connecting, choose how much information to disclose or engage with others' emotions, and can easily leave unhelpful groups.

Social media also facilitates connection building in unique ways. Social media search capabilities helped participants find others with similar diagnoses. Young adults with cancer enjoyed getting a sense of others' personalities through their social media profiles. Participants also referenced the ability to congregate large audiences on social media and the ease of use of already-familiar platforms for social support.

Downsides of Web-Based Social Support

Young adults with cancer also face downsides and barriers for social support on social media, including disheartening content, participation burdens, others' bad behavior, privacy concerns, and other shortcomings of social media platforms.

Disheartening Content

News about others' declining health and the deaths of friends is one of the main downsides to web-based social support. Losing friends on the web can "hurt [their] hope" [Female, 29 years, breast cancer, ongoing therapies] or create a *hard and painful* experience that "adds to a little bit [of], you know, the heartache" [Female, 36 years, breast cancer]. Reading about others' anxieties or negative outlooks—sometimes including worries that participants had not yet considered—was also discouraging. Similarly, *hard truth* posts (ie, photos of scars and harsh treatment realities), horror stories, and other unwanted information (ie, survival rates) heightened feelings of being overwhelmed. Reflecting on typical responses to new group members, one participant said the following:

> *Okay, like, back off a little bit, like, you know? Like they just started this process. This journey is very hard. You know, they don't want to hear your horror story right away.* [Female, 30 years, breast cancer, completed treatment]

Participation Burden

Actively participating in web-based social support can also be emotionally taxing. Talking about cancer so often, being on the web at all times, and lending support can be draining, especially when feeling overwhelmed with one's own treatment or recovery. Although posttreatment young adults often desire to support others in treatment, some feel that doing so is difficult. Providing this support can exacerbate the *survivor's guilt*, especially if the person in treatment dies. Anticipating this experience made some posttreatment young adults hesitant to provide support on the web.

Other participants felt that supporting others in treatment forced them to relive their own traumatizing experiences. One participant explained the following:

> *I was a mentor for a couple people, and I actually had to pull away because I kept reliving what I went through every time they were going through their next step, and it just, kind of pulled on my heartstrings. It would just bother me when I heard someone had a worse-case scenario than I did.* [Female, 38 years, breast cancer, ongoing therapies]

Others encountered high volumes of requests for support. One participant described a web-based connection asking for near-constant support and sending countless messages even after stating that she was busy. Participants who regularly posted about their cancer on Twitter and Instagram received an overwhelming number of direct messages with cancer-related questions; answering quickly became burdensome.

Bad Behavior From Others

Beyond sharing terrifying stories with newly diagnosed young adults and unreasonable support demands, information sharing and giving advice can become troublesome. People often share false or questionable health information with a tone of authority, sometimes becoming pushy or insistent. Participants noted people on the web asking for (seeking) individual health recommendations that required consultation from a doctor. One participant provided the following anecdote:

> *I have a very rare tumor in my leg, and so one of the options if treatment didn't work was amputation...And I just remember this one person also saying, like bombarding me..., "Why would you want to put yourself through being poisoned? Why would you want to put yourself through all of that? Just go get a consult, just go, amputation is the best option." And that really weighed on me, especially while I was actively going through treatment. And these people's opinions, they have, the ability to be like very aggressive or very harassing about them.* [Female, 32 years, sarcoma, completed treatment]

Another participant was bullied in a Facebook group for admonishing other members' harsh behavior; they were criticizing a woman who disclosed her worst fear was losing her hair. A different participant complained about the unrealistically positive groups.

Privacy Concerns

Some young adults fear being treated differently, cancer-related stigma, and discrimination if employers knew about their cancer status. In light of these concerns, some participants preferred sharing private messages with other young adults with cancer rather than posting publicly. Others cited concerns about data security on platforms such as Facebook. In group contexts, participants worried someone might share information outside of the group or participate in a group video chat while others can hear. Finally, a few noted concerns about being *catfished* or connecting with someone who is pretending and people joining groups only to promote products or events.

Other Shortcomings of Social Media

Poor design features of social media were noted as shortcomings of web-based social support by over a third of participants. For example, long group threads that lacked organization (eg, posts not in time order) or notifications can be overwhelming, cause someone to miss potentially helpful posts, and hinder meaningful conversations:

> *I would miss things, and especially in the Facebook groups, they just, like, posts get jumbled up.* [Female, 32 years, lung cancer, in treatment]

Conversely, more often, participants complained about too many notifications:

> *Leading up to surgery, I was like psyching myself out. So, I kind of shut off the notifications on Facebook....* [Female, 31 years, ovarian cancer, completed treatment]

> *although, at the same time, they can be kind of overwhelming when you have a notification for every time anyone does anything, which kind of...disincentivizes you to kind of keep on [the app].* [Male, 27 years, Hodgkin lymphoma, completed treatment]

Other design flaws included apps and platforms that did not provide sufficient profile options or information. For example, apps that do not indicate whether someone is active or inactive on the site can prevent connections:

> *If I search for someone that's like in their mid 30s, that had this diagnosis, but they haven't logged on for like a month, then I'm not going to send them a friend request or I'm not going to send them a message of, like, "Hey, let's like let's be friends forever." I would rather find someone else that has a totally different diagnosis, but that's my friend, but that was on yesterday.* [Female, 38 years, uterine endometrial cancer, completed treatment]

Designs that exclude people with nonbinary gender identities by requiring users to select "male" or "female" were also disliked. One participant shared the following:

> *You feel very alone because like I would say a common LGBTQ feeling is alone. Cancer, alone. And when you put them together It's even worse.* [Male, 18 years, Hodgkin lymphoma, completed treatment]

Similarly, another participant advocated for inclusive peer groups:

> *I think just being able to have that option [non-binary] is, like, the start of them at least feeling like they're included in this. You do a medical intake and it's male or female, like what, what if this person feels like they're non-binary...there's never a box for that.* [Female, 38 years, breast cancer, completed treatment]

In private online groups, such as Facebook groups, the number and variety of group members can present issues. Some participants liked big groups for crowdsourcing information; however, they found that they often did not make meaningful relationships in large groups:

> *I go on there from time to time, like, you know, we'll talk to each other a little bit, ask questions, kind of share stories, things like that on Facebook, like in our own like private group that's full like just thousands upon thousands of people all over the world.* [Female, 24 years, Hodgkin lymphoma, completed treatment]

In addition, diversity in big groups can make it difficult to find diagnosis-specific information:

> *I don't ever post in there, and I don't read a lot. And because there's just so many people that it just seems too vague and overwhelming.* [Female, 31 years, thyroid cancer, ongoing therapies]

Discussion

Principal Findings

Many young adults with cancer turn to social media when they need peer-to-peer support. Experiences of social isolation among young adults with cancer have been well documented [3,4,6-9]. Social media holds promise to meet unmet support needs; most of our participants found that connecting with others on the web offered an important means of feeling less alone. They went on the web seeking shared connections, using both general platforms such as Facebook and Instagram as well as specialized spaces such as forums hosted by Caring Bridge or Stupid Cancer to help meet their needs.

These digital resources help young adults gather information on key topics tailored to their diagnoses, life stages, and communication preferences. Among our participants, it was clear that social media can help access essential information while working around the inherent problems of navigating a cancer diagnosis. The range of platforms, technology types, and online support communities can offer multiple avenues of support, helping to efficiently meet different needs at different times. For example, immunocompromised individuals do not have the option of attending an in-person support group, so a private Facebook group or Twitter chat can offer much-needed information or help them cope. Doing so likely meets support needs that cannot be met by others in their support network; cancer-specific social media is used more among survivors with fewer close support resources [42].

The larger size of many social media groups—on Facebook and elsewhere—makes it increasingly possible for individuals to find someone with a similar diagnosis or a specific personal challenge [43,44]. Social media becomes more useful as the diversity and number of users increase (ie, network effects); more peers lead to more opportunities to connect to similar experiences [45]. The scale of general audience social media communities allows for the increased possibility of a user finding, for example, someone else with the same rare genetic mutation, food allergy, or relationship status that one would be unlikely to come across in the face-to-face world through hospital-organized or geography-based programs. Participants in this project perceived value in being able to crowdsource instrumental support, particularly without concern for specificity of issue, geography, or time; however, large group discussions can be overwhelming, making it difficult to build close relationships with others.

Convenience is critical—young adults with cancer desire support that meets them where they are and when they need it [13,14]. Social media groups also allow these young adults to have additional agency over the depth, timing, and frequency of cancer-related social interactions. Participants in most social media groups can maintain a degree of anonymity, if desired, and choose how much they share, as well as how often they participate, all in ways substantially different from in-person support. In addition, as several participants mentioned, there is a special and appreciated opportunity to control the pace of relationships such that established and safe web-based connections have the chance to move to other communication channels and degrees of depth when both parties agree.

Along with the opportunity to search for difficult-to-find information and receive emotional support, participants also noted that the opportunity to help others is a significant benefit of these online groups. Giving back offers a chance to build esteem and shift focus from one's own challenges while getting the emotional and mental health benefits of participating in mutual sharing [46,47].

Social support via social media comes with challenges that also offer lessons about how to best create, manage, and suggest these resources for young adults with cancer. Participants mentioned downsides such as the difficulty of seeing others struggle or the difficulty of being connected to the cancer community nonstop, as well as problematic group behavior of asking for specific advice without being willing to engage a health care professional. Young adults with cancer are challenged with dealing with exaggerated, unsupported, and misleading information on the web and across social media [48,49]. Many of these challenges can also exist with in-person relationships as well; however, the access and opportunity to engage in interactions on the web is greater, so the considerations are slightly different, where one's digital presence does not fade, and reminders of pain and loss are harder to avoid [50].

Considering these potential downsides, online groups have the possibility of using design features and moderation to change norms, reduce these burdens, and maximize support for users. Improved outcomes could come from design elements, such as tools, to flag problematic posts. In-platform prompts (eg, "want to review?") can encourage communities to intervene to reduce harmful content [51] and provide individuals with effective prompts to rethink or edit what they share [52,53]. Platforms should also leverage features for peer matching based on emotional needs (eg, "I would like to offer support" or "I am just here to observe"*)* so people can control their emotional labor; the ability to *signal* availability, without the cognitive or emotional burden of an explanation, can function as a socially acceptable warning or active invitation for support requests. Similarly, clearly stated community standards to reduce offensive or misleading content; tools to allow for content flagging, reporting, and shadow banning (ie, hiding posts or comments from future views) to allow the communication to participate in reducing harmful content; and active platform moderators to intervene could aid in ensuring a consistent, useful culture. Finally, newer technologies such as chatbots could reduce the downsides of social media-based support by taking on emotional engagement and coaching individuals in how to most constructively discuss their circumstances.

Limitations and Future Directions

This study had some limitations. Young adults responded to recruitment emails or social media posts shared directly (or indirectly through likes) from the Stupid Cancer community; thus, participants may differ from other young adults with cancer who are less digitally connected to strong cancer advocacy organizations. Future extensions of this work should use different recruitment strategies (eg, snowball sampling, recruitment from other organizations, and paid social media recruitment) to hear from less connected populations for other, and potentially greater, peer support needs. How young adults may be receiving support from sources other than social media and thus feeling less inclined to connect is also important to consider in further research. The sample was also primarily female, identified as White, and breast cancer was the most common diagnosis (15/45, 33%). More representative and inclusive samples of young adults of varying ages, balanced for gender, and with a variety of cancer diagnoses are needed to understand unique needs and challenges. It would also be fruitful to contribute to emerging evidence [54,55] and investigate whether family and friends use social media in similar ways to support young adults with cancer in their lives or for their own caregiver support. Similarly, hearing from health care providers and clinical teams about their experiences recommending resources or using social media to support young adult patients is needed to better understand how and when peer support fits within clinical care [49]. In addition, our interviews were conducted before the scale and the impact of COVID-19 were known. Although some participants referenced the impact of the pandemic on their web-based support use organically, participants largely focused on life before the pandemic. Follow-up studies are needed to determine novel or evolving benefits and downside of web-based support during and after the pandemic, where many social connections have a greater emphasis on technology-based interactions.

With growing evidence for the benefits of web-based cancer support, in spite of downsides, there is a need to determine how to best encourage young adults with cancer to try out social media support options that may work for them. To do that, we can focus more on *when* young adults use social support [37], specifically when they initiate or engage with web-based social support and how their use changes through their cancer timeline, as well as how clinicians can better highlight perceived benefits directly to patients and advocate for the management of downsides.

Conclusions

Social media provides beneficial social support for young adults to connect with peers about cancer experiences. More social media options where young adults can comfortably share their concerns are needed. Barriers to social media support could be reduced through content moderation, customizable features for content flagging and discussion size, flexible profile creation to signal identity and support desires, and secure platforms with large user bases to facilitate meaningful connections for shared, often diagnosis-specific experiences.

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Interview guides and deidentified transcripts are available upon request from the corresponding author. The data are not publicly available because of privacy restrictions.

Conflicts of Interest

BL is a cofounder, board member, and a consultant at *Gryt Health*, a digital oncology company. CB is a research advisor to *Gryt Health*, and a board member to *Stupid Cancer*, a nonprofit young adult cancer organization. The other authors declare no conflicts of interest.

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Original Paper

Stakeholders’ Perspectives on eHealth Support in Colorectal Cancer Survivorship: Qualitative Interview Study

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Abstract

Background: eHealth interventions may represent the way forward in following up patients with colorectal cancer (CRC) after hospital discharge to support them in coping with the illness, strengthen their self-management, and increase their quality of life. By involving end users of eHealth in cocreation processes when designing eHealth solutions, an acceptable and relevant product can be secured. Stakeholders’ perspectives could aid in closing the gap between research-developed products and the implementation of eHealth services in real-life scenarios.

Objective: This study aims to explore the views of patients with CRC, their informal caregivers, and health care professionals (HCPs) on information technology and the design of eHealth support in CRC care.

Methods: A qualitative, explorative design was used to conduct 31 semistructured individual interviews with 41% (13/31) patients with CRC, 29% (9/31) informal caregivers, and 29% (9/31) HCPs recruited from the gastrosurgical ward of a university hospital in southwestern Norway. A semistructured interview guide was used for data collection, and the data were analyzed by systematic text condensation.

Results: Participants described the diverse experiences of patients with CRC seeking web-based information. Age and digital competence were highlighted as influencers of the use of information technology. Patients rarely received advice from HCPs about relevant and secure websites containing information on CRC diagnosis and treatment. Features of desired eHealth interventions in following up patients with CRC were patient education, health monitoring, and communication with HCPs.

Conclusions: Several elements affect the activities of patients with CRC seeking health information. Age, inexperience with computer technology, and lack of access to web-based health information may reduce the ability of patients with CRC to engage in decision-making processes regarding illness and treatment. An eHealth service for patients with CRC should comprise features for information, education, and support for self-management and should aim to be individually adapted to the patient’s age and digital competence. Involving end users of eHealth services is necessary to ensure high-quality tailored services that are perceived as user friendly and relevant to the end users.

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KEYWORDS

cancer patients; carers; colorectal cancer; digital competence; eHealth; health care professionals; follow-up service; web-based information seeking, self-management support; treatment burden; mobile phone

Introduction

The World Health Organization [1] defines eHealth as “the use of information and communication technologies (ICT) for health.” The development of eHealth solutions in health care services is a growing field of interest in academic and clinical research. In cancer care, eHealth interventions are designed to help patients cope with cancer and treatment side effects, strengthen self-management, and improve their quality of life (QoL) [2]. QoL consists of physical, psychological, social, spiritual, and environmental values [3]. Cella and Tulsky [4] proposed a definition of QoL for use in cancer care that includes the patient’s own preferences into the level of impairment: “patients’ appraisal of and satisfaction with their current level of functioning compared with what they perceive to be possible or ideal [p. 329].”

Colorectal cancer (CRC) is among the most frequent cancer diagnoses worldwide, with nearly 2.0 million new cases in 2018 [5]. Follow-up of curatively treated patients with CRC involves recurrence surveillance and prevention, health maintenance, and psychosocial support [6]. A decrease in postoperative length of stay during primary surgical treatment has been observed for patients with CRC [7]. Many patients may experience feelings of emptiness and insecurity without professional care when they return home after hospitalization [8]. In the follow-up phase, eHealth tools, such as mobile apps, can be used for self-reporting of side effects of adjuvant CRC treatments [9], to enhance the capacity to self-manage and increase QoL [10] and help patients to access social media (eg, Facebook, Twitter, cancer survivor networks) for information and peer support [11]. For patients to be able to access eHealth tools, they need digital competence, including information and data literacy (ie, ability to search, filter, evaluate, and manage digital content), and communication and collaboration skills (ie, interaction, sharing, netiquette, and digital identity) [12].

Patients with CRC have reported an extensive and prolonged need for information and knowledge about their cancer diagnosis, treatments, and prospects [13]. The internet is an increasingly important source of health-related information for gaining increased knowledge and the ability to engage in health care decisions [14]. In Norway, 96% of the households have internet access; 95% of the population in all regions uses the internet daily; and, on average, there are nearly 8 devices with internet access per household [15]. A recent study on eHealth use among 18,500 Norwegians aged more than 40 years showed that nearly 53% of the participants had used an eHealth service during the last year and that eHealth use was positively influenced by younger age, being a woman, or having higher education or higher socioeconomic status [16]. Cancer patients have been found to use the internet for health information from the time of their diagnosis, and they continue to use it through their survivorship [17]. Issues for which cancer patients use the internet to gain information include cancer diagnosis, cancer treatment and side effects, health insurance and financial issues, and genetics and heritability [18]. Although many cancer patients consult web-based sources for health information, research shows that they use their oncologists or other relevant health care professionals (HCPs) as their primary source of information. This gives the HCP an opportunity to provide their patients with information on reliable websites [19].

The growing number of patients with CRC requires a more flexible and dynamic follow-up approach for curative CRC treatment [20]. To help meet support needs of patients with CRC during the vulnerable period in which they manage a changed life situation following a cancer diagnosis, eHealth interventions using smart applications may be one way forward [1]. Health information is an important feature of eHealth, and eHealth services are perceived as safe and reliable sources of health information [21]. eHealth is closely connected to social innovations, where digital solutions are developed in cocreation processes with end users such as patients and HCPs with the aim of creating new, improved, and efficient health care services [22]. The implementation of eHealth interventions is challenged by a gap between research-produced innovations and the actual use of such innovations in clinical practice [23]. To close the gap, cocreation processes are suggested in the design of eHealth applications to ensure that the end product will meet the needs of technology users and contribute to desired outcomes [24]. The aims of this study are to explore how patients with CRC, their informal caregivers, and HCPs with experience in CRC treatment and care relate to web-based health information and map out their thoughts on future eHealth services to improve self-management in CRC care.

The research questions developed were as follows:

1. What is the experience of patients, informal caregivers, and HCPs with information and communication technology (ICT) for CRC management?
2. How should eHealth services be designed, and which needs should they meet in supporting patients with CRC following primary surgical treatment?

Methods

Design

This was a qualitative, explorative study that used semistructured individual interviews [25] to explore experiences of ICT among patients with CRC, their informal caregivers, and HCPs. Data were collected on the use behaviors of ICT (eg, internet, smart apps, electronic medical journals) from the time of diagnosis, during surgical treatment and after hospital discharge, and on preferences and desired outcomes for future eHealth applications.

Ethical approval was provided by the National Committee for Research Ethics in the Social Sciences and Humanities (No. 2017/284) and by the university hospital research ethics board. All participants provided informed consent for participation in the study.

Eligibility and Recruitment

Eligible participants were adult patients (aged 18-80 years) diagnosed with CRC and surgically treated with curative intent and their adult informal caregivers, as appointed by the patient. In addition, the study recruited HCPs with more than 1 year of experience in CRC treatment and care in a surgical ward. All participants were required to understand and speak Norwegian.

Patients and their informal caregivers were recruited by a study nurse at a surgical outpatient clinic at a university hospital in Norway who provided them with oral and written information on the study purpose. A staff nurse at a gastroenterological surgical ward at the aforementioned university hospital recruited the HCPs. All the patients who were approached agreed to participate. Reasons for nonparticipation among informal caregivers and HCPs were not recorded. One HCP withdrew consent because of a changed work schedule.

A model of information power by Malterud et al [26] guided the total number of interviews, indicating a narrow study aim: participants experienced with CRC treatment and care, a strong dialog during interviews, clear theoretical underpinnings, and an appropriate thematic analysis.

Data Collection

Data collection was carried out as part of a larger interview study on the transition from hospital to home and the follow-up needs of patients with CRC. Single interviews with patients were carried out at the location of their preference, either in office facilities at the university hospital, at the university, or in the homes of patients. One of the interviews with informal caregivers was carried out at the university hospital, another in an informal caregiver's home, and the rest by telephone. Interviews with HCPs were conducted at suitable locations in the university hospital. The interviews with patients, HCPs, and 2 of the informal caregivers were conducted by the author (AMLH), who is a nurse and associate professor (PhD) experienced in qualitative research. A professor of nursing experienced in qualitative research performed the majority of the interviews with informal caregivers. Both interviewers have research experience in the field of chronic and long-term illness and eHealth. A semistructured interview guide was used to guide the interviews, and the themes on eHealth and digital competence were informed by earlier research on digital information technology in a cancer survivorship context [13,17-20] (Textbox 1). The interviewer used follow-up questions, such as "Have I understood you correctly when you say...?" to confirm the interviewees' answers. The interview guide was pilot-tested by a patient together with an informal caregiver and an HCP.

Textbox 1. Interview guide.

Colorectal cancer patients and informal caregivers—use of social media and information technology

- What experience do you have of the use of technology such as mobile phones, tablets, PCs?
- Have you accessed websites or eHealth applications during the time of diagnosis or before or after surgical treatment, for example, an app on your mobile or social media?
- What type of health information do you envisage obtaining through internet sources or applications?
- What should such an eHealth service look like, and how should it function to support your self-management and information needs? Who would you like to be able to communicate with via an eHealth service (eg, other patients, relatives, your general practitioner, hospital personnel, support groups)?
- If you use information and communication technology, how do you use these to support your relative or spouse in self-management of illness and follow-up of treatment? (informal caregivers only)

Health care professionals—technological information support

- What is your impression of where patients obtain information related to illness and treatment?
- What is your impression of patients' use of social media as support in disease management and follow-up of treatment?
- What benefit do you think patients gain from using social media?
- What type of health information do you envisage the patient receiving through an eHealth solution?
- What should such a technological aid look like, how should it function, and what features should be included?

Data collection continued until no new data emerged within each of the 3 study populations.

The interviews lasted for a total 35 to 90 minutes. The telephone interviews lasted shorter than face-to-face interviews. All interviews were audiotaped and transcribed verbatim by a health care secretary experienced in transcription for research purposes. To preserve anonymity, any information that might reveal a participant's identity was removed during transcription. A total of 23,913 words were transcribed from interviews on eHealth and digital competence. The transcripts were uploaded to NVivo software (QSR International) [27].

Data Analysis

A stepwise systematic text condensation guided the data analysis [28]. First, the transcripts were read repeatedly and comprehensively to gain an overall first impression and identify the preliminary themes. Second, deductive coding of meaning units (participants' quotes) within each of the preliminary themes was performed. The deductive coding was based on an earlier work on eHealth concept development [1] and research on eHealth within cancer populations [13,17-20]. Third, the codes were sorted into categories, which formed the final main themes in the fourth step. The transcripts from each interview were arranged in 3 clusters (ie, HCPs, patients, and informal caregivers), and the clusters were then merged during coding in NVivo.

To achieve trustworthy results, the same researcher involved in the informal caregiver interviews validated the data analysis by reading a sample of the transcripts and coded data material. In an analysis meeting between the author and researcher, the categorization into final themes continued until agreement was reached.

Stepwise data analysis is shown in Multimedia Appendix 1. Findings constituting the 3 main themes derived from the data, *Seeking health information*, *Factors affecting the use of information technology*, and *Future eHealth services for colorectal patients*, with corresponding subthemes, are presented later. Participants' quotes are provided to add documentary and aesthetic value to the findings [29].

Results

Participants

The study comprised a total of 31 participants: 41% (13/31) patients surgically treated for CRC, 29% (9/31) informal caregivers, and 29% (9/31) HCPs. The median ages were 65 years for patients (range 46-79 years), 68 years for informal caregivers (range 43-77 years), and 33 years for HCPs (range 22-52 years). The majority of the participants were women, with 4 being patients, 6 informal caregivers, and 7 HCPs. A total of 8 patients were diagnosed with colon cancer, whereas 5 were diagnosed with rectal cancer. Among the informal caregivers, 8 were spouses and 1 was an adult offspring. All but one informal caregiver lived with the patient. Information on reimbursement paid informal caregivers was not collected. The majority of HCPs were nurses (n=7). A total of 5 HCPs had 1 to 3 years of work experience in CRC treatment and care, whereas 4 had over 3 years of experience. Participants' characteristics are presented in Table 1.

Table 1. Characteristics of the study sample (N=31).

Characteristic	Participants		
	CRC[a] patients (n=13)	Informal caregivers (n=9)	HCP[b] (n=9)
Age (years), range	46-79	43-77	22-52
Sex, n (%)			
Male	9 (69)	3 (33)	2 (22)
Female	4 (30)	6 (66)	7 (77)
Diagnosis, n (%)		N/A[c]	N/A
Colon cancer	8 (61)		
Rectal cancer	5 (38)		
Educational status of patients and informal caregivers, n (%)			N/A
Primary school	3 (23)	1 (11)	
High school	4 (30)	5 (55)	
College or university	6 (46)	2 (22)	
Missing	N/A	1 (11)	
Informal caregiver relation, n (%)			N/A
Spouse	N/A	8 (88)	
Adult child	N/A	1 (11)	
Employment status of patients and informal caregivers, n (%)			N/A
Employed full time	2 (15)	3 (33)	
Employed part time	2 (15)	1 (11)	
Retired	7 (53)	2 (22)	
Disability support	N/A	2 (22)	
Sick leave	2 (15)	N/A	
Missing	N/A	1 (11)	
Health care profession, n (%)	N/A	N/A	
Nurse			7 (77)
Surgeon			2 (22)
Work experience in CRC treatment and care (years), n (%)	N/A	N/A	
1-3			5 (55)
4-7			2 (22)
>10			2 (22)

[a] CRC: colorectal cancer.

[b] HCP: health care professionals.

[c] N/A: not applicable.

Seeking Health Information

The first theme concerns *health information sources* and *using the internet to access health information*.

The patients and informal caregivers obtained information on illness and treatment from several different sources. One of the main sources was written information provided during hospitalization and at discharge. Both patients and informal caregivers preferred speaking to HCPs about their concerns and needs, especially the coordinator for the cancer treatment pathway, who followed up the patients throughout diagnosis and treatment:

> *They said if there is anything you wonder about, some questions, please call us! We have a contact person and a telephone number directly to the ward. Then we feel safe.* [Informal caregiver, Interview 5]

Some of the patients stated that turning to *a real person* for information was preferable for getting the message across and avoiding misunderstandings:

> *We must not replace the human factor with those smartphones. That makes me worried! I value a phone number much more than a URL... [Smiling] Gosh, now I feel old!* [Patient, Interview 10]

The patients were divided in their perceptions about using the internet to access health-related information about their cancer diagnosis and treatment. One of the patients said enthusiastically that it was her responsibility to keep herself informed and described how she used the internet to gain knowledge:

> *I think it is important. I google. Now I google a lot on cancer markers. I should know something about it, since it's very new to me. I use the iPhone for everything. Read journals, read about the epicrisis, and retrieved information from them. I think it's the right way to go, very important, so let's talk about it!* [Patient, Interview 2]

Other patients were skeptical about searching for web-based information and about what they read on the internet. "Everyone is a google-doctor these days!" one patient said. Patients feared that the uncritical use of internet sources to access health information might lead to health anxiety. When asked if he used the internet to access health information, one patient answered:

> *No! For the simple reason that there is so much on that internet, you'll get sick just from reading it. I try to relate to the information I get from the hospital and my GP, easy and simple! If you start reading...before you know it, you'll have one foot in the grave. I'm sorry, but I'm against it.* [Patient, Interview 10]

Several patients and informal caregivers said that they searched for health information on a need-to-know basis, claiming that it was not in their interest to search for more information. Others became inclined to distance themselves from the cancer diagnosis as soon as they had their tumor surgically removed. In the HCP's view, the patients' need to search for web-based information was, in many cases, determined by diagnosis and the outcome of the surgical treatment:

> *After receiving information from us, the vast majority of our patients go home thinking that they are healed. It is a positive cancer group we work with. They are so super ready to get well! "Get it out of my body, I want it to be gone!" Then they hope it's gone, and for many of them, the cancer is gone.* [HCP, interview 2]
>
> *The idea is that once you have removed a cancerous tumour, you should be able to be yourself again.* [HCP, Interview 4]

Factors Affecting the Use of Information Technology

The second theme is made up of the following 3 categories: *The age dimension*, *Lack of digital competence*, and *Support to find relevant information*. The participants talked about several factors that might contribute to patients' and informal caregivers' actual use of eHealth solutions, and the age factor was mentioned by nearly all the participants. HCPs shared stories of how the patients, young and old, brought their smartphones and tablets to the hospital and used them to google symptoms or manage medical appointments. The majority of comments referred to old age as preventing patients and informal caregivers from using the technology. Although some pointed toward an emerging digital era within health care services, a generational change was thought necessary before one would see an increase in the use of eHealth:

> *We're in a transition phase. Eventually, those who are older...they do not even know what Facebook is, but in 10 years' time the situation will be different, everyone will have Facebook then, and will know how to use a computer.* [HCP, Interview 3]

This opinion was shared by patients who claimed that they were probably the last generation not to use ICT. Not all respondents thought of old age as an inhibiting factor for technology use, but they highlighted a lack of technology experience and low digital competence as possibly greater contributing factors:

> *To get hold of digital information is fine for me, but among my own age group, there has been a complaint that you do not get the pension on paper anymore. We are probably in a transition period where a generation is dying out in which some people have had jobs where technology has not been so prominent, and then we have the new generations to come. When our generation is gone, I think everything can go digital.* [Patient, Interview 2]

A second factor highlighted by participants was how lack of experience and interest in information technology may affect behavior and habits in the use of web-based health information. Some of the patients and informal caregivers expressed no interest in using the internet to access health information and were satisfied with more traditional information sources, such as written and oral information provided by the cancer pathway coordinator, the surgeon, or their general practitioner (GP). They also expressed uncertainty and concern about having to answer questions about cookies and how to get past them:

> *And it often pops up, like...ehh..."accept", right? Then I do not always know what it is, so I do nothing. Is there something to accept? Does it matter, the cookie stuff?* [Patient, Interview 1]

Patients also shared stories of having been more or less forced into using ICT through work, by eager children or grandchildren, or by the digitalization of welfare services:

> *I had to. I have not been interested in it, but then I had to. Banks, bills, things like that. So, I felt I had to.* [Patient, Interview 9]

Some patients spoke of how the introduction of technology in the work context gave them valuable experience of information technology, which would help them become informed patients:

> *I was lucky and was part of a workplace where we got computers in the 80s. It has been the key to success. If you are involved in systems and are willing to change, then you will succeed.* [Patient, Interview 6]

None of the patients or informal caregivers had received advice from their HCP on the secure use of the internet to access health information, and only a few reported having been asked by their HCP whether they had accessed the internet for information related to the CRC and treatment before hospitalization. One of the informal caregivers said:

> *They [the HCP] probably thought he was too old, so it was never mentioned.* [Informal caregiver, Interview 7]

One patient was advised by an HCP not to search too much for web-based health information, whereas another expressed the need for guidance on secure web pages outside the patient information platforms:

> *It would have been very helpful, because you spend a lot of time searching for information you trust. Okay, you have the patient information platform where you can find the information that is about you, but otherwise, no!* [Patient, Interview 6]

HCPs found that many patients asked for information on how to log on to the internet. As a result, written login-information was included as part of the pretreatment information at admission. In general, the lack of guidance on accessing web-based health information was confirmed by the HCPs:

> *I think they (the patients) google a bit, but I have not asked them specifically if they have actually searched for information about the disease.* [HCP, Interview 1]

Future eHealth Services for Patients With CRC

This theme comprises the categories *Content of health services*, *eHealth service quality*, *User interface (UI) of the service*, and *Delivering eHealth*. Thoughts on the content and functions of future eHealth services in CRC care were mainly expressed by patients and HCPs.

They explained how patients worry in the presurgical phase, and was suggested that comprehensive information on CRC and its treatments should be available not only to manage symptoms and bodily changes following hospital discharge but also to prepare for surgery:

> *I often use pictures to describe what we (surgeons) do. It could just as easily have been animated; I think. They could watch a 10-minute film clip...And something about follow-up, what is the usual follow-up with hospital checks, a little about wound treatment. There are probably many who wonder...when can I have a shower, (how to) keep the wound dry, how long should the staples or the stitches be left in? When to remove these strips, and stuff like that. When to contact a doctor? In terms of infection, what is common?* [HCP, Interview 9]

Presurgical worry was confirmed by several of the patients who said they had many questions and did not know what to expect:

> *I think it would be great if it [the eHealth application] contained everything the doctors explain, in different ways. What are the steps, what are the expectations, what can happen, how can you contribute yourself, what are the risks? If you get an infection, what then? Everything we've talked about could be in it.* [Patient, Interview 6]

Several patients and HCPs proposed that an eHealth service could contain lifestyle advice on matters such as diet and physical activity and how to deal with family matters, especially for patients with small children. Informal caregivers expressed the need for information on how to help the patient recover, be able to ask questions, and get an answer from an HCP:

> *Let's say you could send a message or an email to the doctor, and you could get an answer, not necessarily the same day, but say in a few days, it would be absolutely fantastic!* [Informal caregiver, Interview 3]

One of the HCPs explained how a chat function using an avatar could be designed:

> *You could actually enter the chat, down there. Then a face of a person comes up...who you chat with, and then you can write your question, there and then.* [HCP]

Some participants suggested using chat functions as a way of getting emotional support and ventilating frustration and anxiety. One HCP explained how she often facilitated conversations between patients and support personnel, such as the hospital chaplain, and how digital chat function might provide support from professional informal caregivers following hospital discharge:

> *In the weeks following surgery, I think there is a lot of pondering among patients. So, somewhere they could to talk to another person and not clam up...Someone who can share their burden.* [HCP, Interview 3]

Regarding the management of illness and follow-up treatment at home, the participants proposed service functions that might ease the transition from in-patient to home. They suggested the use of checklists and patient cases or patient histories to monitor their health condition and obtain advice on how to deal with symptoms:

> *They could make [patient] cases. Then you could enter your own symptoms, like that and like that, and then it [the advice] would come up.* [Patient, Interview 7]
>
> *As a rule, they need a checklist. What should one really be aware of? The skin around the ostomy for example, or "How much have I had to drink today? Because now I've been admitted with dehydration again." Or "What is really normal when it comes to ileostomy or colon ostomy output?" Yes, a checklist could have been helpful.* [HCP, Interview 5]

Both patients and HCPs suggested that reminders by SMS be included in the eHealth service to help with the administration of medical appointments. One patient said there was a need for a reminder function related to the 5-year follow-up plan, providing the time and place of the appointment, coordinated with the general practitioners' appointments, required blood tests, and computerized tomography scanning. This idea was supported by HCPs:

> *I think there are many good things about it [an eHealth follow-up service], such as a text message notification about your medical appointments. I think it is very good. A lot of people feel stressed about it: "When is it?" "Where did I put the note?" "Were there any changes?" Then you get a reminder a day or two before the appointment. I think it seems very safe and good, so it's nice stuff!* [HCP, Interview 3]

The participants were concerned with the quality and relevance of eHealth service functions. Information on cancer illness and treatments had to be easily perceived and updated to be acknowledged as relevant. In the HCP's experience, patients read and perceived the information they received very literally; so, the information had to be relevant and up to date. Otherwise, the patients would perceive the information as incorrect or contradictory and would become frustrated and confused. Some of the HCPs experienced information provision as complex:

> *When we inform, it is a little generous maybe, with good intentions. It is difficult to get things detailed enough, and at the same time, sufficiently universal.* [HCP, Interview 3]

This was confirmed by one of the patients, who experienced difficulty in the fact that different treatments required different information:

> *Before the operation, there were many questions. Of course, that app could contain some facts. But again, some people have large parts of their intestine removed, others only a piece. How much should they [HCP] write? To write something that will capture everyone's experience, you have to write in general terms. Otherwise, you have to write in detail about lots of different things, and people will be confused as to what applies to them and what does not apply to them.* [Patient, Interview 5]

The UI of an eHealth service raised some concerns among the participants as to whether the application should be accessed through smartphones, tablets, or computers or connected to an existing public eHealth platform. They highlighted the importance of considering how most people used digital devices, that the UI requirements should be adapted to the user's digital competence and skills, and that not all patients would benefit equally from an eHealth service:

> *I think an app will be easiest for most people, considering that most people have a smartphone or a tablet.* [Patient, interview 2]

> *I imagine they have to have their own tablet. Or should there be something lying on each bedside table? Should there be apps for mobiles? Yes, most people have fancy phones, but then you have those who do not. Should you have a paper version for some people? I don't know, actually, but it's an interesting question. We live in a technological world.* [HCP, Interview 2]

In the final category, the HCP wondered whether an eHealth service provided by professionals in the specialist health care service would be too time consuming. In their view, including an eHealth service in a busy clinical practice might turn out to be too demanding to manage. They suggested that future eHealth services could benefit from having dedicated personnel to deliver the service.

Discussion

Principal Findings

The primary aim of this study is to explore the views of patients with CRC, their informal caregivers, and HCPs on ICT for CRC management and their thoughts on future eHealth services for supporting patients and informal caregivers through the CRC treatment pathway and follow-up. Overall, the participants of this study contributed to an increased understanding of digital information for health and highlighted the important aspects to be considered when designing eHealth services for patients treated for CRC and their informal caregivers. The first overarching theme demonstrated the web-based information-seeking behavior of patients and informal caregivers and how it may depend on individual characteristics (eg, age, digital competence), the ability or inclination to trust web-based health information, and whether HCPs facilitate the use of web-based resources to gain knowledge about the cancer diagnosis and its treatment. These conditions appear to be intertwined and must be seen in relation to each other, in the sense that lack of digital competence and guidance on how to use the internet to find health-related information can create uncertainty regarding the quality and relevance of the information, leading one to question whether one can trust the information and its source. Trustworthiness in seeking web-based health information was found to rely on the expertise of the website authors; the quality of information; and the patient's age, sex, and perceived health status [30].

The second theme identified relevant content for a future eHealth service, not only to support patients' self-management after surgery but also in the presurgical phase to ameliorate presurgical worry. The delivery of relevant health information through a patient's eHealth service may provide the patient with the level of health literacy needed to prepare for treatment, engage in discussions with the HCP on treatment options, and conduct necessary self-management at home after surgery [31]. Thus, this study suggests that an eHealth service for patients with CRC might be introduced to the patient early in the treatment pathway, preferably before primary surgery. Adequate cancer care relies on available information, and HCPs are encouraged to provide their patients with access to web-based information sources as a complement to oral and written information [32]. To achieve this, the HCP needs to have the necessary skills and resources to access relevant web-based health information [33].

The participants suggested a range of features for an eHealth service that could meet the support needs of patients with CRC and informal caregivers. The desired features proposed by the participants included communicable elements, such as a chat function to meet the patient's need for multifaceted informational support for their medical condition and emotional support to cope with the cancer diagnosis. Findings from the second theme also recommend the development of eHealth services with high acceptability and an appropriate UI. The current extensive use of smartphones and tablets among hospitalized patients was confirmed by the interviewees and provides the context for choosing interfaces for eHealth services. In 2017, approximately 342 million people were registered as mobile phone users in Western Europe [34]. This opens up a new scenario for eHealth designers. A design that focuses on user-friendliness, is intuitive, and provides accurate and easily accessible information will be required by future users of eHealth services [35]. This study was performed in a country with high internet access and use [15], a social good not available to everyone in a global context. In the *2030 Agenda for Sustainable Development*, the United Nations made “universal and affordable access to the Internet in the least developed countries by 2020” as one of their development goals [36]. Successful goal achievement may increase the uptake and use of smartphones and facilitate active interest in personal health care [37].

Comparison With Prior Work

Finding, accessing, and understanding the required health information are among the self-management tasks that cancer patients associate with a negative impact on their daily life and well-being [38]. Age was described as a contributing factor in the use of the internet to find health information. Younger age can be a benefit for internet use [16], and a recent study of 9005 chronically ill individuals confirms that the use of digital information technologies to obtain health information declines with age [38]. Regarding patients with CRC, Wieldraaijer et al [13] found that younger patients (<65 years) searched for health information themselves more often than older patients who usually consulted their HCPs more. Although older users of ICT should be considered a heterogeneous group [39], HCPs are encouraged to provide both instrumental and social support to engage older cancer patients in accessing and using internet-based health information, such as individually tailored education and training, and facilitate the use of health technology [38].

The findings on the design of eHealth services to support patients with CRC highlight that technology acceptance and usefulness are important aspects to consider and that variations in user acceptance and engagement can be expected. Nadal et al [40] proposed a continuum of mobile health technology acceptance to be applied in the health domain, where the individual moves through pre- and postadoption phases of technology. The participants in this study reported high availability of mobile devices among patients with CRC. This finding suggests an increased familiarity with mobile phone use among patients with CRC to access digital health apps, which may be an advantage when introducing mobile health to patients, where one can expect most patients to have moved past the perceived ease-of-use phase of the technology acceptance cycle [40].

The second overarching theme reveals the content of remote eHealth services that the stakeholders find supportive and useful, not only following surgical treatment but also in the presurgical phase. Presurgical worry was reported by the majority of the participants as an issue to be targeted using eHealth. This finding supports earlier research findings that eHealth is useful not only for postsurgical follow-up but also throughout the CRC trajectory. Chapman et al [41] suggested that patients with CRC benefit from presurgical information and education delivered by smartphones and tablets, which are found to improve QoL and mental health.

Furthermore, this study shows that patients and informal caregivers are in need of contact with health care specialists following discharge for the patient to recover well and to engage in the recovery process by self-monitoring and taking action for health improvement. Our findings suggest that future CRC eHealth services may be offered to patients at discharge to facilitate communication with HCPs in the early stages of recovery. Drott et al [9] showed that patients with CRC experienced increased engagement in self-management by using smartphones to communicate treatment side effects to clinicians. On the other hand, this study reveals that from the HCP’s point of view, a follow-up eHealth service offered for CRC at discharge would be too time consuming. As a result of the social distancing required by the COVID-19 pandemic, eHealth solutions (eg, video consultations) have been increasingly used in specialist health care services [42] and may represent a changed view of the use of technology in health care delivery. In designing future eHealth solutions, it is important to consider both patients and HCP as users of the technology and involve them in discussions regarding the area of use and service delivery.

The strengths of this study include a multiple-perspective approach to data collection and the use of a validated data analysis framework [28]. A range of eHealth application features were proposed by the participants, which provide valuable input into the design of future eHealth services. Targeting the needs of end users before introducing them to the technology is crucial for ensuring high levels of usability and user satisfaction [24]. The use of a purposive sampling technique secured participant samples rich in information on CRC treatment and care and living with CRC [43]. A continuous evaluation of sample size adequacy was applied during data collection, following Malterud et al [26] model of information power.

Limitations

This study has some limitations. This study involved only one study site. Recruiting from multiple study sites might have resulted in a more varied participant sample, ensuring the generalizability and external validity of the findings [44]. The majority of HCPs were women and nurses. Future research may benefit from a more balanced HCP sample with regard to sex and work profession. For practical reasons, most informal caregivers were interviewed by telephone, which may have yielded less rich data from this sample. Although telephonic interviews may create a bias resulting in loss of data and lower quality of findings, they may also save resources and provide access to geographically disparate participants, as shown in this study [45]. The study was performed in a context dominated by high internet access and use; thus, the study findings may not be generalizable to regions with low internet access.

Conclusions

This study shows that the increasing use of the internet to manage serious illnesses and treatments, digitalization of health care services, and engagement of stakeholders (ie, patients with CRC, informal caregivers, and HCP). Several elements come into play and affect the health-information-seeking behavior of patients with CRC and their informal caregivers. Age and lower digital competence may hinder the patients from accessing web-based health information. HCPs report a shift in the approach of patients with CRC to gaining health information through web-based channels, but patients are seldom guided toward accessing web-based health information that is trustworthy and of high quality. An eHealth service for patients with CRC may comprise elements of information, education, and support for self-management of pre- and postsurgical treatment and should be adapted to the patient’s age and digital competence. Cocreation of eHealth services with stakeholders is recommended to ensure tailored services of high quality that are perceived as user friendly and valuable by end users.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Display of data analysis according to systematic text condensation steps 1 to 4.
[DOCX File , 15 KB - cancer_v7i3e28279_app1.docx]

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Abbreviations

CRC: colorectal cancer
HCP: health care professional
ICT: information and communication technology
QoL: quality of life
UI: user interface

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Original Paper

Gaps in Public Awareness About BRCA and Genetic Testing in Prostate Cancer: Social Media Landscape Analysis

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Abstract

Background: Genetic testing, particularly for *BRCA1/2*, is increasingly important in prostate cancer (PCa) care, with impact on PCa management and hereditary cancer risk. However, the extent of public awareness and online discourse on social media is unknown, and presents opportunities to identify gaps and enhance population awareness and uptake of advances in PCa precision medicine.

Objective: The objective of this study was to characterize activity and engagement across multiple social media platforms (Twitter, Facebook, and YouTube) regarding *BRCA* and genetic testing for PCa compared with breast cancer, which has a long history of public awareness, advocacy, and prominent social media presence.

Methods: The Symplur Signals online analytics platform was used to obtain metrics for tweets about (1) #BRCA and #breastcancer, (2) #BRCA and #prostatecancer, (3) #genetictesting and #breastcancer, and (4) #genetictesting and #prostatecancer from 2016 to 2020. We examined the total number of tweets, users, and reach for each hashtag, and performed content analysis for a subset of tweets. Facebook and YouTube were queried using analogous search terms, and engagement metrics were calculated.

Results: During a 5-year period, there were 10,005 tweets for #BRCA and #breastcancer, versus 1008 tweets about #BRCA and #prostatecancer. There were also more tweets about #genetictesting and #breastcancer (n=1748), compared with #genetic testing and #prostatecancer (n=328). Tweets about genetic testing (12,921,954) and *BRCA* (75,724,795) in breast cancer also had substantially greater reach than those about PCa (1,463,777 and 4,849,905, respectively). Facebook *groups* and *pages* regarding PCa and *BRCA*/genetic testing had fewer average members, new members, and new posts, as well as fewer likes and followers, compared with breast cancer. Facebook *videos* had more engagement than YouTube videos across both PCa and breast cancer content.

Conclusions: There is substantially less social media engagement about *BRCA* and genetic testing in PCa compared with breast cancer. This landscape analysis provides insights into strategies for leveraging social media platforms to increase public awareness about PCa germline testing, including use of Facebook to share video content and Twitter for discussions with health professionals.

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KEYWORDS

genetic testing; BRCA; prostate cancer; breast cancer; social media; infodemiology

Introduction

Genetic testing, particularly for *BRCA1* and *BRCA2*, has an increasing role in prostate cancer (PCa) management, screening, and hereditary cancer risk assessment [1-4]. Up to 12%-15% of metastatic disease and 5%-7% of early stage disease involve inherited genetic mutations in cancer risk genes [5,6]. PCa is the leading cancer diagnosed in US men, and inherited PCa impacts thousands of men [7]. Furthermore, hereditary cancer has important implications for family members, informing additional cancer risks and screening measures. Importantly, recommendations for PCa genetic testing have significantly expanded to include a large subset of men with or at risk for PCa [1,3,4]. For men with metastatic, castration-resistant PCa who carry *BRCA* mutations, the FDA has approved 2 poly-ADP ribose polymerase (PARP) inhibitors as targeted therapy after progression on standard therapy [8-10]. *BRCA* mutation status is also included in guidelines for PCa screening [4], and men with *BRCA2* mutations have more reclassification during active surveillance for favorable-risk disease [11].

Despite the importance of genetic factors in PCa management and hereditary cancer risk, the extent of public awareness is unclear. Previous studies have shown that public awareness and social media discourse are substantially greater for breast cancer compared with PCa [12,13]; however, these studies did not investigate discussions about genetics. Breast cancer is the leading cancer diagnosis among US women [7], and is a useful comparator for PCa because both can be inherited, and genetic mutations in *BRCA1/2* also affect screening and treatment recommendations in breast cancer [4,14].

As much as 3 in 4 US adults use 1 or more social media sites [15]. People increasingly use social media to look for health information, share their experiences, and communicate with others, which ultimately impacts their health beliefs and behaviors [16-18]. Social media provides unique insights into how people talk about, behave, and look for an array of health topics. These data have been used to inform prevention programming and messaging, and to scale-up prevention efforts and increase reach [19,20].

This topic is important, as recent data suggest that germline testing is underutilized in PCa [21], and that participating in social networks influences clinical decision making and health behaviors among patients with PCa [22]. From prevention, to treatment, to survivorship, social media provides an important space for communities and the general public to learn and share information about cancer and cancer prevention [20,23-25].

Our objective was to examine the current social media landscape regarding *BRCA* and genetic testing in PCa relative to breast cancer to provide insights into public awareness and inform strategies to enhance dissemination.

Methods

We characterized activity and engagement across multiple social media platforms (Twitter, Facebook, and YouTube) regarding *BRCA* and #genetictesting for PCa compared with breast cancer.

Twitter

The Symplur Signals platform was used to examine analytics for all tweets between 2016 and 2020 with the hashtags (1) #BRCA AND #breastcancer, (2) #BRCA AND #prostatecancer, (3) #genetictesting AND #breastcancer, and (4) #genetictesting AND #prostatecancer. We calculated the total number of tweets, users, and impressions (ie, potential accounts reached).

To further characterize the content and contributors, in June 2019, we exported all unique 2018 tweets for each hashtag and manually coded all PCa tweets due to the smaller sample size, a random 10% sample about #breastcancer #BRCA, and a random 50% sample about #breastcancer #genetictesting. A codebook was created through team consensus, based on our previous work [26]. Perceived race/ethnicity was coded by team consensus, as in prior studies [27]. Misinformation was assessed in comparison to guidelines and published literature [28]. The codebook was tested in a random sample with checks to verify intercoder variability and refined by the study team. Disagreements about codes were resolved by consensus.

Facebook

From March to April 2020, we searched Facebook using the same 4 terms. To mitigate bias associated with Facebook's user-centric search function, we cleared and unlinked prior account information [29]. The first 40 results for each term were examined. The Facebook search included the categories "Groups," "Pages," and "Videos." We excluded duplicates and unrelated results.

We examined public metadata for Facebook groups, pages, and videos. For groups, we examined average number of members, average number of new posts and members within 30 days, and public versus private. For pages, we examined average followers, like counts, and date of page creation. For groups and pages, we analyzed their primary focus based on the provided descriptions, including awareness, support, treatment, research, and news (not mutually exclusive). For public Facebook videos, we counted average views, likes, and comments at the time of collection.

YouTube

From March to April 2020, we searched YouTube using the same 4 terms as above after clearing account history, and examined the first 40 results for each. We excluded duplicates and unrelated results. We counted average views, likes, and comments at the time of collection. We standardized likes per video, views, and engagement rates.

Statistical Analysis

Both PCa search terms were combined and compared with breast cancer terms. Summary statistics and 95% confidence intervals were calculated using SAS (SAS Institute) and Stata/IC 16 (StataCorp).

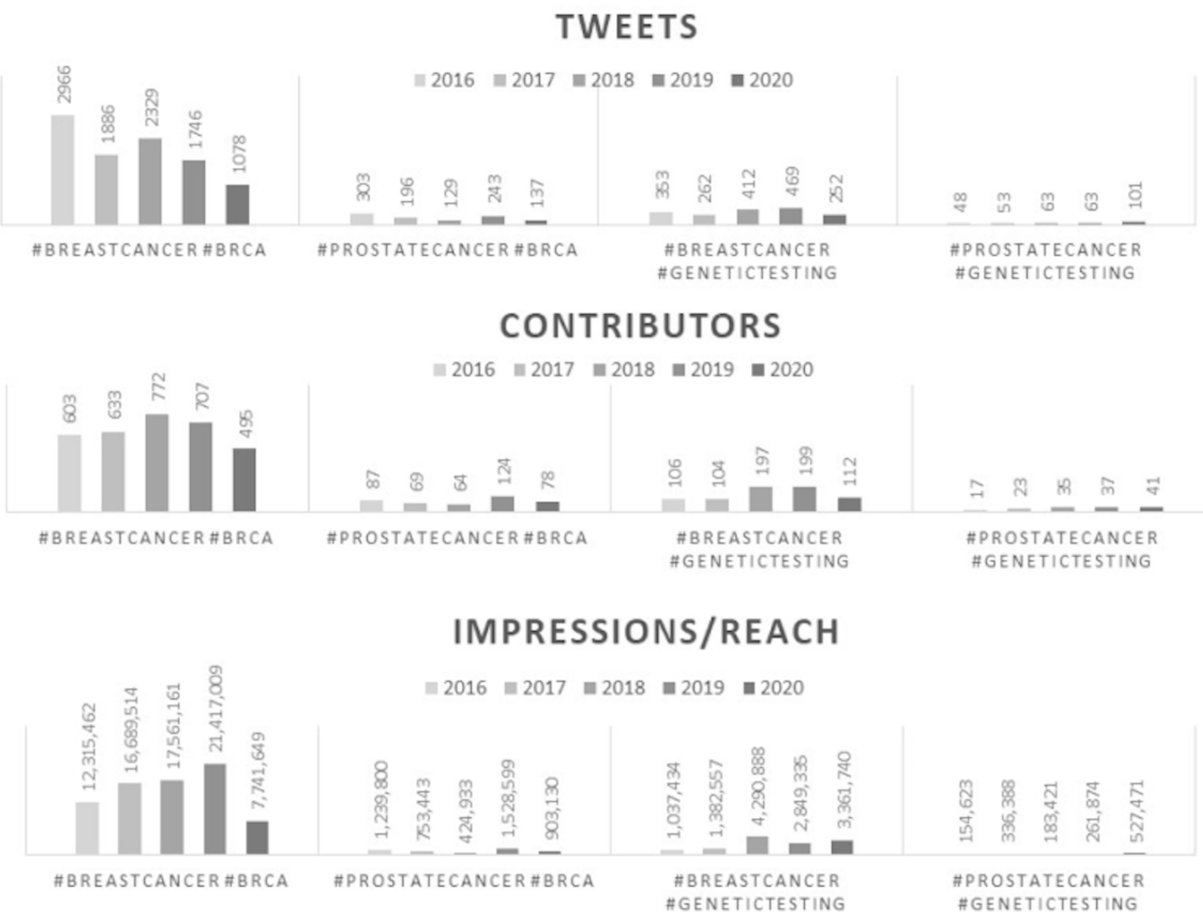
Results

Twitter

From 2016 to 2020, in PCa and breast cancer there were 1008 and 10,005 tweets about *BRCA*, and 328 and 1748 tweets about genetic testing, respectively (see Figure 1 for trend over time). Users and reach were also substantially higher for *BRCA* and genetic testing in breast cancer relative to PCa throughout 5-year period.

Coding of a subset of Tweets is shown in Multimedia Appendix 1. The most common type of post was sharing an article link. Sentiment was mostly neutral. Misinformation was rare. Gender was mentioned more often than race. For tweets about *BRCA*, the most common tweeters were foundations/advocacy groups followed by health professionals, whereas for tweets about genetic testing, foundations/advocacy groups and commercial entities were the most common. Among individual Twitter contributors, most were perceived as White and female for all topics except PCa genetic testing for which the largest number of users were perceived as White males.

Figure 1. Comparison of Tweets, Contributors, and Impressions/Reach for BRCA and Genetic Testing in Breast Cancer versus Prostate Cancer (2016-2020).



Facebook Groups and Pages

Table 1 shows results for 73 Facebook groups and 80 Facebook pages. PCa groups had fewer average members than breast cancer groups. This was consistent with other variables including average number of posts and members in the past 30 days. For Facebook pages, breast cancer pages had higher followers and likes than PCa. Among PCa and breast cancer groups and pages, most focused on awareness, support, and treatment (Multimedia Appendix 2).

Table 1. Analysis of Facebook groups and pages comparing prostate and breast cancer in March 2020 (n=153).

Facebook feature	Prostate cancer *BRCA*/genetic testing[a]	Breast cancer *BRCA*/genetic testing[a]
Groups (n=73)		
Total posts	35	38
Average members (range)	1744 (36-13,767)	4203 (58-16,863)
Average posts in the past 30 days (range)	198 (0-2816)	451 (3-2777)
Average new members in the past 30 days (range)	61 (0-527)	117 (0-992)
Public, n/N (%)	5/35 (14)	6/38 (16)
Created range	2006-2019	2007-2019
Pages (n=80)		
Total posts	40	40
Average followers (range)	17,215 (13-225,550)	151,858 (6-5,079,917)
Average likes (range)	17,422 (13-231,855)	174,785 (6-5,989,522)
Created range	2008-2019	2007-2019

[a] First 40 search results included from each category; Facebook groups/pages within categories are mutually exclusive.

Facebook and YouTube Videos

Among 230 videos analyzed (Table 2), Facebook videos exhibited higher view counts and more comments. Average likes per view for PCa videos on Facebook were similar to that of YouTube, while breast cancer had more likes per view on Facebook than YouTube. Engagement rate for PCa was slightly higher on YouTube, whereas for breast cancer it was higher on Facebook.

Table 2. Comparing Facebook and YouTube video characteristics by means and 95% confidence intervals, March-April 2020.

Characteristics	Prostate cancer *BRCA*/genetic testing (n=119)		Breast cancer *BRCA*/genetic testing (n=111)	
	Facebook (n=58)	YouTube (n=61)	Facebook (n=66)	YouTube (n=45)
Views	22,595 (4530-40,659)	282 (203-360)	22,169 (4529-40,162)	3,250 (1467-5033)
Likes	204 (42-366)	3 (2-4)	227 (75-379)	13 (7-19)
Comments	29.4 (9.9-49.0)	0.2 (0.1-0.3)	17.8 (5.4-30.3)	0.5 (0.2-0.8)
Likes per view	0.018 (0.011-0.024)	0.012 (0.009-0.015)	0.026 (0.013-0.039)	0.005 (0.004-0.007)
Engagement rate[a]	1.90 (1.29-2.51)	1.31 (0.94-1.68)	2.77 (1.47-4.07)	0.58 (0.43-0.72)
Video length, mm:ss	6:28 (2:33-10:23)	10:14 (6:42-13:47)	3:17 (2:25-4:10)	7:16 (3:23-11:09)

[a] Engagement rate is the addition of number of likes, dislikes, and comments divided by the total number of views multiplied by 100. Videos within are mutually exclusive.

Discussion

Our results show substantial discussion about *BRCA* and genetic testing on popular social networks, although with more participation and engagement for breast cancer than PCa. This corroborates previous studies showing that PCa in general has less social media engagement [12,13], and raises less funding through crowdfunding than breast cancer [30]. Since PCa germline testing guidelines have expanded [3,4], thousands of men are eligible for testing, which may inform management and hereditary cancer risk. As the majority of adults look online for health information and social media use among older adults continues to rise [15,31], a lack of social discourse about PCa and genetic testing may hinder men from knowing that this option is available.

Our results raise concern for modest social media activity and participation, and lack of public awareness about the importance of PCa germline testing; follow-up studies are needed to determine whether this is hindering the impact of genetic advances. Future research is also warranted to draw from the greater social media experience in breast cancer, and to examine the potential for targeted social media campaigns to increase awareness and uptake of genetic evaluation for PCa.

A positive finding of the study was the minimal presence of misinformation on Twitter related to genetic testing and *BRCA* in breast cancer or PCa. This is in stark contrast to previous studies suggesting a substantial amount of misinformation about PCa on other social networks such as YouTube [28]. A possible explanation was the high proportion of tweets from health care professionals and foundations.

A limitation of this study is that only a subset of social media platforms and posts including these specific hashtags/search terms was evaluated. Additionally, coding of certain variables, such as perceived gender and race/ethnicity, is inherently subjective. Strengths include the first landscape analysis of social media activity related to *BRCA* and genetic testing in PCa, compared with breast cancer. These data are useful to inform public awareness strategies. Although YouTube is the largest overall video-sharing network, we found that videos about genetic testing had greater reach on Facebook, suggesting that it should be used to disseminate video content to the public. In addition, we found that Twitter is a valuable resource to follow research updates about germline testing for health care professionals and other stakeholders.

In conclusion, there is substantially less social media activity regarding *BRCA* and genetic testing in PCa relative to breast cancer. These results highlight a major need to increase public awareness and support for genetic testing for PCa to enhance the impact of the precision medicine era.

Acknowledgments

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Conflicts of Interest

SL reports equity in Gilead. VNG reports speaker agreements with Janssen, Invitae, and Ambry Genetics; research funding from the Department of Defense and the Prostate Cancer Foundation; stock ownership in Novopyxis. Others have nothing to disclose.

Multimedia Appendix 1
Supplemental Table 1.
[DOCX File , 17 KB - cancer_v7i3e27063_app1.docx]

Multimedia Appendix 2
Supplemental Table 2.
[DOCX File , 13 KB - cancer_v7i3e27063_app2.docx]

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Original Paper

Strategies for the Identification and Prevention of Survey Fraud: Data Analysis of a Web-Based Survey

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Abstract

Background: To assess the impact of COVID-19 on cancer survivors, we fielded a survey promoted via email and social media in winter 2020. Examination of the data showed suspicious patterns that warranted serious review.

Objective: The aim of this paper is to review the methods used to identify and prevent fraudulent survey responses.

Methods: As precautions, we included a Completely Automated Public Turing test to tell Computers and Humans Apart (CAPTCHA), a hidden question, and instructions for respondents to type a specific word. To identify likely fraudulent data, we defined a priori indicators that warranted elimination or suspicion. If a survey contained two or more suspicious indicators, the survey was eliminated. We examined differences between the retained and eliminated data sets.

Results: Of the total responses (N=1977), nearly three-fourths (n=1408) were dropped and one-fourth (n=569) were retained after data quality checking. Comparisons of the two data sets showed statistically significant differences across almost all demographic characteristics.

Conclusions: Numerous precautions beyond the inclusion of a CAPTCHA are needed when fielding web-based surveys, particularly if a financial incentive is offered.

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KEYWORDS

cancer survivors; pandemic; COVID-19; fraudulent responses; survey; research methods; cancer patients; fraud; CAPTCHA; data integrity; online surveys

Introduction

The COVID-19 pandemic resulted in significant delays to health care administration. To assess the impact of the pandemic on cancer survivors in the United States, the study team fielded a survey in the winter of 2020. The survey was promoted via email and, briefly, via social media. The volume of results in a short time period suggested that the data should be reviewed for fraudulent responses.

Social media can be an efficient way to disseminate web-based surveys [1-5]. According to the Pew Research Center, in 2021, 72% of adults in the United States were estimated to use at least one form of social media [6]. However, ensuring data integrity of studies when using social media remains a challenge. This study describes the data integrity methods used to identify fraudulent and suspicious data in a web-based survey that was briefly open to the public via social media.

Methods

Participant Sample

We recruited cancer survivors primarily via an email request sent to physician liaisons and cancer registrars at institutions accredited by the Commission on Cancer (CoC). The study invitation, which came directly from the CoC, asked recipients to forward the invitation to their cancer center survivorship coordinator, who in turn was asked to forward the invitation to patients. Emails were sent on October 13, 2020, followed by two reminders, each 1 week apart. In addition, the study team disseminated the survey to community partners on October 8, 2020; posted on the Association of Community Cancer Centers eXchange and Association of Oncology Social Work listservs; and included the survey link in a George Washington University newsletter to health care professionals.

Incentives

Participants were asked to complete a 20-minute survey and were told they would receive a US $25 gift card to thank them for their time.

Precautions

To dissuade bots, we included a Completely Automated Public Turing test to tell Computers and Humans Apart (CAPTCHA), a question asking how the participant heard about the survey, time stamps, open-ended questions, and pairs of items that could be compared for consistency. After receiving over 1000 responses in the first 3 days after opening the survey, we examined the data and identified suspicious patterns. We then removed all links from social media and added additional precautions based on extant literature about optimizing valid responses for public-access surveys [7-9]: including a hidden item that could only be detected by bots, requiring participants to retype a word, and requiring participants to confirm their understanding that fraudulent responses would not be compensated.

Measures

Our survey questions included demographics and health history: age, sex, and gender identity; sexual orientation; race/ethnicity; marital status; household size; education; income; age at diagnosis; cancer stage; cancer type; employment status; and insurance type. We also included questions related to COVID-19 and patient-reported outcomes.

Data Cleaning

Data were exported from Research Electronic Data Capture (REDCap) and analyzed in SAS 9.4 (SAS Institute). As of Thursday, December 3, 2020, we had received 1977 responses. We thus developed criteria to identify suspicious and fraudulent data.

We began by eliminating those who were ineligible: respondents who were living outside of the United States, had stage 0 cancer, had no cancer diagnosis (n=83), or reported that they had only nonmelanoma skin cancer (n=46) [10]. We then eliminated respondents who were missing data on ≥35% of survey questions (n=149). Next, we excluded respondents who reported contradictory responses, including discordant gender (eg, both cisgender male and cisgender female status) (n=12) and discordant sex assigned at birth with anatomical site of cancer (eg, cisgender male with uterine cancer) (n=37).

We analyzed irregularities in the remaining data (n=1650) and eliminated responses that contained two or more suspicious indicators (Table 1). Criteria for a suspicious indicator included differences between reported and calculated age or reported and calculated time between treatment and diagnosis; report of a type of cancer that is very rare for the respondent's age group; incongruent patterns of hearing about the survey relative to distribution dates; suspicious open-text responses (including fake addresses); repeat email addresses; and unusual time stamps. Table 1 presents a summary of the types of fraudulent and suspicious responses, and Figure 1 shows the elimination sequence.

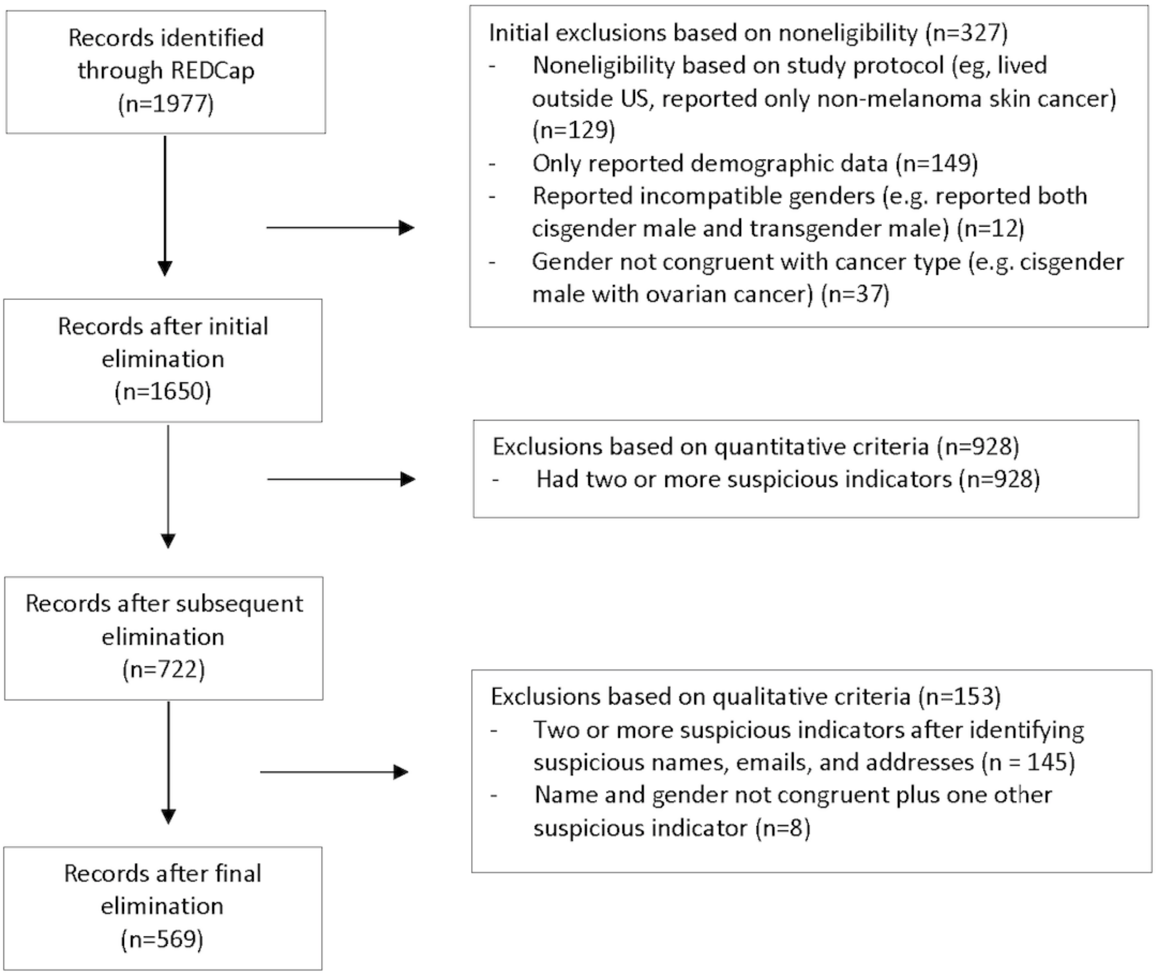
We sent emails to all respondents excluded from the final data set to alert them that their responses had not passed a quality check, and we welcomed them to reach out to the study team with any questions. We received only 1 response, which said: "Why." We also emailed all of the respondents who were retained in the data set and instructed them on how to claim their incentive. We received 1 response from a person who did not recall participating in the study. As additional quality control, we reviewed a subset of data for respondents who indicated hearing about the survey from a specific community partner. Of the 35 respondents who indicated hearing about the survey from this partner, we excluded 30. Upon member checking, all 5 participants retained in the data set were confirmed as clients of the community partner, and only 1 of the excluded respondents was a legitimate client.

Table 1. Types of fraudulent or suspicious data identified in eliminated survey responses (n=1081).[a]

Description	Value, n (%)
Year of birth is reported as 2020, or reported age and age calculated from reported date of birth are different by more than 1 year	250 (17.8)
Reported age is <40 years and cancer type is rare for those aged <40 years	283 (20.1)
Respondents indicate a survey source prior to dissemination of the survey from that source	820 (58.2)
Open-ended comments focus on information technology rather than answering the question asked	56 (4)
Open-ended telehealth comments are duplicates	34 (2.4)
Final open-ended suggestion responses are duplicates	107 (7.6)
Email addresses are duplicates	20 (1.4)
Time since diagnosis is <2 years, but time since treatment is 2-5 years	11 (0.8)
Time since diagnosis is ≤5 years, but time since treatment is >5 years	57 (4)
Suspicious survey time (at least 10 surveys completed in succession within 5 minutes of each other or completed between midnight and 4 AM EST)	986 (70)
Email/address is suspicious (for email: at least 10 random numbers or letters in a row, or strange punctuation or capitalization; for address: incomplete address, address of a business, address is not real, address includes quotation marks, or pattern of strange capitalization or spacing)	166 (11.8)
Name/suffix is suspicious (first and last name flipped, part of last name in first name field or vice versa, male suffix and female name, random letters or numbers in suffix field)	78 (5.5)

[a] Individuals could be counted in as many indicators as their responses suggested; thus, the n values do not add up to the total of excluded data.

Figure 1. Flow chart of survey response elimination. REDCap: Research Electronic Data Capture.



Data Analysis

After eliminating responses deemed as fraudulent, we used means and frequencies to create a demographics table comparing respondents who were included with those who were excluded. We used chi-square or Fisher exact tests to examine differences between groups.

Ethical Review

This study was deemed exempt by the George Washington University Institutional Review Board (IRB) (NCR202819).

Results

Of the total sample (N=1977), 1408 responses were excluded (327 due to ineligibility and 1081 due to suspicious responses) and 569 were retained. Most surveys eliminated were dated October 9-11, 2020 (n=1072). These dates align with the period when the survey link was posted on social media.

Comparisons of retained and excluded respondents showed statistically significant differences across most demographic characteristics (Table 2). There were lower rates of cisgender male, transgender/gender fluid/two-spirit identification (*P*<.001) and higher rates of cisgender female identification (*P*<.001) among retained versus excluded respondents. There was a higher prevalence of straight-identifying respondents in the retained sample versus the excluded sample (*P*<.001). There were lower rates of respondents reporting Native American/Alaska Native/Pacific Islander race/ethnicity (*P*<.001) and higher rates of those reporting White race/ethnicity in the retained sample versus the excluded sample (*P*<.001). The numbers of single individuals were similar in the two samples, but higher rates of divorced/separated and widowed people were observed in the retained sample versus the excluded sample (*P*<.001). There were higher rates of college completion and graduate school as well as annual incomes greater than US $100,000 among the retained sample versus the excluded sample (*P*<.001). The mean age of the retained sample was significantly older (56 vs 42 years old, *P*<.001).

Table 2. Differences between respondents in the retained and excluded samples.

Characteristic	Retained sample (n=569)	Excluded sample (n=1081)	*P* value
Current age (years), mean (SD)	55.9 (13.1)	41.4 (8.2)	<.001
Gender, n (%)[a,b]			
Cisgender male	132 (23.2)	575 (53.2)	<.001
Transgender male, transgender female, gender fluid, or two-spirit	1 (0.2)	32 (3.0)	<.001
Cisgender female	399 (70.1)	463 (42.8)	<.001
Other/prefer not to answer/Do not understand the question	40 (7.0)	14 (1.3)	<.001
Sexual orientation, n (%)[b]			<.001
Straight	532 (93.5)	984 (91.0)	
Lesbian, gay, homosexual, bisexual/pansexual, queer, two-spirit	23 (4.0)	89 (8.2)	
Other/prefer not to answer/do not understand the question	14 (2.5)	8 (0.7)	
Race/ethnicity, n (%)[a,b]			
Asian	19 (3.3)	58 (5.4)	.06
Black	83 (14.6)	200 (18.5)	.045
Hispanic/Latinx	42 (7.4)	90 (8.3)	.50
Native American/Alaska Native/Pacific Islander	17 (3.0)	83 (7.7)	<.001
White	411 (72.2)	677 (62.6)	<.001
Partnership status, n (%)[b]			<.001
Single	93 (16.3)	152 (14.1)	
Married/partnered	388 (68.2)	884 (81.8)	
Divorced/separated	60 (10.5)	37 (3.4)	
Widowed	28 (4.9)	8 (0.7)	
Number of individuals in household, mean (SD)	2.6 (1.3)	3.3 (0.9)	<.001
Education, n (%)[b]			<.001
Some high school or less	17 (3.0)	38 (3.5)	
High school diploma or GED[c]/vocational school	88 (15.8)	294 (27.2)	
Some college	164 (28.8)	415 (38.4)	
Completed 4-year degree	156 (27.4)	261 (24.1)	
Graduate school	144 (25.3)	73 (6.8)	
Annual household income (US $), n (%)[b]			<.001
<25,000	59 (10.4)	46 (4.3)	
25,001-50,000	106 (18.6)	383 (35.4)	
50,001-75,000	124 (21.7)	375 (34.7)	
75,001-100,000	61 (10.7)	182 (16.8)	
>100,000	129 (22.7)	93 (8.6)	
I prefer not to answer	90 (15.8)	1 (0.09)	
Age at cancer diagnosis (years), mean (SD)	51.4 (13.4)	36.8 (8.6)	<.001
Cancer stage, n (%)[b]			<.001
I	172 (30.2)	456 (42.2)	
II	167 (29.4)	367 (34.0)	
III	88 (15.5)	177 (16.4)	

Characteristic	Retained sample (n=569)	Excluded sample (n=1081)	*P* value
IV	62 (10.9)	51 (4.7)	
Unknown	66 (11.6)	24 (2.2)	
Cancer type, n (%)[a,b]			
Melanoma	26 (4.6)	57 (5.3)	.53
Lung	23 (4)	199 (18.4)	<.001
Prostate	37 (6.5)	90 (8.3)	.19
Breast	328 (57.6)	161 (14.9)	<.001
Colorectal	39 (6.9)	117 (10.8)	.008
Kidney	8 (1.4)	63 (5.8)	<.001
Bladder	8 (1.4)	83 (7.7)	<.001
Blood cancer (leukemia, lymphoma, myeloma)	44 (7.7)	82 (7.6)	.92
Uterine/cervical	32 (5.6)	160 (14.8)	<.001
Thyroid	31 (5.5)	91 (8.4)	.03
Other	62 (10.9)	13 (1.2)	<.001
Time since cancer treatment (years), n (%)[b]			<.001
<2	238 (43.4)	476 (44.1)	
2-5	168 (30.7)	488 (45.2)	
>5	142 (25.9)	116 (10.7)	
Cancer care status, n (%)[a,b]			
My cancer is in remission or no evidence of disease	447 (78.6)	612 (56.6)	<.001
I have chronic cancer	77 (13.5)	240 (22.2)	<.001
I am receiving palliative care	30 (5.3)	253 (23.4)	<.001
I am in hospice care	0 (0)	60 (5.6)	<.001
None of these apply to me	42 (7.4)	39 (3.6)	<.001
Part of a tribe or territory, n (%)[b]	41 (7.2)	397 (38.1)	<.001
Employment status, n (%)[a,b]			
Retired	198 (34.8)	48 (4.4)	<.001
Paid work (full- or part-time)	251 (44.1)	667 (61.7)	<.001
Unpaid work (homemaker, volunteer)	44 (7.7)	127 (11.8)	.01
Unemployed	77 (13.5)	247 (22.9)	<.001
Insurance type, n (%)[a,b]			
Private insurance	320 (56.2)	436 (40.3)	<.001
Medicaid	83 (14.6)	491 (45.4)	<.001
Medicare	210 (36.9)	633 (58.6)	<.001
Tricare/COBRA[d]/other	48 (8.4)	64 (5.9)	.054
I do not have health insurance	31 (5.5)	45 (4.2)	.24
Self-reported health, n (%)[b]			<.001
Excellent/very good	165 (29.0)	375 (34.7)	
Good	226 (39.7)	318 (29.4)	
Fair	101 (17.8)	254 (23.5)	

Characteristic	Retained sample (n=569)	Excluded sample (n=1081)	*P* value
Poor	17 (3.0)	133 (12.3)	

[a] Respondents could select multiple responses for this question.

[b] Responses may not add up to n=569 or n=1081 due to missing data or multiple responses.

[c] GED: General Educational Development.

[d] COBRA: Consolidated Omnibus Budget Reconciliation Act.

The samples also differed in cancer stage, type, health status, and insurance coverage status. The retained sample reported more stage IV cancer and a higher percentage of breast cancer than the excluded sample. The excluded sample reported more lung, kidney, bladder, and uterine/cervical cancers than the retained sample (*P*<.001). A greater percentage of the retained versus excluded sample reported completing treatment more than 5 years ago (142/569, 25.9%, vs 116/1081, 10.7%; *P*<.001). A greater percentage of those in the retained sample indicated their cancer was in remission or had no evidence of disease (447/569, 78.6%, vs 612/1081, 56.6%; *P*<.001), while a greater percentage of the excluded sample reported receiving palliative care (253/1081, 23.4%, vs 30/569, 5.3%; *P*<.001) and hospice (60/1081, 5.6%, vs 0/569, 0%; *P*<.001). A greater percentage of the retained sample reported having private insurance (320/569, 56.2%), while more of the excluded sample reported having Medicaid (491/1081, 45.4%) and/or Medicare (633/1081, 58.6%). Finally, respondents in the retained sample were more likely to report their health as "good" (226/569, 39.7%, vs 318/1081, 29.4%) and less likely to report their health as "poor" (17/569, 3.0%, vs 133/1081, 12.3%) compared to the excluded sample (*P*<.001).

Discussion

Principal Findings

Numerous indications support the greater integrity of the data in the retained sample (n=569) compared to the excluded sample (n=1081). First, discordant data reported by the same respondent, such as the anatomical site of their cancer not being physically possible for their reported sex/gender, were clear signs of random survey completion. Second, the younger mean age of the excluded sample combined with cancers more likely to be diagnosed at a later age (eg, lung, kidney, and bladder cancers), more serious disease (chronic, receiving palliative care, or hospice), and poorer health is highly suspicious. Conversely, the higher self-reported diagnosis of breast cancer in the retained sample aligns with the authors' prior research experience in more easily recruiting breast cancer survivors than those with a history of other cancers.

This study contributes to the literature by providing guidance for identifying potentially fraudulent data. Importantly, use of screening questions and CAPTCHA was insufficient to dissuade fraudulent respondents. Consistent with past research, we found that examining repeated personal data across responses [11], duplicate open text responses [12], response inconsistency [12], and low-probability responses [12] helped to identify potentially fraudulent responses. Additionally, we found that examining differences between the retained and excluded samples bolstered our confidence in the retained sample (ie, demographic characteristics such as mean age and cancer type corresponded more closely with the demographics of participants in prior cancer survivorship research conducted by the authors as well as cancer statistics).

Ethical Considerations

Social media is an efficient and cost-effective method for health research. However, the potential for loss of data integrity must be weighed with the efficiency and cost-effectiveness [1-5]. The distance created between researchers and participants in internet survey–based research may lead to participants feeling less self-conscious about unethical behavior and more motivated to obtain incentives for which they are ineligible. Precautions to improve confidence in data integrity, however, may inadvertently prevent participation by eligible persons as well. For example, persons using the same computer who are eligible to participate in a study may be omitted from data based on their identical IP addresses. People with less technological savvy or visual challenges may be dissuaded from survey completion by the CAPTCHA. People whose first language does not match the language of the survey may be dissuaded due to instructions to type words in a language in which they are not facile. Finally, the capture of geographic location (IP address) in combination with multiple identifying questions has implications for the anonymity of respondents. Prevention and detection of fraudulent responses may, therefore, require increased justification for IRB review to collect geolocation and identifying data that would not otherwise be needed.

Recommendations to Prevent Fraudulent Data

To minimize bot contamination and reduce duplicate entries, precautions similar to those taken in this study are warranted. Additional recommendations include using software with fraud prevention and detection capabilities (eg, Qualtrics), capturing IP addresses, capturing time stamps for both start and stop times, including a required open text question, and distributing surveys only to closed groups on social media or avoiding social media altogether. If social media is used, financial incentives should be avoided. If providing financial incentives, (1) require participants to check a box indicating they acknowledge that responses from ineligible respondents or those who respond multiple times will not receive the financial incentive and downplay the incentive, and (2) indicate that investigators reserve the right to confirm eligibility by telephone (or other means) and include a required telephone number field.

Recommendations to Identify Fraudulent Data

Once data are collected, data integrity checks such as those in Table 2 can help researchers detect potentially fraudulent responses. In addition, the use of different trackable URLs for different dissemination channels may facilitate the identification of the dissemination source of suspicious data.

Limitations

The criteria used to eliminate responses were subjective, and it is impossible to know if all fraudulent data were removed. The authors erred on the side of potentially eliminating valid responses rather than retaining responses that were likely to be invalid. Limitations in our ability to detect potentially fraudulent responses included the inability to capture IP addresses or completion times.

Conclusion

Providing a survey incentive in combination with social media recruitment may increase the likelihood of fraudulent activity. CAPTCHA alone is unlikely to prevent fraudulent responses in internet-based research promoted on social media. Precautions to prevent and detect fraud are important for the validity of research findings. Ethical considerations of participant privacy and incentive payments should be weighed with data integrity concerns to ensure valid, meaningful health research results.

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Conflicts of Interest

None declared.

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Abbreviations

CAPTCHA: Completely Automated Public Turing test to tell Computers and Humans Apart
COC: Commission on Cancer

IRB: Institutional Review Board
REDCap: Research Electronic Data Capture

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Original Paper

Analysis of Population Differences in Digital Conversations About Cancer Clinical Trials: Advanced Data Mining and Extraction Study

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Abstract

Background: Racial and ethnic diversity in clinical trials for cancer treatment is essential for the development of treatments that are effective for all patients and for identifying potential differences in toxicity between different demographics. Mining of social media discussions about clinical trials has been used previously to identify patient barriers to enrollment in clinical trials; however, a comprehensive breakdown of sentiments and barriers by various racial and ethnic groups is lacking.

Objective: The aim of this study is to use an innovative methodology to analyze web-based conversations about cancer clinical trials and to identify and compare conversation topics, barriers, and sentiments between different racial and ethnic populations.

Methods: We analyzed 372,283 web-based conversations about cancer clinical trials, of which 179,339 (48.17%) of the discussions had identifiable race information about the individual posting the conversations. Using sophisticated machine learning software and analyses, we were able to identify key sentiments and feelings, topics of interest, and barriers to clinical trials across racial groups. The stage of treatment could also be identified in many of the discussions, allowing for a unique insight into how the sentiments and challenges of patients change throughout the treatment process for each racial group.

Results: We observed that only 4.01% (372,283/9,284,284) of cancer-related discussions referenced clinical trials. Within these discussions, topics of interest and identified clinical trial barriers discussed by all racial and ethnic groups throughout the treatment process included health care professional interactions, cost of care, fear, anxiety and lack of awareness, risks, treatment experiences, and the clinical trial enrollment process. Health care professional interactions, cost of care, and enrollment processes were notably discussed more frequently in minority populations. Other minor variations in the frequency of discussion topics between ethnic and racial groups throughout the treatment process were identified.

Conclusions: This study demonstrates the power of digital search technology in health care research. The results are also valuable for identifying the ideal content and timing for the delivery of clinical trial information and resources for different racial and ethnic groups.

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KEYWORDS

cancer; clinical trials; data mining; text extraction; social media; race and ethnicity; health communication; health care disparities; natural language processing

Introduction

Background

The internet age has opened up a wealth of web-based health-related information for patient access. Most recently, the increased use of social media has allowed patients to use blogs, web-based forums, and support groups for education, support, and connection with other patients undergoing similar health care experiences. New data mining technologies have allowed us to use this wealth of information to gain valuable and timely insights into areas such as adverse drug effects [1-3] and the spread of infectious diseases [4,5]. Advancements in natural language processing and machine learning algorithms now allow for the examination of patient ideas, sentiments, and feelings about a range of topics [6,7]. This is known as sentiment analysis and is being increasingly used in the health care domain to gain unfiltered insight into patient satisfaction and efficacy of care from web-based patient input [8,9]. This information is useful for health care providers to optimize their services and improve patient care.

The Pew Research Center, which has tracked the demographics of internet users since 2005, has found comparable social media use between different racial and ethnic groups. As of June 2019, 73% of White, 69% of Black, and 70% of Hispanic people regularly used social media [10]. However, although their use time is similar, the details of the health care sites visited and information sought and shared by different races or ethnic groups have not been thoroughly examined. The race or ethnicity of the poster is not always evident in social media posts, but when it is provided, researchers gain the opportunity to sort these discussions by demographics and gain valuable insights into health care topics and barriers relevant to each group.

Study Goals

In this study, we focus our analysis on the differing trends in discussions of cancer clinical trials between different racial or ethnic groups of social media users. Currently, there is a disconnect between the large number of available clinical trials testing potentially active new drugs and the relatively small number of patients with cancer willing to enroll in these clinical trials. The national average is well under 10% of all patients with cancer enrolled in clinical trials. Furthermore, recent studies have shown that enrollment into cancer clinical trials in the United States between 2010 and 2016 underrepresented some racial and ethnic minority groups [11]. This finding is alarming because as many as 20% of new drugs being tested in clinical trials can have different pharmacokinetics, pharmacodynamics, and safety profiles among different racial and ethnic groups, which can lead to disparities in treatment response, morbidity, and mortality, leading to trial results that are not indicative of the patient population [12,13]. These realities necessitate that clinical trials evaluating new therapies include a diverse population with the necessary numbers of ethnic minority participants to detect differences in these outcomes and provide equitable health care for all.

Social media is increasingly being recognized for its potential to connect patients with clinical trial information and education, aid in recruitment, and identify patient concerns and barriers to enrollment [14]. In a recent study, Peng et al [15] mined discussions from web-based cancer forums to identify clinical trial sentiments, priority areas of discussion, barriers, and opportunities for patient outreach. Many of these social media studies, however, analyze conversations from limited, targeted cancer-related sites and lack demographic information on the individuals posting the conversations. In this study, we used a powerful research method to search for patient discussions about clinical trials across the internet. This is an innovative discovery-based approach in which topics emerge from conversations instead of preimposing topics to mine. The large number of discussions we found allowed us to extract a substantial subset of conversations with identifiable race or ethnicity of the poster and to examine the similarities and differences in their thoughts and ideas on cancer clinical trials by sentiment analysis. Data were further categorized by treatment stage, which provides additional insight into the relationship of each group with the clinical trial process. This is a demonstration of the usefulness of this technology in health care research, and the results may be valuable for tailoring clinical trial education, enrollment, and delivery to various racial and ethnic groups.

Methods

CulturIntel Search Methodology

CultureIntel, a data science affiliate of CIEN+, has developed a novel methodology that mines unstructured qualitative data. Advanced search techniques such as web spiders, crawlers, and site scraping are able to *listen* to web-based conversations about cancer clinical trials and extract topical information and tagged data into a database. By not preselecting sites for analysis, we are able to look at the full universe of conversations that are available to gain unbiased and spontaneous insights into our topic of interest. This technology has been used previously to understand barriers to the treatment of women of color living with breast cancer [16] and to examine suicide-related digital conversations among teenagers and adults with epilepsy [17]. The CulturIntel methodology is 100% compliant with the General Data Protection Regulation requirements. All the conversations collected were open-source, public conversations. The data content was anonymous and not stored after the analysis.

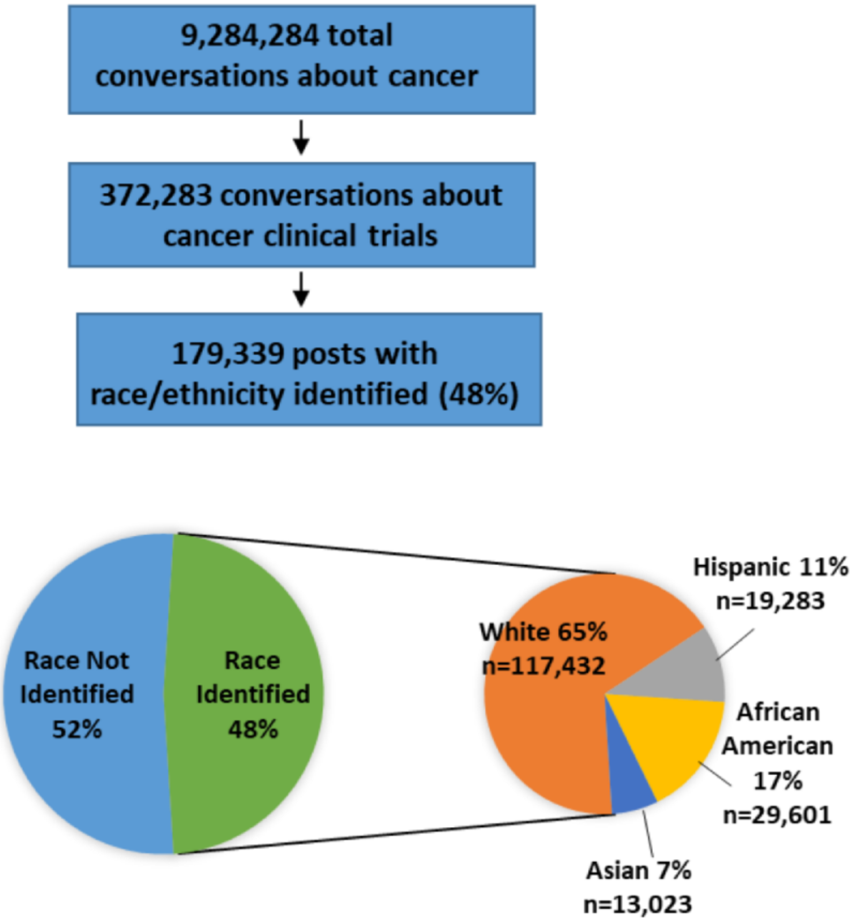
Data Collection

This analysis was conducted on digital conversations in the English language from IP addresses in the United States for a 12-month period ending on June 21, 2018.

Sites and Users

Conversations were primarily found on message boards and other topical sites that numbered in the tens of thousands. Users could have more than one post included if they were part of a unique post. Multiple user posts within a conversation and shared or linked comments were counted once, whereas users' posts across different discussions or sites were counted separately. A total of 9,284,284 conversations about cancer were identified, of which 372,283 (4.01%) were related to cancer clinical trials. Of these 372,283 discussions, 179,339 (48.17%) had identifiable racial or ethnic information. The racial or ethnic distributions are shown in Figure 1. When the race or ethnicity of a user could not be identified, it was still included in the *overall* results.

Figure 1. Description of online discussions included in the data and demographic categorization of analyzed posts.



Content Analysis

Natural language processing, text analytics, artificial intelligence, and social data mining were used to extract information from the collected conversations, including (1) the relationship of the posting individual to the patient, (2) the type of post or question, (3) the sentiment or feelings of the poster, (4) stage of cancer treatment from post semantics, (4) topics of discussion, and (5) perceived barriers. Topics, sentiments, and stages were not preselected but rather emerged from the data. The study protocol, algorithm parameters, and checks to ensure the relevance of the data extracted were all performed by an in-person study team. Sentiment analysis was also human supervised to ensure the accuracy of the attribution of the sentiment to a conversation.

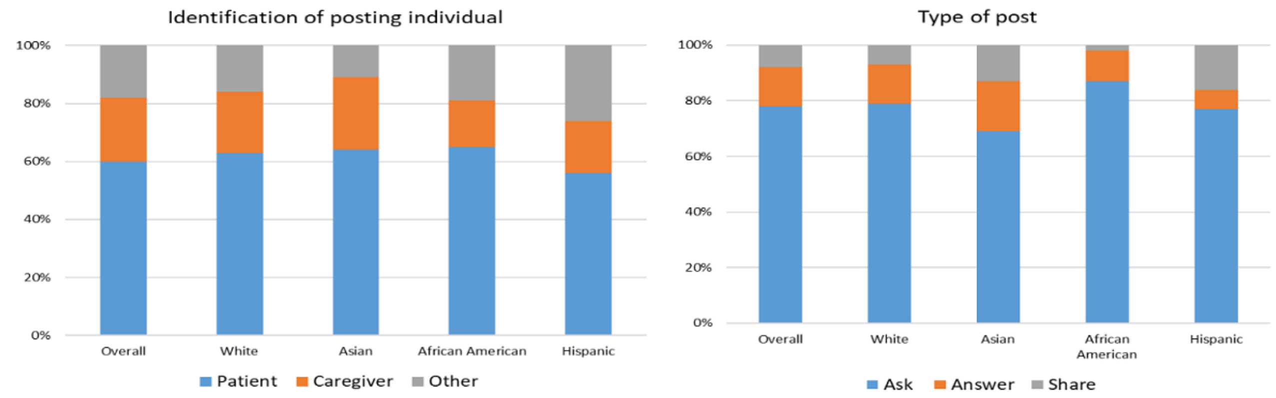
Results

Content Demographics

We conducted a comprehensive web-based search for conversations about cancer clinical trials over a 12-month period ending on June 21, 2018. A total of 9,284,284 conversations about cancer were detected, with 372,283 referencing clinical trials. Of the 372,283 clinical trial conversations, 179,339 (48.17%) were posted by individuals with identifiable race or ethnicity. Of these 179,339 conversations, 117,432 (65.48%) were posted by individuals categorized as White, 19,283 (10.75%) by Hispanics, 29,601 (16.51%) by African Americans, and 13,023 (7.26%) by Asians (Figure 1). These conversations were found on disease-related topical sites (134,483/372,283, 36.12%), social networks (52,329/372,283, 14.06%), message boards (152,184/372,283, 40.88%), and blogs (33,092/372,283, 8.89%).

Overall, 60% (223,384/372,283) of the posts were from the patients themselves, 22.05% (82,103/372,283) were from a caregiver, and 18.22% (67,283/372,283) were from another individual and classified as *other*. These distributions were similar across ethnic groups, only varying slightly in the *other* category, with Hispanics having more and Asians having fewer posts by individuals in this category (Figure 2). The vast majority of the posts analyzed for "type of post" (214,009/276,069, 77.52%) were questions seeking information (ie, "...I know some of my forum will have the valuable experiences that may assist as to what direction I take in terms of considering trials?"), whereas 14.43% (39,829/276,069) were answering questions (ie, "Treatments were painless and quick and the staff was lovely.") and 8.01% (22,231/276,069) were sharing information or support (ie, "There are lots of great people on this site who are both living with cancer and have a loved one with cancer. They have been instrumental in helping me get through the experience of dealing with the trials process"). The posts by African Americans were more likely to be questions than posts from other groups, while posts by Hispanics were twice as likely to share information and support (Figure 2).

Figure 2. Analysis of posting individuals and type of post.



Sentiment Analysis

Sentiment analysis, also called emotion artificial intelligence or opinion mining, is a method used to analyze natural language processing, computational linguistics, texts, and biometrics. This method is often used to analyze information collected from web-based social media. We applied sentiment analysis to study the data we collected and categorize attitudes, opinions, and reactions to cancer clinical trial–related information by race and ethnicity. With our analysis methods, we found that 74.07% (275,659/372,156) of the posts with identifiable sentiment were neutral in nature (ie, "What are the possible risks, side effects, and benefits of the study treatment compared to my current treatment?"), 15.12% (56,274/372,156) were negative (ie, "...its so much regret with which I wake up everyday and feel so sad I trusted these doctors"), and 10.81% (40,223/372,156) were positive (ie "I'm very excited to participate in a clinical trial"). The results were relatively similar across the different groups, although African Americans and Hispanics had slightly more negative posts than the overall population, whereas Asians posted a higher percentage of neutral posts (Figure 3). The negative topics includes lack of awareness (145,090/372,283, 38.97%), fear and anxiety (115,563/372,283, 31.04%), and concerns about health care professionals (HCPs; 41,235/372,283, 11.08%), costs (40,092/372,283, 10.77%), and logistics (31,674/372,283, 8.51%). Positive posts were categorized as hopeful, contributory, or grateful for the support as illustrated in Figure 3. Posts by African Americans were the most hopeful, whereas Hispanics expressed the most gratefulness for support (Figure 3).

Most posts across all groups were neutral in nature. These posts were primarily questions and are categorized in Figure 3 as *what*, *how*, and *where* questions. White individuals and Asians asked more *what* questions, that is, seeking information about clinical trials, whereas African Americans and Hispanics asked more logistical questions about the *where* and *how* information pertaining to clinical trial access (Figure 3).

Mindset sentiments were also analyzed and are summarized in Figure 4. Posts were designated as *fearful* (41,371/372,283, 11.11%; ie, "I am trying to find ways to cope with this news. 3 days ago I was diagnosed with stage 4 lung cancer. I am completely devastated."), *hopeful* (134,901/372,283, 36.24%); (ie, "I have faith in god and trust in my doctors that I will be cured."), *empowered* (182,481/372,283, 49.02%); (ie, "I will do anything and everything it will take to beat this!"), or *resigned* (15,381/372,283, 4.13%); (ie, "I have always heard lung cancer is a death sentence and survival is nil. I am wondering where things go from here."). The distribution of these sentiments was very similar across racial groups, although posts by Hispanics were more often categorized as *empowered* (12,030/19,115, 62.93% vs 182,481/372,283, 49.02%). Very few posts were categorized as resigned or fearful (Figure 4).

Figure 3. Categorization of post sentiments and details of positive posts and neutral questions.

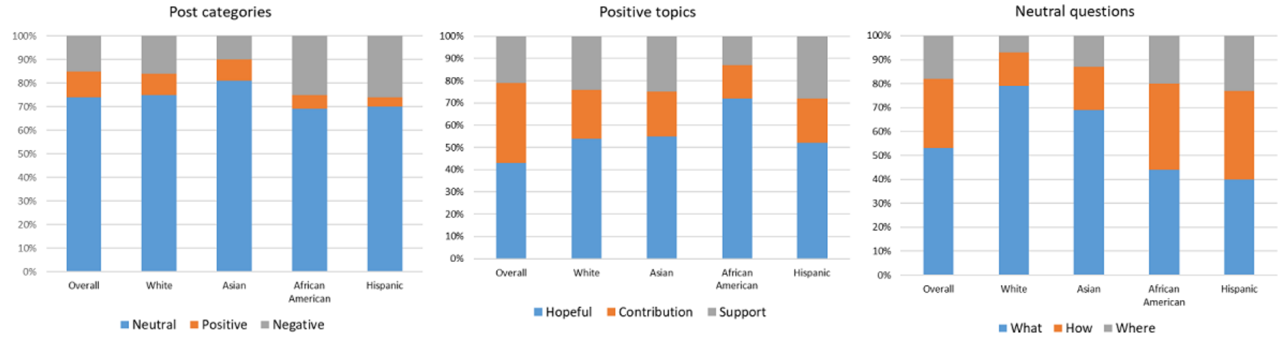
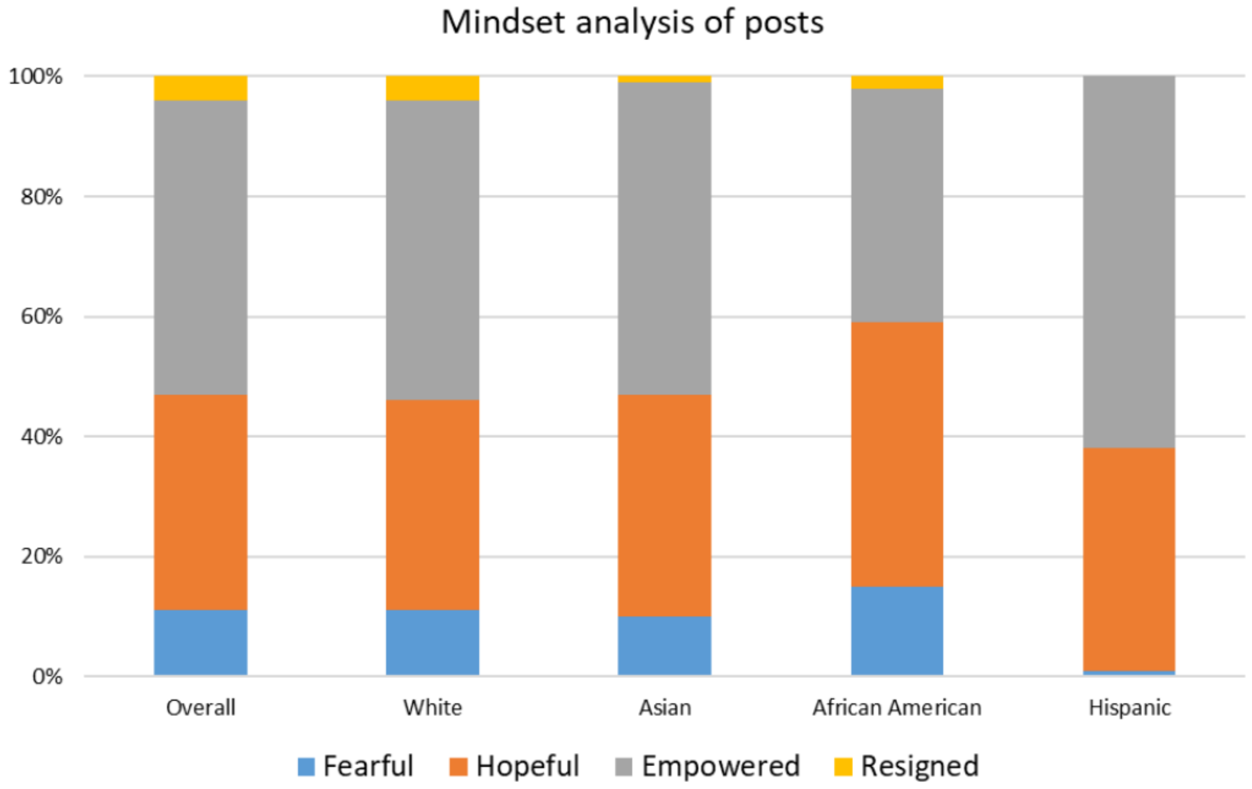


Figure 4. Mindset analysis of posts by race or ethnicity.



Treatment Stages

CultureIntel used human-assisted text mining to categorize 4 stages of cancer treatment the referenced patient was currently undergoing. The *coping* stage was defined as coming to grips with disease realities and impacts (ie, “...polyps can appear one year and also take some time (years) to become cancerous.”); the *treating* stage was defined as enduring the treatment process (ie, “They want to do a Selective Internal Radiation Therapy along with continued Chemo. Has anyone had this done before?”); the *monitoring* stage was defined as ongoing evaluation of treatment success or efficacy and disease status (ie, “...and the oncologist is now suggesting Lonsurf. My understanding of Lonsurf is that this is a matter of buying her a few more months...”); and the *adjusting* stage was defined as changes or stabilization of disease state and/or treatment plan (ie, “I was diagnosed with breast cancer 3 weeks ago...now I am told I have a spot on one of my lungs...I am so scared”). The distribution of posts from each racial or ethnic group during the 4 treatment stages is shown in Table 1. Of particular note, we found that Hispanics do not often share posts in the sites analyzed at the coping stage. The reasons for this are not known, but it is possible that this population prefers to seek and share information on the web when they are further along in the treatment process (Table 1).

Table 1. Discussions at stages of treatment.

Race or ethnicity	Coping, n (%)	Treating, n (%)	Monitoring, n (%)	Adjusting, n (%)
Overall	17,443 (19.12)	97,332 (26.05)	78,487 (21.01)	126,343 (33.82)
White individuals	20,182 (16.81)	34,723 (28.93)	25,311 (21.09)	39,809 (33.17)
Asians	1937 (12.41)	5215 (33.4)	3095 (19.82)	5365 (34.36)
African Americans	3009 (10.03)	13,876 (46.28)	6674 (22.26)	6422 (21.42)
Hispanics	0 (0)	8456 (41.49)	7812 (38.33)	4112 (20.18)

Discussion Topics

Analysis of the topics discussed identified seven main categories: (1) availability, (2) enrollment process, (3) tests or procedures, (4) medications or hospital stays, (5) HCP details, (6) risks, and (7) benefits and costs. A detailed analysis of these topics across treatment stages and racial or ethnic groups is shown in Figure 5. There are some distinct differences in the topics discussed overall by the different groups. African Americans and Hispanics discuss HCPs and cost and enrollment three times more often than the overall population. Hispanics also discussed medications and hospital stays 60% more often than other groups. Asians discuss HCPs twice as often as individuals who were White and the overall population (Figure 5).

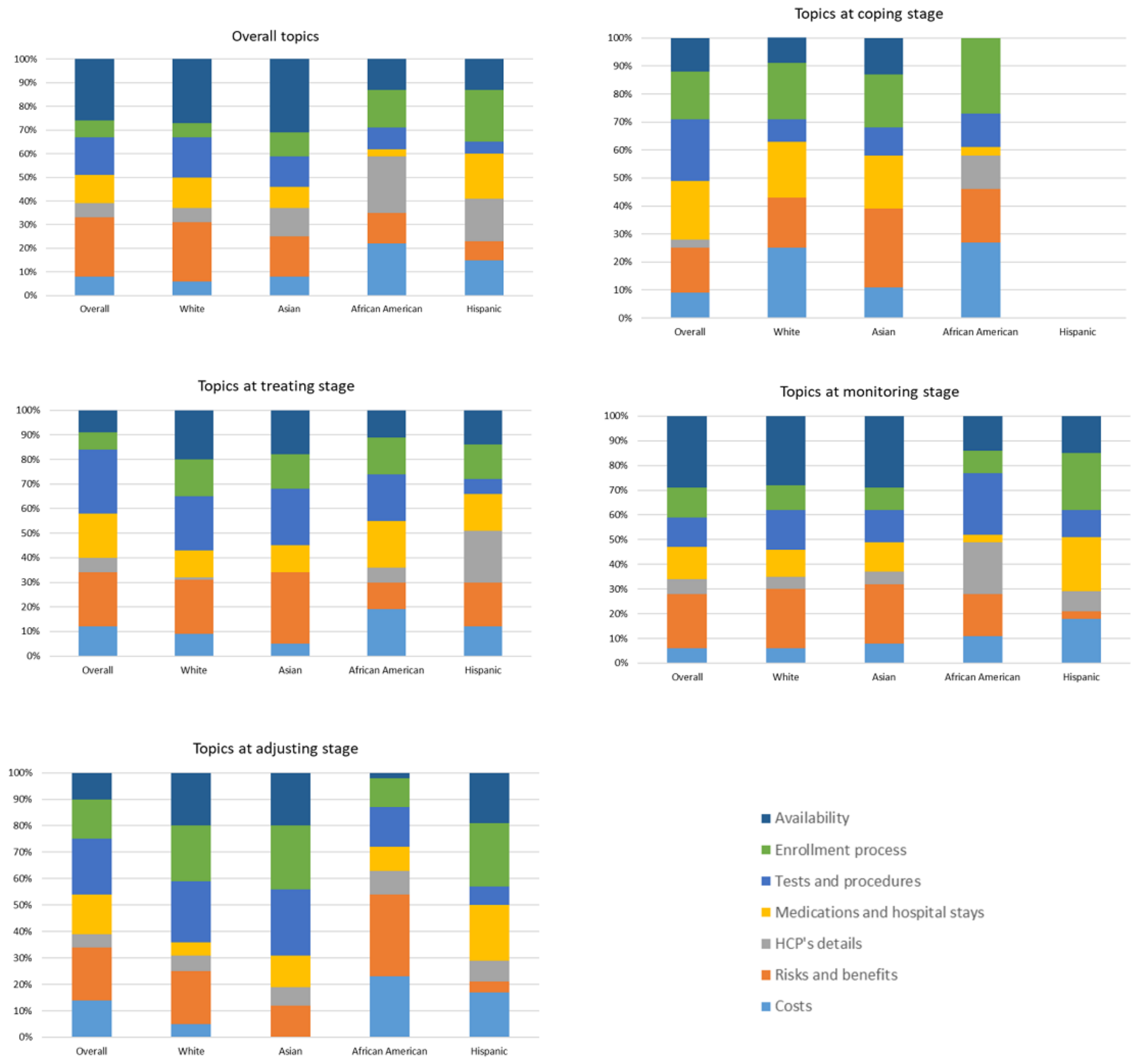
The focus on HCP and costs persisted throughout the treatment process. At the coping stage, African Americans were 3 times more likely to discuss costs and four times more likely to discuss HCP details. As Hispanics did not often share at this stage in our analysis, this method cannot evaluate their concerns at this stage. Asians, however, were less likely to discuss tests and procedures and 1.7 times more likely to discuss risks and benefits.

At the treatment stage, all groups were more likely to discuss the enrollment process. African Americans were 3.5 times more likely to discuss HCP details, and White individuals and Asians were twice as likely to discuss clinical trial availability.

At the monitoring stage, cost is more likely to be discussed by African Americans and Hispanics (2 and 3 times more, respectively). HCP details (3.5 times more) and tests or procedures (2 times more) were also discussed more by African Americans, whereas medications, hospital stays, and enrollment processes were discussed more by Hispanics.

At the adjusting stage, White individuals, Asians, and Hispanics discussed clinical trial availability and enrollment more often than African Americans. Modest differences were also seen in discussions about cost (1.6 times more), risk benefits (1.5 times more), and HCP details (two times more) for African Americans.

Figure 5. Comparison of top discussion topics by treatment stage and race or ethnicity. HCP: health care professional.

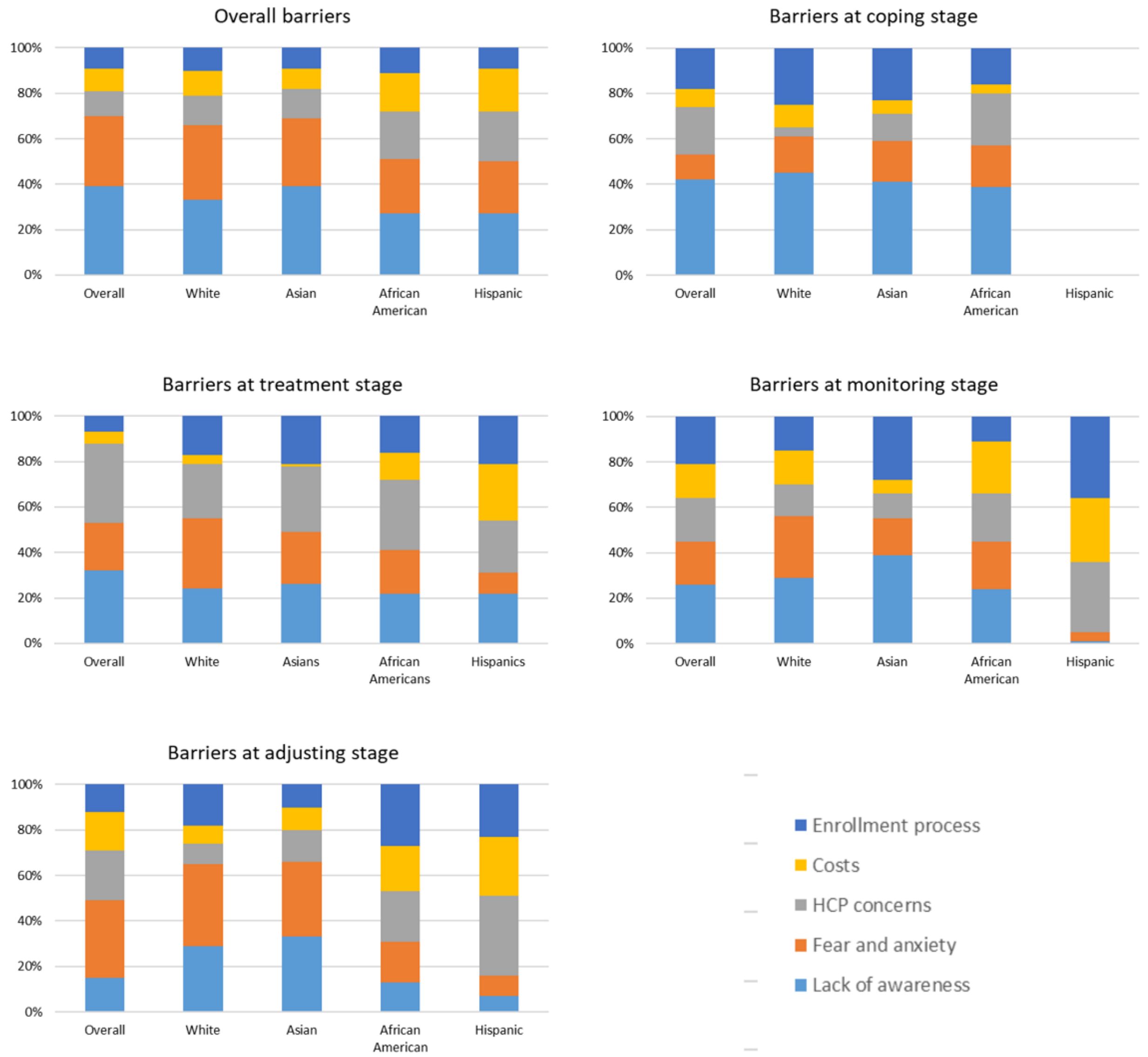


Barriers to Clinical Trial Enrollment

Barriers identified from the discussions included (1) lack of awareness, (2) fear and anxiety, (3) HCP concerns, (4) costs, and (5) the enrollment process. Overall, lack of awareness and fear and anxiety are the biggest barriers discussed by White individuals and Asians, whereas African Americans and Hispanics were more likely to discuss HCP concerns (three times more). The enrollment process is also more of a concern for African Americans and Hispanics (2 times and 3 times more than overall, respectively), and cost was discussed twice as often among Hispanics (Figure 6).

When analyzed by treatment stage, White individuals discussed HCP less frequently at the coping stage (5.2 times less) than Asians or African Americans. As noted above, Hispanics did not share at this stage, so their discussions were not available for analysis. At the treatment stage, costs became a major barrier discussed by Hispanics (discussed 5 times more) and, to a lesser extent, African Americans (2.6 times). The enrollment process became more of a concern for all groups. At the monitoring stage, Hispanics discussed the lack of awareness less frequently and increased discussions on cost, HCP, and enrollment issues. Posts by African Americans were more likely to mention cost as a barrier, whereas Asians discussed awareness and White individuals discussed fear. At the adjusting stage, significant differences were seen in the ranking of barriers, with White individuals and Asians noting more fear and less awareness, whereas African Americans were more likely to discuss HCPs, costs, and enrollment barriers.

Figure 6. Comparison of clinical trial barriers by treatment stage and race or ethnicity. HCP: health care professional.



Discussion

Principal Findings

In this study, we used a powerful new digital search technology to examine web-based social media posts for sentiments, top topics of interest, and barriers to enrollment in cancer clinical trials across varying racial and ethnic populations.

This type of social media analysis is innovative in its ability to mine large amounts of unstructured data and in its use of pattern recognition and adaptability instead of structured model assumptions. The ability to mine hundreds of thousands of web-based discussions across tens of thousands of sites allows us to nonintrusively capture spontaneous, real-time conversations about clinical trials from diverse populations. The high volume of discussions analyzed in this study gives us a unique opportunity to begin to thoroughly dissect these concerns by treatment stage and race or ethnicity and better understand the sentiments and feelings of the groups throughout the cancer care process.

In our analysis, issues related to HCP interactions, cost of care, fear, anxiety, and lack of awareness dominate the discussions among all racial and ethnic groups, but there are notable differences in the frequency of these topics and barriers discussed on the web by different populations. There is a wealth of literature on the barriers minorities face in clinical trial enrollment, and our data reiterate many of those findings, especially the significant roles of the HCP and patient relationship and discrepancies in the financial burden of care [18-21].

HCPs are the first line of interaction with cancer patients and are meant to fill in information gaps that patients have about their complete care, including disease expectations, treatment, symptom management, and costs of care. Unfortunately, data from this study and others show that some patients are not satisfied as they are not able to meet their needs. Although this study did not identify specific HCP issues, other studies have reported specific concerns. For example, many community physicians that minorities are most likely to access are not equipped to provide adequate information on these topics. These HCPs do not have the knowledge and/or time to research clinical trial options for all patients and lack adequate administrative support to assist patients with the enrollment and eligibility requirements [18,20]. Furthermore, many studies have noted implicit bias of physicians toward minorities, which may hinder appropriate discussions of clinical trial risks and benefits. These studies found that physicians may presume that minority patients cannot adhere to trial regulations or fear patient rejection from the trial [18,21]. Importantly, many clinical trials are not adequately designed to account for differences in baseline organ function and comorbidities that can differ between minority groups, leading to the failure of these patients to meet enrollment criteria [22,23].

Another significant barrier in the patient and provider relationship is trust. Minorities, especially African Americans, are much more likely to mention provider distrust as a health care barrier. This phenomenon has roots in the inequities in health care that these groups have experienced and past unethical research practices by the research community [24]. A recent meta-analysis by Hurd et al [25] examined the role of patient trust in oncology clinical trials and found that distrust of HCPs is most prominent at the periods of care transition, that is, transferring from a community physician to a cancer clinic for treatment and back again for monitoring or surveillance by the community physician. This is reflected in our data, particularly for African Americans, as illustrated in Figures 5 and 6, with increases in HCP concerns peaking at the coping and monitoring stages.

With increased recognition of the lack of diversity in clinical trials, considerable progress has been made in finding ways to better connect minority populations with clinical trial opportunities. The FDA recently published guidance on enrollment practices, eligibility criteria, and clinical trial design to enhance diversity [26]. Outreach by clinical trial sites to community physicians, leadership roles, committees committed to diversity, cultural training of physicians, community advisory boards and lay community representatives, culturally literate patient navigators, and culturally appropriate patient education [27-30] are all steps that have been shown to have a positive effect on minority clinical trial enrollment [18-21]. Recommendations to address minority distrust of HCPs include provider and support staff diversity, discussion of research transparency, and statement of overall clinical trial goals. The community mindset of some populations can also be leveraged to emphasize altruism and benefits to the community [31].

Besides HCPs and enrollment concerns, we found treatment cost to be a disproportionate concern for African Americans and Hispanics. This correlates with current research on minority clinical trial barriers [32-34] and is a significant topic that needs to be addressed. Direct costs of treatment are often covered by insurance policies under the requirements of the Affordable Care Act; however, older grandfathered plans and Medicaid often do not cover National Cancer Institute–designated centers in the network [33,34]. In addition to treatment costs, indirect care costs such as travel and lodging for patients who reside far from the treatment center are also of great concern. Some studies have shown that financial assistance plans increased enrollment of low-income and rural patients with financial barriers related to lodging and travel and that this intervention decreased this specific patient concern throughout their treatment process [35]. The widespread use of financial assistance has been limited, however, because of ethical concerns regarding the coercion of financially burdened patients to participate. The American Society of Clinical Oncology has issued recommendations on clinical trials to include health policy changes, cost transparency, clear incentives that do not coerce, and improved cost data [32].

Limitations

There are many limitations to this type of study. Although we were able to identify demographic information for many of the posters, more than half of the posters were unidentifiable. There may be a bias to the posts that were identifiable, and misidentification events are possible. Second, the feelings expressed in web-based forums may be different or skewed more negatively than feelings expressed elsewhere, such as during physician visits. In addition, whereas we did not include multiple posts by a single user within a thread or conversation, if users posted in multiple threads or on multiple sites, they may have been counted multiple times. We did not have access to other avenues that patients use offline to discuss and share information, which is evident in the lack of data on Hispanics in the coping stage, which may not allow us to obtain a complete analysis of all groups at all stages of treatment. Finally, we did not have information on clinical diagnoses, treatment offerings, treatment adherence, or outcomes for patients that would affect their sentiments.

Conclusions

Overall, this study provides detailed insights into the content and sentiments of web-based discussions regarding clinical trials. This information is valuable for identifying the ideal content and timing for the delivery of clinical trial information and resources for different racial and ethnic groups. Information on feelings and sentiments reveals opportunities to leverage hopeful and empowered feelings and dispel fears and misconceptions about clinical trial participation. Detailed information on clinical trial barriers, including distrust of HCPs, financial disparities, and the need for tailored education and enrollment assistance for minorities, is useful for developing strategies, policies, and practices to minimize health care inequality and increase the recruitment of minorities into clinical trials.

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Conflicts of Interest

None declared.

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Abbreviations

HCP: health care professional

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Original Paper

Usability, Acceptability, and Safety Analysis of a Computer-Tailored Web-Based Exercise Intervention (ExerciseGuide) for Individuals With Metastatic Prostate Cancer: Multi-Methods Laboratory-Based Study

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Abstract

Background: Digital health interventions such as tailored websites are emerging as valuable tools to provide individualized exercise and behavioral change information for individuals diagnosed with cancer.

Objective: The aim of this study is to investigate and iteratively refine the acceptability and usability of a web-based exercise intervention (*ExerciseGuide*) for men with metastatic prostate cancer and determine how well individuals can replicate the video-based exercise prescription.

Methods: A laboratory-based multi-methods design was used, incorporating questionnaires, think-aloud tests, interviews, and movement screening among 11 men aged 63 to 82 years with metastatic prostate cancer. Overall, 9 participants were undergoing androgen deprivation therapy, and 2 were completing chemotherapy. Data were collected in two waves, with changes made for quality improvement after participant 5.

Results: The intervention's usability score was deemed moderate overall but improved after modifications (from 60, SD 2.9 to 69.6, SD 2.2 out of 100). Overall, the participants found the intervention acceptable, with scores improving from wave 1 (24.2, SD 1.1 out of 30) to wave 2 (26.3, SD 2.1 out of 30). The personalized multimodal exercise prescription and computer-tailored education were seen as valuable. After wave 1, website navigation videos were added, medical terminology was simplified, and a telehealth component was included after expert real-time telehealth support was requested. Wave 2 changes included the added variety for aerobic exercise modes, reduced computer-tailoring question loads, and improved consistency of style and grammar. Finally, the participants could replicate the resistance exercise videos to a satisfactory level as judged by the movement screen; however, additional technique cueing within the videos is recommended to address safety concerns.

Conclusions: The acceptability and usability of *ExerciseGuide* were deemed satisfactory. Various problems were identified and resolved. Notably, the participants requested the inclusion of personalized expert support through telehealth. The resistance training algorithms were shown to provide appropriate content safely, and the users could replicate the exercise technique unaided to a satisfactory level. This study has optimized the *ExerciseGuide* intervention for further investigation in this population.

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KEYWORDS

exercise; metastatic prostate cancer; behavioral change; eHealth; computer-tailoring; usability; acceptability

Introduction

Background

Prostate cancer is the most prevalent cancer type and the second most common cause of cancer-related deaths among Australian men [1]. The 5-year survival rate for prostate cancer diagnosed at stage 1 (localized cancer) is 95% [2]. In contrast, the survival rate for stage 4 cancers (cancer metastasized beyond the tissues directly adjacent to the prostate gland) is just 36.4% [2]. However, therapeutic advances in the management of metastatic prostate cancer continue to extend survival time, necessitating a focus on supportive care to optimize quality of life, maintain function, and further improve the survival rate [3,4]. For example, individuals living with metastatic prostate cancer often present with numerous physical and psychological concerns, including cancer-related fatigue, urinary incontinence, pain, increased fat mass, reduced muscle mass, anxiety, and depression [4].

It has been well established that multimodal exercise (an intervention based on the combination of physical exercises of different components, such as cardiorespiratory and muscular strength) has been shown to maintain or improve well-being and physical functioning, including among men with localized prostate cancer [5]. However, until recently, exercise interventions were avoided for many individuals diagnosed with metastatic prostate cancer, particularly those with bone lesions, for fear of adverse events. Recent studies, including those by Galvao et al [6] and Cormie et al [7], have demonstrated the safety and preliminary efficacy of individually tailored, modular (designed to avoid excessive loading of lesion sites), and clinic-based exercise programs using randomized controlled trials, thus indicating that individually tailored exercise may provide a powerful addition to improve supportive care in this population.

Currently, individually tailored supervised exercise interventions delivered by oncology-trained exercise professionals are not extensively available outside of urban areas [6,8,9]. The time-related demands and financial pressures faced by men with metastatic prostate cancer may lead to reluctance or inability to attend supervised clinic-based exercise programs [4,10]. Recently, Brown et al [11] commenced research into a home-based exercise approach for individuals with metastatic prostate cancer, which uses a one-time face-to-face exercise assessment, print-based material, and weekly telephone contact for remote supervision and behavioral change counseling. To further increase the scalability, accessibility, and adherence to home-based exercise, the addition of digital technologies to this type of home-based exercise intervention may be advantageous.

One type of digital technology that could be a viable tool in exercise interventions is a computer-tailored website or app (where content material is adapted, with the aid of algorithms within the website or app, to the specific characteristics of a particular person). In 3 recent studies, Golsteijn et al [12], Trinh et al [13], and Kenfield et al [14] have all demonstrated the feasibility and acceptability of using web- or app-based tools to increase physical activity levels in individuals with prostate cancer (only Trinh et al [13] had individuals with metastatic cancer, 36%). However, these interventions focused on improving behaviors such as reducing sedentary levels and increasing moderate-to-vigorous physical activity levels. Furthermore, the three interventions did not provide tailored exercise programming [12-14]. Given that individuals with metastatic prostate cancer have varying levels of capacity and those with bone metastasis require tailored exercise programs that consider the location, extent, and type of metastatic lesion, personalized multimodal programs are exceptionally vital [5,6,8,15].

Engagement with digital physical activity interventions is considered important for their effectiveness, and thus evaluating the factors that influence engagement within tools such as *ExerciseGuide* is vital [16]. Perski et al [16] proposed a conceptual framework in which engagement with an intervention is influenced by factors such as the content and delivery of the tool, as well as the target population and environment. Delivery can be assessed by evaluating usability and the ease with which a platform can be used to attain a particular goal [17]. Acceptability is another concept that can be used to predict user engagement [18]. Acceptability is defined as "a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention” [19]. Therefore, following a user-centered approach, it is important to have the usability and acceptability of the intervention’s design and content assessed by individuals with metastatic prostate cancer.

Furthermore, the safety implications of computer-tailored exercise prescription in this population are unknown. It is necessary to determine whether individuals with metastatic prostate cancer can adequately replicate exercise without hands-on technique modification when needed. To answer these questions, we designed a laboratory-based study incorporating both quantitative and qualitative usability and acceptability user evaluations, as well as objective movement screening. This allows small-scale assessment of the intervention and iterative refinement before progressing to a larger-scale study [20].

Aims

This study aims to (1) examine and refine the acceptability and usability of a web-based exercise intervention (known as *ExerciseGuide*) for individuals with metastatic prostate cancer and (2) examine the safety of video-guided resistance exercises used within the *ExerciseGuide* intervention.

Methods

Study Design

Overview

This study is a laboratory-based assessment that used both qualitative and quantitative approaches. This trial was registered in the Australian New Zealand Clinical Trials Registry (ACTRN12618001978257) and approved by the University of Adelaide Human Research Ethics Committee. Study materials, including the participant information sheet and data request forms, are available through the Open Science Framework.

ExerciseGuide Intervention Development

The design and development process of the web-based exercise website (*ExerciseGuide*) used a multidisciplinary approach (exercise physiology, behavioral science, public health, medical oncology, and urology) that was guided by the intervention mapping protocol [21] and preliminary research [6,22,23].

Participants and Screening

Men with metastatic prostate cancer were recruited using convenience sampling methods, which involved advertising the study through social media and intermediaries (oncologists, nurses, participant registries, and support groups). Previous evidence has shown that more than 80% of the usability issues can be detected with 5-9 participants and 90%-95% using 10-12 participants [24]; therefore, a sample size of approximately 10 participants was proposed.

To be eligible, participants needed to be diagnosed with metastatic prostate cancer, able to obtain consent to participate from their physician, able to attend a single 90- to 120-minute face-to-face session at the University of Adelaide (Adelaide) or the University of Melbourne (Melbourne), confident of their ability to participate in some form of moderate resistance exercise for 5 minutes or more, and able to read and write in English. The participant flow is presented in Figure 1.

Figure 1. Participant flow chart for individuals with metastatic prostate cancer.

Study Procedure

Overview

To investigate the study aims, four assessment blocks were used: (1) a think-aloud usability test, (2) questionnaires to assess usability and acceptability, (3) exercise demonstration and movement screening to determine the safety and potential efficacy of video-guided resistance exercises, and (4) qualitative interviews further assessing acceptability and perceived usefulness. In all, two iterative cycles were conducted, with website alterations made after the fifth and eleventh participants based on usability issues identified across the assessment blocks.

The participants were sent a link to the self-administered baseline questionnaire through REDCap (Research Electronic Data Capture; Vanderbilt University) 24 hours before arriving at the laboratory for testing. The questionnaire was used to collect general and prostate cancer–specific demographic data, including prostate-specific antigen score (ng/mL), time since disease diagnosis (years), and the number of bone metastases. Physical activity behavior was measured using the modified Godin Leisure-Time Exercise Questionnaire. The weekly frequencies (longer than 15 minutes) of vigorous, moderate, and light physical activities were weighted and summed to obtain a total score in units [25]. The 2-week test-retest reliability was found to be high [26]. The 12-item Short Form Survey, which is a reliable and valid instrument for adults with cancer, was used to quantify health-related quality of life [27]. Internet use was gauged based on a question used in the study by Short et al [28], and internet confidence (3 items rated on a 0-100 scale) questions were study specific.

Assessment Block 1: Usability Testing Using the Think-Aloud Testing Methodology

A concurrent think-aloud approach was used to identify usability issues within the website. This approach has been recognized as one of the most effective and commonly used tools to understand usability in eHealth work, especially when used in conjunction with other methods [17,29]. The laboratory location was chosen because laboratory studies have shown results similar to those obtained in field testing, while being time and resource efficient [30]. The *ExerciseGuide* website was presented on either a Windows (Microsoft Corporation) or Apple (Apple Inc) laptop, as chosen by the participants. A researcher (HELE) asked the participants to verbally narrate their thought processes and feelings while completing the designated tasks on the *ExerciseGuide* website (Multimedia Appendix 1). The tasks included logging in, answering module questions (to read tailored content), generating their personalized exercise prescription, watching videos, and identifying key tools such as the library and frequently asked questions (Figure 2). When the participants fell silent for approximately 30 seconds or became stuck in a particular task, they were encouraged to express what they were thinking. The think-aloud sessions were audiotaped, and written notes were taken by the researcher.

Figure 2. *ExerciseGuide* website screenshots of (1) the home page (top left), (2) Making It Last module tailoring questions (top right), (3) My Exercise Plan module (bottom left), and (4) library page (bottom right).

Welcome to Exercise Guide

Exercise is an impressive drug that can provide a wide array of physical and psychological benefits for men with metastatic prostate cancer. Exercise Guide program aim's to give you reliable and effective exercise advice. You can think of the program as a compass - you can use it as you like, when you like, to get to where you want to go.

My Exercise Plan

Exercise prescription module

INTRODUCTION:

There is not a one-size-fits-all approach to exercise. For it to be truly beneficial and manageable, your exercise regime should be personalized just for you. It should take into account your current circumstances, activity levels and other injuries.

Please answer all the questions to receive your tailored exercise program. It will include components such as:

- A resistance training program to increase your muscular strength
- An aerobic fitness program to help improve your endurance
- A mobility program

In your everyday life, do you experience pain when you:

Note: This may or may not relate to you metastases.

		Yes	No
Pull a heavy door open?	edit #3	○	●
Push a heavy door open with your arms?	edit #4	○	●
Lift your arms above your head whilst holding a heavy object?	edit #5	○	●
Bend or straighten your elbow whilst holding a heavy item?	edit #6	○	●
Completing activities like picking up heavy boxes in your lower back?	edit #7	●	○

Making it last

Keep planning

It is great to see that you already have an exercise plan. You are well ahead of the game. Planning has been shown to be an effective strategy for helping people to adopt new exercise behaviours. Having a plan helps to translate intentions into actions.

The research evidence focuses on a specific type of planning. This is described below. You might like to consider how you like to plan compares to the type of specific planning we are talking about. If it is working for you though, no need to reinvent the wheel. Feel free to skip to the next section.

What type of planning has been shown to work?

Plans that have been shown to work have two key features: Specific details about your intentions and a plan B.

The ExerciseGuide program can help you with the what.

But you will need to fill in when, where and with who.

Friends and family can be your biggest motivators

If you are not feeling well, how will you modify your routine?

If you exercise outside, what will you do in bad weather?

If you aren't motivated, what will you do to make sure you stick to your plan?

Once you have the specific details written down you can have plan B taken care of by including **If then** statements about key barriers. Consider these situations:

Welcome to the EXERCISE GUIDE Library

The information found within this library is here to give you additional resources to read if you like. You make click on the subject headers/tags (to the left) if there is a particular topic that interests you. If you have resources of your own that you have found very useful and would like to share, please let us know (holly.evans@adelaide.edu.au) and we can share with the men using this website.

Assessment Block 2: Usability and Acceptability Questionnaires

A questionnaire was administered in private after the completion of think-aloud testing. Website usability was assessed using the System Usability Scale (SUS), which includes 10 questions rated from 1 (strongly disagree) to 5 (strongly agree) [31]. It is the most commonly used questionnaire for the assessment of perceived usability [32]. The reliability of the SUS (coefficient α) was high, and the concurrent validity was significantly correlated [32].

For the purpose of this study, 6 questions were used to determine participant perception of intervention acceptability using a 5-point Likert scale (from 1=strongly disagree to 5=strongly agree) [19,28]. The questions were used previously by Short et al [28], and the internal consistency of the SUS was found to be high [28]. The purpose was to examine if the website was interesting, credible, easy to understand, relevant, and if the participants were likely to recommend the website to a friend.

Assessment Block 3: Resistance Exercise Demonstration and Movement Screening Analysis

A qualified exercise physiologist (HELE) reviewed the resistance exercise prescription that the participants generated using the *ExerciseGuide* website within the think-aloud protocol to determine if any of the recommended exercises were inappropriate. Any exercise deemed unsafe based on the location of the metastases would not be completed. The participants were asked to replicate each exercise under the direct observation of the exercise professional. For each exercise, they were able to watch the exercise demonstration video and read the written instructions as many times as needed. The participants selected the resistance exercise band that they felt would produce an effort of 6-7 out of 10 on the OMNI Perceived Exertion Scale for Resistance Exercise and completed 8 repetitions. The participant was recorded using 2 iPads (Apple Inc; 30 frames per second, 1080p) mounted on tripods positioned orthogonal to each other. Camera 1 was positioned to record the sagittal movement plane and camera 2 the frontal plane [33]. The participants reported a verbal pain score (0-10) during and after the exercise and a verbal rating of perceived exertion (0-10) after the exercise. The exercise was halted if the pain level score was higher than 3 out of 10 or if the technique was unsafe.

The movement screening analysis was completed by 5 independent exercise physiologists, accredited by Exercise and Sports Science Australia, each with more than 5 years of clinical experience (Table 1). The video recordings of each resistance exercise were assessed using a standardized form developed by an exercise physiologist (HELE) a priori based on evidence-based movement quality assessment (Multimedia Appendix 2). Each exercise was individually scored in terms of both safety and efficacy items (between 6 and 8 items per exercise) on a scale of –1 (unsatisfactory, with major concerns) to 2 (good). The exercise physiologists were encouraged to provide notes regarding the movement issues where applicable. Before analysis, the scores were transformed to reflect a positive score ranging from 1 to 4 for each item. The item scores were then added to create an overall movement score. The information collected was also used to determine the interrater reliability of the tool among the experts.

Table 1. Reviewer (exercise physiologist) characteristics.

Reviewer	Occupational setting	Experience (years)	Gender	Current location
1	Private practice	9	Female	Victoria, Australia
2	Public health	9	Female	Victoria, Australia
3	University and private practice	20	Female	Queensland, Australia
4	Private practice	5	Female	New South Wales, Australia
5	Private practice	7	Male	South Australia, Australia

Assessment Block 4: Qualitative Interviews

Finally, the participants completed a one-on-one short semistructured interview with a researcher (HELE) to identify further technical issues, investigate user experiences, and obtain feedback to improve site content and usability. The interview guide consisted of 8 open-ended questions (Multimedia Appendix 3). The interviews were audiotaped and transcribed verbatim.

Data Analysis

Quantitative analyses were performed using Jamovi software (version 1.6.3; The Jamovi project). Descriptive statistics were calculated with mean values and SDs for normally distributed data and medians with range or percentage for nonnormal and categorical data. In addition, intraclass correlation coefficients were calculated to determine the interrater reliability of the overall exercise movement screening scores.

The qualitative data collected were analyzed using thematic analysis as described by Braun and Clarke [34]. This process has previously been used to analyze data from usability think-aloud studies and involves data familiarization, generation of initial codes, theme identification, refining of themes, and theme names [34]. In this study, an initial set of themes was produced and organized by the first author (HELE) using Microsoft Excel (Microsoft Corporation) and iteratively refined with a second author (CES), leading to the discovery of new themes or renaming of existing themes. Descriptive quotes illustrating the themes were identified and reviewed by all the authors. The results were reported based on the topic area (ie, usability, acceptability, and safety) rather than through assessment block to aid interpretation in accordance with the study aims.

Ethics Approval and Consent to Participate

This study was performed in accordance with the principles of the Declaration of Helsinki. Ethical clearance was obtained from the University of Adelaide Research Ethics Committee (H-2017-174). The participants were required to provide signed, freely given informed consent at the time of enrollment.

Results

Participant Characteristics

A total of 11 men with metastatic prostate cancer were recruited for this study, and their characteristics are presented in Table 2. Most of the participants were married and residing in a major city. There were no significant differences in the characteristics of the participants between cycle 1 and cycle 2. Confidence in internet use was moderate on average.

Table 2. Participant characteristics (N=11).

Characteristics	Cycle 1 (n=5)	Cycle 2 (n=6)	Total (N=11)
Age (years), mean (SD)	74.8 (7.2)	72 (6.5)	73.37 (6.7)
BMI (kg/m^2), mean (SD)	27.13 (2.2)	29.9 (6.1)	28.6 (4.7)
Married, n (%)	4 (80)	6 (100)	10 (91)
Location, n (%)			
Major city	4 (80)	6 (100)	10 (91)
Very remote	1 (20)	0 (0)	1 (9)
Education, n (%)			
Secondary school	3 (60)	1 (17)	4 (36)
Trade, technical certificate, or diploma	2 (40)	1 (17)	3 (27)
University or other tertiary	0 (0)	2 (33)	2 (18)
Postgraduate	0 (0)	2 (33)	2 (18)
Employment, n (%)			
Employed full time	1 (20)	0 (0)	1 (9)
Employed part time	0 (0)	0 (0)	0 (0)
Self-employed	0 (0)	1 (16.7)	1 (9)
Retired	3 (60)	4 (67)	7 (64)
Volunteer	1 (20)	1 (17)	2 (18)
Current PSA[a] level, ng/mL, median (IQR)	0.32 (0-6.32)	0.015 (0.10-2.23)	0.02 (0-4.17)
Time since metastatic disease diagnosis, years, mean (SD)	2 (0.8)	2.6 (3.1)	2.3 (2.2)
Individuals with ≥1 bone lesion, n (%)	4 (80)	5 (83)	9 (82)
Comorbidities, mean (SD)[b]	2.8 (1.5)	2.7 (0.9)	2.7 (1.2)
Self-reported quality of life (SF-12[c]), mean (SD)[d]			
PCS-12[e] (physical score)	46.23 (5.6)	36.80 (12.8)	41.09 (10.9)
MCS-12[f] (mental score)	58.9 (3.3)	52.1 (4.3)	55.3 (5)
Self-reported physical activity, mean (SD)			
Aerobic physical activity (GLTEQ[g] units)[h]	53.8 (22.3)	32.8 (21.9)	42.4 (23.7)
Resistance training sessions (per week)	2.2 (1.7)	2.2 (1.3)	2.2 (1.5)
Average internet use (hours per week), n (%)			
≥6	1 (20)	4 (67)	5 (45)
3-5	2 (40)	0 (0)	3 (18)
2-3	1 (20)	1 (17)	2 (18)
≥1	0 (0)	1 (17)	1 (9)
None	1 (20)	0 (0)	1 (9)
Confidence to use the internet (0-100 scale)[i], mean (SD)			
Finding information on the internet	63.6 (30.1)	72.2 (36.1)	68.3 (33.7)
Using the internet to interact with others (eg, social media)	53.2 (36.4)	55.2 (20)	54.3 (28.6)
Using an interactive website to help increase physical activity	44 (39.9)	46.3 (40.9)	45.3 (40.5)

[a] PSA: prostate-specific antigen.

[b] Comorbidities include hypertension, osteoarthritis, chronic nonspecific back pain, osteoporosis, type 2 diabetes, cardiovascular disease, and mental health conditions.

[c] SF-12: 12-item Short Form Survey.

[d] Scores range from 0 to 100, where 0 implies the lowest level of quality of life, and 100 indicates the highest level of quality of life.

[e] PCS-12: Physical Component Score.

[f] MCS-12: Mental Component Score.

[g] GLTEQ: Godin Leisure-Time Exercise Questionnaire.

[h] Self-reported physical activity level from the Godin Leisure-Time Exercise Questionnaire. Physical activity score (units) = strenuous (9 METs × times/week) + moderate (5 METs × times/week) + light (3 METs × times/week). One metabolic equivalent (MET) is the amount of oxygen consumed while sitting at rest and is equal to 3.5 mL of oxygen per kg body weight × minutes [26].

[i] Confidence in using the internet scored on a scale from 0 to 100 (0=not confident at all, 100=extremely confident).

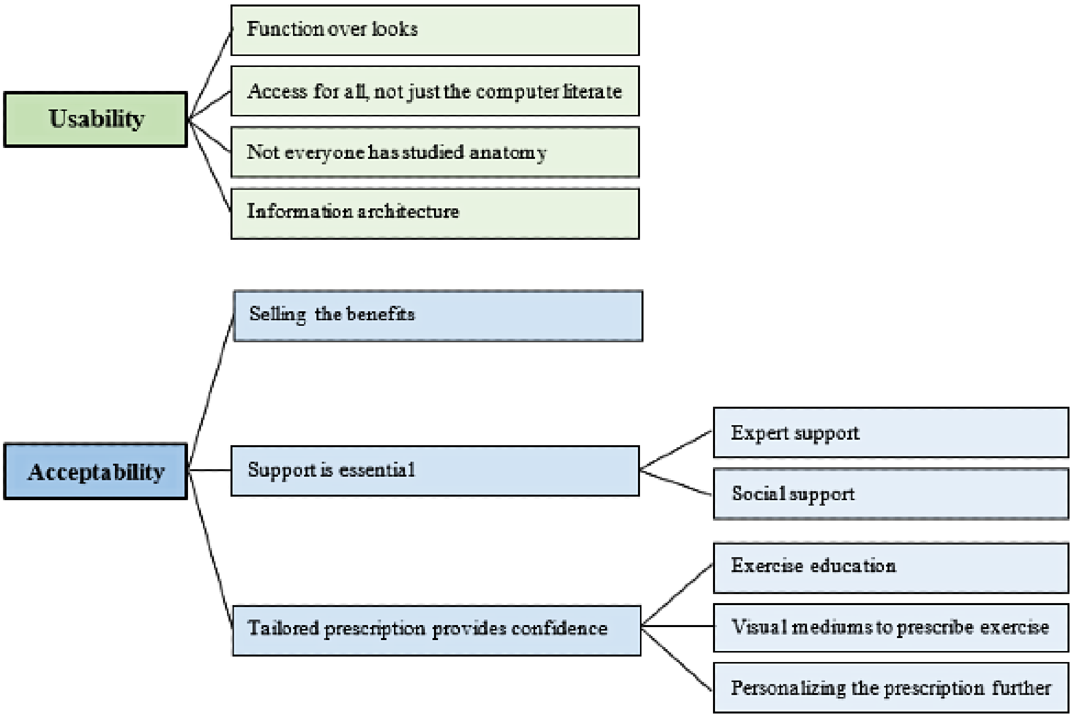
Usability

Overview

There was an increase in the usability score from 60 (SD 2.9) to 69.6 (SD 2.2) out of 100 between cycle 1 and cycle 2, indicating that the changes suggested by the participants increased the usability to *slightly above average* (based on industry standards) [31]. Qualitative feedback regarding usability is summarized below. A list of changes made to the website based on user feedback is presented in Multimedia Appendix 4.

The qualitative usability feedback centered around four themes, as shown in Figure 3. The participants discussed the need for simplicity in the website design and suggested that the function should trump looks, that the design needs to account for those with lower computer literacy, and that the terminology should be simplified but not come across as patronizing. They also observed that efforts to reduce information overload are required.

Figure 3. Coding structure derived from thematic analysis.



Theme 1: Function Over Looks

The participants (5/11, 45%) reported that esthetics were not as important as the functionality of a website:“ It is not very ornate, but I think the simplicity is helpful because it gives you the specifics, and it’s not offensive in any way.” [ID 03, aged 78 years, <1 year after diagnosis]. Of the 11 participants, 2 (18%) reported that this desire was linked to their gender:

> *I didn’t need it to look more pretty, I don’t care about that...a lot of males in my age group wouldn’t be all that worried about that either.* [ID 07, aged 72 years, 3 years after diagnosis]

In general, the participants liked that the website was plain but straightforward, and that made the website user friendly.

Theme 2: Access for All, Not Just the Computer Literate

Of the 11 participants, 3 (27%) believed that aspects of the website were not designed for individuals with lower literacy levels:

> *You are 80% simple, but I still looked at it and went ehhhh...it was a bit daunting.* [ID 11, aged 65 years, 1 year after diagnosis]

Questionnaires used to tailor content and the website navigation videos should be further simplified. Of the 11 participants, 3 (27%) could not get the videos to play, and 5 (45%) found that the introduction videos moved through information too quickly. Of the 11 participants, 1 (9%) man with low computer literacy could not complete the think-aloud protocol without support and preferred an option where information could be printed for him:

> *I'm very unfamiliar with them [computers]. If you wrote it all on a piece of paper, then it would be easy, but it's not like that.* [ID 02, aged 82 years, 4 years after diagnosis]

In addition, another participant suggested that the use of closed captions would increase usability for individuals with hearing concerns.

Theme 3: Not Everyone Has Studied Anatomy

The participants also desired more lay language in the health education provided. The use of medical terminology hampered usability in this population: "The explanations need to be for someone like me who hasn't done anatomy." [ID 06, aged 73 years, 1 year after diagnosis]. Of the 11 participants, 5 (45%) men questioned words such as androgen deprivation therapy, neutrophils, and hypertrophy. Information should be presented in laymen's language without being patronizing. Of the 11 participants, 1 (9%) suggested that terminology is still useful but could be linked to a quick and easy definition: "Where we have terminology, put in there so if the person hovers their mouse or their stylus over the word, then the definition would pop up?" [ID 07, aged 72 years, 3 years after diagnosis].

Theme 4: Information Architecture

The flexible modular design was seen as clear and user friendly by 55% (6/11) of the participants. The modules reduced the content into smaller bite-sized chunks and allowed simple navigation: "I like the way it is modulised, so I can come into it any time and examine any part of it, then go away and come back and do another module later." [ID 09, aged 78 years, 6 years after diagnosis]. Most of the men (8/11, 73%) appreciated the flexible nature, where they could read the information that was most meaningful to them.

Furthermore, the use of computer tailoring was a standout for many of the participants (5/11, 45%) because it reduced the amount of content within the website:

> *I thought the way it was designed to cater for individual people instead of a one-size-fits-all...That was a standout I thought.* [ID 01, aged 74 years, 8 years after diagnosis]

However, of the 11 participants, 4 (36%) still felt that the website was very content dense and that modules and associated tailoring questions could be condensed or split. Furthermore, of the 11 participants, 1 (9%) believed that introducing the website and providing examples of how the website can be used may improve usability:

> *Introducing the options of how to use the website at the outset, either sequentially or dipping in where appropriate. Going through the whole thing end to end, that's fairly daunting because of the amount of information.* [ID 08, aged 64 years, 2 years after diagnosis]

Acceptability

Overview

Overall, the participants' perceptions of the website were largely positive across both cycles (Table 3). Of note, the participants were in strong agreement that they would be happy to recommend the website to a friend with the same diagnosis (11/11, 100% reporting agree or strongly agree). The lowest score revolved around the ease of understanding of the information presented. A list of changes made to the *ExerciseGuide* intervention based on user feedback is presented in Multimedia Appendix 5 [35].

Each item was scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The overall acceptability score was the sum of the scores from all 6 questions. The total overall acceptability mean score for cycle 1 was 24.2 (SD 1.1) and cycle 2 was 26.3 (SD 2.1). The combined mean score was 25.4 (SD 2).

The participants' qualitative feedback centered around the factors that they believed would improve the website (Figure 3). More strongly, selling the benefits of exercise was deemed important, as was support from both experts and those close to the participants. Finally, confidence in completing the exercises safely and effectively was also noted.

Table 3. Website acceptability ratings (N=11).

Acceptability item	Cycle 1 (n=5), mean (SD)	Cycle 2 (n=6), mean (SD)	Total (N=11), mean (SD)
The information provided to me on the website was interesting.	4 (0)	4.33 (0.5)	4.2 (0.4)
The information provided to me on the website was credible.	4 (0)	4.5 (0.5)	4.2 (0.5)
The information provided to me on the website was easy to understand.	3.6 (0.9)	4.2 (0.4)	3.9 (0.7)
The information provided to the website was relevant to me personally.	4 (0)	4.33 (0.52)	4.2 (0.4)
I would recommend the website to a friend with the same diagnosis as me.	4.4 (0.6)	4.7 (0.5)	4.6 (0.5)
The website seems like it was written for someone like me in mind.	4.2 (0.8)	4.3 (0.5)	4.3 (0.7)

Theme 1: Selling the Benefits

Of the 11 participants, 3 (27%) noted the importance of exercise, and 2 (18%) believed that there was not enough emphasis on explaining the benefits of exercise:

> *You need to sell the story. Explain the research behind it, that it's not a myth. That there is lots of evidence with prostate cancer, that Australia is leading the field.* [ID 08, aged 64 years, 2 years after diagnosis]

Another participant believed that the website should sell the benefits of exercise as soon as possible, rather than just addressing the benefits in one module that may not be accessed:

> *The home page doesn't explain enough...you are trying to sell an idea to a person who is going to say fuey, I don't need that...you are selling the concept.* [ID 04, aged 63 years, <1 year after diagnosis]

Theme 2: Support Is Essential

Support by experts, family, and friends emerged as an important aspect of the intervention to improve adherence to an exercise program and help guide the website's use.

Expert Support

Expert support was highlighted as a method of support deemed valuable by 36% (4/11) of the participants. Having access to an expert may increase confidence in the exercises prescribed because the participants could ask questions about the website, have exercises modified, identify exercise barriers and facilitators, and receive external motivation:

> *It would be good to have a backup, some actually contacting the person saying how's it going, did you like the exercises? You know...just to be a buddy.* [ID 07, aged 72 years, 3 years after diagnosis]

The desired regularity of contact varied between weekly and monthly interactions, and video conferencing, phone calls, and emails were all acceptable. Of the 11 participants, 2 (18%) noted that the support would only be useful if it were personalized rather than automated.

Social Support

A supportive social environment was reported as the other possible facilitator to intervention adherence: "The real attraction about going out [to exercise with friends] is to stop midway through for a coffee and a chat, and I think that makes a big thing." [ID 01, aged 74 years, 8 years after diagnosis]. Of the 11 participants, 2 (18%) believed that encouraging participants to develop, reconnect, or enhance social support structures such as family or friends to prompt and support exercise adherence would be effective.

Theme 3: Tailored Prescription Provides Confidence

The participants discussed a lack of confidence in exercising because they were unsure of what exercises were safe and effective. Supplying tailored prostate cancer–specific exercise information, which could be modified to suit the participant, was highlighted as a way to increase confidence.

Exercise Education

There was an appreciation that the website provided tailored prostate cancer–specific information: "I understand that it is good to exercise, but I haven't had a definition of how much to do, and this may give me that information, which will be good." [ID 03, 78 years old, newly diagnosed]. In general, the multimodal exercise program was positively received by all participants: "They [the exercises] were within my abilities but there again, with the different therabands, it's probably going to be suitable for a big range of people." [ID 01, aged 74 years, 8 years after diagnosis]. Of the 11 participants, 3 (27%) wanted additional options of aerobic activity, rather than just walking or cycling, and 2 (18%) requested a tailored stretching program.

Visual Mediums to Prescribe Exercise

Video-based exercise prescription was seen as an appropriate and useful medium by all participants. In general, the participants typically used the on-demand videos rather than the written instructions:

> *The videos were great. The presenter was well spoken, you could hear what he was saying. They were crisp and clear. Easy to follow. Easy to backtrack.* [ID 04, aged 63 years, newly diagnosed]

Of the 11 participants, 9 (82%) reported feeling confident in completing the exercises without additional support after watching the videos, and 4 (36%) were comfortable returning to the videos as often as needed to ensure that their technique was correct. Of the 11 participants, 1 (9%) noted that the exercise trainer could have more readily explained what muscles should be focused on and explain why the exercise would be useful from a functional perspective:

> *The trainer could have explained what muscles he was using. That way, the person knows why he is doing that exercise; they are not just a sheep following a thing...He did on some, but he needed to acknowledge why.* [ID 07, aged 72 years, 3 years after diagnosis]

There was a perception that many men may overload themselves when exercising, which may lead to an increased risk of injury (2/11, 18%). Providing simple ways to monitor their exercise intensity was highlighted and may reduce the risk of injury in this population:

> *I think that this [rate of perceived exertion information] is really important. Sweeping generalization comes up, but men tend to push themselves slightly harder than they should. They are competing with themselves, and that can lead to injury.* [ID 06, aged 73 years, 1 year after diagnosis]

Personalizing the Prescription Further

Multiple participants (7/11, 64%) provided further information to support individual autoregulation. Of the 11 participants, 4 (36%) discussed techniques to increase or decrease their exercise intensity to suit how they feel on the day, and 1 (9%) noted that not all participants wanted to make progress regarding their exercise intensity. Maintenance of strength and aerobic fitness are noteworthy goals, especially for those who do not enjoy exercise. Tailoring messages to avoid pushing individuals into making progress regarding their exercise intensity may improve adherence:

> *Once you get to a fitness level that suits you, why push it. Where here is it's saying you need to make it harder to challenge yourself...I don't think we need to challenge ourselves. I think it is just a challenge just to exercise for some people.* [ID 04, aged 63 years, <1 year after diagnosis]

Finally, 27% (3/11) of the men found that the program needed to include modifications to suit those already doing some form of exercise to reduce confusion and possible overload. As long as safety concerns have been addressed, the *ExerciseGuide* program should sit within an individual's exercise schedule, rather than completely changing it.

Safety-Movement Screening

The website prescribed 6.6 (SD 1.5) exercises per participant on average. A total of 18 of the possible 25 exercises available were prescribed. No exercises were removed for safety reasons, as judged by the participant or by a supervising exercise physiologist. The participants reported a mean rate of perceived exertion score of 6.2 (SD 1.2) and a mean verbally reported pain score of 0.2 (SD 0.3) (possible range 0-10). Of the 11 participants, 2 (18%) reported a pain level of 3-4 out of 10 on 3 different exercises (single leg lift, seated knee extension, and seated march). On both accounts, the pain was linked to previous knee injuries and was not recorded as bone pain. Pain resolved once the movement ceased.

Overall, no exercises were deemed unsatisfactory, with all meeting the cutoff point for safety defined as a rating of *satisfactory* or *good*, as demonstrated in Multimedia Appendix 6. Only reviewer 2 scored 1 exercise as unsatisfactory (seated triceps extension). However, it is noteworthy that the intraclass correlation coefficients for the combined item scores demonstrated very low interrater reliability among the assessors (0-0.592).

When viewing the mean scores of the individual items within each exercise, it was clear that overall, participants set up satisfactorily (3.6, SD 0.3 out of 4). Of the 11 participants, only 2 (18%) set up in an unsatisfactory manner: 1 in the seated row and 1 in the incline push-up. On average, the participants could complete the movements in a slow, controlled manner (3.8, SD 0.2 out of 4) as directed. However, it was notable in the triceps extension and bicep curl exercises that the individuals did not satisfactorily maintain appropriate elbow positions that would isolate the target muscle groups, increasing loads around the thoracic region. In addition, in the lower body exercises that required resisted knee flexion and extension, the individuals did not satisfactorily maintain their torso vertical, which may lead to additional strain through the anterior hip and lumbar spine.

Discussion

Principal Findings

This is the first study to examine the acceptability, usability, and safety aspects of a web-based exercise intervention tailored directly for individuals with metastatic prostate cancer. Overall, the participants found the tailored intervention acceptable and a user-friendly method of delivering credible health-based education, exercise prescription, and behavioral change advice. This is in line with previous studies in older adults with localized prostate cancer [14].

The participants were more interested in functionality than esthetics. This is in accordance with the Technology Acceptance Model, which posits that use is determined by the perceived ease of use and usefulness of technology [36]. Alterations made after the first cycle, including increased text size (from 12 point to 15 point), greater format consistency, and education to upskill users in website use, mirror existing eHealth recommendations [37].

The use of computer tailoring within the *ExerciseGuide* intervention was viewed as a strength by the participants. Older adults have been reported to have difficulty filtering out useful information from generalized text because of changes in working memory [38]. Tailoring information ensures personal relevance, individualized exercise prescription, and limitation of superfluous information [39]. Notably, additional tailoring occurred after the first iterative cycle, with the aim of increasing the personalization of exercise and reducing the amount of content. An improvement in both relevance and ease of understanding the scores was achieved in cycle 2. However, the use of questionnaires within each module to collate tailoring information still has some limitations. Ghalibaf et al [40] reported decreased usability and acceptability because participants find providing the system with information time consuming. Further research is needed to determine other user-friendly and accurate methods of information collection.

There was disagreement among the participants regarding the use of medical terminology within the intervention. Previous studies corroborate the viewpoint of several of the participants who deemed simplified language to be important for usability [41,42]. However, other participants in this study appreciated the use of medical descriptions. As such, if medical terminology is used, it should be clearly explained, thus providing a chance to improve the health literacy of participants.

Most of the participants emphasized the need for multiple avenues of personalized expert support throughout the *ExerciseGuide* intervention to ensure higher levels of uptake, adherence, and safety. Haberlin et al [43] reported a need for on-site exercise prescription and behavioral change support at the start of a physical activity eHealth intervention. However, the participants in this study were comfortable with remote telehealth technology such as teleconferencing (otherwise known as real-time video counseling), phone conferencing, email, and instant messaging as vehicles of support from health professionals. It is theorized that the injection of this type of technology into home-based exercise prescription can increase supervision and improve the participant–health professional relationship while still being a cost-effective and accessible intervention [44,45]. Interestingly, Byaruhanga et al [46] reported that real-time video counseling could enhance physical activity behaviors in clinical populations compared with usual care. However, other telehealth tools (eg, email and SMS) also have benefits such as accessibility, satisfaction, and comfort [47]. Further research is still needed to explore the efficacy of different types of technology for exercise prescription and support in this population and others.

The computer-tailored resistance exercise prescription was effective at prescribing clinically recommended exercises to the patients in this study. The participants reported finding the resistance exercise demonstration videos easy to follow and could replicate them to at least a satisfactory level, as judged by the novel movement screen. However, the movement screen analysis indicated that when prescribing distance-based exercise programs to individuals with metastatic prostate cancer, exercise professionals should focus on body positioning to allow greater isolation of the targeted muscles and reduce the mechanical load on bone lesions. Highlighting proper positioning by emphasizing the important cues in the video, explaining why isolation is important, and encouraging visual cues (ie, mirrors) are all methods that could be beneficial.

Strengths and Limitations

A strength of this evaluation was the emphasis on user-centered assessment and the novel approach to appraising exercise prescription safety within a tailored web-based intervention. However, this study should be evaluated within its limitations. Overall, the sample population consisted of Caucasian, English-speaking men with a relatively high level of exercise activity and internet experience and may not reflect the full range of user experiences. Second, the methodology did not include safety testing for aerobic exercise because of resource constraints, and the interclass correlation for the movement screening tool was very low. Third, the study recruited a small number of participants. The sample size is typical for usability testing, and the researchers felt that data saturation for the qualitative components was achieved. However, it is possible that a greater range of feedback would have been captured in a larger sample. Finally, the sample website did not contain all the behavioral change and other educational content planned for the full website. The authors felt that the participants would experience the main components of the abridged website's design and content.

Conclusions

This preliminary study exemplifies how evidence-based theory and the target users' input can facilitate the development of a web-based exercise intervention to meet the needs and preferences of this population. On account of the iterative nature of this study, numerous issues were identified and resolved. A prominent finding was the request for distance-based personalized support as an addition to the intervention in the form of video conferencing, phone conferencing, or SMS. Overall, the design and content within *ExerciseGuide* were viewed as acceptable and user friendly. The resistance training algorithms were shown to provide appropriate content safely, and users could replicate the exercise technique unaided to a satisfactory level. This study will be used to further refine the *ExerciseGuide* website. The next phase of testing will be conducted to determine the feasibility and preliminary efficacy of the tool [35].

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Authors' Contributions

CES, CCF, DAG, RUN, CV, SC, ADV, GW, GK, and NB collaborated to design the study and the successful grant application. All authors contributed to the study protocol. HELE and CCF adapted the exercise prescription work by DAG and RUN into computer algorithms. HELE and CES drafted the manuscript, and all authors contributed to reviewing the draft manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Think-aloud test instructions.
[DOCX File , 16 KB - cancer_v7i3e28370_app1.docx]

Multimedia Appendix 2

Movement screening proforma.
[DOCX File , 53 KB - cancer_v7i3e28370_app2.docx]

Multimedia Appendix 3
Semistructured interview guide.
[DOCX File , 15 KB - cancer_v7i3e28370_app3.docx]

Multimedia Appendix 4
Think-aloud modifications.
[DOCX File , 16 KB - cancer_v7i3e28370_app4.docx]

Multimedia Appendix 5
<italic>ExerciseGuide</italic> intervention-specific changes pre- and postusability study.
[DOCX File , 21 KB - cancer_v7i3e28370_app5.docx]

Multimedia Appendix 6
Movement screening scores and intraclass correlation to estimate interrater reliability.
[DOCX File , 19 KB - cancer_v7i3e28370_app6.docx]

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Abbreviations

REDCap: Research Electronic Data Capture
SUS: System Usability Scale

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Review

Current Evidence and Directions for Future Research in eHealth Physical Activity Interventions for Adults Affected by Cancer: Systematic Review

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Abstract

Background: Physical activity (PA) interventions can increase PA and improve well-being among adults affected by cancer; however, most adults do not meet cancer-specific PA recommendations. Lack of time, facility access, and travel distances are barriers to participation in PA interventions. eHealth technologies may address some of these barriers, serving as a viable way to promote PA behavior change in this population. However, no review from July 2018 has synthesized available evidence across eHealth and cancer types or examined the use of behavioral theory and behavior change techniques (BCTs), leaving important gaps in knowledge.

Objective: This review aims to provide a comprehensive, updated overview of evidence on eHealth PA interventions for adults with cancer by describing the current state of the literature, exploring associations between intervention characteristics and effectiveness, and identifying future research needs.

Methods: MEDLINE, Embase, CINAHL, SportDiscus, Scopus, and CENTRAL were searched for eHealth PA interventions for adults affected by cancer. Study selection and data extraction were performed in duplicate, with consultation from the senior author (NCR). BCT coding, risk of bias, and completeness of reporting were performed using standardized tools. Results were summarized via narrative synthesis and harvest plots. Weight analyses were conducted to explore the associations between intervention characteristics and effectiveness.

Results: A total of 71 articles (67 studies) involving 6655 participants (mean age 56.7 years, SD 8.2) were included. Nearly 50% (32/67) of the articles were published after July 2018. Significant postintervention PA increases were noted in 52% (35/67) of the studies, and PA maintenance was noted in 41% (5/12) of the studies that included a follow-up. Study duration, primary objectives, and eHealth modality (eg, websites, activity trackers, and SMS text messaging) varied widely. Social cognitive theory (23/67, 34%) was the most used theory. The mean number of BCTs used across the studies was 13.5 (SD 5.5), with self-monitoring, credible sources, and goal setting being used in >90% of studies. Weight analyses showed the greatest associations between increased PA levels and PA as a primary outcome (0.621), interventions using websites (0.656) or mobile apps (0.563), interventions integrating multiple behavioral theories (0.750), and interventions using BCTs of problem solving (0.657) and action planning (0.645). All studies had concerns with high risk of bias, mostly because of the risk of confounding, measurement bias, and incomplete reporting.

Conclusions: A range of eHealth PA interventions may increase PA levels among adults affected by cancer, and specific components (eg, websites, use of theory, and action planning) may be linked to greater effectiveness. However, more work is needed to ascertain and optimize effectiveness, measure long-term effects, and address concerns with bias and incomplete reporting. This evidence is required to support arguments for integrating eHealth within PA promotion in oncology.

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KEYWORDS

eHealth; electronic health; mHealth; cancer; oncology; physical activity; exercise; systematic review; mobile phone

Introduction

Background

Physical activity (PA) can improve physical and psychosocial well-being among adults diagnosed with cancer. Benefits reported throughout the cancer trajectory (ie, from diagnosis onward) include enhanced physical functioning and quality of life, as well as reduced negative effects of cancer and treatment-related side effects [1]. Consequently, cancer-specific PA guidelines have been published, recommending at least 90 minutes of weekly moderate-intensity aerobic PA (note: before 2019, 150 minutes were recommended) and strength training for ≥2 days each week [2,3]. These guidelines have also been endorsed by leading cancer support organizations [4]. Despite this evidence, most adults diagnosed with cancer do not achieve the recommended PA levels [5].

Thus, developing and testing interventions to increase PA levels is a priority. As described in recent systematic reviews and meta-analyses, most interventions designed to enhance PA levels among individuals with cancer have been delivered face-to-face in fitness facilities, and findings suggest that such interventions can enhance physical and psychosocial well-being [6]. However, among adults diagnosed with cancer, barriers such as lack of time, limited access to facilities, and travel distances can hinder participation in face-to-face PA interventions [7]. Barriers to PA have been exacerbated during the COVID-19 pandemic, with most face-to-face PA opportunities being limited or canceled and adults with cancer reporting decreased PA and increased sedentary time [8].

eHealth technologies, including telephones, websites, email, and mobile health (mHealth) technologies (eg, SMS text messaging, smartphones, wearable technology, and apps) may be useful to address some of these barriers to PA and reach a wider audience of adults living with cancer [9-11]. The prevalence of and preference for using eHealth is increasing rapidly among adults with cancer, with the National Cancer Institute prioritizing research into the effective use of eHealth in the context of PA promotion for adults with cancer [12-14]. Reviews summarizing the effects of eHealth to promote PA in adults with cancer suggest that technology-supported PA interventions may enhance PA levels and health-related quality of life and decrease fatigue [15-19]. Notwithstanding the evidence to date, important gaps in knowledge remain. First, only studies published before July 2018 have been reviewed. As the field of eHealth PA interventions is rapidly growing and evolving, an update is needed. Second, reviews have had limited scope with regard to study design (eg, randomized controlled trials [RCTs] only [18]), population (eg, women with breast cancer only [19]), and technology components (eg, activity trackers or mHealth only [16,17,19]). Expanding eligibility criteria to include various study designs, cancer types, and the full range of eHealth technologies is required to provide a more comprehensive overview of the effects of eHealth PA interventions in oncology. Finally, despite evidence supporting the role of behavior change techniques (BCTs) and theories (eg, theory of planned behavior) in PA interventions, the integration of BCTs and theory with eHealth PA interventions has received limited attention [15,18,20-22]. Roberts et al [15] examined the use of theory and BCTs for 15 eHealth PA interventions published before November 2016, whereas Kiss et al [18] coded BCTs for 16 interventions, many of which were duplicates from Roberts et al [15], published before July 2018.

Objectives

Thus, the purpose of this review is to summarize evidence on the use of eHealth to support PA behavior change among adults diagnosed with cancer. The specific objectives are to (1) describe the current state of the literature on the effectiveness of eHealth in supporting PA behavior change (pre- to postintervention and follow-ups, where available), (2) explore intervention characteristics that may promote PA behavior change (eg, eHealth components, use of theory, and BCTs), and (3) identify research needs for future work.

Methods

The review protocol was registered prospectively via PROSPERO (International Prospective Register of Systematic Reviews): CRD42020162181. Reporting of the results follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for systematic reviews [23].

Search Strategy

For identifying relevant studies, a search strategy covering the major topics of health technology, cancer, and PA was developed in MEDLINE (R) using existing reviews to guide the selection of search terms. It was then refined, finalized, and translated to the other databases used herein with the help of a university librarian (Table S1 in Multimedia Appendix 1). MEDLINE (R) and Epub Ahead of Print, In-Process and Other Non-Indexed Citations and Daily (OVID), Embase (OVID), CENTRAL (OVID), CINAHL (EBSCO), Sport Discus (EBSCO), and Scopus were searched from database inception through to December 18, 2019. This search was updated on January 7, 2021.

Eligibility Criteria

To be included, articles had to (1) comprise adult participants aged ≥18 years diagnosed with cancer, (2) evaluate a PA intervention that used technology (mobile app, SMS text messages, wearable activity tracker, website, email, or other eHealth) as an active component in the intervention to support behavior change, (3) measure and report on PA levels (objectively or subjectively), (4) be published in English, and (5) be published in a peer-reviewed journal (conference abstracts and gray literature were not included). Articles were excluded if they (1) involved adults whose only cancer diagnosis occurred during childhood, adults without a history of cancer, or caregivers; (2) used telephone contact as the only technology component in the intervention; (3) used technology for the measurement of outcomes only (eg, accelerometer for PA measurement pre- or postintervention); (4) lacked a PA intervention (eg, observational study of PA behavior); (5) reported ongoing trials without full results being available (ie, protocols); and (6) the full text was unavailable. Interventions could be either partially supervised (ie, some human contact) or unsupervised (ie, entirely automated), and the amount of technology use within interventions was not quantified.

Study Selection

After importing all search results into EndNote X9.2 (Clarivate Analytics), the first author conducted automatic and subsequent manual deduplication. Unique articles were exported to Rayyan (Rayyan Systems) for screening according to the eligibility criteria [24]. Title and abstract screening were conducted concurrently by the first author by removing all articles that did not meet the criteria. Articles with titles and abstracts that lacked enough information to make a decision were carried forward to the full-text screening stage. Full texts of the remaining articles were obtained and screened independently by the first (ME) and second authors (MME), who recorded their decisions as well as reasons for exclusion where applicable. The 2 authors then met to discuss the decisions and resolve disagreements based on additional reviews of the articles. Disagreements that could not be resolved directly were resolved via discussion with the senior author (NCR) to yield the final list of included articles.

Data Extraction

Before data extraction, a standardized data extraction table was developed and refined using 3 test articles. The final data extraction table included (1) participant information (age, cancer diagnosis, and eligibility criteria), (2) study design (timing, eligibility and recruitment rates, and recruitment methods), (3) intervention details (groups, objectives, duration, active components, technology integration, BCTs according to the Michie behavior change taxonomy comprising 93 BCTs across 16 categories [25], and use of theory), (4) outcomes (participant numbers, demographics, primary and secondary outcomes, PA-related outcomes, adherence or completion to intervention, and technology use), and (5) additional factors (key findings, challenges, and limitations). It was decided that theory would be recorded only when explicitly described in the included studies. Data were then extracted independently by the first (ME) and second authors (MME), with each author being responsible for half the number of articles. For confirming the reliability of the extraction, 5 random articles were exchanged between authors, extracted a second time, and the data were compared between extractions. Because of minor discrepancies, coding of BCTs was repeated for all articles, and discussions were held between the first and second authors to reach a consensus. The authors did not complete BCT coder training before BCT coding. No other discrepancies were noted. Any missing information was denoted using the phrase *not reported* in the data extraction table. Attempts were made to fill in missing information via protocol papers and other related publications for each study. The authors of the included articles were not contacted directly for additional information.

Risk of Bias and Completeness of Reporting

The Cochrane risk of bias (RoB) tool (RoB-2) was used for multiarm interventions, which included evaluations for RoB in five domains: (1) randomization, (2) deviation from the intended intervention, (3) missing outcome data, (4) measurement of the outcome, and (5) selection of reported results [26]. The ROBINS-I (RoB in nonrandomized studies of interventions) tool, which evaluates bias across seven domains: (1) confounding, (2) participant selection, (3) classification of intervention, (4) deviation from intended intervention, (5) missing data, (6) outcome measurement, and (7) selection of reported results was used for single-arm designs [27]. An overall RoB was given according to the highest RoB rating in any domain for each study. For example, a study with high RoB in domain 1 and low RoB across all other domains received a high overall RoB rating. The completeness of reporting was evaluated using the CONSORT (Consolidated Standards of Reporting Trials)–eHealth checklist, with items assessed as reported, not reported, or not applicable [28]. The completeness of reporting score was calculated for each article as the percentage of applicable items that were reported. These assessments were performed independently by the first (ME) and second authors (MME). Verification was performed by exchanging 5 random articles between authors for repeat assessment, and no discrepancies were documented.

Data Synthesis and Analysis

To summarize the data extracted from each article, descriptive statistics were calculated for participant demographics, adherence, and completion. Intervention details were categorized and summarized, whereas results were converted to standardized metrics where possible to enable comparison across studies. Because of the substantial heterogeneity of the studies with regards to population, intervention, comparison, and outcome, meta-analyses were not performed. Instead, extracted data across studies were summarized using narrative synthesis techniques, and summary tables were presented [29]. Harvest plots were created to provide a visual summary of study effects on PA outcomes, including PA levels directly postintervention and PA maintenance at follow-up, providing an overview of intervention effectiveness on PA levels [30]. Following recommendations, harvest plots were prepared with studies grouped according to the statistical significance of their PA outcomes (PA increase, PA decrease, or no change) [30]. Bar heights were used to distinguish between RCTs (high) and other study designs (low), whereas shading was used to specify how PA was measured (subjective, objective, or both). For addressing objective 2, weight analyses were conducted to explore associations between independent variables (intervention characteristics: use of supervised elements, various types of eHealth, theory, and BCTs) and the dependent variable (PA levels) [31]. Weight was calculated for each independent or dependent variable pair by dividing the number of studies featuring each independent variable and reporting a significant improvement in the dependent variable by the total number of studies featuring the independent variable. Weights range from 0-1, with a higher value indicating a stronger association between the independent variable and significant changes in PA levels. Weights are presented to three decimal places and are equivalent to percentages (ie, 0.123 could also be read as 12.3%). The weight for each independent or dependent variable pairing was then compared with the overall weight for all studies to explore if the presence of certain intervention characteristics was associated with a higher weight (ie, more often linked with significant changes in PA levels). For continuous independent variables (duration and number of BCTs used), studies were grouped according to the mean value (greater than or less than the mean). For BCTs, weights were only calculated for the most common BCTs or BCT categories (ie, used in at least 50% of interventions) to minimize the introduction of further bias when calculating weights using only a small number of independent or dependent variable pairs [31].

Results

Study Selection

After deduplication, 4022 citations were screened at the title or abstract level; of the 4022 citations, 3873 (96.29%) were removed as they did not meet the eligibility criteria. During full-text screening, the agreement between the first 2 authors on the 145 articles was 82.1%, with decisions for articles where no agreement was reached (26/145, 17.9%) being resolved via discussion with the senior author (NCR). Of the 145 articles, 74 (51.0%) articles were excluded during full-text screening, and, overall, 71 (49.0%) articles representing 67 unique studies were included [32-102]. Figure 1 presents an overview of the study selection, with reasons for article exclusion. The remainder of the results are presented according to the number of unique studies (n=67). Tables 1 and 2 provide more information on each of the included studies and their respective PA interventions.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of article selection. PA: physical activity.

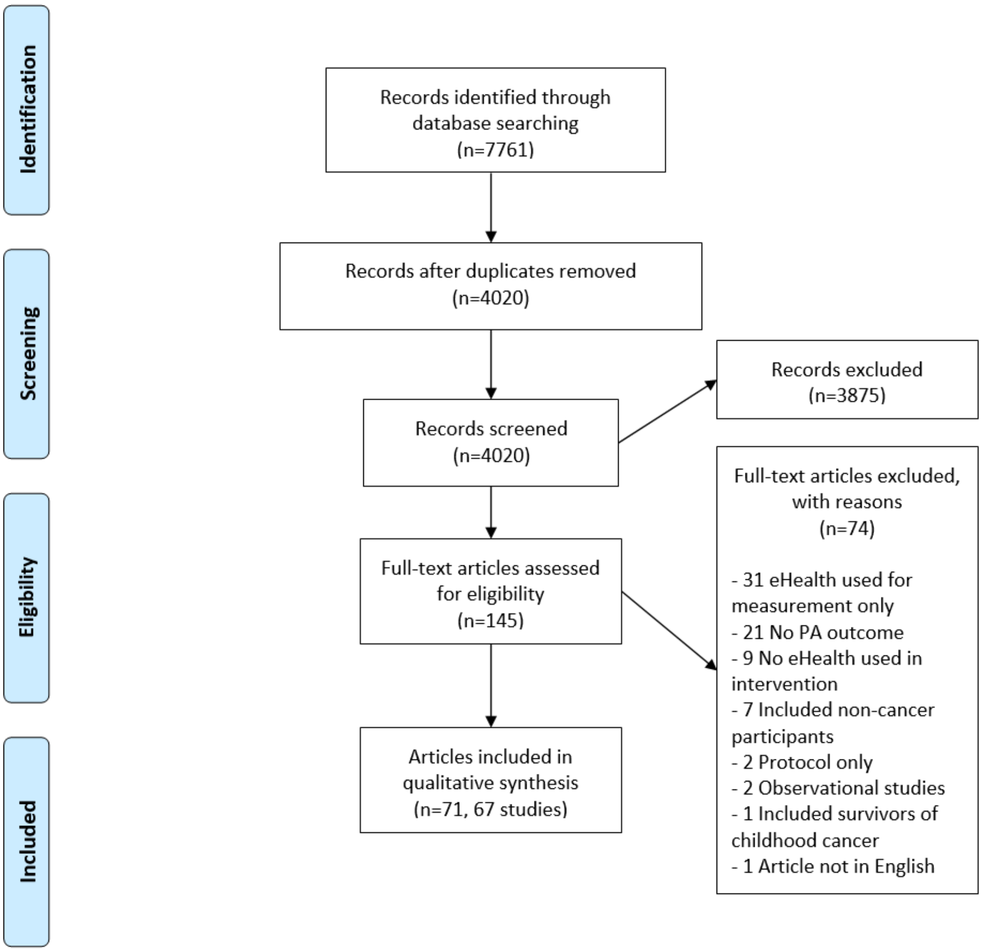


Table 1. Overview of study type, participant characteristics, and outcomes[a].

Reference	Study type	Participant characteristics	Study outcomes
Mayo et al [32]	RCT[b]	Cancer: advanced mixed Treatment: any n=26 Age (years), median: 57.0 Female (%): 46	Primary outcome: Fatigue Secondary outcome: PA[c], physical and psychosocial
Maxwell-Smith et al [33]	RCT	Cancer: mixed Treatment: off n=68 Age (years), mean (SD): 64.1 (7.9) Female (%): 50 Caucasian (%): 97	Primary outcome: PA Secondary outcome: Sedentary and physical
Park et al [34]	RCT	Cancer: advanced prostate Treatment: any n=21 Age (years), median: 66.5 Female (%): 0	Primary outcome: Psychosocial Secondary outcome: PA
Gomersall et al [35]	RCT	Cancer: any Treatment: any n=36 Age (years), mean (SD): 64.8 (9.6) Female (%): 36	Primary outcome: Feasibility Secondary outcome: PA and sedentary
Gehring et al [36]	RCT	Cancer: brain Treatment: off n=34 Age (years): 48.0 Female (%): 56	Primary outcome: Feasibility Secondary outcome: PA, physical, and psychosocial
Singh et al [37]	RCT	Cancer: breast Treatment: any n=52 Age (years), mean (SD): 51.2 (9.0) Female (%): 100	Primary outcome: PA Secondary outcome: Feasibility
Buscemi et al [38]	RCT	Cancer: breast Treatment: any n=80 Age (years), mean (SD): 52.5 (11.4) Female (%): 100 Caucasian (%): 0	Primary outcome: PA, Nutrition
Chapman et al [39]	RCT	Cancer: breast Treatment: off n=101 Age (years), mean (SD): 59.1 (8.2) Female (%): 100 Caucasian (%): 93	Primary outcome: PA Secondary outcome: Psychosocial
Fazzino et al [40]	RCT	Cancer: breast Treatment: off n=142 Age (years), mean (SD): 58.6 (8.0) Female (%): 100 Caucasian (%): 97	Primary outcome: Physical Secondary outcome: PA
Hartman et al [41]	RCT	Cancer: breast Treatment: off n=42 Age (years), mean (SD): 57.9 (11.3) Female (%): 100 Caucasian (%): 81	Primary outcome: Psychosocial Secondary outcome: PA

Reference	Study type	Participant characteristics	Study outcomes
Hatchett et al [42]	RCT	• Cancer: breast • Treatment: off • n=74 • Female (%:) 100 • Caucasian (%): 95	• Primary outcome: PA • Secondary outcome: Sedentary
Lynch et al [43,44]	RCT	• Cancer: breast • Treatment: off • n=83 • Age (years), mean (SD): 61.6 (6.4) • Female (%): 100	• Primary outcome: PA • Secondary outcome: Sedentary
McNeil et al [45]	RCT	• Cancer: breast • Treatment: off • n=45 • Age (years), mean (SD): 58.7 (9.3) • Female (%): 100 • Caucasian (%): 80	• Primary outcome: PA • Secondary outcome: Sedentary, Physical, Psychosocial
Park et al [46]	RCT	• Cancer: breast • Treatment: off • n=356 • Age (years), mean (SD): 50.3 (9.5) • Female (%): 100	• Primary outcome: PA
Paxton et al [47]	RCT	• Cancer: breast • Treatment: off • n=71 • Age (years), mean (SD): 52.2 (8.5) • Female (%): 100	• Primary outcome: PA • Secondary outcome: Nutrition
Pope et al [48]	RCT	• Cancer: breast • Treatment: off • n=30 • Female (%): 100 • Caucasian (%): 97	• Primary outcome: PA • Secondary outcome: Sedentary, physical, and psychosocial
Short et al [49]	RCT	• Cancer: breast • Treatment: off • n=492 • Age (years), mean (SD): 55.1 (9.7) • Female (%): 100	• Primary outcome: Feasibility • Secondary outcome: PA
Uhm et al [50]	RCT	• Cancer: breast • Treatment: off • n=356 • Age (years), mean (SD): 50.3 (9.5) • Female (%): 100	• Primary outcome: PA
Weiner et al [51]	RCT	• Cancer: breast • Treatment: off • n=87 • Age (years): 57.2 • Female (%): 100 • % Caucasian (%): 82	• Primary outcome: PA • Secondary outcome: Sedentary
Allicock et al [52]	RCT	• Cancer: breast • Treatment: off • n=22 • Age (years), mean (SD): 52.2 (9.2) • Female (%): 100 • Caucasian (%): 0	• Primary outcome: Feasibility • Secondary outcome: PA, Nutrition
Gokal et al [53]	RCT		• Primary outcome: Psychosocial • Secondary outcome: PA

Reference	Study type	Participant characteristics	Study outcomes
		- Cancer: breast - Treatment: on - n=50 - Age (years): 52.2 - Female (%): 100	
Van Blarigan et al [54]	RCT	- Cancer: colorectal - Treatment: off - n=41 - Age (years), mean (SD): 54.0 (11.0) - Female (%): 59 - Caucasian (%): 73	- Primary outcome: Feasibility - Secondary outcome: PA
Haggerty et al [55]	RCT	- Cancer: endometrial - Treatment: off - n=41 - Age (years), mean (SD): 59.7 (8.7) - Female (%): 100 - Caucasian (%): 78	- Primary outcome: Physical - Secondary outcome: PA
Chow et al [56]	RCT	- Cancer: leukemia lymphoma - Treatment: off - n=41 - Age (years): 45.1 - Female (%): 49 - Caucasian (%): 78	- Primary outcome: Feasibility - Secondary outcome: PA, Physical, psychosocial, and nutrition
Edbrooke et al [57]	RCT	- Cancer: lung - Treatment: on - n=80 - Age (years), mean (SD): 63.1 (12.3) - Female (%): 44	- Primary outcome: Physical - Secondary outcome: PA, Psychosocial
Cox et al [58]	RCT	- Cancer: mixed - Treatment: any - n=37 - Age (years): 59.7 - Female (%): 0 - Caucasian (%): 84	- Primary outcome: Physical - Secondary outcome: PA
Forbes et al [59]	RCT	- Cancer: mixed - Treatment: any - n=95 - Age (years), mean (SD): 65.1 (8.5) - Female (%): 56 - Caucasian (%): 99	- Primary outcome: Feasibility - Secondary outcome: PA, Psychosocial
Golsteijn et al [60]	RCT	- Cancer: mixed - Treatment: any - n=478 - Age (years): 66.5 - Female (%): 13	- Primary outcome: PA - Secondary outcome: Physical, Fatigue, Psychosocial
Ormel et al [61]	RCT	- Cancer: mixed - Treatment: any - n=32 - Age (years): 33.6 - Female (%): 13	- Primary outcome: Feasibility - Secondary outcome: PA
Webb et al [62,63]	RCT	- Cancer: mixed - Treatment: any - n=207 - Female (%): 74 - Caucasian (%): 97	- Primary outcome: PA - Secondary outcome: Psychosocial

Reference	Study type	Participant characteristics	Study outcomes
Bantum et al [64]	RCT	• Cancer: mixed • Treatment: off • n=352 • Age (years), mean (SD): 50.9 (11.0) • Female (%): 82 • Caucasian (%): 87	• Primary outcome: Fatigue • Secondary outcome: PA, psychosocial, and nutrition
Frensham et al [65,66]	RCT	• Cancer: mixed • Treatment: off • n=91 • Age (years), mean (SD): 65.8 (9.4) • Female (%): 52 • Caucasian (%): 96	• Primary outcome: PA • Secondary outcome: Physical and psychosocial
Gell et al [67]	RCT	• Cancer: mixed • Treatment: off • n=66 • Age (years), mean (SD): 61.4 (9.0) • Female (%): 83 • Caucasian (%): 99	• Primary outcome: Feasibility • Secondary outcome: PA
Kanera et al [68,69]	RCT	• Cancer: mixed • Treatment: off • n=462 • Age (years), mean (SD): 55.9 (11.4) • Female (%): 80	• Primary outcome: PA • Secondary outcome: Nutrition
Mayer et al [70]	RCT	• Cancer: mixed • Treatment: off • n=284 • Age (years), mean (SD): 58.6 (14.0) • Female (%): 52 • Caucasian (%): 89	• Primary outcome: PA
Park et al [71]	RCT	• Cancer: mixed • Treatment: off • n=162 • Age (years), mean (SD): 51.8 (8.0) • Female (%): 88	• Primary outcome: PA • Secondary outcome: Psychosocial
Valle et al [72]	RCT	• Cancer: mixed • Treatment: off • n=86 • Age (years): 31.7 • Female (%): 91 • Caucasian (%): 91	• Primary outcome: Feasibility • Secondary outcome: PA, physical, and psychosocial
Rabin et al [73]	RCT	• Cancer: mixed • Treatment: off • n=18 • Age (years), mean (SD): 32.2 (5.6) • Female (%): 56 • Caucasian (%): 84	• Primary outcome: PA • Secondary outcome: Feasibility, fatigue, and psychosocial
Robertson et al [74]	RCT	• Cancer: mixed • Treatment: off • n=78 • Age (years), mean (SD): 55.1 (13.5) • Female (%): 91 • Caucasian (%): 80	• Primary outcome: Feasibility • Secondary outcome: PA and psychosocial
Yun et al [75]	RCT	• Cancer: mixed • Treatment: off • n=394 • Age (years), mean (SD): 54.0 (11.0) • Female (%): 61	• Primary outcome: PA • Secondary outcome: Physical and psychosocial

Reference	Study type	Participant characteristics	Study outcomes
Shang et al [76]	RCT	• Cancer: mixed • Treatment: on • n=126 • Age (years), mean (SD): 60.2 (10.6) • Female (%): 39 • Caucasian (%): 81	• Primary outcome: PA
Villaron et al [77]	RCT	• Cancer: mixed • Treatment: on • Female (%): 0	• Primary outcome: PA • Secondary outcome: Fatigue and psychosocial
Chan et al [78]	RCT	• Cancer: prostate • Treatment: any • n=202 • Age (years), median: 70 • Female (%): 0 • Caucasian (%): 93	• Primary outcome: Feasibility • Secondary outcome: PA and nutrition
Kenfield et al [79]	RCT	• Cancer: prostate • Treatment: off • n=78 • Age (years), median: 65 • Female (%): 0 • Caucasian (%): 78	• Primary outcome: Feasibility • Secondary outcome: PA and psychosocial
Alibhai et al [80]	RCT	• Cancer: prostate • Treatment: on • n=53 • Age (years): 70.0 • Female (%): 0 • Caucasian (%): 72	• Primary outcome: Feasibility • Secondary outcome: PA, physical, and psychosocial
Bade et al [81]	Other	• Cancer: advanced lung • Treatment: any • n=37 • Age (years), mean (SD): 66.4 (8.6) • Female (%): 30	• Primary outcome: PA
Naito et al [82]	Other	• Cancer: advanced mixed • Treatment: on • n=30 • Age (years), median: 75 • Female (%): 33	• Primary outcome: Feasibility • Secondary outcome: PA
Befort et al [83]	Other	• Cancer: breast • Treatment: off • n=34 • Age (years), mean (SD): 58.9 (7.8) • Female (%): 100 • Caucasian (%): 97	• Primary outcome: Physical • Secondary outcome: Feasibility, PA, and nutrition
Nápoles et al [84]	Other	• Cancer: breast • Treatment: off • n=23 • Age (years), mean (SD): 55.8 (13.1) • Female (%): 100	• Primary outcome: Feasibility • Secondary outcome: PA, fatigue, and psychosocial
Pope et al [85]	Other	• Cancer: breast • Treatment: off • n=10 • Age (years), mean (SD): 45.8 (10.2) • Female (%): 100 • Caucasian (%): 90	• Primary outcome: Feasibility • Secondary outcome: PA, physical, and psychosocial
Spark et al [86]	Other		

Reference	Study type	Participant characteristics	Study outcomes
		- Cancer: breast - Treatment: off - n=29 - Age (years), mean (SD): 54.9 (8.8) - Female (%): 100 - Caucasian (%): 97	- Primary outcome: Feasibility - Secondary outcome: PA, physical, and nutrition
Wilson et al [87]	Other	- Cancer: breast - Treatment: off - n=22 - Age (years): 55.0 - Female (%): 100 - Caucasian (%): 0	- Primary outcome: Feasibility - Secondary outcome: PA and physical
Chung et al [88]	Other	- Cancer: breast - Treatment: off - n=54 - Age (years), mean (SD): 44.5 (6.40) - Female (%): 100 - Caucasian (%): 0	- Primary outcome: PA - Secondary outcome: Psychosocial
Nyrop et al [89]	Other	- Cancer: breast - Treatment: on - n=100 - Age (years), mean (SD): 48.3 (9.4) - Female (%): 100 - Caucasian (%): 69	- Primary outcome: PA
Cairo et al [90]	Other	- Cancer: breast - Treatment: on - n=127 - Age (years), mean (SD): 54.1 (9.0) - Female (%): 100 - Caucasian (%): 95	- Primary outcome: PA, Nutrition - Secondary outcome: Fatigue and psychosocial
Cheong et al [91]	Other	- Cancer: colorectal - Treatment: on - n=75 - Age (years), mean (SD): 58.3 (11.7) - Female (%): 41	- Primary outcome: PA - Secondary outcome: Feasibility, physical, and psychosocial
Groen et al [92]	Other	- Cancer: lung - Treatment: any - n=34 - Age (years), mean (SD): 59.6 (8.4) - Female (%): 47	- Primary outcome: Feasibility - Secondary outcome: PA and psychosocial
Hong et al [93]	Other	- Cancer: mixed - Treatment: any - n=26 - Age (years), median: 69 - Female (%): 69 - Caucasian (%): 73	- Primary outcome: Psychosocial - Secondary outcome: Feasibility and PA
McCarroll et al [94]	Other	- Cancer: mixed - Treatment: any - n=50 - Age (years), mean (SD): 58.4 (10.3) - Female (%): 100 - Caucasian (%): 88	- Primary outcome: Feasibility - Secondary outcome: PA, physical, psychosocial, and nutrition
MacDonald et al [95]	Other	- Cancer: mixed - Treatment: any - n=35 - Age (years), mean (SD): 55.0 (15.9) - Female (%): 63	- Primary outcome: Feasibility - Secondary outcome: PA, physical, and psychosocial

Reference	Study type	Participant characteristics	Study outcomes
Gell et al [96]	Other	• Cancer: mixed • Treatment: off • n=24 • Age (years), mean (SD): 57.5 (10.4) • Female (%): 83 • Caucasian (%): 92	• Primary outcome: PA • Secondary outcome: Feasibility
Puszkiewicz et al [97]	Other	• Cancer: mixed • Treatment: off • n=45 • Age (years), mean (SD): 64.6 (13.4) • Female (%): 51	• Primary outcome: Feasibility • Secondary outcome: PA, fatigue, and psychosocial
Short et al [98]	Other	• Cancer: mixed • Treatment: off • n=12 • Age (years), mean (SD): 56.0 (11.1) • Female (%): 60	• Primary outcome: Feasibility • Secondary outcome: PA
Abbott et al [99]	Other	• Cancer: mixed • Treatment: on • n=39 • Age (years): 57.0 • Female (%): 69 • Caucasian (%): 97	• Primary outcome: Fatigue • Secondary outcome: PA
Javaheri et al [100]	Other	• Cancer: mixed • Treatment: on • n=21 • Age (years), median: 56 • Female (%): 86	• Primary outcome: Feasibility • Secondary outcome: PA and psychosocial
Zhang et al [101]	Other	• Cancer: ovarian • Treatment: any • n=10 • Age (years), median: 63 • Female (%): 100 • Caucasian (%): 100	• Primary outcome: Feasibility • Secondary outcome: PA
Trinh et al [102]	Other	• Cancer: prostate • Treatment: on • n=46 • Age (years), mean (SD): 73.2 (7.3) • Female (%): 0 • Caucasian (%): 80	• Primary outcome: Feasibility • Secondary outcome: PA, sedentary, and psychosocial

[a] Studies were sorted by study type, cancer type, and treatment. Of note, some articles did not report certain participant characteristics, such as ethnicity or age.

[b] RCT: randomized controlled trial.

[c] PA: physical activity.

Table 2. Overview of intervention duration, supervision, physical activity measure, delivery components, use of theory, and behavior change techniques[a].

Reference	Intervention design	PA[b]	Delivery		Theory	Total number of BCT[c]/ number of BCT categories covered
			eHealth	Additional		
Mayo et al [32]	Duration (weeks): 16; follow-up (weeks): 24; no supervision	Objective	WAT[d] and phone	Exercise goal or program and phone counseling	Theory on etiology and treatment of cancer-related fatigue	13/8
Maxwell-Smith et al [33]	Duration (weeks): 12; partial supervision	Objective	Website, WAT, and SMS text messaging	Print materials, phone counseling, in-person counseling, and group interaction	HAPA[e]	15/9
Park et al [34]	Duration (weeks): 8; partial supervision	Subjective and objective	SMS text messaging	PA log, print materials, and in-person counseling	SDT[f]	14/9
Gomersall et al [35]	Duration (weeks): 12; partial supervision	Subjective and objective	SMS text messaging	Exercise goal or program and in-person counseling	SCT[g]	16/10
Gehring et al [36]	Duration (weeks): 26; partial supervision	Subjective	Website, WAT, and email	PA log, print materials, and in-person counseling	None	9/5
Singh et al [37]	Duration (weeks): 12; partial supervision	Subjective and objective	Website and WAT	Print materials and in-person counseling	TPB[h]	7/5
Buscemi et al [38]	Duration (weeks): 6; no supervision	Subjective	SMS text messaging and mobile app	Phone counseling	None	6/5
Chapman et al [39]	Duration (weeks): 4; follow-up (weeks): 12; no supervision	Subjective	Website	None	TTM[i]	6/2
Fazzino et al [40]	Duration (weeks): 52; no supervision	Subjective and objective	WAT and phone	Exercise goal or program, PA log, phone counseling, group interaction, and DVD	SCT	11/8
Hartman et al [41]	Duration (weeks): 12; partial supervision	Objective	Website, WAT, email, and phone	Exercise goal or program, phone counseling, and in-person counseling	TTM and SCT	13/8
Hatchett et al [42]	Duration (weeks): 12; no supervision	Subjective	Email	None	SCT	16/10
Lynch et al [43,44]	Duration (weeks): 12; partial supervision	Objective	Website and WAT	Exercise goal or program, print materials, phone counseling, and in-person counseling	Behavior change strategies	16/8
McNeil et al [45]	Duration (weeks): 12; follow-up (weeks): 24; no supervision	Objective	WAT, email, and phone	PA log and phone counseling	None	13/7
Park et al [46]	Duration (weeks): 12; no supervision	Subjective	WAT and mobile app	Exercise goal or program	None	11/7
Paxton et al [47]	Duration (weeks): 12; no supervision	Subjective	Website and email	Exercise goal or program	SCT, TTM, goal-setting theory, and social marketing	24/12
Pope et al [48]	Duration (weeks): 10; no supervision	Objective	Website and WAT	Exercise goal or program and group interaction	SCT	21/12
Short et al [49]	Duration (weeks): 12; no supervision	Subjective	Website and email	None	SCT	18/11

Reference	Intervention design	PA[b]	Delivery		Theory	Total number of BCT[c]/ number of BCT categories covered
			eHealth	Additional		
Uhm et al [50]	Duration (weeks): 12; no supervision	Subjective	WAT and mobile app	Exercise goal or program	None	14/9
Weiner et al [51]	Duration (weeks): 12; no supervision	Objective	WAT, email, and phone	Phone counseling and in-person counseling	SCT	17/10
Allicock et al [52]	Duration (weeks): 4; no supervision	Subjective and objective	SMS text messaging and mobile app	PA log and print materials	SCT	9/8
Gokal et al [53]	Duration (weeks): 12; no supervision	Subjective and objective	WAT	PA log	TPB	12/8
Van Blarigan et al [54]	Duration (weeks): 12; partial supervision	Objective	Website, WAT, and SMS text messaging	Print materials	TPB	12/9
Haggerty et al [55]	Duration (weeks): 24; no supervision	Subjective	Website, SMS text messaging, and phone	Exercise goal or program and PA log	None	15/8
Chow et al [56]	Duration (weeks): 16; no supervision	Subjective and objective	WAT, email, SMS text messaging, mobile app, and phone	Phone counseling and group interaction	SDT	12/6
Edbrooke et al [57]	Duration (weeks): 8; follow-up (weeks): 26; partial supervision	Objective	WAT, SMS text messaging, and phone	Exercise goal or program, PA log, phone counseling, in-person counseling, and DVD	None	18/11
Cox et al [58]	Duration (weeks): 26; no supervision	Subjective and objective	Website, WAT, email, and phone	Exercise goal or program and group interaction	SCT and TTM	8/6
Forbes et al [59]	Duration (weeks): 9; no supervision	Subjective	Website and email	None	Unspecified *theory-based*	16/10
Golsteijn et al [60]	Duration (weeks): 26; follow-up (weeks): 16; no supervision	Subjective and objective	Website and WAT	None	SCT, TTM, HAPA, I-Change model, and health belief model	16/10
Ormel et al [61]	Duration (weeks): 12; no supervision	Subjective	Email, mobile app, and phone	PA log and phone counseling	None	9/7
Webb et al [62,63]	Duration (weeks): 12; follow-up (weeks): 24; no supervision	Subjective	Website	PA log, print materials, group interaction, and DVD	SCT and TPB	24/12
Bantum et al [64]	Duration (weeks): 6; no supervision	Subjective	Website and phone	Print materials and group interaction	None	18/10
Frensham et al [65,66]	Duration (weeks): 12; follow-up (weeks): 24; no supervision	Objective	Website and WAT	Exercise goal or program, PA log, and group interaction	SCT	9/5
Gell et al [67]	Duration (weeks): 8; partial supervision	Objective	Website, WAT, SMS text messaging, and phone	In-person counseling	SCT	11/6
Kanera et al [68,69]	Duration (weeks): 26; no supervision	Subjective	Website and email	None	SCT	14/7
Mayer et al [70]	Duration (weeks): 26; no supervision	Subjective	WAT, mobile app, and phone	Print materials, phone counseling, and group interaction	SDT	16/10
Park et al [71]	Duration (weeks): 4; no supervision	Subjective	WAT	Exercise goal or program, PA log, and DVD	None	10/8

Reference	Intervention design	PA[b]	Delivery		Theory	Total number of BCT[c]/ number of BCT categories covered
			eHealth	Additional		
Valle et al [72]	Duration (weeks): 12; no supervision	Subjective	Website	Exercise goal or program, PA log, and group interaction	SCT	19/11
Rabin et al [73]	Duration (weeks): 12; no supervision	Subjective	Website and email	None	SCT and TTM	14/9
Robertson et al [74]	Duration (weeks): 4; no supervision	Subjective and objective	Website, WAT, SMS text messaging, and mobile app	None	SDT, behavior change wheel, and motivational interviewing	23/14
Yun et al [75]	Duration (weeks): 12; follow-up (weeks): 24; partial supervision	Subjective	Website and phone	Print materials, phone counseling, and in-person counseling	None	10/6
Shang et al [76]	Duration (weeks): 12; no supervision	Subjective and objective	WAT and phone	Exercise goal or program, PA log, and phone counseling	None	14/8
Villaron et al [77]	Duration (weeks): 8; no supervision	Objective	WAT and SMS text messaging	Print materials	None	11/8
Chan et al [78]	Duration (weeks): 12; follow-up (weeks): 24; no supervision	Subjective	Website, WAT, SMS text messaging, and phone	Phone counseling	SCT	10/8
Kenfield et al [79]	Duration (weeks): 12; no supervision	Subjective and objective	Website, WAT, email, and SMS text messaging	Exercise goal or program	TPB	18/10
Alibhai et al [80]	Duration (weeks): 26; partial supervision	Subjective and objective	WAT, mobile app, and phone	Exercise goal or program, phone counseling, and group interaction	None	11/9
Bade et al [81]	Duration (weeks): 4; no supervision	Objective	WAT, SMS text messaging, and phone	Phone counseling	Prospect theory and gain-framed messaging	11/7
Naito et al [82]	Duration (weeks): 8; partial supervision	Objective	WAT	Exercise goal or program and in-person counseling	None	12/7
Befort et al [83]	Duration (weeks): 26; no supervision	Subjective	WAT and phone	Exercise goal or program, PA log, phone counseling, group interaction, and DVD	SCT	13/9
Nápoles et al [84]	Duration (weeks): 8; no supervision	Objective	WAT, mobile app, and phone	Print materials and phone counseling	SCT	11/7
Pope et al [85]	Duration (weeks): 10; no supervision	Objective	Mobile app	Group interaction	SCT	9/6
Spark et al [86]	Duration (weeks): 26; follow-up (weeks): 52; no supervision	Objective	SMS text messaging	Phone counseling	None	15/7
Wilson et al [87]	Duration (weeks): 8; partial supervision	Objective	WAT	Exercise goal or program and group interaction	Health belief model	9/7
Chung et al [88]	Duration (weeks): 6; no supervision	Objective	Mobile app	PA log and group interaction	None	5/5
Nyrop et al [89]	Duration (weeks): 12; no supervision	Subjective and objective	Website and WAT	PA log and print materials	None	5/5

Reference	Intervention design	PA[b]	Delivery		Theory	Total number of BCT[c]/ number of BCT categories covered
			eHealth	Additional		
Cairo et al [90]	Duration (weeks): 24; no supervision	Subjective	SMS text messaging and mobile app	Print materials and DVD	None	5/5
Cheong et al [91]	Duration (weeks): 12; no supervision	Subjective	WAT and mobile app	Exercise goal or program	None	16/10
Groen et al [92]	Duration (weeks): 16; no supervision	Subjective	Website	None	None	10/6
Hong et al [93]	Duration (weeks): 10; no supervision	Subjective	Website	None	Goal-setting theory	—[j]
McCarroll et al [94]	Duration (weeks): 4; no supervision	Subjective	Mobile app	None	SCT	13/8
MacDonald et al [95]	Duration (weeks): 8; follow-up (weeks): 20; no supervision	Subjective	Website, WAT, mobile app, and phone	Exercise goal or program and phone counseling	Motivational interviewing and cognitive behavioral therapy	42/12
Gell et al [96]	Duration (weeks): 4; partial supervision	Objective	Website, WAT, SMS text messaging, and phone	Phone counseling and in-person counseling	SCT	14/8
Puszkiewicz et al [97]	Duration (weeks): 6; no supervision	Subjective	Mobile app	None	None	14/10
Short et al [98]	Duration (weeks): 2; partial supervision	Subjective	Email and mobile app	Phone counseling and in-person counseling	None	9/6
Abbott et al [99]	Duration (weeks): 12; partial supervision	Subjective	WAT and SMS text messaging	PA log, print materials, and in-person counseling	Gain-framed messaging	12/9
Javaheri et al [100]	Duration (weeks): 4; partial supervision	Objective	WAT and phone	Exercise goal or program, PA log, print materials, phone counseling, and in-person counseling	None	9/6
Zhang et al [101]	Duration (weeks): 26; partial supervision	Subjective and objective	Website, WAT, and phone	Exercise goal or program, phone counseling, group interaction, and DVD	None	8/7
Trinh et al [102]	Duration (weeks): 12; follow-up (weeks): 24; partial supervision	Objective	Website and WAT	None	None	14/8

[a] Studies were sorted by study type, cancer type, and treatment. The follow-up duration is listed as total duration in weeks from baseline. Behavior change techniques (BCTs) are listed as the total number of BCTs and the number of BCT categories covered.

[b] PA: physical activity.

[c] BCT: behavior change technique.

[d] WAT: wearable activity tracker.

[e] HAPA: health action process approach.

[f] SDT: social determination theory.

[g] SCT: social cognitive theory.

[h] TPB: theory of planned behavior.

[i] TTM: transtheoretical model.

[j] Did not provide sufficient details to code BCTs.

Current State of the Literature

Study Characteristics

Studies were conducted in 8 different countries: United States (34/67, 51%), Australia (9/67, 13%), Canada (7/67, 10%), South Korea (7/67, 10%), The Netherlands (5/67, 8%), the United Kingdom (3/67, 5%), Japan (1/67, 2%), and France (1/67, 2%). Almost 50% of the articles (32/67, 48%) were published after July 2018 (Figure S1, Multimedia Appendix 1).

Participant Characteristics

A total of 6655 participants were enrolled across 67 studies with a median sample size of 51 (range 10-492). Participants were, on average, 56.7 (SD 8.2) years old. Approximately one in 3 studies recruited breast cancer survivors (24/67, 38%) or included multiple cancer types (23/67, 34%); 57% (38/67) of studies including only those who had completed treatment. Ethnicity was reported in 60% (40/67) of the studies, and 79.2% (SD 28.1%) of the participants were Caucasian. Only 9% (6/67) of the studies intentionally recruited non-Caucasian participants.

Study or Intervention Design

Approximately 67% (45/67) of studies used randomized trial designs with ≥2 study groups, whereas the remaining 33% (22/67) were nonrandomized single or two-arm trials. Across studies, the duration ranged from 1-52 weeks, with a median of 12 weeks. A total of 12 (18%) studies reported outcomes at a follow-up time point to assess the maintenance of intervention effects. Although all articles listed PA as an objective, their primary objectives varied widely. PA was the primary outcome of interest in 43% (29/67) of the studies. Other primary outcomes included feasibility (26/67, 39%), physical function (5/67, 8%), psychosocial function (4/67, 6%), and fatigue (3/67, 5%).

All the described interventions were either partially supervised (18/67, 27%), with both in-person and unsupervised components, or fully unsupervised (49/67, 72%). The interventions used between one and five technology components, with two (27/67, 40%) being the most common. Wearable devices (41/67, 61%) and websites (32/67, 48%) were the most frequently used technology components for delivering intervention content. Other common technology components used were SMS text messages (19/67, 28%), mobile apps (18/67, 27%), and email (15/67, 22%). Telephone contact was used in 37% (25/67) of the interventions. Figure S2 in Multimedia Appendix 1 presents the trends in eHealth used in the included studies over time. A specific exercise program or prescription was provided in 37% (25/67) of the studies, whereas PA logs were used in 28% (19/67). Instructions via print materials (16/67, 24%) and DVD (7/67, 10%) were less common. Finally, many studies provided additional interaction via phone counseling (25/67, 37%), in-person counseling (16/67, 24%), or group-based formats (16/67, 24%).

Use of Theory and BCTs

More than one-third of the trials (26/67, 39%) did not report using behavioral theories to guide intervention design. Of the remaining studies, 34% (23/67) used social cognitive theory, 9% (6/67) used the transtheoretical model, and 9% (6/67) used the theory of planned behavior, whereas various other theories were applied in 25% (17/67) of studies [103-105].

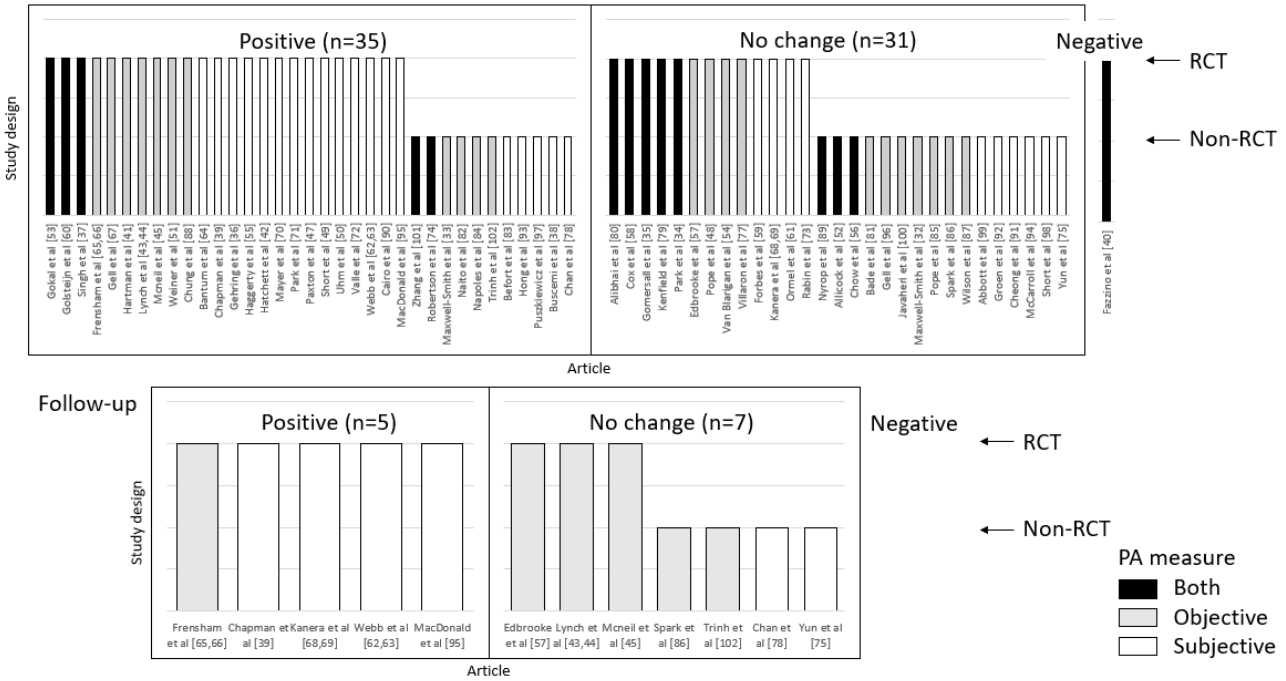
With respect to BCTs, across all studies, 69% (64/93) BCTs (covering 15 of 16 categories) were implemented at least once [25]. The number of techniques applied ranged from 5-42, across 2-14 categories of the behavior change taxonomy, with 9 (8/67, 12%) being the most common. The frequency of use of the most common BCTs and all behavior change categories used are displayed in Figure S3 of Multimedia Appendix 1. The four techniques (*self-monitoring of behavior*, *credible source*, *goal-setting of behavior*, and *adding objects to the environment*) and four categories (*goals and planning*, *feedback and monitoring*, *antecedents*, and *comparison of outcomes*) were found in >90% of the studies. In contrast, the prevalence of four categories (*regulation*, *scheduled consequences*, *covert learning*, and *identity*) was <10%.

PA Outcomes

The measurement of PA was highly variable across studies. Subjective PA measures were used in 45% (30/67) of the studies, whereas 33% (22/67) used objective measures, and the remaining 22% (15/67) used both. The subjective PA questionnaires used were the Godin Leisure Time Exercise Questionnaire (16/67, 24%), International PA Questionnaire (10/67, 15%), as well as 17 other questionnaires (19/67, 28%) [106,107]. Accelerometers and pedometers were used to measure PA objectively in 39% (26/67) and 10% (7/67) of the studies, respectively. These included both research-grade and commercial sensors.

As seen in Figure 2, statistically significant postintervention improvements in PA behavior were reported in 52% (35/67; 18 between-group, 17 within-group) of interventions. The remaining 32 interventions reported in no change (29/67, 43%), decreases in PA (1/67, 2%), or did not report on statistical significance (2/67, 3%). Studies that found statistically significant changes in PA, as well as those that did not, included participants with mixed cancer types, stages, and treatment status. The only intervention where PA decreased significantly was a 52-week RCT for patients with off-treatment breast cancer [40]. Only 18% (12/67) of interventions tracked participants beyond the intervention (ie, between 12 and 52 weeks postintervention) to assess PA maintenance. Significant improvements in PA behavior were measured in 42% (5/67; 4 measured significant improvements directly postintervention) of the studies at the follow-up assessment (Figure 2). The remaining 58% (7/67; 4 measured significant improvements directly postintervention) of the studies reported no change.

Figure 2. Harvest plots for physical activity outcomes. Studies were grouped according to the statistical significance of their physical activity outcomes (physical activity increase, physical activity decrease, or no change). Bar height distinguishes between randomized controlled trials (high) and other study designs (low). Shading specifies how physical activity was measured (subjective, objective, or both). PA: physical activity; RCT: randomized controlled trial.

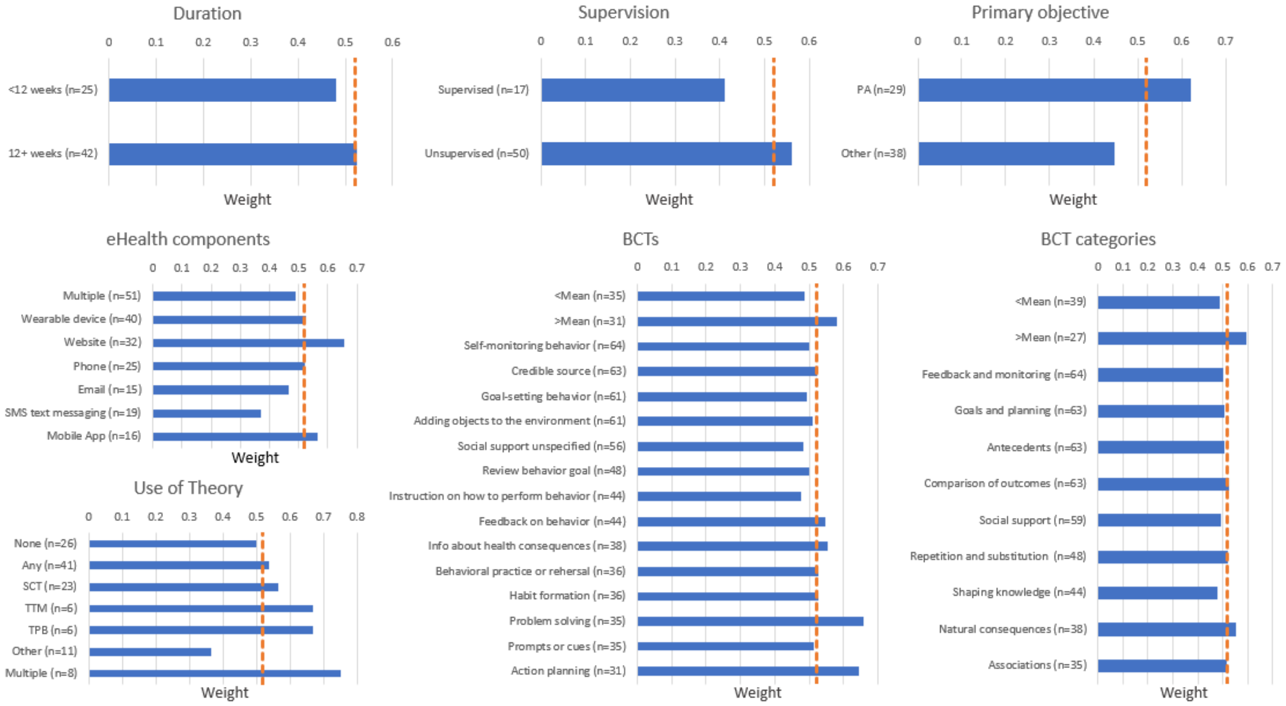


Intervention Characteristics That May Promote PA Behavior Change: Weight Analysis

Primary Outcomes and Supervision

The results of the weight analyses, which were used to explore associations between intervention elements and PA outcomes, are presented in Figure 3. Studies with PA as the primary outcome (29/67, 43%) had a weight of 0.621, compared with 0.447 when PA was a secondary outcome (38/67, 57%). Interventions that were unsupervised (ie, no in-person elements during the intervention period; 50/67, 75%) had a weight of 0.560, whereas those with some supervision (17/67, 25%) had a weight of 0.412.

Figure 3. Weight analyses grouped by intervention characteristics. The orange dotted line represents the weight of significant changes in physical activity levels across all 67 studies (0.522). BCT: behavior change technique; PA: physical activity; SCT: social cognitive theory; TPB: theory of planned behavior; TTM: transtheoretical model.



eHealth Components

When a wearable device (40/67, 60%) or app (16/67, 24%) was used in an intervention, the weights were 0.525 and 0.563, respectively, as compared with a weight of 0.522 across all 67 studies. The use of websites as part of the intervention was associated with a weight of 0.656 (32/67, 48%), whereas SMS text messaging (0.368; 19/67, 28%), email (0.467; 15/67, 22%), and the use of multiple technologies (0.490; 51/67, 76%) had lower weights.

Use of Theory

The use of any behavioral theory in an intervention (41/67, 61%) was associated with a weight of 0.528, whereas interventions that did not report the use of theory (26/67, 39%) had a weight of 0.500. The most common theories, social cognitive theory (23/67, 34%; 0.565), transtheoretical model (6/67, 9%; 0.667), and theory of planned behavior (6/67, 9%; 0.667), were all associated with weights >0.522 [103-105]. When multiple theories were used in a single intervention (8/67, 12%), the weight increased to 0.750. The weights for other theories were not calculated because of the small number of studies using each one.

Behavior Change Techniques

The weight of 46% (31/67) of the interventions that incorporated more than the mean number of 13.5 BCTs was 0.581, whereas the weight of the 52% (35/67) of the interventions that used less than 13.5 BCTs was 0.486. Among the 14 BCTs used in at least 45% of the interventions, *problem solving* (0.657; 35/67, 52%) and *action planning* (0.645; 31/67, 46%) had the highest weights. The remaining weights ranged from 0.477-0.553 (Figure 3). Of the nine BCT categories coded in ≥50% of the interventions, category 5 *natural consequences* (0.553; 38/67, 57%) and category 9 *comparison of outcomes* (0.524; 63/67, 94%) were associated with the highest weights.

RoB and Completeness of Reporting

The overall RoB among the 45 RCTs ranged from some risk (4/45, 8%) to high risk (41/45, 91%). This was largely because of RoB in deviation from the intended intervention (7/45, 15% some risk; 38/45, 84% high risk) and measurement of the outcome (31/45, 68% high risk). Most studies had a low RoB for the remaining categories (n=34-44, depending on the category). Because of the risk of confounding, 95% (21/22) of the nonrandomized studies were found to have critical RoB. RoB in the measurement of outcome was moderate (10/67, 15%) or serious (9/67, 13%) for most single-arm studies, whereas it remained low across other categories (see Figure S4 in Multimedia Appendix 1 for RoB among the included studies [32-102]). If not for the lack of blinding, then only 58% of studies would have had a high overall high RoB, mainly because of bias in outcome measurement owing to the reliance on self-reported PA. Mean completeness of reporting was moderate, with 69.4% (71.4% for RCTs and 65.2% for nonrandomized studies) of applicable CONSORT-eHealth items covered in the included publications. Nearly one-third of the applicable items (mean of 30.6%, SD 9.4%) were not reported. For RCTs and nonrandomized studies, mean values of 15.5% (SD 3.4%) and 32.4% (SD 4.7%), respectively, of CONSORT-eHealth items (overall mean 20.8%, SD 8.8%) were not applicable on a case-by-case basis.

Discussion

Principal Findings

The purpose of this review was to provide a comprehensive, updated overview of eHealth intervention research designed to promote PA and to explore intervention characteristics (ie, duration, delivery modalities, use of theory, and BCTs) associated with increased PA levels. Many of the included studies were published after July 2018 and focused on feasibility, which indicates the rapidly growing yet early state of the field. Across the studies, there was substantial heterogeneity in the participants, interventions, and outcomes. All studies had high RoB for some domains, and incomplete reporting was problematic. Nevertheless, findings suggest that eHealth may be an effective strategy to enhance PA levels with selected modalities, BCTs, and behavioral theories that potentially enhance effectiveness.

Current State of the Literature

The growing number of published articles reporting on eHealth PA interventions for adults with cancer (48% of articles published since July 2018) aligns with several funding calls for eHealth research, institutional strategic priorities, and the growing prevalence of, and preference for, eHealth among adults with cancer [12-14]. With the restrictions imposed by the COVID-19 pandemic on face-to-face PA programs, continued acceleration in this field is expected [108]. The COVID-19 pandemic has highlighted the need for eHealth PA interventions in oncology, and such interventions will continue to remain relevant beyond the pandemic, especially for improving the reach of PA interventions to underserved populations with cancer (eg, remote or rural) [8,108]. For example, an ongoing study in Canada that aims to bring exercise oncology programs to remote and rural cancer populations has delivered all classes remotely during the COVID-19 pandemic and will continue to offer videoconference-based programs (NCT04478851) [109,110]. As many of the included studies tested the feasibility of using eHealth for PA promotion in adults with cancer (36%) using single-arm designs or smaller RCTs, the findings on the effectiveness to change PA levels remain largely preliminary. Next steps could include study designs, such as factorial RCTs or alternative trial designs with the capacity to quantify the contribution of intervention effectiveness from various technology components, theories, and BCTs. Finally, larger multisite RCTs or meta-analyses of comparable studies to strengthen the evidence for the effectiveness of these interventions will be required to continue to grow our knowledge [111-113].

Overall, this review highlights that eHealth interventions can increase PA levels, with 52% of the studies reporting significant increases in postintervention PA. Previous reviews have reported that 50%-80% of eHealth PA interventions for adults with cancer reported significant improvements in PA levels [15-19]. Differences in these findings maybe because of the inclusion of studies that were underpowered to detect changes in PA levels (ie, feasibility trials and those aiming to impact a primary outcome other than PA levels), as well as intervention heterogeneity (ie, varied duration, delivery modalities, use of theory, and BCTs). Nevertheless, eHealth PA interventions have the potential to enhance PA levels, although optimization is required. The first step to optimization is to examine eHealth PA intervention components and their impact on effectiveness to change PA behavior.

Intervention Characteristics That May Promote PA Behavior Change

Findings from this review show that both well-established eHealth components (eg, informational websites) and emerging technologies (eg, mHealth) were associated with increased PA levels both when used alone or in combination with other eHealth. Researchers are encouraged to consider the pros and cons for each type of eHealth when designing eHealth PA interventions. For example, the pros of mHealth include the ability to deliver real-time, context-aware behavior change interventions; passively monitor PA; and relative ubiquity in developed countries (eg, nearly 90% of Canadians own a smartphone) [11,114,115]. Meanwhile, websites that have the highest weight of any eHealth component may be selected for their familiarity and ease of use among older adults [116]. Moving forward, remaining flexible to align eHealth interventions with participant needs and preferences will likely be important [117,118].

A finding from this review that stands in contrast to those of previous reviews in exercise oncology is that a higher percentage of unsupervised interventions (56%; those without face-to-face interaction) were successful at increasing PA levels compared with those that were partially supervised (41%; those with one or more face-to-face components) [7,119]. This may be because of feelings of autonomy promoted by unsupervised interventions, a factor that has been linked to increased intrinsic motivation and PA behavior change [120-122]. In addition, it may be in part because of the more frequent use of behavioral theories (unsupervised: 63%; supervised: 56%) and BCTs (unsupervised mean: 13.8; supervised mean: 11.8) in the included unsupervised interventions, which have been associated with effectiveness in web-based behavioral interventions [123]. Direct comparisons of unsupervised and partially supervised eHealth PA interventions will be required to draw definitive conclusions on their relative effectiveness.

Recommendations have been made to use behavioral theories to guide intervention design to enhance the effectiveness of behavior change interventions [21,22]. Common behavioral theories, such as social cognitive theory, the transtheoretical model, and the theory of planned behavior, have been used in roughly half of eHealth PA interventions for adults with cancer [103-105]. Although the weights for studies using social cognitive theory, the transtheoretical model, the theory of planned behavior, or multiple theories (0.565-0.750) were higher than of those using none at all (0.500), 50% of the interventions that were not theory based also resulted in significant increases in PA levels. Furthermore, it is possible that some articles may have drawn upon theoretically based intervention components without explicitly discussing the use of theory. These mixed results add to the ongoing debate on the role of behavioral theories in real-world interventions [124]. Further examination of the use of theory (eg, theoretical integration and/or use of technology-specific models or theories) is needed to understand its impact, or lack thereof, in eHealth PA interventions.

The most commonly used BCTs in this review of eHealth PA interventions were goal setting and self-monitoring, which is similar to what has been reported in face-to-face PA interventions [20]. However, more BCTs were used across studies in this review, for both mean number per study and overall variety, than in reviews assessing face-to-face interventions [20]. Notably, current findings align with earlier research that has also suggested that certain BCTs may be more effective than others [20,125,126]. Further research is needed to understand the use of BCTs (ie, types and combinations) and their potential impact on intervention effectiveness in eHealth PA research. Indeed, these weight analyses revealed that eHealth interventions with more BCTs were more likely to report significant improvements in PA levels.

RoB and Completeness of Reporting

Most reviewed studies (93%) had high overall RoB (ie, in one or more domains). This was, in large part, because of the lack of blinding. The inability to blind participants and researchers to PA interventions is a commonly reported limitation, irrespective of eHealth use [18,127]. Consequently, if this domain were removed, then the RoB would remain high in only 58% of the studies, primarily because of the reliance on self-reported PA outcomes [128]. Where possible, researchers may wish to integrate both objective and subjective PA measures into studies to reduce RoB [128]. Objective PA assessment is increasingly accessible, given the activity trackers in mHealth (eg, phones) and decreasing costs. Finally, the finding that all included studies were incompletely reported is problematic. Researchers are urged to follow the reporting guidelines appropriate for their study design, which can be found on the web [129].

Limitations

There are important considerations to keep in mind when interpreting the findings. The broad inclusion criteria of the review, although selected intentionally to provide a comprehensive overview of this emerging field, hindered the ability to perform quantitative meta-analyses. Despite the systematic review, additional articles may have been missed if published in gray literature or in other languages. Although weight analyses were performed to provide insights for future research, their outputs must be interpreted with caution, as they are not a measure of statistical significance. Any reported associations remain purely exploratory and must be substantiated in future robust study designs. In addition, more than half of the included studies were underpowered to detect changes in PA as a secondary outcome, which is likely to bias weights toward the null. Some study characteristics in the weight analyses were represented in only a few studies, and most studies used complex interventions, making it difficult to identify the effect of individual components on outcomes. Finally, the authors did not complete BCT coder training before extraction, which may have led to some inaccuracies in BCT coding. However, efforts were made to minimize errors by double checking all codes and discussing with the senior author (NCR), an expert in PA behavior change, as needed.

Research Needs and Opportunities

Consolidating the evidence on eHealth PA interventions for adults with cancer led to the identification of several research needs and opportunities that remain to be addressed. First, only 9 studies featured follow-up assessments to track PA behavior change after intervention completion. Examining the long-term maintenance of PA is critical to determine whether these interventions can have a lasting impact on PA levels. Second, it will be important to explore whether completely unsupervised eHealth interventions or eHealth interventions with limited supervision can rival the effectiveness of face-to-face supervised PA programs to increase PA levels in adults with cancer. Such work is needed to advocate for eHealth use in this field and may be crucial to the implementation of scalable PA programs for adults with cancer. Third, examining the effectiveness of videoconferencing platforms, which have surged in popularity during the COVID-19 pandemic, is warranted. Videoconferencing has the potential to leverage the advantages of supervised interventions (eg, live tailored feedback, social interaction, and accountability) while remaining accessible [108]. Fourth, given the rapidly evolving nature of eHealth, testing effectiveness using fully powered alternative trial designs (eg, SMART [sequential multiple assignment randomized trial], microrandomized trials, and factorial RCTs) is warranted so that evaluation can better match the pace of development, heighten external validity, and inform the translation of evidence to practice [112,113]. Such designs also allow researchers to establish definitive links between intervention components and changes in PA levels, allowing for systematic optimization of effectiveness. Finally, evaluations of cost-effectiveness are needed to inform real-world implementations of eHealth PA behavior change programs, as none were reported herein [130].

Conclusions

This review summarizes findings from the rapidly growing field of eHealth PA interventions for adults affected by cancer. Although eHealth use in these interventions varies widely, the results are suggestive of positive outcomes. Furthermore, most studies integrated BCTs and relevant theories. Efforts are required to understand eHealth PA interventions better by exploring the impact on PA maintenance, investigating ways to optimize their effectiveness (by using BCTs, theories, and emerging technologies), and affirming effectiveness by applying well-powered alternative trial designs. Despite the early and evolving nature of this field, positive results suggest there is a case for integrating eHealth with efforts to promote PA, health, and well-being for adults affected by cancer.

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Authors' Contributions

M Ester, MHM, MM, and SNCR conceived the study. M Ester and SNCR developed the protocol. M Ester performed the search and article processing. M Ester and M Eisele performed the article selection and data extraction. M Ester and M Eisele completed the data synthesis or analyses. M Ester, AW, and SNCR wrote the first draft of the manuscript. All authors reviewed, edited, and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional information on the review methodology and the included studies.
[DOCX File , 397 KB - cancer_v7i3e28852_app1.docx]

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Abbreviations

BCT: behavior change technique
CONSORT: Consolidated Standards of Reporting Trials
mHealth: mobile health
PA: physical activity
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO: International Prospective Register of Systematic Reviews
RCT: randomized controlled trial
RoB: risk of bias
ROBINS-I: risk of bias in nonrandomized studies of interventions
SMART: sequential multiple assignment randomized trial

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Original Paper

A Natural Language Processing–Assisted Extraction System for Gleason Scores: Development and Usability Study

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Abstract

Background: Natural language processing (NLP) offers significantly faster variable extraction compared to traditional human extraction but cannot interpret complicated notes as well as humans can. Thus, we hypothesized that an "NLP-assisted" extraction system, which uses humans for complicated notes and NLP for uncomplicated notes, could produce faster extraction without compromising accuracy.

Objective: The aim of this study was to develop and pilot an NLP-assisted extraction system to leverage the strengths of both human and NLP extraction of prostate cancer Gleason scores.

Methods: We collected all available clinical and pathology notes for prostate cancer patients in an unselected academic biobank cohort. We developed an NLP system to extract prostate cancer Gleason scores from both clinical and pathology notes. Next, we designed and implemented the NLP-assisted extraction system algorithm to categorize notes into "uncomplicated" and "complicated" notes. Uncomplicated notes were assigned to NLP extraction and complicated notes were assigned to human extraction. We randomly reviewed 200 patients to assess the accuracy and speed of our NLP-assisted extraction system and compared it to NLP extraction alone and human extraction alone.

Results: Of the 2051 patients in our cohort, the NLP system extracted a prostate surgery Gleason score from 1147 (55.92%) patients and a prostate biopsy Gleason score from 1624 (79.18%) patients. Our NLP-assisted extraction system had an overall accuracy rate of 98.7%, which was similar to the accuracy of human extraction alone (97.5%; P=.17) and significantly higher than the accuracy of NLP extraction alone (95.3%; P<.001). Moreover, our NLP-assisted extraction system reduced the workload of human extractors by approximately 95%, resulting in an average extraction time of 12.7 seconds per patient (vs 256.1 seconds per patient for human extraction alone).

Conclusions: We demonstrated that an NLP-assisted extraction system was able to achieve much faster Gleason score extraction compared to traditional human extraction without sacrificing accuracy.

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KEYWORDS

NLP; Gleason score; prostate cancer; natural language processing

Introduction

In recent years, the widespread adoption of electronic health record (EHR) systems has led to a dramatic rise in the amount of clinical data available for research and improvement of patient care. Unfortunately, large amounts of clinical data are found only within medical notes (ie, clinical or pathology notes written by health care providers) and are stored as unstructured free text. Thus, clinically important data require manual extraction by human experts, a process which can be slow, expensive, difficult to scale and reproduce, and prone to human errors.

Natural language processing (NLP), a technology at the intersection of computational linguistics, computer science, and artificial intelligence, can permit much faster and more scalable information extraction compared to manual, human extraction [1]. However, NLP systems typically have difficulty interpreting and extracting information documented within highly complex notes or sentence structures. Although the majority of real-world medical notes provide simple yet accurate clinical information, there is inevitably a proportion of medical notes which can be hard to interpret for NLP systems for a variety of reasons (inaccurate documentation, conflicting information, insufficient context, etc). In theory, an NLP system can not only provide extraction capabilities, but may also distinguish whether the note being extracted is “uncomplicated,” defined as any note easily processed by NLP, or “complicated,” defined as any note not easily processed by NLP. Thus, if during its processing, NLP can successfully discern uncomplicated versus complicated notes, an NLP-assisted extraction system can be devised where uncomplicated notes are allocated for NLP review, while complicated notes are allocated for human review. In essence, the NLP system “assists” the human extractor by reducing his or her workload but does not replace the human entirely. This system leverages the fact that NLP can review and process uncomplicated notes much faster than can humans, while humans are much more accurate than are NLP systems at interpreting and deciphering complicated notes.

We developed and piloted our NLP-assisted extraction system for the collection of prostate cancer Gleason score (GS) data in order to clinically annotate an institutional prostate cancer biobank. GS describes the histologic grade of prostate cancers and plays a crucial role in the prognostication and risk stratification of newly diagnosed prostate cancer patients [2-4]. However, GS is often unavailable in research databases because it is stored as unstructured data within clinical and pathology notes, which require human extraction. There is currently a paucity of NLP solutions for extracting GS from both clinical and pathology notes, and these existing options are limited by either accuracy or scope [5-8].

Thus, we developed an NLP-assisted extraction system for encoding GS from medical notes. We assessed the accuracy and speed of our NLP-assisted extraction system and compared it to extraction with NLP alone and humans alone. We hypothesized that our NLP-assisted extraction system would greatly improve the speed of data extraction compared to human extraction alone, while maintaining the accuracy of human extractors.

Methods

Data Ascertainment

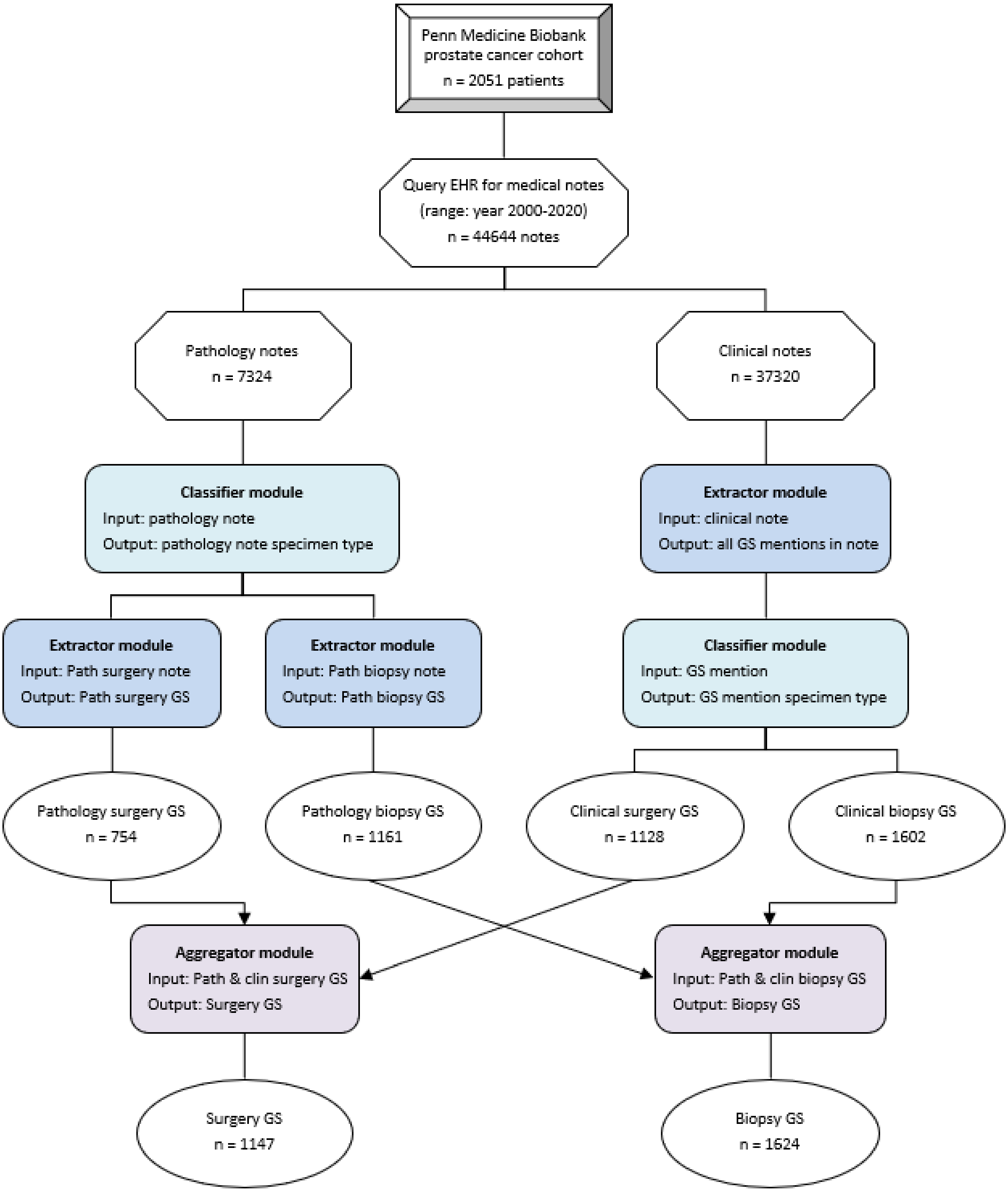
For this University of Pennsylvania Institutional Review Board–approved study, we queried all eligible Penn Medicine Biobank patients who were diagnosed with prostate cancer using a combination of International Classification of Disease (ICD) 9 and 10 codes and data from our institution’s cancer registry. This cohort has undergone manual review and represents a reference standard cohort of unselected biobank participants with a current or past history of prostate cancer. Our EHR data is warehoused on the University of Pennsylvania Health System’s EPIC Clarity system. The Penn Data Analytics Center queried this system for all available clinical and pathology notes for each patient in our cohort ranging from January 1, 2001, through January 31, 2020. Clinical notes were defined as any free-text note written by a health care provider in the EHR, including but not limited to office visit notes and telephone notes written by medical oncologists, radiation oncologists, urologists, physician assistants, and nurses. Pathology notes were defined as any free-text note written by the pathology department and associated with a pathology evaluation. Both clinical and pathology notes were collected because GS may be found in both note types.

Gleason Score Extraction

Our objective was to extract the highest GS from both prostate surgeries and prostate needle biopsies because the highest GS is used clinically for treatment decisions and prognostication. The GS identified from prostate surgery and biopsy may differ, as they are typically obtained at different times and possibly from different areas of the prostate. A fully specified GS comprises 3 components: primary GS (P), secondary GS (S), and total GS (T). As per the International Society of Urological Pathology consensus [9], the primary GS (range 3-5) and secondary GS (range 3-5) describe the first and second most prevalent histology grades in a prostate cancer specimen, respectively. For example, if a prostate biopsy specimen contained 15% grade 3, 55% grade 4, and 30% grade 5, then the primary GS would be 4 and the secondary GS would be 5. The total GS (range 6-10) is defined as the additive sum of the primary and secondary GS (ie, P+S=T). A total GS lower than 6 is possible but is considered benign and not “cancer” and thus did not appear in our prostate cancer cohort.

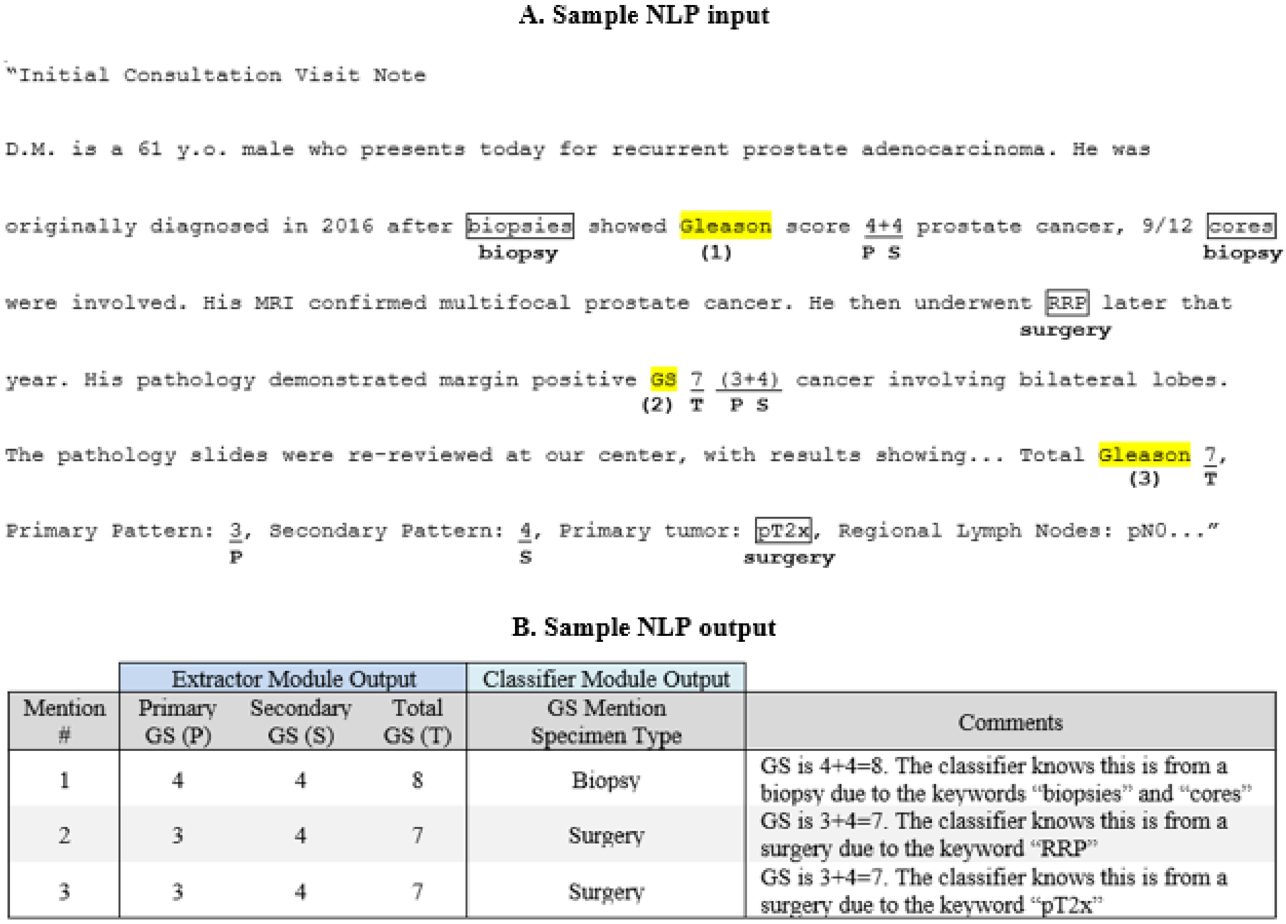
We developed an NLP system to extract GS from both prostate biopsy and surgery for all patients in our cohort. The NLP extraction process was accomplished using multiple modules in conjunction with each other (Figure 1). We designed 3 types of modules: extractor modules, classifier modules, and aggregator modules. Extractor modules identify mentions of GS in the notes based on a specified lexicon (eg, “GS,” “Gleason,” etc) and then extract the adjacent GS components for each mention of GS. Classifier modules determine whether the extracted GS was derived from a prostate biopsy or prostate surgery using another specified lexicon (eg, “RRP,” indicating retropubic radical prostatectomy, or “PNBx,” indicating prostate needle biopsy). Lexicons were built based on input from clinical experts.

Figure 1. Flow diagram for our Gleason score NLP extractor. EHR: electronic health record.



An example of how the extractor and classifier modules work for clinical notes is described in Figure 2. First, the extractor module identifies all mentions of GS (labeled 1, 2, 3, etc) in the clinical note. For each GS found, the extractor module searches the surrounding text for the 3 GS components and then outputs these score components. If only 2 of the 3 components are found, then the third one is derived based on the following equation: P+S=T (eg, T=7 is derived from P=4 and S=3). If no GS is found, the output is documented this way. Second, the classifier module searches the surrounding text, applying a lexicon based on a tiered-priority system where more specific terms (eg "Prostatectomy") take precedence over less specific terms (eg, "Pathologic Stage"). Furthermore, if no classification is possible based on the initial search, then the search area is broadened. After searching, the classifier module outputs the specimen type of the GS mention: either prostate biopsy or prostate surgery. More details on these algorithms can be found in the simplified pseudocodes in Multimedia Appendix 1 Table S1 A and B.

Figure 2. Example of Gleason score extractor and classifier module logic for clinical notes. NLP: natural language processing.



A. Sample NLP input

"Initial Consultation Visit Note

D.M. is a 61 y.o. male who presents today for recurrent prostate adenocarcinoma. He was originally diagnosed in 2016 after biopsies showed Gleason score 4+4 prostate cancer, 9/12 cores were involved. His MRI confirmed multifocal prostate cancer. He then underwent RRP later that year. His pathology demonstrated margin positive GS 7 (3+4) cancer involving bilateral lobes. The pathology slides were re-reviewed at our center, with results showing... Total Gleason 7, Primary Pattern: 3, Secondary Pattern: 4, Primary tumor: pT2x, Regional Lymph Nodes: pN0..."

B. Sample NLP output

	Extractor Module Output			Classifier Module Output	
Mention #	Primary GS (P)	Secondary GS (S)	Total GS (T)	GS Mention Specimen Type	Comments
1	4	4	8	Biopsy	GS is 4+4=8. The classifier knows this is from a biopsy due to the keywords "biopsies" and "cores"
2	3	4	7	Surgery	GS is 3+4=7. The classifier knows this is from a surgery due to the keyword "RRP"
3	3	4	7	Surgery	GS is 3+4=7. The classifier knows this is from a surgery due to the keyword "pT2x"

Finally, the aggregator module calculates and assigns a set of patient-level GS—1 for prostate surgery and 1 for prostate biopsy—for each patient. The final prostate surgery GS is calculated based on the maximum extracted GS from either pathology or clinical notes for any prostate surgery according to the algorithm found in Multimedia Appendix 1 Table S1. Similarly, the final prostate biopsy GS is calculated based on the maximum extracted GS for any prostate biopsy, from either pathology or clinical notes. These final values are subsequently encoded into a structured data format.

Each module was designed from the ground up by a practicing oncologist, SY, so that the NLP system logic would best mirror the mental extraction process performed by clinicians when they are looking for GS in medical notes. For example, due to innate differences in the way GS is typically recorded in clinical versus pathology notes, the extractor and classifier modules were slightly different for the two note types and also arranged differently (see Figure 1 and Table S1 A and B, Multimedia Appendix 1). For pathology notes, a classifier module was applied first, followed by the extractor module. This was because each pathology could only contain either prostate biopsy or surgery information but not both. For clinical notes, the extractor module was applied first followed by the classifier module. This was because each clinical note could have multiple GS mentions, and each of those mentions could be from a different specimen source. Thus, the classifier module could be applied only after the extractor module found a GS mention.

NLP-Assisted Extraction System

We additionally constructed an NLP algorithm that could distinguish uncomplicated versus complicated notes. The algorithm designates a note as complicated if the extracted information is inaccurate (eg, "Gleason score was 3+4=8"), incomplete (eg, "Primary GS was 4," but no information was provided on secondary or total GS), or conflicting (eg, prostate surgery GS from pathology note was "4+4=8," but the clinical note was "4+3=7"; see Table S1 C, Multimedia Appendix 1 for more details). Rather than using objective measures of complexity, we chose to use this set of criteria because it was clinically based and deemed to be a suitable proxy for the level of complexity in the extracted note. Uncomplicated notes were defined as any note not designated as complicated.

Accuracy Assessment

We randomly selected 200 patients for manual human review to assess the accuracy of our NLP system (100 charts reviewed by author SY and 100 charts reviewed by author AL). During human extraction, the extractor was blinded to the NLP results. Discrepancies between the NLP system and human extraction were then manually reviewed by consensus and analyzed to determine the cause of the discrepancy. Discrepancies were assigned to be due to either NLP error or human error. The accuracy of the NLP system and human extraction were calculated based on the number of NLP and human errors, respectively. Differences in accuracy were calculated using the

Fisher exact test. *P* values ≤.05 were considered statistically significant.

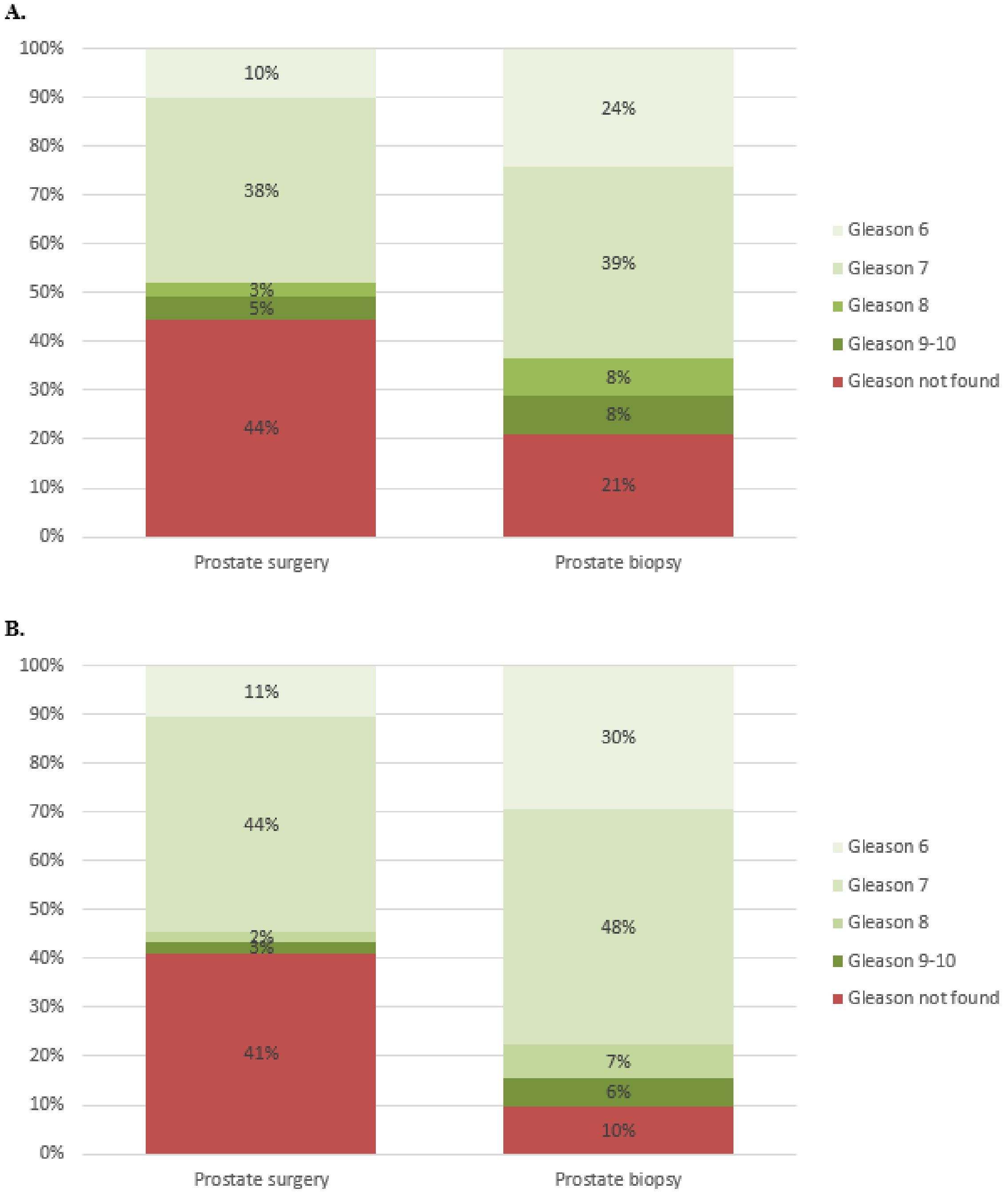
Results

General Trends

We identified 2051 prostate cancer patients from the Penn Medicine Biobank cohort, for whom 7324 pathology notes and 37,320 clinical notes were queried from our EHR data warehouse. Of note, each patient could have multiple pathology and clinical notes in the EHR (average of 3.6 pathology and 18.2 clinical notes per patient).

Based on the queried pathology and clinical notes, the NLP system successfully produced a result for all 2051 patients in our cohort: either a GS or “not found” if no GS was documented in our EHR. The distribution of results is shown in Figure 3A. The distribution of the prostate surgery GS was higher than that of the prostate biopsy GS as expected, as patients with a lower GS on biopsies are less likely to receive surgery and due to the phenomenon of pathologic upgrading. The NLP system also identified a total of 199/4102 (4.85%) notes as complicated, including 66/2051 (3.23%) prostate surgery and 133/2051 (6.48%) prostate biopsy notes. The remaining notes were therefore identified as uncomplicated.

Figure 3. Distribution of NLP Gleason score extractor results for (A) the full cohort and (B) the randomly selected 200 patients. NLP: natural language processing.

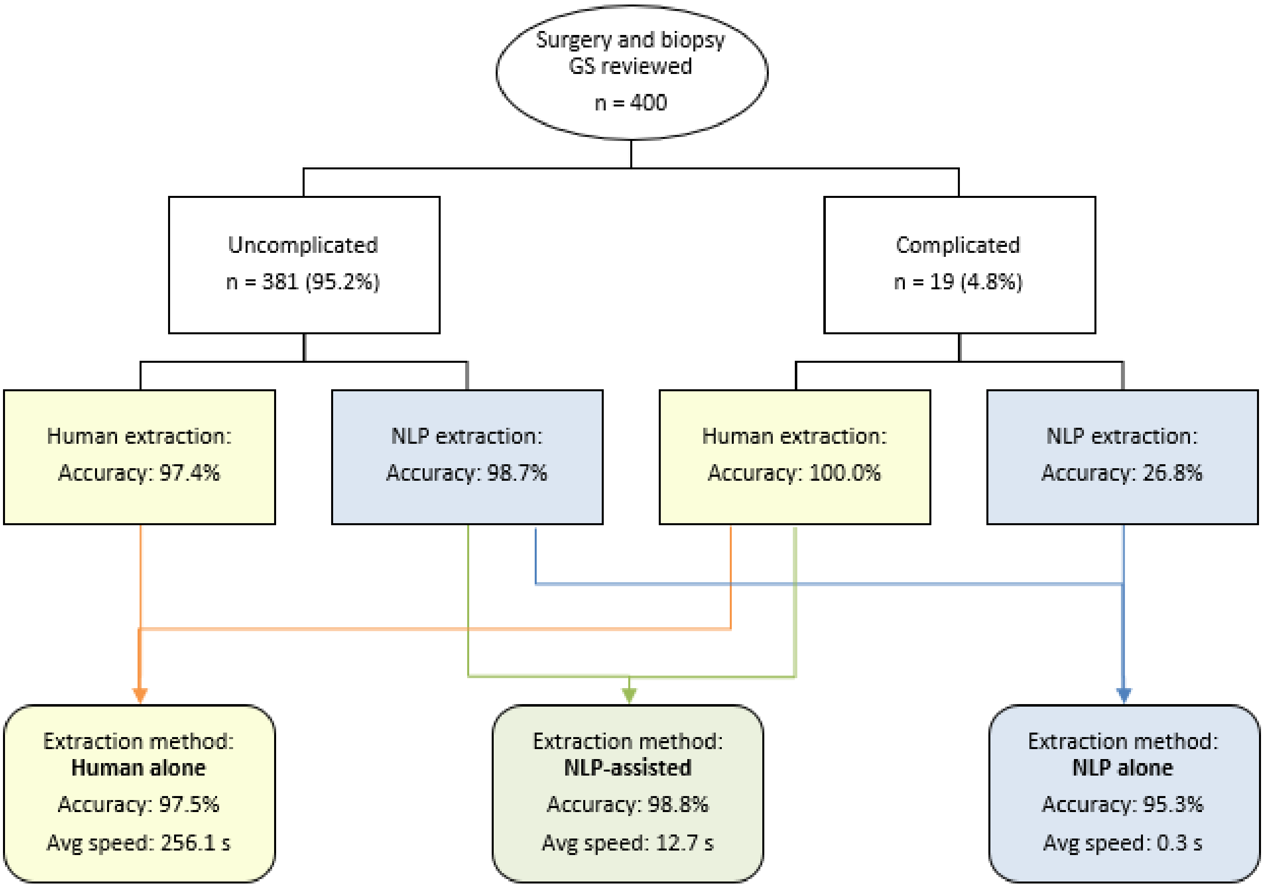


Accuracy Assessment

From the full cohort, 200 patients were randomly selected, and a human extractor manually extracted both a prostate surgery and prostate biopsy GS. Thus, a total of 400 GS (200 prostate surgery GS and 200 prostate biopsy GS) was compared to NLP results for accuracy. The distribution of results is shown in Figure 3B.

Among these 400 prostate surgeries and biopsies, 19 (4.8%) were identified as complicated (see Figure 4). Among the 381 uncomplicated notes, there were 10 human errors (accuracy 371/381, 97.4%) and 5 NLP errors (accuracy 376/381, 98.7%). Further characterization of the NLP errors is shown in Multimedia Appendix 2 Table S2. Thus, among uncomplicated notes, human and NLP accuracy was similar (*P*=.30). Among the 19 complicated notes, there were 0 human errors (accuracy 19/19, 100.0%) and 14 NLP errors (accuracy 5/19, 26.8%). Thus, among complicated notes, human extraction was significantly more accurate than was NLP extraction (*P*=.02). Details of the breakdown in accuracy between prostate surgeries and biopsies are displayed in Multimedia Appendix 3 Table S3.

Figure 4. Accuracy and average extraction time for the three extraction methods.



With human extraction alone, both uncomplicated and complicated notes would be assigned to human extraction, producing an overall accuracy rate of 97.5%. With NLP extraction alone, both uncomplicated and complicated notes would be assigned to NLP extraction, producing an overall accuracy rate of 95.3%. In the NLP-assisted extraction system, uncomplicated notes were assigned to NLP extraction while complicated notes are assigned to human extraction. This produced an overall accuracy of 98.8%. The overall accuracy of the NLP-assisted extraction system was similar to that of human extraction alone (*P*=.17), while it was significantly more accurate than that of NLP extraction alone (*P*<.001).

Extraction Time Analysis

The NLP system extracted GS from all of the pathology notes in approximately 60 seconds and from all clinical notes in 486 seconds. In total, the NLP system processed the full data set for 2051 patients in 546 seconds, which equates to approximately 0.27 seconds per patient (see Figure 4). In comparison, human extraction times were much longer: SY required an average of 306.0 seconds per patient, and AL required an average of 206.3 seconds per note. Thus, the average human extraction time was 256.1 seconds per note. In the NLP-assisted extraction model, approximately 5% of notes required human extraction. Thus, the NLP-assisted approach took an estimated weighted average of 12.7 seconds per note.

Discussion

We constructed an NLP GS extraction system which collected GS from both pathology and clinical notes with high accuracy. We also implemented and assessed an NLP-assisted extraction system that exhibited superior extraction times compared to that of human extraction alone, while maintaining comparable accuracy. Thus, we demonstrated that an NLP-assisted extraction system is capable of using both NLP and human extraction to maximize the strengths of each while overcoming their respective weaknesses.

Charles Friedman [10] states that any health care technology, including NLP systems, should follow the “fundamental theorem” of biomedical informatics: a person working in partnership with an information resource is “better” than that same person unassisted. Our NLP-assisted extraction model aims to achieve this principle by designing our NLP tool to serve as an “intelligent assistant” to the human extractor, working together with humans to create an extraction system which is both fast and accurate.

We believe that this combination of superior accuracy and faster extraction time can greatly accelerate data collection during the establishment of large clinical data warehouses, which can in turn expedite clinical research, quality improvement projects, clinical decision support tools, etc. Although our NLP-assisted extraction model requires approximately 5% of the notes to still be manually reviewed by a human extractor, this also means we can reduce the workload of human extractors by approximately 95%. By extension, this can potentially reduce the cost of variable extraction by approximately 95%, which is important since human extractors represent a major source of cost for establishing most large clinical databases.

NLP solutions have additional benefits. First, NLP can produce highly reliable and standardized extractions compared to human extraction. Extraction style and criteria may vary slightly between different extractors and sometimes even between different times for the same extractor. NLP systems, on the other hand, provide standardized and reproducible results. Second, NLP systems can reduce omission errors due to cognitive biases to which all human tasks are prone. Third, NLP systems are scalable. If a researcher wanted to double the scope of their database, it would require a doubling of the workload for human extractors. However, NLP systems require only electricity and computing costs to execute and therefore can be expanded at scale to meet the needs of researchers with minimal cost.

Finally, the increased speed and scalability of the NLP extraction unlocks important database features that traditional databases lack. For example, NLP extraction allows continuous updates for the database. Because new data are entered by health care workers into the EHR on a daily basis, any clinical database that strives to provide up-to-date clinical data will require human extractors to continuously review new data as they are entered. This task can be both expensive and time-consuming. For example, most current large clinical databases take months to years to provide up-to-date data due the time required for manual human extractors. This limits the ability of clinical researchers and quality-improvement researchers to answer clinically important questions in a timely manner.

Of course, our NLP-assisted model still requires the availability of human extractors, which might not be accessible to all research groups. For researchers hoping to build a clinical database without any human extraction, our NLP system might still provide utility, as it was able to extract GS elements with an accuracy of over 95%.

Currently, there are not many publicly available NLP solutions for adequate extraction of GS. Two previous projects were implemented but were limited to extraction of GS from pathology notes alone [6,7]. However, in the real world, pathology notes are often unavailable for a proportion of patients, especially patients who switch hospital systems during the course of their oncologic care, which happens more frequently for prostate cancer patients due to their longer survival times. Therefore, for many patients, the only source of GS is from their clinical notes. One previous single-institution project also recognized the importance of extraction from clinical notes and sought to extract GS from both clinical and pathology notes [8]. However, they were only able to extract GS with an accuracy of 91% and only from prostate surgery GS. By comparison, our NLP system had an accuracy 95% accuracy, which compares favorably, and we were able to extract both prostate surgery and biopsy GS. To our knowledge, no previously published systems were able to extract both prostate surgery and prostate biopsy GS from clinical notes.

Our NLP system has many important strengths. First, this NLP system was designed from the ground up by a practicing oncologist. Thus, the NLP system was organized and built from the start to best mirror the workflow and thought processes of an oncologist reading medical notes, taking advantage of the various mental shortcuts used by domain experts. Second, we developed our NLP system to extract from both pathology and clinical notes. Pathology notes are generally more structured and thus an easier task for NLP systems, which is why most previous GS extraction systems only worked on pathology notes. On the other hand, clinical notes are much less structured, and thus applying NLP systems to clinical notes with great accuracy is a harder task. Third, we required that our NLP system extract GS from both prostate surgery and prostate biopsies, something which has not been accomplished before. This task is trivial for pathology notes (as pathology notes are usually clearly labeled as either prostate surgery or prostate biopsy) but is much more difficult for clinical notes where this information needs to be gleaned from the free text and placed into context. Finally, we were able to design and successfully implement an NLP-assisted extraction system that achieved significantly higher accuracy rates than did the NLP-only extraction system. It should be noted that our algorithm for distinguishing between uncomplicated and complicated notes played a pivotal role in the high accuracy of our NLP system, as the NLP-human synergy can only work if the proper notes are assigned to human extractors. Here, we again took advantage of the expert domain knowledge available to us and leveraged a clinically based algorithm.

Our study does have some notable limitations. First, we selected only 200 patients for manual review, and therefore the study was not powered to detect small differences in accuracy between the different extraction methods. However, even with only 200 patients reviewed, we were still able to detect a statistically significant difference in accuracy between the NLP-assisted and NLP-only extraction models. Second, we conducted a single-institution study, and therefore external validity may be limited. However, our institution notably does not have standardized templates for clinical notes between health care providers. Thus, our clinical notes likely contained a wide variability of wordings, sentence structures, and note formatting between different providers, similar to those of other institutions.

In conclusion, we successfully designed and implemented an NLP-assisted extraction system to extract Gleason scores from medical notes with almost 99% accuracy, a significantly faster and cheaper solution over human extraction alone. In future works, we will expand our NLP-assisted extraction system for the extraction of other clinically important variables.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Pseudocode for the natural language processing modules.
[DOCX File , 16 KB - cancer_v7i3e27970_app1.docx]

Multimedia Appendix 2
Characterization of natural language processing errors among uncomplicated notes.
[DOCX File , 13 KB - cancer_v7i3e27970_app2.docx]

Multimedia Appendix 3
Breakdown of accuracy for human and natural language processing extraction between prostate surgeries and biopsies.
[DOCX File , 14 KB - cancer_v7i3e27970_app3.docx]

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Abbreviations

GS: Gleason score
EHR: electronic health record
ICD: International Classification of Disease:
NLP: natural language processing
P: primary Gleason score
S: secondary Gleason score
T: total Gleason score

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Review

Prostate Cancer Risk Calculators for Healthy Populations: Systematic Review

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Abstract

Background: Screening for prostate cancer has long been a debated, complex topic. The use of risk calculators for prostate cancer is recommended for determining patients' individual risk of cancer and the subsequent need for a prostate biopsy. These tools could lead to better discrimination of patients in need of invasive diagnostic procedures and optimized allocation of health care resources

Objective: The goal of the research was to systematically review available literature on the performance of current prostate cancer risk calculators in healthy populations by comparing the relative impact of individual items on different cohorts and on the models' overall performance.

Methods: We performed a systematic review of available prostate cancer risk calculators targeted at healthy populations. We included studies published from January 2000 to March 2021 in English, Spanish, French, Portuguese, or German. Two reviewers independently decided for or against inclusion based on abstracts. A third reviewer intervened in case of disagreements. From the selected titles, we extracted information regarding the purpose of the manuscript, analyzed calculators, population for which it was calibrated, included risk factors, and the model's overall accuracy.

Results: We included a total of 18 calculators from 53 different manuscripts. The most commonly analyzed ones were the Prostate Cancer Prevention Trial (PCPT) and European Randomized Study on Prostate Cancer (ERSPC) risk calculators developed from North American and European cohorts, respectively. Both calculators provided high diagnostic ability of aggressive prostate cancer (AUC as high as 0.798 for PCPT and 0.91 for ERSPC). We found 9 calculators developed from scratch for specific populations that reached a diagnostic ability as high as 0.938. The most commonly included risk factors in the calculators were age, prostate specific antigen levels, and digital rectal examination findings. Additional calculators included race and detailed personal and family history.

Conclusions: Both the PCPR and ERSPC risk calculators have been successfully adapted for cohorts other than the ones they were originally created for with no loss of diagnostic ability. Furthermore, designing calculators from scratch considering each population's sociocultural differences has resulted in risk tools that can be well adapted to be valid in more patients. The best risk calculator for prostate cancer will be that which has been calibrated for its intended population and can be easily reproduced and implemented.

Trial Registration: PROSPERO CRD42021242110; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=242110

(JMIR Cancer 2021;7(3):e30430) doi:10.2196/30430

KEYWORDS

prostate cancer; risk calculator; risk reduction

Introduction

According to the World Health Organization, the 2020 global incidence of prostate cancer was 1,414,259 cases, which represented 7.3% of all the new cancer cases. It represents the fourth most common type of cancer [1]. In Mexico, prostate cancer is the leading type of cancer death in men 50 years and older [2]. Early prostate cancer detection could help to accurately discriminate indolent from aggressive cancers and significantly reduce the overuse of invasive diagnostic techniques and the side effects associated with cancer treatment [3]. A randomized study on the European population who underwent screening showed a progressive 51% reduction in prostate cancer mortality in individuals up to age 75 years [4].

Currently, there is no evidence to support or refute the implementation of widespread early screening programs for prostate cancer; and the position of international guidelines on who and when to screen has constantly pivoted. Thus, active surveillance must be based carefully on individualized weight of risk factors [5,6]. For example, the combination of family history of prostate cancer, personal medical history, serum biomarker levels, and sociocultural aspects has led to the creation of tools that can more accurately predict individual risk for prostate cancer and focalize screening strategies for populations at higher risk. These tools, or risk calculators, could lead to a reduction in the overdiagnosis of prostate cancer and its subsequent overtreatment [7]. The European Randomized Study of Prostate Cancer (ERSPC) risk calculator (RC) and the Prostate Cancer Prevention Trial (PCPT) RC are two well-known prostate cancer risk calculators that have been extensively validated in independent cohorts in their original versions; recent, updated versions of both calculators have shown promising results in populations other than the ones for which they were originally developed [8]. Other well-known, externally validated predictive models like the Prostate Health Index (PHI), which includes more biomarkers, are important tools in reducing unnecessary prostate biopsies [9]. All of these predictive models have been used among diverse populations with different results regarding each risk factor's individual predictive value for prostate cancer, as well as the models' overall performance.

Prostate cancer screening is based in the combination of serum prostate specific antigen (PSA), digital rectal examination (DRE), and sometimes additional urine biomarkers. Additional tools such as magnetic resonance imaging (MRI) and risk calculators may help decide the need for a biopsy [10]. Advanced imaging techniques and access to biopsy are not always available, particularly in lower- and middle-income countries, which renders risk calculators a viable option to decide which patients are in need of additional screening and for optimizing allocation of health care resources. A systematic review on prostate cancer risk calculators in a healthy population could summarize current tools available to primary care physicians and encourage the adaptation or creation of new risk calculators adjusted to each population's sociocultural variations [11].

The aim of our study was to systematically review available literature on current prostate cancer risk calculators in healthy population by comparing the relative impact of individual items on different cohorts and the models' overall performance.

Methods

Search Methods

A systematic review was performed in April 2021. We searched MEDLINE via PubMed and Latin American and Caribbean Health Sciences via LILACS for publications between January 1, 2000 and April 1, 2021. We used 3 combined queries as follows: ("2000/01/01"[Date–Publication]: "2021/04/01"[Date–Publication]) AND ((cancer of prostate [MeSH terms]) OR (prostate cancer [MeSH terms])) OR (prostate cancer [text word]) AND ((risk prediction [text word]) OR (risk model [text word])) OR (risk calculator [text word]). We extracted the resulting titles and abstracts into a spreadsheet. This systematic review was registered at PROSPERO [CRD42021242110].

Selection Criteria

Articles were included if they met the following criteria:

- Authors presented a new risk calculator for prostate cancer OR authors validated or modified an existing risk calculator in a different population OR authors compared predictive capabilities of 2 or more risk calculators
- Article was in either Spanish, English, French, Portuguese, or German
- Article explicitly described the calculator's predictive capability

Articles were excluded if any of the following were true:

- Article presented or analyzed a calculator for nonhealthy population such as models to predict aggressiveness or relapse in a population already diagnosed with prostate cancer
- Reported risk factors were mainly genomic (eg, polymorphisms) or considered inaccessible for general practitioners or in settings with limited resourced (eg, MRI)

Data Extraction and Analysis

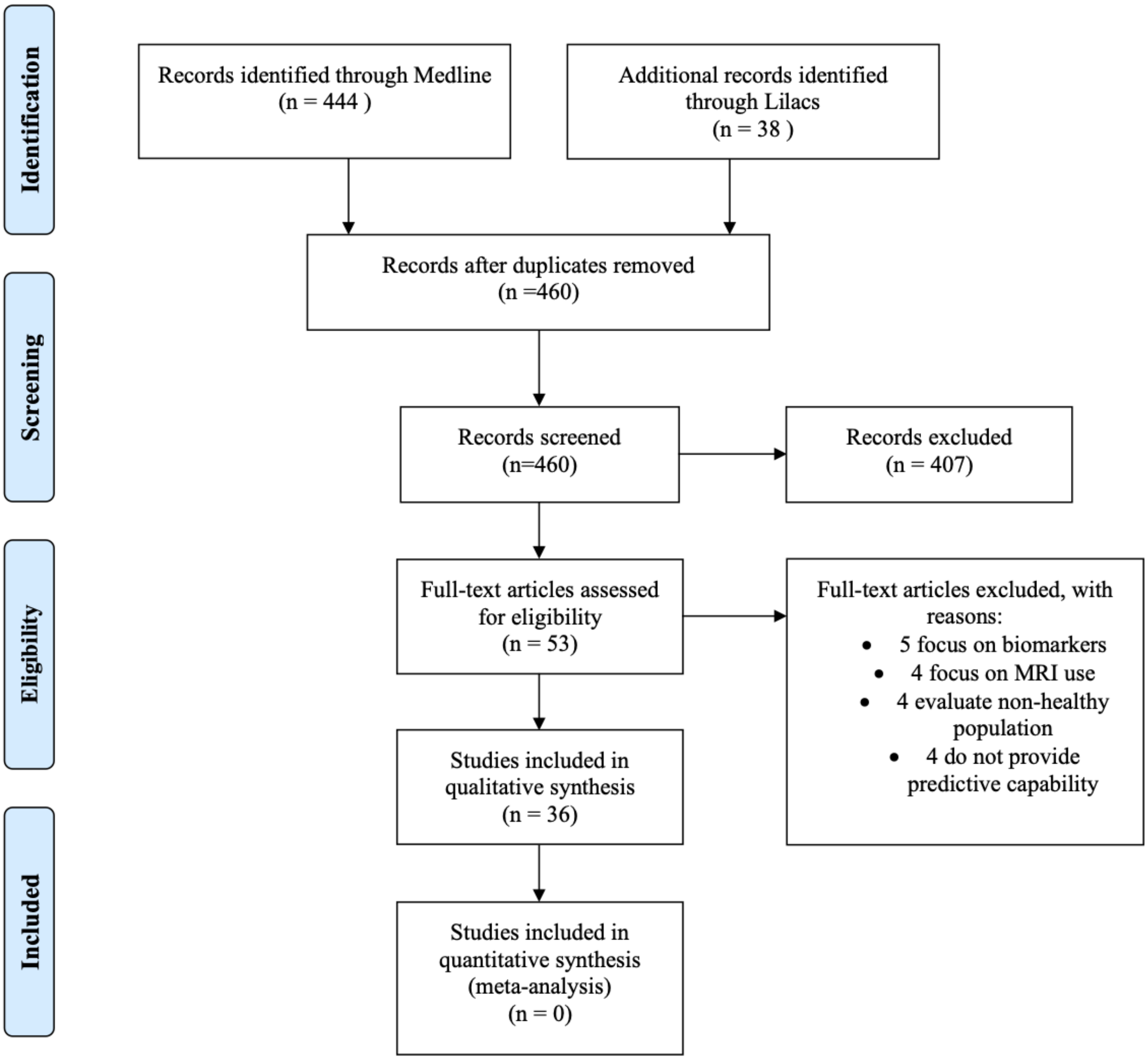
Using the listed criteria, two authors independently reviewed the titles and abstracts and decided for or against inclusion. We included titles if both reviewers agreed on inclusion and vice versa for exclusion. If the reviewers disagreed, a third reviewer decided on the article's inclusion. We then obtained the full text for selected titles, screened them for final inclusion eligibility, and extracted the data from selected articles. From each included article, we extracted the objective, study design, number of participants and their inclusion criteria, name of the proposed or analyzed model, methodology for the development or analysis of each model's included risk factors and their impact measurements, validation methodology, and each model's prediction capability. From the extracted data, we then summarized the risk factors and their impact measurements for prostate cancer according to each model that included them.

Results

Our search resulted in 460 articles after excluding duplicates. We reviewed all results and agreed on 53 articles that passed the title and abstract stage, in which we evaluated the complete text. We then excluded an additional 17 titles: 5 that focused on biomarkers as predictors, 4 that evaluated the use of MRI techniques, 4 on nonhealthy population that predicted recurrence of disease, and 4 that did not specify risk or prediction ability.

We then extracted information on the remaining 36 studies and classified them as articles that evaluated or calibrated risk calculators in a new population, studies that compared 2 or more existing risk calculators in a specific population, and studies that proposed and validated a novel risk calculator. We identified a total of 18 risk calculators in the 36 included studies. We did not perform a metanalysis of the individual risk factors as the reported impact measurements were too heterogenous (Figure 1).

Figure 1. PRISMA flowchart of included studies.



We first identified the most commonly studied risk calculators and the risk factors they include in their original versions. The most mentioned risk calculators were the ERSPC, PCPT, and PHI.

The ERSPC RC, in its original version for use by medical personnel (R3 version), includes MRI information if available, PSA levels, results of a prior biopsy, and results of a DRE and prostate volume measured by transrectal ultrasound [12]. In its original version, the PCPT RC includes age, race, PSA levels, family history of prostate cancer, results of a DRE, results of a prior biopsy, and when available, free PSA, prostate cancer antigen 3, and T2:ERG [13]. On the other hand, the PHI calculates risk with a mathematical approach that includes PSA, free PSA, and prostate specific antigen isoform p2 [14]. Since their introduction, all these calculators have undergone external modifications with additional risk factors. Additionally, we found calculators that were developed de novo and that include different risk factors from the canonical ERPSC and PCPT RCs. For example, the Lifestyle Risk Prediction Model for Prostate Cancer by Kim et al [15] includes height, weight, glucose levels, meat and alcohol consumption, smoking status, and physical activity. The risk calculator by Albright et al [16] incorporates a detailed extended family history to calculate the risk of prostate cancer, and the risk calculator by Jalali et al [17] combines traditional measurements of PSA and DRE with family history.

In Table 1, we present the summary of all articles in the systematic review. A single article may have evaluated multiple risk calculators or may have had multiple purposes. A total of 18 articles evaluated the PCPT RC (1 optimized it with the prostate health index, 1 optimized it with detailed family history, 14 calibrated or assessed it in a new population, and 2 assessed it in a new population while also comparing it with a different calculator). Similarly, 14 articles evaluated the ERSPC RC in its level 3 version (1 optimized it with the PHI, and 13 calibrated it in a new population, out of which 7 also compared it to a different calculator [essentially the PCPT RC or a new calculator]). We found 9 articles describing a new risk calculator as well as their area under the curve (AUC) and calibration. The table also describes the predictive capacity that each study found for the analyzed risk calculators. For example, depending on the populations in which they were used, the PCPT RC had AUCs ranging from as low as 0.562 to as high as 0.813, while the ERSPC RC reported AUCs from 0.68 to 0.86. These AUCs also varied depending on whether the calculator was applied to any prostate cancer or to high-grade prostate cancer. AUCs are generally higher when looking for high-grade cancers. For example, for the PCPT RC, AUCs for prostate cancer peaked at 0.783, while those for high-grade prostate cancer could be as high as 0.813. Furthermore, risk calculators created from scratch also showed high predictive capabilities on their target population, such as the Korean Prostate Cancer Risk Calculator (AUC 0.887) by Kim et al [15], which uses socioenvironmental aspects of their population to create the predictive models, and the risk calculator by Albright et al [16], which stratifies risk depending on the number of extended family members with prostate cancer.

In Table 2, we detail the reported impact measures associated with each risk factor by risk calculator. Not all studies specified the impact measures of each individual risk factor but rather reported only the calculator's overall predictive ability, as described in Table 2. For those that did specify, elevated PSA levels and a positive DRE conferred the highest risk for prostate cancer. For example, log PSA as a predictor in the PCPT RC conferred an HR of 5.42 and an OR of 1.8 for prostate cancer, while a positive DRE showed significant ORs from 2.2 to as high as 8.22 in the Korean Prostate Cancer RC. A positive family history of prostate cancer also conferred higher odds in the PCPT RC. On the other hand, and as is expected, a prior negative biopsy was found as a protective factor for prostate cancer (with HRs of 0.14 and 0.64 as found in the PCPT RC). Race was not significant in any of the calculators that specified its impact measures.

Table 1. Summary of models in included studies.

Model and country	Article	Year	Purpose	End point	Sample size	Study type	AUC[a]	Notes
PCPT[b]RC[c]								
Ireland	Loeb, et al [18]	2017	A[d]	Gleason ≥7	892	1[e]	0.697	Inclusion of PHI[f] into an existing calculator
US	Auffenberg, et al [19]	2017	B[g]	Absence of cancer, Gleason <7, Gleason ≥7	11,809	2[h]	0.621 (0.607-0.64)	—[i]
Ireland	Lundon, et al [20]	2015	B	Risk of any prostate cancer diagnosis and risk of high-grade disease	556	2	PC[j]: 0.628; high-grade PC: 0.798	—
Switzerland	Poyet, et al [21]	2016	B	Gleason ≥7 and/or T stage ≥T2b	1615	2	PC: 0.66; high-grade PC: 0.69	Validation in a Swiss cohort
North America and Europe	Ankerst, et al [22]	2018	B,C[k]	Gleason ≥7, <7, or no cancer	15,611	2	0.723 (0.709-0.737)	Compares AUC to PBCG[l] RC
Switzerland	Poyet, et al [11]	2016	B	PC or significant PC (Gleason ≥7)	1996	2	PC: 0.66; significant PC: 0.70	Compares and calibrates new versions of PCPT and ERSPC[m]
US	Kaplan, et al [23]	2010	B	PC or significant PC (Gleason ≥7)	624	1	Not specified	Validates PCPT in high-risk individuals
International	Ankerst, et al [13]	2012	B	Each cohort’s criteria	25,733	2	ERSPC Goeteborg 1: 0.72; ERSPC Goeteborg 2-6: 0.562; ERSPC Rotterdam 1: 0.7; ERSPC Rotterdam 2-3: 0.61; ERSPC Tarn: 0.667; SABOR[n]: 0.654; Cleveland Clinic: 0.588; ProtecT: 0.639; Tyrol: 0.667; Durham: 0.715	—
Portugal	Cavadas, et al [24]	2010	B,C	Positive biopsy	493	2	0.744 (0.705-0.781)	—
Sweden	Grill, et al [25]	2015	A	Same as PCPT RC	55,158 cases + 632,218 controls	3[o]	Not specified	Adds detailed family history to PCPT RC
Canada	Trottier, el al [26]	2011	B,C	PC or high-grade PC	982	2	0.63	—
US	Carbunaru, et al [27]	2019	B,C	PC and significant PC	954	2	Significant PC: 0.64 (0.61-0.68)	—
Mexico	Liang, et al [28]	2013	B	PC and significant PC	826	2	PC: 0.785; high-grade PC: 0.766	—
US	Nguyen, et al [29]	2010	B	PC or high-grade PC	3482	2	PC: 0.57; high-grade PC: 0.6	—
China	Zhu, et al [30]	2012	B,C	PC or high-grade PC	495	2	PC: 0.783 (0.737-0.83); high-grade PC: 0.813 (0.764-0.862)	—
US	Liang, et al [31]	2013	B	PC or high-grade PC	1021	2	Not specified	—
US	Nam, et al [32]	2011	B,C	PC or high-grade PC	2130	2	PC: 0.61 (0.59-0.64); aggressive PC: 0.67 (0.64-0.7)	—
US	Parekh, et al [14]	2006	B	PC or high-grade PC	446	2	0.655 (0.602-0.708)	Uses PCPT in an ethnically diverse population
Finasteride-adjusted PCPT RC								

Model and country	Article	Year	Purpose	End point	Sample size	Study type	AUC[a]	Notes
Mexico	Liang, et al [33]	2012	B	PC	837	2	PC: 0.784; high-grade PC: 0.768	—
ERSPC RC (level 3)								
US	Loeb, et al [18]	2017	A	Gleason ≥7	892	1	0.711	Inclusion of PHI into an existing calculator
Europe	Van Vugt, et al [34]	2010	B	Positive sextant prostate biopsy	1825 Finnish men + 531 Swedish men	2	Finnish cohort 0.76 (0.74-0.79), Swedish cohort 0.78 (0.73-0.83)	—
Netherlands	Gayet, et al [35]	2018	B	Gleason ≥7 and/or T stage ≥T2b	1812	2	PC: 0.78 (0.76-0.8); significant PC: 0.91 (0.89-0.92)	—
Ireland	Lundon, et al [20]	2015	B,C	Risk of any PC diagnosis and risk of high-grade disease	556	2	PC: 0.588; high-grade PC: 0.69	—
South Africa	Kowlessur, et al [36]	2020	B	Gleason ≥7 and/or T stage ≥T2b	475	2	PC: 0.738 (0.695-0.781); significant PC: 0.833 (0.789-0.876)	Calibration of ERSPC for South African Population
Switzerland	Poyet, et al [21]	2016	B	Gleason ≥7 and/or T stage ≥T2b	1615	2	PC: 0.64; high-grade PC: 0.70	Validation in a Swiss cohort
Spain	Gómez-Gómez, et al [37]	2017	B,D[p]	Gleason ≥7 and/or T stage ≥T2b	749	2	PC: 0.69 (0.65-0.74), high-grade PC: 0.74 (0.70-0.79)	Also evaluates variability with a subsequent PSA[q] sample
Switzerland	Poyet, et al [11]	2016	B,C	PC or high-grade PC	1996	2	PC: 0.65; significant PC: 0.73	Compares and calibrates new versions of PCPT and ERSPC
Canada	Trottier, et al [26]	2011	B,C	PC or high-grade PC	982	2	0.71	—
China, Netherlands	Chen, et al [38]	2021	B,C	PC or high-grade PC	6741	2	European cohort: PC: 0.79 (0.77-0.81); high-grade PC: 0.86 (0.84-0.89); Chinese cohort: PC: 0.74 (0.72-0.76); high-grade PC: 0.74 (0.72-0.76)	Compares CPCC[r] RC to ERSPC RC
Portugal	Cavadas, et al [24]	2010	B,C	Positive biopsy	493	2	0.801 (0.764-0.834)	—
Netherlands	Van Vugt, et al [39]	2012	B	Positive sextant prostate biopsy	320	2	0.77 (0.72-0.83)	—
China	Zhu, et al [30]	2012	B,C	PC or high-grade PC	495	2	PC: 0.831 (0.79-0.872); high-grade PC: 0.852 (0.807-0.897)	—
Europe	Roobol, et al [40]	2015	B,C,D	Positive sextant prostate biopsy	1185	2	PC: 0.72; clinically relevant PC: 0.68	Uses an ERSPC model that includes PHI
ERSPC RC (level 4)								
Netherlands	Gayet, et al [35]	2018	B	Gleason ≥7 and/or T stage ≥T2b	1812	2	PC: 0.62 (0.56-0.67); significant PC: 0.74 (0.66-0.81)	—
Europe	Roobol, et al [40]	2015	B,C,D	Positive sextant prostate biopsy	1185	2	PC: 0.72 (0.67-0.77)	Uses an ERSPC model that includes PHI
MUSIC[s] model								
US	Auffenberg, et al [19]	2017	A,C	Absence of cancer, Gleason <7, Gleason ≥7	11,809	2	0.63 (0.613-0.65)	—

Model and country	Article	Year	Purpose	End point	Sample size	Study type	AUC[a]	Notes
CPCC RC								
China	Chen, et al [41]	2016	A,C	PC or high-grade PC	924 patients for model development + 911 patients for model validation	2	PC: 0.801 (0.771-0.831); high-grade PC: 0.826 (0.796-0.857)	Compares CPCC RC to ERSPC RC
China, Netherlands	Chen, et al [38]	2021	B,C	PC or high-grade PC	6741	2	European cohort: PC: 0.77 (0.75-0.79); high-grade PC: 0.86 (0.83-0.88); Chinese cohort: PC 0.77 (0.74-0.77); high-grade PC: 0.77 (0.75-0.79)	—
ProstateCheck								
Switzerland	Poyet, et al [21]	2016	B,C	Gleason ≥7 and/or T stage ≥T2b	1615	2	PC: 0.69 (0.67-0.73); high-grade PC: 0.72 (0.69-0.77)	ProstateCheck is based on the ERSPC
Sunnybrook normogram-based PC RC								
US	Nam, et al [32]	2011	B,C	PC or high-grade PC	2130	2	PC: 0.67 (0.65-0.69); aggressive PC: 0.72 (0.7-0.75)	—
PHI model								
Ireland	Foley, et al [42]	2016	D	Low grade PCA: Gleason 6; High-grade PCA: Gleason ≥7.	250	2	PC: 0.71; high-grade PC: 0.78	Development of a model that incorporates PHI score
PBCG RC								
North America and Europe	Ankerst, et al [22]	2018	D,C	Gleason ≥7, <7, or no cancer	15,611	2	0.755 (0.742-0.768)	Compares AUC to PCPT RC
US	Carbunaru, et al [27]	2019	B,C	PC and significant PC	954	2	Significant PC: 0.65 (0.62-0.68)	
Next-generation PC RC								
Canada	Nam, et al [43]	2018	D	Gleason ≥7	5639 patients with a prostate biopsy + 979 patients with PC	2	Model 1: concordance index 0.74 (0.72-0.76); model 2: concordance index 0.71 (0.69-0.72)	—
Seoul National University PC RC								
South Korea	Jeong, et al [44]	2014	D,C	PC	3482	2	Development cohort: 0.786; validation cohort: 0.811	Mobile app-based RC
Indonesian PC RC								
Indonesia	Yuri, et al [45]	2015	D,C	Not specified	1957	2	0.938 (0.93-0.95)	—
Korean PC RC								
South Korea	Yoon, et al [46]	2012	D	Positive biopsy	602	2	0.9 (0.89-0.92)	—
Unnamed model by Albright, et al								
US	Albright, et al [16]	2015	D	PC	635,433	2	Not specified	Model uses extended detailed family history
Unnamed model by Loeb, et al								

Model and country	Article	Year	Purpose	End point	Sample size	Study type	AUC[a]	Notes
US	Loeb, et al [18]	2017	D	Gleason ≥7	892	1	0.746	Development of a model that incorporates PHI score
Unnamed model by Kim, et al								
South Korea	Kim, et al [15]	2018	D	ICD-10 code C61	1,179,172 for model development + 389,539 for model validation	2	0.887 (0.879-0.895)	Based on epidemiologic factors rather than PSA
Unnamed model by Jalali, et al								
Ireland	Jalali, et al [17]	2020	D,C	PC or high-grade PC	4801	2	PC: 0.674 (0.659-0.689); high-grade PC: 0.721 (0.701-0.741)	Calculator informs need for prostate biopsy
Unnamed model by Chen, et al								
Taiwan	Chen, et al [47]	2020	A,D	PC or high-grade PC	1545	2	PC: 0.795; high-grade PC: 0.869	App-based calculator

[a] AUC: area under the curve.

[b] PCPT: Prostate Cancer Prevention Trial.

[c] RC: risk calculator.

[d] A: optimizes an existing model.

[e] 1: clinical trial.

[f] PHI: prostate health index.

[g] B: calibrates and/or assesses discrimination of an existing model in a specific population.

[h] 2: cohort.

[i] PC: prostate cancer.

[j] C: compares two or more existing models in a specific population.

[k] PBCG: Prostate Biopsy Collaborative Group.

[l] ERSPC: European Randomized Study on Screening for Prostate Cancer.

[m] SABOR: San Antonio Center of Biomarkers of Risk for Prostate Cancer.

[n] 3: case control.

[o] D: presents and validates a new model.

[p] PSA: prostate specific antigen.

[q] CPCC: Chinese Prostate Cancer Consortium.

[r] MUSIC: Michigan Urological Surgery Improvement Collaborative.

Table 2. Impact measure of risk factors included in prostate cancer risk calculators.

Risk factor and model	Author	Impact measure	*P* value	Notes
Age				
ERSPC[a] RC[b]	Trottier, et al [26]	Mean risk 0.31	—[c]	Age >70
PCPT[d] RC	Trottier, et al [26]	Mean risk 0.53	—	Age >70
CPCC[e] RC model 1	Chen, et al [41]	OR[f] 1.074 (1.050-1.098)	<.001	—
Unnamed model by Kim, et al	Kim, et al [15]	HR[g] 1.26 (1.245-1.276)	<.001	As “age-mean_age”
Korean PC[h] RC	Yoon, et al [46]	OR 1.06 (1.04-1.08)	<.001	—
Race				
ERSPC RC	Trottier, et al [26]	Mean risk 0.25	—	Hispanic
PCPT RC	Kaplan, et al [23]	HR 1.1 (0.58-2.08)	.76	African American race
—	Trottier, et al [26]	Mean risk 0.48	—	Hispanic
Family history of PC				
ERSPC RC	Trottier, et al [26]	Mean risk 0.28	—	—
PCPT RC	Kaplan, et al [23]	HR 1.16 (0.60-2.25)	.67	—
—	Trottier, et al [26]	Mean risk 0.51	—	—
—	Yuang, et al [28]	OR 1.31 (1.11-1.55)	<.001	—
Unnamed model by Liang Y, et al	Yuang, et al [28]	OR 3.23 (1.89-5.54)	<.001	—
PSA [i]				
ERSPC RC	Trottier, et al [26]	Mean risk 0.35	—	>6 ng/mL
PCPT RC	Kaplan, et al [23]	HR 5.42 (3.90-7.52)	—	As log PSA
—	Trottier, et al [26]	Mean risk 0.56	—	>6 ng/mL
—	Yuang, et al [28]	OR 1.8 (1.46-2.21)	<.001	As log PSA
CPCC RC model 1	Chen, et al [41]	OR 7.7219 (4.3644-13.6625)	<.001	As log PSA
Korean PC RC	Yoon, et al [46]	OR 4.31 (3.29-5.65)	<.001	As log PSA
Unnamed model by Liang Y, et al	Yuang, et al [28]	OR 2.34 (2.13-2.56)	<.001	As log PSA
Free PSA				
CPCC RC model 1	Chen, et al [41]	OR 0.015 (0.0016-0.1407)	<.001	As free PSA ratio
Korean PC RC	Yoon, et al [46]	OR 2.74 (2.12-3.40)	<.001	As log free PSA
DRE [+] [j]				
ERSPC RC	Trottier, et al [26]	Mean risk 0.45	—	—
PCPT RC	Kaplan, et al [23]	HR 0.45 (0.16-1.24)	.12	—
—	Trottier, et al [26]	Mean risk 0.61	—	—
—	Yuang, et al [28]	OR 2.47 (2.03-3.01)	<.001	—
CPCC RC model 1	Chen, et al [41]	OR 2.2031 (1.5268-3.1788)	<.001	—
Unnamed model by Liang Y, et al	Yuang, et al [28]	OR 4.22 (2.91-6.14)	<.001	—
Korean PC RC	Yoon, et al [46]	OR 8.22 (5.44-12.4)	<.001	—
Previous biopsy				
ERSPC RC	Trottier, et al [26]	Mean risk 0.15	—	—
PCPT RC	Kaplan, et al [23]	HR 0.14 (0.05-0.37)	<.001	Prior negative biopsy
—	Trottier, et al [26]	Mean risk 0.45	—	—
—	Yuang, et al [28]	OR 0.64 (0.53-0.78)	<.001	Prior negative biopsy
Unnamed model by Liang Y, et al	Yuang, et al [28]	OR 0.13 (0.07-0.23)	<.001	Prior negative biopsy

Risk factor and model	Author	Impact measure	*P* value	Notes
TRU [k]				
ERSPC RC	Trottier, et al [26]	Mean risk 0.2	—	≥42 mL
PCPT RC	Trottier, et al [26]	Mean risk 0.49	—	≥42 mL
Korean PC RC	Yoon, et al [46]	OR 4.05 (2.79-5.88)	—	—

[a] ERSPC: European Randomized Study on Screening for Prostate Cancer.

[b] RC: risk calculator.

[c] Not applicable.

[d] PCPT: Prostate Cancer Prevention Trial.

[e] CPCC: Chinese Prostate Cancer Consortium.

[f] OR: odds ratio.

[g] HR: hazard ratio.

[h] PC: prostate cancer.

[i] PSA: prostate specific antigen.

[j] DRE [+]: positive/altered digital rectal examination.

[k] TRU: transrectal ultrasound.

Discussion

Principal Findings

Our study's most important findings were that most available risk prediction tools for prostate cancer are optimizations (ie, improvement of the predictive capacity of existing calculators) or recalibration (ie, applying an existing one to a different population) of the PCPT RC or ERSPC RC. Furthermore, some authors presented and validated a new calculator from scratch. Whatever the mechanism, all risk calculators that have been optimized, calibrated, or created with a specific population in mind seem to have adequately high prediction capabilities.

In our study, we have provided a comprehensive description of available risk calculators for prostate cancer and their predictive capability in healthy population. Due to the nature of prostate cancer; when, who, and even if, to screen, has always been a controversial topic. Before the PSA era, overdiagnosis and overtreatment were major concerns. Since the implementation of PSA screening, there has been a reported decrease of 53% in prostate cancer mortality in the United States. However, North American guidelines have shifted between their position to screen or not using PSA [48]. Furthermore, the recent introduction of novel serum-based models that complement PSA, such as the PHI, have improved the detection capability of clinically significant prostate cancer. A combination of several individual factors into a prediction model could more accurately predict cases of prostate cancer that need to be treated and reduce the number of unnecessary biopsies and their complications [49].

Although there have been recent improvements in detection of prostate cancer with the use of novel biomarkers and advanced imaging techniques, these are not widely available, especially in low- and middle-resource settings, and cannot be widely applicable at the primary level, which renders the use of reproducible predictive models based on data available at primary settings essential for decision making at a larger scale. Despite this, the two most commonly used models for predicting prostate cancer, the PCPT RC and ERSPC RC, were created and validated with North American and European populations and may not have the same predictive capabilities when applied as they are, in different populations. To further emphasize this, people of non-European ancestries make up less than 15% of the available genome-wide association study of prostate cancer [50]. However, our systematic review found numerous cases of calibration of these tools for different population with results similar to the originals. One of such examples is the external validation by Chen et al [47] of the ERSPC RC in a Chinese cohort, in which they found an AUC of 0.74 for any prostate cancer and a similar AUC of 0.74 for high-grade prostate cancer, while also finding in the same cohort an AUC of 0.77 for any or high-grade prostate cancer using the Chinese Prostate Cancer Consortium (CPCC) RC. They thus concluded that an Asian-adapted ERSPC RC and application of the CPCC RC in a European PSA-based screening reduce unnecessary biopsies; however, they stress the need for external validation before implementing a risk calculator.

Still, our review found that fewer than 10 of the included articles focused on calibrating these calculators on non-European or non–North American populations: most of them in Asia, 1 in South Africa, and 1 in Mexico. The underrepresentation of an ethnically diverse population for the calibration of these tools results in fewer available predictive models in the settings where they would be most beneficial. For example, the study by Liang et al [28] of the PCPT RC in a Mexican population resulted in an AUC of 0.785 for high-grade prostate cancer, even higher than the tool's AUC when applied to European populations in other studies. Similarly, the calibration by Kowlessur et al [36] of the ERSPC RC for a South African population resulted in a high AUC of 0.833 for high-grade prostate cancer. Knowing that these tools can be easily adapted and calibrated for populations in lower-resource settings could encourage researchers to adjust these calculators to settings that still struggle with the overperformance of invasive biopsies.

Although the characteristics of the included studies did not allow for a meta-analysis of the individual risk factors or the tools' overall predictive capabilities, it seems that both the ERSPC RC and PCPT RC have similarly high predictive capabilities. Zhu et al [30] reported an AUC of up to 0.813 for the PCPT RC in a Chinese cohort, and Gayet et al [35] reported an AUC of 0.91 in the ERSPC RC in a Dutch cohort. Either of these calculators could be potentially adapted to new populations depending on the availability of transrectal ultrasound, which is one of the included items for calculating risk in the ERSPC RC that the PCPT RC does not include. In the end, it is not about determining which risk calculator is best but about making sure that whichever one is used is calibrated and adapted to its intended recipients. That is, the best calculator will be one that is accessible, valid, and reproducible.

The creation of new tools targeted at new populations is also a valid alternative to calibrating existing ones, and this can also yield optimal results. For example, the calculator by Yuri et al [45] designed for an Indonesian population resulted in an AUC of 0.938 when using a simple list of 5 items. Similarly, the calculator by Kim et al [15] designed for a South Korean population reached an AUC of 0.887 and focused on epidemiologic factors over serum markers.

Limitations

Our study's main limitation is that the nature of the included articles did not allow for the evaluation of bias as per the Cochrane manual. However, we find that the potential risk for bias is low as each author describes the specific way the calculators are calibrated. Its main strength is that it provides a comprehensive description of available risk calculators and how they can be successfully adapted for different target populations.

Conclusion

Although most existing risk calculators for prostate cancer were developed with European or North American populations, their calibration for populations in different settings leads to equally high predictive capacities and yields tools that could be used in resource-limited settings. Risk calculators that included multiple items should be used over prior techniques using markers alone in order to decrease unnecessary procedures in healthy populations at lower risk for prostate cancer. Although screening for prostate cancer remains a shared decision based on individual preference and apparent risk, the development and improvement of predictive tools could lead to optimal algorithms that consider patients' greatest benefit and help for better allocation of health care resources.

Authors' Contributions

NRN and ABJ conceived and designed the trial. ABJ, FPH, and NRN reviewed extracted titles and abstracts. All authors extracted data from the included studies into the review proper. ABJ and NRN analyzed the data. ABJ wrote the manuscript. All authors critically reviewed the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AUC: area under the curve
CPCC: Chinese Prostate Cancer Consortium
DRE: digital rectal examination
ERSPC: European Randomized Study on Prostate Cancer
MRI: magnetic resonance imaging
PCPT: Prostate Cancer Prevention Trial
PHI: Prostate Health Index
PSA: prostate specific antigen
RC: risk calculator

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Review

Nursing Student Perceptions and Attitudes Toward Patients With Cancer After Education and Mentoring: Integrative Review

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Abstract

Background: Knowledge about nursing student attitudes toward patients with cancer after an educational intervention and mentoring support is limited. This review examined the literature on this topic.

Objective: This integrative review aims to explore the literature on the experiences of students who participate in an oncology elective or educational course on cancer and their attitudes toward cancer.

Methods: A comprehensive search was conducted using PubMed, CINAHL, and MEDLINE databases. Each study was systematically assessed. An evidence table was completed to identify the key aspects of each study that was reviewed.

Results: There is insufficient information on the impact of nursing student education on the attitudes and skills of nursing students caring for patients with cancer. An integrative review was completed on the impact of education and mentoring for nursing students on cancer care, which yielded 10 studies that were reviewed. These studies indicate that educational intervention and mentoring improve the confidence and ability of nursing students to care for patients with cancer.

Conclusions: Student nurses need to be armed with knowledge, skills, and positive attitudes while caring for patients with cancer. Nursing students perform best when they have accurate information, positive role models, and mentoring by experienced oncology professionals, to support proficiency in caring for patients with cancer. The lack of knowledge of nursing students in the areas of cancer care, treatment, and patient support requires additional education and research to promote expertise and positive attitudes toward cancer and treating patients with cancer. This will support nursing students' ability to care for patients with cancer as well as develop future educational interventions to shape nursing student attitude and knowledge. This integrative review also identifies the positive impact on the attitudes of other health care professionals who have received training or education on cancer.

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KEYWORDS

nursing students; nurse; cancer; attitudes; health care professionals; nursing; cancer patients; oncology; patient support; continuing education; mentoring

Introduction

Background

Cancer is a significant health problem worldwide and continues to be one of the most feared diseases globally. Each year, nearly 2 million people are diagnosed with cancer and there are over 600,000 deaths in the United States [1]. The latest estimates of new cancer cases in the United States in 2020 are 1.8 million new cancer cases diagnosed as well as over 600,000 deaths in 2020 [1]. The death rate of cancer has continued to decrease by more than 2.9 fewer cancer deaths from 1991 to 2017, which results in more long-term medical and support needs for patients with cancer [1]. Cancer affects a patient's daily life and can affect the ability to cope with the effects of illness and treatment side effects [2]. Studies have been conducted to understand the perspectives of health care professionals regarding the needs of patients with cancer or their attitudes that can be used to improve patient care and quality of life [3-9]. Nurses play a vital role in providing quality care to patients with cancer.

Nursing students need accurate information, positive role models, and mentoring to participate in caring for patients with cancer. The more nursing students are prepared, the more confidence is gained by nurses and nursing students while caring for patients with cancer. Lack of preparation by nurses can lead to anxiety, stress, and fear of caring for patients [10]. Few previous studies have examined nurses' knowledge and attitudes regarding cancer and cancer care services. Interventions and education to help prepare nursing students for caring for patients with cancer have the potential to improve the quality of care for these patients. The results of currently available studies will provide future guidance and development of content for nursing education and practice, which will help to improve the quality of nursing care for patients with cancer and their families.

Objectives

Formal nursing academic education has been successful in the development of a capable, trained, proficient, competent, and skilled workforce that supports patients with cancer [11,12]. It is essential that undergraduate nursing students need preparation for practice, which motivates students to care for patients with cancer competently. [7]. Nursing students have limited direct exposure to oncology and survivorship in many educational settings [13]. e-learning in the context of nursing care and oncology is an alternative method in the context of continuing education to deliver advanced nursing instruction [14]. There is limited research on the impact and influence of additional education on nursing students' attitudes and perceptions toward oncology and survivorship. This integrative review identifies the positive impact on the attitudes of other health care professionals who have received training or education on cancer. This integrative review explores the literature on the experiences of nursing students who participate in an oncology elective or an educational course on cancer and their attitudes toward cancer.

Methods

Literature Search

An electronic search of literature was conducted using the PubMed, CINAHL, PubMed, and MEDLINE databases. Additional literature was obtained by reviewing the reference lists of all the identified articles. Search terms included, *cancer*, *knowledge*, *attitudes*, and *nursing students*. The sample size of the studies reviewed included 30-688 nurses.

In addition to searching multiple databases, citation searches were completed. The articles were manually screened by the team. Peer review by the team members was completed on the articles that were found and summarized, as well as a summary of the articles identified. Reviews were excluded. Owing to the lack of articles on all types of health care personnel in the literature, although nursing students were the focus of the review, additional types of health care students (physicians) were included in the final articles for the study, which further identified a need for additional research in this area related to nursing students.

This integrative review will explore nursing students' perceptions about caring for patients with cancer and survivorship and help identify the needs for further education and intervention.

Data Evaluation and Analysis

The selection process resulted in 10 articles with a wide range of methodological approaches. Multiple articles were reviewed, and relevant articles were synthesized. The authors independently appraised the studies and discussed them. The studies were rated on a scale of high or low [15] related to the relevance of the study to the purpose of the review. An evaluation was performed using the Johns Hopkins tool for review [16]. Studies were also reviewed for research design, methods, and data analysis. The final information yielded 10 relevant studies. A dissertation that was a quantitative study by Burns [17] was reviewed as this initial research has been used as a tool to measure knowledge and attitudes toward cancer. Two tools by Burns [17] and Haley [18] were used in subsequent studies [3,17-22].

The studies were reviewed and scored to evaluate the inclusion criteria. The Johns Hopkins Evidence-Based Practice tool was used. The inclusion of the team helped strengthen the results via multiple content expert analysis.

Results

Literature Search

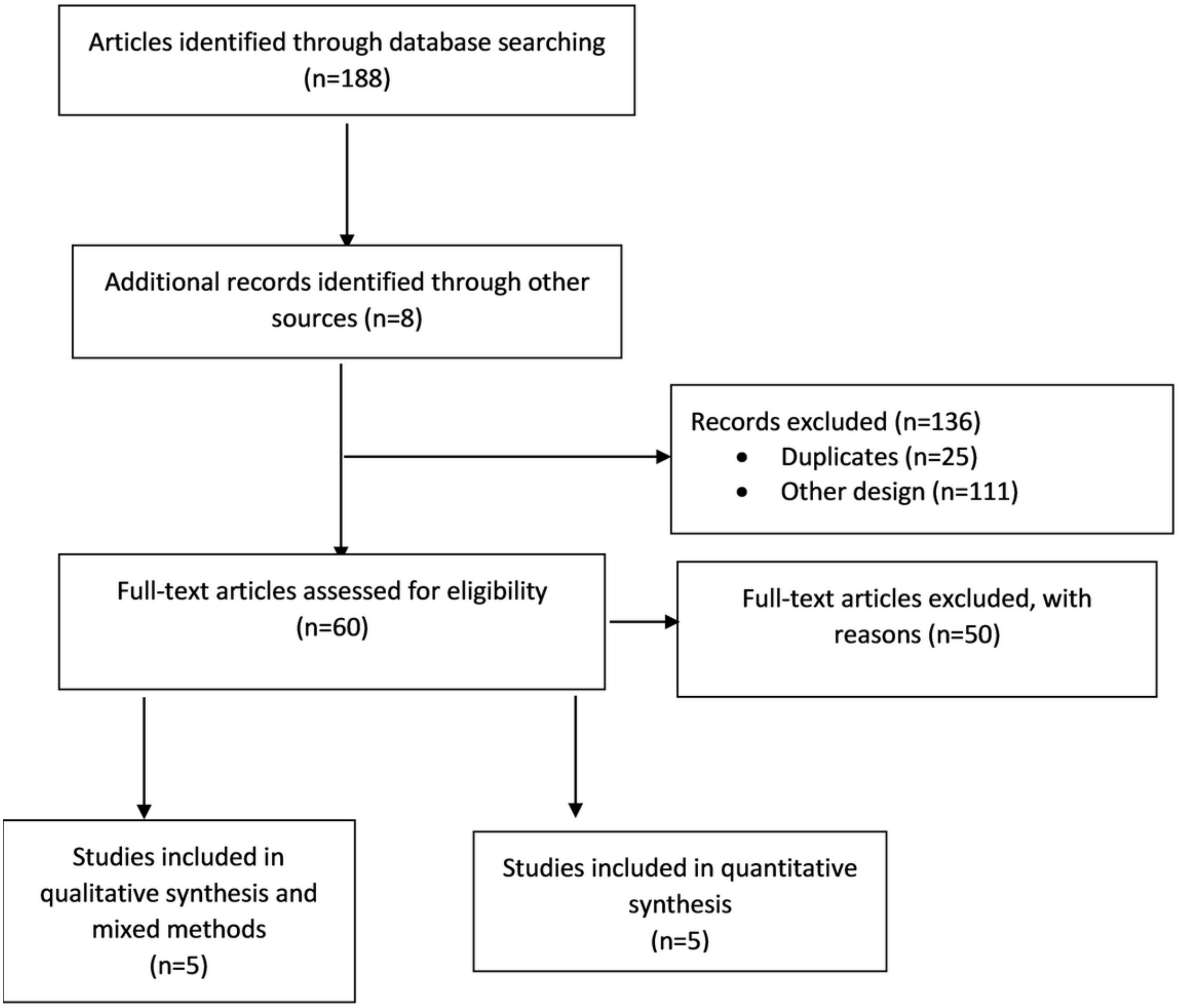
Articles that were screened and evaluated for inclusion comprised studies that were qualitative and quantitative research articles published in the period between 1981 and 2019. Commentaries and books were excluded. The titles and abstracts were screened to fit the inclusion and exclusion criteria. The final screening narrowed down the total information to 10 articles after exclusion of nonrelevant articles.

This integrative review identified 10 studies focused on nursing students' attitudes toward knowledge about cancer, attitudes, and experiences of caring for patients with cancer. Studies involving nursing students and multidisciplinary professional groups containing students were included.

The search was carried out in October 2019 and included all the results from the databases up to that date. All articles written in English were also included. A PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) [15,23] flow chart was used to search the relevant literature (Figure 1).

The lack of consistency in the measurement of cancer attitudes was a finding in this review. Various studies have attempted to address face and content validity, although the approaches and questions varied between most of the studies. There is limited research on the knowledge and attitudes of nursing students in the literature. In addition, the lack of research in this area supports the gap in measuring and addressing the knowledge and attitudes of health care providers in caring for patients with cancer.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) flow diagram.



Data Evaluation and Analysis

The selection process resulted in 10 articles (Table 1) with a wide range of methodological approaches. Again, team members reviewed the articles based on the Johns Hopkins tool and ranked articles using a high or low scale for consideration for inclusion and the processes outlined in Whittemore and Knafl [24].

As the studies were reviewed, key areas were noted in the review process that will be fully described in the following sections. These areas included nursing students' attitudes and knowledge of caring for patients with cancer, factors that affect nursing students toward caring for patients with cancer, nurses and health care professionals' attitudes toward cancer, work experience in cancer care, and education and training on cancer care as key areas identified.

Table 1. Articles and methodological approaches.

Study (country)	Key points	Design and sample	Notes and discussion
Dedeli et al, 2016 (Turkey) [20]	Generally, there was a positive attitude toward cancer. Nurses who had more experience with cancer care and who had more experience in caring for patients with cancer showed attitudes that are more positive.	Descriptive; sample of 332 nurses; used Turkish version of the attitudes toward cancer scale	Recommendation was that experienced nurses should care for patients with cancer.
Cunningham & Bater 2017 (United Kingdom) [4,5]	In this study, 2 sets of participants' attitudes in 2003-2004 and 2016-2017 are compared. Current nursing students exhibited positive attitudes in cancer care.	Convenience sample of 152 students in 2003 and 154 students in 2016; questionnaire provided and optional interview taken	In second study, mentoring and clinical experience are more common and more positive attitudes were noted in second cohort.
Edwards et al, 2016a (United Kingdom) [6]	Two key findings in this study are (1) students were interested in meeting patients with cancer outside clinical environment and (2) lecture and practical experience with clinicians and patients are important for developing confidence and competence of students in cancer care.	Descriptive, explorative, and qualitative design; semistructured interviews with 12 student nurses and 7 stakeholders. The interviews were audiotaped, transcribed, and analyzed using content analysis.	This study helped support the need for further development of cancer education experiences for nursing students based on the responses and themes identified through the research study.
Edwards et al, 2016b (United Kingdom) [7]	Study evaluates undergraduate curriculum content on cancer education.	Intervention study had two groups: 84 participants in intervention group and 91 in comparison group. Pre-post test was administered.	Study found that new model to deliver cancer education may improve knowledge, attitude, and confidence regarding cancer by student nurse population in study. Study recommends further development and research.
Felton et al, 1981 (United States of America) [8]	Purpose of the study was to measure attitudes toward cancer pre and posteducation intervention.	Pre- and posteducation sample of 545 nurses and nursing students on cancer attitude survey	Study supports need for educators to identify attitudes and plan education to help support positive attitudes.
Hsu et al, 2019 (Taiwan) [25]	Study supports implementing education intervention to increase nursing student knowledge, confidence, and skill in cancer care.	Random study with 213 students using 2 group pretest and posttest surveys.	One group received outcome-based program with simulated exercises and the control group had objective-based education, which was traditional design. Experimental group had educator with more experience and outcome-based simulation included.
Kapucu et al, 2018 (Turkey) [10]	Nursing students felt working with patients with cancer was *difficult*.	Focus groups with 61 participants and survey questionnaire with 129 participants; mixed methods study	Authors recommend additional research and focus on cancer care and ways to support patients with cancer.
Kav et al, 2013 (Turkey) [2]	Nursing students felt care was difficult and expressed fear and uncertainty in caring for patients with cancer.	Described study with questionnaire n=167 and 2 focus groups of nursing students as participants	Student participants suggested need for additional orientation and clinical placement to prepare for cancer patient care. Mentors were helpful including preceptors and nurses in learning to care for patients with cancer.
Powell et al, 2019 (Canada) [11]	The students had an observation experience in their first year nursing before clinical experience to help learn about cancer and perspectives of cancer care.	Qualitative: 10 first-year nursing students participated in individual semistructured interviews	This study felt that low-risk observation experience was an opportunity for students to learn about cancer care and nursing roles in treating cancer.
Sharour et al, 2017 (Jordan) [12]	Age was noted as an influencing factor in the participants' attitude, as younger study participants had more negative attitudes toward cancer and death and dying patients with cancer. Less experienced students had more negative attitude and responses.	Descriptive study with 100 nursing students participating; one time survey of students on Frommelt Attitude toward care of the dying scale and death attitude profile-revised scale	Study conclusions note that training and education can help support knowledge and attitudes. Nurses in the study with more experience and training had more positive attitudes noted.

Nursing Students' Attitudes and Experience With Cancer and Caring for Patients With Cancer

Nursing students and nurses' attitudes have been infrequently studied. Four studies specifically attempted to evaluate nursing student attitudes through a variety of interventions. Kapucu and Bulut [10] found that 80.6% of student nurse participants felt it was difficult to work with patients who have cancer, whereas 85.3% stated it was difficult to provide care to patients with cancer. Two studies [7,8] measured students' attitudes after providing an educational intervention. In another study, academic levels and age of the students were the determinants of the study [20]. The more experience an individual had, the higher was the positive perception toward cancer [20]. In two studies [2,10], most students expressed fear, hopelessness, and uncertainty.

Kav emphasized that students need to overcome fear, hopelessness, uncertainty, and the association of cancer with death. Implementing orientation programs, meeting the professional oncology team and communication on past and present experiences, increasing the time of clinical practice placements, and motivational activities are needed for students to gain more confidence and remove fears in caring for patients with cancer [2]. All studies recommend further research in the area of nursing student support and education to improve nursing students' confidence and ability to care for patients with cancer.

Factors That Affect Nursing Students Toward Caring for Patients With Cancer

Nursing students reported that their feelings toward patients were negatively affected because of poor communication, lack of confidence, and difficulty in providing physical care [10,25]. Students' lack of knowledge and experience, fear of patients and family members, and fear of pain were reasons for the students' negative feelings [10]. Therefore, it is recommended that students receive better training on patients with cancer and the needs and issues of their care [10]. The skill of supporting patients during cancer care was recognized as a skill that can be developed through education and exposure to patients with cancer and families through direct experience.

One study identified that students felt formal education as well as partnering with cancer clinical experts and patients with cancer and their families was important to help them feel confident and prepared to help care for patients with cancer [6]. A significant relationship was identified between nurses' attitudes toward cancer and factors such as age, gender, years of experience in oncology, and support working with experienced staff. The results of a study of over 300 nurses suggested that female nurses aged >40 or with >10 years of experience displayed positive attitudes toward patients with cancer [20].

Another study conducted in 2006 [4] found that students who were initially worried about cancer identified that past experiences and having clinical support and education positively influenced their outlook of cancer and caring for patients with cancer. The same study was repeated 10 years later, with another cohort of students that supported the initial finding that the positive perceptions of caring for patients with cancer continued through education and support interventions. Confidence in providing care by students increased in a later study from 62.2% in 2004 to 75.34% in 2017. In addition, perceived skill in providing care by students also increased, as in 2003, 77.6% felt they lacked skills to care for patients with cancer, whereas in 2017 only 37% felt they lacked skills to care for patients with cancer. Changes in beliefs and attitudes were noted, and students reported increased confidence with a positive outlook and attitude toward caring for patients with cancer. The second cohort of nursing students was found to have a different work environment than a decade ago. Previously, mentor support and additional learning in clinical areas were not as prevalent. The first cohort helped mentor the second cohort by providing advice and support [5].

On the basis of these findings, an increase in awareness and knowledge of the cancer disease and treatment continuum may support increased effectiveness in preparing students to treat patients with cancer [5]. The student nurses reported that they were fearful, worried, and experienced feelings of pity when providing care for patients experiencing pain or who had a terminal illness. A common perception among students is that cancer is often a terminal illness that prevents students from working in oncology settings [10,25]. These studies indicate that efforts are needed to educate nursing students and nurses in the area of cancer care.

Nurses and Health Care Professional Attitudes Toward Cancer

The studies presented in this review noted that nursing students and health care professionals often have negative attitudes toward cancer and caring for patients with cancer. Clinical decision-making is a challenge for health care professionals when they express negative attitudes toward cancer [21,25]. This study proposed that educational programs could remove fear and create a positive image of cancer in health care professionals. In addition, this study identified the need for education to help support and improve attitudes toward cancer to provide high-quality care to patients.

Understanding and guiding health care professionals' behaviors in a positive direction can improve the quality of care of patients and families. The experience of both physicians and nurses correlated positively with improved attitudes toward caring for patients with cancer. In contrast, less experienced professionals were more afraid of cancer and death. Efforts are needed to educate health care professionals on the psychosocial aspects of terminal care for patients with cancer.

Work Experience in Cancer Care Setting

Nurses' attitudes toward patients with cancer are affected by many factors such as age, years of experience in oncology, gender, knowledge of the disease process, and clinical experience in cancer units. In addition, more experienced nurses had a positive attitude toward patients with cancer and helped patients cope with chemotherapy, radiation therapy, or any complications associated with cancer treatment [20]. According to Sharour et al [12], younger students expressed negative attitudes toward patients with cancer. Increased support through academic and formal training has been shown through these studies to positively impact attitudes toward patients with cancer. Confident and skilled nurses are able to manage patients in difficult situations. Improving support, knowledge, and education for nursing students are critical elements that will improve communication and eliminate fear while caring for patients with cancer.

Education and Training on Cancer Care

Lack of knowledge of cancer care among students is evident in the literature. Effective clinical classroom and clinical education aspects are crucial for improving nursing students' attitudes toward caring for patients with cancer. Such education should include information on cancer treatment and survivorship and the assigned time spent in various oncology settings. Key components for success include a strong orientation to cancer care and clinical cancer care settings, mentorship and role modeling by staff and teachers, feedback and communication during cancer care experiences, elective oncology courses in nursing programs, and faculty support for students to support the development of competency in caring for patients with cancer [10,25]. Oncology content should be required, and elective courses should be offered to help further develop skills and expertise in cancer care and treatment. Students should be partnered with strong clinical expert mentors who are clinical experts who also provide a positive supportive environment to learn the nuances of cancer care. In addition, an observational educational experience was identified to improve nursing students' knowledge [11,25]. Through this observation and study, students gained a new perspective on cancer care.

Nurses and student nurses who received training reported positive perceptions when caring for patients with cancer. Students feel that meeting patients with cancer outside the hospital setting might help them to create more confidence in talking and managing patients with cancer. The inclusion of cancer content in the undergraduate curriculum supports nursing students' ability to develop positive attitudes while strengthening their knowledge base while increasing experience and confidence in caring for patients with cancer, which will improve quality of care.

Summary

There is a lack of literature highlighting cancer education and clinical experience as an intervention in the undergraduate nursing student population. There is also a lack of literature that evaluates the impact of such education on the care delivery experience in cancer post intervention. The skills and knowledge gained through such an intervention could improve nursing student confidence and quality of care. Additional research would help to identify and address what specific training is needed to help improve nursing students' skill levels and attitudes toward cancer care [6,7]. Important findings from the studies include the recommendation that nursing students benefit from participation in the classroom and clinical experiences to improve knowledge and skills in oncology nursing. Oncology content should be included in the core curriculum of undergraduate programs. In addition, students should work with oncology nurse mentors who are clinical experts and bedside educators to provide positive learning experiences [13,25]. Specific directed education of nursing students as well as formal research to measure the impact of education and training on cancer care and the impact on nursing students and patients is needed.

Discussion

Principal Findings

As noted in the studies and key findings, many nursing students experience a variety of feelings, including fear, hopelessness, anxiety, and being unprepared to provide care to patients with cancer. The outcomes of these studies indicate that education plays a key role in alleviating fear, hopelessness, and promoting confidence in nurses and nursing students in taking care of patients with cancer. In the articles found in the study, key themes of the need for education, mentorship, and support of nursing students were key findings. The few published studies confirm the noted improvement in students' confidence in caring for patients with cancer after formal educational support and mentoring. There is limited availability of these types of studies within the literature as evidenced by this integrative review.

Limitations

There are limitations in the literature as well as in this review. The inclusion of health care professional students was incorporated into the study to identify the key findings of education on cancer care. The needs of nursing students warrant further exploration to determine what needs nursing students have compared with other disciplines. In addition, the limited availability of articles increases the challenge of fully outlining the impact of education on nursing student attitudes. Additional manual search of articles could have potentially strengthened the study if additional time could be provided to continue citation searching and potentially expand search terms for the study. Although there is a lack of research studies, the impact of education and mentoring support was a finding available in these few studies.

Most studies have focused on performing research in one setting. A broader focus in scope and multiple institutions are required, which would include many types of institutions and multiple countries. Several investigators have acknowledged that single-survey instruments alone are not always appropriate for analyzing the nature of attitudes of nursing students. Few tools and formal programs were found to support nursing students in their training to care for patients with cancer in the curriculum. In addition, there is limited research overall on the subject area of nursing students and their attitudes toward patients with cancer. With some undergraduate programs, there is limited information and focus on the care of oncology patients.

Comparison With Previous Work

Working with patients who have cancer and their families can be challenging because of the complexity of patient care needs in this population. One study noted a significant relationship between nurses' attitudes toward cancer and factors such as age, gender, years of experience in oncology, and support at work from experienced staff [20]. The results suggested that nurses aged >40 years or those with >10 years of experience displayed positive attitudes toward cancer [20].

Health care professionals have expressed negative attitudes toward cancer, and changing these attitudes has been noted to be challenging [10]. Kapucu and Bulut [10] explained that most of the students in the study expressed sorrow, worry, and pity and were not psychologically ready to provide care for patients with cancer. Moreover, 80% of the students believed it was difficult to work with patients who have cancer and care for them. Because of this study, a training course in cancer care was added to the nursing curriculum to improve knowledge in cancer care [10].

Cunningham and Bater [5] asserted that observation experiences in oncology clinics are important for students to gain experience and be ready to care for patients with cancer. Kav et al [2] reported that effective student orientation programs, organizing meeting share experiences, motivating activities, and role modeling by staff and teachers help students to communicate efficiently with patients who have cancer. In another study, Cunningham and Bater [4,5] compared the results of student nurses' experiences of caring for patients with cancer between 2003 and 2004 and repeated in 2016-2017. There is a significant shift in between the results. The overall experience of caring for patients with cancer increased from 66% in 2003-2004 to 75.34% in 2016-2017. In addition, differences were noted in the confidence level in caring for patients with cancer, which increased from 34% to 96%. Another interesting difference noticed in this study is that the number of females enrolled in oncology nursing increased and the male workforce decreased in the span of 10 years. The current generation student nurses have more support in terms of mentoring, clinical education, and theoretical knowledge compared with the previous students. Younger and female students both showed negative attitudes and emotions compared with senior and experienced nurses. This study indicated that the level of experience and qualification is an important criterion in caring for patients with cancer. Highly qualified nurses can manage patients with cancer in difficult situations [12].

A new model to deliver cancer care education on cancer and survivorship was introduced by Edwards et al [6,7], where participants were divided into intervention and comparison groups and provided with different cancer education programs for 3.5 days and 2 days. The intervention group demonstrated more positive attitudes toward caring for patients with cancer and more confidence in their ability to deliver cancer care related to the comparison group. This new model for the delivery of cancer education focused on survivorship through involvement with patients, families, and oncology clinical experts may improve knowledge attitudes and confidence in delivering cancer care [6,7].

Almost all the reviewed studies were conducted with Turkish and UK nursing students or nurses. Therefore, the results are not generalizable because of the cultural differences and notable differences in education programs [13]. In addition, studies that evaluate educational and mentoring interventions in cancer care for nursing students and nurses who are not homogenous subjects have not been completed. Identifying strategies and educational needs for cancer care in nursing students and nursing populations remain as gaps in the literature. Future research is needed to identify and further develop specific educational and clinical opportunities that support positive attitudes and improve skill levels for cancer care in nursing students [13].

However, there are limited studies in the United States on undergraduate nursing students toward caring for patients with cancer. Many international studies were found on this topic. In summary, key themes that were identified in the review of the literature include lack of training for health care professionals, including nurses on cancer care and survivorship, and lack of measurement of nurse and health care attitudes. A few international studies [2,6,7,10,21] highlighted an educational intervention and impact on nursing attitudes. These studies indicate that educational interventions such as initial orientation programs, regular meetings, and sharing experiences, including mandatory oncology courses in the nursing student's curriculum, collaboration with patients, and support from physicians and senior nurses help to support cancer care knowledge and attitudes by health care professionals in these studies.

Implications for Research

This review found little research on the attitudes of nursing students or nurses toward cancer after being provided an educational intervention. Further study of the impact of educational programs and training on student nurses and nurses can help identify what improvements can be made in the education of nursing students and nurses. Owing to the large incidence of cancer, nursing attitudes and knowledge need further study. On the basis on the findings and lack of research, a descriptive study is recommended to investigate nursing students' perceptions about cancer and cancer survivorship.

Implications for Education and Practice

Improving the attitudes of undergraduate nursing students helps them become more confident in caring for patients with cancer. Mentoring nursing students through classroom education and access to experienced practicing oncology nurses can strengthen the skills of nursing students [13]. The variety of roles of oncology nurses in the inpatient and outpatient settings offer great possibilities to help expose nursing students to cancer care by nursing experts. Oncology nursing education can be incorporated into the curriculum through a variety of education or observation experiences [11]. In addition, faculty, experienced oncology nurses, and other health care professionals with experience in caring for patients with cancer can provide extra support to student nurses. Educational programs can increase knowledge about cancer care and treatment, while decreasing fear and improving student nurse skills and confidence. Oncology nursing courses that provide knowledge, skills, and attitudes toward caring for patients should be included in nursing curricula.

There is some research in the literature on health care professionals' attitudes toward caring for patients with cancer; however, there is limited research on nursing care. Further exploration of additional content on cancer will help prepare future nurses caring for patients with cancer. There is also the potential for incorporating electives to allow students to further expand their knowledge of cancer care (Textbox 1).

Textbox 1. Best practices for allowing students to expand their knowledge.

Best practices

- Increase the amount of educational training and clinical rotations for nursing students
- Mentor undergraduate nursing students by placing them with experienced oncology nurses. Offer internships and other clinical programs to increase exposure to cancer care
- Offer elective oncology classes as part of the curriculum for undergraduate nursing students

Knowledge Translation

Experienced oncology nurses can support student nurses through mentoring and sharing knowledge and skills with student nurses in clinical and classroom settings. Inclusion of certain electives and updating the curricula of nursing programs could potentially impact nursing student attitudes toward cancer, as has been noted in other disciplines. The studies reviewed support education and clinical experiences to help increase knowledge and alleviate anxiety in caring for patients with cancer (Textbox 2).

To help prepare and support students, faculty can support students in self-assessment on their educational needs and feelings about caring for patients with cancer. Students can be supported through educational interventions, access to experienced nurse faculty and practicing experts in cancer care to help provide mentorship and support to students in their journey in caring for patients with cancer. Expanding current strategies such as increasing clinical or observation experiences and additional formal training can be used to address knowledge gaps and fear for inexperienced student nurses new to the oncology field.

Textbox 2. Clinical experiences to help increase knowledge translation.

Knowledge translation

- Nursing attitudes toward cancer using an educational intervention is perceived to improve attitudes but has had little research
- Inclusion of electives and education into nursing programs could potentially impact nursing student attitudes toward cancer as has been noted in other disciplines
- Nursing students often receive little education on oncology and often feel unprepared in caring for patients with cancer

Conclusions

Efforts must focus on identifying, developing, and testing interventions to improve nurses' attitudes and their expertise in cancer care. Previous research has noted the need for additional studies to be conducted as well as the need for a nursing curriculum to include education to improve attitudes to better understand what interventions support the expertise needed to provide high-quality care to patients with cancer. Furthermore, it appears that nursing students recognize the need for additional training through the common themes of fear and lack of confidence in supporting people with cancer. A preceptor-based clinic teaching method is another innovative way to train and create a positive attitude toward patients with critical ailments. There have been efforts and exercises conducted in this area, such as the clinical teaching blended learning program, which was conducted from September 2019 to December 2019 and included 150 nurse preceptors [26]. Although there are innovative methods that aim to focus on improving nurses' attitudes and expertise toward patients with chronic conditions, the area still needs a significant impetus. This will take time, attention, and focus to help strengthen cancer care expertise in the nursing student population.

Patients and caregivers impacted by cancer need to be able to manage the short- and long-term effects of cancer treatment and the long-term impact of cancer. Cancer cases are approaching 2 million patients per year, with increases noted in the survivorship of patients with cancer. As patients with cancer are prevalent in all parts of the health care system during and after treatment, nursing students and nurses need to have expertise, experience, and confidence to provide high-quality care and support patients and families of patients living with cancer. Undergraduate nursing education can provide a differentiating position to help prepare nurses to support patients with cancer and to improve the quality of life for those impacted by cancer. The studies included in this integrative review studied general attitudes of health care personnel toward cancer or death and dying. In studies that evaluated professional attitudes, the need for additional education and support from health care personnel was a common theme. Little research on attitudes or the impact of an educational intervention on attitudes is present in the literature. Further research is needed to determine effective strategies to increase competency in cancer care for nursing students and to understand the attitudes of nursing students. This would help identify innovative educational strategies that are effective in increasing the knowledge and attitudes of nursing students and nurses toward patients with cancer.

Conflicts of Interest

BW is part of the paid nurse speaker’s bureau for Genetech and AMGEN. Genetech and AMGEN had no influence on the results of this article.

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Review and Meta-Analyses

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Original Paper

Selecting a Subset Based on the Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events for Patient-Reported Symptom Monitoring in Lung Cancer Treatment: Mixed Methods Study

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Abstract

Background: The Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) item library covers a wide range of symptoms relevant to oncology care. There is a need to select a subset of items relevant to specific patient populations to enable the implementation of PRO-CTCAE–based symptom monitoring in clinical practice.

Objective: The aim of this study is to develop a PRO-CTCAE–based subset relevant to patients with lung cancer that can be used for monitoring during multidisciplinary clinical practice.

Methods: The PRO-CTCAE–based subset for patients with lung cancer was generated using a mixed methods approach based on the European Organization for Research and Treatment of Cancer guidelines for developing questionnaires, comprising a literature review and semistructured interviews with both patients with lung cancer and health care practitioners (HCPs). Both patients and HCPs were queried on the relevance and impact of all PRO-CTCAE items. The results were summarized, and after a final round of expert review, a selection of clinically relevant items for patients with lung cancer was made.

Results: A heterogeneous group of patients with lung cancer (n=25) from different treatment modalities and HCPs (n=22) participated in the study. A final list of eight relevant PRO-CTCAE items was created: decreased appetite, cough, shortness of breath, fatigue, constipation, nausea, sadness, and pain (general).

Conclusions: On the basis of the literature and both professional and patient input, a subset of PRO-CTCAE items has been identified for use in patients with lung cancer in clinical practice. Future work is needed to confirm the validity and effectiveness of this PRO-CTCAE–based lung cancer subset internationally and in real-world clinical practice settings.

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KEYWORDS

PRO-CTCAE; lung cancer; side effects; patient-reported outcomes; PROM; symptomatic adverse events

Introduction

Background

Lung cancer is the most common cancer in men and the third most common cancer in women worldwide [1]. Treatment options are often multidisciplinary, including surgery, chemotherapy, radiation therapy, targeted therapy, immunotherapy, or a combination of these treatments [2]. Owing to both the tumor and the (combination of) treatments, patients can experience a wide range of symptoms and toxicities that impair their health-related quality of life (HRQoL) and require careful management [3]. Historically, toxicities have been rated by health care practitioners (HCPs) most typically using the

Common Terminology Criteria for Adverse Events (CTCAE), which is broadly implemented to monitor toxicity in oncology trials and clinical care [4]. The concept of *clinician scoring* has recently been challenged by a number of studies that have observed relatively high levels of disagreement between toxicities reported by clinicians and patients [5-7].

Patient-reported outcome measures (PROMs) have been demonstrated to improve patient-clinician communication about symptoms and are therefore increasingly recognized as an important source of information in clinical decision-making [8-10]. PROMs could also function as a tool for routine toxicity management as part of clinical care. In two previous randomized trials, Basch et al [11] and Denis et al [12] used a selection of patient-reported symptoms to monitor symptoms during chemotherapy in patients with metastatic cancer and lung cancer, respectively. These trials have shown that PROM symptom monitoring not only improves symptom management but also significantly improves HRQoL and overall survival [11-14]. Potential underlying mechanisms for these positive results include an earlier and therefore more effective response to progressively evolving symptoms, including timely initiation of supportive treatments, dose modifications, and early referrals [11,12,15,16].

On the basis of the results of these trials, there has been a growing call for the development and implementation of standardized patient-reported symptom monitoring tools for use in both clinical research and clinical practice [14,17]. A major advance in this direction has been the development and testing of the US National Cancer Institute's Patient-Reported Outcome Version of the CTCAE (PRO-CTCAE). The PRO-CTCAE is developed through a consortium of patient-reported outcome (PRO) researchers, clinical investigators, trial sponsors, patient advocates, and the Food and Drug Administration (FDA), and it comprises 124 items, based on 78 CTCAE toxicities considered appropriate for patient reporting [18]. These items have been comprehensively validated in English-speaking patients [19] and have been translated and linguistically validated in a large number of languages, including Dutch [20].

Frequent administration of the complete library of PRO-CTCAE items is considered impractical and burdensome [18,21]. However, this validated item library of symptoms can form the basis of a PRO monitoring subset. Conforming to what the FDA has described, the selection of a relevant item set is of critical importance to provide insights into the most important toxicities for the treatments that are being evaluated [22]. Several studies have focused on creating a subset of PRO-CTCAE. Examples include an item subset for patients with bladder cancer receiving chemotherapy and immunotherapy, and a subset of patients receiving immunotherapy in metastatic melanoma [23-25]. Similar to most cancer diagnoses, lung cancer is often treated in a multidisciplinary setting, including a treatment plan for multiple modalities and a variety of involved health care professionals [26]. These multidisciplinary teams can use PROMs to improve the collective monitoring of patients [27].

Objective

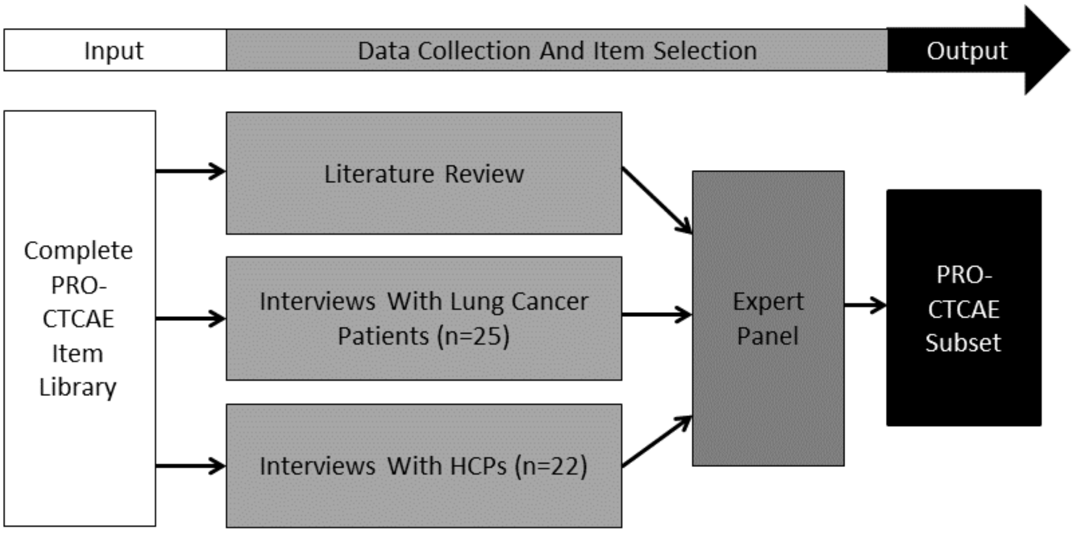
The aim of this study is to systematically develop a multidisciplinary subset of PRO-CTCAE items that are clinically relevant for patients with lung cancer and that can be used for monitoring during multidisciplinary clinical practice.

Methods

Item Identification

A schematic overview of the subset identification method is presented in Figure 1. The original PRO-CTCAE item library was the main source and starting point for the development of the lung cancer subset. The procedure to identify relevant items for the subset approximates phase 1 of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Group guidelines for developing PROMs [28]. Three sources were used to compile the relevant item list.

Figure 1. A schematic overview of the item identification process. HCP: health care practitioner; PRO-CTCAE: Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events.



First, a literature search was conducted to ensure the identification of all relevant toxicities from both the literature and existing questionnaires. We used the PubMed database, with the following search terms: *non-small cell lung cancerORsmall cell lung cancer AND adverse events OR toxicities OR symptoms OR side effects AND Chemotherapy OR Radiation OR Chemo radiation OR Immunotherapy OR targeted therapy OR surgery*. From these results, the literature that included existing questionnaires and reviews on lung cancer toxicity was selected. Next, we identified the PRO-CTCAE items that corresponded to the symptoms derived from the literature. The literature study was conducted as comparative evidence to be used complementary to the data collected from the patients and HCPs.

Second, the patients' perspectives were included to ensure content validity [29]. A heterogeneous sample (n=25) of patients with lung cancer was invited to participate in a semistructured interview. Patients were recruited from the Netherlands Cancer Institute. We used purposive sampling to include patients varying in terms of age, sex, stage, and treatment type. The eligibility criteria were as follows: aged ≥18 years; able to provide informed consent; either currently undergoing lung cancer treatment (at least 2 weeks after the start of treatment) or in follow-up (having completed lung cancer treatment within the previous 6 months); and basic fluency in the Dutch language. The exclusion criteria were psychological or cognitive problems as judged by the HCP, which would interfere with participating in an interview.

Finally, the HCPs working in the Netherlands Cancer Institute (n=22) in the field of lung cancer, including pulmonologists (n=4), radiation oncologists (n=12), thoracic surgeons (n=3), and nurse specialists or physician assistants (n=3) specialized in the treatment of lung cancer, were invited for an interview to provide their opinions about the most relevant items to be included in a lung cancer subset.

Interview Procedures

A scripted interview guide was used based on the EORTC guidelines [28]. During the first part of the interview, patients were asked to freely describe their experiences and symptoms. Subsequently, patients were asked to complete the PRO-CTCAE item library by filling out a questionnaire that included all items. This was followed by a debriefing interview to determine what the experienced symptoms meant to the patient, the extent to which patients had experienced the symptoms, and if they had experienced any symptoms not included in the questionnaire. Patients were encouraged to comment on the PRO-CTCAE symptom terms and were asked to rate each symptom for relevance using a scale of 1 (not relevant) to 4 (very relevant) [28]. Patients were asked to select a maximum of 10 most impactful symptoms to assess the importance of the PRO-CTCAE symptoms. Finally, patients were asked to identify symptoms that should definitely be included or excluded.

The HCPs took part in a semistructured interview in which they were shown the complete PRO-CTCAE item list and were asked if (1) there were symptoms included that the medical specialists considered clinically relevant (scored as 1) or irrelevant (scored as 2; in terms of treatability and urgency) for patients with lung cancer and (2) if symptoms were missing from the list that they considered relevant. The reasons for relevance or irrelevance were specified.

Item Selection

An overview table was created based on the complete PRO-CTCAE item library, in which the results of the data collection were collected and ranked. For literature data, the prevalence of the item in the included literature sources was calculated (*literature score*). Next, for patient data, the mean relevance score for each PRO-CTCAE item was calculated *(patient relevance score)*. The top 10 items (based on the *patient relevance score*) were reviewed and compared to gain insight into the different treatment modalities. Finally, for the HCP data, the percentage of HCPs who rated it as relevant was calculated *(HCP relevance score)*. The table was then sorted from high to low using the *patient relevance score* data as the primary rank, followed by the *HCP relevance score* and the *literature score.*

For the final item selection, the ranked list of items was reviewed by an expert review panel, including a pulmonologist, a radiation oncologist, an epidemiologist, and two public health experts. During this process, the relevance scores of the patients were of primary importance in the selection of items. The expert review consisted of three rounds. First, all items with a low patient relevance score (<2) were reviewed. Next, items with a high patient relevance score (>2.5) were reviewed. The third round consisted of a review of items with a relevance score between 2 and 2.5. Decisions to include or exclude items from the final list were based on the following features: (1) lack of clinical relevance (in terms of treatability and urgency), (2) upsetting items, and (3) redundancy (multiple closely related items) [28]. As the goal was to generate a subset of items most relevant for clinical practice without creating excessive respondent burden, the item that was indicated most relevant by the patients was chosen in case of redundancy (eg, fatigue and insomnia). The discussions continued until a consensus was reached over the final item selection.

Results

The Literature

Table 1 provides an overview of the selected studies. Relevant literature included the following existing questionnaires: the EORTC Quality of Life core questionnaire (QLQ) C30 and the EORTC QLQ Lung Cancer module (EORTC QLQ LC13), the Development of the Functional Assessment of Cancer Therapy-Lung, and the MD Anderson Symptom Inventory for lung cancer [30-33]. More recent efforts to define relevant patient outcomes in lung cancer by Mak et al [34], Reeve et al [35], and Koller et al [36] were included as well. From the study by Koller et al [36], we included a list of quality of life issues as rated by patients and HCPs in phase 1 of the EORTC Module Development Guidelines [28].

Table 1. The Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events items that were identified in the literature for each included source.

PRO-CTCAE[a] item	Study					
	Aaronson et al[b] [30]	Cella et al[c] [32]	Cleeland et al[d] [33]	Koller et al[e] [36]	Mak et al[f] [34]	Reeve et al[g] [35]
Fatigue	✓[h]	✓	✓	✓	✓	✓
Shortness of breath	✓	✓	✓	✓	✓	✓
Cough					✓	
Decreased appetite	✓	✓	✓			
Pain	✓	✓		✓	✓	✓
Dizziness	✓			✓		
Constipation	✓		✓			✓
Insomnia	✓	✓	✓			✓
Nausea	✓	✓	✓	✓		
Rash				✓		
Sadness	✓	✓	✓			✓
Difficulty swallowing	✓			✓		
Decreased sexual interest				✓		
Diarrhea						✓
Anxious	✓					
Hoarseness	✓					
Vomiting	✓		✓			
Numbness and tingling	✓		✓	✓		
Memory			✓	✓		✓
Concentration	✓					✓
Voice quality changes	✓					
Hair loss	✓	✓				
Acne				✓		
Nail loss				✓		
Nail ridging				✓		
Nail discoloration				✓		

[a] PRO-CTCAE: Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events.

[b] Development of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life core questionnaire (QLQ) C30 and the EORTC QLQ Lung Cancer module (EORTC QLQ LC13).

[c] Development of the Functional Assessment of Cancer Therapy-Lung.

[d] Development of MD Anderson Symptom Inventory for lung cancer.

[e] Based on the phase 1 study of the international study to revise the European Organization for Research and Treatment of Cancer questionnaire for assessing quality of life in lung cancer patients.

[f] Delphi study with health care professionals in the field of lung cancer.

[g] Systematic literature review and expert panel.

[h] Item present.

The following 24 PRO-CTCAE items were identified from the selected literature: *fatigue*, *shortness of breath*, *decreased appetite*, *pain*, *dizziness*, *constipation*, *insomnia*, *nausea*, *sad or discouraged*, *difficulty swallowing*, *anxious*, *hoarseness*, *vomiting*, *numbness and tingling*, *concentration*, *voice quality changes*, *hair loss*, *memory*, *rash*, *decreased libido*, *acne*, *nail loss*, *nail ridging*, and *nail discoloration*.

Patient Interviews

Table 2 presents an overview of the patients and treatment characteristics. The mean age of the patients was 66 years (SD 8). The stage distribution was as follows: stage I, 8% (2/25); stage II, 12% (3/25); stage III, 36% (9/25); and stage IV, 44% (11/25). A broad range of treatment modalities (radiotherapy, 3/25, 12%; stereotactic radiotherapy, 2/25, 8%; concurrent chemotherapy and radiation, 5/25, 20%; surgery, 5/25, 20%; and systemic treatment such as chemotherapy, 1/25, 4%; immunotherapy, 6/25, 24%; and targeted therapy, 3/25, 12%) were included.

Table 2. Characteristics of all patients participating in the item selection interviews (n=25).

Patient characteristics	Values
Gender, n (%)	
Female	13 (48)
Male	12 (52)
Age (years), mean (SD; range)	66 (8; 55-79)
Lung cancer stage, n (%)	
Stage I	2 (8)
Stage II	3 (12)
Stage III	9 (36)
Stage IV	11 (44)
Treatment modality, n (%)	
Surgery	5 (20)
Radiotherapy	3 (12)
Stereotactic radiotherapy	2 (8)
Concurrent chemoradiation	5 (20)
Systemic treatments	
Chemotherapy	1 (4)
Immunotherapy	6 (24)
Targeted therapy	3 (12)
Treatment status, n (%)	
On treatment	14 (56)
<1 month posttreatment	9 (36)
1-3 months posttreatment	2 (8)
Highest level of education, n (%)	
Primary school	3 (12)
Lower vocational education	2 (8)
High school	9 (36)
Higher vocational education	6 (24)
Scientific education	5 (20)

Fatigue was scored as the most relevant symptom from the patient's perspective, with a *patient relevance score* of 85.7. Seven other items were scored above 2.5 (*shortness of breath, cough, insomnia, decreased appetite, dizziness, constipation, nausea, and sadness*).

When reviewing the items per treatment modality, the top 10 items per modality category (radiotherapy, systemic treatment, concurrent chemoradiation, and surgery) were compared. *Fatigue*, *shortness of breath*, and *cough* overlapped in all modalities, and *dizziness*, *hives*, and *constipation* overlapped in three out of four modalities. Some items were present in two of the four categories, including *sadness* for systemic therapy and surgery, *itchy skin* and *joint pain* for both radiotherapy and surgery, and *insomnia* in concurrent radiation and surgery. Although most items overlapped between categories, the different treatment modalities seemed to influence the type of symptoms that were described as most relevant by the patients. Radiotherapy-specific symptoms included *taste changes*, *dry skin*, *headache*, and *bruises*. The concurrent chemoradiation-specific symptoms were *urinary frequency*, *heart palpitations*, and *difficulty swallowing*. Items specifically relevant for systemic treatment (ie, chemotherapy, immunotherapy, and targeted therapy) were *discouraged*, *anxiety*, and *nausea*. Finally, patients treated with surgery described *flatulence* and *achieve and maintain an erection*.

HCP Interviews

The participating HCPs reported having experience with a variety of treatment modalities. They had experience with chemoradiation 77% (17/22), immunotherapy 23% (5/22), surgery 18% (4/22), radiotherapy 59% (13/22), chemotherapy 18% (4/22), and experimental or targeted therapies 9% (2/22). Of the participating HCPs, 36 items had an HCP relevance score <50%. The items that were identified as most relevant by the HCPs included *shortness of breath*, *wheezing*, *fatigue*, *decreased appetite*, *nausea*, *difficulty with swallowing*, *vomiting*, and *headache*.

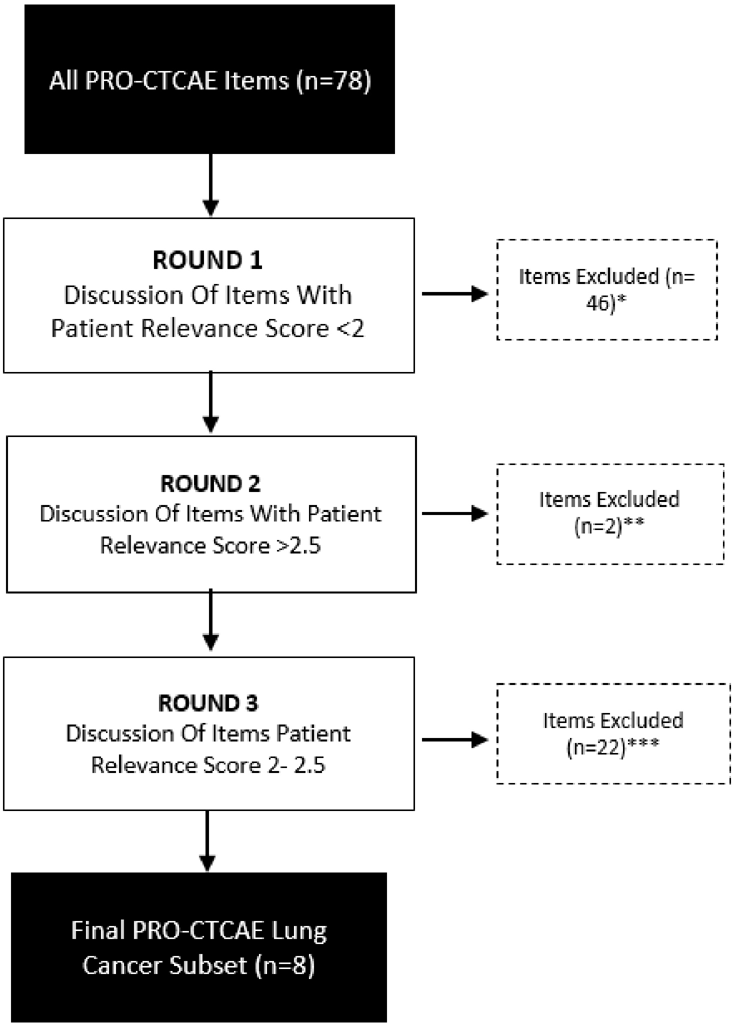
Item Selection

All PRO-CTCAE items were ranked by *patient relevance score* first followed by *HCP relevance score* and finally *literature score*, which is shown in Multimedia Appendix 1. An overview of the item selection process is shown in the flowchart in Figure 2. In round 1, 46 items were excluded. These items had a low *patient relevance score* of <2. The expert panel collectively agreed to eliminate these items. In round 2, items with a high patient relevance score of >2.5 were discussed for inclusion. This list consisted of eight items, including *fatigue*, *shortness of breath*, *cough*, *insomnia*, *decreased appetite*, *dizziness*, *constipation*, and *sadness*. Experts agreed to include all these items with the exception of *insomnia* and *dizziness*. The item *fatigue* was chosen over *insomnia* because fatigue covers more than insomnia, and these items are known to be highly correlated. Furthermore, *fatigue* was scored more frequently across all data sources than *insomnia* (patients, HCPs, and the literature). There was no expert consensus on the inclusion of *dizziness* based on clinical relevance. Moreover, this item scored relatively low on the *HCP relevance score* and the *literature score* compared with the other items in round 2 and was therefore not included.

In round 3, 23 items with a *patient relevance score* between 2 and 2.5 were discussed. Uniform agreement for exclusion of the following items was reached: *urinary urgency*, *decreased libido*, *body odor*, *itchy skin*, *flatulence*, *concentration*, *increased sweating*, *achievement and maintenance of erection*, *urinary frequency*, and *dry skin*. The remaining items were discussed by the expert panel. Of these items, *nausea* was ranked the highest with a *patient relevance score* of 2.42, an *HCP relevance score* of 71.4, and a *literature score* of 50. On the basis of these scores and the judgment of clinical relevance, the expert panel decided to include this item in the final list. The item *taste changes* and *difficulty swallowing* were excluded because of their correlation with the higher-ranked item *decreased appetite*. The item *rash* was excluded because of the low level of clinical relevance based on the expert panel, as well as the low *literature score* (12.5). The item *joint pain* had a *higher patient relevance* score than the item for *general pain* (2.33 and 2.29, respectively). However, in light of the clinical use of the questionnaire, the item *general pain* was preferred because it would cover more than solely joint pain and was therefore included in the list. The items *discouraged* and *anxious* were excluded because the higher ranking and the correlating item *sadness* was already included. The item *wheezing* was excluded because the higher ranking and correlation item *shortness of breath* was already included in round 2.

Therefore, the final list of eight items included *fatigue*, *cough*, *shortness of breath*, *decreased appetite*, *constipation*, *nausea*, *general pain*, and *sadness*.

Figure 2. Flowchart of the item selection process. PRO-CTCAE: Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events.



** Ringing in ears, muscle pain, decreased sweating, voice changes, chills, diarrhea, blurred vision, bloating, change in usual urine color, swelling, heartburn, numbness and tingling, hair loss, sensitivity to sunlight, abdominal pain, visual floaters, memory, radiation skin reaction, unable to have orgasm, dry mouth, urinary incontinence, pain with sexual intercourse, fecal incontinence, hot flashes, missed expected menstrual period, pain and swelling at injection site, hand-foot syndrome, painful urination, acne, watery eyes, ejaculation, skin darkening, hiccups, flashing lights, nail loss, hives, bed or pressure sores, vaginal dryness, nail ridging, cracking at the corners of the mouth, nail discoloration, vaginal discharge, breast swelling and tenderness, irregular periods or vaginal bleeding, mouth or throat sores, nosebleed, and stretch marks.*

***Insomnia and dizziness.*

****Nausea, taste changes, rash, joint pain, dry skin, general pain, discouraged, wheezing, urinary frequency, keeping or maintaining an erection, anxious, increased sweating, difficulty swallowing, concentration, palpitations, headache, flatulence, bruises, hoarseness, vomiting, itchy skin, body odor, decreased libido, and urinary urgency.*

Discussion

Principal Findings

To our knowledge, this is the first study to develop a PRO-CTCAE–based subset for the PRO-based monitoring of toxicity in patients with lung cancer. This subset enables the incorporation of patient perspectives in clinical monitoring of patients with lung cancer using the well-established and FDA-endorsed PRO-CTCAE item library. This study may serve as an example for the future development of other site-specific PRO-CTCAE–based subsets for symptom monitoring in clinical practice.

Previously, there have been successful efforts of PRO-based monitoring in several trials showing improved symptom management, HRQoL, and even overall survival [11-14]. Basch et al [11] performed a trial (n=766) testing PRO-based monitoring in patients treated with chemotherapy for advanced solid tumors. This trial used a list of 12 common symptoms based on previous literature [37]. Denis et al [38] performed a similar PRO-based monitoring trial in patients with lung cancer (n=121). Both author groups did not report on the development of the symptoms list, but they performed a study on the capability of symptom lists to detect lung cancer relapse [38]. When comparing our final item list with the lists used by Denis et al [38] and Basch et al [11], our study results seem to be fairly consistent with the symptom lists used in these successful PRO-based monitoring trials. In total, 50% (4/8) of items are listed in both lists, that is, cough, shortness of breath, decreased appetite, pain, and fatigue (Denis et al [38] used weakness) [14,17]. Two items, constipation and nausea, were only listed by Basch et al [17]. Finally, sadness was not a part of the two PRO-based monitoring trials. Sadness and depression are however closely related and often sadness may indicate an occurrence or development of depression [14,17]. Items that were not included in our list because they were not included in the PRO-CTCAE item library were *fever, facial swelling, lump under the skin, voice changes coughing up blood,* and *body weight.* Other items that did not correspond with our subset were *painful urination, diarrhea, hot flashes,* and *tingling,* which were included in the more heterogeneous trial of Basch et al [17].

The study results are also in line with previous efforts of creating a symptom subset. A recent study created anatomic site-specific PRO-CTCAE item sets, including items for thorax radiation [39]. Their results were based on 30 patients who received thoracic radiation (including 16 patients with lung cancer). Their proposed relevant item set is in line with the results of this study [39]. Few previous studies have systematically selected a subset of PRO-CTCAE items [23,25]. Nissen et al [25] specifically aimed at three types of drugs and their adverse events in the treatment of metastatic prostate cancer, which were mainly based on FDA, European Medicine Agency, and randomized controlled trial reports and included relatively small samples of patients' interviews (n=16). This resulted in a relatively large subset of 25 PRO-CTCAE items compared with this study. Even though the number of items tested by Nissen et al [25] was considered feasible, they were tested in a setting of a one-time measurement only. Therefore, the presented subset might be a more feasible choice for weekly monitoring over a longer period. Moreover, the length of the subset was also comparable with the questionnaires used in previous successful trials that performed weekly monitoring [11,14]. Furthermore, this study, along with other studies, was performed in different target populations with slightly different aims, for example, Tolstrup et al [24] focused on immunotherapy in metastatic melanoma, and the study by Taarnhøj et al [23] focused on chemo- and immunotherapy for bladder cancer, whereas in this study, it was a requirement from our sponsor of Dutch medical specialists involved in the treatment of patients with lung cancer to have the same questionnaire for the (often) multimodality lung cancer treatment.

Strengths and Limitations

The key strength of this study is the use of a mixed method approach that includes the literature, patients, and expert perspectives. This study included a patient sample that reflected the stage distribution of the lung cancer population and included a variety of treatment modalities that are frequently used in clinical practice [40]. This multidisciplinary subset allows the monitoring of patient symptoms during the entire treatment course and therefore facilitates implementation within clinical care settings [41]. The emphasis on the patient and expert perspective may facilitate the implementation of PROMs within clinical cancer care, so the chance that this subset is perceived as valuable to the clinician is more likely to enable successful clinical implementation [16].

Our subset is a valuable PRO tool because it enables reliable remote monitoring, which can help provide necessary care to patients while minimizing the use of health care facilities. Remote monitoring using directly integrated PROM results in the electronic health record is expected to be successful because it minimizes barriers for use within the daily clinical routine [42].

The findings of this study are subject to several limitations. A methodological choice to let patients rate the items on a scale of 1 to 4, as opposed to the binary HCP rating that was used in this study, might have influenced the comparability of both results. However, we believe the 1 to 4 scale gives the patients a tool to rate the relative importance of their own experience, where an HCP can judge relevance or irrelevance based on a large number of cases and expertise.

For this subset, a set of items that were intended as a core set for multidisciplinary use were selected. Despite the advantages of multidisciplinary use and implementation, one could argue that the treatment experience may vary based on the different treatment modalities, and this could cause symptoms to be missed in patients depending on the specific treatment that is given. The results of this study showed that some symptoms were experienced as specifically relevant for distinct treatment modalities. One may consider adding these treatment-specific items when the subset is solely used in the context of one treatment modality. Moreover, we encouraged the use of the PRO-CTCAE's *other symptoms* item, in which a patient can freely report and score additional symptoms.

An arguable weakness that needs to be considered when interpreting these findings is that this study was designed as an EORTC phase 1 or 2 study to develop guidelines for developing PROMs (hence the relatively small sample). This entails that in order to make statements with regard to psychometric properties, acceptability, and compliance, further international field testing is needed. This study was a single-center study, and multicenter verification is certainly needed. Nonetheless, the PRO-CTCAE item library has proven to be a valid and reliable questionnaire in previous studies, and it has only recently been linguistically validated in Dutch-speaking patients [19,20]. Moreover, the PRO-CTCAE subset with the additional items of body weight and temperature and a specification of *coughing up blood* is currently being tested in the trial *SYMPRO-Lung* (Symptom Monitoring With Patient-Reported Outcomes Using a Web Application Among Lung Cancer Patients in the Netherlands; Netherlands Trial Register: NL7897).

Conclusions

This study presents a subset of PRO-CTCAE items for multidisciplinary PRO monitoring of patients with lung cancer during and after treatment. The results of the final item selection were considered relevant for monitoring patients with lung cancer. Continued efforts are needed to further validate the psychometric properties and the value of the PRO-CTCAE lung cancer subset in real-world clinical practice.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Relevance scores for all Patient-Reported Outcomes Version of the Common Terminology Criteria of Adverse Events items in order of relevance.
[DOCX File , 21 KB - cancer_v7i3e26574_app1.docx]

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Abbreviations

CTCAE: Common Terminology Criteria for Adverse Events
EORTC: European Organization for Research and Treatment of Cancer
FDA: Food and Drug Administration
HCP: health care practitioner
HRQoL: health-related quality of life
PRO: patient-reported outcome
PRO-CTCAE: Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events
PROM: patient-reported outcome measure
QLQ: Quality of Life core questionnaire
SYMPRO-Lung: Symptom Monitoring With Patient-Reported Outcomes Using a Web Application Among Lung Cancer Patients in the Netherlands

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