
JMIR Cancer

Impact Factor (2024): 3.3
Volume 6 (2020), Issue 2 ISSN 2369-1999 Editor in Chief: Naomi Cahill, PhD, RD

Contents

Viewpoints

- Telehealth and Palliative Care for Patients With Cancer: Implications of the COVID-19 Pandemic ([e20288](#))
Udhayvir Grewal, Stephanie Terauchi, Muhammad Beg. 3
- Virtual Cancer Care During the COVID-19 Pandemic and Beyond: A Call for Evaluation ([e24222](#))
Oren Levine, Michael McGillion, Mark Levine. 9
- The Impact of COVID-19 on Cancer Screening: Challenges and Opportunities ([e21697](#))
Ramon Cancino, Zhaohui Su, Ruben Mesa, Gail Tomlinson, Jing Wang. 25

Original Papers

- The Tablet-Based, Engagement, Assessment, Support, and Sign-Posting (EASSi) Tool for Facilitating and Structuring Sexual Well-Being Conversations in Routine Prostate Cancer Care: Mixed-Methods Study ([e20137](#))
Eilís McCaughan, Carrie Flannagan, Kader Parahoo, John Connaghan, Roma Maguire, Mary Steele, Samantha Thompson, Suneil Jain, Michael Kirby, Nuala Brady, Seán O'Connor. 14
- Information Needs About Cancer Treatment, Fertility, and Pregnancy: Qualitative Descriptive Study of Reddit Threads ([e17771](#))
Ria Garg, Nevena Rebi, Mary De Vera. 38
- Beliefs and Information Seeking in Patients With Cancer in Southwest China: Survey Study ([e16138](#))
Juan Xie, Shi Xie, Ying Cheng, Zhe He. 48
- eHealth Practices in Cancer Survivors With BMI in Overweight or Obese Categories: Latent Class Analysis Study ([e24137](#))
Annie Lin, Sharon Baik, David Aaby, Leslie Tello, Twila Linville, Nabil Alshurafa, Bonnie Spring. 59
- Patterns of Use of Smartphone-Based Interventions Among Latina Breast Cancer Survivors: Secondary Analysis of a Pilot Randomized Controlled Trial ([e17538](#))
Sharon Baik, Laura Oswald, Joanna Buscemi, Diana Buitrago, Francisco Iacobelli, Alejandra Perez-Tamayo, Judith Guitelman, Frank Penedo, Betina Yanez. 70
- Differences in Electronic Personal Health Information Tool Use Between Rural and Urban Cancer Patients in the United States: Secondary Data Analysis ([e17352](#))
Alexandra Greenberg-Worisek, Liaa Ferede, Joyce Balls-Berry, Ian Marigi, Emily Valentin Mendez, Numra Bajwa, Melody Ouk, Minerva Orellana, Felicity Enders. 82

Web-Based Lifestyle Interventions for Prostate Cancer Survivors: Qualitative Study (e19362) Elizabeth Wang, Rebecca Graff, June Chan, Crystal Langlais, Jeanette Broering, Justin Ramsdill, Elizabeth Kessler, Kerri Winters-Stone, Erin Van Blarigan, Stacey Kenfield.	92
Assessment of Data Usage of Cancer e-Interventions (ADUCI) Framework for Health App Use of Cancer Patients and Their Caregivers: Framework Development Study (e18230) Natalie Heynsbergh, Seung O, Patricia Livingston.	109
Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study (e18143) Teresa A'mar, J Beatty, Catherine Fedorenko, Daniel Markowitz, Thomas Corey, Jane Lange, Stephen Schwartz, Bin Huang, Jessica Chubak, Ruth Etzioni.	119
Evaluation of a Remote Symptom Assessment and Management (SAM) System for People Receiving Adjuvant Chemotherapy for Breast or Colorectal Cancer: Mixed Methods Study (e22825) Lisa Whitehead, Laura Emery, Deborah Kirk, Diane Twigg, Deborah Brown, Joanna Dewar.	129

Corrigenda and Addenda

Correction: Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study (e23821) Teresa A'mar, J Beatty, Catherine Fedorenko, Daniel Markowitz, Thomas Corey, Jane Lange, Stephen Schwartz, Bin Huang, Jessica Chubak, Ruth Etzioni.	141
--	-----

Viewpoint

Telehealth and Palliative Care for Patients With Cancer: Implications of the COVID-19 Pandemic

Udhayvir Singh Grewal¹, MD; Stephanie Terauchi^{2,3}, MD; Muhammad Shaalan Beg^{2,3}, MD

¹Department of Internal Medicine, Louisiana State University Health Sciences Center, Shreveport, LA, United States

²Department of Internal Medicine, University of Texas Southwestern Medical Center, Dallas, TX, United States

³Simmons Comprehensive Cancer Center, University of Texas Southwestern Medical Center, Dallas, TX, United States

Corresponding Author:

Muhammad Shaalan Beg, MD

Simmons Comprehensive Cancer Center

University of Texas Southwestern Medical Center

5323 Harry Hines Blvd

Dallas, TX,

United States

Phone: 1 5136416314

Email: muhammad.beg@utsouthwestern.edu

Abstract

It has been reported that the incidence of SARS-CoV-2 infection is higher in patients with cancer than in the general population and that patients with cancer are at an increased risk of developing severe life-threatening complications from COVID-19. Increased transmission and poor outcomes noted in emerging data on patients with cancer and COVID-19 call for aggressive isolation and minimization of nosocomial exposure. Palliative care and oncology providers are posed with unique challenges due to the ongoing COVID-19 pandemic. Telepalliative care is the use of telehealth services for remotely delivering palliative care to patients through videoconferencing, telephonic communication, or remote symptom monitoring. It offers great promise in addressing the palliative and supportive care needs of patients with advanced cancer during the ongoing pandemic. We discuss the case of a 75-year-old woman who was initiated on second-line chemotherapy, to highlight how innovations in technology and telehealth-based interventions can be used to address patients' palliative and supportive care needs in the ongoing epidemic.

(*JMIR Cancer* 2020;6(2):e20288) doi:[10.2196/20288](https://doi.org/10.2196/20288)

KEYWORDS

COVID-19; telehealth; palliative care; telepalliative care; patients with cancer; telemedicine

Cancer and COVID-19

A nationwide analysis from China has indicated that the incidence of SARS-CoV-2 infection is higher in patients with cancer than in the general population and that patients with cancer are at an increased risk of developing severe life-threatening complications from COVID-19. Compared to patients without cancer, patients with cancer are about 3.5 times more likely to be admitted to the intensive care unit or die due to complications of COVID-19 [1]. The increased risk of infection and complications in these patients could be due to immunosuppression caused by the cancer itself or myelosuppression secondary to treatment, such as chemotherapy [2]. Due to the increased risk of complications in patients with cancer, there is growing concern about these patients experiencing delays in the delivery of necessary care and medical services, including palliative and supportive care [3].

Palliative medicine is a vital component of cancer care, and it can be provided in a variety of clinical settings, including outpatient clinics, inpatient consultations, dedicated palliative medicine units, long-term care facilities, and home-based care. Although inpatient palliative medicine is usually more common in practice, the delivery of outpatient palliative care has been growing, and it has been shown to improve the quality of life and overall well-being of patients with cancer [4].

Palliative care and oncology providers are posed with unique challenges due to the ongoing COVID-19 pandemic. Increased transmission and poor outcomes noted in emerging data on patients with cancer and COVID-19 call for aggressive isolation and minimization of nosocomial exposure [1]. Health care providers are challenged to innovate and develop care delivery systems that can balance the benefits of the care delivered with the risk and burden posed to patients by exposure to health care personnel. The decision to treat patients and risk exposure and

infection-related complications needs to be weighed against the risk that is posed by the delay in treatments. Providing palliative care to cancer survivors during the ongoing pandemic may be as daunting a challenge as those presented by therapeutic dilemmas.

Telehealth and Telepalliative Care

Telehealth has been defined by the US Health Resources and Service Administration as “the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration” [5]. Several studies have suggested that telehealth is not only cost-effective, but also associated with encouragingly high levels of patient satisfaction [6-8]. Telehealth services have helped bridge travel-related barriers in a cost-effective manner. The implementation of telehealth-based interventions has also been associated with improved overall outcomes, such as improved medication compliance rates and shorter hospital stays [9]. As the number of COVID-19 cases continues to rise across the world, health care systems have been adopting virtual treatment options to minimize the need for physical meetings between patients and health care providers. This has been considered the new normal for both physicians and patients. Virtual care has shown promise in terms of reducing the number of emergency room visits, conserving health care resources, and minimizing the spread of COVID-19 [10].

Telepalliative care is the use of telehealth services for remotely delivering palliative care to patients through videoconferencing, telephonic communication, or remote symptom monitoring. Although careful planning is needed to set up and implement a robust system for its delivery, telepalliative care has been widely accepted by patients, and it can be used for various patient populations, including patients who are very susceptible to infection [11].

Let us consider the case of a patient in need of palliative care in the era of COVID-19.

Ms Smith is a 75-year-old woman with metastatic pancreatic cancer and worsening back pain. She has considered starting second-line chemotherapy, and has been referred to a palliative care program. Ms Smith lives alone, and a neighbor drives her to and from the clinic on chemotherapy days. Due to the COVID-19-related reduction in clinical staff, palliative care clinical services have been reduced. The next available clinic encounter is in 14 days.

How Can Technology and Telehealth-Based Services be Used to Meet Ms Smith’s Palliative Care Needs in Light of the Ongoing Pandemic?

Studies have shown that virtual visits do not compromise the quality of care and are as effective as in-person visits for delivering palliative care [12]. Videoconferencing can be a valid tool for Ms Smith’s initial assessment. In our experience, apps embedded in electronic health records (eg, Epic, MyChart, and

BlueJeans) and free-standing apps (eg, Doximity Dialer) can be effective modes of virtual communication between patients and clinicians. Audio-visual platforms for videoconferencing provide an opportunity for palliative care physicians to interact with patients, obtain a medical history, and assess current symptom burden. Physicians can use a virtual physical exam, supplemented by patient self-examination, to augment their clinical assessment. These measures can be used to estimate the current functional status of the patient and evaluate certain physical characteristics, such as vital signs, general physical appearance, cardiorespiratory status, changes in skin and extremities, and changes in performance status [13].

During an initial virtual visit, the palliative care provider can address the patient’s pain, which is a common symptom experienced by patients with cancer. Managing pain for a patient with cancer is a significant challenge, and it has a significant impact on patients’ overall outcomes. Uncontrolled pain can lead to hospitalization, which can increase the chance of COVID-19 exposure [14]. Effective communication between patients and their palliative care team can improve pain management and patient satisfaction [15]. Furthermore, the efficacy of patient-physician interactions via videoconferencing is comparable to that of in-person evaluation and care [16]. Patient history and virtual physical exam data augmented with data from patient self-examination can help physicians make an accurate assessment of the patient’s pain [17]. Knowing the location and nature of the pain, aggravating and relieving factors, and relationship between pain and posture can help physicians determine the etiology of pain and inform the subsequent management.

Although telehealth can be an effective way to manage pain and other aspects of patient care, prior legislation prohibited health care providers from prescribing opioids solely through telehealth services. However, because the COVID-19 pandemic has been declared a national emergency, the United States Drug Enforcement Administration, under the conditions outlined in the Ryan Haight Act (Title 21, United States Code, Section 802[54][D]), has allowed physicians to prescribe controlled substances (schedule II-IV) through telehealth services, even for patients that physicians have not evaluated in person [18]. This change in legislation has removed pre-existing barriers and has allowed physicians to continue to provide pain and symptom management to those who need it most.

Depression, anxiety, and psychological distress are important issues that affect a significant proportion of patients with cancer, especially those with metastatic disease. Virtual visits may also be used as an opportunity to identify psychological distress and emotional stressors. Telepsychiatry-based interventions have been increasingly incorporated into mainstream practice and have shown accurate results and overall outcomes comparable to those of in-person interventions [19].

Virtual visits can also be used as an opportunity for advance care planning with the patient. Per the White House Coronavirus Task Force, epidemiological models have predicted about 100,000 deaths associated with COVID-19 in the United States alone [20]. These estimates call for timely advance care planning with patients at a higher risk of mortality due to COVID-19,

such as patients with cancer. Therefore, regular telehealth visits with patients with cancer should also focus on advance care planning, specifically in reference to the ongoing pandemic. Proactive discussions with patients about their health care expectations and goals would facilitate the appropriate delivery of care to these patients, should they contract COVID-19 and develop serious complications [21]. These conversations are intimate and potentially emotional for patients with cancer. Telehealth services, such as videoconferencing, help maintain a personal connection by allowing physicians to engage with and be responsive to their patients' cues. The clinician should maintain the best possible environment for consultations and ask for the patient's permission before beginning a consultation. Acknowledging the patient's emotions and providing defined pauses to allow patients to reflect on, summarize, and repeat information are important when providing a virtual consultation.

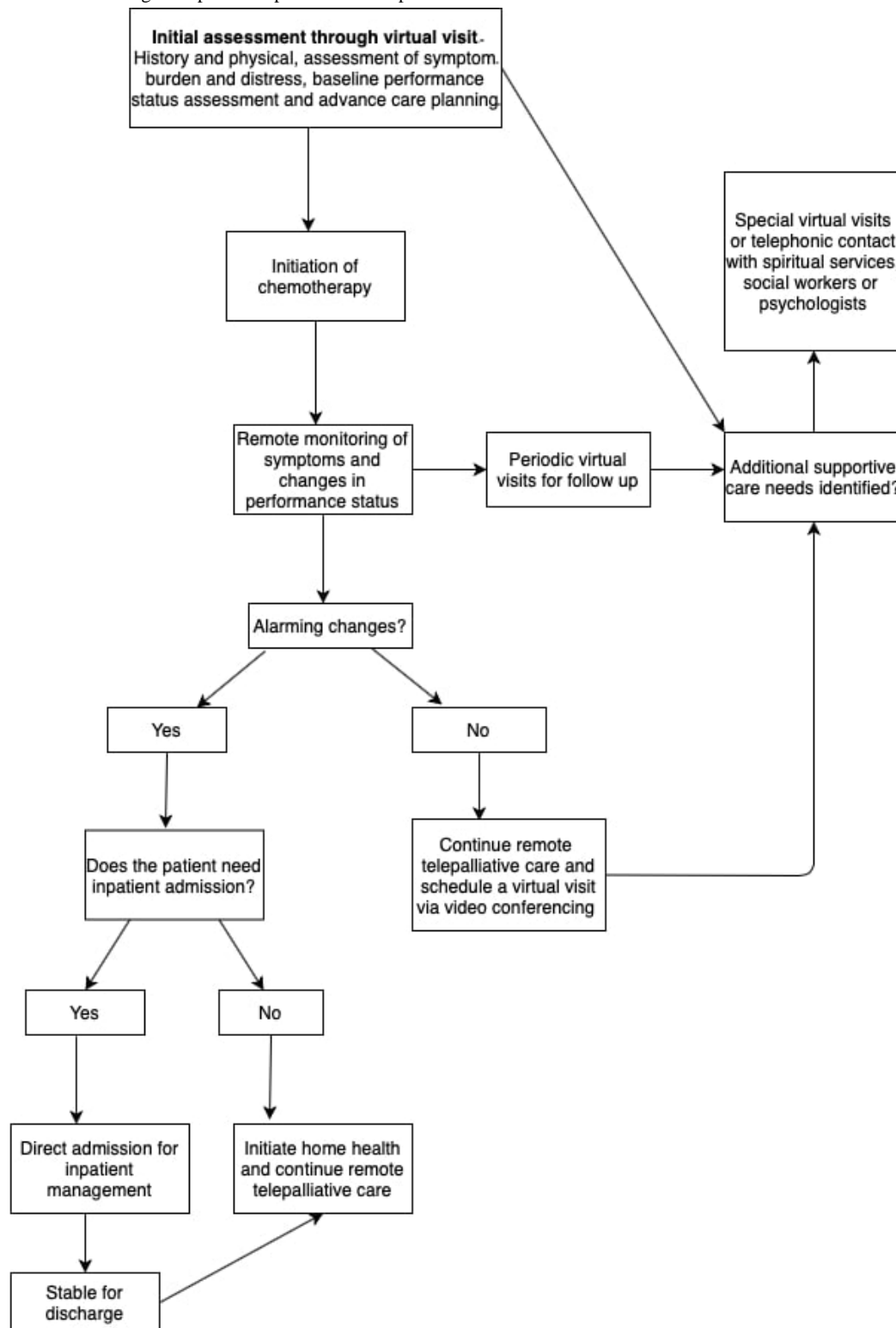
For subsequent patient monitoring and ongoing palliative care delivery, telemonitoring or home-based telehealth services can be employed. These also allow for the remote monitoring of symptoms after the patient starts systemic chemotherapy. Electronic telehealth-based tools can be used for the remote symptom management of the patient. A questionnaire based on the different symptoms of chemotherapy-associated toxicity can be self-administered by the patient and recorded via a remote mobile phone. The results of the questionnaire can be used to automatically generate advice for managing the patient's symptoms. This advice is then sent to the patient's remote

device. If the symptoms are significantly concerning, then a notification can be sent to the physician's handset, prompting an appropriate response [22]. Therefore, continuous telemonitoring allows for regular checks on the functional status and general well-being of the patient. It can also alert providers to significant events, such as the development of serious adverse effects associated with chemotherapy.

Alerting clinicians to major changes in patient-reported outcomes can allow health care providers to intervene early by managing treatment-related side effects before they cause complications. This provides an opportunity to use outpatient services or arrange direct admissions to the hospital for fluid resuscitation or pain control, thereby preventing the need for emergency department visits. Patients who do not require immediate hospitalization or dedicated medical care after discharge can be considered for home-based health care, along with telepalliative care for symptom management.

Follow-up virtual visits can be conducted via videoconferencing. During these visits, the need for special medical or additional supportive care can be addressed. Telepalliative care allows for continued multidisciplinary management and addresses a patient's well-being. In a time when the feeling of uncertainty is high, access to a multidisciplinary supportive care team can help with the emotional well-being of patients and their family. [Figure 1](#) illustrates a telepalliative care-based plan for patients. Visits with spiritual care providers, social workers, and psychologists can be conducted through telehealth services.

Figure 1. Flowchart demonstrating a telepalliative plan of care for patients with metastatic cancer who are initiated on second-line therapy.



Conclusion

Telepalliative care offers great promise in addressing the palliative and supportive care needs of patients with advanced cancer during the ongoing pandemic. Continuous telemonitoring can be used to remotely monitor crucial patient-reported outcomes, such as pain and respiratory distress. Periodic virtual visits can provide oncology and palliative care providers the opportunity to address additional care needs and assess alarming

changes that warrant hospitalization. However, the implementation of telepalliative care is limited by several barriers, such as limited remuneration by insurance agencies and poor access for communities with limited internet access. Various state-specific regulations and strict requirements for medical licensure and credentialing would also geographically limit the delivery of telepalliative care [23]. The ripple effect of COVID-19 will outlast the pandemic itself, and the impacts of this ripple effect on the health care delivery system and health

care for patients with cancer will last longer. It is important to devise strategies for delivering effective palliative care to patients with advanced cancer. Telehealth-based interventions offer promise for the remote delivery of palliative care and

effective symptom management. Telehealth and technology services should be implemented in clinical practice in a sustainable and patient-centric manner.

Conflicts of Interest

None to declare.

References

- Liang W, Guan W, Chen R, Wang W, Li J, Xu K, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. *Lancet Oncol* 2020 Mar;21(3):335-337 [FREE Full text] [doi: [10.1016/S1470-2045\(20\)30096-6](https://doi.org/10.1016/S1470-2045(20)30096-6)] [Medline: [32066541](https://pubmed.ncbi.nlm.nih.gov/32066541/)]
- Rolston KVI. Infections in Cancer Patients with Solid Tumors: A Review. *Infect Dis Ther* 2017 Mar;6(1):69-83 [FREE Full text] [doi: [10.1007/s40121-017-0146-1](https://doi.org/10.1007/s40121-017-0146-1)] [Medline: [28160269](https://pubmed.ncbi.nlm.nih.gov/28160269/)]
- Al-Quteimat OM, Amer AM. The Impact of the COVID-19 Pandemic on Cancer Patients. *Am J Clin Oncol* 2020 Jun;43(6):452-455 [FREE Full text] [doi: [10.1097/COC.0000000000000712](https://doi.org/10.1097/COC.0000000000000712)] [Medline: [32304435](https://pubmed.ncbi.nlm.nih.gov/32304435/)]
- Temel J, Greer J, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010 Aug 19;363(8):733-742. [doi: [10.1056/NEJMoa1000678](https://doi.org/10.1056/NEJMoa1000678)] [Medline: [20818875](https://pubmed.ncbi.nlm.nih.gov/20818875/)]
- Telehealth Programs. HRSA. URL: <https://www.hrsa.gov/rural-health/telehealth> [accessed 2020-10-28]
- Hiratsuka V, Delafield R, Starks H, Ambrose AJ, Mau MM. Patient and provider perspectives on using telemedicine for chronic disease management among Native Hawaiian and Alaska Native people. *Int J Circumpolar Health* 2013;72 [FREE Full text] [doi: [10.3402/ijch.v72i0.21401](https://doi.org/10.3402/ijch.v72i0.21401)] [Medline: [23977642](https://pubmed.ncbi.nlm.nih.gov/23977642/)]
- Comín-Colet J, Enjuanes C, Verdú-Rotellar JM, Linas A, Ruiz-Rodríguez P, González-Robledo G, et al. Impact on clinical events and healthcare costs of adding telemedicine to multidisciplinary disease management programmes for heart failure: Results of a randomized controlled trial. *J Telemed Telecare* 2016 Jul;22(5):282-295. [doi: [10.1177/1357633X15600583](https://doi.org/10.1177/1357633X15600583)] [Medline: [26350543](https://pubmed.ncbi.nlm.nih.gov/26350543/)]
- Turvey C, Fortney J. The Use of Telemedicine and Mobile Technology to Promote Population Health and Population Management for Psychiatric Disorders. *Curr Psychiatry Rep* 2017 Oct 16;19(11):88. [doi: [10.1007/s11920-017-0844-0](https://doi.org/10.1007/s11920-017-0844-0)] [Medline: [29035422](https://pubmed.ncbi.nlm.nih.gov/29035422/)]
- American Hospital Association. Telehealth: Helping Hospitals Deliver CostEffective Care. AHA. URL: <https://www.aha.org/system/files/content/16/16telehealthissuebrief.pdf> [accessed 2020-10-28]
- Khairat S, Meng C, Xu Y, Edson B, Gianforaro R. Interpreting COVID-19 and Virtual Care Trends: Cohort Study. *JMIR Public Health Surveill* 2020 Apr 15;6(2):e18811 [FREE Full text] [doi: [10.2196/18811](https://doi.org/10.2196/18811)] [Medline: [32252023](https://pubmed.ncbi.nlm.nih.gov/32252023/)]
- AlDossary S, Martin-Khan MG, Bradford NK, Smith AC. A systematic review of the methodologies used to evaluate telemedicine service initiatives in hospital facilities. *Int J Med Inform* 2017 Jan;97:171-194. [doi: [10.1016/j.ijmedinf.2016.10.012](https://doi.org/10.1016/j.ijmedinf.2016.10.012)] [Medline: [27919377](https://pubmed.ncbi.nlm.nih.gov/27919377/)]
- Read Paul L, Salmon C, Sinnarajah A, Spice R. Web-based videoconferencing for rural palliative care consultation with elderly patients at home. *Support Care Cancer* 2019 Sep;27(9):3321-3330. [doi: [10.1007/s00520-018-4580-8](https://doi.org/10.1007/s00520-018-4580-8)] [Medline: [30613908](https://pubmed.ncbi.nlm.nih.gov/30613908/)]
- Ansary AM, Martinez JN, Scott JD. The virtual physical exam in the 21st century. *J Telemed Telecare* 2019 Nov 06;1357633X19878330. [doi: [10.1177/1357633X19878330](https://doi.org/10.1177/1357633X19878330)] [Medline: [31690169](https://pubmed.ncbi.nlm.nih.gov/31690169/)]
- Scarborough BM, Smith CB. Optimal pain management for patients with cancer in the modern era. *CA Cancer J Clin* 2018 May;68(3):182-196 [FREE Full text] [doi: [10.3322/caac.21453](https://doi.org/10.3322/caac.21453)] [Medline: [29603142](https://pubmed.ncbi.nlm.nih.gov/29603142/)]
- Beck SL, Towsley GL, Berry PH, Lindau K, Field RB, Jensen S. Core aspects of satisfaction with pain management: cancer patients' perspectives. *J Pain Symptom Manage* 2010 Jan;39(1):100-115 [FREE Full text] [doi: [10.1016/j.jpainsymman.2009.06.009](https://doi.org/10.1016/j.jpainsymman.2009.06.009)] [Medline: [19879107](https://pubmed.ncbi.nlm.nih.gov/19879107/)]
- Appel PR, Bleiberg J, Noiseux J. Self-regulation training for chronic pain: can it be done effectively by telemedicine? *Telemed J E Health* 2002;8(4):361-368. [doi: [10.1089/15305620260507495](https://doi.org/10.1089/15305620260507495)] [Medline: [12626105](https://pubmed.ncbi.nlm.nih.gov/12626105/)]
- Burton R, Boedeker B. Application of telemedicine in a pain clinic: the changing face of medical practice. *Pain Med* 2000 Dec;1(4):351-357. [doi: [10.1046/j.1526-4637.2000.00039.x](https://doi.org/10.1046/j.1526-4637.2000.00039.x)] [Medline: [15101881](https://pubmed.ncbi.nlm.nih.gov/15101881/)]
- U.S. Department of Justice Drug Enforcement Administration. COVID-19 Information Page. Diversion Control Division. URL: <https://www.deadiversion.usdoj.gov/coronavirus.html> [accessed 2020-04-15]
- Hublely S, Lynch SB, Schneck C, Thomas M, Shore J. Review of key telepsychiatry outcomes. *World J Psychiatry* 2016 Jun 22;6(2):269-282 [FREE Full text] [doi: [10.5498/wjp.v6.i2.269](https://doi.org/10.5498/wjp.v6.i2.269)] [Medline: [27354970](https://pubmed.ncbi.nlm.nih.gov/27354970/)]

20. Cole D, Bohn K, Bash D. US could see millions of coronavirus cases and 100,000 or more deaths, Fauci says. CNN Politics. 2020 Mar 30. URL: <https://www.cnn.com/2020/03/29/politics/coronavirus-deaths-cases-anthony-fauci-cnntv/index.html> [accessed 2020-03-30]
21. Zhou F, Yu T, Du R, Fan G, Liu Y, Liu Z, et al. Clinical course and risk factors for mortality of adult inpatients with COVID-19 in Wuhan, China: a retrospective cohort study. *Lancet* 2020 Mar 28;395(10229):1054-1062 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)30566-3](https://doi.org/10.1016/S0140-6736(20)30566-3)] [Medline: [32171076](https://pubmed.ncbi.nlm.nih.gov/32171076/)]
22. Maguire R, Fox PA, McCann L, Miaskowski C, Kotronoulas G, Miller M, et al. The eSMART study protocol: a randomised controlled trial to evaluate electronic symptom management using the advanced symptom management system (ASyMS) remote technology for patients with cancer. *BMJ Open* 2017 Jun 06;7(5):e015016. [doi: [10.1136/bmjopen-2016-015016](https://doi.org/10.1136/bmjopen-2016-015016)] [Medline: [28592577](https://pubmed.ncbi.nlm.nih.gov/28592577/)]
23. Dandachi D, Lee C, Morgan RO, Tavakoli-Tabasi S, Giordano TP, Rodriguez-Barradas MC. Integration of telehealth services in the healthcare system: with emphasis on the experience of patients living with HIV. *J Investig Med* 2019 Jun;67(5):815-820. [doi: [10.1136/jim-2018-000872](https://doi.org/10.1136/jim-2018-000872)] [Medline: [30826803](https://pubmed.ncbi.nlm.nih.gov/30826803/)]

Edited by G Eysenbach; submitted 18.05.20; peer-reviewed by H Fatoum; comments to author 11.06.20; revised version received 27.06.20; accepted 11.08.20; published 24.11.20.

Please cite as:

Grewal US, Terauchi S, Beg MS

Telehealth and Palliative Care for Patients With Cancer: Implications of the COVID-19 Pandemic

JMIR Cancer 2020;6(2):e20288

URL: <http://cancer.jmir.org/2020/2/e20288/>

doi: [10.2196/20288](https://doi.org/10.2196/20288)

PMID: [33049695](https://pubmed.ncbi.nlm.nih.gov/33049695/)

©Udhayvir Singh Grewal, Stephanie Terauchi, Muhammad Shaalan Beg. Originally published in *JMIR Cancer* (<http://cancer.jmir.org>), 24.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Cancer*, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Viewpoint

Virtual Cancer Care During the COVID-19 Pandemic and Beyond: A Call for Evaluation

Oren Hannun Levine^{1,2*}, MSc, MD; Michael McGillion^{3*}, RN, DPhil; Mark Levine^{1,2*}, MSc, MD

¹Department of Oncology, McMaster University, Hamilton, ON, Canada

²Hamilton Health Sciences - Juravinski Cancer Centre, Hamilton, ON, Canada

³School of Nursing, McMaster University, Hamilton, ON, Canada

* all authors contributed equally

Corresponding Author:

Mark Levine, MSc, MD

Department of Oncology

McMaster University

Room 104, G Wing

711 Concession Street

Hamilton, ON, L8V 1C3

Canada

Phone: 1 905 527 2299 ext 42176

Email: mlevine@mcmaster.ca

Abstract

The interplay of virtual care and cancer care in the context of the COVID-19 pandemic is unique and unprecedented. Patients with cancer are at increased risk of SARS-CoV-2 infection and have worse outcomes than patients with COVID-19 who do not have cancer. Virtual care has been introduced quickly and extemporaneously in cancer treatment centers worldwide to maintain COVID-19-free zones. The outbreak of COVID-19 in a cancer center could have devastating consequences. The virtual care intervention that was first used in our cancer center, as well as many others, was a landline telephone in an office or clinic that connected a clinician with a patient. There is a lack of virtual care evaluation from the perspectives of patients and oncology health care providers. A number of factors for assessing oncology care delivered through a virtual care intervention have been described, including patient rapport, frailty, delicate conversations, team-based care, resident education, patient safety, technical effectiveness, privacy, operational effectiveness, and resource utilization. These factors are organized according to the National Quality Forum framework for the assessment of telehealth in oncology. This includes the following 4 domains of assessing outcomes: experience, access to care, effectiveness, and financial impact or cost. In terms of virtual care and oncology, the pandemic has opened the door to change. The lessons learned during the initial period of the pandemic have given rise to opportunities for the evolution of long-term virtual care. The opportunity to evaluate and improve virtual care should be seized upon.

(*JMIR Cancer* 2020;6(2):e24222) doi:[10.2196/24222](https://doi.org/10.2196/24222)

KEYWORDS

care; patient-physician relationship; patient-centered care; oncology care delivery; virtual visits; telehealth; virtual care; cancer; oncology; evaluation; COVID-19

Introduction

The COVID-19 pandemic has catapulted virtual care into the forefront of oncology practice [1-7]. The interplay of virtual care and cancer care in the context of the pandemic is unique and unprecedented [1-7]. Patients with cancer are at increased risk of SARS-CoV-2 infection because of immunosuppression [8,9] and frequent visits to cancer centers for therapy, which potentially increases their risk of contracting and transmitting

COVID-19 [9]. Furthermore, the outcomes of patients with cancer and COVID-19 are likely worse than those of patients with COVID-19 who do not have cancer [10-14]. The introduction of virtual care during the onset of the pandemic was an emergency strategy for maintaining cancer centers as COVID-19-free zones to avoid any potential interruption in treatments.

In this commentary, virtual care is defined as an interaction between clinicians and patients that occurs remotely through

communication or information technologies with the aim of facilitating or maximizing the quality and effectiveness of patient care [15,16]. During the onset of the pandemic, a landline telephone in an office or clinic was first used in our cancer center to conduct consultations and follow-up assessments, share test results with patients and families, and have delicate and difficult conversations. The use of telephone landlines was our first immediate option for remote care during the pandemic crisis. This experience stimulated our thoughts on virtual care and our need to increase capacity in this regard. Initially, there was limited video connectivity in cancer centers. However, this is now changing, and the pandemic has allowed for virtual care approaches to evolve.

Virtual care has been introduced quickly and has featured extemporaneous implementation under time pressure [1-7]. It

is anticipated that there will be pressure to continue virtual care in oncology because of its efficiency and potential to cut costs [17]. However, there is a lack of virtual care evaluation from the perspectives of patients and oncology health care providers. Herein, we consider the impact of the virtualization of oncology practices with respect to a number of factors. Based on our recent experience with virtual care, albeit mostly telephone-based care, we highlight opportunities to evaluate models of care in oncology practices that incorporate any virtual technology. The factors that we consider are organized according to the National Quality Form framework for the assessment of telehealth in oncology. This includes the following 4 domains of assessing outcomes: experience, access to care, effectiveness, and financial impact or cost [18] (Table 1).

Table 1. National Quality Forum telehealth measurement framework.

Factors	Domains ^a			
	Access to care	Financial impact or cost	Experience	Effectiveness
Patient rapport			+	
Patient frailty			+	
Delicate conversations			+	
Multidisciplinary care	+			
Role of the nurse	+			
Resident education				+
Patient safety			+	+
Technical effectiveness				+
Privacy				+
Operational effectiveness		+		+
Resource utilization		+		

^aThe domain related to a factor.

Experience

Patient Rapport

Establishing a strong rapport with patients is important for building trust [19]. A patient's first visit to a cancer center is often the most important for building strong clinician-patient relationships [19]. Diagnoses, prognoses, and treatment options are usually addressed in the first consultation visit. Furthermore, the physical examination can impact the care plan, and thorough assessments may contribute to a sense of trust with medical care. With remote care, it can be more challenging to establish patient rapport. Strong rapport is helpful for identifying when a patient's status has changed (eg, cancer spread) and providing compassionate care [19,20]. Methods for optimizing the sense of connectedness between patients and care providers during virtual care requires further study.

Patient Frailty

Many patients with cancer are older adults who have other comorbid medical illnesses. Frailty is not an illness; it is a syndrome that combines the effects of natural aging with the

outcomes of multiple long-term conditions, such as the loss of fitness and reserves [21]. Chemotherapy is often associated with toxicity, which can sometimes be life-threatening, and toxicity tends to increase with age. However, there are older patients whose physical conditions are robust. It is important to be able to assess the frailty of the patient to avoid the risk of excessive toxicity and undertreatment. The reliability of remote frailty assessments requires exploration.

Delicate Conversations

Bad news conversations can be very difficult during remote care, especially over the phone [22,23]. Even when using video-based technology, it may not be possible to pick up on body language and visual cues to gauge how a patient is receiving information. The parameters of video-based communication can limit direct eye contact and leave room for miscommunication and the indeterminacy of one's intent [24]. Thus, it remains unclear whether visits scheduled for potentially sensitive conversations should be done virtually or in person. If such conversations are done in person during the time of a pandemic, the patient must arrive alone for what may be a

difficult and anxiety-provoking experience. Assessing patient experience may help define a reasonable standard.

Access to Care

Multidisciplinary Care

Multidisciplinary clinics are an important part of specialized oncology care at any major cancer center [25]. Surgical, medical, and radiation oncologists assess patients together in order to make a treatment recommendation. Usually, this requires multiple people in 1 room and violates physical distancing recommendations. Virtual technology allows multiple specialists to interact with a patient at the same time, but it can be cumbersome and logistically challenging. Patient and care provider satisfaction is an important measure for ensuring that multidisciplinary care is sustainable in a virtual model.

Role of the Nurse

In many cancer centers, the model of nursing is a shared-care model between oncologists and nurses. Nurses have many responsibilities regarding patient care, including symptom assessment, health education, and triaging calls regarding treatment toxicity and the psychologic, emotional, and social aspects of care [26]. There is potential for the nurse's role to be marginalized due to virtual care. We see a need for the in-depth evaluation of the impact of virtual care on the supportive and relational aspects of nursing work.

Effectiveness

Resident Education

Another challenge is incorporating medical student and postgraduate resident education into virtual practice. Traditionally, in clinics, a resident enters a patient examining room to take an illness history and perform a physical examination. Afterward, they leave the room and confer with the staff oncologist, which is an opportunity for on-the-fly teaching. Upon returning to the patient together with the staff oncologist, there is a chance for bedside teaching. This process cannot be performed with remote care. Recently, there has been a shift toward competency-based residency education, which emphasizes direct observation and feedback [27,28]. Video calls may allow for the observation of a resident's communication skills. However, whether this is sufficient to establish a trainee's competence for clinical practice requires validation.

Patient Safety

It is routine for a patient to be weighed at every visit. Weight can be an important clue for determining changes in health status and the need to change drug dosing. Standardized symptom assessments are completed before visiting the clinician. These assessments also serve as a screen for important changes in health status. However, the uptake of online symptom screening has been inconsistent. Without these early warning signs, are patients more likely to experience toxicity? Health services research could help elucidate this question.

Technical Effectiveness

It is important to keep in mind that many patients do not have access to video calling software, high-speed internet, or email [29-31]. Furthermore, the patient's prior experience with technology may affect the success of virtual encounters [29-31]. Occasionally, sound quality, language barriers, and hearing impairment make it difficult to determine if information has been understood correctly. Other barriers to virtual communication include somnolence and confusion from chemotherapy, supportive medications (eg, narcotics), or advanced cancer [32].

Privacy

Patients and care providers must trust that the information being transmitted during care is private and secure [30,31,33]. When health care practices are conducted virtually and all information is transferred electronically, the situation becomes more complex. There remains much to be learned about implementing and scaling virtual care in oncology per the Hospital Level 7 integration standards for seamless and cybersecure hospital-to-home connection [34]. The best practices for implementing virtual care models that measurably preserve patients' and families' privacy and ensure the security of data throughout the virtual care process are paramount [34].

Financial Impact or Cost

Operational Effectiveness

Patient convenience and clinical service-related satisfaction may be enhanced through virtual care, as costly parking fees and lengthy periods in waiting rooms can be avoided. Physician reimbursement was an issue during the beginning of the pandemic due to the rapid implementation of virtual care in oncology, but this has been addressed [33]. From the clinician's perspective, follow-up visits may be shorter, allowing for more patient assessments. However, if a patient is unavailable, is time lost through repeated attempts to contact that patient? Whether virtual care in oncology is more efficient than in-person care remains unknown, but this should be studied [33,35].

Resource Utilization

If patients perceive a lack of access to cancer centers when urgent in-person assessments are needed, they may resort to visiting the emergency department for symptom complaints or treatment toxicity. Administrative data should be scrutinized to assess the impact of virtual care on acute care resource utilization [35].

Conclusion

In terms of virtual care and oncology, the COVID-19 pandemic has opened the door to change. The lessons learned during the initial period of the pandemic have given rise to opportunities for the evolution of long-term virtual care. It would be unfortunate not to learn from our experiences through thoughtful and scholarly assessment. Assessment measures should span the areas of experience, access to care, effectiveness, and financial impact or cost. The opportunity to evaluate and improve virtual care should be seized upon.

Conflicts of Interest

None declared.

References

1. Mullangi S, Schleicher SM, Aviki EM. Innovation in Cancer Care Delivery in the Era of COVID-19. *JCO Oncol Pract* 2020 Nov;16(11):718-719. [doi: [10.1200/OP.20.00336](https://doi.org/10.1200/OP.20.00336)] [Medline: [32552318](https://pubmed.ncbi.nlm.nih.gov/32552318/)]
2. Mulvey TM, Jacobson JO. COVID-19 and Cancer Care: Ensuring Safety While Transforming Care Delivery. *J Clin Oncol* 2020 Oct 01;38(28):3248-3251. [doi: [10.1200/JCO.20.01474](https://doi.org/10.1200/JCO.20.01474)] [Medline: [32749939](https://pubmed.ncbi.nlm.nih.gov/32749939/)]
3. The Lancet Oncology. COVID-19: global consequences for oncology. *Lancet Oncol* 2020 Apr;21(4):467 [FREE Full text] [doi: [10.1016/S1470-2045\(20\)30175-3](https://doi.org/10.1016/S1470-2045(20)30175-3)] [Medline: [32240603](https://pubmed.ncbi.nlm.nih.gov/32240603/)]
4. van de Haar J, Hoes LR, Coles CE, Seamon K, Fröhling S, Jäger D, et al. Caring for patients with cancer in the COVID-19 era. *Nat Med* 2020 May;26(5):665-671. [doi: [10.1038/s41591-020-0874-8](https://doi.org/10.1038/s41591-020-0874-8)] [Medline: [32405058](https://pubmed.ncbi.nlm.nih.gov/32405058/)]
5. Cinar P, Cox J, Kamal A, Bickel K, Krzyzanowska M, Armitage J, et al. Oncology Care Delivery in the COVID-19 Pandemic: An Opportunity to Study Innovations and Outcomes. *JCO Oncol Pract* 2020 Aug;16(8):431-434. [doi: [10.1200/OP.20.00326](https://doi.org/10.1200/OP.20.00326)] [Medline: [32463764](https://pubmed.ncbi.nlm.nih.gov/32463764/)]
6. Segelov E, Underhill C, Prenen H, Karapetis C, Jackson C, Nott L, et al. Practical Considerations for Treating Patients With Cancer in the COVID-19 Pandemic. *JCO Oncol Pract* 2020 Aug;16(8):467-482. [doi: [10.1200/OP.20.00229](https://doi.org/10.1200/OP.20.00229)] [Medline: [32401686](https://pubmed.ncbi.nlm.nih.gov/32401686/)]
7. Schrag D, Hershman DL, Basch E. Oncology Practice During the COVID-19 Pandemic. *JAMA* 2020 May 26;323(20):2005-2006. [doi: [10.1001/jama.2020.6236](https://doi.org/10.1001/jama.2020.6236)] [Medline: [32282023](https://pubmed.ncbi.nlm.nih.gov/32282023/)]
8. Dai M, Liu D, Liu M, Zhou F, Li G, Chen Z, et al. Patients with Cancer Appear More Vulnerable to SARS-CoV-2: A Multicenter Study during the COVID-19 Outbreak. *Cancer Discov* 2020 Jun;10(6):783-791 [FREE Full text] [doi: [10.1158/2159-8290.CD-20-0422](https://doi.org/10.1158/2159-8290.CD-20-0422)] [Medline: [32345594](https://pubmed.ncbi.nlm.nih.gov/32345594/)]
9. London JW, Fazio-Eynullayeva E, Palchuk MB, Sankey P, McNair C. Effects of the COVID-19 Pandemic on Cancer-Related Patient Encounters. *JCO Clin Cancer Inform* 2020 Jul;4:657-665 [FREE Full text] [doi: [10.1200/CCI.20.00068](https://doi.org/10.1200/CCI.20.00068)] [Medline: [32716647](https://pubmed.ncbi.nlm.nih.gov/32716647/)]
10. Liang W, Guan W, Chen R, Wang W, Li J, Xu K, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. *Lancet Oncol* 2020 Mar;21(3):335-337 [FREE Full text] [doi: [10.1016/S1470-2045\(20\)30096-6](https://doi.org/10.1016/S1470-2045(20)30096-6)] [Medline: [32066541](https://pubmed.ncbi.nlm.nih.gov/32066541/)]
11. Wang D, Hu B, Hu C, Zhu F, Liu X, Zhang J, et al. Clinical Characteristics of 138 Hospitalized Patients With 2019 Novel Coronavirus-Infected Pneumonia in Wuhan, China. *JAMA* 2020 Mar 17;323(11):1061-1069 [FREE Full text] [doi: [10.1001/jama.2020.1585](https://doi.org/10.1001/jama.2020.1585)] [Medline: [32031570](https://pubmed.ncbi.nlm.nih.gov/32031570/)]
12. Miyashita H, Mikami T, Chopra N, Yamada T, Chernyavsky S, Rizk D, et al. Do patients with cancer have a poorer prognosis of COVID-19? An experience in New York City. *Ann Oncol* 2020 Aug;31(8):1088-1089 [FREE Full text] [doi: [10.1016/j.annonc.2020.04.006](https://doi.org/10.1016/j.annonc.2020.04.006)] [Medline: [32330541](https://pubmed.ncbi.nlm.nih.gov/32330541/)]
13. Mehta V, Goel S, Kabarriti R, Cole D, Goldfinger M, Acuna-Villaorduna A, et al. Case Fatality Rate of Cancer Patients with COVID-19 in a New York Hospital System. *Cancer Discov* 2020 Jul;10(7):935-941 [FREE Full text] [doi: [10.1158/2159-8290.CD-20-0516](https://doi.org/10.1158/2159-8290.CD-20-0516)] [Medline: [32357994](https://pubmed.ncbi.nlm.nih.gov/32357994/)]
14. Kuderer NM, Choueiri TK, Shah DP, Shyr Y, Rubinstein SM, Rivera DR, COVID-19 and Cancer Consortium. Clinical impact of COVID-19 on patients with cancer (CCC19): a cohort study. *Lancet* 2020 Jun 20;395(10241):1907-1918 [FREE Full text] [doi: [10.1016/S0140-6736\(20\)31187-9](https://doi.org/10.1016/S0140-6736(20)31187-9)] [Medline: [32473681](https://pubmed.ncbi.nlm.nih.gov/32473681/)]
15. Schwamm LH, Erskine A, Licurse A. A digital embrace to blunt the curve of COVID19 pandemic. *NPJ Digit Med* 2020 May 04;3:64 [FREE Full text] [doi: [10.1038/s41746-020-0279-6](https://doi.org/10.1038/s41746-020-0279-6)] [Medline: [32377575](https://pubmed.ncbi.nlm.nih.gov/32377575/)]
16. Canadian Medical Association. Virtual Care In Canada: Discussion paper. CMA Health Summit. URL: https://www.cma.ca/sites/default/files/pdf/News/Virtual_Care_discussionpaper_v2EN.pdf [accessed 2020-11-13]
17. Meti N, Rossos PG, Cheung MC, Singh S. Virtual Cancer Care During and Beyond the COVID-19 Pandemic: We Need to Get It Right. *JCO Oncol Pract* 2020 Sep;16(9):527-529. [doi: [10.1200/OP.20.00281](https://doi.org/10.1200/OP.20.00281)] [Medline: [32401684](https://pubmed.ncbi.nlm.nih.gov/32401684/)]
18. Rising KL, Ward MM, Goldwater JC, Bhagianadh D, Hollander JE. Framework to Advance Oncology-Related Telehealth. *JCO Clin Cancer Inform* 2018 Dec;2:1-11 [FREE Full text] [doi: [10.1200/CCI.17.00156](https://doi.org/10.1200/CCI.17.00156)] [Medline: [30652582](https://pubmed.ncbi.nlm.nih.gov/30652582/)]
19. American Society of Clinical Oncology. Communication: What Do Patients Want and Need? *J Oncol Pract* 2008 Sep;4(5):249-253 [FREE Full text] [doi: [10.1200/JOP.0856501](https://doi.org/10.1200/JOP.0856501)] [Medline: [29452527](https://pubmed.ncbi.nlm.nih.gov/29452527/)]
20. Journey Mapping in Cancer Care Maps. BC Patient Safety & Quality Council. 2019 Feb 01. URL: <https://bcpsqc.ca/resource/journey-mapping-in-cancer-care-maps> [accessed 2020-11-13]
21. Pal SK, Katheria V, Hurria A. Evaluating the older patient with cancer: understanding frailty and the geriatric assessment. *CA Cancer J Clin* 2010;60(2):120-132 [FREE Full text] [doi: [10.3322/caac.20059](https://doi.org/10.3322/caac.20059)] [Medline: [20173172](https://pubmed.ncbi.nlm.nih.gov/20173172/)]
22. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004 Jan 24;363(9405):312-319. [doi: [10.1016/S0140-6736\(03\)15392-5](https://doi.org/10.1016/S0140-6736(03)15392-5)] [Medline: [14751707](https://pubmed.ncbi.nlm.nih.gov/14751707/)]

23. Baile WF, Buckman R, Lenzi R, Globler G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5(4):302-311 [FREE Full text] [doi: [10.1634/theoncologist.5-4-302](https://doi.org/10.1634/theoncologist.5-4-302)] [Medline: [10964998](https://pubmed.ncbi.nlm.nih.gov/10964998/)]
24. Adams RD. Virtual meeting 101: Body language tips for Zoom, Teams, and life. TechRepublic. 2020 Jul 10. URL: <https://www.techrepublic.com/article/virtual-meeting-101-body-language-tips-for-zoom-teams-and-life> [accessed 2020-11-13]
25. Selby P, Popescu R, Lawler M, Butcher H, Costa A. The Value and Future Developments of Multidisciplinary Team Cancer Care. *Am Soc Clin Oncol Educ Book* 2019 Jan;39:332-340 [FREE Full text] [doi: [10.1200/EDBK_236857](https://doi.org/10.1200/EDBK_236857)] [Medline: [31099640](https://pubmed.ncbi.nlm.nih.gov/31099640/)]
26. Rieger PT, Yarbro CH. Role of the Oncology Nurse. In: Kufe DW, Pollock RE, Weichselbaum RR, Bast RCJ, Gansler TS, Holland JF, et al, editors. Kufe DW, Pollock RE, Weichselbaum RR. editors. *Holland-Frei Cancer Medicine*. 6th edition. Hamilton (ON): BC Decker; 2003.
27. Harris KA, Nousiainen MT, Reznick R. Competency-based resident education-The Canadian perspective. *Surgery* 2020 Apr;167(4):681-684. [doi: [10.1016/j.surg.2019.06.033](https://doi.org/10.1016/j.surg.2019.06.033)] [Medline: [31431292](https://pubmed.ncbi.nlm.nih.gov/31431292/)]
28. Frank JR, Snell L, Englander R, Holmboe ES, ICBME Collaborators. Implementing competency-based medical education: Moving forward. *Med Teach* 2017 Jun;39(6):568-573. [doi: [10.1080/0142159X.2017.1315069](https://doi.org/10.1080/0142159X.2017.1315069)] [Medline: [28598743](https://pubmed.ncbi.nlm.nih.gov/28598743/)]
29. Virtual Care: Recommendations for Scaling Up Virtual Medical Services. Canadian Medical Association. 2020 Feb. URL: <https://www.cma.ca/sites/default/files/pdf/virtual-care/ReportoftheVirtualCareTaskForce.pdf> [accessed 2020-11-13]
30. Anthony BJ. Use of Telemedicine and Virtual Care for Remote Treatment in Response to COVID-19 Pandemic. *J Med Syst* 2020 Jun 15;44(7):132 [FREE Full text] [doi: [10.1007/s10916-020-01596-5](https://doi.org/10.1007/s10916-020-01596-5)] [Medline: [32542571](https://pubmed.ncbi.nlm.nih.gov/32542571/)]
31. Kruse CS, Karem P, Shifflett K, Vegi L, Ravi K, Brooks M. Evaluating barriers to adopting telemedicine worldwide: A systematic review. *J Telemed Telecare* 2018 Jan;24(1):4-12 [FREE Full text] [doi: [10.1177/1357633X16674087](https://doi.org/10.1177/1357633X16674087)] [Medline: [29320966](https://pubmed.ncbi.nlm.nih.gov/29320966/)]
32. Ozguroglu M, Sari O, Turna H. Devastating effects of chemotherapy: deafness and acute renal failure in a patient with epithelial ovarian cancer. *Int J Gynecol Cancer* 2006;16 Suppl 1:394-396. [doi: [10.1111/j.1525-1438.2006.00214.x](https://doi.org/10.1111/j.1525-1438.2006.00214.x)] [Medline: [16515631](https://pubmed.ncbi.nlm.nih.gov/16515631/)]
33. Kichloo A, Albosta M, Dettloff K, Wani F, El-Amir Z, Singh J, et al. Telemedicine, the current COVID-19 pandemic and the future: a narrative review and perspectives moving forward in the USA. *Fam Med Community Health* 2020 Aug;8(3) [FREE Full text] [doi: [10.1136/fmch-2020-000530](https://doi.org/10.1136/fmch-2020-000530)] [Medline: [32816942](https://pubmed.ncbi.nlm.nih.gov/32816942/)]
34. Moorman BA, Cockle RA. Medical device integration using mobile telecommunications infrastructure. *Biomed Instrum Technol* 2013;47(3):224-232. [doi: [10.2345/0899-8205-47.3.224](https://doi.org/10.2345/0899-8205-47.3.224)] [Medline: [23692108](https://pubmed.ncbi.nlm.nih.gov/23692108/)]
35. Nord G, Rising KL, Band RA, Carr BG, Hollander JE. On-demand synchronous audio video telemedicine visits are cost effective. *Am J Emerg Med* 2019 May;37(5):890-894. [doi: [10.1016/j.ajem.2018.08.017](https://doi.org/10.1016/j.ajem.2018.08.017)] [Medline: [30100333](https://pubmed.ncbi.nlm.nih.gov/30100333/)]

Edited by G Eysenbach; submitted 10.09.20; peer-reviewed by F Holl, Z Su; comments to author 29.09.20; revised version received 08.11.20; accepted 10.11.20; published 24.11.20.

Please cite as:

Levine OH, McGillion M, Levine M

Virtual Cancer Care During the COVID-19 Pandemic and Beyond: A Call for Evaluation

JMIR Cancer 2020;6(2):e24222

URL: <http://cancer.jmir.org/2020/2/e24222/>

doi: [10.2196/24222](https://doi.org/10.2196/24222)

PMID: [33180741](https://pubmed.ncbi.nlm.nih.gov/33180741/)

©Oren Hannun Levine, Michael McGillion, Mark Levine. Originally published in *JMIR Cancer* (<http://cancer.jmir.org>), 24.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Cancer*, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

The Tablet-Based, Engagement, Assessment, Support, and Sign-Posting (EASSi) Tool for Facilitating and Structuring Sexual Well-Being Conversations in Routine Prostate Cancer Care: Mixed-Methods Study

Eilís McCaughan¹, PhD; Carrie Flannagan¹, PhD; Kader Parahoo¹, PhD; John Connaghan², MSc; Roma Maguire², PhD; Mary Steele³, PhD; Samantha Thompson⁴, BSc; Suneil Jain^{5,6}, MB, BAO, MCRP, FRCP, PhD; Michael Kirby^{7,8}, MBBS, FRCP; Nuala Brady⁹, PhD; Seán R O'Connor¹⁰, PhD

¹Institute of Nursing & Health Research, Ulster University, Newtownabbey, United Kingdom

²Department of Computing and Information Sciences, University of Strathclyde, Glasgow, United Kingdom

³Faculty of Social and Human Sciences, Centre for Clinical and Community Applications of Health Psychology, University of Southampton, Southampton, United Kingdom

⁴Urology Department, Belfast City Hospital, Belfast, United Kingdom

⁵Centre for Cancer Research and Cell Biology, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, Belfast, United Kingdom

⁶Clinical Oncology, Northern Ireland Cancer Centre, Belfast City Hospital, Belfast, United Kingdom

⁷Faculty of Health and Human Sciences, University of Hertfordshire, Hatfield, United Kingdom

⁸The Prostate Centre, London, United Kingdom

⁹Northern Health and Social Care Trust, Antrim, United Kingdom

¹⁰Centre for Public Health, Royal Victoria Hospital, Queen's University Belfast, Belfast, United Kingdom

Corresponding Author:

Eilís McCaughan, PhD

Institute of Nursing & Health Research

Ulster University

Shore Road

Newtownabbey, BT37 0QB

United Kingdom

Phone: 44 2870124091

Email: em.mccaughan@ulster.ac.uk

Abstract

Background: Long-term side-effects associated with different prostate cancer treatment approaches are common. Sexual challenges are the most frequently occurring issues and can result in increased psychological morbidity. It is recognized that barriers to communication can make initiating discussions around sexual concerns in routine practice difficult. Health care professionals need to routinely initiate conversations, effectively engage with patients, and assess needs in order to provide essential support. One proposed method that could support health care professionals to do this involves the use of prompts or structured frameworks to guide conversations.

Objective: This study aimed to assess feasibility, acceptability, and satisfaction with the tablet-based Engagement, Assessment, Support, and Sign-posting (EASSi) tool designed to facilitate and structure sexual well-being discussions in routine prostate cancer care.

Methods: Health care professionals (n=8) used the EASSi tool during 89 posttreatment appointments. Quantitative data were recorded based on program usage and surveys completed by health care professionals and patients. Qualitative data exploring perceptions on use of the tool were gathered using semistructured interviews with all health care professionals (n=8) and a sample of patients (n=10).

Results: Surveys were completed by health care professionals immediately following each appointment (n=89, 100%). Postal surveys were returned by 59 patients (66%). Health care professionals and patients reported that the tool helped facilitate discussions (81/89, 91% and 50/59, 85%, respectively) and that information provided was relevant (82/89, 92% and 50/59, 85%, respectively).

The mean conversation duration was 6.01 minutes (SD 2.91). Qualitative synthesis identified the tool's ability to initiate and structure discussions, improve the "depth" of conversations, and normalize sexual concerns.

Conclusions: The EASSi tool was appropriate and acceptable for use in practice and provided a flexible approach to facilitate routine brief conversations and deliver essential sexual well-being support. Further work will be conducted to evaluate the effectiveness of using the tablet-based tool in prostate cancer care settings.

(*JMIR Cancer* 2020;6(2):e20137) doi:[10.2196/20137](https://doi.org/10.2196/20137)

KEYWORDS

prostate cancer; sexual well-being; quality of life; communication

Introduction

Background

Prostate cancer is the single most common cancer among men [1,2], and long-term side-effects associated with different treatment approaches are common [3]. Sexual challenges are the most frequently occurring sequelae [4,5], with rates of sexual dysfunction having a moderate to severe impact on quality of life of 31%-64% reported after radical prostatectomy and external beam radiotherapy [6,7]. In a recent large-scale survey, 81% of men reported poor sexual function after treatment [8]. Changes to sexual function are subsequently regarded as a major issue that can result in higher levels of anxiety, depression, relational dissatisfaction, and reduced overall quality of life [9,10]. Current guidelines [11,12] support delivery of psychosexual care for prostate cancer patients and recommend a minimal level of support throughout all phases of care. This includes provision of information tailored to needs, advice about potential adverse effects of treatment, and ongoing access to specialist services including erectile dysfunction clinics. Despite this, sexual aspects of recovery are often not discussed [13-15], and services are not provided consistently across settings. Men frequently report that they do not receive adequate information and support to manage sexual concerns. This has been associated with increased psychological morbidity [16,17].

It is recognized that initiating discussions around sexual concerns in routine practice can be problematic [18-20]. Health care professionals can regard patients' sexual lives as being too personal to ask about [21,22] and may feel unequipped to deal with sexual issues, reporting a lack of resources to offer patients if they identify a problem [23]. There is evidence that attitudinal barriers and beliefs can lead health care professionals to actively avoid initiating discussions [24]. Fear of personal embarrassment or fear of causing offence and uncertainty over whose role it is to discuss sexual issues have been identified as possible reasons for the low profile of sexual concerns [20]. Men can also feel uncertain about discussing concerns and may not be fully aware of the potential side-effects of treatment on sexual function. Despite these barriers, given their frequency and substantial impact [9], sexual concerns should be discussed with all patients. To adequately address sexual well-being issues, health care professionals need to initiate conversations and effectively engage with patients and assess needs in order to provide essential support and appropriate evidence-based management [25]. One proposed method that could support health care professionals to do this is the use of prompts or structured frameworks to guide conversations [26,27]. This approach may

enhance patient-provider communication, particularly around complex or sensitive sexual issues by ensuring a more standardized provision of information [28].

Objectives

The systematically developed online Engagement, Assessment, Support, and Sign-posting (EASSi) tool was designed to facilitate and structure brief sexual well-being discussions in routine prostate cancer care. An iterative and theory-based process modeled on the person-based approach was used to inform development, design, and testing of the tool [29]. This method was primarily used to ensure that development was in close collaboration with end users and to optimize acceptability, feasibility, and engagement. The EASSi tool, based on a previously published conceptual framework [30], is accessed via a tablet device and includes approximately 15 to 20 "pages" with large text on a screen. The text is intended to be viewed by both the health care professional and the patient and used as part of a shared conversation. The tool's programming uses algorithms to provide information tailored to treatment type and partner status. An accompanying printed sign-posting sheet is also included to provide personalized support resources. The aim of this study was to assess the feasibility and acceptability of the tablet-based EASSi tool, and health care professional and patient satisfaction with the tool in routine prostate cancer care settings.

Methods

Study Design

A mixed-methods approach was employed according to program usage data and surveys completed by health care professionals and men with prostate cancer following use of the EASSi tool. A minimum sample size of 50 appointments was selected a priori to ensure sufficient data were gathered. Additional qualitative data exploring user perceptions were also gathered using in-depth semistructured interviews with the health care professionals and a randomly selected sample of patients. For the qualitative component, recommendations of the consolidated criteria for reporting qualitative research (COREQ) were followed [31]. Interviews were led by a researcher with extensive experience in conducting cancer research (EMcC).

Study Population and Setting

Participants were health care professionals working in prostate cancer care and men attending routine appointments as part of treatment or follow-up. No exclusions were applied to age, treatment type, stage of the disease (for patients), or years of

clinical experience (for health care professionals). Written informed consent was obtained from all participants. Ethical approval for the study was provided via the Office for Research Ethics Committees Northern Ireland (ORECNI) (reference number: 17/NI/014).

Data Collection

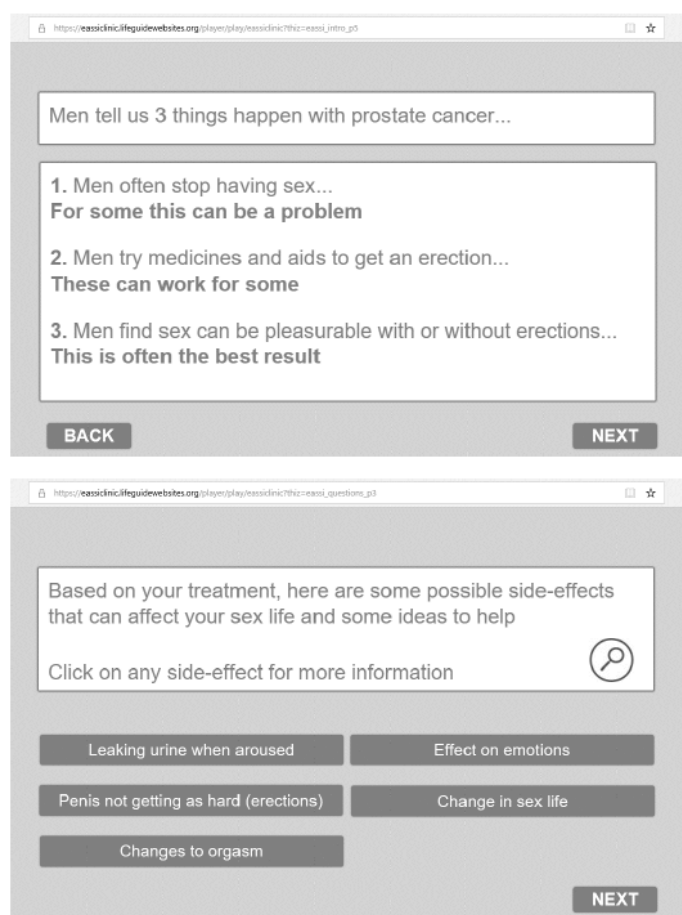
The EASSi tool was built using “LifeGuide” open source software [32]. Components and design features of the tool are summarized in Figure 1. Figure 2 includes screenshots of the EASSi tool. Of the four sections included, the “Engagement” section is focused on ensuring that routine sexual well-being discussions take place, acknowledging that sexual issues are

not easy to discuss, and recognizing that associated side-effects of treatment can have a substantial impact. The “Assessment” section includes questions on treatment type and relationship status to provide tailored support based on responses to these “nonsensitive” questions. The “Support” section aims to provide appropriate information on common sexual challenges (relevant to treatment and relationship status). It also aims to normalize these issues and provide information on coping strategies. Lastly, the “Sign-posting” section provides details relating to other supports, including online self-management, erectile dysfunction clinic information, and resources specific to individual needs (such as information on online support groups for men).

Figure 1. Purpose and outline content of the Engagement, Assessment, Support, and Sign-Posting (EASSi) tool.

Section	Rationale and purpose	Outline content
Engagement	Sexual challenges are a major problem and are often not addressed Section used to: <ul style="list-style-type: none"> - Ensure healthcare professionals take the lead in initiating conversations with all men - Normalise sexual concerns - Explain that a brief conversation about sex and prostate cancer will take place 	Includes explanation that: <ul style="list-style-type: none"> - Sex can be a difficult subject which is not easy to talk about, but it is an important part of life - At the end a sheet will be provided with more detailed information and resources
Assessment	Basic assessment is needed to provide tailored support Section used to: <ul style="list-style-type: none"> - Ask about treatment type - Stage of treatment - Relationship status 	Section asks three questions including: Have you had any of the following treatments? <ol style="list-style-type: none"> 1. Radiotherapy 2. Hormone therapy 3. Surgery 4. Combined radio and hormone therapy
Support	There are many sexual side-effects of treatment but also things that can help Section used to: <ul style="list-style-type: none"> - Provide information on expected sexual challenges - Acknowledge sex life will change - Give brief advice on... What can be done Widening understanding of sex 	Section provides advice (based on treatment) including: List of possible side-effects and some ideas to help. For example: Hormone side-effect 1: Less interest in having sex Advice: <ul style="list-style-type: none"> - The treatment affects the level of testosterone in your body - This has an effect on your sex drive - Even if you have less sex drive, you can still feel pleasure And gives other advice on: <ul style="list-style-type: none"> - need to think about sex in new ways, try new things and have patience and persistence
Sign-posting	After providing essential support need to signpost to other services Section used to: <ul style="list-style-type: none"> - Point towards additional resources or services 	Section includes provision of printed sign-posting sheet including: <ul style="list-style-type: none"> - Online self-management resource - Other information and support resources to address sexual challenges - Useful tips and exercises

Figure 2. Screenshots showing pages from the "Engagement" and "Support" sections of the tablet-based Engagement, Assessment, Support, and Sign-Posting (EASSi) tool.



All health care professionals received a standardized 30-minute familiarization and training program in use of the tool. During the evaluation, researchers working at each clinical site (CF and JC) set up the tablet (a 9-inch screen Samsung Galaxy Tab A, Android tablet) prior to each patient appointment. They then entered a unique nonidentifiable study identification and gave the tablet to the health care professional. Consecutive patients from clinic lists at four primary and secondary care sites within three National Health Service Trusts in Northern Ireland and Scotland were identified. The EASSi tool was then used as part of a discussion about sexual well-being issues following treatment. Health care professionals completed the brief survey at the end of the tool immediately after each use. Patient participants were provided with a pack containing an evaluation survey and a stamped addressed envelope for return and were asked to return the survey within 1 week of the appointment.

Analysis

Data were gathered from program usage analytics and from postappointment surveys on usability and usefulness completed by all participants. Patients also completed a survey on sexual well-being attitudes and beliefs. Survey responses were based on four or nine-point Likert scales indicating level of agreement with each statement or question. Data were imported into SPSS Statistics for Windows version 25 (IBM Corp), which was used to perform a descriptive analysis.

Qualitative data were collected from follow-up, telephone, or face-to-face interviews conducted in quiet nonclinical rooms within a hospital setting. All interviews were conducted within 1 week of the appointment. Semistructured interview schedules were developed based on previous research [33]. These consisted of open-ended questions focused on exploring the experience of using the EASSi tool. Interviews were audio recorded and transcribed verbatim. Field notes were also recorded. These were summarized to support analysis and interpretation of data and were sent to participants for review on request. Reflexive thematic analysis was used to synthesize data [34]. Feasibility and acceptability were examined using program usage data (including duration of discussions and pages viewed), as well as responses to quantitative survey questions, which were reported as mean values and percentage agreement scores. Satisfaction with use of the EASSi tool was assessed using qualitative findings from the open-ended survey questions and from the interviews that explored participant experiences of use.

Results

Participant Characteristics

Eight health care professionals (three urology and oncology specialist nurses, one well-being nurse, two oncology doctors, a general practitioner, and a cancer support worker) used the EASSi tool during consecutive patient appointments. For a small

number of appointments (5/94, 5%), the health care professional deemed it unsuitable to use the EASSi tool as the patient was medically unstable or was attending the appointment with a family member (other than a partner). The EASSi tool was therefore used during 89 patient appointments. Of these, 53 were at clinical sites in Northern Ireland (primary care: n=4; secondary care: n=49) and 36 were at sites in Scotland (secondary care: n=26; posttreatment well-being clinics: n=10). Twenty-six patients (29%) had surgical treatment only, with the majority having had surgery within the past 6 months (n=22, 85%). Seven patients (8%) had or were receiving radiotherapy, while 9 (10%) were on ongoing hormone therapy only. The remainder (n=47, 53%) had or were receiving combined radiotherapy and hormone therapy. Most patients reported having had no previous sexual care discussions with a health care professional (n=52, 58%). The majority had a partner (n=83, 93%).

Program Usage Data

The mean duration of conversations that took place using the EASSi tool was 6.01 minutes (SD 2.91), ranging from 2.62 to 11.74 minutes. The greatest amount of time was spent in the "Support" section (3.32 minutes, SD 1.12), with 1.03 minutes (SD 0.74) spent in the "Engagement" section, 0.59 minutes (SD 0.33) spent in the "Assessment" section, and 1.23 minutes (SD 0.74) spent in the "Sign-posting" section. Approximately two side-effect pages were viewed during each use; however, this number ranged from 0 to 6. The most frequently viewed side-effect pages were on "loss of erections" and "loss of interest in sex." No technical issues with use of the tablet were identified during use.

Postappointment Survey Findings

Surveys completed after use (n=89 appointments) indicated that health care professionals viewed the EASSi tool as being valuable for helping to talk about sexual well-being (mean score 7.7/9, SD 1.3; 91% agreement) and for providing relevant information to the patient (mean score 7.1/9, SD 1.5; 92% agreement). The tool was also viewed as simple to use (mean score 8.3/9, SD 0.9; 98% agreement). Thirty patients did not return their postal surveys, and evaluation data were therefore available for 59 (66%) of the 89 patients who took part in a sexual well-being discussion using the EASSi tool. Patient surveys also indicated that the tool was seen as helping the sexual well-being discussion (mean score 3.4/4, SD: 0.8; 85% agreement) and providing relevant information (mean score 3.3/4, SD 0.7; 85% agreement). While free text comments made by health care professionals and patients in the survey also indicated that the EASSi tool was seen as useful, there were differing perspectives. For example, after some appointments, health care professionals reported that the tool was less useful as the patient was "not concerned" about sexual issues, whereas patients (commenting on the same appointment) were typically more positive, stating how valuable the conversation was (Table 1). This was further supported by other data from the surveys, which indicated that patients agreed with the statement that talking about sexual well-being was important to them (mean score 3.5/4, SD 0.5; 88% agreement). The additional survey questions around sexual attitudes and beliefs identified that patients disagreed with the statement that they were uncomfortable discussing sexual well-being during appointments (mean score 1.8/4, SD 1.4; 46% agreement) (Table 2).

Table 1. Examples from individual appointments demonstrating where the perspectives of health care professionals and patients on “usefulness” of the EASSi tool differed or were consistent.

Health care professional views on “usefulness” of the discussion	Patient views on the same discussion	Views differed (-) or were consistent (+)
“...patient and his wife expressed they were not concerned about absent sexual function” [Clinical nurse specialist, Uro-oncology]	“I read through the information on the tablet and found it informative” [6 months after radiotherapy, ongoing hormone therapy, has a current partner]	-
“...patient was keen to focus on fatigue and emotions rather than sexual function” [Clinical nurse specialist, Surgical oncology]	“it was useful finding out about side-effects on your sex life in general, including the information on erectile dysfunction” [less than 6 months after radiotherapy, ongoing hormone therapy, no current partner]	-
“...patient was not sexually active and not really concerned about sex life at all” [Clinical nurse specialist, Uro-oncology]	“dealing with the nurse about sex was far more informative and helpful than dealing with the doctor. I could have done with this type of appointment when first diagnosed” [more than 6 months after radiotherapy, ongoing hormone therapy, has a current partner]	-
“...they were not concerned. They were able to get erections, with dry orgasms” [Clinical nurse specialist, Urology]	“...it made the discussion easier, especially around lack of sex drive and the problems resulting from treatment. The conversation could have actually been longer” [more than 6 months after radiotherapy, ongoing hormone therapy, has a current partner]	-
“...it was very useful, it made discussing the topic easier and covered more depth and detail. Very easy to discuss delicate area” [General practitioner]	“...it helped with understanding the positives of aftercare after prostate cancer and with knowing there is good support after surgery. The info provided was helpful” [more than 6 months after surgery, has a current partner]	+
“...it prompted me to suggest getting more advice from the GP and ask about a trial of a PDE5 inhibitor” [Clinical nurse specialist, Uro-oncology]	“...getting the tablet explained was good, it helped a lot” [less than 6 months after radiotherapy, has a current partner]	+
“...This gentleman was very open to the discussion and use of the technology to assist the conversation. Made conversation easier. He recognized himself in the issues presented” [Nurse, Oncology]	“...having read all the literature given to me at the start (several times) I knew what to expect but it is helpful to discuss where you are and to set yourself some goals” [less than 6 months after radiotherapy, has a current partner]	+

Table 2. Mean scores and percentage agreement for statements exploring patient sexual attitudes and beliefs.

Question	Score (/4) ^a , mean (SD)	Percentage agreement
I understand how my treatment for prostate cancer might affect my sexual well-being	3.5 (1.1)	89
I am uncomfortable talking about sexual issues with health care professionals	1.8 (1.4) ^b	46
Health care professionals should make time to discuss sexual well-being with me	3.2 (1.2)	80
I feel confident that health care professionals have the ability to address my sexual concerns	3.4 (1.1)	85
Discussing sexual well-being is essential to my health outcomes	3.1 (1.3)	78
Some health care professionals are more comfortable talking about sexual issues with me than others	2.1 (1.2)	53
I expect health care professionals to ask me about my sexual concerns	3.2 (1.3)	80

^aScore of 1, strongly disagree; 2, disagree; 3, agree; 4, strongly agree.

^bIndicates disagreement with the statement.

Qualitative Interview Findings

Semistructured interviews were held with all eight health care professionals who used the tool and with a randomly selected

sample of men (n=10). Interviews lasted approximately 1 hour. The analysis identified three key themes around use of the EASSi tool.

Theme 1: Moving From Optional to Routine Conversations

Health Care Professionals

Health care professionals acknowledged that using the EASSi tool increased the frequency with which they discussed sexual well-being and that it had an immediate positive impact by enabling easier initiation of discussions with a wider group of patients, including those they might not have conversations with if not using the tool. They also observed that conversations were associated with less awkwardness than they had expected. While some felt there were still men for whom it would be inappropriate to discuss sexual well-being, it was reflected upon by others that this represented a degree of “gate-keeping,” which could be used as a mechanism to avoid initiating conversations. Health care professionals found that the purposeful design of the tool helped to “manage” the conversation and provided a mechanism to direct the conversation, ensuring greater consistency and leading to a less “ad-hoc” approach when discussing sexual concerns with patients.

Patients

Patients welcomed the discussion, stating how it was presented in a comfortable and professional manner. Patients also recognized how the role of the partner was acknowledged using the tool. They also stated that the tablet format was straightforward, and they valued the limited words on the screen. One patient made the following statement:

Actually, it was very easy to follow, just a few words on each screen... we could stop and discuss anything at any time point. [Patient #7, male]

Theme 2: Improving Depth of Conversations and Support Provided

Health Care Professionals

Health care professionals found that the tool enhanced conversations and facilitated a “higher level” of patient involvement. It was acknowledged that before using the EASSi tool, sexual issues were often not discussed during appointments or were only addressed superficially by providing limited information on erectile dysfunction. Health care professionals described how a greater “depth” of information was provided, including simple but clear information on how patients’ sexual lives could be impacted and practical advice on how to manage these issues. Expectations around recovery were addressed and a wider understanding of intimacy was introduced, moving away from a focus on erectile dysfunction only. One professional commented as follows:

...without using [it] today the value of the consultation would have been hugely inferior. [Consultant urologist, male]

Some health care professionals described how discussions were “collaborative” and provided more than just delivery of information. The pages outlining treatment side-effects were seen as being the most interactive element, introducing an opportunity for patients to “take the lead” in identifying side-effects of interest to them. Following the first use, health care professionals reported becoming more confident using the

tool, integrating it into practice, sharing the screen with patients, and adapting the content to suit their own communication style. There were practical issues reported. For example, some men did not have their glasses with them or were reluctant to read the screen. Such issues were often compensated for by the health care professional taking a greater lead in the discussion.

The “Sign-posting” pages and accompanying printed hand-out were regarded as important components by health care professionals. Their value was seen in terms of the ability to direct patients toward resources appropriate to their needs and advice to “get started.” They were also seen as a useful “prompt or reminder,” reinforcing key messages from the discussion.

Patients

Patients reported that conversations were useful and straightforward. For some, it was the first meaningful discussion about the sexual consequences of treatment. One patient commented as follows:

Apart from before treatment when I was told that my erections would go, nobody has mentioned the sex thing. After chatting to the nurse last Friday using the computer, I was able to better understand why I was feeling so different. [Patient #9, male]

Some reported that the tool provided a “sense of control” by selecting information that was most relevant to them. One patient commented as follows:

I could press what buttons I wanted...I never would have asked out loud about dry orgasms! [Patient #2, male]

Others indicated that they felt comfortable just listening to the health care professional. One patient commented as follows:

Sex is not something that bothers me at the moment but I'm glad it was mentioned, and I think it should be talked about. [Patient #6, male]

Theme 3: Normalizing Sexual Well-Being Issues in Routine Practice

Health Care Professionals

Health care professionals described how the EASSi tool and discussing sexual well-being routinely had alerted them to how important sexual well-being care is. They described how discussions being a standard aspect of care might result in men being more comfortable with initiating future discussions. Examples of this included patients being more able to seek out further information (from the sign-posting sheet) or discuss issues with other health care professionals, even after active treatment. One professional made the following comment:

It might not be right now, but they now know that they can talk about it with you. [Specialist oncology nurse, female]

For more experienced clinicians, the EASSi tool was regarded as a way of embedding sexual well-being conversations into routine practice. Having used the tool with several patients, one professional made the following statement:

Providing information about sexual care simply needs to be something that everyone in the clinic just knows and that we do it as routine. [Consultant urologist, male]

Patients

Overall, patients felt that the tool helped “normalize” sexual issues, treating the topic in the same way as other symptoms. They also felt reassured that their experiences were not unique and were more common than they previously thought.

Discussion

Principal Findings

This study evaluated a systematically developed tool designed to facilitate and structure sexual well-being discussions in prostate cancer care. The tablet-based EASSi tool was used as part of sexual well-being conversations in primary and secondary care settings. Overall, health care professionals and patients found the tool to be acceptable and appropriate and were satisfied with its use during appointments. It was found to facilitate brief but meaningful discussions that were feasible as part of routine appointments by providing a “standardized” mechanism to initiate discussions, ensuring that sexual well-being was consistently raised as a topic. It was also reported that the tool was useful for improving overall communication around sexual well-being through provision of fundamental information and support tailored to treatment and relationship status. Health care professionals and patients did have contrasting perspectives around the need for use of the tool. There was evidence that some health care professionals may have underestimated and downplayed the value of the sexual well-being discussions to patients, who regarded the discussions as valuable and important. Patients also highlighted some regret that they had not had similar discussions prior to or earlier in treatment. While there are valid clinical reasons why a sexual well-being discussion might not take place during an appointment, for example, high levels of patient distress and medical instability, “gate-keeping” or assumptions about readiness or willingness to discuss sexual issues can lead to patients not receiving appropriate information and support [35]. Ensuring that discussions occur routinely should be an important part of supporting patients to manage alterations to sexual function and expectations around recovery [16,36].

Strengths and Limitations

The particular strengths of the EASSi tool were that it was concise and simple to use, included an engagement section to initiate conversations in a standard manner that limited potential embarrassment, used “nonsensitive” language throughout, and provided support based on individual need. Onward referral to other more specialist services included within the “Sign-posting” section alongside other readily accessible support options was also seen as valuable. Another perceived strength of the tool was its flexibility, with scope to facilitate a brief conversation or be used as a part of a more involved discussion. A limitation of the study was that the perspectives of the 30 (34%) patients

who did not return the evaluation survey after the appointment were unknown.

Study Implications

This evaluation provides initial support for use of the EASSi tool in practice. Findings indicated that the tool was appropriate and acceptable for use and promoted delivery of routine sexual care for men with prostate cancer. The EASSi tool incorporates components aimed at ensuring that discussions are more routine and that essential support is provided as part of prostate cancer care. These techniques include changes to the physical environment (the tablet device itself), as well as delivery of appropriate information and the use of patient prompts in the form of a printed handout used to reinforce key messages and point to effective evidence-based self-management resources. The theoretical underpinning of the EASSi tool may be similar to models, such as the 5 A’s approach (ask, assess, advise, agree, and assist), which have been used as frameworks to initiate, standardize, and guide brief behavior change interventions [37]. The tool can be used across settings and without specific training or expertise in sexual care counselling. In addition, the tool might be used during pretreatment consultations to assist with improving a patient’s awareness of the possible impact of different treatment options on sexual well-being and to reduce decisional regret, which is often experienced when patients feel they had a passive role in treatment decision-making [9,38]. The tool could also be viewed by patients alone (not only during appointments with a health professional) to help provide information on the side-effects of treatment and on approaches to help manage these effects. One other potential application that could be explored further is use of the tool to structure sexual well-being conversations during remote appointments delivered via telephone or videoconferencing facilities [39].

The tool was identified as being useful for addressing barriers to sexual well-being discussions and supporting health care professionals to initiate discussions by facilitating brief discussions that normalized sexual issues and provided patients with essential support. The findings do suggest that health care professionals may underestimate how important sexual well-being discussions are for patients. Additional research should be conducted to help health care professionals explore their views on sexual issues and overcome barriers to discussing sexual well-being with patients. Further work will also be conducted to evaluate the effectiveness of using the tool in different cancer care settings.

Conclusions

The EASSi tool may provide a practical format to guide routine sexual well-being discussions in clinical practice. The tool also includes tangible take home messages for prostate cancer survivors in the form of a printed “sign-posting” sheet. Use of the tool in practice may promote increased engagement around sexual well-being to ensure fundamental support is provided to men and their partners. This could potentially address current gaps in the lack of routine provision of sexual well-being support for men living with prostate cancer.

Acknowledgments

The authors would like to thank the Movember Foundation and Prostate Cancer UK for providing funding and support for the TrueNORTH maximizing sexual well-being project, which this study is a part of. Additional funding was provided by the HSC Research & Development Division, Northern Ireland. The funders had no role in study design, data collection and analysis, or preparation of the manuscript. The intervention was developed using the LifeGuide software, which was partly funded by the National Institute for Health Research Southampton Biomedical Research Centre.

Conflicts of Interest

None declared.

References

1. Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin* 2019 Sep 11;69(5):363-385 [FREE Full text] [doi: [10.3322/caac.21565](https://doi.org/10.3322/caac.21565)] [Medline: [31184787](https://pubmed.ncbi.nlm.nih.gov/31184787/)]
2. Pishgar P, Ebrahimi E, Saeedi Moghaddam S, Fitzmaurice C, Amini E. Global, Regional and National Burden of Prostate Cancer, 1990 to 2015: Results from the Global Burden of Disease Study 2015. *J Urol* 2018 May;199(5):1224-1232. [doi: [10.1016/j.juro.2017.10.044](https://doi.org/10.1016/j.juro.2017.10.044)] [Medline: [29129779](https://pubmed.ncbi.nlm.nih.gov/29129779/)]
3. Donovan JL, Hamdy FC, Lane JA, Mason M, Metcalfe C, Walsh E, et al. Patient-Reported Outcomes after Monitoring, Surgery, or Radiotherapy for Prostate Cancer. *N Engl J Med* 2016 Oct 13;375(15):1425-1437. [doi: [10.1056/nejmoa1606221](https://doi.org/10.1056/nejmoa1606221)]
4. Wong MC, Goggins WB, Wang HH, Fung FD, Leung C, Wong SY, et al. Global Incidence and Mortality for Prostate Cancer: Analysis of Temporal Patterns and Trends in 36 Countries. *Eur Urol* 2016 Nov;70(5):862-874. [doi: [10.1016/j.eururo.2016.05.043](https://doi.org/10.1016/j.eururo.2016.05.043)] [Medline: [27289567](https://pubmed.ncbi.nlm.nih.gov/27289567/)]
5. Haahr MK, Azawi NH, Andersen LG, Carlson S, Lund L. A Retrospective Study of Erectile Function and Use of Erectile Aids in Prostate Cancer Patients After Radical Prostatectomy in Denmark. *Sex Med* 2017 Sep;5(3):e156-e162 [FREE Full text] [doi: [10.1016/j.esxm.2017.06.003](https://doi.org/10.1016/j.esxm.2017.06.003)] [Medline: [28778680](https://pubmed.ncbi.nlm.nih.gov/28778680/)]
6. Gaither TW, Awad MA, Osterberg EC, Murphy GP, Allen IE, Chang A, et al. The Natural History of Erectile Dysfunction After Prostatic Radiotherapy: A Systematic Review and Meta-Analysis. *J Sex Med* 2017 Sep;14(9):1071-1078. [doi: [10.1016/j.jsxm.2017.07.010](https://doi.org/10.1016/j.jsxm.2017.07.010)] [Medline: [28859870](https://pubmed.ncbi.nlm.nih.gov/28859870/)]
7. Brundage M, Sydes MR, Parulekar WR, Warde P, Cowan R, Bezjak A, et al. Impact of Radiotherapy When Added to Androgen-Deprivation Therapy for Locally Advanced Prostate Cancer: Long-Term Quality-of-Life Outcomes From the NCIC CTG PR3/MRC PR07 Randomized Trial. *JCO* 2015 Jul 01;33(19):2151-2157. [doi: [10.1200/jco.2014.57.8724](https://doi.org/10.1200/jco.2014.57.8724)]
8. Downing A, Wright P, Hounsome L, Selby P, Wilding S, Watson E, et al. Quality of life in men living with advanced and localised prostate cancer in the UK: a population-based study. *The Lancet Oncology* 2019 Mar;20(3):436-447. [doi: [10.1016/s1470-2045\(18\)30780-0](https://doi.org/10.1016/s1470-2045(18)30780-0)]
9. Talvitie A, Ojala H, Tammela T, Koivisto A, Pietilä I. Factors related to self-rated health and life satisfaction one year after radical prostatectomy for localised prostate cancer: a cross-sectional survey. *Scand J Caring Sci* 2019 Sep 13;33(3):688-697. [doi: [10.1111/scs.12664](https://doi.org/10.1111/scs.12664)] [Medline: [30866074](https://pubmed.ncbi.nlm.nih.gov/30866074/)]
10. Ross L, Rottmann N, Andersen KK, Hoybye MT, Johansen C, Dalton SO. Distress after a psychosocial cancer rehabilitation course. Main effects and effect modification in a randomised trial at 12 months of follow-up. *Acta Oncologica* 2015 Mar 09;54(5):735-742. [doi: [10.3109/0284186x.2014.998278](https://doi.org/10.3109/0284186x.2014.998278)]
11. Prostate cancer: diagnosis and management. National Institute for Health and Care Excellence. URL: <https://www.nice.org.uk/guidance/ng131> [accessed 2019-07-01]
12. Resnick MJ, Lacchetti C, Penson DF. Prostate Cancer Survivorship Care Guidelines: American Society of Clinical Oncology Practice Guideline Endorsement. *JOP* 2015 May;11(3):e445-e449. [doi: [10.1200/jop.2015.004606](https://doi.org/10.1200/jop.2015.004606)]
13. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? *Psychooncology* 2015 Sep 22;24(9):1167-1173. [doi: [10.1002/pon.3736](https://doi.org/10.1002/pon.3736)] [Medline: [25534170](https://pubmed.ncbi.nlm.nih.gov/25534170/)]
14. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology* 2012 Jun 10;21(6):594-601 [FREE Full text] [doi: [10.1002/pon.1947](https://doi.org/10.1002/pon.1947)] [Medline: [21394821](https://pubmed.ncbi.nlm.nih.gov/21394821/)]
15. Ussher JM, Perz J, Gilbert E, Wong WT, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. *Psychol Health* 2013 Dec;28(12):1370-1390. [doi: [10.1080/08870446.2013.811242](https://doi.org/10.1080/08870446.2013.811242)] [Medline: [23805956](https://pubmed.ncbi.nlm.nih.gov/23805956/)]
16. Almont T, Farsi F, Krakowski I, El Osta R, Bondil P, Huyghe E. Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. *Support Care Cancer* 2019 Mar 14;27(3):887-894. [doi: [10.1007/s00520-018-4376-x](https://doi.org/10.1007/s00520-018-4376-x)] [Medline: [30109489](https://pubmed.ncbi.nlm.nih.gov/30109489/)]

17. Albaugh JA, Sufrin N, Lapin BR, Petkewicz J, Tenfelde S. Life after prostate cancer treatment: a mixed methods study of the experiences of men with sexual dysfunction and their partners. *BMC Urol* 2017 Jun 15;17(1):45 [FREE Full text] [doi: [10.1186/s12894-017-0231-5](https://doi.org/10.1186/s12894-017-0231-5)] [Medline: [28619019](https://pubmed.ncbi.nlm.nih.gov/28619019/)]
18. Annerstedt CF, Glasdam S. Nurses' attitudes towards support for and communication about sexual health-A qualitative study from the perspectives of oncological nurses. *J Clin Nurs* 2019 Oct 20;28(19-20):3556-3566. [doi: [10.1111/jocn.14949](https://doi.org/10.1111/jocn.14949)] [Medline: [31165516](https://pubmed.ncbi.nlm.nih.gov/31165516/)]
19. Gilbert E, Perz J, Ussher J. Talking about sex with health professionals: the experience of people with cancer and their partners. *Eur J Cancer Care (Engl)* 2016 Mar 10;25(2):280-293. [doi: [10.1111/ecc.12216](https://doi.org/10.1111/ecc.12216)] [Medline: [25040442](https://pubmed.ncbi.nlm.nih.gov/25040442/)]
20. Julien JO, Thom B, Kline NE. Identification of Barriers to Sexual Health Assessment in Oncology Nursing Practice. *Oncology Nursing Forum* 2010 May 3;37(3):E186-E190. [doi: [10.1188/10.onf.e186-e190](https://doi.org/10.1188/10.onf.e186-e190)]
21. Speer SA, Tucker SR, McPhillips R, Peters S. The clinical communication and information challenges associated with the psychosexual aspects of prostate cancer treatment. *Soc Sci Med* 2017 Jul;185:17-26. [doi: [10.1016/j.socscimed.2017.05.011](https://doi.org/10.1016/j.socscimed.2017.05.011)] [Medline: [28549250](https://pubmed.ncbi.nlm.nih.gov/28549250/)]
22. Krouwel E, Nicolai M, van Steijn-van Tol A, Putter H, Osanto S, Pelger R, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. *Eur J Oncol Nurs* 2015 Dec;19(6):707-715. [doi: [10.1016/j.ejon.2015.05.005](https://doi.org/10.1016/j.ejon.2015.05.005)] [Medline: [26051072](https://pubmed.ncbi.nlm.nih.gov/26051072/)]
23. Leonardi-Warren K, Neff I, Mancuso M, Wenger B, Galbraith M, Fink R. Sexual Health: Exploring Patient Needs and Healthcare Provider Comfort and Knowledge. *CJON* 2016 Dec 1;20(6):E162-E167. [doi: [10.1188/16.cjon.e162-e167](https://doi.org/10.1188/16.cjon.e162-e167)]
24. O'Connor SR, Connaghan J, Maguire R, Kotronoulas G, Flannagan C, Jain S, et al. Healthcare professional perceived barriers and facilitators to discussing sexual wellbeing with patients after diagnosis of chronic illness: A mixed-methods evidence synthesis. *Patient Educ Couns* 2019 May;102(5):850-863. [doi: [10.1016/j.pec.2018.12.015](https://doi.org/10.1016/j.pec.2018.12.015)] [Medline: [30578104](https://pubmed.ncbi.nlm.nih.gov/30578104/)]
25. Zhou ES, Bober SL, Nekhlyudov L, Hu JC, Kantoff PW, Recklitis CJ. Physical and emotional health information needs and preferences of long-term prostate cancer survivors. *Patient Educ Couns* 2016 Dec;99(12):2049-2054 [FREE Full text] [doi: [10.1016/j.pec.2016.07.017](https://doi.org/10.1016/j.pec.2016.07.017)] [Medline: [27439668](https://pubmed.ncbi.nlm.nih.gov/27439668/)]
26. Lenzen SA, Daniëls R, van Bokhoven MA, van der Weijden T, Beurskens A. Development of a conversation approach for practice nurses aimed at making shared decisions on goals and action plans with primary care patients. *BMC Health Serv Res* 2018 Nov 26;18(1):891 [FREE Full text] [doi: [10.1186/s12913-018-3734-1](https://doi.org/10.1186/s12913-018-3734-1)] [Medline: [30477566](https://pubmed.ncbi.nlm.nih.gov/30477566/)]
27. Vromans RD, van Eenbergen MC, Pauws SC, Geleijnse G, van der Poel HG, van de Poll-Franse LV, et al. Communicative aspects of decision aids for localized prostate cancer treatment - A systematic review. *Urol Oncol* 2019 Jul;37(7):409-429. [doi: [10.1016/j.urolonc.2019.04.005](https://doi.org/10.1016/j.urolonc.2019.04.005)] [Medline: [31053529](https://pubmed.ncbi.nlm.nih.gov/31053529/)]
28. Singy P, Bourquin C, Sulstarova B, Stiefel F. The impact of communication skills training in oncology: a linguistic analysis. *J Cancer Educ* 2012 Jun;27(3):404-408. [doi: [10.1007/s13187-012-0385-5](https://doi.org/10.1007/s13187-012-0385-5)] [Medline: [22714790](https://pubmed.ncbi.nlm.nih.gov/22714790/)]
29. Yardley L, Ainsworth B, Arden-Close E, Muller I. The person-based approach to enhancing the acceptability and feasibility of interventions. *Pilot Feasibility Stud* 2015 Oct 26;1(1):37 [FREE Full text] [doi: [10.1186/s40814-015-0033-z](https://doi.org/10.1186/s40814-015-0033-z)] [Medline: [27965815](https://pubmed.ncbi.nlm.nih.gov/27965815/)]
30. McCaughan E, Parahoo K, Flannagan C, Maguire R, Connaghan J, Steele M, et al. Development of a conceptual framework to improve sexual wellbeing communication in routine prostate cancer care. *Patient Educ Couns* 2020 Jun;103(6):1150-1160. [doi: [10.1016/j.pec.2020.01.014](https://doi.org/10.1016/j.pec.2020.01.014)] [Medline: [32029296](https://pubmed.ncbi.nlm.nih.gov/32029296/)]
31. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007 Dec 16;19(6):349-357. [doi: [10.1093/intqhc/mzm042](https://doi.org/10.1093/intqhc/mzm042)] [Medline: [17872937](https://pubmed.ncbi.nlm.nih.gov/17872937/)]
32. LifeGuide Online. URL: <https://www.lifeguideonline.org> [accessed 2018-05-01]
33. McCaughan E, McKenna S, McSorley O, Parahoo K. The experience and perceptions of men with prostate cancer and their partners of the CONNECT psychosocial intervention: a qualitative exploration. *J Adv Nurs* 2015 Aug 26;71(8):1871-1882. [doi: [10.1111/jan.12648](https://doi.org/10.1111/jan.12648)] [Medline: [25818026](https://pubmed.ncbi.nlm.nih.gov/25818026/)]
34. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006 Jan;3(2):77-101. [doi: [10.1191/1478088706qp0630a](https://doi.org/10.1191/1478088706qp0630a)]
35. Canzona MR, Ledford CJW, Fisher CL, Garcia D, Raleigh M, Kalish VB. Clinician barriers to initiating sexual health conversations with breast cancer survivors: The influence of assumptions and situational constraints. *Fam Syst Health* 2018 Mar;36(1):20-28. [doi: [10.1037/fsh0000307](https://doi.org/10.1037/fsh0000307)] [Medline: [29608082](https://pubmed.ncbi.nlm.nih.gov/29608082/)]
36. Carrier J, Edwards D, Harden J. Men's perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life. *JBIS Database of Systematic Reviews and Implementation Reports* 2018;16(4):892-972. [doi: [10.11124/jbisrir-2017-003566](https://doi.org/10.11124/jbisrir-2017-003566)]
37. Glasgow RE, Emont S, Miller DC. Assessing delivery of the five 'As' for patient-centered counseling. *Health Promot Int* 2006 Sep 04;21(3):245-255. [doi: [10.1093/heapro/dal017](https://doi.org/10.1093/heapro/dal017)] [Medline: [16751630](https://pubmed.ncbi.nlm.nih.gov/16751630/)]
38. Wollersheim BM, van Stam M, Bosch RJ, Pos FJ, Tillier CN, van der Poel HG, et al. Unmet expectations in prostate cancer patients and their association with decision regret. *J Cancer Surviv* 2020 Oct 08;14(5):731-738. [doi: [10.1007/s11764-020-00888-6](https://doi.org/10.1007/s11764-020-00888-6)] [Medline: [32385837](https://pubmed.ncbi.nlm.nih.gov/32385837/)]

39. Novara G, Checcucci E, Crestani A, Abrate A, Esperto F, Pavan N, Research Urology Network (RUN). Telehealth in Urology: A Systematic Review of the Literature. How Much Can Telemedicine Be Useful During and After the COVID-19 Pandemic? *Eur Urol* 2020 Jun 18 [FREE Full text] [doi: [10.1016/j.eururo.2020.06.025](https://doi.org/10.1016/j.eururo.2020.06.025)] [Medline: [32616405](https://pubmed.ncbi.nlm.nih.gov/32616405/)]

Abbreviations

EASSi: Engagement, Assessment, Support, and Sign-posting

Edited by G Strudwick; submitted 11.05.20; peer-reviewed by M van Eenbergen, V Osadchiy; comments to author 02.06.20; revised version received 22.09.20; accepted 11.10.20; published 04.12.20.

Please cite as:

McCaughan E, Flannagan C, Parahoo K, Connaghan J, Maguire R, Steele M, Thompson S, Jain S, Kirby M, Brady N, O'Connor SR The Tablet-Based, Engagement, Assessment, Support, and Sign-Posting (EASSi) Tool for Facilitating and Structuring Sexual Well-Being Conversations in Routine Prostate Cancer Care: Mixed-Methods Study

JMIR Cancer 2020;6(2):e20137

URL: <http://cancer.jmir.org/2020/2/e20137/>

doi: [10.2196/20137](https://doi.org/10.2196/20137)

PMID: [33275109](https://pubmed.ncbi.nlm.nih.gov/33275109/)

©Eilís McCaughan, Carrie Flannagan, Kader Parahoo, John Connaghan, Roma Maguire, Mary Steele, Samantha Thompson, Suneil Jain, Michael Kirby, Nuala Brady, Seán R O'Connor. Originally published in *JMIR Cancer* (<http://cancer.jmir.org>), 04.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Cancer*, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Viewpoint

The Impact of COVID-19 on Cancer Screening: Challenges and Opportunities

Ramon S Cancino^{1,2}, MD, MS; Zhaohui Su², MA, PhD; Ruben Mesa^{2,3}, MD; Gail E Tomlinson^{2,4}, MD, PhD; Jing Wang^{2,5}, PhD, MPH, MSN, RN

¹Department of Family & Community Medicine, Joe R & Teresa Lozano Long School of Medicine, UT Health San Antonio, San Antonio, TX, United States

²Center on Smart and Connected Health Technologies, Mays Cancer Center, School of Nursing, UT Health San Antonio, San Antonio, TX, United States

³Department of Medicine, Joe R & Teresa Lozano Long School of Medicine, UT Health San Antonio, San Antonio, TX, United States

⁴Department of Pediatrics, Joe R & Teresa Lozano Long School of Medicine, UT Health San Antonio, San Antonio, TX, United States

⁵School of Nursing, UT Health San Antonio, San Antonio, TX, United States

Corresponding Author:

Ramon S Cancino, MD, MS

Department of Family & Community Medicine

Joe R & Teresa Lozano Long School of Medicine

UT Health San Antonio

7703 Floyd Curl Dr

San Antonio, TX, 78229

United States

Phone: 1 2165710888

Email: cancinor@uthscsa.edu

Abstract

Cancer is a leading cause of death in the United States and across the globe. Cancer screening is an effective preventive measure that can reduce cancer incidence and mortality. While cancer screening is integral to cancer control and prevention, due to the COVID-19 outbreak many screenings have either been canceled or postponed, leaving a vast number of patients without access to recommended health care services. This disruption to cancer screening services may have a significant impact on patients, health care practitioners, and health systems. In this paper, we aim to offer a comprehensive view of the impact of COVID-19 on cancer screening. We present the challenges COVID-19 has exerted on patients, health care practitioners, and health systems as well as potential opportunities that could help address these challenges.

(*JMIR Cancer* 2020;6(2):e21697) doi:[10.2196/21697](https://doi.org/10.2196/21697)

KEYWORDS

cancer; screening; COVID-19; coronavirus; telemedicine; social determinants; health; education; training; social media; campaign; branding; cobranding

Introduction

It is estimated that 606,520 Americans will die from cancer in 2020 [1], which is 4 times the number of recent projected deaths due to COVID-19 [2]. While cancer prevention and screening is integral to personal and population health, the cancer industry is experiencing seismic changes due to the COVID-19 outbreak [3,4]. Disruptions brought by COVID-19 have significantly interrupted almost all aspects of cancer control and prevention infrastructures, including canceled cancer screening services [3], deferred elective surgeries [5], dismantled therapeutic regimens [4], and furloughed health care practitioners [6].

One of the most severely impacted cancer control and prevention services is cancer screening. Cancer screening utilizes medical tests to identify precancerous lesions before cancer is formed or to detect cancer before it progresses into more advanced stages [7,8]. Screening is an effective prevention mechanism that could substantially reduce cancer incidence and mortality rates in patients [9-12]. While not curative, cancer screening has potential to decrease the burden of cancer [13]. Evidence shows that for women of all ages at average risk, screening is linked to an approximate 20% reduction in breast cancer mortality [14]. Data analysis further indicates that 3 times the deaths resulting from colorectal cancer would be avoided with

one third of current costs if colorectal cancer screening rates in people aged 50-70 years improved to 80% [15]. For the genetically predisposed individual, the benefit of prescribed cancer screening has an even greater impact [16,17].

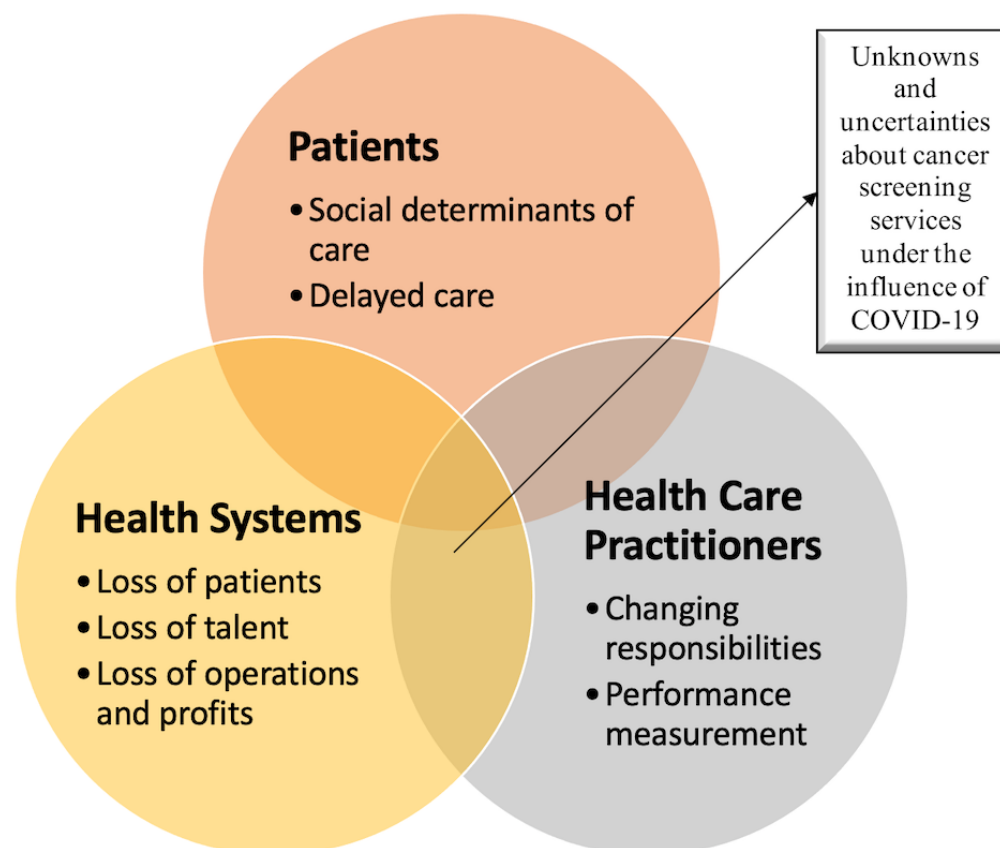
Cancer screening plays a critical role in early cancer detection, but COVID-19 has significantly hampered the cancer screening infrastructure [3]. To adjust the provision of health care resources, many cancer agencies have championed the idea of halting cancer screening services to patients [18-20]. After a US national emergency was declared on March 13, 2020, institutions such as the American Cancer Society have made the recommendation that people should pause their cancer screening plans during the COVID-19 outbreak until further notice [19]. This recommendation, along with other contextual factors (eg, social isolation measures), has caused drastic disruptions in cancer screening services. It is estimated that as a result of COVID-19, screenings for cancers of the breast, colon, and cervix have dropped by 94%, 86%, and 94% between January 20, 2020, and April 21, 2020, respectively [21]. Little is known about the impact the current pandemic will have on the cancer screening and prevention activities of patients, health

care practitioners, and health systems. To bridge this gap, we aim to present the challenges COVID-19 has exerted on patients, health care practitioners, and health systems as well as potential opportunities that could help address these challenges.

Cancer Screening Challenges, Opportunities, and Solutions

Successful cancer screening is often carried out as a result of synergistic collaborations between patients, health care practitioners, and health systems [22-24]. Furthermore, as no evidence is available on the origin of the virus and no effective vaccine or curative medicine is available, both patients and health care practitioners also experience the shared unknowns and uncertainties regarding COVID-19. These uncertainties are also experienced by health systems, whose financial futures may be threatened. Therefore, to acknowledge the shared interests of patients, health care practitioners, and health systems in cancer screening, we organized evidence and insights around these key stakeholders to provide a connected and comprehensive understanding of the impact of COVID-19 on cancer screening (Figure 1).

Figure 1. Summary of challenges patients, health care professionals, and health systems face due to COVID-19.



Patients

Social determinants of health could be understood as the condition in which people are born, grow, live, work, and age [25]. In other words, as opposed to biological factors (eg, genetic traits), social determinants of health are a range of social,

economic, political, and environmental factors that contribute to individuals' health conditions and disparities, such as inequalities in cancer screening [26-28]. Results show that patients who have poor social determinants of health, such as lack of insurance, low income, and living in a deprived neighborhood, are often less likely to adopt cancer screening

[28-30]. Evidence from randomized clinical trials further indicates that, compared to patients with private insurance, patients with Medicaid or with no insurance received reduced benefits from the same intervention program [31]. These combined insights may help explain why screenings for cancers have dropped significantly since January 2020 (eg, breast cancer screening has dropped by 94%) [21]. The experience of dramatic events, such as the COVID-19 pandemic, losing health insurance, and lack of access to health care, and in some situations caring for ill family members, may exert added psychological pressure on patients and further impact the ability to receive services and increase their risk of medical conditions such as cancer [32,33].

Another social determinant of health, economic stability, has been greatly affected. Due to the impact of COVID-19, unemployment rates rose to a historical 20.6% in the United States, with more than 31 million workers filing unemployment claims between March 1, 2020, and May 2, 2020 [34]. It is estimated that 26.6 million workers and their dependents may lose their employer-based insurance [35]. This undoubtedly can have a detrimental effect on individuals' physical and psychological health, as health insurance status is often considered as a key social determinant of health that has substantial influence on individuals' ability to access health care services [36,37].

Canceling or postponing cancer screenings may not equate to avoiding a cancer diagnosis but delayed cancer diagnoses could lead to increased mortality. On the contrary, the drastic decrease of cancer screenings in the United States and across the globe may have severe consequences, such as an unexpected rise in cancer incidence and later-stage cancer diagnosis, and in turn, more cancer deaths in patients [11,38-41]. While patients might be in great need for help during this crisis, assistance from health care practitioners was also interrupted due to the COVID-19 pandemic [42]. Furthermore, the accumulated need to screen those patients whose exams or procedures were postponed could directly impact *other* patients whose exams or procedures are now also due, creating downstream cancer screening delays.

Health Care Practitioners

One of the most impacted populations by COVID-19 is the health care practitioner community [43,44]. During the SARS (severe acute respiratory syndrome) outbreak, health care workers and hospital systems experienced measurable negative psychological impacts [45-48]. Due to the current outbreak, health care practitioners may have experienced a variety of multilevel stressors, such as (1) interruptions in routine job duties and responsibilities, (2) limited knowledge and data, and (3) worries about job security due to decreased patient volumes. COVID-19 has caused significant upheavals in the cancer health care infrastructure, including disturbed clinical visits, canceled or delayed medical surgery or procedures, and bridled therapeutic strategies [44,49]. For health care practitioners, these changes force them to tackle constant unexpected disruptions to routine job duties and responsibilities, such as the need to quickly learn and adopt telemedicine tools until COVID-19 ceases to be a threat to society. This unexpected need to adopt telemedicine may cause stress in health care practitioners, as

some of them may be forced into adopting technology-based health solutions without necessary knowledge or adequate training in place [50]. These changes in job duties and responsibilities may put extra pressure on health care practitioners, above and beyond the levels of stress experienced by the general public in the face of COVID-19. For some health care practitioners, in addition to the unique work requirements and responsibilities they shoulder during the COVID-19 pandemic, the fear of being exposed to SARS-CoV-2 at work may cause additional stress and anxiety [43]. This, in turn, may cause detrimental consequences on their psychological health and their performance in administering cancer care and treatment to patients.

Without key information from insurance payers, health care practitioners may lack the necessary data needed to identify those who need cancer screening [27,51]. Though many health care practitioners have access to electronic health record systems, information stored in these systems is often too outdated and inaccurate to be utilized [51,52]. This suggests that limited data may also hamper health practitioners' ability to help patients. Therefore, due to these issues coupled with COVID-19-related cancer screening cancellations and delays [21], health care professionals' performance in value-based contracts are at risk [53]. One consequence could be decreased screening rates and the resulting poor performance in cancer screening metrics, which in turn can lead to decreased quality incentives [54,55].

Reduced successful cancer care could be manifested in terms of decreased profits and diminished research funding [53], which may then result in downstream cost reduction and job loss. As a matter of fact, health care institutions, including hospitals and nonprofit organizations, such as the American Cancer Society, have been downsizing in the form of furloughs and layoffs [6]. According to the Labor Department, 1.4 million health care practitioners have lost their job since January 2020 [56]. This grim job reality could exert additional pressure to the unknowns and uncertainties health care practitioners are facing while trying to protect themselves and patients from COVID-19.

Health Systems

In the context of cancer screening, the impact of COVID-19 on health systems can be best illustrated in terms of loss: (1) loss of lives, (2) loss of talent, and (3) loss of operational activity and revenues. Globally, it is estimated that 2,324,069 elective cancer surgeries (37.7% of all 1,735,483 elective surgical operations) were canceled or postponed during the 12-week peak disruptions caused by COVID-19 [5]. These cancellations and delays could cause cancer disparities to become more pronounced. It is difficult to know how these discontinued services could further negatively impact the patient-provider relationship.

It is also hard to predict how patients will respond to cancer screening messages from health care practitioners post COVID-19. Public perception of health care safety could impact utilization patterns of health care [57-59]. Since COVID-19 is seen as highly infectious and can be contracted from direct contact with others [60,61], it is possible that the current avoidance of health care may continue and patients without

symptoms may opt to not be screened for preventive care. This could have a detrimental effect on patients' health, as many chronic medical condition such as cancer, high blood pressure, and diabetes are often asymptomatic until needing urgent attention [62-64]. Furthermore, drastic changes in patients' social determinants of health (eg, health insurance status, geographic distance from health care center and associated transportation needs, etc) may also contribute to the development of other non-cancer-related illnesses [65-68], resulting in competing interests in health care decisions that could further dampen patients' motivation to seek cancer screening services [69]. This, in turn, may also contribute to an increase of later-stage cancer diagnosis in patients. Early data from the United Kingdom predicts a substantial increase in the number of avoidable cancer-related deaths in England [70]. Other estimates predict COVID-19 will result in 10,000 excess deaths from breast and colorectal cancer [71].

Health care practitioners are losing their jobs, partially due to the dwindled demands for health care services caused by COVID-19. Overall, 1.4 million health care practitioners lost their jobs since January 2020 [56]. Though the potential impact of COVID-19 on medical and nursing school enrollments is yet to be ascertained, it is possible that COVID-19 may have a negative impact on health care practitioners' ability to provide high-quality education. Moreover, the impact of reduced patient contact and virtual learning on educational milestone attainment are yet to be determined.

While it is difficult to pinpoint the exact impact of disrupted cancer screening services on the loss of life or loss of talent in the health care industry, it is easier to describe the decreased activity and estimated the loss of profits in the health care industry caused by COVID-19. According to the American Hospital Association, due to the impact of this coronavirus, the estimated loss of US hospitals and health systems between February 2020 and June 2020 would amount to \$202.6 billion [53]. This loss of profit may also have an impact on patients and health care practitioners, considering that loss of profits often translate into reduced investments in cancer research [6]. However, while these numbers present a dismal reality, opportunities and solutions that could address the challenges caused by COVID-19 on cancer screening are also available.

The impact of these health system issues on cancer screening measures are coming to light, especially as it relates to cancer screening. The World Health Organization warned of a worldwide decrease in health services for noncommunicable diseases [72]. These results include predicted increases in avoidable cancer deaths [70]. Many health care systems are finding fewer cancer diagnoses during the pandemic [73,74]. Fewer diagnoses can have financial impact on health care systems, especially when the United States spent roughly \$87.8 billion on cancer-related health care in 2014 [75].

Cancer Screening for At-Risk Patient Populations

We also need to pay attention to where the COVID-19 pandemic hit hardest and where cancer screening rates are the lowest in

our community [76-85]. Patients with low socioeconomic status (SES) or identify as minority, including racial and ethnic underserved minorities such as Hispanics and African Americans, and the LGBTQ (lesbian, gay, bisexual, transgender, and queer or questioning) sexual and gender minorities. It is important to recognize that there is a huge overlap between patients with low SES and those with minority status—rather than face the double impact of being poor and disenfranchised (eg, heightened risks for cancer) [84,86-88], as a result of COVID-19, they now face the additional impact of the need to pay extra attention and allocate already limited resources to protect themselves against the coronavirus while also tackling unemployment or hazardous working conditions [89-91].

It is important to note that the impact of missing a cancer screening is not the same for every population [92,93]. Evidence suggests that marginalized individuals such as racial minorities are more likely to benefit from cancer screening [94]. Research also indicates that cancer screening is more cost-effective for high-risk races and ethnicities, such as Asians (\$71,451 per quality-adjusted life year [QALY]), Hispanics (\$76,070/QALY), African Americans (\$80,278/QALY), compared to non-Hispanic White individuals (\$122,428/QALY) [95]. While these findings further support the importance of cancer screening, they also indicate that the likelihood of missing a diagnosis by delayed or missed screening will be amplified among these minority populations. In other words, screening is integral to these populations' protection against cancer.

COVID-19 has also helped expose many health disparities minorities face, especially structured and systematic health inequalities such as violence against women [77,96-99]. Prior to COVID-19, data from the World Health Organization already painted a horrifying picture where 1 in 3 women will become a victim of sexual or physical violence in a relationship at some point in their life [100]. A growing body of literature suggests that, as the pandemic and lockdown measures bring continuing financial blows and forced "close" time with their partners, women worldwide are experiencing more frequent and dangerous forms of abuse [77,96,98].

With so many people taking a stand and making their voice heard over injustice, as exemplified by the belated realization of police brutality in the United States, there is a societal need to pay attention to the disparities and inequalities that, we, as a population, are experiencing on a daily basis. "Pay inequity" [101] or "violence against women" [77,100] are more than inhumane terminologies or irrelevant phenomena to leave as inheritance for future generations—rather, these disparities are negatively impacting our grandmothers, mothers, and daughters' well-being and making them less likely to screen for cancer [102,103] and thus more at risk for missing early cancer detection [104-106]. It is questionable as to how likely a woman experiencing domestic violence will undertake the initiative to screen for breast cancer amid the pandemic, even if she is aware that lumps in her breasts have appeared or changed. The ramifications of COVID-19 are thus profound.

More attention from health care practitioners are required to address these issues while improving screening rates for the highest at-risk populations. In other words, these health

disparities that minorities face are meaningful and life-or-death facts that health care practitioners must acknowledge and address.

Some of the approaches to more universal access to cancer screening using traditional and organized outreach measures include local mammography vans for breast cancer [38,107], fecal immunochemical test (FIT) or other at-home stool tests for colon cancer detection [108,109], and cost-effective technology-based solutions such as social media campaigns [110,111], so that a broader population can be served and the widening cancer disparities can be alleviated. In the fight against inequalities, preventative measures such as cancer screening are more relevant to underserved populations than ever before. Since COVID-19 is more likely to be deadly for marginalized individuals with chronic conditions and cancer [112-116], it is important to ensure people can fight to overcome social determinants and injustices with maintaining a healthy and cancer-free body.

Opportunities and Solutions

Telemedicine Opportunities and Technology-Based Solutions

With the advances in science and technology, the application of telemedicine in cancer care and management is gaining momentum [117-119]. Telemedicine, which literally means “healing at a distance” [120], could be understood as the delivery of health care services aiming to advance personal and population health [121]. Telemedicine allows timely, accessible, and cost-effective health care delivery to the patients, which renders itself a practical solution to COVID-19-induced constraints such as social distancing and self-isolation [122-124]. Telemedicine tools such as virtual reality devices have been found to be useful for training health care practitioners [125]. As virtual reality can offer remote yet realistic training experiences, it facilitates training for health care professionals in a time when social isolation is the norm. Telemedicine has been shown to be effective in underserved geographically remote populations. Emerging technologies such as artificial intelligence (AI) also have great potential in facilitating cancer screening [119].

On a higher-technological scale, using a deep learning technique, researchers found that AI can help identify faces of patients with cancer from those without [126]. This promising finding, not currently in use, suggests that AI-based telemedicine tools have the future potential to assist patients and health care practitioners with cancer screening and improve screening accuracy.

While promising telemedicine opportunities are present, to successfully implement telemedicine in cancer care and primary care, education and training should be made available to both patients and health care practitioners [118]. Research conducted by Stanford University shows that 47% of physicians and 73% of medical students surveyed indicated that they are considering taking additional courses to better prepare for innovations in health care (eg, data science, AI) [127]. While it is imperative to update college curricula to reflect health care needs identified

in practice [128,129], it is important to note that telemedicine education and training should be considered as a long-term investment, rather than a short-term experiment. In other words, as technology advances, telemedicine education and training programs should also be updated regularly and frequently to ensure health care practitioners are up to date with telemedicine opportunities for the benefits of self and patients [130,131].

According to the Pew Research Center, approximately 96% of Americans own a cellphone of some kind [132]. Considering the prevalence of smart devices patients own, health care practitioners may face questions like “Which mobile apps can help me better take care of my health?” from patients more frequently in the future. There is also a boom in the medical app market. It was estimated that there were approximately 325,000 health apps available to patients in 2017, equating to 3.7 billion app downloads in total [133]. As mobile health (mHealth) continues to gather momentum, health care practitioners may also need to “prescribe” mobile apps to patients to protect them from ill-suited (eg, apps addressing different sets of needs) or poorly developed apps (eg, apps filled with misinformation or lack of scientific underpinning) [134]. Technology competence might be an integral part to effective patient-provider communication [123]. To embrace future technology-based health care challenges, health care practitioners may have to train their telemedicine muscles with regular education to be able to adequately answer patients’ questions and concerns about telemedicine.

Leveraging Social Media to Boost Cancer Screening

In addition to boosting health care professionals’ core competence with regard to telemedicine [131], health systems should also consider adopting integrated marketing campaigns, such as social media campaigns, to increase screening awareness and adoption rates in patients. Social media campaigns could be understood as the use of social media platforms to deliver persuasive communication strategies to the target audience in order to change their attitudes and behavior to improve health. One key advantage of social media campaigns is that as persuasive strategies adopted in these campaigns are evidence-based and tailored to the target audience [135,136], they often yield desirable campaign outcomes [137-139].

Social media campaigns may be extremely useful for promoting cancer screening services to at-risk populations. Compared to integrated marketing campaigns distributed via traditional media platforms, social media campaigns can be distributed remotely with limited costs and therefore have the added advantages of cost-effectiveness and scalability [135,136]. This advantage might be more pronounced in the era of COVID-19; since lockdowns and social distancing measures have limited people’s ability to physically disseminate campaign messages, campaign mechanisms that can virtually distribute promotional information are desired. Evidence suggests that social media campaigns are effective in raising cancer screening awareness in the target audience [110,111,140]. Promising findings show that social media campaigns on lung cancer screening using Google and Facebook to reach at-risk populations yielded click-through rates above the industry standard [110]. These insights suggest that health care professionals can consider using social media

campaigns to reach at-risk populations, such as minorities with pronounced needs to be screened for cancer, to further address the widening cancer disparities exacerbated by COVID-19.

Conclusion

The systemic disruption and tragedy that COVID-19 has brought to patients, practitioners, and health care systems is an opportunity for innovative solutions, especially in cancer prevention and screening [141-143]. Cancer prevention and screening professionals need to innovate in this current environment to continue to decrease the burden of cancer in communities. We need agile short-term plans tailored to the current COVID-19 infection control strategies as well as long-term plans that account for the capricious, costly, and deadly nature of cancer and its intersection with other widespread health problems, such as viral infections similar to the current pandemic. We offer some post-COVID-19 screening enhancement recommendations below:

- Breast cancer screening
 - Mobile mammography unit

- Cervical cancer screening
 - Pap smears +/- cotesting per guidelines
- Colon cancer screening
 - Enhanced workflows for FIT or Cologuard with appropriate patients
- General solutions:
 - Proactive outreach to patients due for screening
 - Social media communication to patients about risks of cancer and safety of screening procedures
 - Initial assessment and results follow-up via telemedicine appointment
 - Masking precautions (patient, clinician, and staff)
 - Social distancing precautions when possible

Complacency is not an option, and health care professionals must diligently work together with other stakeholders and across disciplines toward solutions to ensure patients, providers, and health systems have the tools and means necessary to screen for cancer *now*.

Acknowledgments

We thank Dr Pam Otto, Dr Randy Wright, Dr Georgia McCann, and the Cancer Prevention and Screening Committee of UT Health San Antonio Mays Cancer Center for informing our work. This work is supported by the Mays Cancer Center (support grant NIH 5P30CA054174) and the Cancer Prevention and Research Institute (PP120089 and PP160011).

Conflicts of Interest

RM is a consultant for Novartis, Sierra Oncology, and LaJolla Pharmaceutical and provides research support to Celgene, Incyte, AbbVie Inc, Samus Therapeutics, Genetech, Promedior, and CTI biopharma.

References

1. Siegel R, Miller K, Jemal A. Cancer statistics, 2020. *CA Cancer J Clin* 2020 Jan;70(1):7-30. [doi: [10.3322/caac.21590](https://doi.org/10.3322/caac.21590)] [Medline: [31912902](https://pubmed.ncbi.nlm.nih.gov/31912902/)]
2. COVID-19 forecasts. Centers for Disease Control and Prevention. 2020. URL: <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/forecasting-us.html> [accessed 2020-09-01]
3. Waterhouse DM, Harvey RD, Hurley P, Levit LA, Kim ES, Klepin HD, et al. Early Impact of COVID-19 on the Conduct of Oncology Clinical Trials and Long-Term Opportunities for Transformation: Findings From an American Society of Clinical Oncology Survey. *JCO Oncology Practice* 2020 Jul;16(7):417-421. [doi: [10.1200/op.20.00275](https://doi.org/10.1200/op.20.00275)]
4. Ren X, Chen B, Hong Y, Liu W, Jiang Q, Yang J, et al. The challenges in colorectal cancer management during COVID-19 epidemic. *Ann Transl Med* 2020 Apr;8(7):498-498 [FREE Full text] [doi: [10.21037/atm.2020.03.158](https://doi.org/10.21037/atm.2020.03.158)] [Medline: [32395542](https://pubmed.ncbi.nlm.nih.gov/32395542/)]
5. CovidSurg Collaborative. Elective surgery cancellations due to the COVID-19 pandemic: global predictive modelling to inform surgical recovery plans. *Br J Surg* 2020 Jun 13;107(11):1440-1449. [doi: [10.1002/bjs.11746](https://doi.org/10.1002/bjs.11746)]
6. American Association for Cancer Research. COVID-19 Hits Cancer Research Funding. *Cancer Discov* 2020 Apr 24;10(6):756-756. [doi: [10.1158/2159-8290.cd-nd2020-007](https://doi.org/10.1158/2159-8290.cd-nd2020-007)]
7. Cancer: Screening. World Health Organization. URL: <https://www.who.int/cancer/prevention/diagnosis-screening/screening/en/> [accessed 2020-09-01]
8. Division of Cancer Prevention and Control. Screening tests. Centers for Disease Control and Prevention. 2020. URL: <https://www.cdc.gov/cancer/dcpc/prevention/screening.htm> [accessed 2020-09-01]
9. Lieberman D, Sullivan BA, Hauser ER, Qin X, Musselwhite LW, O'Leary MC, et al. Baseline Colonoscopy Findings Associated With 10-Year Outcomes in a Screening Cohort Undergoing Colonoscopy Surveillance. *Gastroenterology* 2020 Mar;158(4):862-874.e8. [doi: [10.1053/j.gastro.2019.07.052](https://doi.org/10.1053/j.gastro.2019.07.052)] [Medline: [31376388](https://pubmed.ncbi.nlm.nih.gov/31376388/)]
10. Ran T, Cheng C, Misselwitz B, Brenner H, Ubels J, Schlander M. Cost-Effectiveness of Colorectal Cancer Screening Strategies-A Systematic Review. *Clin Gastroenterol Hepatol* 2019 Sep;17(10):1969-1981.e15. [doi: [10.1016/j.cgh.2019.01.014](https://doi.org/10.1016/j.cgh.2019.01.014)] [Medline: [30659991](https://pubmed.ncbi.nlm.nih.gov/30659991/)]

11. Miller EA, Pinsky PF, Schoen RE, Prorok PC, Church TR. Effect of flexible sigmoidoscopy screening on colorectal cancer incidence and mortality: long-term follow-up of the randomised US PLCO cancer screening trial. 2019 Feb;4(2):101-110. [doi: [10.1016/s2468-1253\(18\)30358-3](https://doi.org/10.1016/s2468-1253(18)30358-3)]
12. Hallowell BD, Endeshaw M, McKenna MT, Senkomago V, Razzaghi H, Saraiya M. Cervical Cancer Death Rates Among U.S.- and Foreign-Born Women: U.S., 2005-2014. *Am J Prev Med* 2019 Jun;56(6):869-874 [FREE Full text] [doi: [10.1016/j.amepre.2019.01.007](https://doi.org/10.1016/j.amepre.2019.01.007)] [Medline: [31005467](https://pubmed.ncbi.nlm.nih.gov/31005467/)]
13. Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board, Curry SJ, Byers T, Hewitt M. Fulfilling the Potential of Cancer Prevention and Early Detection. Washington DC: National Academies Press (US); 2003.
14. Myers ER, Moorman P, Gierisch JM, Havrilesky LJ, Grimm LJ, Ghate S, et al. Benefits and Harms of Breast Cancer Screening: A Systematic Review. *JAMA* 2015 Oct 20;314(15):1615-1634. [doi: [10.1001/jama.2015.13183](https://doi.org/10.1001/jama.2015.13183)] [Medline: [26501537](https://pubmed.ncbi.nlm.nih.gov/26501537/)]
15. Ladabaum U, Mannalithara A, Meester RG, Gupta S, Schoen RE. Cost-Effectiveness and National Effects of Initiating Colorectal Cancer Screening for Average-Risk Persons at Age 45 Years Instead of 50 Years. *Gastroenterology* 2019 Jul;157(1):137-148 [FREE Full text] [doi: [10.1053/j.gastro.2019.03.023](https://doi.org/10.1053/j.gastro.2019.03.023)] [Medline: [30930021](https://pubmed.ncbi.nlm.nih.gov/30930021/)]
16. Gupta S, Provenzale D, Regenbogen SE, Hampel H, Slavin TP, Hall MJ, et al. NCCN Guidelines Insights: Genetic/Familial High-Risk Assessment: Colorectal, Version 3.2017. *J Natl Compr Canc Netw* 2017 Dec 09;15(12):1465-1475. [doi: [10.6004/jnccn.2017.0176](https://doi.org/10.6004/jnccn.2017.0176)] [Medline: [29223984](https://pubmed.ncbi.nlm.nih.gov/29223984/)]
17. Daly M, Pilarski R, Yurgelun M, Berry MP, Buys SS, Dickson P, et al. NCCN Guidelines Insights: Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic, Version 1.2020. *J Natl Compr Canc Netw* 2020 Apr;18(4):380-391. [doi: [10.6004/jnccn.2020.0017](https://doi.org/10.6004/jnccn.2020.0017)] [Medline: [32259785](https://pubmed.ncbi.nlm.nih.gov/32259785/)]
18. ASBrS and ACR joint statement on breast screening exams during the COVID-19 pandemic. The American Society of Breast Surgeons. 2020 Mar 26. URL: <https://www.breastsurgeons.org/news/?id=45> [accessed 2020-09-01]
19. Falco M. Common questions about the new coronavirus outbreak. American Cancer Society. 2020 Oct 12. URL: <https://www.cancer.org/latest-news/common-questions-about-the-new-coronavirus-outbreak.html> [accessed 2020-10-19]
20. ASCCP interim guidance for timing of diagnostic and treatment procedures for patients with abnormal cervical screening test. American Society for Colposcopy and Cervical Pathology. 2020 Mar 19. URL: <https://www.asccp.org/covid-19> [accessed 2020-09-01]
21. Preventive cancer screenings during COVID-19 pandemic. Epic Health Research Network. 2020. URL: <https://ehrn.org/articles/delays-in-preventive-cancer-screenings-during-covid-19-pandemic> [accessed 2020-09-01]
22. Warner ET, Lathan CS. Race and sex differences in patient provider communication and awareness of lung cancer screening in the health information National Trends Survey, 2013-2017. *Prev Med* 2019 Jul;124:84-90. [doi: [10.1016/j.yjmed.2019.05.001](https://doi.org/10.1016/j.yjmed.2019.05.001)] [Medline: [31054908](https://pubmed.ncbi.nlm.nih.gov/31054908/)]
23. Williamson S, Patterson J, Crosby R, Johnson R, Sandhu H, Johnson S, et al. Communication of cancer screening results by letter, telephone or in person: A mixed methods systematic review of the effect on attendee anxiety, understanding and preferences. *Prev Med Rep* 2019 Mar;13:189-195 [FREE Full text] [doi: [10.1016/j.pmedr.2018.12.016](https://doi.org/10.1016/j.pmedr.2018.12.016)] [Medline: [30666286](https://pubmed.ncbi.nlm.nih.gov/30666286/)]
24. Sava MG, Dolan JG, May JH, Vargas LG. A personalized approach of patient-health care provider communication regarding colorectal cancer screening options. *Med Decis Making* 2018 Apr 03;38(5):601-613. [doi: [10.1177/0272989x18763802](https://doi.org/10.1177/0272989x18763802)]
25. Social determinants of health. World Health Organization. URL: https://www.who.int/social_determinants/en/ [accessed 2020-09-01]
26. Mosquera I, Mendizabal N, Martín U, Bacigalupe A, Aldasoro E, Portillo I, from the Desberdinak Group. Inequalities in participation in colorectal cancer screening programmes: a systematic review. *Eur J Public Health* 2020 Jun 01;30(3):416-425. [doi: [10.1093/eurpub/ckz236](https://doi.org/10.1093/eurpub/ckz236)] [Medline: [32361732](https://pubmed.ncbi.nlm.nih.gov/32361732/)]
27. Abdelsattar ZM, Hendren S, Wong SL. The impact of health insurance on cancer care in disadvantaged communities. *Cancer* 2017 Apr 01;123(7):1219-1227 [FREE Full text] [doi: [10.1002/cncr.30431](https://doi.org/10.1002/cncr.30431)] [Medline: [27859019](https://pubmed.ncbi.nlm.nih.gov/27859019/)]
28. Lofters A, Schuler A, Slater M, Baxter N, Persaud N, Pinto A, et al. Using self-reported data on the social determinants of health in primary care to identify cancer screening disparities: opportunities and challenges. *BMC Fam Pract* 2017 Feb 28;18(1):31 [FREE Full text] [doi: [10.1186/s12875-017-0599-z](https://doi.org/10.1186/s12875-017-0599-z)] [Medline: [28241787](https://pubmed.ncbi.nlm.nih.gov/28241787/)]
29. Kurani SS, McCoy RG, Lampman MA, Doubeni CA, Finney Rutten LJ, Inselman JW, et al. Association of Neighborhood Measures of Social Determinants of Health With Breast, Cervical, and Colorectal Cancer Screening Rates in the US Midwest. *JAMA Netw Open* 2020 Mar 02;3(3):e200618 [FREE Full text] [doi: [10.1001/jamanetworkopen.2020.0618](https://doi.org/10.1001/jamanetworkopen.2020.0618)] [Medline: [32150271](https://pubmed.ncbi.nlm.nih.gov/32150271/)]
30. Coughlin SS. Social determinants of colorectal cancer risk, stage, and survival: a systematic review. *Int J Colorectal Dis* 2020 Jun 21;35(6):985-995. [doi: [10.1007/s00384-020-03585-z](https://doi.org/10.1007/s00384-020-03585-z)] [Medline: [32314192](https://pubmed.ncbi.nlm.nih.gov/32314192/)]
31. Unger JM, Blanke CD, LeBlanc M, Barlow WE, Vaidya R, Ramsey SD, et al. Association of Patient Demographic Characteristics and Insurance Status With Survival in Cancer Randomized Clinical Trials With Positive Findings. *JAMA Netw Open* 2020 Apr 01;3(4):e203842 [FREE Full text] [doi: [10.1001/jamanetworkopen.2020.3842](https://doi.org/10.1001/jamanetworkopen.2020.3842)] [Medline: [32352530](https://pubmed.ncbi.nlm.nih.gov/32352530/)]
32. Man RX, Lack DA, Wyatt CE, Murray V. The effect of natural disasters on cancer care: a systematic review. *The Lancet Oncology* 2018 Sep;19(9):e482-e499. [doi: [10.1016/s1470-2045\(18\)30412-1](https://doi.org/10.1016/s1470-2045(18)30412-1)]

33. Prohaska T, Peters K. Impact of Natural Disasters on Health Outcomes and Cancer Among Older Adults. *Gerontologist* 2019 May 17;59(Suppl 1):S50-S56. [doi: [10.1093/geront/gnz018](https://doi.org/10.1093/geront/gnz018)] [Medline: [31100141](https://pubmed.ncbi.nlm.nih.gov/31100141/)]
34. Unemployment insurance weekly claims. US Department of Labor. 2020. URL: <https://oui.doleta.gov/unemploy/claims.asp> [accessed 2020-09-01]
35. Garfield R, Claxton G, Damico A, Levitt L. Eligibility for ACA health coverage following job loss. Kaiser Family Foundation. 2020 May 13. URL: <https://www.kff.org/coronavirus-covid-19/issue-brief/eligibility-for-aca-health-coverage-following-job-loss/> [accessed 2020-09-01]
36. Smith MA, Weiss JM, Potvien A, Schumacher JR, Gangnon RE, Kim DH, et al. Insurance Coverage for CT Colonography Screening: Impact on Overall Colorectal Cancer Screening Rates. *Radiology* 2017 Sep;284(3):717-724 [FREE Full text] [doi: [10.1148/radiol.2017170924](https://doi.org/10.1148/radiol.2017170924)] [Medline: [28696184](https://pubmed.ncbi.nlm.nih.gov/28696184/)]
37. Moss JL, Murphy J, Filiaci VL, Wenzel LB, Minasian L, Temkin SM. Disparities in health-related quality of life in women undergoing treatment for advanced ovarian cancer: the role of individual-level and contextual social determinants. *Support Care Cancer* 2019 Feb 12;27(2):531-538 [FREE Full text] [doi: [10.1007/s00520-018-4340-9](https://doi.org/10.1007/s00520-018-4340-9)] [Medline: [30003341](https://pubmed.ncbi.nlm.nih.gov/30003341/)]
38. Vang S, Margolies LR, Jandorf L. Mobile Mammography Participation Among Medically Underserved Women: A Systematic Review. *Prev Chronic Dis* 2018 Nov 15;15:E140 [FREE Full text] [doi: [10.5888/pcd15.180291](https://doi.org/10.5888/pcd15.180291)] [Medline: [30447104](https://pubmed.ncbi.nlm.nih.gov/30447104/)]
39. Tarver WL, Haggstrom DA. The Use of Cancer-Specific Patient-Centered Technologies Among Underserved Populations in the United States: Systematic Review. *J Med Internet Res* 2019 Apr 23;21(4):e10256 [FREE Full text] [doi: [10.2196/10256](https://doi.org/10.2196/10256)] [Medline: [31012855](https://pubmed.ncbi.nlm.nih.gov/31012855/)]
40. Houghton LC, Howland RE, McDonald JA. Mobilizing Breast Cancer Prevention Research Through Smartphone Apps: A Systematic Review of the Literature. *Front Public Health* 2019 Nov 6;7:298 [FREE Full text] [doi: [10.3389/fpubh.2019.00298](https://doi.org/10.3389/fpubh.2019.00298)] [Medline: [31781525](https://pubmed.ncbi.nlm.nih.gov/31781525/)]
41. Uy C, Lopez J, Trinh-Shevrin C, Kwon S, Sherman S, Liang P. Text Messaging Interventions on Cancer Screening Rates: A Systematic Review. *J Med Internet Res* 2017 Aug 24;19(8):e296 [FREE Full text] [doi: [10.2196/jmir.7893](https://doi.org/10.2196/jmir.7893)] [Medline: [28838885](https://pubmed.ncbi.nlm.nih.gov/28838885/)]
42. Romeo A, Castelli L, Franco P. The Effect of COVID-19 on Radiation Oncology Professionals and Patients With Cancer: From Trauma to Psychological Growth. *Adv Radiat Oncol* 2020 Jul;5(4):705-706 [FREE Full text] [doi: [10.1016/j.adro.2020.04.024](https://doi.org/10.1016/j.adro.2020.04.024)] [Medline: [32395671](https://pubmed.ncbi.nlm.nih.gov/32395671/)]
43. Shanafelt T, Ripp J, Trockel M. Understanding and Addressing Sources of Anxiety Among Health Care Professionals During the COVID-19 Pandemic. *JAMA* 2020 Jun 02;323(21):2133-2134. [doi: [10.1001/jama.2020.5893](https://doi.org/10.1001/jama.2020.5893)] [Medline: [32259193](https://pubmed.ncbi.nlm.nih.gov/32259193/)]
44. Desideri I, Pilleron S, Battisti NML, Gomes F, de Glas N, Neuendorff NR, et al. Caring for older patients with cancer during the COVID-19 pandemic: A Young International Society of Geriatric Oncology (SIOG) global perspective. *J Geriatr Oncol* 2020 Sep;11(7):1175-1181 [FREE Full text] [doi: [10.1016/j.jgo.2020.05.001](https://doi.org/10.1016/j.jgo.2020.05.001)] [Medline: [32402764](https://pubmed.ncbi.nlm.nih.gov/32402764/)]
45. Maunder R, Lancee W, Balderson K, Bennett J, Borgundvaag B, Evans S, et al. Long-term psychological and occupational effects of providing hospital healthcare during SARS outbreak. *Emerg Infect Dis* 2006 Dec;12(12):1924-1932 [FREE Full text] [doi: [10.3201/eid1212.060584](https://doi.org/10.3201/eid1212.060584)] [Medline: [17326946](https://pubmed.ncbi.nlm.nih.gov/17326946/)]
46. Maunder R, Hunter J, Vincent L, Bennett J, Peladeau N, Leszcz M, et al. The immediate psychological and occupational impact of the 2003 SARS outbreak in a teaching hospital. *CMAJ* 2003 May 13;168(10):1245-1251. [Medline: [12743065](https://pubmed.ncbi.nlm.nih.gov/12743065/)]
47. Grace SL, Hershenfield K, Robertson E, Stewart DE. The occupational and psychosocial impact of SARS on academic physicians in three affected hospitals. *Psychosomatics* 2005 Sep;46(5):385-391 [FREE Full text] [doi: [10.1176/appi.psy.46.5.385](https://doi.org/10.1176/appi.psy.46.5.385)] [Medline: [16145182](https://pubmed.ncbi.nlm.nih.gov/16145182/)]
48. Chu D, Chen R, Ku C, Chou P. The impact of SARS on hospital performance. *BMC Health Serv Res* 2008 Nov 06;8(1):228 [FREE Full text] [doi: [10.1186/1472-6963-8-228](https://doi.org/10.1186/1472-6963-8-228)] [Medline: [18990210](https://pubmed.ncbi.nlm.nih.gov/18990210/)]
49. Segelov E, Underhill C, Prenen H, Karapetis C, Jackson C, Nott L, et al. Practical Considerations for Treating Patients With Cancer in the COVID-19 Pandemic. *JCO Oncology Practice* 2020 Aug;16(8):467-482. [doi: [10.1200/op.20.00229](https://doi.org/10.1200/op.20.00229)]
50. Meti N, Rossos PG, Cheung MC, Singh S. Virtual Cancer Care During and Beyond the COVID-19 Pandemic: We Need to Get It Right. *JCO Oncology Practice* 2020 Sep;16(9):527-529. [doi: [10.1200/op.20.00281](https://doi.org/10.1200/op.20.00281)]
51. Cole AM, Pflugeisen B, Schwartz MR, Miller SC. Cross sectional study to assess the accuracy of electronic health record data to identify patients in need of lung cancer screening. *BMC Res Notes* 2018 Jan 10;11(1):14 [FREE Full text] [doi: [10.1186/s13104-018-3124-0](https://doi.org/10.1186/s13104-018-3124-0)] [Medline: [29321038](https://pubmed.ncbi.nlm.nih.gov/29321038/)]
52. Marino M, Angier H, Valenzuela S, Hoopes M, Killerby M, Blackburn B, et al. Medicaid coverage accuracy in electronic health records. *Prev Med Rep* 2018 Sep;11:297-304 [FREE Full text] [doi: [10.1016/j.pmedr.2018.07.009](https://doi.org/10.1016/j.pmedr.2018.07.009)] [Medline: [30116701](https://pubmed.ncbi.nlm.nih.gov/30116701/)]
53. Hospitals and health systems face unprecedented financial pressures due to COVID-19. American Hospital Association. 2020 May. URL: <https://www.aha.org/guidesreports/2020-05-05-hospitals-and-health-systems-face-unprecedented-financial-pressure-due> [accessed 2020-09-01]
54. Petersen LA, Woodard LD, Urech T, Daw C, Sookanan S. Does pay-for-performance improve the quality of health care? *Ann Intern Med* 2006 Aug 15;145(4):265-272. [doi: [10.7326/0003-4819-145-4-200608150-00006](https://doi.org/10.7326/0003-4819-145-4-200608150-00006)] [Medline: [16908917](https://pubmed.ncbi.nlm.nih.gov/16908917/)]

55. Green E, Peterson KS, Markiewicz K, O'Brien J, Aarring NM. Cautionary study on the effects of pay for performance on quality of care: a pilot randomised controlled trial using standardised patients. *BMJ Qual Saf* 2020 Aug 06;29(8):664-671. [doi: [10.1136/bmjqs-2019-010260](https://doi.org/10.1136/bmjqs-2019-010260)] [Medline: [31907323](https://pubmed.ncbi.nlm.nih.gov/31907323/)]
56. The employment situation—September 2020. US Bureau of Labor Statistics. 2020 Oct 2. URL: <https://www.bls.gov/news.release/pdf/empst.pdf> [accessed 2020-10-19]
57. Bednarczyk RA, Chu SL, Sickler H, Shaw J, Nadeau JA, McNutt L. Low uptake of influenza vaccine among university students: Evaluating predictors beyond cost and safety concerns. *Vaccine* 2015 Mar 30;33(14):1659-1663. [doi: [10.1016/j.vaccine.2015.02.033](https://doi.org/10.1016/j.vaccine.2015.02.033)] [Medline: [25728320](https://pubmed.ncbi.nlm.nih.gov/25728320/)]
58. Cronholm PF, Bowman MA. Women with safety concerns report fewer gender-specific preventive healthcare services. *J Womens Health (Larchmt)* 2009 Jul;18(7):1011-1018. [doi: [10.1089/jwh.2008.0968](https://doi.org/10.1089/jwh.2008.0968)] [Medline: [19563248](https://pubmed.ncbi.nlm.nih.gov/19563248/)]
59. Akbar S, Coiera E, Magrabi F. Safety concerns with consumer-facing mobile health applications and their consequences: a scoping review. *J Am Med Inform Assoc* 2020 Feb 01;27(2):330-340 [FREE Full text] [doi: [10.1093/jamia/ocz175](https://doi.org/10.1093/jamia/ocz175)] [Medline: [31599936](https://pubmed.ncbi.nlm.nih.gov/31599936/)]
60. Sun P, Lu X, Xu C, Sun W, Pan B. Understanding of COVID-19 based on current evidence. *J Med Virol* 2020 Jun 05;92(6):548-551 [FREE Full text] [doi: [10.1002/jmv.25722](https://doi.org/10.1002/jmv.25722)] [Medline: [32096567](https://pubmed.ncbi.nlm.nih.gov/32096567/)]
61. Dowd JB, Andriano L, Brazel DM, Rotondi V, Block P, Ding X, et al. Demographic science aids in understanding the spread and fatality rates of COVID-19. *Proc Natl Acad Sci U S A* 2020 May 05;117(18):9696-9698 [FREE Full text] [doi: [10.1073/pnas.2004911117](https://doi.org/10.1073/pnas.2004911117)] [Medline: [32300018](https://pubmed.ncbi.nlm.nih.gov/32300018/)]
62. Muggah E, Graves E, Bennett C, Manuel DG. Ascertainment of chronic diseases using population health data: a comparison of health administrative data and patient self-report. *BMC Public Health* 2013 Jan 09;13(1):16 [FREE Full text] [doi: [10.1186/1471-2458-13-16](https://doi.org/10.1186/1471-2458-13-16)] [Medline: [23302258](https://pubmed.ncbi.nlm.nih.gov/23302258/)]
63. Beaglehole R, Epping-Jordan J, Patel V, Chopra M, Ebrahim S, Kidd M, et al. Improving the prevention and management of chronic disease in low-income and middle-income countries: a priority for primary health care. *The Lancet* 2008 Sep;372(9642):940-949. [doi: [10.1016/s0140-6736\(08\)61404-x](https://doi.org/10.1016/s0140-6736(08)61404-x)]
64. Wendimagegn NF, Bezuidenhout M. The integrated health service model: the approach to restrain the vicious cycle to chronic diseases. *BMC Health Serv Res* 2019 May 31;19(1):347 [FREE Full text] [doi: [10.1186/s12913-019-4179-x](https://doi.org/10.1186/s12913-019-4179-x)] [Medline: [31151451](https://pubmed.ncbi.nlm.nih.gov/31151451/)]
65. Nomura S, Parsons AJ, Hirabayashi M, Kinoshita R, Liao Y, Hodgson S. Social determinants of mid- to long-term disaster impacts on health: A systematic review. *International Journal of Disaster Risk Reduction* 2016 Jun;16:53-67. [doi: [10.1016/j.ijdrr.2016.01.013](https://doi.org/10.1016/j.ijdrr.2016.01.013)]
66. Prüss-Ustün A, Wolf J, Corvalán C, Neville T, Bos R, Neira M. Diseases due to unhealthy environments: an updated estimate of the global burden of disease attributable to environmental determinants of health. *J Public Health (Oxf)* 2017 Sep 01;39(3):464-475 [FREE Full text] [doi: [10.1093/pubmed/fdw085](https://doi.org/10.1093/pubmed/fdw085)] [Medline: [27621336](https://pubmed.ncbi.nlm.nih.gov/27621336/)]
67. Ruckert A, Labonté R. Health inequities in the age of austerity: The need for social protection policies. *Soc Sci Med* 2017 Aug;187:306-311. [doi: [10.1016/j.socscimed.2017.03.029](https://doi.org/10.1016/j.socscimed.2017.03.029)] [Medline: [28359581](https://pubmed.ncbi.nlm.nih.gov/28359581/)]
68. Cockerham WC, Hamby BW, Oates GR. The Social Determinants of Chronic Disease. *Am J Prev Med* 2017 Jan;52(1S1):S5-S12 [FREE Full text] [doi: [10.1016/j.amepre.2016.09.010](https://doi.org/10.1016/j.amepre.2016.09.010)] [Medline: [27989293](https://pubmed.ncbi.nlm.nih.gov/27989293/)]
69. Rosland A, Kieffer EC, Tipirneni R, Kullgren JT, Kirch M, Arntson EK, et al. Diagnosis and Care of Chronic Health Conditions Among Medicaid Expansion Enrollees: a Mixed-Methods Observational Study. *J Gen Intern Med* 2019 Nov 11;34(11):2549-2558. [doi: [10.1007/s11606-019-05323-w](https://doi.org/10.1007/s11606-019-05323-w)] [Medline: [31512184](https://pubmed.ncbi.nlm.nih.gov/31512184/)]
70. Maringe C, Spicer J, Morris M, Purushotham A, Nolte E, Sullivan R, et al. The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study. *The Lancet Oncology* 2020 Aug;21(8):1023-1034. [doi: [10.1016/s1470-2045\(20\)30388-0](https://doi.org/10.1016/s1470-2045(20)30388-0)]
71. Sharpless NE. COVID-19 and cancer. *Science* 2020 Jun 19;368(6497):1290-1290. [doi: [10.1126/science.abd3377](https://doi.org/10.1126/science.abd3377)] [Medline: [32554570](https://pubmed.ncbi.nlm.nih.gov/32554570/)]
72. COVID-19 significantly impacts health services for noncommunicable diseases. World Health Organization. 2020 Jun 1. URL: <https://www.who.int/news-room/detail/01-06-2020-covid-19-significantly-impacts-health-services-for-noncommunicable-diseases> [accessed 2020-09-01]
73. Kaufman HW, Chen Z, Niles J, Fesko Y. Changes in the Number of US Patients With Newly Identified Cancer Before and During the Coronavirus Disease 2019 (COVID-19) Pandemic. *JAMA Netw Open* 2020 Aug 03;3(8):e2017267 [FREE Full text] [doi: [10.1001/jamanetworkopen.2020.17267](https://doi.org/10.1001/jamanetworkopen.2020.17267)] [Medline: [32749465](https://pubmed.ncbi.nlm.nih.gov/32749465/)]
74. Dinmohamed AG, Visser O, Verhoeven RHA, Louwman MWJ, van Nederveen FH, Willems SM, et al. Fewer cancer diagnoses during the COVID-19 epidemic in the Netherlands. *The Lancet Oncology* 2020 Jun;21(6):750-751. [doi: [10.1016/s1470-2045\(20\)30265-5](https://doi.org/10.1016/s1470-2045(20)30265-5)]
75. Total Expenses and Percent Distribution Selected Conditions by Source of Payment: United States, 2014 (generated interactively). Agency for Healthcare Research and Quality. URL: <https://bit.ly/3o7ZW1h> [accessed 2020-09-01]
76. Chowkwanyun M, Reed AL. Racial Health Disparities and Covid-19 — Caution and Context. *N Engl J Med* 2020 Jul 16;383(3):201-203. [doi: [10.1056/nejmp2012910](https://doi.org/10.1056/nejmp2012910)]

77. United Nations Development Programme. Gender-based violence and COVID-19. United Nations. 2020 May 11. URL: <https://www.undp.org/content/undp/en/home/librarypage/womens-empowerment/gender-based-violence-and-covid-19.html> [accessed 2020-09-01]
78. Bhala N, Curry G, Martineau AR, Agyemang C, Bhopal R. Sharpening the global focus on ethnicity and race in the time of COVID-19. *The Lancet* 2020 May;395(10238):1673-1676. [doi: [10.1016/s0140-6736\(20\)31102-8](https://doi.org/10.1016/s0140-6736(20)31102-8)]
79. Aldridge RW, Lewer D, Katikireddi SV, Mathur R, Pathak N, Burns R, et al. Black, Asian and Minority Ethnic groups in England are at increased risk of death from COVID-19: indirect standardisation of NHS mortality data. *Wellcome Open Res* 2020 May 6;5:88. [doi: [10.12688/wellcomeopenres.15922.1](https://doi.org/10.12688/wellcomeopenres.15922.1)]
80. Nardi C, Sandhu P, Selix N. Cervical Cancer Screening Among Minorities in the United States. *The Journal for Nurse Practitioners* 2016 Nov;12(10):675-682. [doi: [10.1016/j.nurpra.2016.08.036](https://doi.org/10.1016/j.nurpra.2016.08.036)]
81. Carter-Harris L, Slaven JE, Monahan PO, Shedd-Steele R, Hanna N, Rawl SM. Understanding lung cancer screening behavior: Racial, gender, and geographic differences among Indiana long-term smokers. *Prev Med Rep* 2018 Jun;10:49-54 [FREE Full text] [doi: [10.1016/j.pmedr.2018.01.018](https://doi.org/10.1016/j.pmedr.2018.01.018)] [Medline: [29552458](https://pubmed.ncbi.nlm.nih.gov/29552458/)]
82. Tabaac AR, Sutter ME, Wall CS, Baker KE. Gender Identity Disparities in Cancer Screening Behaviors. *Am J Prev Med* 2018 Mar;54(3):385-393. [doi: [10.1016/j.amepre.2017.11.009](https://doi.org/10.1016/j.amepre.2017.11.009)] [Medline: [29338956](https://pubmed.ncbi.nlm.nih.gov/29338956/)]
83. Eke R, Tariq T, Li T, Irfan FB. Colorectal cancer screening in hospitalized patients: results from the Nationwide Inpatient Sample. *European Journal of Cancer Prevention* 2019;28(5):413-419. [doi: [10.1097/cej.0000000000000488](https://doi.org/10.1097/cej.0000000000000488)]
84. Akinlotan M, Bolin JN, Helduser J, Ojinnaka C, Lichorad A, McClellan D. Cervical Cancer Screening Barriers and Risk Factor Knowledge Among Uninsured Women. *J Community Health* 2017 Aug 2;42(4):770-778 [FREE Full text] [doi: [10.1007/s10900-017-0316-9](https://doi.org/10.1007/s10900-017-0316-9)] [Medline: [28155005](https://pubmed.ncbi.nlm.nih.gov/28155005/)]
85. Sharma KP, DeGroff A, Scott L, Shrestha S, Melillo S, Sabatino SA. Correlates of colorectal cancer screening rates in primary care clinics serving low income, medically underserved populations. *Prev Med* 2019 Sep;126:105774 [FREE Full text] [doi: [10.1016/j.yjmed.2019.105774](https://doi.org/10.1016/j.yjmed.2019.105774)] [Medline: [31319118](https://pubmed.ncbi.nlm.nih.gov/31319118/)]
86. Efuni E, Schofield E, Duhamel KN, Villagra C, Cohen N, Reid F, et al. Optimism, Worry, and Colorectal Cancer Screening among Low-income Latinos. *Health Behavior and Policy Review* 2018 Mar 01;5(2):23-32. [doi: [10.14485/hbpr.5.2.3](https://doi.org/10.14485/hbpr.5.2.3)]
87. Liang W, Guan W, Chen R, Wang W, Li J, Xu K, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. *The Lancet Oncology* 2020 Mar;21(3):335-337. [doi: [10.1016/s1470-2045\(20\)30096-6](https://doi.org/10.1016/s1470-2045(20)30096-6)]
88. Mandelblatt J, Andrews H, Kao R, Wallace R, Kerner J. The late-stage diagnosis of colorectal cancer: demographic and socioeconomic factors. *Am J Public Health* 1996 Dec;86(12):1794-1797. [doi: [10.2105/ajph.86.12.1794](https://doi.org/10.2105/ajph.86.12.1794)] [Medline: [9003140](https://pubmed.ncbi.nlm.nih.gov/9003140/)]
89. Negi NJ, Swanberg JE, Clouser JM, Harmon-Darrow C. Working under conditions of social vulnerability: Depression among Latina/o immigrant horse workers. *Cultur Divers Ethnic Minor Psychol* 2020 Jan;26(1):54-60. [doi: [10.1037/cdp0000276](https://doi.org/10.1037/cdp0000276)] [Medline: [31021147](https://pubmed.ncbi.nlm.nih.gov/31021147/)]
90. Humphrey J, Lindstrom M, Barton K, Shrestha P, Carlton E, Adgate J, et al. Social and Environmental Neighborhood Typologies and Lung Function in a Low-Income, Urban Population. *Int J Environ Res Public Health* 2019 Mar 29;16(7):1133. [doi: [10.3390/ijerph16071133](https://doi.org/10.3390/ijerph16071133)] [Medline: [30934853](https://pubmed.ncbi.nlm.nih.gov/30934853/)]
91. Fujishiro K, MacDonald LA, Howard VJ. Job complexity and hazardous working conditions: How do they explain educational gradient in mortality? *J Occup Health Psychol* 2020 Jun;25(3):176-186. [doi: [10.1037/ocp0000171](https://doi.org/10.1037/ocp0000171)] [Medline: [31566401](https://pubmed.ncbi.nlm.nih.gov/31566401/)]
92. Lin J, Rodriguez S, Zhou H, Sparks AD, Simmens SJ, Amdur R. Racial disparities in late-stage prostate cancer: A SEER database analysis 2005–2015. *JCO* 2019 Mar 01;37(7_suppl):115-115. [doi: [10.1200/jco.2019.37.7_suppl.115](https://doi.org/10.1200/jco.2019.37.7_suppl.115)]
93. Amini A, Jones B, Yeh N, Guntupalli S, Kavanagh B, Karam S, et al. Disparities in disease presentation in the four screenable cancers according to health insurance status. *Public Health* 2016 Sep;138:50-56. [doi: [10.1016/j.puhe.2016.03.014](https://doi.org/10.1016/j.puhe.2016.03.014)] [Medline: [27091437](https://pubmed.ncbi.nlm.nih.gov/27091437/)]
94. Yang DX, Soulos PR, Davis B, Gross CP, Yu JB. Impact of Widespread Cervical Cancer Screening: Number of Cancers Prevented and Changes in Race-specific Incidence. *Am J Clin Oncol* 2018 Mar;41(3):289-294 [FREE Full text] [doi: [10.1097/COC.0000000000000264](https://doi.org/10.1097/COC.0000000000000264)] [Medline: [26808257](https://pubmed.ncbi.nlm.nih.gov/26808257/)]
95. Saumoy M, Schneider Y, Shen N, Kahaleh M, Sharaiha RZ, Shah SC. Cost Effectiveness of Gastric Cancer Screening According to Race and Ethnicity. *Gastroenterology* 2018 Sep;155(3):648-660. [doi: [10.1053/j.gastro.2018.05.026](https://doi.org/10.1053/j.gastro.2018.05.026)] [Medline: [29778607](https://pubmed.ncbi.nlm.nih.gov/29778607/)]
96. Roesch E, Amin A, Gupta J, García-Moreno C. Violence against women during covid-19 pandemic restrictions. *BMJ* 2020 May 07;369:m1712. [doi: [10.1136/bmj.m1712](https://doi.org/10.1136/bmj.m1712)] [Medline: [32381644](https://pubmed.ncbi.nlm.nih.gov/32381644/)]
97. Allen-Ebrahimian B. China's domestic violence epidemic. *Axios*. 2020 May 7. URL: <https://www.axios.com/china-domestic-violence-coronavirus-quarantine-7b00c3ba-35bc-4d16-afdd-b76ecfb28882.html> [accessed 2020-09-01]
98. Taub A. A new Covid-19 crisis: Domestic abuse rises worldwide. *The New York Times*. 2020 Apr 14. URL: <https://www.nytimes.com/2020/04/06/world/coronavirus-domestic-violence.html> [accessed 2020-09-01]
99. Peterman A, Potts A, O'Donnell M, Thompson K, Shah N, Oertelt-Prigione S, et al. Pandemics and violence against women and children. Washington, DC: Center for Global Development; 2020 Apr. URL: https://www.researchgate.net/publication/341654631_Pandemics_and_Violence_Against_Women_and_Children [accessed 2020-09-01]
100. WHO, Department of Reproductive Health and Research, London School of Hygiene and Tropical Medicine, South African Medical Research Council. Global and regional estimates of violence against women: Prevalence and health effects of

- intimate partner violence and nonpartner sexual violence. World Health Organization. 2013. URL: <https://www.who.int/reproductivehealth/publications/violence/9789241564625/en/> [accessed 2020-09-01]
101. Work experience-people 15 years old and over, by total money earnings, age, race, Hispanic origin, sex, and disability status. United States Census Bureau. 2020. URL: <https://www.census.gov/data/tables/time-series/demo/income-poverty/cps-pinc/pinc-05.html> [accessed 2020-09-01]
 102. Levinson KL, Jernigan AM, Flocke SA, Tergas AI, Gunderson CC, Huh WK, et al. Intimate partner violence and barriers to cervical cancer screening: A gynecologic oncology fellow research network study. *Journal of Lower Genital Tract Disease* 2016;20(1):47-51. [doi: [10.1097/igt.0000000000000153](https://doi.org/10.1097/igt.0000000000000153)]
 103. Massetti GM, Townsend JS, Thomas CC, Basile KC, Richardson LC. Healthcare Access and Cancer Screening Among Victims of Intimate Partner Violence. *J Womens Health (Larchmt)* 2018 May;27(5):607-614 [FREE Full text] [doi: [10.1089/jwh.2017.6402](https://doi.org/10.1089/jwh.2017.6402)] [Medline: [28880705](https://pubmed.ncbi.nlm.nih.gov/28880705/)]
 104. Coker AL, Hopenhayn C, DeSimone CP, Bush HM, Crofford L. Violence against Women Raises Risk of Cervical Cancer. *J Womens Health (Larchmt)* 2009 Aug;18(8):1179-1185. [doi: [10.1089/jwh.2008.1048](https://doi.org/10.1089/jwh.2008.1048)] [Medline: [19630537](https://pubmed.ncbi.nlm.nih.gov/19630537/)]
 105. Alcalá HE, Mitchell E, Keim-Malpass J. Adverse Childhood Experiences and Cervical Cancer Screening. *J Womens Health (Larchmt)* 2017 Jan;26(1):58-63. [doi: [10.1089/jwh.2016.5823](https://doi.org/10.1089/jwh.2016.5823)] [Medline: [27500413](https://pubmed.ncbi.nlm.nih.gov/27500413/)]
 106. Reingle Gonzalez JM, Jetelina KK, Olague S, Wondrack JG. Violence against women increases cancer diagnoses: Results from a meta-analytic review. *Prev Med* 2018 Sep;114:168-179. [doi: [10.1016/j.ypmed.2018.07.008](https://doi.org/10.1016/j.ypmed.2018.07.008)] [Medline: [29981792](https://pubmed.ncbi.nlm.nih.gov/29981792/)]
 107. Guillaume E, Launay L, Dejardin O, Bouvier V, Guittet L, Déan P, et al. Could mobile mammography reduce social and geographic inequalities in breast cancer screening participation? *Prev Med* 2017 Jul;100:84-88. [doi: [10.1016/j.ypmed.2017.04.006](https://doi.org/10.1016/j.ypmed.2017.04.006)] [Medline: [28408217](https://pubmed.ncbi.nlm.nih.gov/28408217/)]
 108. O'Donoghue D, Sheahan K, MacMathuna P, Stephens RB, Fenlon H, Morrin M, et al. A National Bowel Cancer Screening Programme using FIT: Achievements and Challenges. *Cancer Prev Res* 2019 Feb 05;12(2):89-94. [doi: [10.1158/1940-6207.capr-18-0182](https://doi.org/10.1158/1940-6207.capr-18-0182)]
 109. Levin TR, Corley DA, Jensen CD, Schottinger JE, Quinn VP, Zauber AG, et al. Effects of Organized Colorectal Cancer Screening on Cancer Incidence and Mortality in a Large Community-Based Population. *Gastroenterology* 2018 Nov;155(5):1383-1391.e5 [FREE Full text] [doi: [10.1053/j.gastro.2018.07.017](https://doi.org/10.1053/j.gastro.2018.07.017)] [Medline: [30031768](https://pubmed.ncbi.nlm.nih.gov/30031768/)]
 110. Jessup DL, Glover Iv M, Daye D, Banzi L, Jones P, Choy G, et al. Implementation of Digital Awareness Strategies to Engage Patients and Providers in a Lung Cancer Screening Program: Retrospective Study. *J Med Internet Res* 2018 Feb 15;20(2):e52 [FREE Full text] [doi: [10.2196/jmir.8932](https://doi.org/10.2196/jmir.8932)] [Medline: [29449199](https://pubmed.ncbi.nlm.nih.gov/29449199/)]
 111. Harty NM, Le Grice K, Cahill C, Bull S, Dwyer A. EndCancer: development and pilot testing of multimedia recruitment for a text message campaign to increase cancer screening. *Mhealth* 2018 Oct;4:50-50 [FREE Full text] [doi: [10.21037/mhealth.2018.10.02](https://doi.org/10.21037/mhealth.2018.10.02)] [Medline: [30505848](https://pubmed.ncbi.nlm.nih.gov/30505848/)]
 112. Guo T, Fan Y, Chen M, Wu X, Zhang L, He T, et al. Cardiovascular Implications of Fatal Outcomes of Patients With Coronavirus Disease 2019 (COVID-19). *JAMA Cardiol* 2020 Jul 01;5(7):811-818 [FREE Full text] [doi: [10.1001/jamacardio.2020.1017](https://doi.org/10.1001/jamacardio.2020.1017)] [Medline: [32219356](https://pubmed.ncbi.nlm.nih.gov/32219356/)]
 113. Xia Y, Jin R, Zhao J, Li W, Shen H. Risk of COVID-19 for patients with cancer. *The Lancet Oncology* 2020 Apr;21(4):e180. [doi: [10.1016/s1470-2045\(20\)30150-9](https://doi.org/10.1016/s1470-2045(20)30150-9)]
 114. Zhang L, Zhu F, Xie L, Wang C, Wang J, Chen R, et al. Clinical characteristics of COVID-19-infected cancer patients: a retrospective case study in three hospitals within Wuhan, China. *Ann Oncol* 2020 Jul;31(7):894-901 [FREE Full text] [doi: [10.1016/j.annonc.2020.03.296](https://doi.org/10.1016/j.annonc.2020.03.296)] [Medline: [32224151](https://pubmed.ncbi.nlm.nih.gov/32224151/)]
 115. Ahmed F, Ahmed N, Pissarides C, Stiglitz J. Why inequality could spread COVID-19. *The Lancet Public Health* 2020 May;5(5):e240. [doi: [10.1016/s2468-2667\(20\)30085-2](https://doi.org/10.1016/s2468-2667(20)30085-2)]
 116. Kuderer N, Choueiri T, Shah D, Shyr Y, Rubinstein S, Rivera D, et al. Clinical impact of COVID-19 on patients with cancer (CCC19): a cohort study. *The Lancet* 2020 Jun;395(10241):1907-1918. [doi: [10.1016/S0140-6736\(20\)31187-9](https://doi.org/10.1016/S0140-6736(20)31187-9)]
 117. Sirintrapun SJ, Lopez AM. Telemedicine in Cancer Care. *American Society of Clinical Oncology Educational Book* 2018 May(38):540-545. [doi: [10.1200/edbk_200141](https://doi.org/10.1200/edbk_200141)]
 118. Fertleman C, Aubugeau-Williams P, Sher C, Lim A, Lumley S, Delacroix S, et al. A Discussion of Virtual Reality As a New Tool for Training Healthcare Professionals. *Front Public Health* 2018 Feb 26;6:44 [FREE Full text] [doi: [10.3389/fpubh.2018.00044](https://doi.org/10.3389/fpubh.2018.00044)] [Medline: [29535997](https://pubmed.ncbi.nlm.nih.gov/29535997/)]
 119. Mette L, Saldívar AMP, Poullard N, Torres I, Seth S, Pollock B, et al. Reaching high-risk underserved individuals for cancer genetic counseling by video-teleconferencing. *J Community Support Oncol* 2016 Apr;14(4):162-168. [doi: [10.12788/jcso.0247](https://doi.org/10.12788/jcso.0247)] [Medline: [27152515](https://pubmed.ncbi.nlm.nih.gov/27152515/)]
 120. Strehle EM, Shabde N. One hundred years of telemedicine: does this new technology have a place in paediatrics? *Arch Dis Child* 2006 Dec 28;91(12):956-959 [FREE Full text] [doi: [10.1136/adc.2006.099622](https://doi.org/10.1136/adc.2006.099622)] [Medline: [17119071](https://pubmed.ncbi.nlm.nih.gov/17119071/)]
 121. Telemedicine: Opportunities and developments in member states. World Health Organization. 2010. URL: https://www.who.int/goe/publications/goe_telemedicine_2010.pdf [accessed 2020-09-01]
 122. Lewis GD, Hatch SS, Wiederhold LR, Swanson TA. Long-Term Institutional Experience With Telemedicine Services for Radiation Oncology: A Potential Model for Long-Term Utilization. *Adv Radiat Oncol* 2020 Jul;5(4):780-782 [FREE Full text] [doi: [10.1016/j.adro.2020.04.018](https://doi.org/10.1016/j.adro.2020.04.018)] [Medline: [32391444](https://pubmed.ncbi.nlm.nih.gov/32391444/)]

123. Ochs M, Mestre D, de Montcheuil G, Pergandi J, Saubesty J, Lombardo E, et al. Training doctors' social skills to break bad news: evaluation of the impact of virtual environment displays on the sense of presence. *J Multimodal User Interfaces* 2019 Jan 4;13(1):41-51. [doi: [10.1007/s12193-018-0289-8](https://doi.org/10.1007/s12193-018-0289-8)]
124. Lopez AM. Telemedicine, telehealth, and e-Health technologies in cancer prevention. In: Alberts DS, Hess LM, editors. *Fundamentals of Cancer Prevention*. Cham: Springer International Publishing; 2019:333-352.
125. Mendu S, Boukhechba M, Gordon J, Datta D, Molina E, Arroyo G, et al. Design of a Culturally-Informed Virtual Human for Educating Hispanic Women about Cervical Cancer. *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare* 2018 May;2018:360-366 [FREE Full text] [doi: [10.1145/3240925.3240968](https://doi.org/10.1145/3240925.3240968)] [Medline: [30555731](https://pubmed.ncbi.nlm.nih.gov/30555731/)]
126. Liang B, Yang N, He G, Huang P, Yang Y. Identification of the Facial Features of Patients With Cancer: A Deep Learning-Based Pilot Study. *J Med Internet Res* 2020 Apr 29;22(4):e17234 [FREE Full text] [doi: [10.2196/17234](https://doi.org/10.2196/17234)] [Medline: [32347802](https://pubmed.ncbi.nlm.nih.gov/32347802/)]
127. The rise of the data-driven physician. Stanford University. 2020. URL: <https://med.stanford.edu/content/dam/sm/school/documents/Health-Trends-Report/Stanford%20Medicine%20Health%20Trends%20Report%202020.pdf> [accessed 2020-10-16]
128. Lee A, Moy L, Kruck SE, Rabang J. The doctor is in, but is academia? Re-tooling IT education for a new era in healthcare. *Journal of Information Systems Education* 2014;25(4):275-282 [FREE Full text]
129. Carroll N, Richardson I, Moloney M, O'Reilly P. Bridging healthcare education and technology solution development through experiential innovation. *Health Technol* 2017 Nov 7;8(4):255-261. [doi: [10.1007/s12553-017-0209-z](https://doi.org/10.1007/s12553-017-0209-z)]
130. Botrugno C. Information technologies in healthcare: Enhancing or dehumanising doctor-patient interaction? *Health (London)* 2019 Dec 18;1363459319891213. [doi: [10.1177/1363459319891213](https://doi.org/10.1177/1363459319891213)] [Medline: [31849239](https://pubmed.ncbi.nlm.nih.gov/31849239/)]
131. Bidgoli H. Successful Integration of Information Technology in Healthcare: Guides for Managers. *JSIS* 2018 Sep 1;13(3):e. [doi: [10.33423/jsis.v13i3.615](https://doi.org/10.33423/jsis.v13i3.615)]
132. Mobile fact sheet. Pew Research Center. 2019 Jun 12. URL: <https://www.pewresearch.org/internet/fact-sheet/mobile/> [accessed 2020-09-01]
133. mHealth Economics 2017/2018 – Connectivity in Digital Health. Research 2 Guidance. 2018. URL: <https://research2guidance.com/product/connectivity-in-digital-health/> [accessed 2020-09-01]
134. Gordon WJ, Landman A, Zhang H, Bates DW. Beyond validation: getting health apps into clinical practice. *NPJ Digit Med* 2020 Feb 3;3(1):14 [FREE Full text] [doi: [10.1038/s41746-019-0212-z](https://doi.org/10.1038/s41746-019-0212-z)] [Medline: [32047860](https://pubmed.ncbi.nlm.nih.gov/32047860/)]
135. Noar SM, Harrington NG, Aldrich RS. The Role of Message Tailoring in the Development of Persuasive Health Communication Messages. *Annals of the International Communication Association* 2016 May 18;33(1):73-133. [doi: [10.1080/23808985.2009.11679085](https://doi.org/10.1080/23808985.2009.11679085)]
136. Wakefield MA, Loken B, Hornik RC. Use of mass media campaigns to change health behaviour. *The Lancet* 2010 Oct;376(9748):1261-1271. [doi: [10.1016/s0140-6736\(10\)60809-4](https://doi.org/10.1016/s0140-6736(10)60809-4)]
137. Key TM, Czaplewski AJ. Upstream social marketing strategy: An integrated marketing communications approach. *Business Horizons* 2017 May;60(3):325-333. [doi: [10.1016/j.bushor.2017.01.006](https://doi.org/10.1016/j.bushor.2017.01.006)]
138. Patti C, Hartley S, van Dessel M, Baack D. Improving integrated marketing communications practices: A comparison of objectives and results. *Journal of Marketing Communications* 2015 Apr 23;23(4):351-370. [doi: [10.1080/13527266.2015.1027251](https://doi.org/10.1080/13527266.2015.1027251)]
139. Merrill RM, Telford CT. Pharmaceutical use according to participation in worksite wellness screening and health campaigns. *Prev Med Rep* 2018 Dec;12:158-163 [FREE Full text] [doi: [10.1016/j.pmedr.2018.09.008](https://doi.org/10.1016/j.pmedr.2018.09.008)] [Medline: [30263886](https://pubmed.ncbi.nlm.nih.gov/30263886/)]
140. Springer SM, McFall A, Hager P, Percy-Laury A, Vinson CA. Lung cancer screening: an emerging cancer control issue presents opportunities for an awareness campaign in rural Michigan. *Cancer Causes Control* 2018 Dec 18;29(12):1257-1263. [doi: [10.1007/s10552-018-1080-6](https://doi.org/10.1007/s10552-018-1080-6)] [Medline: [30229401](https://pubmed.ncbi.nlm.nih.gov/30229401/)]
141. Shaukat A, Church T. Colorectal cancer screening in the USA in the wake of COVID-19. 2020 Aug;5(8):726-727. [doi: [10.1016/s2468-1253\(20\)30191-6](https://doi.org/10.1016/s2468-1253(20)30191-6)]
142. Nodora J, Gupta S, Howard N, Motadel K, Propst T, Rodriguez J, et al. The COVID-19 Pandemic: Identifying Adaptive Solutions for Colorectal Cancer Screening in Underserved Communities. *J Natl Cancer Inst* 2020 Aug 11;2020 [FREE Full text] [doi: [10.1093/jnci/djaa117](https://doi.org/10.1093/jnci/djaa117)] [Medline: [32780851](https://pubmed.ncbi.nlm.nih.gov/32780851/)]
143. Del Vecchio Blanco G, Calabrese E, Biancone L, Monteleone G, Paoluzi OA. The impact of COVID-19 pandemic in the colorectal cancer prevention. *Int J Colorectal Dis* 2020 Oct 04;35(10):1951-1954 [FREE Full text] [doi: [10.1007/s00384-020-03635-6](https://doi.org/10.1007/s00384-020-03635-6)] [Medline: [32500432](https://pubmed.ncbi.nlm.nih.gov/32500432/)]

Abbreviations

AI: artificial intelligence

FIT: fecal immunochemical test

LGBTQ: lesbian, gay, bisexual, transgender, and queer or questioning

mHealth: mobile health

QALY: quality-adjusted life year
SARS: severe acute respiratory syndrome
SES: socioeconomic status

Edited by G Eysenbach; submitted 24.06.20; peer-reviewed by P Sun, P Zou; comments to author 11.08.20; revised version received 24.09.20; accepted 30.09.20; published 29.10.20.

Please cite as:

*Cancino RS, Su Z, Mesa R, Tomlinson GE, Wang J
The Impact of COVID-19 on Cancer Screening: Challenges and Opportunities
JMIR Cancer 2020;6(2):e21697
URL: <http://cancer.jmir.org/2020/2/e21697/>
doi: [10.2196/21697](https://doi.org/10.2196/21697)
PMID: [33027039](https://pubmed.ncbi.nlm.nih.gov/33027039/)*

©Ramon S Cancino, Zhaohui Su, Ruben Mesa, Gail E Tomlinson, Jing Wang. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 29.10.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Information Needs About Cancer Treatment, Fertility, and Pregnancy: Qualitative Descriptive Study of Reddit Threads

Ria Garg^{1,2*}, BSc; Nevena Rebić^{1,2,3*}, BSc(Pharm); Mary A De Vera^{1,2,3*}, PhD

¹Faculty of Pharmaceutical Sciences, University of British Columbia, Vancouver, BC, Canada

²Collaboration for Outcomes Research and Evaluation, University of British Columbia, Vancouver, BC, Canada

³Arthritis Research Canada, Richmond, BC, Canada

* all authors contributed equally

Corresponding Author:

Mary A De Vera, PhD

Faculty of Pharmaceutical Sciences

University of British Columbia

2405 Wesbrook Mall

Vancouver, BC

Canada

Phone: 1 604 207 040

Email: mdevera@mail.ubc.ca

Abstract

Background: A reproductive health implication of the increasing incidence of cancer among women is the impact of cancer treatment on fertility.

Objective: As patients are increasingly using the internet, particularly online forums, to seek and share experiences, our objective was to understand information needs about cancer treatment, fertility, and pregnancy of women with cancer as well as their caregivers.

Methods: We searched threads (original posts and responses) on four subreddit sites of Reddit (“r/Cancer,” “r/TryingForABaby,” “r/BabyBumps,” and “r/Infertility”) over a 5 - year period between February 4th, 2014 and February 4th, 2019. Threads with original posts involving a lived experience or question regarding cancer treatment and female fertility and/or pregnancy or parenting/having children from the perspective of either patient or caregiver were included in our analysis. We analyzed threads using thematic analysis.

Results: From 963 Reddit threads identified, 69 were analyzed, including 56 with original posts by women with cancer and 13 with original posts by caregivers. From threads made by patients, we identified themes on becoming a part of an online community, impacts of cancer treatment and fertility concerns on self and social relationships, making family planning decisions, and experiences with medical team. We also identified a theme on the impact of cancer treatment and fertility concerns on caregivers.

Conclusions: Reddit provided a rich pool of data for analyzing the information needs of women facing cancer. Our findings demonstrate the far-reaching impacts of cancer treatment and fertility on physical, mental, and psychosocial health for both patients and their caregivers.

(*JMIR Cancer* 2020;6(2):e17771) doi:[10.2196/17771](https://doi.org/10.2196/17771)

KEYWORDS

cancer treatment; health information; oncofertility; fertility; pregnancy; reproduction; social support

Introduction

There is need to better support women with cancer as they deal with cancer treatment and impacts on fertility [1], from clinical aspects such as fertility preservation to psychosocial aspects spanning psychological, social, behavioural, and ethical considerations [2]. This is important, as treatments used in

cancer (including chemotherapy, radiotherapy, and surgery) may affect fertility by impairing reproductive and endocrine functions [1,3]. Of particular interest is health information needs, which arise when individuals perceive gaps in their knowledge regarding a specific health-related topic [4]. In 2016, Benedict et al [5] surveyed 346 women who had completed cancer treatment at a single center about their fertility information

needs and found that up to 62% reported unmet information across topics queried such as risk of infertility, risk of early menopause, and options to preserve their fertility. Although it is important to understand information needs based on questions queried by researchers, drawing this information from patients without prompts is also necessary to identify other areas of priority. A potential source of patient-centered information is social media and online forums [6]. As more patients access these mediums to seek accounts of personal experiences from others navigating similar issues, so forms a valuable, naturally generated pool of data for examining patients' information needs, which has yet to be fully utilized [7]. Thus, our aim was to conduct a qualitative descriptive study of threads on the social news website, Reddit. We sought to address the following research question: what are the information needs regarding cancer treatment, fertility, and pregnancy of women diagnosed with cancer and/or their caregivers/partners.

Methods

Study Design and Data Source

We conducted a qualitative descriptive study of online discussions, using data gathered from Reddit. Here, submitted content is organized according to subreddits on specific subjects ("r/subject"). Users ("Redditors") can subscribe to subreddits and participate in conversations ("threads") by either starting an original thread or commenting on other users' threads. Reddit offers a large and variable platform for information gathering, the site has over 430 million monthly active users, averages 21 billion screen views per month, and ranks as the 5th most visited website in the US as of December 23rd, 2019 [8]. Reddit is composed of user-generated content, allowing users to share media, follow one another, and share anecdotal information in the form of personal experiences. Redditors can share publicly accessible content as anonymity is provided with the use of pseudonyms and usernames [9]. Users can freely share personal experiences and engage in open and honest discussion without feeling restricted, a barrier present on other social media platforms such as Facebook, which mandate individuals accessing the website to use their real names [10].

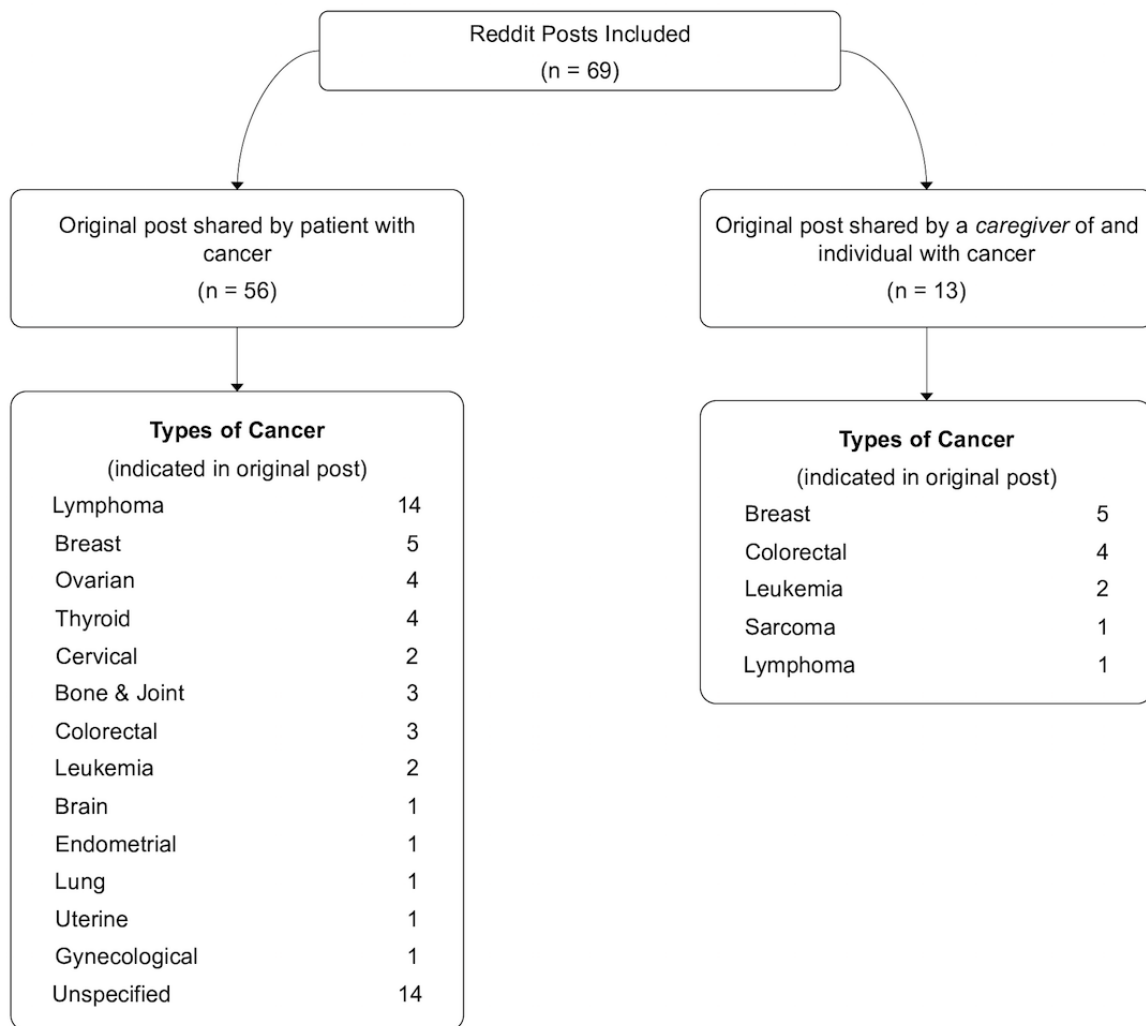
Search Strategy

Our strategy aimed to identify threads over a 5-year period between February 4th, 2014 and February 4th, 2019 through a systematic approach to searching subreddits and the application of specific inclusion and exclusion criteria. Given that there is no specific subreddit for oncofertility, we searched four relevant subreddits: r/Cancer, r/BabyBumps, r/Tryingforababy, and r/Infertility. Threads were gathered from each subreddit by searching relevant terms or words. For example, given that the subject matter of r/Cancer subreddit related to the maternal disease of interest, terms included the following: fertility, infertility, menopause, pregnancy, and pregnant. Conversely, for the 3 subreddits related to reproductive health, terms included the following: cancer, chemotherapy, and radiation. At this stage, selected threads included an original post and at least one comment/response.

We then reviewed the original post to apply the following inclusion criteria: indicating having a diagnosis of cancer *and* having received or may receive gonadotoxic treatment (eg, chemotherapy, radiotherapy) *and* sharing a lived experience, concern, or information need regarding female fertility or pregnancy. We also considered threads where the original post was shared by a caregiver of an individual with cancer who had received or may receive gonadotoxic treatment. For our purposes, we defined caregiver as any individual providing support to a woman with a cancer diagnosis. The search results are summarized in [Multimedia Appendix 1](#). The application of the inclusion criteria to threads was conducted by two authors (RG and NR) and discrepancies were discussed and resolved.

Data Extraction

We downloaded threads meeting inclusion criteria as portable document files. We extracted the following information: author of the original thread (ie, patient with cancer or caregiver), average thread length (ie, the number of comments/replies to the original post), average number of unique users participating in each thread. Where possible, we also extracted information on the type of cancer and cancer treatment(s), as outlined in [Figure 1](#).

Figure 1. Types of cancer indicated in original posts of included Reddit threads.

Qualitative Analysis

We conducted two separate thematic analyses, the first for threads with original posts by patients with cancer and the second for threads with original posts by caregivers. Thematic analysis is a form of descriptive qualitative analysis applied to all final threads (original post and comments) included in the study to review and interpret narrative data through the identification of themes [11,12]. The value of a thematic study design is its ability to formulate a deeper understanding of the studied population's viewpoint, actions, and relationships [11,12]. We used de novo line by line coding where every line in the transcript is used to formulate emerging ideas. These ideas were transcribed into codes or a short phrase representing key attributes of narrative information. Following, codes were sorted and organized to identify patterns and formulate subcategories. Themes were named and defined based on these results. We used NVivo 12 (QSR International) for all analyses.

Ethics

According to the University of British Columbia's Behavioral Research Ethics Board, given our use of publicly available information from a social network site (ie, one that does not require an account or password to access content) and the fact that we did not use privately sourced data, this research is exempt from review.

Results

Search Results

Altogether, we downloaded 963 threads across 4 subreddits, "r/Cancer," "r/Tryingforababy," "r/BabyBumps," and "r/Infertility" between February 4th, 2014 and February 4th, 2019. Overall, 69 reddit threads were included in our analysis. For 56 threads, the original post was shared by a patient with cancer, and for 13, the original post was shared by a caregiver. All original posts were by unique individuals as assessed by their usernames. Table 1 summarizes information on included threads.

Table 1. Summary of Reddit threads.

Author of original post, Subreddit	Subscribers, n	Threads ^a downloaded, n	Threads included, n	Average thread length ^b , n	Average number of unique users, n
Patient with cancer					
r/Cancer	24700	214	17	8.2	5.2
r/Tryingforababy	32000	200	8	9.9	6.9
r/BabyBumps	117000	275	12	27.8	17
r/Infertility	13000	274	19	15	9.5
Caregiver					
r/Cancer	24700	214	12	10.8	6.6
r/BabyBumps	117000	275	1	5	4

^aBetween February 4th, 2014 and February 4th, 2019.

^bAverage length of thread is defined as the number of comments/replies to the original post.

Qualitative Results

Thematic analysis of threads where the original post was shared by a patient with cancer resulted in 5 themes: 1) becoming a part of an online community; 2) impact of cancer treatment and fertility concerns on self; 3) impact of cancer treatment and fertility concerns on social relationships; 4) making family planning decisions; and 5) experiences with medical team. Thematic analysis of threads where the original post was shared by a caregiver resulted in an additional theme on 6) impact of cancer treatment and fertility concerns on the caregiver. These themes, corresponding conceptual categories, and representative quotations are described as follows. To provide context to quotations, we included information on subreddit, type of cancer, and cancer treatment, where available. Additional representative quotations for identified themes are available in [Multimedia Appendix 2](#).

Theme 1: Becoming a Part of an Online Community

Women diagnosed with cancer often have questions or concerns regarding the impact of cancer treatment on their state of fertility leading them to seek a community for social support. In our study, we found that women used Reddit to join an online community for reasons captured by the following 4 conceptual categories.

Subtheme 1: Connecting With Individuals Facing Similar Circumstances

Many women expressed a desire to or gratitude for connecting with individuals who have faced similar circumstances, reporting feeling isolated among family and friends who are unable to understand their experiences. Statements of gratefulness such as, "This community has provided me with comfort through, knowing there are others that can completely relate to me" (r/Infertility; unspecified cancer; chemotherapy), highlight the capacity for an online community to provide support and help users feel that they are not alone. Others expressed difficulty finding a community they identified with prior to discovering Reddit, as one user shared, "I was under the impression that people like me just didn't exist!" (r/BabyBumps; bone and joint cancer; chemotherapy, radiotherapy, and surgery). Women valued Reddit's online community, expressing gratitude for

having the opportunity to connect with others, as one user stated, "I'm in tears realizing that you all are so kind" (r/Infertility; lymphoma; radiotherapy), when describing the positive impact other Redditors have had on her life.

Subtheme 2: Seeking Advice or Information From Others Online

Women often turn to Reddit's online communities to pose questions and ask for information regarding cancer treatment and fertility. Many users asked others to share their personal experiences to help them anticipate future challenges, as one user stated, "I'm looking for any information about what others may have experienced and what I should expect" (r/Cancer; leukemia; chemotherapy). Aside from information, women also sought advice to aid their decision-making. For example, prior to undergoing chemotherapy, one user shared how she felt overwhelmed by the uncertain state of her fertility and was seeking advice for how best to cope, stating, "I feel helpless. What do I do now?" (r/Cancer; bone and joint cancer; chemotherapy).

Subtheme 3: Sharing Personal Victories

Online discussions have given women a platform for documenting their triumphs and sharing positive testimonials. Many users shared their experiences of having children after cancer treatment, expressing how fortunate they felt after overcoming the obstacles they faced in their journey to conceive. One user highlighted the steps she took postchemotherapy to preserve fertility despite low chances of natural conception and shared the joy she felt once she was able to conceive, stating, "Our little man is truly a miracle baby" (r/BabyBumps; ovarian cancer; chemotherapy, surgery). Other women shared personal victories in the form of remaining determined to conceive despite facing challenges with fertility. One user shared remaining hopeful for her future childbearing ability despite undergoing systemic cancer treatment, stating, "Multiple health issues going against chances of my pregnancy but HOPE IS ON!" (r/Infertility; colorectal cancer; chemotherapy, radiotherapy, surgery).

Subtheme 4: Providing Social Support

Participation in online communities allowed users to provide social support, defined as actions that encourage or help another's journey to having children. Users would respond to others with statements such as, "First, congrats on beating cancer! That must not have been easy. I hope IVF is successful" (r/Infertility; breast cancer; chemotherapy), capturing congratulatory and encouraging sentiments. Users also provided information by sharing personal accounts of their experiences with fertility post cancer treatment, describing steps they had taken to conceive, or directing others to resources.

Theme 2: Impact of Cancer Treatment and Fertility Concerns on Self

Cancer treatments and fertility concerns may affect an individual in many ways, as outlined by 2 conceptual categories.

Subtheme 1: Coping With Physical Impacts of Cancer Treatments

Cancer treatments, such as radiotherapy and chemotherapy, may have systemic health impacts. Users used Reddit forums to discuss symptoms of premature menopause after cancer treatment, with many expressing difficulty coping with the physical impacts. They shared how certain symptoms may remain persistent even after cancer treatment has been stopped. As one user stated, "It has been over a year since my last treatment and I am still having them (hot flashes) regularly" (r/Cancer; cancer unspecified; chemotherapy). Users reported experiencing a broad spectrum of physical symptoms post cancer treatment, stating, "I had some nerve damage which is irreversible. Its not just dryness, the skin changes and deteriorates" (r/Cancer; leukemia; chemotherapy).

Subtheme 2: Navigating Fertility Concerns

Users shared feelings of emotional distress; many found processing all the information regarding cancer treatment and its adverse effects on future fertility to be overwhelming. One user described navigating cancer treatment decisions as "the start of a nightmare I never imagined I would be in" (r/Cancer; sarcoma; chemotherapy) due to the lack of clarity regarding cancer treatment impacts on future fertility. Many women struggled with disentangling their post cancer treatment symptoms from premature menopause, which may occur after systemic cancer treatment. One user stated, "I know early menopause is a very real possibility with chemotherapy but I'm only 25. Is it possible that these (symptoms) are just temporary" (r/Cancer; lymphoma; chemotherapy). Women who experienced cancer treatment induced infertility shared stories of struggle to move past their cancer diagnosis and feeling as if their choice to conceive in the future was taken away from them. One user stated, "I'm losing my potential child before I ever had a chance to realize I wanted him" (r/Cancer; sarcoma; chemotherapy).

Theme 3: Impact of Cancer Treatment and Fertility Concerns on Social Relationships

The impacts of cancer treatment and fertility concerns on individuals' social relationships is outlined by 2 conceptual categories.

Subtheme 1: Shaping Intimate Partner Relationships

Cancer treatment and fertility concerns may impact a woman's perception of their partners, defined as the individual who has chosen to share their life with the women with cancer. Many women described internalizing their struggles with conception and blaming themselves for not providing their partner with a child. One user shared feeling sad and guilty after undergoing cancer treatment, stating, "If he had only fallen in love with some other girl, he wouldn't have had to deal with all of this" (r/Cancer; Ovarian; Chemotherapy). Users also shared experiencing strained partner relationships due to a perceived lack of understanding or inability to appropriately acknowledge their fertility concerns and struggles with conception. One user shared, "when I mention I'm upset about losing my fertility and he (my husband) tries to tell me it isn't as important as my life. Well no shit, but I can still be upset about it" (r/Cancer; gynecological; chemoradiation).

Subtheme 2: Navigating Changing Self-Identity

An individual's changing self-identity related to cancer treatment and its impacts on fertility may also impact their social relationships. Many women wrote about alienating themselves from their family and friends, as they feared discussing the topic of fertility. Some shared feeling resentment towards others with children, stating, "I'll either see baby posts on Facebook or come across women with a child in public, and feel so bitter and angry towards them" (r/Infertility; lung cancer; chemotherapy, surgery), and described surrounding themselves with friends and family who were able to conceive as a reminder of their own struggles. Others reported feeling frustrated that their inability to conceive was oversimplified and misunderstood. One user expressed feeling pressured to conceive quickly from her mother-in-law, stating, "I'm pretty sure (she) thinks her son married a defective uterus" (r/Infertility; unspecified; chemotherapy).

Theme 4: Making Family Planning Decisions

Prior to receiving cancer treatment, women are required to make several important decisions related to future fertility and family planning. The questions and concerns women may come across while making family planning decisions are outlined by 2 conceptual categories.

Subtheme 1: Perspectives Regarding Fertility Treatments

Prophylactic fertility preservation treatments, such as egg freezing, need to occur prior to receiving cancer therapy; as such, a women's cancer severity, prognosis, and desire for children in the future may influence her decision to pursue fertility treatment. Some women reported feeling uncomfortable delaying cancer treatment to pursue fertility treatment due to the risk of cancer recurrence or progression, stating, "the idea of waiting while this really aggressive tumor grew inside of me was...unsettling" (r/Infertility; breast cancer; chemotherapy). Others believed they might regret not attempting fertility preservation and shared either a desire to receive treatment or gratitude for having already received prophylactic fertility treatment. Many women also struggled with uncertainty when deciding if they should pursue fertility preservation. One user shared, "How do I know if I will regret not having kids?? Right

now it sounds ok, but in 10 years” (r/Infertility; lymphoma; chemotherapy), struggling to decide whether she should delay chemotherapy to pursue fertility treatment.

Subtheme 2: Financial Concerns

Decisions about fertility treatment and family planning may also be influenced by an individual’s financial state. Several women shared concerns about pursuing fertility treatments due to financial constraints, as one user stated, “IVF (in vitro fertilization) is a long ways a way. The cancer basically depleted our savings” (r/TryingForABaby; unspecified; chemotherapy). Others reported becoming skeptical of the benefits of fertility treatments, such as in vitro fertilization, after investing thousands of dollars into medical treatments without achieving favorable outcomes. As one user stated, “Sunken cost fallacy is something I think of all the time. Especially with our frozen (eggs) we still have” (r/Infertility; lymphoma; chemotherapy).

Theme 5: Experiences With Medical Team

When receiving cancer or fertility treatments, women require assistance from their medical team, which may include an oncologist, gynaecologist, obstetrician, and reproductive endocrinologist. However, several Reddit users expressed challenges with their medical team as outlined by 2 conceptual categories.

Subtheme 1: Seeking Doctor With Relevant Patient Experience

Many users felt their doctors did not focus enough on their state of fertility during and after cancer treatment, leading them to seek doctors who have experience working with premenopausal cancer patients with fertility concerns. Several users shared the positive impact a physician with relevant patient care experience had on their fertility journey. When describing how her endocrinologist tailored treatments to her reproductive needs, one user stated, “experience with cancer patients is a must” (r/Infertility; ovarian cancer; chemotherapy, surgery). Another user stated, “Everyone there was ready to call it quits and wrote me off” (r/Infertility; unspecified; chemotherapy), sharing her struggles with fertility treatment until she connected with a more experienced endocrinologist who was able to offer her further treatment options and support her desire to conceive.

Subtheme 2: Feeling Lack of Support

Many women shared incidences of miscommunication regarding the impact of cancer treatment on their fertility with their medical team. Several women articulated a lack of focus on fertility preservation during cancer treatment. One user said, “I feel like my doctor heard my history, saw my test results and has basically written me off” (r/Infertility; lymphoma; radiation), feeling her desire to protect her fertility was dismissed as secondary to her cancer diagnosis. Others felt frustrated, having to constantly self-advocate for their fertility concerns to be addressed by their medical team. One user described the high level of persistence she exercised for her medical team to consider her fertility status, stating, “Why do I have to be the one to take initiative?” (r/Tryingforababy; cancer unspecified; chemotherapy). Some felt disheartened about their ability to conceive after their doctor expressed discouraging views about their fertility post cancer treatment, as one user stated, “the dr

came in and said he thinks it is best if I stop trying (to conceive). That was the end of that” (r/Infertility; lymphoma; chemotherapy, radiotherapy, surgery).

Theme 6: Impact of Cancer Treatment and Fertility Concerns on the Caregiver

Caregivers of cancer patients, including partners, family members, and friends, may also be impacted by their loved one’s cancer treatment and fertility concerns. The caregivers’ involvement in their loved one’s cancer treatment is outlined by the 2 following conceptual categories.

Subtheme 1: Searching for Avenues of Support for Cancer Patient

Caregivers of cancer patients turned to Reddit in search of avenues of social support for their loved ones. Many inquired how they could support their loved ones. One user stated, “I want to send her something to show support, but I’m not sure what would be best?” (r/Cancer; breast cancer; chemotherapy). Caregivers sought information regarding cancer treatment and impacts on fertility to remain informed about the possible treatments and likely outcomes available for their loved ones, such as one user who asked, “In this circumstance, is there any possibility of having a child at this point (post cancer treatment) through fertility treatments and specialists?” (r/Cancer; colorectal cancer; radiotherapy, chemotherapy).

Subtheme 2: Coping With Cancer Treatment and Fertility Concerns

Caregivers of cancer patients may also experience emotional distress regarding cancer treatment and fertility concerns. Many users expressed feeling stressed, worried, and anxious watching their loved one struggle with uncertainty related to disease prognosis and fertility, sharing, “I know my family is experiencing emotions all too painfully familiar to everyone here” (r/Cancer; sarcoma; chemotherapy). Some intimate partners expressed their frustrations concerning their inability to have children, as one user shared, “Would have been nice to know that possibility (infertility) before she went through radiation but radiologist never mentioned it” (r/Cancer; colorectal cancer; radiotherapy, surgery). However, others worried their emotions may be perceived as resentment by their partner with cancer. After his wife experienced chemotherapy induced menopause, one user shared, “I cannot convince her that this is the case. She thinks I’m angry, that I blame her and her ‘defective body’ (her words)” (r/Cancer; colorectal cancer; radiotherapy, chemotherapy), using Reddit to process his own emotions.

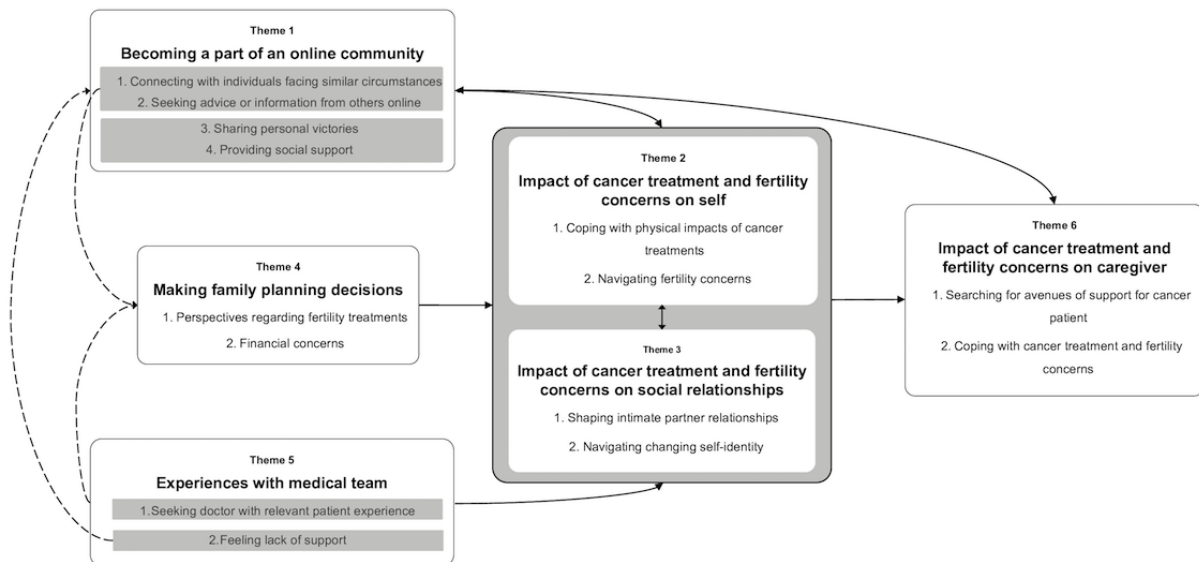
Thematic Map Describing Relationships Between Themes

The thematic map in [Figure 2](#) outlines the interrelationships between the 6 identified themes. Experiencing cancer treatment and fertility concerns may affect women in various areas of their life, leading to impacts on self (Theme 2) which may also impact their social relationships (Theme 3), and vice versa. As women cope with the impacts of cancer treatment and fertility concerns, they may turn to Reddit to seek or share information and connect with others facing similar circumstances, leading

them to join an online community (Theme 1). A woman's medical team is an integral component of her cancer treatment experience (Theme 5); therefore, her experiences with such a team may further contribute to the impact of cancer treatment and fertility concerns on self and social relationships (Theme 2 and 3). If women feel a lack of support from their medical team, this may lead them to seek support from other sources, such as Reddit's online community (Theme 1). In addition to

their medical team (Theme 5), as women connect with others online and seek advice (Theme 1). This may also influence their family planning decisions (Theme 4), which overall contributes to the impact of cancer treatment on the patient and their social relationships (Theme 2 and 3). Finally, caregivers are also impacted by cancer treatment and fertility concerns (Theme 6), leading to them seek an online community (Theme 1).

Figure 2. Thematic map of identified themes. Solid arrows depict relationships between themes, while dashed arrows depict relationships between categories across and within themes.



Discussion

Using a systematic approach to searching Reddit threads and applying thematic analysis to those that met our study inclusion criteria, we identified themes that captured the information needs of women with cancer regarding cancer treatment and fertility that led them to this online community. Furthermore, since we also considered Reddit threads initiated by caregivers of women with cancer, we identified an additional theme regarding the impact of cancer treatment and fertility concerns on the caregiver. Key findings include the far-reaching impacts of cancer treatment and effects of fertility issues on physical and psychosocial health for women with cancer and the perceived lack of support, particularly from their medical team. The impacts on personal relationships must also be acknowledged, from both perspectives of women with cancer and their caregivers. Altogether, our study findings have implications for highlighting ongoing challenges in oncofertility and the need for better support for women with cancer, particularly when addressing their concerns and information needs regarding cancer treatment and fertility.

Our study adds to the body of work on the information needs of women with cancer regarding cancer treatment and fertility concerns by systematically searching and applying qualitative research methods to publicly available threads on the popular and widely accessed social news website, Reddit. Prior qualitative studies have used more traditional methods of interviews and focus groups and have largely focused on women

with breast cancer in single centers. In 2003, Thewes et al [13] explored the fertility and menopause related information needs of young women with a diagnosis of breast cancer. Participants discussed psychosocial impacts of unmet information, identified a desire for receiving fertility related information, and reported a discord between the perceived importance of fertility among doctors and cancer patients [13]. Additionally, a 2004 study by Partridge et al [14] investigated the concerns experienced by women diagnosed with breast cancer and reported that 73% of participants expressed some degree of concern regarding fertility. They also explored factors that may influence women as they make cancer treatment decisions, such as age, desire for more children, or prior difficulty conceiving [14]. In comparison to the abovementioned studies, our study offers a broader perspective on the impacts of undergoing cancer treatment and experiencing fertility concerns, as they may not be isolated events in a woman's life. Our findings demonstrate how cancer therapy and fertility concerns affect both the individual's physical and psychosocial health, their social relationships, and interactions with their healthcare team, as well as how these factors may influence their decision making. Notably, our study also identified the impact of financial considerations when making family planning decisions and the role of online mediums for sharing information, connecting with others, and finding avenues of social support.

Given our use of publicly available online data through Reddit, our study adds to the body of literature describing the role of the internet as a source of information regarding cancer

treatment and fertility. A recent 2019 study by Brochu et al [15] surveyed women (n = 313) and men (n = 254) seen in Canadian fertility and urology clinics to assess their use of internet-based resources for accessing infertility-related information and support. The authors reported that a greater majority of participants sought information from the internet about fertility than from noninternet sources (87.8% vs 12.2%, respectively) and noted that women in particular were significantly more likely to use the internet to search for both medical information and patient experiences shared online related to cancer therapy and infertility [15]. Indeed, the findings of this survey reflected the themes elucidated in our study, particularly theme 1, which describes how women with cancer used Reddit to join an online community through connecting with others facing similar circumstances, seeking advice, sharing personal experiences, and providing support.

Additionally, a noteworthy finding of our study is the perceived lack of support from medical teams captured in Theme 5, particularly regarding fertility information needs. This is consistent with a prior systematic review by Logan et al [16], which stated that cancer patients place great importance on their oncofertility care and have unmet support needs. Interestingly, though threads mentioned oncologists, gynaecologists, obstetricians, and reproductive endocrinologists, we did not note mentions of allied healthcare providers who may also have roles in providing education and support to women with cancer regarding cancer treatment and fertility. A recent scoping review by Anazodo et al [17] on oncofertility services in cancer care identified several key domains required for appropriate medical and psychological oncofertility provision, including providing quality information about fertility risk and preservation options to patients, timely service provision, and age-appropriate care before, during, and post cancer treatment and further developed competency framework for developing such services and training staff. Additionally, in order to facilitate service provision, The authors noted the importance of establishing referral pathways, defining the role and scope of practice of all involved health care providers, improving communication amongst the patient's healthcare team, and ensuring all members of the healthcare team have received adequate oncofertility training. Of particular note is the potential to specifically target oncofertility training towards allied health professionals (eg, nurses, social workers, psychologists, and physician assistants) who maintain direct and long-term relationships with cancer patients. Although work in this field is limited, one pilot study suggests that allied health professional are interested in and perceived a benefit from receiving expanded training in discussing reproductive health concerns with cancer patients [18].

Finally, unique to our study is the consideration of perspectives from caregivers of women with cancer, which elucidated a theme that highlights that they, too, are affected by cancer treatment and impacts on fertility, emotionally and psychosocially. In their systematic review and meta-synthesis,

LeSeure and Chongkham-ang [19] highlighted the importance of caregiving, particularly in cancer, over the past decade and discussed recommendations for continued research involving such individuals. The desire for caregivers to remain involved in their loved one's cancer journey is also supported by our findings, as caregivers used Reddit to inquire about the impacts of cancer treatment on fertility. Overall, our study highlights a need for supporting caregivers as they may also be impacted by cancer treatment and fertility concerns.

Strengths and limitations of our study warrant discussion. We demonstrated a systematic approach to identifying and applying qualitative research methodology to eligible subreddit threads to elucidate themes pertaining to information needs of women with cancer regarding cancer treatment and fertility. Although such an approach is gaining popularity in other areas, particularly mental health and rheumatology [20] (including a recent study by our research team [7]), it has not been widely used in psycho-oncology research and, to our knowledge, there is only one prior study [21] applying content analysis on Reddit threads specifically regarding cancer, which has been published as an abstract. Properties of Reddit, including use of pseudonyms that provide users anonymity and unrestricted word count for thread entries, may contribute to greater authenticity of discussions, which may not be applicable to other social media sites such as Facebook [22-25]. However, there is potential selection bias with respect to individuals who may be more likely to use Reddit, including those who have access to the internet. Furthermore, the anonymity leads to lack of demographic and disease information about users. Nonetheless, we were able to extract information on type of cancer diagnosed for the majority of included threads from the patient arm (42 of 56 posts) and caregiver arm (13 of 13 posts) of the study. Furthermore, we were also able to extract information on the type of cancer treatment. Although the self-reported nature may be a limitation, given the specificity of a cancer diagnosis, we anticipate a high likelihood that original posts are written by individuals experiencing the impacts of the disease and its treatment on fertility. Finally, although we identified themes that touch on fertility-related issues for women with cancer and the perceived lack of support, particularly from their medical team, use of Reddit threads as our data source precluded ability to further probe into these issues.

In conclusion, women with cancer receiving gonadotoxic treatment are among the many patients who consult internet resources to ask questions and seek information about fertility and reproductive health. We demonstrated that online communities, specifically Reddit, provide a naturally generated data source for understanding information needs of these patients. Findings on the far-reaching impacts of cancer treatment and fertility on physical, mental, and psychosocial health for both patients and their caregivers and perceived lack of support from medical teams speak to a need for implementing multifaceted approaches for support.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Results of systematic review performed to identify Reddit threads regarding cancer and fertility concerns.

[[PDF File \(Adobe PDF File\), 24 KB - cancer_v6i2e17771_app1.pdf](#)]

Multimedia Appendix 2

Illustrative quotes for themes on information needs and concerns posted on Reddit forums about fertility and cancer.

[[PDF File \(Adobe PDF File\), 81 KB - cancer_v6i2e17771_app2.pdf](#)]

References

1. Waimey KE, Smith BM, Confino R, Jeruss JS, Pavone ME. Understanding Fertility in Young Female Cancer Patients. *J Womens Health (Larchmt)* 2015 Oct;24(10):812-818 [[FREE Full text](#)] [doi: [10.1089/jwh.2015.5194](https://doi.org/10.1089/jwh.2015.5194)] [Medline: [26075731](https://pubmed.ncbi.nlm.nih.gov/26075731/)]
2. Lang-Rollin I, Berberich G. Psycho-oncology. *Dialogues Clin Neurosci* 2018 Mar;20(1):13-22. [doi: [10.31887/dcms.2018.20.1/ilangrollin](https://doi.org/10.31887/dcms.2018.20.1/ilangrollin)]
3. Maltaris T, Seufert R, Fischl F, Schaffrath M, Pollow K, Koelbl H, et al. The effect of cancer treatment on female fertility and strategies for preserving fertility. *Eur J Obstet Gynecol Reprod Biol* 2007 Feb;130(2):148-155. [doi: [10.1016/j.ejogrb.2006.08.006](https://doi.org/10.1016/j.ejogrb.2006.08.006)] [Medline: [16979280](https://pubmed.ncbi.nlm.nih.gov/16979280/)]
4. Ormandy P. Defining information need in health - assimilating complex theories derived from information science. *Health Expect* 2011 Mar;14(1):92-104 [[FREE Full text](#)] [doi: [10.1111/j.1369-7625.2010.00598.x](https://doi.org/10.1111/j.1369-7625.2010.00598.x)] [Medline: [20550592](https://pubmed.ncbi.nlm.nih.gov/20550592/)]
5. Benedict C, Thom B, N Friedman D, Diotallevi D, M Pottenger E, J Raghunathan N, et al. Young adult female cancer survivors' unmet information needs and reproductive concerns contribute to decisional conflict regarding posttreatment fertility preservation. *Cancer* 2016 Jul 01;122(13):2101-2109 [[FREE Full text](#)] [doi: [10.1002/cncr.29917](https://doi.org/10.1002/cncr.29917)] [Medline: [27213483](https://pubmed.ncbi.nlm.nih.gov/27213483/)]
6. de Man AM, Rashedi A, Nelen W, Anazodo A, Rademaker A, de Roo S, et al. Female fertility in the cancer setting: availability and quality of online health information. *Hum Fertil (Camb)* 2020 Sep 19;23(3):170-178. [doi: [10.1080/14647273.2018.1506891](https://doi.org/10.1080/14647273.2018.1506891)] [Medline: [30230389](https://pubmed.ncbi.nlm.nih.gov/30230389/)]
7. Chew C, Rebić N, Baldwin C, Amiri N, Proulx L, De Vera MA. "r/Thritis", Pregnancy, and Parenting: A Qualitative Descriptive Study of Reddit Forums to Explore Information Needs and Concerns of Women With Rheumatoid Arthritis. *ACR Open Rheumatol* 2019 Oct 15;1(8):485-492 [[FREE Full text](#)] [doi: [10.1002/acr2.11069](https://doi.org/10.1002/acr2.11069)] [Medline: [31777829](https://pubmed.ncbi.nlm.nih.gov/31777829/)]
8. Reddit I. Reddit by Numbers. Published 2020. URL: <https://www.redditinc.com/press>
9. Shelton M, Lo K, Nardi B. Online Media Forums as Separate Social Lives: A Qualitative Study of Disclosure Within and Beyond Reddit. In: Paper presented at: iConference. 2015 Mar 24 Presented at: iCoference 2015; 2015 March 24 - 27; Newport Beach, California.
10. Newman M, Lauterbach D, Munson S, Resnick P, Morris M. It's not that i don't have problems, i'm just not putting them on facebook: challenges and opportunities in using online social networks for health. 2011 Presented at: ACM 2011 Conference on Computer Supported Cooperative Work; 2011 March 19 - 23; Hangzhou, China. [doi: [10.1145/1958824.1958876](https://doi.org/10.1145/1958824.1958876)]
11. Sandelowski M. Whatever happened to qualitative description? *Res. Nurs. Health* 2000 Aug;23(4):334-340. [doi: [10.1002/1098-240x\(200008\)23:4<334::aid-nur9>3.0.co;2-g](https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g)]
12. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013 Sep 11;15(3):398-405. [doi: [10.1111/nhs.12048](https://doi.org/10.1111/nhs.12048)] [Medline: [23480423](https://pubmed.ncbi.nlm.nih.gov/23480423/)]
13. Thewes B, Meiser B, Rickard J, Friedlander M. The fertility and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. *Psychooncology* 2003 Jul;12(5):500-511. [doi: [10.1002/pon.685](https://doi.org/10.1002/pon.685)] [Medline: [12833562](https://pubmed.ncbi.nlm.nih.gov/12833562/)]
14. Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, et al. Web-Based Survey of Fertility Issues in Young Women With Breast Cancer. *JCO* 2004 Oct 15;22(20):4174-4183. [doi: [10.1200/jco.2004.01.159](https://doi.org/10.1200/jco.2004.01.159)]
15. Brochu F, Robins S, Miner SA, Grunberg PH, Chan P, Lo K, et al. Searching the Internet for Infertility Information: A Survey of Patient Needs and Preferences. *J Med Internet Res* 2019 Dec 12;21(12):e15132 [[FREE Full text](#)] [doi: [10.2196/15132](https://doi.org/10.2196/15132)] [Medline: [31829963](https://pubmed.ncbi.nlm.nih.gov/31829963/)]
16. Logan S, Perz J, Ussher J, Peate M, Anazodo A. A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age. *Psychooncology* 2018 Feb 13;27(2):401-409. [doi: [10.1002/pon.4502](https://doi.org/10.1002/pon.4502)] [Medline: [28734119](https://pubmed.ncbi.nlm.nih.gov/28734119/)]
17. Anazodo A, Laws P, Logan S, Saunders C, Travaglia J, Gerstl B, et al. How can we improve oncofertility care for patients? A systematic scoping review of current international practice and models of care. *Hum Reprod Update* 2019 Mar 01;25(2):159-179 [[FREE Full text](#)] [doi: [10.1093/humupd/dmy038](https://doi.org/10.1093/humupd/dmy038)] [Medline: [30462263](https://pubmed.ncbi.nlm.nih.gov/30462263/)]

18. Quinn GP, Woodruff TK, Knapp CA, Bowman ML, Reinecke J, Vadaparampil ST. Expanding the Oncofertility Workforce: Training Allied Health Professionals to Improve Health Outcomes for Adolescents and Young Adults. *J Adolesc Young Adult Oncol* 2016 Sep;5(3):292-296 [FREE Full text] [doi: [10.1089/jayao.2016.0003](https://doi.org/10.1089/jayao.2016.0003)] [Medline: [26978683](https://pubmed.ncbi.nlm.nih.gov/26978683/)]
19. LeSeure P, Chongkham-Ang S. The Experience of Caregivers Living with Cancer Patients: A Systematic Review and Meta-Synthesis. *J Pers Med* 2015 Nov 19;5(4):406-439. [doi: [10.3390/jpm5040406](https://doi.org/10.3390/jpm5040406)] [Medline: [26610573](https://pubmed.ncbi.nlm.nih.gov/26610573/)]
20. Derksen C, Serlachius A, Petrie KJ, Dalbeth N. "What say ye gout experts?" a content analysis of questions about gout posted on the social news website Reddit. *BMC Musculoskelet Disord* 2017 Nov 23;18(1):488 [FREE Full text] [doi: [10.1186/s12891-017-1856-y](https://doi.org/10.1186/s12891-017-1856-y)] [Medline: [29169350](https://pubmed.ncbi.nlm.nih.gov/29169350/)]
21. Thomas J, Zheng R, Prabhu A, Heron D, Beriwal S. Content Analysis of Posts About Cancer on the Social Media Website Reddit. *International Journal of Radiation Oncology*Biophysics* 2019 Sep;105(1):E461-E462. [doi: [10.1016/j.ijrobp.2019.06.1420](https://doi.org/10.1016/j.ijrobp.2019.06.1420)]
22. Barney LJ, Griffiths KM, Banfield MA. Explicit and implicit information needs of people with depression: a qualitative investigation of problems reported on an online depression support forum. *BMC Psychiatry* 2011 May 18;11(1). [doi: [10.1186/1471-244x-11-88](https://doi.org/10.1186/1471-244x-11-88)]
23. Corrigan P. How stigma interferes with mental health care. *American Psychologist* 2004 Oct;59(7):614-625. [doi: [10.1037/0003-066x.59.7.614](https://doi.org/10.1037/0003-066x.59.7.614)]
24. De Choudhury S. Mental Health Discourse on reddit: Self-Disclosure, Social Support, and Anonymity. 2015 Jun 01 Presented at: Paper presented at: International AAAI Conference on Web and Social Media; Jun 1-4, 2014; Ann Arbor, Michigan.
25. Newman M, Lauterbach D, Munson S, Resnick P, Morris M. It's not that i don't have problems, i'm just not putting them on facebook: challenges and opportunities in using online social networks for health. 2011 Mar 19 Presented at: Paper presented at: ACM Conference on Computer Supported Cooperative Work; 2011 Mar 19-23; Hangzhou, China p. A. [doi: [10.1145/1958824.1958876](https://doi.org/10.1145/1958824.1958876)]

Edited by D Vollmer Dahlke; submitted 10.01.20; peer-reviewed by A Anazodo, J Wienert, D Diethei; comments to author 03.06.20; revised version received 11.06.20; accepted 22.08.20; published 02.12.20.

Please cite as:

Garg R, Rebić N, De Vera MA

Information Needs About Cancer Treatment, Fertility, and Pregnancy: Qualitative Descriptive Study of Reddit Threads

JMIR Cancer 2020;6(2):e17771

URL: <http://cancer.jmir.org/2020/2/e17771/>

doi: [10.2196/17771](https://doi.org/10.2196/17771)

PMID: [33263547](https://pubmed.ncbi.nlm.nih.gov/33263547/)

©Ria Garg, Nevena Rebić, Mary A De Vera. Originally published in *JMIR Cancer* (<http://cancer.jmir.org>), 02.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Cancer*, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Beliefs and Information Seeking in Patients With Cancer in Southwest China: Survey Study

Juan Xie¹, BS; Shi Xie², BA; Ying Cheng¹, PhD; Zhe He³, PhD

¹School of Information Management, Nanjing University, Nanjing, China

²Jinling College, Nanjing University, Nanjing, China

³School of Information, College of Communication and Information, Florida State University, Tallahassee, FL, United States

Corresponding Author:

Ying Cheng, PhD

School of Information Management

Nanjing University

163 Xianlin Road

Nanjing, 210023

China

Phone: 86 13851838364

Email: chengy@nju.edu.cn

Abstract

Background: Although previous studies have reported the cancer information-seeking behaviors among patients in high-income countries, the cancer information-seeking practices of patients living in low- and middle-income areas are less known.

Objective: This study investigated the beliefs and information-seeking patterns of cancer patients in southwest China.

Methods: A questionnaire was designed, and data were collected in two hospitals (N=285) in southwest China. Statistical analyses included bivariate analyses and regressions.

Results: Patients' attitudes towards cancer fatalism were significantly influenced by marital status ($P<.001$), education ($P<.001$), and household income ($P<.001$). Moreover, endorsing fatalistic belief was positively associated with age ($r=0.35$, $P<.001$). The regression model showed that younger patients (odds ratio [OR] 0.96, 95% CI 0.93-0.99) and those with higher education (OR 1.75, 95% CI 1.09-2.81) were more likely to seek information. Additionally, patients who were less confident in getting information were more likely to find information (OR 1.70, 95% CI 1.15-2.52), while fatalism belief was not significant in the regression (OR 0.65, 95% CI 0.22-1.95).

Conclusions: This study explored the information-seeking patterns of cancer patients in southwest China. It was found that many Chinese people endorsed cancer fatalism. These pessimistic beliefs about the potential to prevent and to cure cancer correlate with rather than cause cancer-related information seeking. However, self-efficacy about the confidence in finding needed cancer information was a significant predictor of information-seeking.

(*JMIR Cancer* 2020;6(2):e16138) doi:[10.2196/16138](https://doi.org/10.2196/16138)

KEYWORDS

cancer information seeking; cancer belief; fatalism; southwest China

Introduction

Background

According to the estimates of World Health Organization, cancer is the second leading cause of global death and is now responsible for 1 in 6 deaths [1]. Information about cancer can benefit patients in decision making, coping with treatment, their psychological well-being, and their quality of life [2,3]. Studying the patterns of patients' cancer-related information-seeking is

thus crucial to high-quality provider-patient communication, improved cancer care, and improved outcomes.

Although previous studies have reported information seeking among cancer patients in high-income countries such as the United States and some European countries [4,5], little is known about cancer-related information patterns among patients living in low- and middle-income regions, where approximately 70% of deaths from cancer occur [1]. In China, while increasing attention has been paid to cancer control and cancer information dissemination [6], most of the work has been conducted in

eastern metropolitan regions such as Beijing [7], Hefei [7], and Nanjing [8], leaving cancer patients in the southwest underrepresented. Southwest China consists of 5 provinces and is 14.40% of China's total population [9]. By 2017, the GDP (gross domestic product) of this region only accounted for 10% of the total GDP [9]; yet, according to national cancer statistics, southwest China had the highest cancer incidence rates, highest cancer mortality rates, and the lowest cancer survival rates in the country [10]. Possible reasons for these include a higher smoking prevalence, limited medical resources, and inadequate cancer screening and treatment [10]. Thus, the education and cancer care of patients in southwest China are concerning.

People's attitudes and beliefs can influence their intentions and behaviors [11]. For example, beliefs about cancer were associated with help-seeking behavior [12]. Furthermore, it was found that Asian individuals were more likely to have fatalistic cancer beliefs [13], for example, that the outcome of cancer is predetermined and arranged by fortune and predestination, and that nothing can be done to control or change the outcome of cancer [14]. One study [15] explored the role of self-efficacy and found that higher self-efficacy beliefs were positively correlated with cancer-screening intentions. However, most of these studies focused on the general public, while the beliefs among cancer patients, especially those from underrepresented regions, are less known.

Prior Work

Cancer Patients' Information Seeking

A seminal work [16] identified the individual differences in cancer information exchange as monitoring and blunting. *Monitoring* indicated the active seeking of information related to cancer, while *blunting* indicated the avoidance of threatening information. Later studies [17-19] further categorized active information behavior as information seeking and information scanning, arguing that scanning was a less active behavior that gathered and came across relevant information incidentally. Information scanning often occurred through mass media [20]. Moreover, Lambert, et al [21] delineated patients' cancer-related information-seeking preferences through an in-depth qualitative study, including three types of active search (intense, complementary, and fortuitous) and two types of information avoidance (minimal and guarded). These five patterns differed in essential characteristics such as the type and amount of information needs, as well as sources. A recent study [2] showed that most people were active seekers, although the prevalence of information avoidance was higher than expected.

Based on theoretical frameworks such as the Health Belief Model [22] and the Comprehensive Model of Information Seeking [23], previous studies [19,24-26] have found differences between information seekers and nonseekers among cancer patients. These studies investigated demographic characteristics (eg, gender, age, income, education) first, and then explored the effects of social determinants (such as having a regular health care provider, salience, cancer type, cancer stage, and treatment type); however, among the different studies, the effects of cancer type and cancer stage were often found to be inconsistent.

Comprehensive reviews [27,28] of information need and sources of information among cancer patients have been conducted; the majority of previous studies focused on patients in diagnosis and treatment stages. Therefore, the most prevalent information need was treatment-related, such as a need for information on the side effects of treatments and treatment options [4,28]. Furthermore, the most frequently used information source was health professionals, followed by cancer survivors and the internet [4,24,29]. Additionally, the differences for information need and sources used between patients of different age, gender, ethnicity or cancer type have also been explored [19,30,31]. For example, a meta-analysis [30] showed that younger cancer patients need more information.

Cancer Beliefs

An individual's beliefs about cancer can affect the way that person copes with cancer-related issues. People holding fatalistic or negative beliefs were found to have delayed diagnoses, avoid screening, and have worse survival outcomes [32]. Cancer fatalism has been operationalized by pessimism, helplessness, and confusion about how to prevent cancer. For example, based on the Health Information National Trends Survey (HINTS) [33], Kobayashi and Smith [34] found that a common perception in the US population was that everything caused cancer, one-third did not believe cancer was preventable, and more than half automatically associated cancer with death. Moreover, some research [13,32,35,36] has suggested ethnic and cultural differences in fatalism about cancer prevention, arguing that people from Eastern cultures tend to hold a more fatalistic attitude; they were found to be less likely to engage in cancer-related information-seeking, cancer screening, and cancer-preventive behaviors such as exercising and having a healthy diet. Cancer-related information seeking was also found to have an impact on the beliefs. For example, Lee et al [37] found that among those with a lower education level and less health knowledge, health-related internet use reduced cancer fatalism.

Previous studies [38] related to cancer beliefs focused mainly on the general public. However, little is known about the beliefs of cancer patients or the relationship between patients' beliefs and their health information seeking. A Turkish study [39] found that the majority of cancer patients and half of their relatives considered cancer as curable and preventable, and their beliefs influenced their wish for information and their efforts to obtain it. To improve the quality of the cancer care continuum, more research about cancer beliefs among patients during treatment and survival is necessary.

Goal of This Study

This study aimed to examine the cancer belief and self-efficacy of cancer patients in southwest China, and the factors influencing their cancer information seeking. A survey was conducted in two hospitals in Chengdu and Meishan. Statistical analyses included bivariate analyses and regression. Findings from this study can help develop effective cancer communication interventions and education strategies to achieve high-quality cancer care.

Methods

Overview

A survey was conducted to explore the cancer beliefs and information seeking of cancer patients in southwest China. The variables of the survey were measured with a self-report questionnaire (Multimedia Appendix 1) which included demographic questions and questions about cancer belief, self-efficacy, and cancer information seeking. The survey was conducted between January 2019 and April 2019.

Recruitment

Patients with cancer were recruited by convenience sampling in Meishan Tumor Hospital and the oncology inpatient department of the First Affiliated Hospital of Chengdu Medical College, located in Meishan and Chengdu, respectively, in southwest China. The two hospitals vary in levels: Chengdu Medical College is a level 3 hospital and Meishan Tumor Hospital is a level 2 hospital. Eligibility criteria for participation were patients who were diagnosed with cancer and who were undergoing treatment. We did not select patients by cancer type or gender because of ethical considerations required by the hospital administrations. One researcher together with a doctor distributed the questionnaires during the doctor's rounds. Each patient was invited to read and sign an informed consent form, which explained the aims, demands, guaranteed anonymity of the study, and that refusing to participate would not influence treatment. They were also asked to answer the questions carefully and were told that the researcher was available when they needed help.

With the aim of estimating the pattern of patients seeking cancer information in southwest China, we calculated the sample size by referring to a sample size calculation for qualitative variable in cross-sectional studies [40]. A previous study [7] in China showed that the portion of participants who reported having looked for information related to cancer may not be more than 28%, so the target sample size for the current study was determined to be 310. Three hundred questionnaires were distributed.

Measures

Cancer Belief

Cancer belief was assessed according to the HINTS (Health Information National Trends Survey) [41] through a guide question "How much do you agree or disagree with each of the following statements?" followed by 5 items: (1) "It seems like everything causes cancer," (2) "There's not much you can do to lower your chances of getting cancer," (3) "There are so many different recommendations about preventing cancer, it's hard to know which ones to follow," (4) "In adults, cancer is more common than heart disease," (5) "When I think about cancer, I automatically think about death." Responses for each item were rated using a 5-point Likert scale ranging from "strongly disagree" to "strongly agree." The internal consistency of these 5 items was (Cronbach $\alpha=.75$). The measurement consisting of 5 items was more reliable (Cronbach $\alpha>.70$) than the measurement with 3 items which has frequently been used in previous studies [34]; therefore, we used the mean of the 5 items

to create a fatalism scale. Items adapted from HINTS5 were translated into Mandarin through back translation and group discussion to guarantee linguistic equivalence between the English and Chinese versions.

Self-Efficacy

Self-efficacy suggests how confident patients are in getting health advice or information they need. From the HINTS [41], we used one item "I am NOT confident in finding cancer-related information I need." The response was rated using a 5-point Likert scale rating ranging from "strongly disagree" to "strongly agree."

Demographic Variables

Based on previous studies [34,37,42] related to cancer information seeking, and the different information practices among cancer patients with different demographic characteristics, we controlled for demographic variables. These variables included age, marital status (single, never been married; married; widowed; divorced), education (primary school or lower, junior school, high school, some college, bachelor's degree or higher), and household annual income (less than 10,000 RMB or approximately US \$1425; 10,000 to 50,000 RMB; 50,000 to 100,000 RMB; greater than 100,000 RMB). As required by the hospital administrations, we did not collect information on participants' gender and their cancer types to avoid identification.

Dependent Variable

Cancer information seeking was measured with 1 item "Have you ever looked for information about cancer from any source?" The response was "yes" or "no." Participants who answered "no" were considered nonseekers.

Statistical Analysis

To investigate the relationship between patients' beliefs and their cancer-related information-seeking behavior, we conducted bivariate analyses as well as multivariate regression analysis. First, the essential characteristics among different group of participants were described. Subsequently, the beliefs and information-seeking differences in demographic variables except age were examined using an analysis of variance (ANOVA) and cross-tabulation (Pearson chi-square test). The relationships between age and beliefs were tested using Pearson correlation while the differences between information seekers and nonseekers were analyzed using two-tailed independent *t* tests. Moreover, the self-efficacy and cancer belief differences between information seekers and nonseekers were explored using two-tailed independent *t* tests. Finally, variables were fitted in a logistic regression to investigate their predictive relationship with cancer information-seeking behavior, before which collinearity diagnostics were conducted (Multimedia Appendix 2). The categorical variable (marital status) was transformed into a dummy variable in the regression. All the analyses were conducted in SPSS (version 23.0; IBM Corp) and the significance level was $P<.05$.

Results

Descriptive Statistics

Demographic characteristics of participants (N=285) are shown in [Table 1](#). Among the 285 patients who completed the survey, the mean age was 51.79 (range 17-95) years old. Most were married (206/285, 72.3%), while the number of patients in the other three categories of marital status were close; and 25.6% (73/285) reported a junior school level of education, followed by high school, primary school or lower, college, and bachelor's degree or higher. Moreover, 48.4% (138/285) reported a

household annual income lower than 10,000 RMB, while the distribution of patients in the other three income categories was fairly equivalent.

The majority of patients (233/285, 81.8%) had looked for cancer-related information. Cancer belief (mean 3.23, SD 0.52) showed a moderate or strong fatalistic view. Among the 5 types of fatalism, "inevitable death" was most common (mean 3.66, SD 0.95), followed by "helplessness" (mean 3.18, SD 0.75), and "prevalence" (mean 3.17, SD 0.70). Furthermore, confidence in getting cancer information among 108 patients was moderate (108/285, 37.9%), while 6.0% (17/285) strongly acknowledged their confidence.

Table 1. Participant demographic data.

Characteristics (N=285)	Patients, n (%)
Age	
≤19	6 (2.1)
20-29	23 (8.1)
30-39	43 (15.1)
40-49	72 (25.3)
50-59	50 (17.5)
60-69	36 (12.6)
70-79	31 (10.9)
80-89	20 (7.0)
≥90	4 (1.4)
Marital status	
Single	26 (9.1)
Married	206 (72.3)
Widowed	30 (10.5)
Divorced	23(8.1)
Education	
Primary school or lower	66 (23.2)
Junior school	73 (25.6)
High school	67 (23.5)
Some college	45 (15.8)
Bachelor's degree or higher	34 (11.9)
Household income (in RMB^a)	
<10,000	138 (48.4)
10,000-50,000	58 (20.4)
50,000-100,000	42 (14.7)
>100,000	47 (16.5)

^aAt the time of publication, an exchange rate of approximately US \$1=0.19 RMB was applicable.

Beliefs and Demographics

We conducted bivariate analyses to investigate the relationship between patients' demographics and their beliefs. Patients' attitudes towards cancer fatalism were significantly related to marital status ($P<.001$), education ($P<.001$), and household

income ($P<.001$) ([Table 2](#)). Moreover, endorsing fatalistic belief was moderately associated with age ($r=0.35$, $P<.001$). A linear regression analysis was conducted to further test the relationship between demographics and cancer fatalism ([Multimedia Appendix 3](#)). It was found that age ($P=.003$), education ($P<.001$), and household income ($P=.04$) still showed significant

correlation with cancer fatalism. On the other hand, marital status ($P<.001$), education ($P<.001$), and household income ($P<.001$) were also related to patients' self-efficacy. Furthermore, older patients were more likely to believe in their

ability to obtain the information they need ($r=-0.41$, $P<.001$). These results were also tested in a linear regression model, in which age ($P<.001$) and education ($P<.001$) remained significant (Multimedia Appendix 3).

Table 2. Results of bivariate analyses.

Variables	Cancer belief		Self-efficacy	
	Value	P value	Value	P value
Marital status, mean (SD)		<.001 ^a		<.001 ^a
Single	2.77 (0.44)		4.08 (0.89)	
Married	3.23 (0.53)		2.88 (1.05)	
Widowed	3.47 (0.28)		2.53 (0.97)	
Divorced	3.44 (0.52)		2.44 (1.31)	
Education, mean (SD)		<.001 ^a		<.001 ^a
Primary school or lower	3.74 (0.37)		2.38 (0.82)	
Junior school	3.40 (0.34)		2.47 (0.97)	
High school	3.11 (0.39)		2.96 (1.12)	
Some college	2.88 (0.35)		3.44 (1.10)	
Bachelor's degree or higher	2.69 (0.40)		4.15 (0.82)	
Household annual income, mean (SD)		<.001 ^a		<.001 ^a
<10,000 RMB	3.27 (0.51)		2.88 (0.99)	
10,000-50,000 RMB	3.28 (0.51)		2.59 (1.09)	
50,000-100,000 RMB	3.39 (0.44)		2.67 (1.12)	
>100,000 RMB	2.92 (0.53)		3.64 (1.19)	
Age, r	0.35	<.001 ^b	-0.41	<.001 ^b

^aANOVA.

^bPearson correlation.

Cancer Information Seeking and Demographics

Our results suggested significant differences between cancer information seekers and nonseekers in marital status ($P<.001$) and education ($P<.001$), while household annual income showed no influence ($P=.45$) (Table 3), and the mean age of nonseekers was significantly higher than that of seekers ($P<.001$). However,

the effect of income became insignificant in the logistic regression (odds ratio [OR] 1.01, 95% CI 0.68-1.48) (Table 4). In the regression model, education level and age were demographic predictors of cancer information-seeking behavior, with younger patients (OR 0.96, 95% CI 0.93-0.99) and those with higher education (OR 1.75, 95% CI 1.09-2.81) being more likely to look for information.

Table 3. Comparison between patients who seek information and those who do not.

Variables	Cancer information seeking		P value
	Seekers (n=233)	Nonseekers (n=52)	
Marital status, n (%)			<.001 ^a
Single	26 (11.2)	0 (0)	
Married	173 (74.2)	33 (63.5)	
Widowed	15 (6.4)	15 (28.8)	
Divorced	19 (8.1)	4 (7.8)	
Education, n (%)			<.001 ^a
Primary school or lower	39 (16.7)	27 (51.9)	
Junior school	58 (24.9)	15 (28.8)	
High school	61 (26.2)	6 (11.5)	
Some college	42 (18.0)	3 (5.8)	
Bachelor's degree or higher	33 (14.2)	1 (1.9)	
Household annual income, n (%)			.45 ^a
<10,000 RMB	109 (46.8)	29 (55.8)	
10,000-50,000 RMB	47 (20.2)	11 (21.2)	
50,000-100,000 RMB	35 (15.0)	7 (13.5)	
>100,000 RMB	42 (18.0)	5 (9.6)	
Age, mean	48.70 (15.97)	65.67 (16.91)	<.001 ^b
Cancer belief, mean (SD)	3.16 (0.52)	3.56 (0.37)	<.001 ^b
Self-efficacy, mean (SD)	3.09 (1.04)	2.14 (1.14)	<.001 ^b

^aPearson chi-square test.

^bt test.

Table 4. Results of logistic regression.

Variables ^a	B	SE	P value	OR ^b (95% CI)
Education	0.56	0.24	.02	1.75 (1.09, 2.81)
Household annual income	0.01	0.20	.98	1.01 (0.68, 1.48)
Marital_single ^c	16.50	7451.17	.99	14576924.17 (0,—)
Marital_married	-0.12	0.65	.85	0.89 (0.25, 3.18)
Marital_widowed	-0.85	0.82	.30	0.43 (0.09, 2.15)
Age	-0.042	0.01	.004	0.96 (0.93, 0.99)
Cancer belief	-0.42	0.56	.45	0.65 (0.22, 1.95)
Self-efficacy	0.53	0.20	.009	1.70 (1.14, 2.52)
Constant	2.95	2.20	.18	19.14 (0,—)

^aModel summaries (Cox and Snell R²= 0.24; Nagelkerke R²=0.38).

^bOR: odds ratio.

^cThis implausibly large odds ratio value was possibly due to the uneven distribution among marital groups, and it should be interpreted with caution.

Cancer Information Seeking and Beliefs

Patients' attitudes towards cancer fatalism ($P<.001$) and their self-efficacy ($P<.001$) were significantly associated with whether to seek information or not (Table 3). Cancer fatalism was higher

in the nonseeking group (nonseeking: mean 3.56; seeking: mean 3.16) and this group also showed a higher level of confidence (nonseeking: mean 2.14; seeking: mean 3.09; it is notable that in the scale of self-efficacy, a higher value means a greater possibility of agreement that the participant is not confident).

However, when tested in the regression model, cancer belief was not found to be a predictor for information seeking (OR 0.65, 95% CI 0.22-1.95) (Table 3), suggesting a complicated relationship between these two variables. Additionally, patients who were less confident in getting information were more likely to find information (OR 1.70, 95% CI 1.15-2.52).

Discussion

Principal Results

To the best of our knowledge, this is the first study to investigate the beliefs and information-seeking behavior of cancer patients in southwest China. It was found that many endorsed cancer fatalism. These pessimistic beliefs about the potential to prevent and to cure cancer were correlated with rather than the cause of cancer-related information seeking. However, self-efficacy was a significant predictor of seeking out information ($P<.001$). Besides, it was found that patients who were younger ($P<.001$) and with higher level of education ($P<.001$) were more likely to find information. The response rate was quite high (285/300, 95%), which might be because (1) we surveyed hospitalized patients, and (2) they were familiar with their doctors and were thus willing to answer the questions.

The Influencing Factors of Cancer Information Seeking

Cancer fatalism is a multidimensional concept often operationalized by beliefs of pessimism, fear, helplessness, confusion, and inevitable death [39]. A previous study [13] found that people from Asian cultures tend to hold a more fatalistic view on negative issues such as having cancer, considering them to be unpreventable and out of one's control. Moreover, the same results have been reported among Asian communities in Western countries [35]; in these communities, individuals were more likely to associate cancer with bad luck, punishment for sins committed in the current or previous life, or the will of a supreme being [43], embedded in religious traditions such as Taoism. The higher fatalism among cancer patients in Chinese society was supported in our study (mean 3.23, SD 0.52). In addition, a study [7] found that the average fatalistic attitude of Chinese public was also slightly above the scale midpoint (mean 3.30, SD 0.80, range 1-5). The similar results suggest that cancer care intervention in our study's region failed to dispel fatalistic views. Additionally, in this study, we found that older patients were more likely to endorse fatalistic beliefs, while those who were better educated held more positive perceptions about cancer, as supported by a Turkish research [39].

Although a previous study [36] found that people who held a negative cancer belief were more likely to be information avoiders; our results did not support this: in the logistics model, there was no predictive relationship between cancer belief and information seeking. One possible explanation is that they might influence each other—on one hand, in the literature, it has been reported that greater information seeking led to decreased fatalism [44], internet-use reduced fatalism [37], and negative health information-seeking experiences might contribute to cancer fatalism [45]; on the other hand, some studies [7,46] found that fatalistic attitudes about cancer were an important barrier to information seeking. A significant correlation was

found in our bivariate analysis ($P<.001$), but cancer fatalism was not a predictor in the regression model ($P=.45$; OR 0.65, 95% CI 0.22-1.95). The bidirectional effects of cancer fatalism and information seeking could be further investigated through a qualitative approach.

In this study, we investigated how confident patients were of their ability to find cancer-related information. Interestingly, we found that older patients were more confident, while those who had higher incomes and were more educated reported to be less confident. One theoretical explanation could be optimistic beliefs about cancer risk among Asians [13]. This belief system allows them to underestimate their chance of suffering from serious outcomes [47]. However, patients with higher socioeconomic status were more likely to be exposed to a more westernized lifestyle and worldview, making them more self-enhancing and self-critical. Thus, older people were found to be more confident than those with higher income and education. On the other hand, as shown in the regression model, patients who were less confident about their information-seeking ability were more likely to look for information. This finding is inconsistent with studies [48,49] that have found that efficacy encourages health information-seeking. The reasons may be two-fold: first, we did not measure self-efficacy through a standard scale as the previous studies did; second, patients reporting less confidence tended to be younger, more educated, and were more likely to seek information. Therefore, the effect of self-efficacy on information seeking deserves future research. Additionally, younger and more educated patients might expect more from the health care system and keep on seeking, since a study found that intense seekers were more likely to be dissatisfied with the cancer information provided [2].

A large percentage of our respondents reported a low household income and low education level, which suggests social and economic gaps between the eastern and western China. For example, in two eastern cities (Beijing and Hefei, Anhui province), the majority of households earn 60,001 RMB or more annually [7], while most participants in this study had an annual household income of 10,000 RMB or lower.

Our analyses also revealed distinct patterns in the information-seeking behavior among different groups of cancer patients. We found that older patients and those who were less educated were less likely to seek information, which is consistent with a previous study [26] conducted in Mexico. This study focused on health-related information-seeking behaviors and preferences among Mexican patients with cancer, showing that older age was the characteristic most strongly associated with not seeking information [26]. Moreover, similar results have been found in some high-income countries; Smith-McLallen et al [50] found that level of education and age significantly contributed to the prediction of patients' seeking intentions in Pennsylvania, while they also indicated that older individuals and those who had lower levels of education were less likely to seek out information from sources other than their doctors. It was also found in a study [2] in Montreal that individuals who avoided information tended to be less educated, while active seekers reported higher education. However, a study [7] in Beijing and Hefei found that age and employment were not related to seeking. Moreover, although education

showed some significant relationships with seeking in the predictive models considering predisposing and enabling variables, the relationship became nonsignificant when including need variables [7].

Practical Suggestions

Given the importance of information seeking to cancer care and outcomes, health practitioners should encourage patients' information seeking behavior and increase their satisfaction. First, education was found to be an important predictor of information seeking, highlighting the importance of narrowing educational gaps together with economic gaps between southwestern and eastern regions in China. This could generally increase patients' health literacy since education and health literacy often overlap [34]. Moreover, many Chinese individuals hold the fatalistic beliefs about cancer. Practitioners should understand the roles of these beliefs better before attempting interventions to improve the access and availability of optimal treatments. For example, the relationship between cancer beliefs and traditional Chinese medicine should be considered. Furthermore, cancer patients undergoing treatment in the hospital are seen by the same fellow or oncologist, which facilitates a steady and trustable relationship. This relationship can form a close tie, which is a fundamental value in the Chinese collectivism culture, to benefit information provision. For example, during hospital stays, oncologists can provide tailored messages, tell the patients how to find information, and guide them in appraising information sources. In addition, oncologists

may also continue to help patients in their information seeking by using email and social networking sites based on the close relationships.

Limitations

There are some limitations in our study. For example, this cross-sectional survey was not equipped to explore the causality between variables. Furthermore, this study only investigated several possible factors influencing beliefs and information seeking. Further research is needed to follow a theoretical framework and explore more factors. This survey was conducted in two hospitals in southwest China, and thus may not be generalizable outside of a similar context. Finally, since the participants of all types of cancer were randomly sampled, the results could be biased by the participants with the majority type of cancer and should be interpreted with caution.

Conclusions

This study explored the information-seeking patterns of cancer patients in southwest China. It was found that many Chinese people endorsed cancer fatalism. These pessimistic beliefs about the potential to prevent and to cure cancer are correlated with cancer-related information seeking, while self-efficacy confidence in finding needed cancer information was a significant predictor of seeking out information. Moreover, this study demonstrated that information seekers and nonseekers differ demographically. These findings reflect a sense of urgency for cancer information dissemination in low- to middle-income regions such as southwest China.

Acknowledgments

This study was financially supported by a project of Humanities and Social Sciences in Nanjing University (No. 2018047).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire_English version.

[DOCX File, 24 KB - [cancer_v6i2e16138_app1.docx](#)]

Multimedia Appendix 2

The results of collinearity diagnosis.

[DOCX File, 22 KB - [cancer_v6i2e16138_app2.docx](#)]

Multimedia Appendix 3

Results of two linear regressions.

[DOCX File, 22 KB - [cancer_v6i2e16138_app3.docx](#)]

References

1. World Health Organization. 2018. Cancer. URL: <https://www.who.int/news-room/fact-sheets/detail/cancer> [accessed 2020-07-30]
2. Loiselle CG. Cancer information-seeking preferences linked to distinct patient experiences and differential satisfaction with cancer care. *Patient Educ Couns* 2019 Jun;102(6):1187-1193. [doi: [10.1016/j.pec.2019.01.009](https://doi.org/10.1016/j.pec.2019.01.009)] [Medline: [30685191](#)]
3. Eisfeld H, Bauer F, Dubois C, Schmidt T, Kastrati K, Hochhaus A, et al. Importance of and Satisfaction with Information about Their Disease in Cancer Patients. *J Cancer Educ* 2019 Jan 25. [doi: [10.1007/s13187-019-1480-7](https://doi.org/10.1007/s13187-019-1480-7)] [Medline: [30684231](#)]

4. Rutten LJF, Agunwamba AA, Wilson P, Chawla N, Vieux S, Blanch-Hartigan D, et al. Cancer-Related Information Seeking Among Cancer Survivors: Trends Over a Decade (2003-2013). *J Cancer Educ* 2016 Jun;31(2):348-357. [doi: [10.1007/s13187-015-0802-7](https://doi.org/10.1007/s13187-015-0802-7)] [Medline: [25712202](https://pubmed.ncbi.nlm.nih.gov/25712202/)]
5. Vogel BA, Bengel J, Helmes AW. Information and decision making: patients' needs and experiences in the course of breast cancer treatment. *Patient Educ Couns* 2008 Apr;71(1):79-85. [doi: [10.1016/j.pec.2007.11.023](https://doi.org/10.1016/j.pec.2007.11.023)] [Medline: [18191933](https://pubmed.ncbi.nlm.nih.gov/18191933/)]
6. Wen C. China's plans to curb cervical cancer. *Lancet Oncol* 2005 Mar;6(3):139-141. [doi: [10.1016/S1470-2045\(05\)01761-4](https://doi.org/10.1016/S1470-2045(05)01761-4)] [Medline: [15737830](https://pubmed.ncbi.nlm.nih.gov/15737830/)]
7. Zhao X, Mao Q, Kreps GL, Yu G, Li Y, Chou SW, et al. Cancer information seekers in china: a preliminary profile. *J Health Commun* 2015;20(5):616-626. [doi: [10.1080/10810730.2015.1012244](https://doi.org/10.1080/10810730.2015.1012244)] [Medline: [25845031](https://pubmed.ncbi.nlm.nih.gov/25845031/)]
8. Zhang Y, Wen N, Chao N. Effects of mobile information-seeking on the intention to obtain reproductive cancer screening among chinese women: testing an integrative model. *Chinese Journal of Communication* 2018 Dec 22;12(1):102-121. [doi: [10.1080/17544750.2018.1528291](https://doi.org/10.1080/17544750.2018.1528291)]
9. National Health Commission of PRC. *China Health Statistic Annual*. Beijing: Peking Union Medical College Press; 2018.
10. Chen W, Zheng R, Baade PD, Zhang S, Zeng H, Bray F, et al. Cancer statistics in China, 2015. *CA Cancer J Clin* 2016;66(2):115-132 [FREE Full text] [doi: [10.3322/caac.21338](https://doi.org/10.3322/caac.21338)] [Medline: [26808342](https://pubmed.ncbi.nlm.nih.gov/26808342/)]
11. Ajzen I. The theory of planned behavior. *Organizational Behavior and Human Decision Processes* 1991 Dec;50(2):179-211. [doi: [10.1016/0749-5978\(91\)90020-T](https://doi.org/10.1016/0749-5978(91)90020-T)]
12. Pedersen AF, Forbes L, Brain K, Hvidberg L, Wulff CN, Lagerlund M, et al. Negative cancer beliefs, recognition of cancer symptoms and anticipated time to help-seeking: an international cancer benchmarking partnership (ICBP) study. *BMC Cancer* 2018 Apr 02;18(1):363 [FREE Full text] [doi: [10.1186/s12885-018-4287-8](https://doi.org/10.1186/s12885-018-4287-8)] [Medline: [29609534](https://pubmed.ncbi.nlm.nih.gov/29609534/)]
13. Kim HK, Lwin MO. Cultural Effects on Cancer Prevention Behaviors: Fatalistic Cancer Beliefs and Risk Optimism Among Asians in Singapore. *Health Commun* 2017 Oct;32(10):1201-1209. [doi: [10.1080/10410236.2016.1214224](https://doi.org/10.1080/10410236.2016.1214224)] [Medline: [27613075](https://pubmed.ncbi.nlm.nih.gov/27613075/)]
14. Cheng H, Sit JWH, Twinn SF, Cheng KKF, Thorne S. Coping with breast cancer survivorship in Chinese women: the role of fatalism or fatalistic voluntarism. *Cancer Nurs* 2013;36(3):236-244. [doi: [10.1097/NCC.0b013e31826542b2](https://doi.org/10.1097/NCC.0b013e31826542b2)] [Medline: [22964870](https://pubmed.ncbi.nlm.nih.gov/22964870/)]
15. Lipkus IM, Johnson C, Amarasekara S, Pan W, Updegraff JA. Predicting Colorectal Cancer Screening among Adults Who Have Never Been Screened: Testing the Interaction between Message Framing and Tailored Risk Feedback. *J Health Commun* 2019;24(3):262-270. [doi: [10.1080/10810730.2019.1597950](https://doi.org/10.1080/10810730.2019.1597950)] [Medline: [30958101](https://pubmed.ncbi.nlm.nih.gov/30958101/)]
16. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer* 1995 Jul 15;76(2):167-177. [Medline: [8625088](https://pubmed.ncbi.nlm.nih.gov/8625088/)]
17. Shim M, Kelly B, Hornik R. Cancer information scanning and seeking behavior is associated with knowledge, lifestyle choices, and screening. *J Health Commun* 2006;11 Suppl 1:157-172. [doi: [10.1080/10810730600637475](https://doi.org/10.1080/10810730600637475)] [Medline: [16641081](https://pubmed.ncbi.nlm.nih.gov/16641081/)]
18. Niederdeppe J, Hornik RC, Kelly BJ, Frosch DL, Romantan A, Stevens RS, et al. Examining the dimensions of cancer-related information seeking and scanning behavior. *Health Commun* 2007;22(2):153-167. [doi: [10.1080/10410230701454189](https://doi.org/10.1080/10410230701454189)] [Medline: [17668995](https://pubmed.ncbi.nlm.nih.gov/17668995/)]
19. Nagler RH, Gray SW, Romantan A, Kelly BJ, DeMichele A, Armstrong K, et al. Differences in information seeking among breast, prostate, and colorectal cancer patients: results from a population-based survey. *Patient Educ Couns* 2010 Dec;81 Suppl:S54-S62 [FREE Full text] [doi: [10.1016/j.pec.2010.09.010](https://doi.org/10.1016/j.pec.2010.09.010)] [Medline: [20934297](https://pubmed.ncbi.nlm.nih.gov/20934297/)]
20. Ruppel EK. Scanning Health Information Sources: Applying and Extending the Comprehensive Model of Information Seeking. *J Health Commun* 2016;21(2):208-216. [doi: [10.1080/10810730.2015.1058438](https://doi.org/10.1080/10810730.2015.1058438)] [Medline: [26716985](https://pubmed.ncbi.nlm.nih.gov/26716985/)]
21. Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer: part 1: understanding differential patterns of active information seeking. *Cancer Nurs* 2009;32(1):11-23; quiz 24. [doi: [10.1097/01.NCC.0000343372.24517.bd](https://doi.org/10.1097/01.NCC.0000343372.24517.bd)] [Medline: [19104197](https://pubmed.ncbi.nlm.nih.gov/19104197/)]
22. Rosenstock IM. Historical Origins of the Health Belief Model. *Health Educ Behav* 1974 Dec 01;2(4):328-335. [doi: [10.1177/109019817400200403](https://doi.org/10.1177/109019817400200403)]
23. Johnson J, Meischke H. A Comprehensive Model of Cancer-Related Information Seeking Applied to Magazines. *Human Comm Res* 1993 Mar;19(3):343-367. [doi: [10.1111/j.1468-2958.1993.tb00305.x](https://doi.org/10.1111/j.1468-2958.1993.tb00305.x)]
24. Mayer DK, Terrin NC, Kreps GL, Menon U, McCance K, Parsons SK, et al. Cancer survivors information seeking behaviors: a comparison of survivors who do and do not seek information about cancer. *Patient Educ Couns* 2007 Mar;65(3):342-350. [doi: [10.1016/j.pec.2006.08.015](https://doi.org/10.1016/j.pec.2006.08.015)] [Medline: [17029864](https://pubmed.ncbi.nlm.nih.gov/17029864/)]
25. Hartoonian N, Ormseth SR, Hanson ER, Bantum EO, Owen JE. Information-seeking in cancer survivors: application of the Comprehensive Model of Information Seeking to HINTS 2007 data. *J Health Commun* 2014;19(11):1308-1325. [doi: [10.1080/10810730.2013.872730](https://doi.org/10.1080/10810730.2013.872730)] [Medline: [24742287](https://pubmed.ncbi.nlm.nih.gov/24742287/)]
26. Soto-Perez-de-Celis E, Perez-Montessoro V, Rojo-Castillo P, Chavarri-Guerra Y. Health-Related Information-Seeking Behaviors and Preferences Among Mexican Patients with Cancer. *J Cancer Educ* 2018 Jun;33(3):505-509. [doi: [10.1007/s13187-018-1334-8](https://doi.org/10.1007/s13187-018-1334-8)] [Medline: [29442291](https://pubmed.ncbi.nlm.nih.gov/29442291/)]

27. Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns* 2005 Jun;57(3):250-261. [doi: [10.1016/j.pec.2004.06.006](https://doi.org/10.1016/j.pec.2004.06.006)] [Medline: [15893206](https://pubmed.ncbi.nlm.nih.gov/15893206/)]
28. Fletcher C, Flight I, Chapman J, Fennell K, Wilson C. The information needs of adult cancer survivors across the cancer continuum: A scoping review. *Patient Educ Couns* 2017 Mar;100(3):383-410. [doi: [10.1016/j.pec.2016.10.008](https://doi.org/10.1016/j.pec.2016.10.008)] [Medline: [27765377](https://pubmed.ncbi.nlm.nih.gov/27765377/)]
29. Miller KA, Ramirez CN, Wojcik KY, Ritt-Olson A, Baezconde-Garbanati L, Thomas SM, et al. Prevalence and correlates of health information-seeking among Hispanic and non-Hispanic childhood cancer survivors. *Support Care Cancer* 2018 Apr;26(4):1305-1313 [FREE Full text] [doi: [10.1007/s00520-017-3956-5](https://doi.org/10.1007/s00520-017-3956-5)] [Medline: [29124416](https://pubmed.ncbi.nlm.nih.gov/29124416/)]
30. Ankem K. Factors influencing information needs among cancer patients: A meta-analysis. *Library & Information Science Research* 2006 Mar;28(1):7-23. [doi: [10.1016/j.lisr.2005.11.003](https://doi.org/10.1016/j.lisr.2005.11.003)]
31. Squiers L, Finney RLJ, Treiman K, Bright MA, Hesse B. Cancer patients' information needs across the cancer care continuum: evidence from the cancer information service. *J Health Commun* 2005;10 Suppl 1:15-34. [doi: [10.1080/10810730500263620](https://doi.org/10.1080/10810730500263620)] [Medline: [16377598](https://pubmed.ncbi.nlm.nih.gov/16377598/)]
32. Min HS, Park J, Kim YA, Yang HK, Park K. Income Difference in Attitudes towards Cancer in General Population: Findings from a National Survey. *J Korean Med Sci* 2018 Aug 13;33(33):e215 [FREE Full text] [doi: [10.3346/jkms.2018.33.e215](https://doi.org/10.3346/jkms.2018.33.e215)] [Medline: [30093846](https://pubmed.ncbi.nlm.nih.gov/30093846/)]
33. National Cancer Institute. 2013. Health information national trends survey 4 cycle 3. URL: <http://hints.cancer.gov> [accessed 2020-07-30]
34. Kobayashi LC, Smith SG. Cancer Fatalism, Literacy, and Cancer Information Seeking in the American Public. *Health Educ Behav* 2016 Aug;43(4):461-470 [FREE Full text] [doi: [10.1177/1090198115604616](https://doi.org/10.1177/1090198115604616)] [Medline: [26377524](https://pubmed.ncbi.nlm.nih.gov/26377524/)]
35. Licqurish S, Phillipson L, Chiang P, Walker J, Walter F, Emery J. Cancer beliefs in ethnic minority populations: a review and meta-synthesis of qualitative studies. *Eur J Cancer Care (Engl)* 2017 Jan;26(1). [doi: [10.1111/ecc.12556](https://doi.org/10.1111/ecc.12556)] [Medline: [27515153](https://pubmed.ncbi.nlm.nih.gov/27515153/)]
36. Nguyen GT, Bellamy SL. Cancer information seeking preferences and experiences: disparities between Asian Americans and Whites in the Health Information National Trends Survey (HINTS). *J Health Commun* 2006;11 Suppl 1:173-180. [doi: [10.1080/10810730600639620](https://doi.org/10.1080/10810730600639620)] [Medline: [16641082](https://pubmed.ncbi.nlm.nih.gov/16641082/)]
37. Lee C, Niederdeppe J, Freres D. Socioeconomic Disparities in Fatalistic Beliefs About Cancer Prevention and the Internet. *J Commun* 2012 Dec;62(6):972-990 [FREE Full text] [doi: [10.1111/j.1460-2466.2012.01683.x](https://doi.org/10.1111/j.1460-2466.2012.01683.x)] [Medline: [25530627](https://pubmed.ncbi.nlm.nih.gov/25530627/)]
38. Sinky TH, Faith J, Lindly O, Thorburn S. Cancer Fatalism and Preferred Sources of Cancer Information: an Assessment Using 2012 HINTS Data. *J Cancer Educ* 2018 Feb;33(1):231-237. [doi: [10.1007/s13187-016-1115-1](https://doi.org/10.1007/s13187-016-1115-1)] [Medline: [27650861](https://pubmed.ncbi.nlm.nih.gov/27650861/)]
39. Kav S, Tokdemir G, Tasdemir R, Yalili A, Dinc D. Patients with cancer and their relatives beliefs, information needs and information-seeking behavior about cancer and treatment. *Asian Pac J Cancer Prev* 2012;13(12):6027-6032 [FREE Full text] [doi: [10.7314/apjcp.2012.13.12.6027](https://doi.org/10.7314/apjcp.2012.13.12.6027)] [Medline: [23464398](https://pubmed.ncbi.nlm.nih.gov/23464398/)]
40. Charan J, Biswas T. How to calculate sample size for different study designs in medical research? *Indian J Psychol Med* 2013 Apr;35(2):121-126 [FREE Full text] [doi: [10.4103/0253-7176.116232](https://doi.org/10.4103/0253-7176.116232)] [Medline: [24049221](https://pubmed.ncbi.nlm.nih.gov/24049221/)]
41. National Cancer Institute. 2017. Health information national trends survey 5 cycle 1. URL: <http://hints.cancer.gov> [accessed 2020-07-30]
42. Halbach SM, Ernstmann N, Kowalski C, Pfaff H, Pfortner T, Wesselmann S, et al. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Educ Couns* 2016 Sep;99(9):1511-1518. [doi: [10.1016/j.pec.2016.06.028](https://doi.org/10.1016/j.pec.2016.06.028)] [Medline: [27378079](https://pubmed.ncbi.nlm.nih.gov/27378079/)]
43. Ong KJ, Back MF, Lu JJ, Shakespeare TS, Wynne CJ. Cultural attitudes to cancer management in traditional South-East Asian patients. *Australas Radiol* 2002 Dec;46(4):370-374. [doi: [10.1046/j.1440-1673.2002.t01-1-01085.x](https://doi.org/10.1046/j.1440-1673.2002.t01-1-01085.x)] [Medline: [12452906](https://pubmed.ncbi.nlm.nih.gov/12452906/)]
44. Valera P, Lian Z, Brotzman L, Reid A. Fatalistic Cancer Beliefs and Information Seeking in Formerly Incarcerated African-American and Hispanic Men: Implications for Cancer Health Communication and Research. *Health Commun* 2018 May;33(5):576-584 [FREE Full text] [doi: [10.1080/10410236.2017.1283564](https://doi.org/10.1080/10410236.2017.1283564)] [Medline: [28278604](https://pubmed.ncbi.nlm.nih.gov/28278604/)]
45. Emanuel AS, Godinho CA, Steinman C, Updegraff JA. Education differences in cancer fatalism: The role of information-seeking experiences. *J Health Psychol* 2018 Oct;23(12):1533-1544. [doi: [10.1177/1359105316664129](https://doi.org/10.1177/1359105316664129)] [Medline: [27553609](https://pubmed.ncbi.nlm.nih.gov/27553609/)]
46. Wigfall LT, Friedman DB. Cancer Information Seeking and Cancer-Related Health Outcomes: A Scoping Review of the Health Information National Trends Survey Literature. *J Health Commun* 2016 Sep;21(9):989-1005 [FREE Full text] [doi: [10.1080/10810730.2016.1184358](https://doi.org/10.1080/10810730.2016.1184358)] [Medline: [27466828](https://pubmed.ncbi.nlm.nih.gov/27466828/)]
47. Ji LJ, Zhang Z, Osborne E, Guan Y. Optimism across cultures: In response to the severe acute respiratory syndrome outbreak. *Asian Journal of Social Psychology* 2004;7(1):25-34. [doi: [10.1111/j.1467-839X.2004.00132.x](https://doi.org/10.1111/j.1467-839X.2004.00132.x)]
48. Selsky C, Luta G, Noone A, Huerta EE, Mandelblatt JS. Internet access and online cancer information seeking among Latino immigrants from safety net clinics. *J Health Commun* 2013;18(1):58-70 [FREE Full text] [doi: [10.1080/10810730.2012.688248](https://doi.org/10.1080/10810730.2012.688248)] [Medline: [23066874](https://pubmed.ncbi.nlm.nih.gov/23066874/)]

49. Lim S, Xue L, Yen CC, Chang L, Chan HC, Tai BC, et al. A study on Singaporean women's acceptance of using mobile phones to seek health information. *Int J Med Inform* 2011 Dec;80(12):e189-e202. [doi: [10.1016/j.ijmedinf.2011.08.007](https://doi.org/10.1016/j.ijmedinf.2011.08.007)] [Medline: [21956003](https://pubmed.ncbi.nlm.nih.gov/21956003/)]
50. Smith-McLallen A, Fishbein M, Hornik RC. Psychosocial determinants of cancer-related information seeking among cancer patients. *J Health Commun* 2011 Feb;16(2):212-225 [FREE Full text] [doi: [10.1080/10810730.2010.522227](https://doi.org/10.1080/10810730.2010.522227)] [Medline: [21207310](https://pubmed.ncbi.nlm.nih.gov/21207310/)]

Abbreviations

ANOVA: analysis of variance

GDP: gross domestic product

HINTS: Health Information National Trends Survey

RMB: Renminbi

Edited by G Eysenbach; submitted 04.09.19; peer-reviewed by X Liu, K Chen, L Tang; comments to author 16.12.19; revised version received 01.01.20; accepted 03.06.20; published 21.08.20.

Please cite as:

Xie J, Xie S, Cheng Y, He Z

Beliefs and Information Seeking in Patients With Cancer in Southwest China: Survey Study

JMIR Cancer 2020;6(2):e16138

URL: <http://cancer.jmir.org/2020/2/e16138/>

doi: [10.2196/16138](https://doi.org/10.2196/16138)

PMID: [32821061](https://pubmed.ncbi.nlm.nih.gov/32821061/)

©Juan Xie, Shi Xie, Ying Cheng, Zhe He. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 21.08.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

eHealth Practices in Cancer Survivors With BMI in Overweight or Obese Categories: Latent Class Analysis Study

Annie Wen Lin^{1,2}, BSc, MSc, PhD, RD; Sharon H Baik^{3,4}, BSc, MSc, PhD; David Aaby², BSc, MSc; Leslie Tello¹; Twila Linville², BSc, MSc; Nabil Alshurafa², BSc, MSc, PhD; Bonnie Spring², BA, MA, PhD

¹Department of Nutrition, Benedictine University, Lisle, IL, United States

²Department of Preventive Medicine, Northwestern University, Chicago, IL, United States

³Department of Supportive Care Medicine, City of Hope Medical Cancer Center, Duarte, CA, United States

⁴Department of Medical Social Sciences, Northwestern University, Chicago, IL, United States

Corresponding Author:

Annie Wen Lin, BSc, MSc, PhD, RD

Department of Nutrition

Benedictine University

5700 College Road

Kindlon Hall, Room 224

Lisle, IL, 60532

United States

Phone: 1 630 829 1145

Email: alin@ben.edu

Abstract

Background: eHealth technologies have been found to facilitate health-promoting practices among cancer survivors with BMI in overweight or obese categories; however, little is known about their engagement with eHealth to promote weight management and facilitate patient-clinician communication.

Objective: The objective of this study was to determine whether eHealth use was associated with sociodemographic characteristics, as well as medical history and experiences (ie, patient-related factors) among cancer survivors with BMI in overweight or obese categories.

Methods: Data were analyzed from a nationally representative cross-sectional survey (National Cancer Institute's Health Information National Trends Survey). Latent class analysis was used to derive distinct classes among cancer survivors based on sociodemographic characteristics, medical attributes, and medical experiences. Logistic regression was used to examine whether class membership was associated with different eHealth practices.

Results: Three distinct classes of cancer survivors with BMI in overweight or obese categories emerged: younger with no comorbidities, younger with comorbidities, and older with comorbidities. Compared to the other classes, the younger with comorbidities class had the highest probability of identifying as female (73%) and Hispanic (46%) and feeling that clinicians did not address their concerns (75%). The older with comorbidities class was 6.5 times more likely than the younger with comorbidities class to share eHealth data with a clinician (odds ratio [OR] 6.53, 95% CI 1.08-39.43). In contrast, the younger with no comorbidities class had a higher likelihood of using a computer to look for health information (OR 1.93, 95% CI 1.10-3.38), using an electronic device to track progress toward a health-related goal (OR 2.02, 95% CI 1.08-3.79), and using the internet to watch health-related YouTube videos (OR 2.70, 95% CI 1.52-4.81) than the older with comorbidities class.

Conclusions: Class membership was associated with different patterns of eHealth engagement, indicating the importance of tailored digital strategies for delivering effective care. Future eHealth weight loss interventions should investigate strategies to engage younger cancer survivors with comorbidities and address racial and ethnic disparities in eHealth use.

(*JMIR Cancer* 2020;6(2):e24137) doi:[10.2196/24137](https://doi.org/10.2196/24137)

KEYWORDS

eHealth; patient communication; cancer survivorship; obesity; behavior

Introduction

More than 17 million cancer survivors reside in the United States, and simulation models predict that the survivorship population will increase to 22 million by January 2030 [1]. The growing prevalence of cancer survivors represents a significant health care challenge especially since they have higher risk for treatment-related morbidities (eg, cardiovascular disease) and cancer than the general population [2-4]. Obesity is considered a major risk factor for chronic disease, modifiable with energy-restricted, high-quality diets, and consistent physical activity [5]. Yet the prevalence of obesity continues to increase rapidly among cancer survivors [6] despite medical recommendations to maintain a healthy weight [7]. The prevalence of obesity among adult cancer survivors has increased 10% since 1997, a significantly faster rate than among those without a history of cancer [6]. However, several issues restrict cancer survivors from accessing nutrition services, including inadequate reimbursement coverage, providers' heavy clinical load, and providers' limited nutrition or behavior change training [8,9]. To increase access to nutrition care, digital technology support for weight management and health promotion (eHealth) is being developed to facilitate healthy lifestyle change [10-12] and patient-clinician communication [13,14].

Many eHealth interventions for cancer survivors, delivered through smartphone apps and internet websites, promote a high-quality diet and physical activity through behavior change techniques [15], such as goal-setting [16-21], self-monitoring of behavior [16-27], modeling of behavior [28], and behavioral feedback [16-19,21,24,26,28,29]. eHealth interventions have shown some promise for assisting cancer survivors with health-promoting behavior change and weight loss [30,31] yet the one size fits all approach is unlikely to be effective for this population [32]. Individuals in the increasingly culturally and linguistically diverse survivor population may have different medical experiences, as well as different digital access and engagement [33]. The few studies [34-37] that have investigated associations among eHealth use, sociodemographic characteristics, and medical history examined the general population rather than cancer survivors. In these studies [34-37], researchers found poorer engagement in eHealth practices among adults who are older, male, in a lower annual income bracket, less healthy, or without a regular provider. Even less is known about how different care experiences are associated with different types of eHealth practices. However, a recent study [38] found that negative medical experiences (ie, low perceived patient-centeredness) were associated with greater engagement in self-management eHealth practices only among those with less education and not among those with more education, suggesting that eHealth use can vary as a function of sociodemographic factors and medical experiences. Further investigation is warranted to understand how and why different combinations of these factors are associated with varied eHealth practices among cancer survivors with BMI in overweight or obese categories. Latent class analysis is a statistical approach that allows an investigation of how the intersection of several patient-related factors are associated with eHealth use. This

type of analysis is useful when there are several variables that can contribute to heterogeneity, such as that observed among cancer survivors and can facilitate understanding to guide optimization of eHealth promotion among different underlying cancer survivor subgroups.

The primary objective of the study was to determine whether distinct classes can be identified based on sociodemographic characteristics, medical history, and medical experiences (eg, patient-related factors) of cancer survivors with BMI in overweight or obese categories. We also investigated whether class membership was associated with eHealth practices for weight management and patient-clinician communication among cancer survivors with BMI in overweight or obese categories.

Methods

National Cancer Institute Health Information National Trends Survey

National Cancer Institute's Health Information National Trends Survey (NCI HINTS) is an ongoing cross-sectional data collection program for nationally representative data about health- and cancer-related communication in the United States. Details regarding the NCI HINTS sampling framework have been previously published [39]. During 2017-2018, self-administered questionnaires from NCI HINTS 5 Cycles 1 and 2 were mailed to households (address-based sampling). Surveys were deemed ineligible if $\leq 49\%$ of the first 2 sections of the questionnaire were completed. The NCI HINTS 5 Cycles 1 and 2 comprised 6862 participants who returned their questionnaires to investigators, with a final collective response rate of 25%. Of these questionnaires, 6789 (99%) were considered completed by study investigators. In our study, participant data were excluded if respondents did not have a cancer history ($n=3735$) and had a BMI $< 25 \text{ kg/m}^2$ ($n=2324$).

Variables

All variables were categorical and were collected in NCI HINTS 5 Cycles 1 and 2. Sociodemographic variables included age, gender, race/ethnicity, and education level. Also included in the analysis were degree of weight above a healthy weight (overweight, class I obesity; class II obesity; class III obesity [40]), presence of medical conditions (diabetes, cardiovascular disease, or depression; hypertension; arthritis), frequency of medical visits in the past year, quality of care, health insurance status, access to medical records, and access to a regular provider. Medical experience characteristics included whether patients felt that (1) their feelings and emotions were addressed by clinicians, (2) they were involved in medical decisions, (3) their clinicians made certain that they understood next steps of care, (4) they received clear explanations from their clinicians, and (5) they were confident in their ability to take care of their own health. Response options for each medical experience questionnaire item were dichotomous (yes or no).

Nine eHealth items (outcome variables) were available across both cycles: access to a health app (1 item); use of electronic means to seek personal medical information (2 items), use of tablets or smartphones to track health and facilitate medical discussions (4 items), and use of the internet as a health resource

(2 items). Response options for these items were dichotomous (yes or no). Since deidentified data were available for public use from the National Cancer Institute, ethical approval was not required for this secondary data analysis.

Statistical Analysis

All analyses were conducted using STATA statistical software (version 15; StataCorp LLC). We used latent class analysis to empirically identify classes for cancer survivors with BMI in overweight or obese categories who exhibited similar sociodemographic and psychosocial characteristics [41]. The latent class model included sampling weights to account for the

study design and to generate estimates and make inferences that reflect the population. The number of classes was selected using the Akaike information criterion (AIC); Schwarz Bayesian information criterion (BIC); Rissanen sample-size adjusted BIC; entropy, with higher values indicating better classification of individuals; and ease of interpretation (ie, the classes distinguished differences from a practical perspective). We examined a series of models, progressing from a 1-class model to a 10-class model, and compared the models using AIC, adjusted BIC, and entropy descriptive fit indices (Table 1) to identify the optimal number of classes [42,43].

Table 1. Latent class model selection diagnostics.

Classes, n	G ² deviance statistic	AIC ^a	BIC ^b	Adjusted ^c BIC	Entropy
1	7815.99	7879.99	8026.96	7925.35	1.00
2	7424.36	7554.36	7852.91	7646.52	0.56
3	7074.80	7270.80	7720.92	7409.73	0.74
4	6930.33	7192.33	7794.02	7378.05	0.77
5	6845.61	7173.61	7926.87	7406.12	0.74
6	6648.00	7042.00	7946.83	7321.30	0.77
7	6574.32	7034.32	8090.72	7360.40	0.82
8	6447.51	6973.51	8181.48	7346.37	0.82
9	6300.65	6892.65	8252.19	7312.29	0.83
10	6238.49	6896.49	8407.60	7362.92	0.83

^aAIC: Akaike information criterion.

^bBIC: Bayesian information criterion.

^cRissanen sample size adjustment.

We determined that the 3-class model was optimal (AIC 7270.80; adjusted BIC 7409.73; entropy 0.74). Specifically, all indicators of model fit (decreased AIC and adjusted BIC, higher entropy) revealed the 2-class model fit better than the 1-class model, and the 3-class model fit better than the 2-class model. Although the slightly lower AIC and adjusted BIC values, and slightly higher entropy indicated the 4-class model fit better than the 3-class model, the 3-class model demonstrated both (1) a relatively larger decrease in the AIC and adjusted BIC values (2-class to 3-class compared to 3-class to 4-class) and (2) and a similar entropy (0.74 in 3-class vs 0.77 in 4-class). Also, the 4-class model seemed to separate Class 1 from the 3-class model into 2 distinct classes; however, these classes did not differ in any meaningful or interpretable way. The 3-class model provided the most clinically interpretable groups.

Maximum conditional probabilities for the categorical indicator variables (ie, sociodemographic, medical, and psychosocial factors) were used to characterize each class. Variables with probabilities greater than 0.50 were highly endorsed [44]. We used logistic regression to examine whether latent class membership was associated with different eHealth behaviors. Each eHealth behavior was modeled separately, using the latent classes as predictors in the model. We evaluated differences between classes using the pseudo class method, with 20

imputations. The pseudo-class method [45] provides conservative estimates of standard error and perform optimally for models with moderate entropy (0.60) and competitively for models with large entropy (0.80). Logistic regression analyses did not adjust for covariates since classes were derived from sociodemographic factors, medical history, and medical experiences, and thus their covariance was already incorporated into the analysis. We present odds ratios (ORs) and 95% confidence intervals from the logistic regression models.

Results

Sample Characteristics

The sample of cancer survivors with BMI in overweight or obese categories (N=730) had a mean age of 66.8 (SD 11.9) years, and these participants were mostly non-Hispanic White individuals (499/730, 76.3%) (Table 2). There was a slightly higher proportion of females (396/730, 55.1%) than males (323/730, 44.9%). Most had a BMI considered overweight (383/730, 52.5%), had health insurance (694/730, 97.3%), and a regular health care provider (624/730, 86.4%). Approximately half of the participants had been offered online access to medical records (313/730, 51.4%). Overall, for all 3 classes, participants had nearly equal probability of being offered online access to medical records (range 43%-54%).

Table 2. Demographic characteristics of the sample (N=730).

Characteristic	Value, n (%)
Age	
Less than 49 years	58 (8.1)
50-64 years	226 (31.7)
65-74 years	250 (35.1)
75 years or older	178 (25.0)
Gender	
Male	323 (44.9)
Female	396 (55.1)
Race/ethnicity	
Non-Hispanic White	499 (76.3)
Black or African American	78 (11.9)
Hispanic	54 (8.3)
Hawaiian/Pacific Islander, Alaskan Native, Asian, or Multiracial ^a	23 (3.5)
Education	
High School or less	202 (28.2)
Some college, professional school	239 (33.4)
College graduate	275 (38.4)
BMI category [40]	
Overweight	383 (52.5)
Obese, class I	214 (29.3)
Obese, class II	75 (10.3)
Obese, class III	58 (7.9)
Diabetes, heart condition, or depression	
Present	405 (57.0)
Absent	306 (43.0)
Hypertension	
Present	449 (62.3)
Absent	272 (37.7)
Arthritis	
Present	351 (48.5)
Absent	373 (51.5)
How many times did you go to a health professional (doctor, nurse) for care	
None	39 (5.4)
1-3 times	292 (40.6)
4+ times	388 (54.0)
Quality of care	
Excellent	300 (44.8)
Very good	231 (34.5)
Good	112 (16.7)
Fair	23 (3.4)
Poor	3 (0.4)
Health insurance	

Characteristic	Value, n (%)
Yes	694 (97.3)
No	19 (2.7)
Offered online access to your medical records	
Yes	313 (51.4)
No	296 (48.6)
Confidence in own ability to take care of health	
Completely confident	7 (1.0)
Very confident	30 (4.1)
Somewhat confident	189 (26.1)
A little confident	345 (47.7)
Not confident at all	153 (21.1)
Regular provider	
Yes	624 (86.4)
No	98 (13.6)
Feelings addressed	
Yes	642 (95.8)
No	28 (4.2)
Involved in decisions	
Yes	660 (97.9)
No	14 (2.1)
Understood next steps	
Yes	666 (99.1)
No	6 (0.9)
Explained clearly	
Yes	668 (99.3)
No	5 (0.7)

^aThese data were grouped for statistical analysis (due to the very small number of participants and model fit).

[Multimedia Appendix 1](#) shows the percentage of participants within each class and the resulting conditional response probabilities of endorsing items, given class membership.

Classes

Class 1 accounted for 41% of the population ([Multimedia Appendix 1](#)). The majority of class 1 was less than 65 years old (77%), had higher than high school education level (80%), and identified as being non-Hispanic White individuals (80%). In this class, there was a higher probability of having a BMI in overweight and obese class I categories (91%) and a lower probability of having medical conditions—diabetes, cardiovascular disease, or depression; hypertension; arthritis—than in the other classes (range 9%-31%). Members in class 1 predominantly had health insurance (98%), visited a regular provider (82%), and felt little to somewhat confident in their ability to take care of their own health (73%). Most reported having positive interactions with their clinicians: they believed that their feelings were addressed (95%), felt involved in decisions (100%), understood next steps in care (100%), and

felt that health-related topics were clearly explained (100%). Class 1 was subsequently labeled *younger with no comorbidities*.

Class 2 represented the smallest class accounting for 4% of the population. A slight majority of its members were less than 64 years old (57%; [Multimedia Appendix 1](#)). Compared to the other classes, class 2 had the highest probability of identifying as female (73%) and having a high school education level or less (60%). The probability of class members identifying as Black or Hispanic adults (63%) was substantially higher than in classes 1 (17%) and 3 (16%). Class 2 had the highest probability of having a BMI in obese class II and III categories (63%) and having medical conditions (% range: 48-95%), and probabilities for this class of seeking care from a health care professional (31%), having a regular provider (43%), and having health insurance (24%) were lower than for other classes. Class 2 had a higher probability of reporting low quality of care (37%) than the other classes; they were more likely to believe their feelings were not addressed by health care professionals (75%) and to feel uninvolved in decisions (73%). Yet there was a high probability of feeling—at a minimum—very confident in their

ability to take care of their own health (56%). Class 2 was subsequently labeled *younger with comorbidities*.

Class 3 represented the largest class and accounted for 55% of the population (Multimedia Appendix 1). The majority of class 3 was 65 years old or above (71%), identified as non-Hispanic White individuals (83%), and had a BMI within either overweight or obese class I categories (81%). There was an even distribution regarding education level among its members. Members of class 3 predominantly had health insurance (99%), had a regular provider (90%), expressed feeling a little to somewhat confident in their ability to take care of health (77%), and reported positive interactions with their clinicians, similar to class 1. Specifically, members in class 3 felt that in medical care, their feelings were addressed (97%), they were involved in decisions (99%), understood the next steps in care (100%), and felt that things were explained clearly (100%). There were differences in medical outcomes between classes 1 and 3, with class 3 having higher probabilities of being diagnosed with all comorbidities—diabetes, cardiovascular disease, or depression; hypertension; arthritis except for obesity (range 64%-80% vs

9%-31%). Class 3 was subsequently labeled *older with comorbidities*.

Association of eHealth Behaviors and Latent Classes

Table 3 presents the associations of eHealth behaviors with latent classes. Logistic regression analyses indicated that, compared with the younger with comorbidities class, the older with comorbidities class had more than a 6-fold increase in the odds of sharing health information from an electronic device or smartphone with a health professional (OR 6.53, 95% CI 1.08-39.43). There were no significant differences in the likelihood of engaging in eHealth behaviors between younger with no comorbidities and younger with comorbidities classes (Table 3). The younger with no comorbidities class had greater odds than the older with comorbidities class of engaging in self-management eHealth practices that do not involve a health care provider, including using a computer to look for health information (OR 1.93, 95% CI 1.10-3.38), using a tablet or smartphone to track progress toward a health-related goal (OR 2.02, 95% CI 1.08-3.79), and using the internet to watch health-related videos on YouTube (OR 2.70, 95% CI 1.52-4.81) (Table 3).

Table 3. Logistic regression models predicting eHealth behaviors using latent classes as predictors.

eHealth Behaviors	Younger with no comorbidities vs younger with comorbidities ^a		Younger with no comorbidities vs older with comorbidities ^a		Older with comorbidities vs younger with comorbidities ^a	
	Odds ratio	95% CI	Odds ratio	95% CI	Odds ratio	95% CI
On your tablet or smartphone, do you have any apps related to health and wellness?	1.28	(0.29, 5.58)	1.61	(0.87, 2.96)	0.80	(0.18, 3.63)
In the past 12 months have you used a computer, smart phone, or other electronic means to look for health or medical information for yourself?	2.73	(0.73, 10.14)	1.93	(1.10, 3.38)	1.41	(0.39, 5.11)
In the past 12 months have you used a computer, smart phone, or other electronic means to look up medical test results?	2.16	(0.55, 8.48)	1.63	(0.99, 2.67)	1.33	(0.34, 5.14)
Has your tablet or smartphone helped you track progress on a health-related goal, such as quitting smoking, losing weight, or increasing physical activity?	2.28	(0.47, 11.02)	2.02	(1.08, 3.79)	1.13	(0.23, 5.46)
Has your tablet or smartphone helped you make a decision about how to treat an illness or condition?	1.25	(0.24, 6.42)	1.16	(0.63, 2.15)	1.08	(0.20, 5.71)
Has your tablet or smartphone helped you in discussions with your health care provider?	1.33	(0.22, 7.85)	0.67	(0.37, 1.23)	1.97	(0.31, 12.50)
Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the last 12 months?	3.63	(0.57, 23.22)	0.56	(0.27, 1.13)	6.53	(1.08, 39.43)
In the last 12 months, have you used the internet to participate in an online forum or support group for people with a similar health or medical issue?	2.11	(0.12, 37.70)	2.50	(0.68, 9.16)	1.40	(0.12, 16.19)
In the last 12 months, have you used the internet to watch a health-related video on YouTube?	1.84	(0.42, 8.11)	2.70	(1.52, 4.81)	0.68	(0.15, 2.99)

^aThis class was used as the reference.

Discussion

Despite the substantial investment in advancing eHealth to extend patient care [46], there is insufficient evidence about how sociodemographic factors, medical history, and medical experiences affect how different groups of cancer survivors use eHealth. As obesity is both prevalent and a significant risk factor for future multimorbidity among cancer survivors, our study objective was to characterize patterns of eHealth use among distinct classes of cancer survivors with BMI in overweight or obese categories. Three classes emerged: younger with no comorbidities; younger with comorbidities; older with comorbidities. People in the older with comorbidities class were less likely to use eHealth self-management technologies than those in the younger-no comorbidities class. However, when compared to those in the younger with comorbidities class, people in the older with comorbidities class were more likely to share health information from an eHealth device with a health professional.

Among cancer survivors with comorbidities, older adults were more likely than younger adults to share their eHealth data with a health care provider in order to facilitate patient-clinician communication. Our finding supports the supposition that eHealth is a promising tool to facilitate patient-clinician communication for older cancer survivors with comorbidities. In comparison, those in the younger with comorbidities class were less likely to have a regular provider, have health insurance, feel involved in medical decisions, or feel they understood next steps of care. They were also more likely to identify as Black or Hispanic individuals and have a lower education level. The characteristics observed in the younger with comorbidities class were consistent with previous reports that Black and Hispanic participants receive less health care than non-Hispanic White participants, and that cancer survivors with lower education are less likely to discuss health-promoting behaviors [47-49]. We also observed that the younger with comorbidities class did not emerge within the 2-class model. This observation suggests that minority groups among cancer survivors with BMI in overweight or obese categories can easily go unnoticed and underrepresented in health care despite having different medical experiences and being at increased risk of having a medical condition, relative to non-Hispanic White adults. A valuable opportunity exists for clinicians and researchers to identify strategies that will improve the medical experiences of underserved minority groups, while leveraging eHealth technology to facilitate health-promoting behaviors.

Compared to those in the older with comorbidities class, cancer survivors in the younger with no comorbidities class were more likely to use a computer to research health information, use a tablet or smartphone to track progress on a health-related goal, and watch health-related videos on YouTube—all types of self-management eHealth behaviors. These differences seemed to be largely driven by the combination of age and medical history as the 2 classes shared similar characteristics for other sociodemographic factors and medical experiences. However, those in the older with comorbidities and younger with no comorbidities classes showed no differences for other eHealth behaviors, such as (1) having health-related apps on their

devices, (2) accessing health records for test results, (3) using electronic devices to treat a condition with clinicians, and (4) participating in a health-related support group. Collectively, these results demonstrate that although younger age and better health status jointly predict greater engagement in using eHealth for self-management, there is no generational divide in having health-related apps, accessing electronic health records, and sharing eHealth data with clinicians among cancer survivors with BMI in overweight or obese categories. Our results show agreement with mixed evidence that age is associated with eHealth use [34,35,37], and echo findings indicating that better health was associated with greater eHealth use to track health and goals [34,35].

The strengths of this study include the use of a large nationwide sample drawn from NCI HINTS which allowed us to use weightings to generate nationally representative estimates. Although the sample analyzed for the current study comprised less than 5% of the NCI HINTS study sample, the estimates are reflective of the population of cancer survivors with BMI in overweight or obese categories. Despite several eHealth weight management interventions in survivor populations, this is the first study to investigate how eHealth is used to manage health and relate to health care providers [50]. An additional strength was the ability to investigate different forms of eHealth usage separately, rather than in aggregate, which allowed us to identify who was more likely to use specific eHealth features to promote weight management and patient-clinician communication. A few limitations should be noted as well. We were unable to determine whether eHealth use would differ for diet, physical activity, or smoking behaviors since the NCI HINTS items did not distinguish between types of health-promoting behaviors. Another limitation is that eHealth use and cancer status were self-reported and, therefore, susceptible to recall bias. Although the data were weighted to generate nationally representative estimates, generalizability may still be limited by reliance on participant self-selection. Replication is warranted using different nationally representative study samples with further investigation on environmental factors, such as rural-urban differences [51]. Additionally, the temporal relationship between patient-related factors and eHealth use has yet to be established.

There is growing interest in the development and usability of eHealth to guide health-promoting behaviors for cancer survivors [52-54], particularly as there is limited access to nutrition services at cancer centers [9]. This study provides new evidence about the feasibility and usability of eHealth among cancer survivors with BMI in overweight or obese categories by investigating how sociodemographic factors, medical history, and medical experiences co-vary with eHealth behaviors. While our results suggest that all cancer survivors use eHealth, some groups engage with eHealth technologies in different ways. Thus, this study highlights the importance of considering the eHealth needs and usage patterns of different types of cancer survivors when developing digital interventions to support health promotion and patient-clinician communication. Our study also reveals that race/ethnicity, as well as medical attributes and experiences, predict eHealth use—lending support to the idea that sociodemographic, medical history, and clinician interactions can collectively influence eHealth engagement.

Further efforts to develop eHealth recommendations tailored for different groups of cancer survivors are needed to optimize survivors' ability to use digital tools to promote health behaviors and reduce treatment-related morbidities and obesity.

Acknowledgments

AWL and SHB acknowledge salary support from National Institutes of Health/National Cancer Institute training grant T32 CA193193 (principal investigator: BS). NA is supported in part by National Institute of Diabetes and Digestive and Kidney Diseases K25DK113242 and National Science Foundation CNS1915847. BS is supported in part by National Institute of Diabetes and Digestive and Kidney Diseases R01s DK108678 and DK125414 and National Cancer Institute P30CA060553. Research reported in this publication was supported, in part, by the National Institutes of Health's National Center for Advancing Translational Sciences (grant number UL1TR001422). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors are grateful for the NCI HINTS investigators for their dedication in data collection and support. The authors would also like to thank the NCI HINTS participants for their contribution to research, as well as the reviewers and copyeditor (Coren Walters-Stewart) for their comments that have improved this manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Latent class model based on patient-related factors of cancer survivors with BMI in overweight or obese categories.

[[DOCX File, 20 KB - cancer_v6i2e24137_app1.docx](#)]

References

1. Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin* 2019 Sep 11;69(5):363-385 [[FREE Full text](#)] [doi: [10.3322/caac.21565](https://doi.org/10.3322/caac.21565)] [Medline: [31184787](https://pubmed.ncbi.nlm.nih.gov/31184787/)]
2. Strongman H, Gadd S, Matthews A, Mansfield KE, Stanway S, Lyon AR, et al. Medium and long-term risks of specific cardiovascular diseases in survivors of 20 adult cancers: a population-based cohort study using multiple linked UK electronic health records databases. *Lancet* 2019 Sep 21;394(10203):1041-1054 [[FREE Full text](#)] [doi: [10.1016/S0140-6736\(19\)31674-5](https://doi.org/10.1016/S0140-6736(19)31674-5)] [Medline: [31443926](https://pubmed.ncbi.nlm.nih.gov/31443926/)]
3. Curtis RE, Freedman DM, Ron E, Ries LAG, Hacker DG, Edwards BK, et al. New malignancies among people who have survived cancer NIH Publ. No 05-5302. SEER Cancer Registries, 1973-2000. Bethesda, MD: National Cancer Institute; 2006. URL: https://seer.cancer.gov/archive/publications/mpmono/MPMonograph_complete.pdf
4. Sogaard M, Thomsen RW, Bossen KS, Sorensen HT, Norgaard M. The impact of comorbidity on cancer survival: a review. *Clin Epidemiol* 2013 Nov 01;5(Suppl 1):3-29 [[FREE Full text](#)] [doi: [10.2147/CLEP.S47150](https://doi.org/10.2147/CLEP.S47150)] [Medline: [24227920](https://pubmed.ncbi.nlm.nih.gov/24227920/)]
5. Dietary Guidelines for Americans 2015-2020. Office of Disease Prevention and Health Promotion. 2015. URL: <https://health.gov/our-work/food-nutrition/2015-2020-dietary-guidelines/guidelines/> [accessed 2020-11-24]
6. Greenlee H, Shi Z, Sardo Molmenti CL, Rundle A, Tsai WY. Trends in Obesity Prevalence in Adults With a History of Cancer: Results From the US National Health Interview Survey, 1997 to 2014. *J Clin Oncol* 2016 Sep 10;34(26):3133-3140 [[FREE Full text](#)] [doi: [10.1200/JCO.2016.66.4391](https://doi.org/10.1200/JCO.2016.66.4391)] [Medline: [27458295](https://pubmed.ncbi.nlm.nih.gov/27458295/)]
7. Pekmezi DW, Demark-Wahnefried W. Updated evidence in support of diet and exercise interventions in cancer survivors. *Acta Oncol* 2011 Feb;50(2):167-178 [[FREE Full text](#)] [doi: [10.3109/0284186X.2010.529822](https://doi.org/10.3109/0284186X.2010.529822)] [Medline: [21091401](https://pubmed.ncbi.nlm.nih.gov/21091401/)]
8. Stump TK, Robinson JK, Yanez B, Penedo F, Ezeofor A, Kircher S, et al. Physicians' perspectives on medication adherence and health promotion among cancer survivors. *Cancer* 2019 Dec 01;125(23):4319-4328. [doi: [10.1002/cncr.32410](https://doi.org/10.1002/cncr.32410)] [Medline: [31448414](https://pubmed.ncbi.nlm.nih.gov/31448414/)]
9. Trujillo EB, Claghorn K, Dixon SW, Hill EB, Braun A, Lipinski E, et al. Inadequate Nutrition Coverage in Outpatient Cancer Centers: Results of a National Survey. *J Oncol* 2019;2019:7462940 [[FREE Full text](#)] [doi: [10.1155/2019/7462940](https://doi.org/10.1155/2019/7462940)] [Medline: [31885583](https://pubmed.ncbi.nlm.nih.gov/31885583/)]
10. Mandracchia F, Llauradó E, Tarro L, Del Bas JM, Valls R, Pedret A, et al. Potential Use of Mobile Phone Applications for Self-Monitoring and Increasing Daily Fruit and Vegetable Consumption: A Systematized Review. *Nutrients* 2019 Mar 22;11(3):686 [[FREE Full text](#)] [doi: [10.3390/nu11030686](https://doi.org/10.3390/nu11030686)] [Medline: [30909484](https://pubmed.ncbi.nlm.nih.gov/30909484/)]
11. Fawcett E, Van Velthoven MH, Meinert E. Long-Term Weight Management Using Wearable Technology in Overweight and Obese Adults: Systematic Review. *JMIR Mhealth Uhealth* 2020 Mar 10;8(3):e13461 [[FREE Full text](#)] [doi: [10.2196/13461](https://doi.org/10.2196/13461)] [Medline: [32154788](https://pubmed.ncbi.nlm.nih.gov/32154788/)]
12. Beleigoli AM, Andrade AQ, Cançado AG, Paulo MN, Diniz MDFH, Ribeiro AL. Web-Based Digital Health Interventions for Weight Loss and Lifestyle Habit Changes in Overweight and Obese Adults: Systematic Review and Meta-Analysis. *J Med Internet Res* 2019 Jan 08;21(1):e298 [[FREE Full text](#)] [doi: [10.2196/jmir.9609](https://doi.org/10.2196/jmir.9609)] [Medline: [30622090](https://pubmed.ncbi.nlm.nih.gov/30622090/)]

13. Karduck J, Chapman-Novakofski K. Results of the Clinician Apps Survey, How Clinicians Working With Patients With Diabetes and Obesity Use Mobile Health Apps. *J Nutr Educ Behav* 2018 Jan;50(1):62-69.e1. [doi: [10.1016/j.jneb.2017.06.004](https://doi.org/10.1016/j.jneb.2017.06.004)] [Medline: [29325664](https://pubmed.ncbi.nlm.nih.gov/29325664/)]
14. Kirkovits T, Schinkoethe T, Drewes C, Gehring C, Bauerfeind I, Harbeck N, et al. eHealth in Modern Patient-Caregiver Communication: High Rate of Acceptance Among Physicians for Additional Support of Breast Cancer Patients During Long-Term Therapy. *JMIR Cancer* 2016 Sep 19;2(2):e14 [FREE Full text] [doi: [10.2196/cancer.5132](https://doi.org/10.2196/cancer.5132)] [Medline: [28410173](https://pubmed.ncbi.nlm.nih.gov/28410173/)]
15. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Ann Behav Med* 2013 Aug 20;46(1):81-95. [doi: [10.1007/s12160-013-9486-6](https://doi.org/10.1007/s12160-013-9486-6)] [Medline: [23512568](https://pubmed.ncbi.nlm.nih.gov/23512568/)]
16. Bantum EO, Albright CL, White KK, Berenberg JL, Layi G, Ritter PL, et al. Surviving and thriving with cancer using a Web-based health behavior change intervention: randomized controlled trial. *J Med Internet Res* 2014 Feb 24;16(2):e54 [FREE Full text] [doi: [10.2196/jmir.3020](https://doi.org/10.2196/jmir.3020)] [Medline: [24566820](https://pubmed.ncbi.nlm.nih.gov/24566820/)]
17. Forbes CC, Blanchard CM, Mummery WK, Courneya KS. Feasibility and Preliminary Efficacy of an Online Intervention to Increase Physical Activity in Nova Scotian Cancer Survivors: A Randomized Controlled Trial. *JMIR Cancer* 2015 Nov 23;1(2):e12 [FREE Full text] [doi: [10.2196/cancer.4586](https://doi.org/10.2196/cancer.4586)] [Medline: [28410166](https://pubmed.ncbi.nlm.nih.gov/28410166/)]
18. Kanera IM, Willems RA, Bolman CAW, Mesters I, Verboon P, Lechner L. Long-term effects of a web-based cancer aftercare intervention on moderate physical activity and vegetable consumption among early cancer survivors: a randomized controlled trial. *Int J Behav Nutr Phys Act* 2017 Feb 10;14(1):19 [FREE Full text] [doi: [10.1186/s12966-017-0474-2](https://doi.org/10.1186/s12966-017-0474-2)] [Medline: [28187725](https://pubmed.ncbi.nlm.nih.gov/28187725/)]
19. Lee MK, Yun YH, Park H, Lee ES, Jung KH, Noh D. A Web-based self-management exercise and diet intervention for breast cancer survivors: pilot randomized controlled trial. *Int J Nurs Stud* 2014 Dec;51(12):1557-1567. [doi: [10.1016/j.ijnurstu.2014.04.012](https://doi.org/10.1016/j.ijnurstu.2014.04.012)] [Medline: [24856854](https://pubmed.ncbi.nlm.nih.gov/24856854/)]
20. Mayer DK, Landucci G, Awoyinka L, Atwood AK, Carmack CL, Demark-Wahnefried W, et al. SurvivorCHESS to increase physical activity in colon cancer survivors: can we get them moving? *J Cancer Surviv* 2018 Feb 9;12(1):82-94 [FREE Full text] [doi: [10.1007/s11764-017-0647-7](https://doi.org/10.1007/s11764-017-0647-7)] [Medline: [28994035](https://pubmed.ncbi.nlm.nih.gov/28994035/)]
21. Rabin C, Dunsiger S, Ness KK, Marcus BH. Internet-Based Physical Activity Intervention Targeting Young Adult Cancer Survivors. *J Adolesc Young Adult Oncol* 2011 Dec;1(4):188-194 [FREE Full text] [doi: [10.1089/jayao.2011.0040](https://doi.org/10.1089/jayao.2011.0040)] [Medline: [23610737](https://pubmed.ncbi.nlm.nih.gov/23610737/)]
22. Ormel HL, van der Schoot GGF, Westerink NL, Sluiter WJ, Gietema JA, Walenkamp AME. Self-monitoring physical activity with a smartphone application in cancer patients: a randomized feasibility study (SMART-trial). *Support Care Cancer* 2018 Nov 21;26(11):3915-3923 [FREE Full text] [doi: [10.1007/s00520-018-4263-5](https://doi.org/10.1007/s00520-018-4263-5)] [Medline: [29785635](https://pubmed.ncbi.nlm.nih.gov/29785635/)]
23. Sajid S, Dale W, Mustian K, Kotwal A, Heckler C, Porto M, et al. Novel physical activity interventions for older patients with prostate cancer on hormone therapy: A pilot randomized study. *J Geriatr Oncol* 2016 Mar;7(2):71-80 [FREE Full text] [doi: [10.1016/j.jgo.2016.02.002](https://doi.org/10.1016/j.jgo.2016.02.002)] [Medline: [26916611](https://pubmed.ncbi.nlm.nih.gov/26916611/)]
24. Uhm KE, Yoo JS, Chung SH, Lee JD, Lee I, Kim JI, et al. Effects of exercise intervention in breast cancer patients: is mobile health (mHealth) with pedometer more effective than conventional program using brochure? *Breast Cancer Res Treat* 2017 Feb 8;161(3):443-452. [doi: [10.1007/s10549-016-4065-8](https://doi.org/10.1007/s10549-016-4065-8)] [Medline: [27933450](https://pubmed.ncbi.nlm.nih.gov/27933450/)]
25. Vallance JK, Courneya KS, Plotnikoff RC, Yasui Y, Mackey JR. Randomized Controlled Trial of the Effects of Print Materials and Step Pedometers on Physical Activity and Quality of Life in Breast Cancer Survivors. *JCO* 2007 Jun 10;25(17):2352-2359. [doi: [10.1200/jco.2006.07.9988](https://doi.org/10.1200/jco.2006.07.9988)]
26. Valle CG, Deal AM, Tate DF. Preventing weight gain in African American breast cancer survivors using smart scales and activity trackers: a randomized controlled pilot study. *J Cancer Surviv* 2017 Feb 8;11(1):133-148 [FREE Full text] [doi: [10.1007/s11764-016-0571-2](https://doi.org/10.1007/s11764-016-0571-2)] [Medline: [27631874](https://pubmed.ncbi.nlm.nih.gov/27631874/)]
27. Yun YH, Lee KS, Kim YW, Park SY, Lee ES, Noh DY, et al. Web-based tailored education program for disease-free cancer survivors with cancer-related fatigue: a randomized controlled trial. *J Clin Oncol* 2012 Apr 20;30(12):1296-1303. [doi: [10.1200/JCO.2011.37.2979](https://doi.org/10.1200/JCO.2011.37.2979)] [Medline: [22412149](https://pubmed.ncbi.nlm.nih.gov/22412149/)]
28. Galiano-Castillo N, Arroyo-Morales M, Lozano-Lozano M, Fernández-Lao C, Martín-Martín L, Del-Moral-Ávila R, et al. Effect of an Internet-based telehealth system on functional capacity and cognition in breast cancer survivors: a secondary analysis of a randomized controlled trial. *Support Care Cancer* 2017 Nov 22;25(11):3551-3559. [doi: [10.1007/s00520-017-3782-9](https://doi.org/10.1007/s00520-017-3782-9)] [Medline: [28639097](https://pubmed.ncbi.nlm.nih.gov/28639097/)]
29. Krebs P, Shtaynberger J, McCabe M, Iocolano M, Williams K, Shuk E, et al. An eHealth Intervention to Increase Physical Activity and Healthy Eating in Older Adult Cancer Survivors: Summative Evaluation Results. *JMIR Cancer* 2017 Mar 01;3(1):e4 [FREE Full text] [doi: [10.2196/cancer.6435](https://doi.org/10.2196/cancer.6435)] [Medline: [28410171](https://pubmed.ncbi.nlm.nih.gov/28410171/)]
30. Kiss N, Baguley BJ, Ball K, Daly RM, Fraser SF, Granger CL, et al. Technology-Supported Self-Guided Nutrition and Physical Activity Interventions for Adults With Cancer: Systematic Review. *JMIR Mhealth Uhealth* 2019 Feb 12;7(2):e12281 [FREE Full text] [doi: [10.2196/12281](https://doi.org/10.2196/12281)] [Medline: [30747720](https://pubmed.ncbi.nlm.nih.gov/30747720/)]
31. Roberts AL, Fisher A, Smith L, Heinrich M, Potts HWW. Digital health behaviour change interventions targeting physical activity and diet in cancer survivors: a systematic review and meta-analysis. *J Cancer Surviv* 2017 Dec 4;11(6):704-719 [FREE Full text] [doi: [10.1007/s11764-017-0632-1](https://doi.org/10.1007/s11764-017-0632-1)] [Medline: [28779220](https://pubmed.ncbi.nlm.nih.gov/28779220/)]

32. Guidry JJ, Torrence W, Herbelin S. Closing the divide: diverse populations and cancer survivorship. *Cancer* 2005 Dec 01;104(11 Suppl):2577-2583 [FREE Full text] [doi: [10.1002/cncr.21251](https://doi.org/10.1002/cncr.21251)] [Medline: [16258930](https://pubmed.ncbi.nlm.nih.gov/16258930/)]
33. Robinson L, Cotten SR, Ono H, Quan-Haase A, Mesch G, Chen W, et al. Digital inequalities and why they matter. *Information, Communication & Society* 2015 Mar 16;18(5):569-582. [doi: [10.1080/1369118x.2015.1012532](https://doi.org/10.1080/1369118x.2015.1012532)]
34. Rising CJ, Jensen RE, Moser RP, Oh A. Characterizing the US Population by Patterns of Mobile Health Use for Health and Behavioral Tracking: Analysis of the National Cancer Institute's Health Information National Trends Survey Data. *J Med Internet Res* 2020 May 14;22(5):e16299 [FREE Full text] [doi: [10.2196/16299](https://doi.org/10.2196/16299)] [Medline: [32406865](https://pubmed.ncbi.nlm.nih.gov/32406865/)]
35. Paré G, Leaver C, Bourget C. Diffusion of the Digital Health Self-Tracking Movement in Canada: Results of a National Survey. *J Med Internet Res* 2018 May 02;20(5):e177 [FREE Full text] [doi: [10.2196/jmir.9388](https://doi.org/10.2196/jmir.9388)] [Medline: [29720359](https://pubmed.ncbi.nlm.nih.gov/29720359/)]
36. Mahmood A, Kedia S, Wyant DK, Ahn S, Bhuyan SS. Use of mobile health applications for health-promoting behavior among individuals with chronic medical conditions. *Digit Health* 2019 Oct 10;5:2055207619882181 [FREE Full text] [doi: [10.1177/2055207619882181](https://doi.org/10.1177/2055207619882181)] [Medline: [31656632](https://pubmed.ncbi.nlm.nih.gov/31656632/)]
37. Nouri SS, Adler-Milstein J, Thao C, Acharya P, Barr-Walker J, Sarkar U, et al. Patient characteristics associated with objective measures of digital health tool use in the United States: A literature review. *J Am Med Inform Assoc* 2020 May 01;27(5):834-841. [doi: [10.1093/jamia/ocaa024](https://doi.org/10.1093/jamia/ocaa024)] [Medline: [32364238](https://pubmed.ncbi.nlm.nih.gov/32364238/)]
38. Senft N, Everson J. eHealth Engagement as a Response to Negative Healthcare Experiences: Cross-Sectional Survey Analysis. *J Med Internet Res* 2018 Dec 05;20(12):e11034 [FREE Full text] [doi: [10.2196/11034](https://doi.org/10.2196/11034)] [Medline: [30518513](https://pubmed.ncbi.nlm.nih.gov/30518513/)]
39. Halpern MT, McCabe MS, Burg MA. The Cancer Survivorship Journey: Models of Care, Disparities, Barriers, and Future Directions. *Am Soc Clin Oncol Educ Book* 2016;35:231-239 [FREE Full text] [doi: [10.1200/EDBK_156039](https://doi.org/10.1200/EDBK_156039)] [Medline: [27249703](https://pubmed.ncbi.nlm.nih.gov/27249703/)]
40. Defining adult overweight and obesity. Centers for Disease Control and Prevention. URL: <https://www.cdc.gov/obesity/adult/defining.html> [accessed 2020-11-17]
41. The Methodology Center. Latent Class Analysis (LCA) Stata plugin. Penn State. 2014. URL: <https://www.methodology.psu.edu/downloads/lcastata/> [accessed 2019-10-01]
42. Muthen B, Asparouhov T. Item response mixture modeling: application to tobacco dependence criteria. *Addict Behav* 2006 Jun;31(6):1050-1066. [doi: [10.1016/j.addbeh.2006.03.026](https://doi.org/10.1016/j.addbeh.2006.03.026)] [Medline: [16675147](https://pubmed.ncbi.nlm.nih.gov/16675147/)]
43. Nylund KL, Asparouhov T, Muthén BO. Deciding on the Number of Classes in Latent Class Analysis and Growth Mixture Modeling: A Monte Carlo Simulation Study. *Structural Equation Modeling: A Multidisciplinary Journal* 2007 Dec 05;14(4):535-569. [doi: [10.1080/10705510701575396](https://doi.org/10.1080/10705510701575396)]
44. Masyn K, Little TD. Latent class analysis finite mixture modeling. In: *The Oxford Handbook of Quantitative Methods: Statistical Analysis*. Oxford, England: Oxford University Press; 2013:551-611.
45. Clark SL, Muthén B. Relating latent class analysis results to variables not included in the analysis. 2009 Apr 22. URL: <https://www.statmodel.com/papers.shtml> [accessed 2020-04-22]
46. Parente ST, Van Horn RL. Valuing hospital investment in information technology: does governance make a difference? *Health Care Financ Rev* 2006;28(2):31-43 [FREE Full text] [Medline: [17427843](https://pubmed.ncbi.nlm.nih.gov/17427843/)]
47. Palmer NR, Geiger AM, Felder TM, Lu L, Case LD, Weaver KE. Racial/Ethnic disparities in health care receipt among male cancer survivors. *Am J Public Health* 2013 Jul;103(7):1306-1313 [FREE Full text] [doi: [10.2105/AJPH.2012.301096](https://doi.org/10.2105/AJPH.2012.301096)] [Medline: [23678936](https://pubmed.ncbi.nlm.nih.gov/23678936/)]
48. Kenzik K, Pisu M, Fouad MN, Martin MY. Are long-term cancer survivors and physicians discussing health promotion and healthy behaviors? *J Cancer Surviv* 2016 Apr 26;10(2):271-279 [FREE Full text] [doi: [10.1007/s11764-015-0473-8](https://doi.org/10.1007/s11764-015-0473-8)] [Medline: [26210659](https://pubmed.ncbi.nlm.nih.gov/26210659/)]
49. National health care quality and disparities report Pub No. 19-0070-EF. Agency for Health Care Research Quality. Rockville, MD: AHRQ; 2019. URL: <https://www.ahrq.gov/research/findings/nhqrdr/index.html> [accessed 2020-11-24]
50. Quintiliani LM, Mann DM, Puputti M, Quinn E, Bowen DJ. Pilot and Feasibility Test of a Mobile Health-Supported Behavioral Counseling Intervention for Weight Management Among Breast Cancer Survivors. *JMIR Cancer* 2016 May 09;2(1):e4 [FREE Full text] [doi: [10.2196/cancer.5305](https://doi.org/10.2196/cancer.5305)] [Medline: [28410174](https://pubmed.ncbi.nlm.nih.gov/28410174/)]
51. Chen X, Orom H, Hay JL, Waters EA, Schofield E, Li Y, et al. Differences in Rural and Urban Health Information Access and Use. *J Rural Health* 2019 Jun 16;35(3):405-417 [FREE Full text] [doi: [10.1111/jrh.12335](https://doi.org/10.1111/jrh.12335)] [Medline: [30444935](https://pubmed.ncbi.nlm.nih.gov/30444935/)]
52. O'Malley DM, Davis SN, Devine KA, Sullivan B, Bator A, Clemow L, et al. Development and usability testing of the e-EXCELS tool to guide cancer survivorship follow-up care. *Psychooncology* 2020 Jan 18;29(1):123-131 [FREE Full text] [doi: [10.1002/pon.5222](https://doi.org/10.1002/pon.5222)] [Medline: [31626397](https://pubmed.ncbi.nlm.nih.gov/31626397/)]
53. Leach CR, Diefenbach MA, Fleszar S, Alfano CM, Stephens RL, Riehman K, et al. A user centered design approach to development of an online self-management program for cancer survivors: Springboard Beyond Cancer. *Psychooncology* 2019 Oct 14;28(10):2060-2067. [doi: [10.1002/pon.5193](https://doi.org/10.1002/pon.5193)] [Medline: [31379069](https://pubmed.ncbi.nlm.nih.gov/31379069/)]
54. Coughlin SS, Besenyi GM, Bowen D, De Leo G. Development of the Physical activity and Your Nutrition for Cancer (PYNC) smartphone app for preventing breast cancer in women. *Mhealth* 2017 Feb 15;3:5-5 [FREE Full text] [doi: [10.21037/mhealth.2017.02.02](https://doi.org/10.21037/mhealth.2017.02.02)] [Medline: [28293621](https://pubmed.ncbi.nlm.nih.gov/28293621/)]

Abbreviations

AIC: Akaike information criterion

BIC: Bayesian information criterion

NCI HINTS: National Cancer Institute Health Information National Trends Survey

OR: odds ratio

Edited by G Eysenbach; submitted 05.09.20; peer-reviewed by A Beilegoli, A Andrade; comments to author 25.09.20; revised version received 19.10.20; accepted 05.11.20; published 03.12.20.

Please cite as:

Lin AW, Baik SH, Aaby D, Tello L, Linville T, Alshurafa N, Spring B

eHealth Practices in Cancer Survivors With BMI in Overweight or Obese Categories: Latent Class Analysis Study

JMIR Cancer 2020;6(2):e24137

URL: <http://cancer.jmir.org/2020/2/e24137/>

doi: [10.2196/24137](https://doi.org/10.2196/24137)

PMID: [33156810](https://pubmed.ncbi.nlm.nih.gov/33156810/)

©Annie Wen Lin, Sharon H Baik, David Aaby, Leslie Tello, Twila Linville, Nabil Alshurafa, Bonnie Spring. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 03.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Patterns of Use of Smartphone-Based Interventions Among Latina Breast Cancer Survivors: Secondary Analysis of a Pilot Randomized Controlled Trial

Sharon H Baik^{1,2}, PhD; Laura B Oswald^{1,3}, PhD; Joanna Buscemi⁴, PhD; Diana Buitrago¹, BA; Francisco Iacobelli⁵, PhD; Alejandra Perez-Tamayo⁶, MD; Judith Guitelman⁷; Frank J Penedo⁸, PhD; Betina Yanez¹, PhD

¹Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

²Department of Supportive Care Medicine, City of Hope, Duarte, CA, United States

³Department of Health Outcomes and Behavior, Moffitt Cancer Center, Tampa, FL, United States

⁴Department of Psychology, DePaul University, Chicago, IL, United States

⁵Department of Computer Science, Northeastern Illinois University, Chicago, IL, United States

⁶Department of Surgery, University of Illinois at Chicago, Chicago, IL, United States

⁷ALAS-WINGS, The Latina Association for Breast Cancer, Chicago, IL, United States

⁸Department of Psychology, University of Miami, Coral Gables, FL, United States

Corresponding Author:

Sharon H Baik, PhD

Department of Supportive Care Medicine

City of Hope

1500 E Duarte Rd

Duarte, CA, 91010

United States

Phone: 1 626 256 4673

Email: shbaik@coh.org

Abstract

Background: Latina breast cancer survivors experience poorer health-related quality of life (HRQoL), greater symptom burden, and more psychosocial needs compared to non-Latina breast cancer survivors. eHealth platforms such as smartphone apps are increasingly being used to deliver psychosocial interventions to cancer survivors. However, few psychosocial eHealth interventions have been developed specifically for Latina breast cancer survivors. Further, little is known about how Latinas, in general, engage with eHealth interventions and whether specific participant characteristics are associated with app use in this population. We evaluated the use of 2 culturally informed, evidence-based smartphone apps for Latina breast cancer survivors—one that was designed to improve HRQoL and reduce symptom burden (*My Guide*) and the other to promote healthy lifestyle behaviors (*My Health*).

Objective: The objectives of our study were to explore the patterns of use of the *My Guide* intervention app and *My Health* attention-control app among Latina breast cancer survivors.

Methods: Eighty Latina breast cancer survivors were randomized to use the *My Guide* or *My Health* app for 6 weeks. Assessments were collected at baseline (T1), immediately after the 6-week intervention (T2), and 2 weeks after T2 (T3). Specific study outcomes included subdomains of HRQoL, symptom burden, cancer-specific distress, cancer-relevant self-efficacy, and breast cancer knowledge.

Results: On average, participants used their assigned app for more than 1 hour per week. Sociodemographic or psychological characteristics were not significantly associated with app use, except for employment status in the *My Health* group. Content related to common physical and emotional symptoms of breast cancer survivors as well as recommendations for nutrition and physical activity were most frequently accessed by *My Guide* and *My Health* participants, respectively. Lastly, clinically meaningful improvements were demonstrated in breast cancer well-being among low app users (ie, <60 minutes of use/week) of *My Guide* and social well-being among high app users (ie, ≥60 minutes of use/week) of *My Health*.

Conclusions: The favorable rates of participant use across both apps suggest that Latina breast cancer survivors are interested in the content delivered across both *My Guide* and *My Health*. Furthermore, since sociodemographic variables, excluding

employment status, and baseline HRQoL (psychological variable) were not related to app use, *My Guide* and *My Health* may be accessible to diverse Latina breast cancer survivors.

Trial Registration: ClinicalTrials.gov NCT03645005; <https://clinicaltrials.gov/ct2/show/NCT03645005>

(*JMIR Cancer* 2020;6(2):e17538) doi:[10.2196/17538](https://doi.org/10.2196/17538)

KEYWORDS

breast cancer; cancer survivorship; Hispanics/Latinas; eHealth; psychosocial intervention; mobile phone

Introduction

Breast cancer is the most prevalent cancer and the leading cause of cancer-related deaths among Latina women in the United States, with an estimated 24,000 new cases diagnosed and 3200 deaths expected annually [1]. Currently, there are more than 200,000 Latina breast cancer survivors living in the United States [2] and this number is expected to continue increasing. Latina breast cancer survivors experience disparities in survivorship outcomes compared to non-Latina breast cancer survivors, including lower health-related quality of life (HRQoL), greater symptom burden, and greater unmet psychosocial needs [3-11]. These factors are associated with poorer health outcomes [12,13] and must be addressed to promote optimal long-term survivorship for Latina breast cancer survivors. However, Latinas are underrepresented in cancer research [9,14] and although a number of psychosocial interventions have demonstrated efficacy for improving HRQoL outcomes among breast cancer survivors [13,15,16], few interventions have been developed specifically for Latina breast cancer survivors [3,9,17]. Further, psychosocial interventions may be more effective when culturally and linguistically tailored to a particular racial/ethnic group [18]. Specifically, some Latina cultural values and beliefs (eg, familism, fatalism, Marianismo) [19,20] may impact health behaviors and outcomes and thus should be considered as intervention approaches that may need to be adapted. In general, culturally adapted interventions have demonstrated moderate-to-large effects [21].

eHealth platforms are increasingly being used to deliver psychosocial interventions to general cancer survivors and have demonstrated positive effects related to psychosocial outcomes and lifestyle behaviors [22,23]. Research shows that Latinas own smartphones and surf the internet using their mobile devices at similar or higher rates than other racial/ethnic groups [24]. Therefore, smartphone-based apps provide an innovative opportunity to implement culturally informed, technology-based, and evidence-based psychosocial interventions for this population to overcome barriers to accessing care and resources and reduce participant and provider burden, and they are more easily scalable than traditional in-person intervention delivery methods. Prior research has demonstrated that physical and psychological outcomes in eHealth interventions are influenced by different measures of adherence or usage (eg, number of logins, modules completed, time spent on app) [25], and higher use of web-based interventions among cancer survivors is associated with specific user characteristics such as having low social support and high illness burden or working and receiving radiation therapy [26,27]. However, little is known about how Latina breast cancer survivors engage with eHealth interventions

or what participant characteristics are associated with eHealth use in this population.

Our team developed and evaluated 2 culturally informed and evidence-based smartphone apps for Latina breast cancer survivors in a 6-week pilot randomized controlled trial. The intervention app, *My Guide*, was designed to improve HRQoL, reduce symptom burden, and reduce cancer-specific distress, and the attention-control app, *My Health*, was designed to promote general health and healthy lifestyle behaviors [28]. Results demonstrated that Latina breast cancer survivors across both study conditions reported temporary decreases in symptom burden and improved breast cancer well-being over time, although there were no differential effects between the apps [29]. The primary objective of this secondary analysis was to report patterns of participant use of the *My Guide* and *My Health* smartphone apps over the course of the pilot randomized controlled trial. More specifically, we provide data on the frequency of specific domains accessed within the *My Guide* and *My Health* apps and the average total duration of app use. Determining the most commonly accessed and viewed topics is clinically important, as it can help inform future refinement of the study apps as well as in-person psychosocial interventions designed to address the most important cancer topics for this understudied population. Furthermore, given the limited research in this area, we explored whether participant characteristics were related to app use as well as whether app use was related to study outcomes over time.

Methods

Study Participants and Design

Women were eligible to participate in the study if they were diagnosed with nonmetastatic stage 0-III breast cancer, had completed active treatment for breast cancer (excluding endocrine therapy), were within 2-24 months of completing treatment, were at least 21 years old, able to read and speak English or Spanish, and able to provide informed consent. Women were excluded if they had a diagnosis of another cancer, serious psychiatric disorder (eg, bipolar disorder, substance dependence), or life-threatening illness (eg, end-stage kidney disease). Study recruitment included advertisements and physician referrals from 2 academic medical centers in the Chicago area and ALAS-WINGS, a community-based organization that serves Latina women with breast cancer.

Eligible participants provided informed consent and completed a sociodemographic questionnaire and psychosocial assessment at baseline (T1) in their preferred language (English or Spanish). Follow-up assessments were completed at postintervention (6 weeks from baseline, T2) and 2 weeks after the intervention (8

weeks from baseline, T3). After providing informed consent, participants were randomized 1:1 to receive either *My Guide* or *My Health* smartphone-based app for 6 weeks, and participants were instructed to use their assigned app for 2 hours per week. Participants continued to have access to their assigned app from T2 to T3, but we did not analyze their usage data (ie, time spent on app, webpages clicked), and reinforcement messages or calls for adherence were not provided during this time.

App use for *My Guide* and *My Health* was supported by trained bilingual telecoaches using a stepped-care approach. Specifically, telecoaching calls were provided to all participants who focused on enhancing their adherence to using their assigned app and addressed any issues or barriers to using the app. All participants received telecoaching calls during the first 2 weeks as well as during the final sixth week. Subsequent telecoaching calls during the third, fourth, and fifth weeks were only made to participants who did not use their app for at least 90 minutes per week (threshold), whereas reinforcing text messages were sent to participants who used their app for 90 minutes or more. Telecoaching was brief (~15 minutes) and delivered using motivational interviewing and goal setting to encourage app use during the study period. Telecoaching calls were audio-recorded and reviewed weekly by a licensed clinical psychologist to ensure fidelity. A threshold of 90 minutes of weekly app use was determined by other web-based studies that also focused on the delivery of symptom management for patients with cancer [30,31]. On average, *My Guide* and *My Health* app users received 3.72 and 4.10 telecoaching calls, respectively, over the 6-week study period. Further details of the study design, development, and protocol are published elsewhere [28]. All study procedures and assessments were approved by the Institutional Review Board at Northwestern University prior to study recruitment.

Study Apps

Both smartphone apps were developed by the Center for Behavioral Intervention Technologies at Northwestern University Feinberg School of Medicine [28]. The content for *My Guide* and *My Health* was culturally informed by Latina cultural values and beliefs (eg, familism, fatalism, Marianismo) [19,20] and developed in collaboration with the Latina Breast Cancer Association, a community partner. Both apps were developed in English and Spanish so that they were each delivered in the participant's preferred language, and all content was available in audio format to address concerns about low literacy.

The *My Guide* app was designed to improve HRQoL and reduce symptom burden among Latina breast cancer survivors. The intervention content was based on models of stress and coping [32-34], prior research on psychosocial adjustment to cancer [35,36], and preliminary results suggesting that self-efficacy in patient-provider communication, cancer-related knowledge, stress management, and social support can improve HRQoL and symptom burden among Latina breast cancer survivors [3,19,35,37-39]. Specifically, the content focused on improving psychosocial adaptation during cancer survivorship, coping with side effects from treatment, stress management, social

support, and breast cancer-related knowledge. *My Health*, the attention-control app, was designed to improve health-promoting behaviors and provided general recommendations for nutrition and exercise, prevention of common chronic illnesses, and other healthy lifestyle behaviors. The control content was based on similar studies of psychosocial interventions among cancer survivors with active controls [31]. Each app comprised of 6 content domains or distinct topic areas (see [Multimedia Appendix 1](#) for a brief summary of each domain and its related content) as well as a media component ("*Listen and Learn*") consisting of videos and audio recordings that were incorporated and complemented information throughout the domains. For example, *My Guide* included informational videos from experts on breast health and common side effects, stories from other cancer survivors, and audio programs of relaxation exercises, whereas *My Health* included videos about healthy eating and lifestyle behaviors. Both apps were designed to be self-guided, such that participants had complete access to all the domains and could freely access any content based on their interest, at their own pace, and at any time.

Measures

All measures were provided in the participants' preferred language of English or Spanish.

Sociodemographic and Cancer-Specific Characteristics

At baseline, participants completed a self-report sociodemographic questionnaire, which included information such as age, ancestry (Mexican vs other), language preference, highest education, annual household income, employment status, and marital status. Additionally, participants self-reported cancer-specific characteristics, which were verified by medical chart review, including stage of disease and type of treatment(s) received.

App Use

Both apps tracked participant use in minutes per week throughout the study period, from which the total 6-week app use was computed by summing the 6 weekly use times. Average weekly use was also computed to help with interpretation (ie, total app use in minutes divided by 6 weeks). Additionally, all actions taken within each app (ie, click data) were tracked for each participant. The log files included the following data for each action: participant information (ie, unique identification number), app information (ie, English vs Spanish, *My Guide* vs *My Health*), and timestamp (date and time) of links clicked. From this data, we extracted information related to the frequency of visits to each webpage (links) in the app for each participant. We were then able to determine the most and least accessed content within each app.

HRQoL

The 36-item Functional Assessment of Cancer Therapy-Breast (FACT-B) [40] measures 5 HRQoL subdomains, namely, physical well-being, emotional well-being, social well-being, functional well-being, and additional breast cancer-related concerns. Respondents were asked to rate their level of agreement with statements regarding concerns over the past 7 days by using a 5-point Likert-type scale from 0 (not at all) to 4 (very much). Higher scores indicate better domain-specific

well-being. The FACT-B has been validated in Spanish [41] and is extensively used among patients with breast cancer [40,41]. Additionally, at baseline, participants completed the rapid version of the Functional Assessment of Cancer Therapy-General (FACT-G7), a valid and reliable 7-item measure of the most prominent HRQoL concerns among cancer survivors [42].

Symptom Burden

The 25-item Breast Cancer Prevention Trial questionnaire [43] consists of 25 common breast cancer-related symptoms. Respondents rated their level of discomfort with each symptom during the past 4 weeks by using a 5-point Likert-type response scale from 0 (not at all) to 4 (extremely). Total scores range from 0 to 100, with higher scores indicating higher breast cancer symptom burden.

Cancer-Specific Distress

The 15-item Impact of Events Scale [44] assesses the frequency of intrusive thoughts or avoidance following a stressful event, specifically cancer, and uses a response scale with 4 points, that is, 0 (not at all), 1 (rarely), 3 (sometimes), and 5 (often). Total scores range from 0 to 75, with higher scores indicating greater distress. The Impact of Events Scale has also been validated in Spanish [45].

Cancer-Relevant Self-Efficacy

The 12-item Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer) [46] assesses one's self-efficacy in emotional resilience, communication, and information seeking in the context of a cancer diagnosis. Respondents rated their confidence using various skills on a 4-point response scale from 1 (not at all) to 4 (extremely). Higher values indicate greater self-efficacy with possible values ranging from 12 to 48. Previous studies have used the CASE-cancer with Latina breast cancer survivors [46,47].

Breast Cancer Knowledge

The 16-item Knowledge about Breast Cancer questionnaire assesses general knowledge about breast cancer diagnosis and treatment. Respondents were asked to answer *true* or *false* to 16 statements. Correct responses were first summed and then divided by the total number of responses to compute an average

correct response score. Total scores range from 0 to 16, with higher scores reflecting better breast cancer knowledge [48]. This questionnaire was previously tested with a large sample of Spanish-speaking Latina breast cancer survivors [48] and used in the initial *My Guide* pilot study [28].

Data Analyses Plan

We conducted linear regression analyses to evaluate whether sociodemographic characteristics (ie, age, language preference, education level, total household income, ancestry, marital status, employment status) or baseline psychological variables (ie, FACT-G7 baseline score) were related to total app use. Clinical significance was determined with $P < .05$, and marginal associations were reported with $P < .10$. Frequencies of total clicks (ie, pages viewed) were calculated for each domain and subdomain within each app, and we used descriptive statistics to describe notable patterns in click-level app use. Given the exploratory nature of these analyses and underpowered sample size to conduct inferential statistics within subgroups of app users, we focused on descriptive statistics to characterize study outcomes across time by high (ie, ≥ 60 minutes per week) versus low (ie, < 60 minutes per week) use of the *My Guide* or *My Health* app. Established minimally important differences for the FACT-B subscales (ie, a minimum of 2 points) [49-51] were used to characterize changes in the HRQoL subdomains across time. The established minimally important differences are not available for other study outcomes.

Results

Sample Characteristics

Latina breast cancer survivors (N=80) were enrolled and randomized to use *My Guide* or *My Health*. However, 2 participants (one from each condition) were withdrawn due to technical issues, resulting in a total of 78 Latina breast cancer survivors analyzed. Table 1 presents the demographic characteristics of the sample. Overall, participants had a mean (SD) age of 52.54 (11.36) years, and most were born outside the United States (55/78, 71%), of Mexican ancestry (50/78, 64%), and with Spanish as their preferred language (50/78, 64%). There were no significant differences in the sociodemographic and clinical characteristics between study conditions ($P > .05$).

Table 1. Baseline sociodemographic and clinical characteristics.

Characteristics	Full sample (n=78)	<i>My Guide</i> app users (n=39)	<i>My Health</i> app users (n=39)
Age (years)			
Mean (SD)	52.54 (11.36)	53.52 (11.25)	51.55 (11.53)
Range	29-75	33-73	29-75
Language preference, n (%)			
English	28 (36)	14 (36)	14 (36)
Spanish	50 (64)	25 (64)	25 (64)
Mexican ancestry, n (%)	50 (64)	25 (64)	25 (64)
Born in the United States, n (%)	23 (30)	14 (36)	9 (23)
High school education or less, n (%)	42 (54)	23 (59)	19 (49)
Annual household income <US \$25,000, n (%)	41 (53)	23 (59)	18 (46)
Employed, n (%)	34 (44)	17 (44)	17 (44)
Married or partnered, n (%)	50 (64)	23 (59)	27 (69)
Stage of breast cancer, n (%)			
0	3 (4)	2 (5)	1 (3)
I	28 (36)	14 (36)	14 (36)
II	32 (41)	16 (41)	16 (41)
III	11 (14)	5 (13)	6 (15)
Did not report	4 (5)	2 (5)	2 (5)
Received chemotherapy, n (%)	45 (58)	21 (54)	24 (62)
Received radiation therapy, n (%)	55 (71)	28 (72)	27 (69)
FACT-G7 ^a baseline score, mean (SD)	19.947 (4.98)	20.053 (5.17)	19.842 (4.86)

^aFACT-G7: Functional Assessment of Cancer Therapy-General 7 items.

App Use

Latina breast cancer survivors used their assigned smartphone app for mean (SD) time of 478.15 (385.84) minutes over the 6-week study period. The mean (SD) weekly app use did not differ between *My Guide* (86.58 [66.08] minutes per week) and

My Health (72.80 [62.57] minutes per week, $t_{76}=-0.95$; $P=.34$). See Table 2 for the total app use for each week, average weekly use, and total use over the 6-week study period. A notable pattern across both apps is the reduced weekly app use during the third week followed by an increase during the subsequent week, presumably after receiving more telecoaching.

Table 2. Total time and average time of app usage.

Weeks	<i>My Guide</i> app users (n=39), time (minutes)		<i>My Health</i> app users (n=39), time (minutes)	
	Mean (SD)	Range	Mean (SD)	Range
Week 1	95.97 (102.72)	0-431	65.74 (73.99)	0-400
Week 2	90.51 (93.80)	0-426	86.33 (105.45)	0-376
Week 3	69.03 (69.87)	0-250	66.79 (72.89)	0-251
Week 4	87.26 (81.30)	0-350	73.26 (74.46)	0-264
Week 5	91.13 (82.30)	0-311	77.69 (89.06)	0-372
Week 6	85.59 (85.51)	0-318	67.00 (81.40)	0-378
Total usage (weeks 1-6)	519.49 (396.51)	0-1612	436.82 (375.43)	0-1551
Average weekly usage	86.58 (66.08)	0-269	72.80 (62.57)	0-259

Predictors of App Use

There were no significant relationships between the sociodemographic characteristics or baseline HRQoL and total

app use (all $P>.10$), except for employment status. Specifically, for *My Health*, participants who were employed used the app for a lesser duration than those who were unemployed ($\beta=-.33$; $P=.04$).

Patterns of App Use

Table 3 presents the click-level data for each domain in each

app. Click-level data for each subdomain is presented in Multimedia Appendix 2.

Table 3. Total number of clicks for each domain within each app.

App type, domains	n (%), Values
My Guide app (n=6368)	
Managing My Emotions	1731 (27.18)
Managing My Symptoms	963 (15.12)
Managing My Health	784 (12.31)
Breast Cancer Medications	318 (4.99)
Family and Friends	608 (9.55)
Community and Everyday Support	685 (10.76)
Listen and Learn (Media)	1279 (20.08)
My Health app (n=7167)	
Diet and Nutrition part 1	1339 (18.68)
Diet and Nutrition part 2	1527 (21.31)
Exercise	1391 (19.41)
Preventing Diabetes and Heart Disease	573 (7.99)
Lifestyle Behaviors	929 (12.96)
Doctor's Recommendations	999 (13.94)
Media	409 (5.71)

My Guide App

Over the 6-week study period, *My Guide* participants clicked on a total of 6368 links or webpages of intervention content within the app. Participants most frequently accessed content within the *Managing My Emotions* domain (1731/6368, 27.18%), followed by *Managing My Symptoms* (963/6368, 15.12%). The vast majority of *My Guide* participants (35/38, 92%) accessed content related to at least one symptom within the *Managing My Symptoms* domain. Participants clicked on the least number of links within the *Breast Cancer Medications* domain (318/6368, 4.99%).

My Health App

Over the 6-week study period, *My Health* participants clicked on a total of 7167 links or webpages of study content within the app. The top 3 domains that participants most frequently accessed were *Diet and Nutrition* (2866/7167, 39.99%) and *Exercise* (1391/7167, 19.41%). The *Preventing Diabetes and Heart Disease* domain had the least number of links clicked (573/7167, 7.99%).

Study Outcomes

Multimedia Appendix 3 and Multimedia Appendix 4 present the unadjusted means and score ranges of the study outcomes at each study assessment by high app use versus low app use of *My Guide* or *My Health*, respectively. For *My Guide*, scores on breast cancer well-being exceeded the minimally important difference threshold from T1 to T2 and T1 to T3 among low app users, while for *My Health*, scores on social well-being exceeded the minimally important difference threshold from T1 to T2 among high app users.

Discussion

This study evaluated the patterns of use of 2 culturally informed, evidence-based smartphone apps designed specifically for Latina breast cancer survivors. On average, participants used their *My Guide* and *My Health* apps for 8.66 hours and 7.28 hours, respectively. In line with prior research, our study integrated strategies to improve participant engagement, including telecoaching to promote optimal adherence to app use [52], cultural relevance and sensitivity, and specific features of the smartphone apps [53] such as ease of use, design aesthetics, and mobile phone features. Additionally, Latina breast cancer survivors spent an average of more than 1 hour per week on *My Guide* or *My Health*, which is comparable to the amount of time, if not more, patients would typically spend with an in-person counselor. These findings suggest that both apps are of interest to Latina breast cancer survivors.

The past decade has seen a significant increase in technology-assisted interventions for patients with cancer [54,55]. However, due to the few culturally adapted web-based interventions for patients with cancer, evaluation of the usage of these apps among minority patients has not been well-studied. The Nuevo Amanecer smartphone app for Latina breast cancer survivors, for example, is a culturally tailored smartphone app for Latina breast cancer survivors, which focuses on physical activity promotion [56]. Results from the Nuevo Amanecer feasibility trial revealed that women checked their physical activity tracking 4-6 times per week but click level data and total minutes spent engaging in the smartphone app were not reported as part of the study findings [56]. Notably, both *My*

Guide and *My Health* demonstrated longer total durations of app use over a shorter time period compared to 2 other web-based tools for breast cancer survivors in general, which reported an average of 5.6 hours [57] and 15.2 minutes [58] of user engagement across the 4-month study time frame. Our use of telecoaching and cultural tailoring of the apps may have enhanced uptake and may explain the higher use of our smartphone app relative to that reported in previously published studies.

With the exception of employment status, sociodemographic factors did not predict app use. These findings suggest that the *My Guide* and *My Health* apps are accessible to a broad group of Latina breast cancer survivors who speak English or Spanish and have varying educational and income backgrounds, age, ancestry, marital status, and baseline HRQoL. These findings also suggest that the scalability of these apps is feasible. Women who were employed were less likely to use the *My Health* app, and this finding may be explained by employed breast cancer survivors having less time to devote to the app. Results also demonstrated clinically meaningful improvements in breast cancer well-being and social well-being among low users of *My Guide* and high users of *My Health*, respectively. Descriptively, low *My Guide* users also reported reduced symptom burden over time. However, it is unclear whether these changes are clinically meaningful due to the lack of established cutoffs for minimally important differences in symptom burden. Additional research is needed to further evaluate the associations between low app use versus high app use and improvements in HRQoL subdomains as well as to determine the optimal level of weekly app use. The finding that high *My Health* users reported improved social well-being over time also warrant further evaluation, as the *My Health* app focuses on promoting general health and healthy behaviors and does not include specific content related to social support or relationships. Follow-up interviews with participants may help contextualize study results and identify specific aspects of the intervention that were beneficial in terms of study outcomes.

Click-level data revealed that users of *My Guide* most frequently accessed content related to psychosocial aspects of the cancer experience followed by physical symptoms, whereas users of *My Health* most frequently accessed content related to nutrition and exercise. These most-clicked domains are consistent with commonly documented concerns among the general population of cancer survivors [59-61], and topics related to managing emotions, managing physical symptoms, and learning healthy lifestyle behaviors after treatment completion may signify the most relevant or engaging intervention content for Latina breast cancer survivors. Providing educational materials on nutrition and exercise may be especially important as Latinas tend to have higher rates of excess body weight and obesity when compared to their non-Latina White counterparts [62,63]. Women randomized to the *My Guide* app were most likely to click on the *Managing My Emotions* module. Issues regarding coping with loss of health status, bodily changes, fear of recurrence, and reduced medical oncology visits can make the transition to survivorship an emotionally challenging time [64], which may explain the greater number of clicks within the *Managing My Emotions* module.

The results from this study should be evaluated within the context of the study limitations. First, click-level data only provide the total number of clicks for each domain and subdomain and do not account for differences in the amount of content across the domains and subdomains. For example, the most or least accessed topics may simply reflect domains that had the most or least number of links, rather than indicating which topics had more or less engagement or interest from participants. Second, rather than the total time spent using the app, another measure of app use such as intensity or depth of engagement with the intervention (eg, proportion of specific app features used out of the total available features) [65] or some other app-related factor that we did not capture may instead be associated with study outcomes. Systematic reviews on eHealth interventions have reported a variety of metrics of app usage [25,66], including measures of frequency (eg, number of logins), duration (eg, time logged in), and activity (eg, page views, modules completed), and demonstrated that intervention outcomes may be affected by different measures of eHealth usage [25]. Third, while our sample had notable sociodemographic characteristics, including being primarily Spanish-speaking, foreign-born, and Mexican ancestry, our results may not generalize to all Latina breast cancer survivors in the United States. Additionally, this study focused on Latina breast cancer survivors who completed active treatment for breast cancer within 2 years, and the differential needs of those further into survivorship may result in different intervention effects. Future research should consider the optimal timepoint within the cancer continuum of administering the intervention as it relates to the hypothesized intervention effects. Fourth, our sample size was relatively small (n=78), which limits the study findings. Lastly, our study time frame of a 6-week intervention period plus a 2-week follow-up may have been enough to establish feasibility; however, this time frame may be too short to demonstrate efficacy. Future studies should evaluate *My Guide* with a larger and more diverse sample of Latina breast cancer survivors, include other objective and comprehensive measures of participant engagement or eHealth usage (eg, frequency of use, time spent on the app, activity completion) [25,65], and examine whether app use is predictive of study outcomes over a longer study period.

In summary, this study contributes to the scarce research regarding eHealth supportive care interventions among Latina breast cancer survivors. The favorable rates of participant use across the study apps suggest that Latina breast cancer survivors are interested in the content delivered across both *My Guide* and *My Health*. Given the paucity of smartphone apps that have been developed for Latina patients, these click-level data may provide useful insights on the most important cancer topics for this historically understudied patient population. The click-level data provide information on the most accessed topics within the study apps, and these findings may lend insights into some of the most relevant survivorship topics for Latina breast cancer survivors. Furthermore, sociodemographic variables, excluding employment status, or HRQoL at study entry were not related to app use for *My Guide* and *My Health*, which suggest the potential for larger uptake among Latina breast cancer survivors. Therefore, these apps may be accessible to diverse Latina breast cancer survivors. Additional research is needed to determine

the effect of eHealth use on psychosocial outcomes among Latina breast cancer survivors and whether a longer intervention time frame is needed for optimal improvements.

Acknowledgments

Research reported in this publication was supported, in part, by the National Institutes of Health's National Cancer Institute, Grant Numbers U54CA202995, U54CA202997, and U54CA203000. Authors SHB and LCB were supported by National Cancer Institute training grant T32-CA-193193. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Conflicts of Interest

Author FJP is a paid consultant for Blue Note Therapeutics for digitizing a CBT intervention to manage anxiety and depression in cancer patients and survivors. The remaining authors report no conflicts of interest.

Multimedia Appendix 1

Domain descriptions for *My Guide* app and *My Health* app.

[DOCX File , 18 KB - [cancer_v6i2e17538_app1.docx](#)]

Multimedia Appendix 2

Number of clicks for each subdomain within each app domain.

[DOCX File , 20 KB - [cancer_v6i2e17538_app2.docx](#)]

Multimedia Appendix 3

Descriptive statistics of study outcomes across time for *My Guide* app.

[DOCX File , 17 KB - [cancer_v6i2e17538_app3.docx](#)]

Multimedia Appendix 4

Descriptive statistics of study outcomes across time for *My Health* app.

[DOCX File , 17 KB - [cancer_v6i2e17538_app4.docx](#)]

References

1. American Cancer Society. Cancer facts & figures for Hispanics/Latinos 2018-2020. Atlanta, GA: American Cancer Society Inc; 2018. URL: <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-hispanics-and-latinos/cancer-facts-and-figures-for-hispanics-and-latinos-2018-2020.pdf> [accessed 2020-03-01]
2. National Cancer Institute. Cancer of the breast (invasive). United States cancer prevalence estimates.: SEER Cancer Statistics Review 1975-2017 URL: https://seer.cancer.gov/csr/1975_2017/browse_csr.php?sectionSEL=4&pageSEL=sect_04_table_24#b [accessed 2020-06-01]
3. Ashing-Giwa KT, Padilla GV, Bohorquez DE, Tejero JS, Garcia M. Understanding the breast cancer experience of Latina women. *Journal of Psychosocial Oncology* 2006;24(3):19-52. [doi: [10.1300/j077v24n03_02](https://doi.org/10.1300/j077v24n03_02)]
4. Eversley R, Estrin D, Dibble S, Wardlaw L, Pedrosa M, Favila-Penney W. Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncology Nursing Forum* 2007;32(2):250-256. [doi: [10.1188/05.onf.250-256](https://doi.org/10.1188/05.onf.250-256)]
5. Spencer SM, Lehman JM, Wynings C, Arena P, Carver CS, Antoni MH, et al. Concerns about breast cancer and relations to psychosocial well-being in a multiethnic sample of early-stage patients. *Health Psychol* 1999;18(2):159-168. [doi: [10.1037/0278-6133.18.2.159](https://doi.org/10.1037/0278-6133.18.2.159)]
6. Yoon J, Malin JL, Tisnado DM, Tao ML, Adams JL, Timmer MJ, et al. Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Res Treat* 2008;108(1):69-77. [doi: [10.1007/s10549-007-9580-1](https://doi.org/10.1007/s10549-007-9580-1)] [Medline: [17638071](https://pubmed.ncbi.nlm.nih.gov/17638071/)]
7. Fu OS, Crew KD, Jacobson JS, Greenlee H, Yu G, Campbell J, et al. Ethnicity and persistent symptom burden in breast cancer survivors. *J Cancer Surviv* 2009;3(4):241-250 [FREE Full text] [doi: [10.1007/s11764-009-0100-7](https://doi.org/10.1007/s11764-009-0100-7)] [Medline: [19859813](https://pubmed.ncbi.nlm.nih.gov/19859813/)]
8. Sammarco A, Konecny LM. Quality of life, social support, and uncertainty among Latina and Caucasian breast cancer survivors: a comparative study. *Oncology Nursing Forum* 2009;37(1):93-99. [doi: [10.1188/10.onf.93-99](https://doi.org/10.1188/10.onf.93-99)]
9. Yanez B, Thompson EH, Stanton AL. Quality of life among Latina breast cancer patients: a systematic review of the literature. *J Cancer Surviv* 2011;5(2):191-207 [FREE Full text] [doi: [10.1007/s11764-011-0171-0](https://doi.org/10.1007/s11764-011-0171-0)] [Medline: [21274649](https://pubmed.ncbi.nlm.nih.gov/21274649/)]

10. Lockett T, Goldstein D, Butow PN, Gebiski V, Aldridge LJ, McGrane J, et al. Psychological morbidity and quality of life of ethnic minority patients with cancer: a systematic review and meta-analysis. *The Lancet Oncology* 2011;12(13):1240-1248. [doi: [10.1016/s1470-2045\(11\)70212-1](https://doi.org/10.1016/s1470-2045(11)70212-1)]
11. Moadel AB, Morgan C, Dutcher J. Psychosocial needs assessment among an underserved, ethnically diverse cancer patient population. *Cancer* 2007;109(2 Suppl):446-454 [FREE Full text] [doi: [10.1002/cncr.22357](https://doi.org/10.1002/cncr.22357)] [Medline: [17123273](https://pubmed.ncbi.nlm.nih.gov/17123273/)]
12. McGregor BA, Antoni MH. Psychological intervention and health outcomes among women treated for breast cancer: a review of stress pathways and biological mediators. *Brain Behav Immun* 2009;23(2):159-166 [FREE Full text] [doi: [10.1016/j.bbi.2008.08.002](https://doi.org/10.1016/j.bbi.2008.08.002)] [Medline: [18778768](https://pubmed.ncbi.nlm.nih.gov/18778768/)]
13. Antoni MH, Lechner SC, Kazi A, Wimberly SR, Sifre T, Urcuyo KR, et al. How stress management improves quality of life after treatment for breast cancer. *J Consult Clin Psychol* 2006;74(6):1143-1152. [doi: [10.1037/0022-006x.74.6.1143](https://doi.org/10.1037/0022-006x.74.6.1143)]
14. Lopez-Class M, Gomez-Duarte J, Graves K, Ashing-Giwa K. A contextual approach to understanding breast cancer survivorship among Latinas. *Psychooncology* 2012;21(2):115-124 [FREE Full text] [doi: [10.1002/pon.1998](https://doi.org/10.1002/pon.1998)] [Medline: [21674680](https://pubmed.ncbi.nlm.nih.gov/21674680/)]
15. Andersen BL, Yang H, Farrar WB, Golden-Kreutz DM, Emery CF, Thornton LM, et al. Psychologic intervention improves survival for breast cancer patients: a randomized clinical trial. *Cancer* 2008;113(12):3450-3458 [FREE Full text] [doi: [10.1002/cncr.23969](https://doi.org/10.1002/cncr.23969)] [Medline: [19016270](https://pubmed.ncbi.nlm.nih.gov/19016270/)]
16. Antoni MH, Wimberly SR, Lechner SC, Kazi A, Sifre T, Urcuyo KR, et al. Reduction of cancer-specific thought intrusions and anxiety symptoms with a stress management intervention among women undergoing treatment for breast cancer. *Am J Psychiatry* 2006;163(10):1791-1797 [FREE Full text] [doi: [10.1176/ajp.2006.163.10.1791](https://doi.org/10.1176/ajp.2006.163.10.1791)] [Medline: [17012691](https://pubmed.ncbi.nlm.nih.gov/17012691/)]
17. Molina Y, Thompson B, Espinoza N, Ceballos R. Breast cancer interventions serving US-based Latinas: current approaches and directions. *Womens Health* 2013;9(4):335-348. [doi: [10.2217/whe.13.30](https://doi.org/10.2217/whe.13.30)] [Medline: [23826775](https://pubmed.ncbi.nlm.nih.gov/23826775/)]
18. Griner D, Smith TB. Culturally adapted mental health intervention: a meta-analytic review. *Psychotherapy* 2006;43(4):531-548. [doi: [10.1037/0033-3204.43.4.531](https://doi.org/10.1037/0033-3204.43.4.531)] [Medline: [22122142](https://pubmed.ncbi.nlm.nih.gov/22122142/)]
19. Nápoles-Springer AM, Ortíz C, O'Brien H, Díaz-Méndez M. Developing a culturally competent peer support intervention for Spanish-speaking Latinas with breast cancer. *J Immigr Minor Health* 2009;11(4):268-280 [FREE Full text] [doi: [10.1007/s10903-008-9128-4](https://doi.org/10.1007/s10903-008-9128-4)] [Medline: [18340533](https://pubmed.ncbi.nlm.nih.gov/18340533/)]
20. Interian A, Díaz-Martínez AM. Considerations for culturally competent cognitive-behavioral therapy for depression with Hispanic patients. *Cogn Behav Pract* 2007;14(1):84-97. [doi: [10.1016/j.cbpra.2006.01.006](https://doi.org/10.1016/j.cbpra.2006.01.006)]
21. Rathod S, Gega L, Degan A, Pikard J, Khan T, Husain N, et al. The current status of culturally adapted mental health interventions: a practice-focused review of meta-analyses. *NDT* 2018;Volume 14:165-178. [doi: [10.2147/ndt.s138430](https://doi.org/10.2147/ndt.s138430)]
22. Duncan M, Moschopoulou E, Herrington E, Deane J, Roylance R, Jones L, SURECAN Investigators. Review of systematic reviews of non-pharmacological interventions to improve quality of life in cancer survivors. *BMJ Open* 2017;7(11):e015860 [FREE Full text] [doi: [10.1136/bmjopen-2017-015860](https://doi.org/10.1136/bmjopen-2017-015860)] [Medline: [29187408](https://pubmed.ncbi.nlm.nih.gov/29187408/)]
23. Seiler A, Klaas V, Tröster G, Fagundes CP. eHealth and mHealth interventions in the treatment of fatigued cancer survivors: A systematic review and meta-analysis. *Psychooncology* 2017;26(9):1239-1253. [doi: [10.1002/pon.4489](https://doi.org/10.1002/pon.4489)] [Medline: [28665554](https://pubmed.ncbi.nlm.nih.gov/28665554/)]
24. Lopez M, Gonzalez-Barrera A, Patten E. Closing the digital divide: Latinos and technology adoption. Washington, D.C: Pew Hispanic Center; 2013. URL: https://www.pewresearch.org/hispanic/wp-content/uploads/sites/5/2013/03/Latinos_Social_Media_and_Mobile_Tech_03-2013_final.pdf [accessed 2020-03-01]
25. Donkin L, Christensen H, Naismith SL, Neal B, Hickie IB, Glozier N. A systematic review of the impact of adherence on the effectiveness of e-therapies. *J Med Internet Res* 2011;13(3):e52 [FREE Full text] [doi: [10.2196/jmir.1772](https://doi.org/10.2196/jmir.1772)] [Medline: [21821503](https://pubmed.ncbi.nlm.nih.gov/21821503/)]
26. Berry DL, Blonquist TM, Patel RA, Halpenny B, McReynolds J. Exposure to a patient-centered, Web-based intervention for managing cancer symptom and quality of life issues: impact on symptom distress. *J Med Internet Res* 2015;17(6):e136 [FREE Full text] [doi: [10.2196/jmir.4190](https://doi.org/10.2196/jmir.4190)] [Medline: [26041682](https://pubmed.ncbi.nlm.nih.gov/26041682/)]
27. Børøsund E, Cvancarova M, Ekstedt M, Moore SM, Ruland CM. How user characteristics affect use patterns in web-based illness management support for patients with breast and prostate cancer. *J Med Internet Res* 2013;15(3):e34 [FREE Full text] [doi: [10.2196/jmir.2285](https://doi.org/10.2196/jmir.2285)] [Medline: [23454601](https://pubmed.ncbi.nlm.nih.gov/23454601/)]
28. Yanez BR, Buitrago D, Buscemi J, Iacobelli F, Adler RF, Corden ME, et al. Study design and protocol for My Guide: An e-health intervention to improve patient-centered outcomes among Hispanic breast cancer survivors. *Contemp Clin Trials* 2018;65:61-68 [FREE Full text] [doi: [10.1016/j.cct.2017.11.018](https://doi.org/10.1016/j.cct.2017.11.018)] [Medline: [29198729](https://pubmed.ncbi.nlm.nih.gov/29198729/)]
29. Yanez B, Oswald L, Baik S, Buitrago D, Iacobelli F, Perez-Tamayo A, et al. Brief culturally informed smartphone interventions decrease breast cancer symptom burden among Latina breast cancer survivors. *Psychooncology* 2020;29(1):195-203 [FREE Full text] [doi: [10.1002/pon.5281](https://doi.org/10.1002/pon.5281)] [Medline: [31693265](https://pubmed.ncbi.nlm.nih.gov/31693265/)]
30. Penedo FJ, Molton I, Dahn JR, Shen B, Kinsinger D, Traeger L, et al. A randomized clinical trial of group-based cognitive-behavioral stress management in localized prostate cancer: development of stress management skills improves quality of life and benefit finding. *Ann Behav Med* 2006;31(3):261-270. [doi: [10.1207/s15324796abm3103_8](https://doi.org/10.1207/s15324796abm3103_8)] [Medline: [16700640](https://pubmed.ncbi.nlm.nih.gov/16700640/)]

31. Yanez B, McGinty HL, Mohr DC, Begale MJ, Dahn JR, Flury SC, et al. Feasibility, acceptability, and preliminary efficacy of a technology-assisted psychosocial intervention for racially diverse men with advanced prostate cancer. *Cancer* 2015;121(24):4407-4415 [FREE Full text] [doi: [10.1002/cncr.29658](https://doi.org/10.1002/cncr.29658)] [Medline: [26348661](https://pubmed.ncbi.nlm.nih.gov/26348661/)]
32. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. *Eur J Pers* 1987;1(3):141-169. [doi: [10.1002/per.2410010304](https://doi.org/10.1002/per.2410010304)]
33. Penedo FJ, Molton I, Dahn JR, Shen B, Kinsinger D, Traeger L, et al. A randomized clinical trial of group-based cognitive-behavioral stress management in localized prostate cancer: development of stress management skills improves quality of life and benefit finding. *Ann Behav Med* 2006;31(3):261-270. [doi: [10.1207/s15324796abm3103_8](https://doi.org/10.1207/s15324796abm3103_8)] [Medline: [16700640](https://pubmed.ncbi.nlm.nih.gov/16700640/)]
34. Yanez B, McGinty HL, Buitrago D, Ramirez AG, Penedo FJ. Cancer outcomes in Hispanics/Latinos in the United States: an integrative review and conceptual model of determinants of health. *J Lat Psychol* 2016;4(2):114-129 [FREE Full text] [doi: [10.1037/lat0000055](https://doi.org/10.1037/lat0000055)] [Medline: [27429867](https://pubmed.ncbi.nlm.nih.gov/27429867/)]
35. Ganz PA, Kwan L, Stanton AL, Bower JE, Belin TR. Physical and psychosocial recovery in the year after primary treatment of breast cancer. *J Clin Oncol* 2011;29(9):1101-1109. [doi: [10.1200/jco.2010.28.8043](https://doi.org/10.1200/jco.2010.28.8043)]
36. Stanton AL, Snider PR. Coping with a breast cancer diagnosis: A prospective study. *Health Psychol* 1993;12(1):16-23. [doi: [10.1037/0278-6133.12.1.16](https://doi.org/10.1037/0278-6133.12.1.16)]
37. Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res* 2007;16(3):413-428. [doi: [10.1007/s11136-006-9138-4](https://doi.org/10.1007/s11136-006-9138-4)] [Medline: [17279444](https://pubmed.ncbi.nlm.nih.gov/17279444/)]
38. Graves KD, Jensen RE, Cañar J, Perret-Gentil M, Leventhal K, Gonzalez F, et al. Through the lens of culture: quality of life among Latina breast cancer survivors. *Breast Cancer Res Treat* 2012;136(2):603-613. [doi: [10.1007/s10549-012-2291-2](https://doi.org/10.1007/s10549-012-2291-2)] [Medline: [23085764](https://pubmed.ncbi.nlm.nih.gov/23085764/)]
39. Yanez B, Maggard Gibbons M, Moreno PI, Jorge A, Stanton AL. Predictors of psychological outcomes in a longitudinal study of Latina breast cancer survivors. *Psychol Health* 2016;31(11):1359-1374. [doi: [10.1080/08870446.2016.1208821](https://doi.org/10.1080/08870446.2016.1208821)] [Medline: [27373454](https://pubmed.ncbi.nlm.nih.gov/27373454/)]
40. Brady MJ, Cella DF, Mo F, Bonomi AE, Tulsky DS, Lloyd SR, et al. Reliability and validity of the functional assessment of cancer therapy-breast quality-of-life instrument. *J Clin Oncol* 1997;15(3):974-986. [doi: [10.1200/jco.1997.15.3.974](https://doi.org/10.1200/jco.1997.15.3.974)]
41. Cella D, Hernandez L, Bonomi AE, Corona M, Vaquero M, Shiimoto G, et al. Spanish language translation and initial validation of the functional assessment of cancer therapy quality-of-life instrument. *Med Care* 1998;36(9):1407-1418. [doi: [10.1097/00005650-199809000-00012](https://doi.org/10.1097/00005650-199809000-00012)] [Medline: [9749663](https://pubmed.ncbi.nlm.nih.gov/9749663/)]
42. Yanez B, Pearman T, Lis CG, Beaumont JL, Cella D. The FACT-G7: a rapid version of the functional assessment of cancer therapy-general (FACT-G) for monitoring symptoms and concerns in oncology practice and research. *Ann Oncol* 2013;24(4):1073-1078 [FREE Full text] [doi: [10.1093/annonc/mds539](https://doi.org/10.1093/annonc/mds539)] [Medline: [23136235](https://pubmed.ncbi.nlm.nih.gov/23136235/)]
43. Stanton AL, Bernards CA, Ganz PA. The BCPT symptom scales: a measure of physical symptoms for women diagnosed with or at risk for breast cancer. *J Natl Cancer Inst* 2005;97(6):448-456. [doi: [10.1093/jnci/dji069](https://doi.org/10.1093/jnci/dji069)] [Medline: [15770009](https://pubmed.ncbi.nlm.nih.gov/15770009/)]
44. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979;41(3):209-218. [doi: [10.1097/00006842-197905000-00004](https://doi.org/10.1097/00006842-197905000-00004)] [Medline: [472086](https://pubmed.ncbi.nlm.nih.gov/472086/)]
45. Báguena M, Villarroya E, Beleña A, Díaz A, Roldán C, Reig R. Propiedades psicométricas de la versión española de la Escala Revisada de Impacto del Estresor (EIE-R). *Análisis Modificación Conducta* 2001;27(114):581-604 [FREE Full text] [doi: [10.33776/amc.v33i149.1218](https://doi.org/10.33776/amc.v33i149.1218)]
46. Wolf MS, Chang C, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). *Patient Educ Couns* 2005;57(3):333-341. [doi: [10.1016/j.pec.2004.09.005](https://doi.org/10.1016/j.pec.2004.09.005)] [Medline: [15893217](https://pubmed.ncbi.nlm.nih.gov/15893217/)]
47. Jean-Pierre P, Fiscella K, Freund KM, Clark J, Darnell J, Holden A, Patient Navigation Research Program Group. Structural and reliability analysis of a patient satisfaction with cancer-related care measure: a multisite patient navigation research program study. *Cancer* 2011;117(4):854-861 [FREE Full text] [doi: [10.1002/cncr.25501](https://doi.org/10.1002/cncr.25501)] [Medline: [20922802](https://pubmed.ncbi.nlm.nih.gov/20922802/)]
48. Chen JY, Diamant AL, Thind A, Maly RC. Determinants of breast cancer knowledge among newly diagnosed, low-income, medically underserved women with breast cancer. *Cancer* 2008;112(5):1153-1161 [FREE Full text] [doi: [10.1002/cncr.23262](https://doi.org/10.1002/cncr.23262)] [Medline: [18189306](https://pubmed.ncbi.nlm.nih.gov/18189306/)]
49. Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health Qual Life Outcomes* 2003;1(79) [FREE Full text] [doi: [10.1186/1477-7525-1-79](https://doi.org/10.1186/1477-7525-1-79)] [Medline: [14678568](https://pubmed.ncbi.nlm.nih.gov/14678568/)]
50. Yost KJ, Eton DT. Combining distribution- and anchor-based approaches to determine minimally important differences: the FACIT experience. *Eval Health Prof* 2005;28(2):172-191. [doi: [10.1177/0163278705275340](https://doi.org/10.1177/0163278705275340)] [Medline: [15851772](https://pubmed.ncbi.nlm.nih.gov/15851772/)]
51. Cella D, Eton DT, Lai J, Peterman AH, Merkel DE. Combining anchor and distribution-based methods to derive minimal clinically important differences on the functional assessment of cancer therapy (FACT) anemia and fatigue scales. *J Pain Symptom Manage* 2002;24(6):547-561. [doi: [10.1016/s0885-3924\(02\)00529-8](https://doi.org/10.1016/s0885-3924(02)00529-8)]
52. Mohr DC, Cuijpers P, Lehman K. Supportive accountability: a model for providing human support to enhance adherence to eHealth interventions. *J Med Internet Res* 2011;13(1):e30 [FREE Full text] [doi: [10.2196/jmir.1602](https://doi.org/10.2196/jmir.1602)] [Medline: [21393123](https://pubmed.ncbi.nlm.nih.gov/21393123/)]

53. Garnett C, Crane D, West R, Brown J, Michie S. Identification of behavior change techniques and engagement strategies to design a smartphone app to reduce alcohol consumption using a formal consensus method. *JMIR Mhealth Uhealth* 2015;3(2):e73 [FREE Full text] [doi: [10.2196/mhealth.3895](https://doi.org/10.2196/mhealth.3895)] [Medline: [26123578](https://pubmed.ncbi.nlm.nih.gov/26123578/)]
54. Penedo FJ, Oswald LB, Kronenfeld JP, Garcia SF, Cella D, Yanez B. The increasing value of eHealth in the delivery of patient-centred cancer care. *Lancet Oncol* 2020(5):e240-e251. [doi: [10.1016/s1470-2045\(20\)30021-8](https://doi.org/10.1016/s1470-2045(20)30021-8)]
55. Triberti S, Savioni L, Sebri V, Pravettoni G. eHealth for improving quality of life in breast cancer patients: a systematic review. *Cancer Treat Rev* 2019;74:1-14. [doi: [10.1016/j.ctrv.2019.01.003](https://doi.org/10.1016/j.ctrv.2019.01.003)] [Medline: [30658289](https://pubmed.ncbi.nlm.nih.gov/30658289/)]
56. Nápoles AM, Santoyo-Olsson J, Chacón L, Stewart AL, Dixit N, Ortiz C. Feasibility of a mobile phone app and telephone coaching survivorship care planning pProgram among Spanish-speaking breast cancer survivors. *JMIR Cancer* 2019;5(2):e13543 [FREE Full text] [doi: [10.2196/13543](https://doi.org/10.2196/13543)] [Medline: [31290395](https://pubmed.ncbi.nlm.nih.gov/31290395/)]
57. van den Berg SW, Peters EJ, Kraaijeveld JF, Gielissen MF, Prins JB. Usage of a generic web-based self-management intervention for breast cancer survivors: substudy analysis of the BREATH trial. *J Med Internet Res* 2013;15(8):e170 [FREE Full text] [doi: [10.2196/jmir.2566](https://doi.org/10.2196/jmir.2566)] [Medline: [23958584](https://pubmed.ncbi.nlm.nih.gov/23958584/)]
58. Kuijpers W, Groen WG, Oldenburg HS, Wouters MW, Aaronson NK, van Harten WH. eHealth for breast cancer survivors: use, feasibility and impact of an interactive portal. *JMIR Cancer* 2016;2(1):e3 [FREE Full text] [doi: [10.2196/cancer.5456](https://doi.org/10.2196/cancer.5456)] [Medline: [28410178](https://pubmed.ncbi.nlm.nih.gov/28410178/)]
59. Stanton AL. Psychosocial concerns and interventions for cancer survivors. *J Clin Oncol* 2006;24(32):5132-5137. [doi: [10.1200/jco.2006.06.8775](https://doi.org/10.1200/jco.2006.06.8775)]
60. Ashing-Giwa KT, Padilla G, Tejero J, Kraemer J, Wright K, Coscarelli A, et al. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psychooncology* 2004;13(6):408-428 [FREE Full text] [doi: [10.1002/pon.750](https://doi.org/10.1002/pon.750)] [Medline: [15188447](https://pubmed.ncbi.nlm.nih.gov/15188447/)]
61. van Londen G, Beckjord E, Dew M, Cuijpers P, Tadic S, Brufsky A. Breast cancer survivorship symptom management: current perspective and future development. *Breast Cancer Manag* 2013;2(1):71-81 [FREE Full text] [doi: [10.2217/bmt.12.63](https://doi.org/10.2217/bmt.12.63)] [Medline: [23814614](https://pubmed.ncbi.nlm.nih.gov/23814614/)]
62. National Center for Health Statistics. Public-use data file and documentation. National Health and Nutrition Examination Survey, 2011-2012. URL: <https://www.cdc.gov/nchs/nhanes/continuousnhanes/default.aspx?BeginYear=2011> [accessed 2020-06-01]
63. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011-2012. *JAMA* 2014;311(8):806-814 [FREE Full text] [doi: [10.1001/jama.2014.732](https://doi.org/10.1001/jama.2014.732)] [Medline: [24570244](https://pubmed.ncbi.nlm.nih.gov/24570244/)]
64. Institute of Medicine, National Research Council. Psychosocial needs of women with breast cancer. In: Hewitt M, Herdman R, Holland J, editors. Meeting Psychosocial Needs of Women with Breast Cancer. Washington, D.C: National Academies Press; 2004.
65. Short CE, DeSmet A, Woods C, Williams SL, Maher C, Middelweerd A, et al. Measuring engagement in eHealth and mHealth behavior change interventions: viewpoint of methodologies. *J Med Internet Res* 2018;20(11):e292 [FREE Full text] [doi: [10.2196/jmir.9397](https://doi.org/10.2196/jmir.9397)] [Medline: [30446482](https://pubmed.ncbi.nlm.nih.gov/30446482/)]
66. Crutzen R, de Nooijer J, Brouwer W, Oenema A, Brug J, de Vries NK. Strategies to facilitate exposure to internet-delivered health behavior change interventions aimed at adolescents or young adults: a systematic review. *Health Educ Behav* 2011;38(1):49-62. [doi: [10.1177/1090198110372878](https://doi.org/10.1177/1090198110372878)] [Medline: [21189422](https://pubmed.ncbi.nlm.nih.gov/21189422/)]

Abbreviations

CASE-cancer: Communication and Attitudinal Self-Efficacy scale for cancer

FACT-B: Functional Assessment of Cancer Therapy-Breast

FACT-G7: Functional Assessment of Cancer Therapy-General 7 items

HRQoL: health-related quality of life

Edited by G Eysenbach; submitted 19.12.19; peer-reviewed by F Petracca, C Valle, G Assam Taarnh?j; comments to author 20.05.20; revised version received 10.06.20; accepted 11.11.20; published 08.12.20.

Please cite as:

Baik SH, Oswald LB, Buscemi J, Buitrago D, Iacobelli F, Perez-Tamayo A, Guitelman J, Penedo FJ, Yanez B

Patterns of Use of Smartphone-Based Interventions Among Latina Breast Cancer Survivors: Secondary Analysis of a Pilot Randomized Controlled Trial

JMIR Cancer 2020;6(2):e17538

URL: <http://cancer.jmir.org/2020/2/e17538/>

doi: [10.2196/17538](https://doi.org/10.2196/17538)

PMID: [33289669](https://pubmed.ncbi.nlm.nih.gov/33289669/)

©Sharon H Baik, Laura B Oswald, Joanna Buscemi, Diana Buitrago, Francisco Iacobelli, Alejandra Perez-Tamayo, Judith Guitelman, Frank J Penedo, Betina Yanez. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 08.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Differences in Electronic Personal Health Information Tool Use Between Rural and Urban Cancer Patients in the United States: Secondary Data Analysis

Alexandra Greenberg-Worisek¹, MPH, PhD; Liaa Ferede²; Joyce Balls-Berry³, PhD; Ian Marigi⁴, BA; Emily Valentin Mendez⁵, BA; Numra Bajwa³, MBBS; Melody Ouk³, MA; Minerva Orellana³, MSc; Felicity Enders³, MPH, PhD

¹Mayo Clinic, Rochester, MN, United States

²University of Minnesota Rochester, Rochester, MN, United States

³Department of Neurologic Surgery, Mayo Clinic, Rochester, MN, United States

⁴Washington University in St Louis, St Louis, MO, United States

⁵University of Puerto Rico School of Medicine, San Juan, Puerto Rico, United States Minor Outlying Islands

Corresponding Author:

Alexandra Greenberg-Worisek, MPH, PhD

Mayo Clinic

200 First St SW

Rochester, MN

United States

Phone: 1 773 354 2018

Email: worisek.alexandra@gmail.com

Abstract

Background: Studies have previously shown that rural cancer patients are diagnosed at later stages of disease. This delay is felt throughout treatment and follow-up, reflected in the fact that rural patients often have poorer clinical outcomes compared with their urban counterparts.

Objective: Few studies have explored whether there is a difference in cancer patients' current use of health information technology tools by residential location.

Methods: Data from 7 cycles of the Health Information National Trends Survey (HINTS, 2003-2017) were merged and analyzed to examine whether differences exist in managing electronic personal health information (ePHI) and emailing health care providers among rural and urban cancer patients. Geographic location was categorized using Rural-Urban Continuum Codes (RUCCs). Bivariate analyses and multivariable logistic regression were used to determine whether associations existed between rural/urban residency and use of health information technology among cancer patients.

Results: Of the 3031 cancer patients/survivors who responded across the 7 cycles of HINTS, 797 (26.9%) resided in rural areas. No difference was found between rural and urban cancer patients in having managed ePHI in the past 12 months (OR 0.78, 95% CI 0.43-1.40). Rural cancer patients were significantly less likely to email health care providers than their urban counterparts (OR 0.52, 95% CI 0.32-0.84).

Conclusions: The digital divide between rural and urban cancer residents does not extend to general ePHI management; however, electronic communication with providers is significantly lower among rural cancer patients than urban cancer patients. Further research is needed to determine whether such disparities extend to other health information technology tools that might benefit rural cancer patients as well as other chronic conditions.

(*JMIR Cancer* 2020;6(2):e17352) doi:[10.2196/17352](https://doi.org/10.2196/17352)

KEYWORDS

cancer; patient engagement; health research; digital divide; disparities

Introduction

Patients with chronic diseases require complex and ongoing care. Specifically, patients with cancer diagnoses require frequent and deep contact with the health care system. This is a particular challenge for rural cancer patients, who must travel on average 48 miles to see their nearest health care provider in person [1,2]. The impact of distance from providers is felt throughout the cancer care continuum, from detection and diagnosis to treatment and follow-up care. For example, rural cancer patients have a significantly lower chance of receiving appropriate chemotherapy than their urban counterparts, due in part to distance and travel time [1,2]. Although many telemedicine centers were established to increase geographic access for rural patients, many are still too far for certain geographic populations [2,3].

The lack of access due to travel distance results in rural cancer patients participating less frequently in regular cancer screening than urban cancer patients, including screenings for more prevalent malignancies, such as breast, colon, and prostate cancer [1]. Due to the lower rates of patients in rural regions getting cancer screenings, they are more likely to be diagnosed with cancer at a later stage than patients who live in an urban region [1]. This may, in part, help to explain why cancer patients in rural regions have a higher mortality rate than cancer patients in urban regions [4]. Efforts have been made in recent years to use technology to creatively reach specific groups of patients in rural areas, such as telemedicine programs aimed at reaching rural Native American communities, or for certain specialties, including ambulatory, inpatient, and perinatal care [5-7].

Accompanying the rise of telemedicine has been increasing internet adoption nationwide, with studies reporting that access to the internet increased for all sociodemographic groups between 2003 and 2014 [8]. This is due in part to advances in technology, which allow individuals to access the internet more freely and on-demand using handheld and portable devices [9]. In parallel with these hardware and internet connectivity advances has been increasing adoption of electronic health records (EHRs) and electronic personal health information (ePHI) tools by health care providers; this has the potential to facilitate increased patient engagement and communication with health care providers [10]. Despite efforts to increase access to the internet and facilitate opportunities for remote interaction with the health care system, populations still lack internet access and connection quality, which affects their ability to access and use ePHI tools; this, in turn, may be further exacerbating the existing health information technology-related digital divide among rural and urban patients.

In this study, we sought to (1) determine the overall use of ePHI tools among cancer patients in urban and rural regions and (2) assess the rate of email communication between cancer patients in urban and rural regions and their health care provider. We hypothesized that urban cancer patients access their ePHI more frequently than rural cancer patients and urban cancer patients communicate via email with their health care provider more frequently than cancer patients in rural regions. To study the rural-urban disparity longitudinally and determine whether it

was growing, we used multiple administrations of the National Cancer Institute's Health Information National Trends Survey (HINTS) data.

Methods

Survey Population and Data Collection

HINTS is a nationally representative survey of noninstitutionalized adults over the age of 18 years in the United States. The survey includes a variety of health-related topics, such as the use of health technology and communication with health care providers. The mode of survey delivery varied across HINTS fieldings and included random digital dialing (RDD) and regular mail distribution. Data from years 2003, 2005, 2008, 2011, 2013, and 2017 were included in the survey. Surveys were distributed through RDD in 2003, 2005, and 2008. Physical mail distribution occurred in years 2008 (in parallel with RDD), 2011, 2013, and 2017. The response rate of random digital dialing was 33.1% in 2003, 20.8% in 2005, and 24.2% in 2008; while the response rate for regular mail administration was 40.0% in 2008, 36.7% in 2011, 35.2% in 2013, and 32.4% in 2017. Further information on data collection, weighted methodologies, and sample frames are available through HINTS methodology reports [11].

Dependent Variables

Our primary objective was to examine the relationship between rural and urban residence and self-management of ePHI online among cancer patients. The original survey item of interest (survey years 2003, 2005, 2008, 2011, and 2013) is as follows:

- “In the last 12 months, have you used the internet to keep track of protected health information, such as care received, test results, or upcoming medical appointments?”

In 2017, more granular items were asked of respondents, and the survey item was changed:

- “In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following?”
 - Make appointments with a health care provider
 - Track health care charges and costs
 - Fill out forms or paperwork related to your health care
 - Look up test results”

Any respondent who answered yes to any of these subitems were categorized as having managed their ePHI online; conversely, respondents who answered no to all 4 subitems were considered to have not managed their ePHI. Before 2017, the question was asked of individuals who previously stated they had regular internet access. In 2017, the question was asked of those who stated they had both regular internet access and access to their electronic health records.

Our secondary objective was to determine whether a difference existed between rural and urban cancer patients in terms of communicating online with their health care provider. The item used in the earlier HINTS deliveries (2003-2013) is as follows:

- “In the last 12 months, have you used email or the internet to communicate with a doctor or doctor's office?”

In 2017, the wording has changed slightly:

- “In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following?
 - Use email or the internet to communicate with a doctor or a doctor’s office.”

Before 2017, the item was only asked of those who stated they had access to the internet. In 2017, the question was asked of all participants, regardless of access to the internet or their EHRs.

Independent Variables

Analyses were restricted to respondents who replied yes in response to the survey item “Have you ever been diagnosed as having cancer?” Additional independent variables included in analyses were age, race/ethnicity, income, gender, and educational level; all were categorical. Age was divided into age groups of 18-34, 35-49, 50-64, 65-74, and 75+. Race/ethnicity was condensed into Hispanic, non-Hispanic white, non-Hispanic black, and non-Hispanic other [12]. Income was organized into 5 categories: <\$20,000, \$20,000 to <\$35,000, \$35,000 to <\$50,000, \$50,000 to <\$75,000, and >\$75,000. Sex was categorized as a binary variable (male or female). Educational level was categorized as less than high school, high school, some college, and college graduate or higher.

Each participant was categorized as being in an urban or rural population following the Rural-Urban Continuum Code (RUCC) through the United States Department of Agriculture [13]. The code categorizes respondents based on their location (population size, metro county, or nonmetro county). The codes are on a scale of 1 to 9; if a region falls under codes 1 to 3, the classification is a metro county with a population of at least 250,000—in other words, an urban category. If a region falls under codes 4 to 9, the classification is a nonmetro county with a population ranging from 2500 to 20,000 individuals—therefore, a rural county.

Statistical Analysis

The use of SAS 9.4 (SAS Institute Inc) allowed for weighted analysis to incorporate jackknife replicate weights to obtain population-level estimates. Briefly, a set of 50 jackknife weights are developed for each survey administration using data from the most recent US Census; this allows the weights to be used in conjunction with survey procedures within SAS to generate population-level estimates based on the survey sample data. Bivariate analyses were conducted to determine whether associations existed between geographic location and each of the independent and dependent variables; this served as an unadjusted analysis. The independent variables previously mentioned (age, race/ethnicity, income, gender, and educational level) were adjusted for using multivariable logistic regression for each dependent variable of interest. Predicted marginals were also calculated to observe any statistical differences over a period of time by adding interaction terms between each independent variable and survey year to the multivariate model one at a time. A complete case analysis was used for both outcomes of interest.

Results

Study Population Characteristics

All percentages reported are weighted to generate population-level estimates using the HINTS jackknife weighting paradigm. A total of 4163 respondents included across HINTS survey administrations reported having been diagnosed with cancer; this included skin cancers. These individuals had higher incomes (883/3498, or 27.6%, reported annual incomes of \$75,000 or higher); were aged 50 years and older (3500/4107, 80.6%); female (2618/4121, 59.2%); and non-Hispanic white (3223/3888, 82.4%). Bivariate analyses showed a statistically significant relationship between sociodemographic characteristics (race/ethnicity, education level, income, and email/documentation) and urban/rural residency status (Table 1).

Table 1. Association between urban/rural status, sociodemographic characteristics, and health information technology use among cancer patients who participated in the Health Information National Trends Survey in 2003, 2005, 2008, 2011, 2013, and 2017 and reported a prior cancer diagnosis (n=4163). Row percentages are weighted to reflect United States population-level estimates.

Characteristic	Rural, n (%)	Urban, n (%)	P value
Sex			.68
Male	287 (18.9)	126 (81.1)	
Female	510 (19.7)	2108 (80.3)	
Age in years			.34
18-34	27 (19.7)	107 (80.3)	
35-49	92 (18.4)	381 (81.6)	
50-64	243 (17.6)	1065 (82.4)	
65-74	219 (22.5)	894 (77.5)	
≥75	213 (19.4)	866 (80.6)	
Race/ethnicity			<.001
Hispanic	13 (10.4)	198 (89.6)	
Non-Hispanic white	678 (21.0)	2545 (79.0)	
Non-Hispanic black	27 (7.6)	253 (92.4)	
Non-Hispanic other	29.9 (16.8)	145 (83.2)	
Education			<.001
Less than high school	119 (26.1)	304 (73.9)	
High school graduate	263 (24.1)	821 (75.9)	
Some college	189 (16.3)	970 (83.7)	
College graduate	207 (14.2)	1192 (85.8)	
Income			<.001
<\$20,000	195 (26.0)	601 (74.0)	
\$20,000-<\$35,000	152 (21.0)	537 (79.0)	
\$35,000-<\$50,000	109 (24.0)	419 (76.0)	
\$50,000-<\$75,000	117 (19.1)	485 (80.9)	
\$75,000+	99 (10.2)	784 (89.8)	
Email/documentation			<.001
Yes	57 (10.4)	500 (89.6)	
No	340 (18.9)	1589 (81.2)	
Made appointments			.06
Yes	22 (13.1)	170 (86.9)	
No	55 (22.0)	247 (78.0)	
Tracked health costs			.34
Yes	16 (14.2)	116 (85.8)	
No	59 (18.8)	299 (81.2)	
Completed forms			.28
Yes	24 (15.0)	116 (85.0)	
No	53 (20.2)	255 (79.8)	
Test results			.17
Yes	24 (13.7)	160 (86.3)	
No	52 (20.1)	262 (79.9)	
Survey year			.03

Characteristic	Rural, n (%)	Urban, n (%)	<i>P</i> value
2003	628 (2.1)	3354 (11.3)	
2005	618 (2.4)	2626 (11.0)	
2008	835 (2.3)	4243 (13.3)	
2011	419 (2.8)	2495 (15.8)	
2013	303 (3.1)	1981 (15.5)	
2017	345 (3.1)	2188 (17.3)	

Electronic Personal Health Information Use Among Rural and Urban Cancer Patients

After adjusting for sex, age, race/ethnicity, education, income, and survey year, no statistically significant association was observed between ePHI use and the urban/rural status of the cancer patients (Table 2). Urban cancer patients accessed ePHI more frequently than rural cancer patients over multiple administrations of HINTS. The only association that persisted after adjustment is between the use of ePHI among cancer

patients and the survey year ($P < .001$). Although a statistically significant association was found between these two variables, the confidence intervals suggest there is no association present between the survey year and cancer patient geography (2011: odds ratio [OR] 1.57, 95% CI 1.02-2.43; 2013: OR 3.38, 95% CI 1.89-6.15; 2017: OR 13.07, 95% CI 8.23-20.75). No association was found between ePHI use and sex, age, income, or race/ethnicity (Table 2). Additionally, there was no statistically significant association between ePHI use and education ($P = .07$).

Table 2. Logistic regression model of electronic personal health information use among patients who reported being diagnosed with cancer grouped by rural and urban status based from the Health Information National Trends Survey (n=1388) in the years 2008, 2011, 2013, and 2017, adjusted for sex, age, race/ethnicity, education, and income.

Characteristics	Odds ratio (95% CI)	P value
Residential area		.40
Urban	Ref ^a	
Rural	0.78 (0.43-1.40)	
Sex		.75
Female	Ref	
Male	0.93 (0.60-1.45)	
Age in years		.52
18-34	Ref	
35-49	0.50 (0.17-1.47)	
50-64	0.48 (0.19-1.22)	
65-74	0.42 (0.16-1.11)	
≥75	0.41 (0.13-1.27)	
Race/ethnicity		.27
Non-Hispanic white	Ref	
Hispanic	0.94 (0.46-1.93)	
Non-Hispanic black	1.16 (0.51-2.64)	
Non-Hispanic other	2.05 (0.98-4.31)	
Education		.07
Less than high school	Ref	
High school graduate	1.03 (0.19-5.50)	
Some college	2.01 (0.38-10.70)	
College graduate	2.04 (0.41-10.03)	
Income		.09
<\$20,000	Ref	
\$20,000-<\$35,000	1.50 (0.62-3.60)	
\$35,000-<\$50,000	1.13 (0.48-2.69)	
\$50,000-<\$75,000	1.93 (0.72-5.15)	
\$75,000+	2.21 (0.90-5.40)	
Survey year		<.001
2008	Ref	
2011	1.57 (1.02-2.43)	
2013	3.38 (1.89-6.15)	
2017	13.07 (8.23-20.75)	

^aRef: reference.

Email Contact With Providers Among Rural and Urban Patients

Rural cancer patients had a 0.52-fold decreased odds of emailing their health care providers as compared with urban cancer patients, adjusting for gender, age, race/ethnicity, education, income, and survey year (95% CI 0.32-0.84, $P=.009$, Table 3). There were statistically significant associations between email

communication with providers and age ($P=.03$), survey year ($P<.001$), and education ($P=.002$); however, confidence intervals for educational levels indicated no statistically significant difference. The association with email communication between cancer patients and health care providers increased with each survey administration. As the age of the respondents increased, respondents were less likely to have communication with their health care provider (Table 3).

Table 3. Logistic regression model of email communication between patients who reported being diagnosed with cancer and health care provider grouped by rural/urban status based on responses from the Health Information National Trends Survey (n=2058) in the years 2003, 2005, 2008, 2011, 2013, and 2017. Adjusted for gender, age, race/ethnicity, education, and income.

Characteristic	Odds ratio (95% CI)	P value
Residential area		.009
Urban	Ref ^a	
Rural	0.52 (0.32-0.84)	
Sex		.22
Female	Ref	
Male	1.20 (0.89-1.61)	
Age in years		.03
18-34	Ref	
35-49	0.33 (0.14-0.77)	
50-64	0.39 (0.17-0.88)	
65-74	0.26 (0.11-0.61)	
≥75	0.25 (0.10-0.64)	
Race/ethnicity		.97
Non-Hispanic white	Ref	
Hispanic	0.86 (0.33-2.24)	
Non-Hispanic black	0.91 (0.42-2.01)	
Non-Hispanic other	1.13 (0.62-2.05)	
Education		.002
Less than high school	Ref	
High school graduate	1.06 (0.35-3.18)	
Some college	2.61 (0.90-7.51)	
College graduate	2.60 (0.87-7.77)	
Income		.10
<\$20,000	Ref	
\$20,000-<\$35,000	0.88 (0.45-1.72)	
\$35,000-<\$50,000	0.95 (0.49-1.82)	
\$50,000-<\$75,000	1.23 (0.64-2.37)	
\$75,000+	2.01 (0.97-4.14)	
Survey year		<.001
2003	Ref	
2005	1.57 (0.96-2.57)	
2008	1.95 (1.12-3.40)	
2011	3.02 (1.68-5.44)	
2013	7.78 (4.51-13.41)	
2017	8.45 (5.15-13.83)	

^aRef: reference.

Discussion

Principal Findings

In this study, we sought to determine whether an association existed between ePHI use and rural/urban residence status

among cancer patients. Additionally, we sought to examine whether a relationship exists between email communication with health care providers and rural/urban residence among cancer patients. No association was found between ePHI use and geography among cancer patients; this lack of association

persisted after adjustment for relevant sociodemographic covariates. However, results did show that rural cancer patients were significantly less likely to email health care providers compared with their urban counterparts.

Prior work has shown no difference in the use of ePHI tools between urban and rural residents in the general population [14]. Our adjusted results lead us to conclude that there is no difference in use of ePHI tools between rural and urban cancer patients, indicating our original hypothesis that a difference existed was incorrect. Rural cancer patients may access their ePHI less than urban cancer patients. There may be several underlying reasons for this trend. First, lower rates of ePHI use may be due in part to lack of awareness; for example, health care providers tend to offer rural patients access to ePHI tools less frequently, which may play a role further exacerbating the digital divide among rural and urban patients [14]. Second, despite advances in the internet and technology, patients in rural regions are at a disadvantage in comparison with patients in urban regions. Individuals who live in a rural region are reported to have lower use of the internet than individuals who live in an urban region [8]. Due to the lack of infrastructure of telecommunication, rural regions typically do not have optimal internet service [15]. This trend persists despite the Federal Communications Commission effort to expand broadband access [15]. A lack of internet access may prevent patients in rural regions from accessing ePHI tools that could potentially improve their quality of care, further perpetuating the existing health information technology divide.

While no association was found between rural and urban residency and ePHI use, a statistically significant association was found between geography and emailing providers. A recent study using HINTS data found a similar disparity among all HINTS participants, with rural participants reporting that they emailed their health care providers significantly less than urban counterparts [12]. While some have hypothesized that individuals with chronic conditions, such as cancer, are more likely to email their health care providers, patients with one or more chronic conditions have actually been shown to have reduced odds of emailing their providers [16]. The results presented here suggest that this disparity may be even more exacerbated among rural patients with chronic conditions. Additional studies are needed to further characterize the barriers to use of email to communicate with providers; we hypothesize that these may include personal factors (such as lack of awareness, unwillingness to adopt ePHI-related technologies, and/or concerns about privacy) as well as structural factors (lack

of access to reliable internet connections, cellular networks, etc).

Strengths and Limitations

A strength of this study is its use of HINTS. This is a nationally representative survey of individuals who are 18 years or older that has been administered several times over the course of 15 years, allowing for longitudinal study of trends. An additional strength is its use of a jackknife weighting paradigm that allows for the generation of population-level estimates. A limitation to this study is that the items analyzed addressing ePHI and email communication were fairly general; this may have limited the ability to identify specific relationships, included the expected ones. Another limitation to this study is smaller sample size in some categories, due to the restriction of the data solely to cancer patients, as well as the inability to determine causation due to the cross-sectional nature of each survey. Furthermore, HINTS did not ask follow-up questions about the frequency of ePHI use and communication in older survey administrations, nor did the survey include items regarding which provider was emailed and what type of online tool was used to carry out these tasks.

Conclusions and Future Directions

We sought to assess the use of ePHI tools and frequency of electronic communication between adult cancer patients and their health care providers and to determine whether a difference existed in use between those living in rural and urban areas of the United States. Although our results demonstrate that there is no statistically significant difference between the rural/urban status of cancer patients and their ePHI use, the data lead us to believe that rural cancer patients access their electronic records less frequently than urban cancer patients. Cancer patients in urban regions are also more likely to communicate with their health care providers via email than rural cancer patients. Although our results demonstrate a relationship present for both email communication and ePHI use, there are many other components that affect the role of internet access and use of these tools that we could not explore due to the limitations present. By increasing the awareness, access, and use of these tools in rural populations, there is the potential to improve the patients' ability to increase self-efficacy with regard to their health care and improve clinical outcomes. Future studies should focus on targeted interventions for rural cancer patients and examine whether the implementation of ePHI and electronic messaging tools affects patient outcomes.

Acknowledgments

HINTS is funded by the National Cancer Institute's Division of Cancer Control and Population Sciences with contract support to Westat, Inc.

Conflicts of Interest

None declared.

References

1. Meilleur A, Subramanian SV, Plascak JJ, Fisher JL, Paskett ED, Lamont EB. Rural residence and cancer outcomes in the United States: issues and challenges. *Cancer Epidemiol Biomarkers Prev* 2013 Oct;22(10):1657-1667 [FREE Full text] [doi: [10.1158/1055-9965.EPI-13-0404](https://doi.org/10.1158/1055-9965.EPI-13-0404)] [Medline: [24097195](https://pubmed.ncbi.nlm.nih.gov/24097195/)]
2. Baldwin L, Cai Y, Larson EH, Dobie SA, Wright GE, Goodman DC, et al. Access to cancer services for rural colorectal cancer patients. *J Rural Health* 2008;24(4):390-399 [FREE Full text] [doi: [10.1111/j.1748-0361.2008.00186.x](https://doi.org/10.1111/j.1748-0361.2008.00186.x)] [Medline: [19007394](https://pubmed.ncbi.nlm.nih.gov/19007394/)]
3. O'Gorman LD, Hogenbirk JC. Driving distance to telemedicine units in northern Ontario as a measure of potential access to healthcare. *Telemed J E Health* 2016 Apr;22(4):269-275. [doi: [10.1089/tmj.2015.0133](https://doi.org/10.1089/tmj.2015.0133)] [Medline: [26451902](https://pubmed.ncbi.nlm.nih.gov/26451902/)]
4. Weaver KE, Geiger AM, Lu L, Case LD. Rural-urban disparities in health status among US cancer survivors. *Cancer* 2013 Mar 01;119(5):1050-1057 [FREE Full text] [doi: [10.1002/cncr.27840](https://doi.org/10.1002/cncr.27840)] [Medline: [23096263](https://pubmed.ncbi.nlm.nih.gov/23096263/)]
5. Kruse CS, Bouffard S, Dougherty M, Parro JS. Telemedicine use in rural Native American communities in the era of the ACA: a systematic literature review. *J Med Syst* 2016 Jun;40(6):145 [FREE Full text] [doi: [10.1007/s10916-016-0503-8](https://doi.org/10.1007/s10916-016-0503-8)] [Medline: [27118011](https://pubmed.ncbi.nlm.nih.gov/27118011/)]
6. Marcin JP, Shaikh U, Steinhorn RH. Addressing health disparities in rural communities using telehealth. *Pediatr Res* 2016 Jan;79(1-2):169-176. [doi: [10.1038/pr.2015.192](https://doi.org/10.1038/pr.2015.192)] [Medline: [26466080](https://pubmed.ncbi.nlm.nih.gov/26466080/)]
7. Charlton M, Schlichting J, Chioreso C, Ward M, Vikas P. Challenges of rural cancer care in the United States. *Oncology (Williston Park)* 2015 Sep;29(9):633-640 [FREE Full text] [Medline: [26384798](https://pubmed.ncbi.nlm.nih.gov/26384798/)]
8. Greenberg-Worisek AJ, Kurani S, Finney Rutten LJ, Blake KD, Moser RP, Hesse BW. Tracking Healthy People 2020 internet, broadband, and mobile device access goals: an update using data from the Health Information National Trends Survey. *J Med Internet Res* 2019 Jun 24;21(6):e13300 [FREE Full text] [doi: [10.2196/13300](https://doi.org/10.2196/13300)] [Medline: [31237238](https://pubmed.ncbi.nlm.nih.gov/31237238/)]
9. Serrano KJ, Thai CL, Greenberg AJ, Blake KD, Moser RP, Hesse BW. Progress on broadband access to the internet and use of mobile devices in the United States. *Public Health Rep* 2017;132(1):27-31 [FREE Full text] [doi: [10.1177/0033354916679365](https://doi.org/10.1177/0033354916679365)] [Medline: [28005473](https://pubmed.ncbi.nlm.nih.gov/28005473/)]
10. Häyriinen K, Saranto K, Nykänen P. Definition, structure, content, use and impacts of electronic health records: a review of the research literature. *Int J Med Inform* 2008 May;77(5):291-304. [doi: [10.1016/j.ijmedinf.2007.09.001](https://doi.org/10.1016/j.ijmedinf.2007.09.001)] [Medline: [17951106](https://pubmed.ncbi.nlm.nih.gov/17951106/)]
11. Health Information National Trends Survey. National Cancer Institute, US Department of Health and Human Services. URL: <https://hints.cancer.gov/> [accessed 2020-07-05]
12. Greenberg-Worisek AJ, Kurani S, Finney Rutten LJ, Blake KD, Moser RP, Hesse BW. Assessing electronic personal health information use: an update on progress toward healthy people 2020 objectives. *Health Policy and Technology* 2019 Sep;8(3):211-220. [doi: [10.1016/j.hlpt.2019.05.010](https://doi.org/10.1016/j.hlpt.2019.05.010)]
13. Rural-Urban Continuum Codes: Documentation. Economic Research Service, US Department of Agriculture. URL: <https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/documentation.aspx> [accessed 2020-07-04]
14. Greenberg AJ, Haney D, Blake KD, Moser RP, Hesse BW. Differences in access to and use of electronic personal health information between rural and urban residents in the United States. *J Rural Health* 2018 Feb;34 Suppl 1:s30-s38. [doi: [10.1111/jrh.12228](https://doi.org/10.1111/jrh.12228)] [Medline: [28075508](https://pubmed.ncbi.nlm.nih.gov/28075508/)]
15. 2018 Broadband Deployment Report. Federal Communication Commission. URL: <https://docs.fcc.gov/public/attachments/FCC-18-10A1.pdf> [accessed 2020-07-02]
16. Greenberg AJ, Falisi AL, Finney RLJ, Chou WS, Patel V, Moser RP, et al. Access to electronic personal health records among patients with multiple chronic conditions: a secondary data analysis. *J Med Internet Res* 2017 Jun 02;19(6):e188 [FREE Full text] [doi: [10.2196/jmir.7417](https://doi.org/10.2196/jmir.7417)] [Medline: [28576755](https://pubmed.ncbi.nlm.nih.gov/28576755/)]

Abbreviations

- EHR:** electronic health record
ePHI: electronic personal health information
HINTS: Health Information National Trends Survey
OR: odds ratio
RDD: random digital dialing
RUCC: Rural-Urban Continuum Code

Edited by K Eddens, G Eysenbach; submitted 09.12.19; peer-reviewed by A Roundtree, L de Witte; comments to author 04.02.20; revised version received 11.02.20; accepted 03.06.20; published 10.08.20.

Please cite as:

*Greenberg-Worisek A, Ferede L, Balls-Berry J, Marigi I, Valentin Mendez E, Bajwa N, Ouk M, Orellana M, Enders F
Differences in Electronic Personal Health Information Tool Use Between Rural and Urban Cancer Patients in the United States:
Secondary Data Analysis*

JMIR Cancer 2020;6(2):e17352

URL: <http://cancer.jmir.org/2020/2/e17352/>

doi: [10.2196/17352](https://doi.org/10.2196/17352)

PMID: [32773369](https://pubmed.ncbi.nlm.nih.gov/32773369/)

©Alexandra Greenberg-Worisek, Liaa Ferede, Joyce Balls-Berry, Ian Marigi, Emily Valentin Mendez, Numra Bajwa, Melody Ouk, Minerva Orellana, Felicity Enders. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 10.08.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Web-Based Lifestyle Interventions for Prostate Cancer Survivors: Qualitative Study

Elizabeth Y Wang^{1,2}, MPH; Rebecca E Graff¹, ScD; June M Chan¹, ScD; Crystal S Langlais¹, MPH; Jeanette M Broering¹, PhD, MPH, RN; Justin W Ramsdill³, MS; Elizabeth R Kessler⁴, MD; Kerri M Winters-Stone³, PhD; Erin L Van Blarigan^{1*}, ScD; Stacey A Kenfield^{1*}, ScD

¹University of California, San Francisco, San Francisco, CA, United States

²Columbia University Vagelos College of Physicians and Surgeons, New York, NY, United States

³Oregon Health and Sciences University, Portland, OR, United States

⁴University of Colorado Cancer Center, Aurora, CO, United States

*these authors contributed equally

Corresponding Author:

Elizabeth Y Wang, MPH

University of California, San Francisco

550 16th St, 6th Floor

Box 1695

San Francisco, CA, 94158

United States

Phone: 1 5622616634

Email: eyw2107@cumc.columbia.edu

Abstract

Background: Exercise and a healthy diet can improve the quality of life and prognosis of prostate cancer survivors, but there have been limited studies on the feasibility of web-based lifestyle interventions in this population.

Objective: This study aims to develop a data-driven grounded theory of web-based engagement by prostate cancer survivors based on their experience in the Community of Wellness, a 12-week randomized clinical trial designed to support healthy diet and exercise habits.

Methods: TrueNTH's Community of Wellness was a four-arm pilot study of men with prostate cancer (N=202) who received progressive levels of behavioral support (level 1: website; level 2: website with individualized diet and exercise recommendations; level 3: website with individualized diet and exercise recommendations, Fitbit, and text messages; and level 4: website with individualized diet and exercise recommendations, Fitbit and text messages, and separate phone calls with an exercise trainer and a registered dietitian). The primary aim of the study is to determine the feasibility and estimate the effects on behaviors (results reported in a separate paper). Following the 12-week intervention, we invited participants to participate in 4 focus groups, one for each intervention level. In this report, we used grounded theory analyses including open, axial, and selective coding to generate codes and themes from the focus group transcripts. Categories were refined across levels using embodied categorization and constant comparative methods.

Results: In total, 20 men with prostate cancer participated in the focus groups: 5, 4, 5, and 6 men in levels 1, 2, 3, and 4, respectively. Participants converged on 5 common factors influencing engagement with the intervention: environment (home environment, competing priorities, and other lifestyle programs), motivation (accountability and discordance experienced within the health care system), preparedness (technology literacy, health literacy, trust, and readiness to change), program design (communication, materials, and customization), and program support (education, ally, and community). Each of these factors influenced the survivors' long-term impressions and habits. We proposed a grounded theory associating these constructs to describe the components contributing to the intuitiveness of a web-based lifestyle intervention.

Conclusions: These analyses suggest that web-based lifestyle interventions are more intuitive when we optimize participants' technology and health literacy; tailor interface design, content, and feedback; and leverage key motivators (ie, health care providers, family members, web-based coach) and environmental factors (ie, familiarity with other lifestyle programs). Together, these grounded theory-based efforts may improve engagement with web-based interventions designed to support prostate cancer survivorship.

KEYWORDS

cancer survivorship; digital health; technology-based intervention; internet-based intervention; usability

Introduction

Prostate cancer is the most common cancer among men in the United States, with more than 190,000 new diagnoses expected in 2020 [1]. The median age at diagnosis is 66 years, and 82% of men are aged 65 years or older [2]. Many men live for decades after their diagnosis and may benefit from adopting healthy dietary and exercise practices to combat prostate cancer symptoms and treatment-related side effects [3-8] in addition to improving their overall health.

Diet and exercise are associated with lower risk of prostate cancer progression [9], prostate cancer-specific mortality [10-13], and treatment-related side effects [14-18]. Specifically, cruciferous vegetables, vegetable fat, fish, and cooked tomatoes [19] have been associated with lower risk of prostate cancer progression and/or mortality, whereas whole milk and poultry with skin have been associated with increased risk of prostate cancer progression and/or mortality [19-27]. Physical activity has also been consistently associated with significant reductions in mortality [26], symptoms, and treatment-related side effects. The 2018 American College of Sports Medicine roundtable recommendations for cancer survivors include 30 min of moderate aerobic training 3 or more times a week for at least 8 to 12 weeks; resistance training alone or the addition of resistance exercise to an aerobic regimen may also improve symptoms [28]. The Exercise and Sports Science Australia recommends that the specifics of the multimodal exercise prescription and total weekly dosage be determined by the patient's needs or goals but similarly supports that cancer survivors should *avoid inactivity* [29]. Unfortunately, many prostate cancer survivors fail to meet physical activity or nutrition recommendations.

Web-based interventions have the potential as scalable modalities to deliver lifestyle interventions in prostate cancer survivors [30]. Previous studies have demonstrated the benefits of web-based interventions in supporting behavior change related to diet, exercise, and smoking cessation for noncancer populations [31-35]. However, there remains to be a lack of data on the specific types and quantities of intervention components needed to change behavior. Thus, we developed a trial [36] to assess the feasibility and acceptability of a web-based intervention for men with prostate cancer. The study focused on the diet and exercise factors mentioned earlier, with particular attention to whether progressive levels of support would lead to increasingly higher levels of behavioral change and improvements in other outcomes such as symptom reduction and quality of life. Our primary feasibility, acceptability, and behavior change results are presented elsewhere.

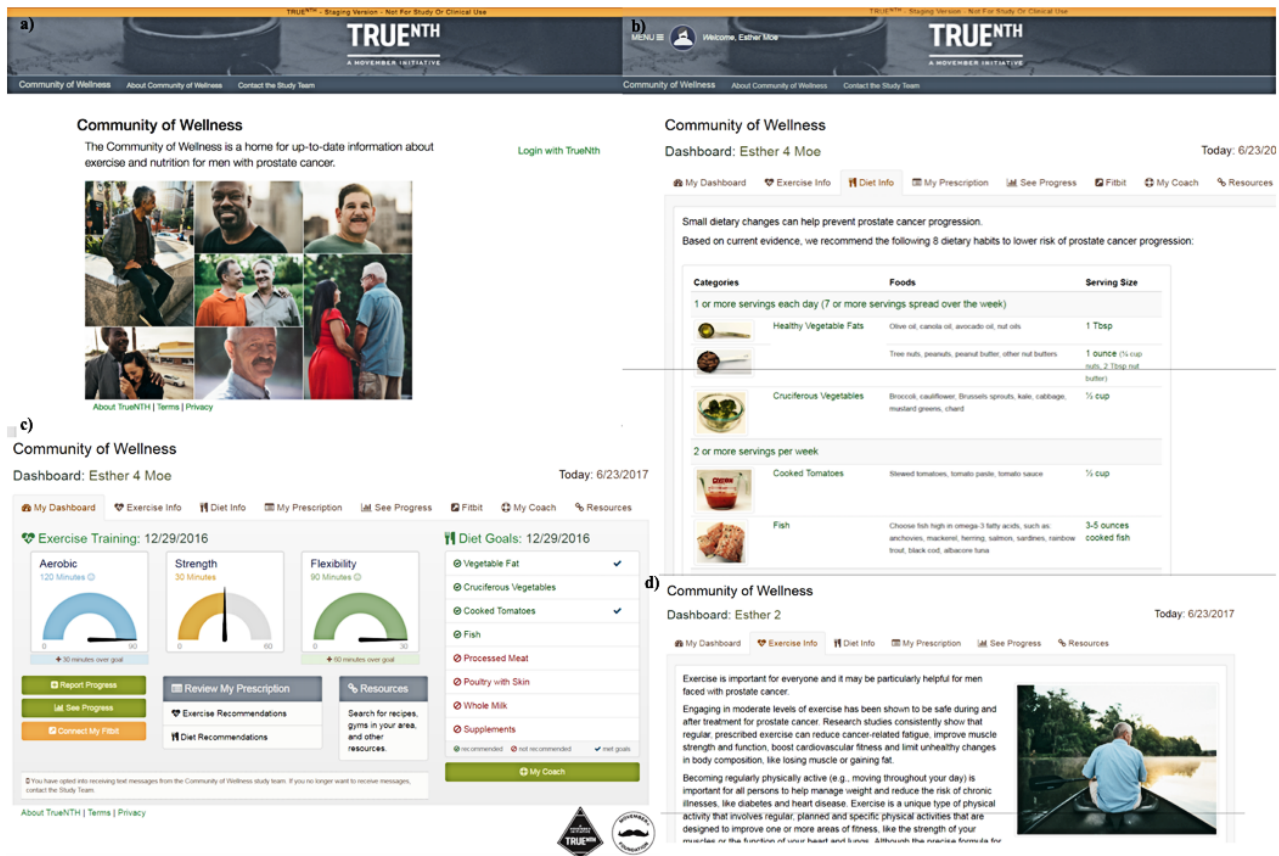
Given the success of recent web-based interventions, we were also interested in the insights underlying the behaviors of prostate cancer survivors navigating a web-based platform. The attitudes, motivations, and perspectives of cancer survivors engaging in a web-based lifestyle intervention are complex and require further study. A prior qualitative study exploring lifestyle change in prostate, colon, and breast cancer survivors after participation in web modules designed to promote physical activity and healthy eating examined barriers to behavior change (knowledge, motivation, and individual reactions to cancer diagnosis) using a thematic analysis approach [37]. However, qualitative evidence to specifically inform intervention design is lacking. To our knowledge, perceptions of web-based interventions for lifestyle change in prostate cancer survivors have not been investigated using a qualitative methodology; as such, a grounded theory qualitative investigation using data-driven analysis would be helpful to inform future web-based intervention design. In this report, we aim to explore the insights of prostate cancer survivors who engaged with a web-based lifestyle intervention and to provide grounded theory-based recommendations to guide future intervention design.

Methods

Design

We conducted a four-arm study called TrueNTH's Community of Wellness (NCT03406013) of men with prostate cancer (N=202) who were randomized to receive progressive levels of behavioral support. The details of the design of the pilot study have been previously published [36], and select screenshots from the website are presented in [Figure 1](#). Men in level 1 had access to prostate cancer-specific diet and exercise resources through a static, informational website. Men in level 2 had access to the website and received individualized diet and exercise recommendations based on a self-report survey completed at the start of the study. Men in level 3 had access to the website and received individualized diet and exercise recommendations and also received a Fitbit device and text messages. Men in level 4 had access to the website and received individualized diet and exercise recommendations, received a Fitbit device and text messages, and were offered a 30-min phone call with an exercise trainer and a 30-min phone call with a registered dietitian. Of note, the Community of Wellness is one of many TrueNTH programs funded by the Movember Foundation, and some men participated in multiple TrueNTH programs concurrently. Reporting in this study is consistent with the consolidated criteria for reporting qualitative research [38].

Figure 1. Screenshots from the Community of Wellness website (different view by level): (a) welcome page (levels 1-4), (b) diet information (levels 1-4), (c) dashboard (level 4), and (d) exercise information (levels 1-4).

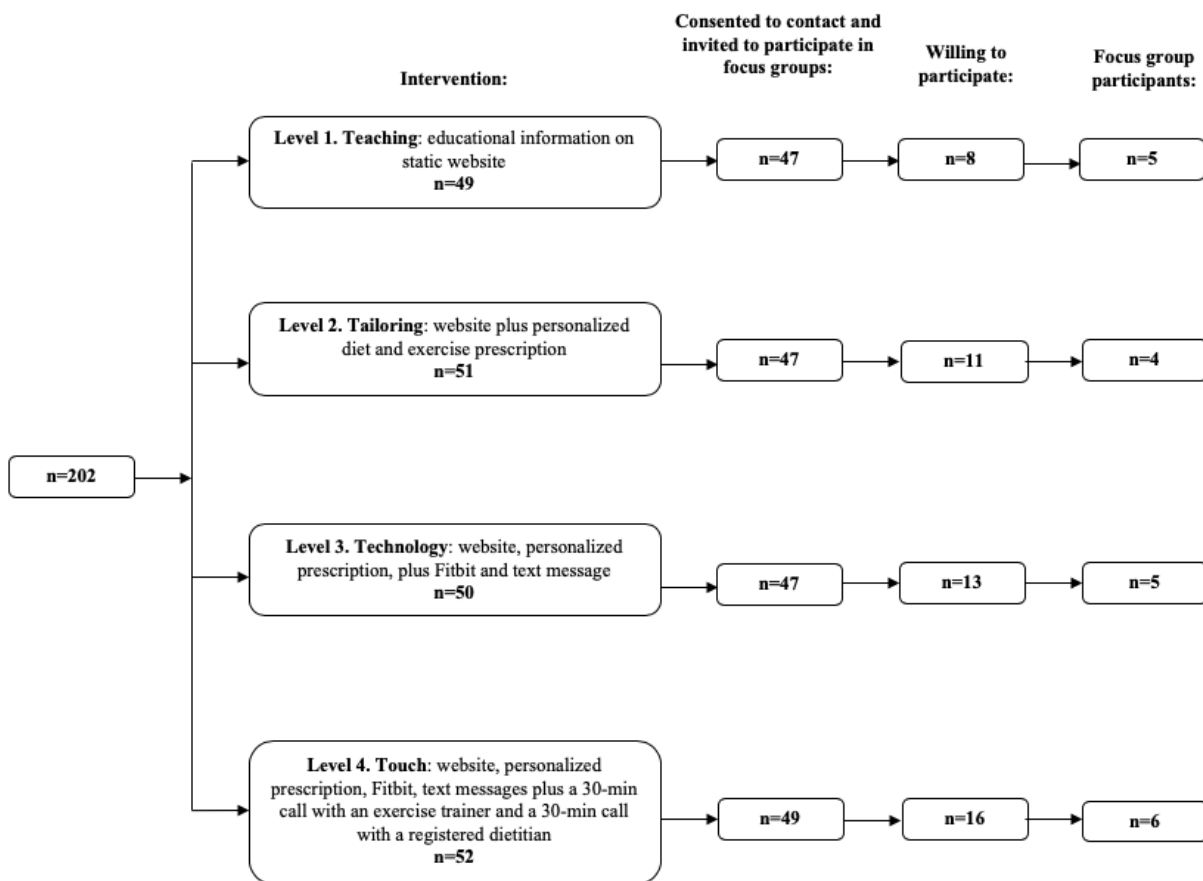


Focus Groups

Men who completed the pilot study and consented to being contacted were invited via email to participate in a focus group. Briefly, for the primary pilot trial, men were recruited through hospital cancer registry databases at the University of California San Francisco, the Oregon Health and Sciences University, and the University of Colorado Denver; at the Cancer of the Prostate Strategic Urologic Research Endeavor registry of men with prostate cancer; and in clinics at the abovementioned institutions.

Each participant consented to participate in both the pilot study and focus group. In total, 48 men were willing to participate in a focus group; of these, 20 men could attend at the scheduled times (Figure 2). We conducted 4 focus groups, one for each intervention level. As participants in the trial could reside throughout the United States, focus groups were conducted via Zoom, a secure, interactive audioconference platform. In the interest of confidentiality, we disabled video calling; however, we used screen sharing so that participants could comment on various aspects of the website.

Figure 2. Community of Wellness study recruitment to intervention and focus groups.



The focus groups were led by a female researcher (RG). She is an assistant professor in epidemiology with 10 years of experience researching urologic cancers, who previously worked in market research and web usability where she gained experience in qualitative research methods. RG first interacted with the participants when scheduling and conducting the focus group. Interviews were semistructured using interview guides (available in [Multimedia Appendix 1](#)) tailored to each group's intervention level (eg, individuals randomized to level 1 were

asked about the website only, etc). Participants were prompted to answer hypothetically if they did not use or recall certain aspects of the program during the study period. Focus groups were recorded and transcribed. Quotations were edited for clarity, and field notes were made after focus groups. Focus groups took place between May and June 2019; the median time from the end of the study to the focus group was 7 months ([Table 1](#)). Men received a US \$25 gift card for participating in the focus group.

Table 1. Self-reported characteristics of 20 men with prostate cancer who participated in a 12-week remotely delivered lifestyle intervention and volunteered for a postintervention focus group.

Characteristics	Level 1 (n=5)	Level 2 (n=4)	Level 3 (n=5)	Level 4 (n=6)	All levels (N=20)
Age at study enrollment (years), median (IQR)	71 (71-74)	73 (69-76)	68 (68-75)	63 (56-70)	70 (66-74)
Ethnicity, n (%)					
White	5 (100)	3 (75)	5 (100)	6 (100)	19 (95)
Other	0 (0)	1 (25)	0 (0)	0 (0)	1 (5)
Months from intervention end date to focus groups, median (IQR)	7 (7-8)	10 (7-14)	7 (6-12)	6 (6-12)	7 (6-12)
Years from diagnosis to intervention start date ^a , median (IQR)	6 (3-8)	4 (1-24)	7 (3-8)	3 (1-4)	4 (1-8)
BMI (at diagnosis), median (IQR)	28 (22-30)	28 (26-29)	23.1 (22-27)	26 (24-32)	27 (23-29)
Stage at diagnosis, n (%)					
T1	1 (20)	1 (25)	1 (20)	1 (17)	4 (20)
T2	3 (60)	1 (25)	4 (80)	2 (33)	10 (50)
T3 or T4	1 (20)	2 (50)	0 (0)	2 (33)	5 (25)
Unknown	0 (0)	0 (0)	0 (0)	1 (17)	1 (5)
Gleason score at diagnosis, n (%)					
<7	1 (20)	1 (25)	1 (20)	2 (33)	5 (25)
7	2 (40)	1 (25)	2 (40)	2 (33)	7 (35)
>7	1 (20)	2 (50)	2 (40)	2 (33)	7 (35)
Unknown	1 (20)	0 (0)	0 (0)	0 (0)	1 (5)
Prostate-specific antigen level (ng/mL), median (IQR)					
At diagnosis	4.5 (4.0-10.0)	5.0 (3.7-9.0)	4.9 (4.0-6.1)	11.6 (6.0-14.0)	6.0 (4.0-11.6)
Most recent	0.4 (0.1-1.0)	0.0 (0.0-0.2)	0.1 (0.1-1.0)	0.1 (0.0-0.2)	0.1 (0.0-0.7)
Treatment type, n (%)					
Radical prostatectomy	2 (40)	3 (75)	2 (40)	3 (50)	10 (50)
Radiation	2 (40)	3 (75)	2 (40)	4 (67)	11 (55)
Medical management					
Androgen deprivation therapy	1 (25)	1 (25)	0 (0)	2 (34)	3 (15)
Abiraterone acetate	0 (0)	0 (0)	0 (0)	1 (17)	N/A ^b
Enzalutamide	1 (25)	0 (0)	0 (0)	0 (0)	N/A
Leuprolide acetate	0 (0)	1 (25)	0 (0)	1 (17)	N/A
Immunotherapy (Sipuleucel-T)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Chemotherapy	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Active surveillance	0 (0)	0 (0)	1 (20)	0 (0)	0 (0)
Other (ie, Radium 223)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Comorbidities					
Total number, median (IQR)	4 (3-7)	4 (2-6)	3 (3-3)	2.5 (1-4)	3 (2-5)
Any, n (%)					
Heart related ^c	4 (80)	1 (25)	4 (80)	3 (50)	12 (60)
Lung related ^d	0 (0)	0 (0)	0 (0)	2 (33)	2 (10)
Other ^e	4 (80)	3 (75)	4 (80)	4 (67)	15 (75)

^aYear of diagnosis only reported for 4 men in level 1, 3 men in level 2, 3 men in level 3, and 5 men in level 4.^bN/A: not applicable.

^cHeart-related comorbidities include hypertension, angina, congestive heart failure, heart attack, irregularity, stroke, peripheral vascular disease, and deep vein thrombosis.

^dLung-related comorbidities include chronic obstructive lung disease, acute respiratory distress syndrome, emphysema, and asthma.

^eOther comorbidities include diabetes, neuropathy, hernia, hearing impairment, arthritis, osteoporosis, and back issues.

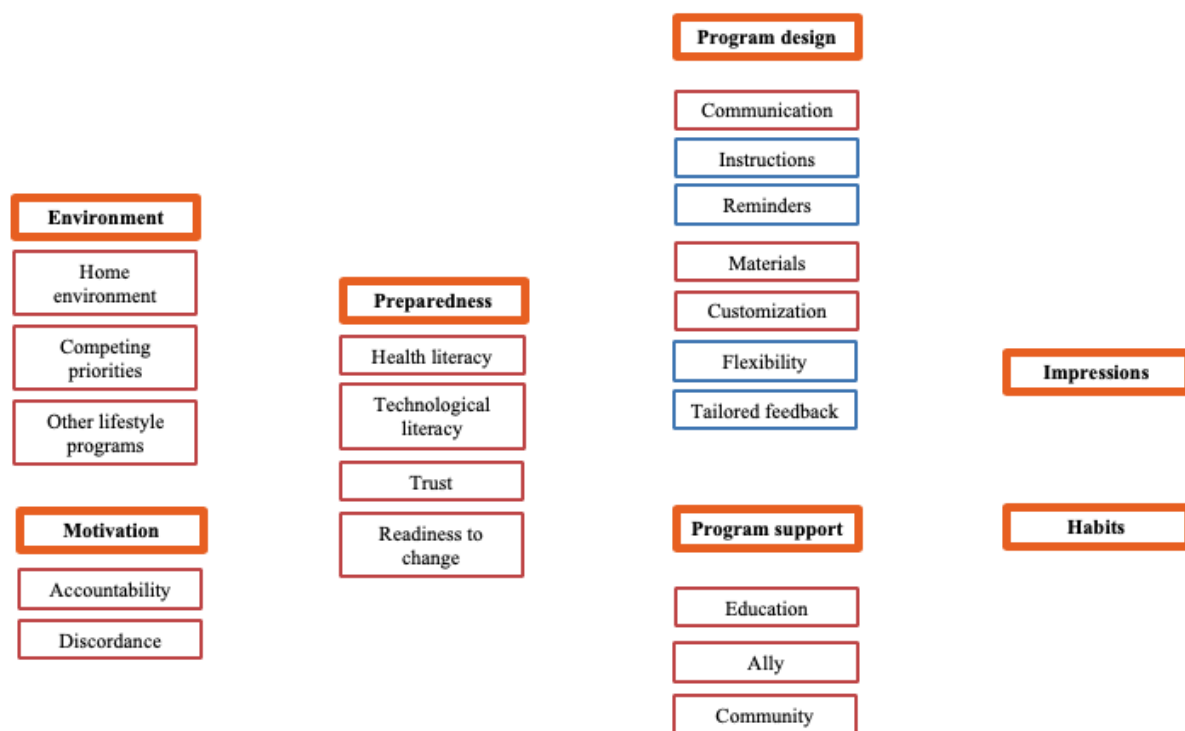
Grounded Theory Analyses

We used a grounded theory approach [39,40]. Coding was completed manually by one investigator (EW) and reviewed with 4 other investigators (SK, JB, RG, and EV); axial codes were managed in Microsoft Excel.

We conducted open, axial, and selective coding (Figure 3). Open, line-by-line coding generated data-driven codes that were

refined into 15 axial codes. Ultimately, through embodied categorization [41] and constant comparative methods (to address the multiple levels) [42], we consolidated the data under 7 selective codes (categories). From these categories, a grounded theory surrounding prostate cancer survivors' use of web-based lifestyle interventions emerged. The codes and their relationships to one another were intermittently discussed and finalized among EW, RG, JB, EV, and SK.

Figure 3. Codes developed using grounded theory analysis: open codes (blue), open codes elevated to axial codes (red), codes elevated to selective codes or categories (orange).



Results

In total, 10% (20/200) men (of pilot study participants) with prostate cancer participated in the focus groups; 5, 4, 5, and 6 men in levels 1, 2, 3, and 4, respectively. The characteristics of the focus group participants are presented in Table 1. The participants were predominantly White and aged >70 years. The median time from diagnosis to intervention start date was 4 years, and the median time from pilot study intervention end to focus groups was 7.3 months. The median BMI of the focus group participants was 26.6 kg/m² (IQR 22.7-29.3). Various prostate cancer grades, stages, and treatments were represented among the participants. The majority of participants reported multiple comorbidities; only 10% (2/20) men reported no comorbidities.

We identified 5 categories influencing intervention engagement: (1) environment (home environment, competing priorities, and other lifestyle programs), (2) motivation (accountability and discordance), (3) preparedness (technology literacy, health literacy, trust, and readiness to change), (4) program design (communication, materials, and customization), and (5) program support (education, ally, and community; Figure 3). We also identified the long-term effects of the interventions (impressions and habits). Each code represents an actionable component contributing to the overall intuitiveness and seamlessness of this web intervention, as demonstrated by participant quotes below.

Environment

Participants discussed the environmental factors influencing their participation and impressions of the program.

Home Environment

Participants' family members and geographic locations played roles in their perceptions and usage of the web-based program:

I've been thinking about this a little bit and the food groups and what's best and what's less good for us is helpful and it's interesting to me, however, real issues are almost barriers to changing diet. Those can be from things that we don't have much control over at all like when we're travelling, restaurants typically don't have the best food, I will say. And sometimes at home, especially for us guys, I think there's an element of gender issue here but in my situation I'm the eater and my wife is the cooker. She needs to be part of this somehow. [Participant 2, level 1, aged 74 years, 4 years since diagnosis]

I looked at [the website] several times and gave me some ideas and stuff. I had joined a fitness club at one time, so it kind of brought back up some of those exercises to my program here. So, we're not close to a gym here. Where I live it's a small community. So, we just do our walking and biking on our own. [Participant 2, level 2, aged 66 years, 1 year since diagnosis]

Competing Priorities

Participants had multiple other commitments often related to their health care. These limited the amount of time and engagement with the web-based program:

For whatever reason, I don't know, I didn't engage with the program. I live a fairly busy life. I'm the president of our local running club and involved in sailing and so many active things that I rarely, other than seeing my medical providers, of which there are so many at this point, I just didn't engage and I don't know why, I didn't. [Participant 2, level 1, aged 74 years, 4 years since diagnosis]

I have to admit that I'm a little confused about how this study, the exercise and diet study relates to the surveys that I receive periodically from your group. But part of my confusion rests with the fact that I'm probably involved in three or four different studies. [Participant 3, level 2, aged 79 years, 24 years since diagnosis]

When people are going...through radiation, going through post radiation, you know, with being tired, whatever, you tend to just kind of space on things. Particularly if you're being jacked up with hormone therapy too. You get kind of fuzzy and you don't sit there and pay as much attention as you might. [Participant 3, level 4, aged 70 years, 3 years since diagnosis]

Other Lifestyle Programs

Participants frequently reflected on components of the web-based program with reference to previous experiences with weight loss programs and other wearable technology. This influenced the attitudes they carried into the program:

...there's several programs you can get on your phone and computer who do the same thing and I've actually tried one or two of them in the past and kept up with it for maybe two days and that's it. [Participant 5, level 1, aged 80 years, 8 years since diagnosis]

I've consulted a nutritionist in the past and probably could use that. [Participant 2, level 1, aged 74 years, 4 years since diagnosis]

I think a cooperative with some of those food services might be something to look at. Obviously, not everybody can do that. But that was a thought. [Participant 2, level 4, aged 53 years, 1 year since diagnosis]

Motivation

Participants discussed factors influencing their motivation to participate in the program.

Accountability

Participants described or alluded to a sense of accountability:

We lie to ourselves about how we're doing. But heart rate and other indicators are hard to fool so I've actually discovered that I have some other issues through my [own heart rate] monitor and that's been good. [Participant 2, level 1, aged 74 years, 4 years since diagnosis]

Probably a shortcoming on my part. I didn't explore the website nearly as much as I probably should have. [Participant 3, level 3, aged 65 years, years since diagnosis not reported]

I can't remember. But, again, I was also sometimes forgetting. And so there were gaps in the data, and I felt really bad about that. You know? Because I hadn't realized that I should have connected the day before or something. [Participant 2, level 4, aged 53 years, 1 year since diagnosis]

Discordance

Participants shared their discordant experiences within the health care system—the web-based intervention occurred amid the background of the confusion that these previous experiences had created:

...urologists...I mentioned sugar to him. He said, no, sugar's not going to make any difference...he says the only thing that has proven to be of any help is cooked tomatoes. And I mentioned this to a couple of nurses, three different nurses and essentially one nurse...said, doctors don't know anything about diet... It'd be nice if urologists would somehow send people to someplace like your website. [Participant 1, level 2, aged 73 years, years since diagnosis not reported]

You folks are in universities whereas we're mixing what we get from our doctors as providers with what you folks are doing to study...maybe you could feel free to comment on what the purpose of all this is...Are the people on your staff the ones who would

stay with this program for years? [Participant 1, level 3, aged 75 years, 7 years since diagnosis]

Preparedness

In addition to environment and motivation, participants' unique skill sets and backgrounds influenced their ability to engage with the program.

Health Literacy

Participants demonstrated varying levels of health literacy (ability to communicate an understanding about prostate cancer and/or the purpose of the study), which affected their interest and engagement with the program:

When it became evident that prostate cells had escaped prior to surgery and were floating around in my bloodstream somewhere. I guess I never felt that sitting around in a group thing was going to do anything to change that. It was a medical science issue, not a communication issue. [Participant 3, level 2, aged 79 years, 24 years since diagnosis]

My primary interest was the diet...I was intrigued to learn so many different ways that diet impacts survivability when you're diagnosed with cancer. So I really just felt it was important, and that's when I kind of delved in. [Participant 6, level 4, aged 56 years old, 1 year since diagnosis]

Tech Literacy

Using a web-based intervention requires some baseline comfort using technology—the participants greatly varied in their preferences, which affected their engagement with the program:

You know I think probably a very natural tendency for all of us, regardless of whether it's prostate cancer or some other life-threatening disease, we tend to hit the internet, if you will, and look for information. I certainly did that in the beginning. [Participant 1, level 1, aged 65 years, years since diagnosis unknown]

Well much to my kids and grandkids consternation, I don't read text messages. [Participant 4, level 3, aged 84 years old, 8 years since diagnosis]

Trust

Participants discussed how their trust has been eroded by past experiences with health care:

One of the frustrations that I have of moving around a bit in the country and having to reestablish relationships is always a challenge because quite frankly, the quality of many of the people I've had to work with, physicians and all this, sometimes is not very high. And you feel valuable when you've found a resource that you can trust, and then to have those people go away is a problem. [Participant 1, level 3, aged 75 years, 7 years since diagnosis]

Readiness for Change

Participants commented on their readiness for behavioral change and experiences shaping this factor:

I guess I'm addicted. I'm always working towards some goal. [Participant 2, level 1, aged 74 years, 4 years since diagnosis]

...I didn't change much but just this awareness that things need to change. Your diet, and you move around a whole lot more. [Participant 4, level 1, aged 71 years, 1 year since diagnosis]

...like most exercise programs, extremely difficult to get the discipline built. And I do recognize that I probably should be doing them, particularly the balance exercises and strength exercises. My diet's probably not going to change much. I'm reminded of a friend's father at 95 coming home from the hospital for a heart attack, stopped at a restaurant, and ordered french fries and onion rings. And his son said, dad, you shouldn't eat like that. He says at 95, he says, what's it going to do? Kill me? So the tendency with diet I think is to say, yeah I know I shouldn't...I had to cut back on some of this stuff, but it doesn't appear to be hurting my health. And maybe that's a message that somehow you need to deliver more strongly. [Participant 3, level 2, aged 79 years, 24 years since diagnosis]

I wouldn't need [informational text messages] like that because, like I said, I'm doing something on my own already and I'm pretty satisfied with it. But that's just my feeling about it. [Participant 3, level 3, aged 65 years, years since diagnosis not reported]

Program Design

Participants reflected on the various components of the program and suggested improvements.

Communication

Comments about how participants hoped communications would be used and how they might be improved:

As I'm looking at this, I'm a little embarrassed to say I didn't find this on the website. Maybe one of the messages would have been really helpful to remind me to look here. [Participant 2, level 3, aged 68 years, 3 years since diagnosis]

I think it would have been nice to have some kind of a general email once in a while every few weeks or more often, just about this whole thing. You know, kind of reminding us what's available to us and maybe asking for feedback even then, as human to human. [Participant 1, level 3, aged 75 years, 7 years since diagnosis]

So I guess the question I have is when you say "coach," I'm not clear. Because is the coach acting as the expert, in terms of information? Or are they acting in terms of holding us accountable and giving us that position. So I'm not really...I guess that's the question, are they there to be the expert role or are they there to be the coach? [Participant 6, level 4, aged 56 years, 1 year since diagnosis]

When receiving the text messages, they came from different numbers...if I was to keep them, I had to kind of keep this whole catalog of texts from different phone numbers. So, if it's possible to standardize the messaging from one sourced number, it would be easier to just have a ready reference for all the information that was provided...I think they're worthy of keeping. [Participant 6, level 4, aged 56 years, 1 year since diagnosis]

Materials

Participants discussed the program materials (recipes, in print vs on the web, and wearable technology):

...again, if I think about different diet programs, they give you the ability to find creative substitutes and creative, not just recipes but be able to say I'm looking for some creative alternatives for when I'm lunch on the go or something like that. [Participant 1, level 1, aged 65 years, years since diagnosis unknown]

I've mastered the ability to print almost anything displayed on a website. So, I don't need to have a mailing. If it's available on the website and I wanted it in print, I can make that happen. [Participant 3, level 2, aged 79 years, 24 years since diagnosis]

I found [the Fitbit] very unhelpful. Number one, I don't know how to read it, and it was hard to put on with one hand. [Participant 4, level 3, aged 84 years, 8 years since diagnosis]

Yeah I think the Fitbit is a little behind. I think as I'd mentioned, the Oura is probably a better route to take. It's just on your fingers. You don't have to worry about it...And to the activities that it doesn't auto-recognize or automatically sync on, you do have to go in there, as you would with any other wearable tech, you do have to go in and kind of manipulate that and add that to it. [Participant 6, level 4, aged 56 years, 1 year since diagnosis]

Customization (Flexibility)

Participants of all levels commented on their desire for increased customization and flexibility—many participants mentioned that their engagement in various aspects of the program would have changed if messaging delivery or content was customized:

If we were talking about things that were targeted based on my activity on the site or my filters or my preferences I might say more often but if it's just more general type information, weekly [text message reminders] would probably be good. [Participant 1, level 1, aged 65 years, years since diagnosis unknown]

...as I recall, the prescription was developed based on a questionnaire that I had submitted to you prior to the beginning or at the beginning of the study. So it at least purported to be specific recommendations to the lifestyle and concerns that I as an individual had in that sense. If that's correct, then it might be helpful to have the opportunity to periodically develop

a new prescription to answer the same questionnaire submitted...it would be helpful maybe every six months or so to give participants the opportunity to complete the questionnaire again with updated information and develop a new prescription. [Participant 3, level 2, aged 79 years, 24 years since diagnosis]

I've had a couple bouts with heart failure, so right now I'm on a salt-free diet and it would be helpful to me to be a little more specific as to what I can eat and what I can't eat regarding that particular restriction. [Participant 4, level 3, aged 84 years, 8 years since diagnosis]

But I think that his idea of having more flexibility is a good one. Being able to tailor it to your particular lifestyle would be beneficial as well. [Participant 3, level 3, aged 65 years, years since diagnosis not reported]

Yeah, and I think [the text messages] were pretty good, even as generic as they were, just to be a reminder and motivator. [Participant 2, level 4, 53 years old, 1 year since diagnosis]

Customization (Tailored Feedback)

The participants commented on the benefits of tailored immediate feedback for meeting their lifestyle goals:

I like [the surveys] because the feedback was immediate and I could put it in and just right away I knew where I was, where I stood as far as doing good or not doing good and I liked that process. [Participant 2, level 2, aged 66 years, 1 year since diagnosis]

I thought it was useful. Like I said, it's kind of a dialogue. It tells you whether you're doing what you should be doing or not, to get the feedback, immediate feedback. [Participant 5, level 4, aged 78 years, 16 years since diagnosis]

I think if [the website] worked in tandem with the coaching process, maybe there would be more visibility on. And so, in terms of that being helpful, yes, I think either you go in, you look, you work with your coach, you see there's a dip...if you convert that sole tool from an extrinsic motivator to more of an intrinsic motivator when you're working with somebody to help you see the benefit of moving through your exercise regime and getting stronger. Right? And so, I think it would work well if you paired it with the coaching process. [Participant 6, level 4, aged 56 years, 1 year since diagnosis]

Program Support

Participants communicated their expectations of various types of support from the web-based program.

Education

Participants from all levels provided suggestions on how to improve the educational component of the intervention:

What I did like about this particular site and participation in this was I felt like I was getting consistent information across diet, diagnosis, symptoms, side effects, and so forth. [Participant 1, level 1, aged 65 years, years since diagnosis unknown]

I guess you could put more links in to connect us to information. I mean there's stuff I have to go searching for on the internet anyway, but you put that information in the stuff that you send to us it might save us a little time...Anything about the disease and its cure. I mean the amount of information available on the internet about prostate, it's almost like drinking out of a fire hydrant. If there's anything special that...you want to make people aware of, that would be good. [Participant 5, level 1, aged 80 years, 8 years since diagnosis]

Anyway, I'd like to see if there was someplace, if I had question, the food and the exercise, if somewhere I could easily go to another website or get these studies that prove [inaudible] is good to prevent cancer. You're just telling us...I'm following it. You're just telling us don't do this, do this, this, this. Without any resources to back it. I'm not seeing the...studies or how extensive [a] study was. [Participant 1, level 2, aged 73 years, years since diagnosis not reported]

Being a non-cooking person which I'm trying to change...I wasn't sure what a cruciferous vegetable was when we started, so just having a list of cruciferous vegetables...So I was just looking for additional resources. In some cases, some ideas in terms of cooking or putting food together, some of those I shared with my wife, some of them were just looked at. You know, when you say, "Eat more fish." It's not really about eating more fish, it was about eating more salmon and related fish in terms of oils. So that type of stuff helped. [Participant 2, level 3, aged 68 years, 3 years since diagnosis]

So, the internet is full of information. Some of it really helpful, some of it really pretty horrid. As part of the resource would be some direction in terms of, "Here's some places you can go to get some really good information about this that might be outside OHSU [Oregon Health and Sciences University]..." [Participant 2, level 3, aged 68 years, 3 years since diagnosis]

Well as I'm looking at it now, it seems to mostly like recipes and things like that. I would be much more interested in technical information about cancer or exercise or something of that sort. [Participant 5, level 4, aged 78 years, 16 years since diagnosis]

I was actually drawn to the diet piece. There was actually some very helpful and not helpful bits of information, like the gentleman that raised the topic of tomatoes. I went down that path and incorporated tomatoes, cooked tomatoes, some ripened tomatoes, all the different types of salsa. Things that really made the meal at some points. And so I thought that was

really helpful. [Participant 6, level 4, aged 56 years, 1 year since diagnosis]

Ally

Participants wanted someone who genuinely cared about their progress available to answer questions and provide support:

Just a couple thoughts on coaches. I think it's definitely helpful to have more of a personal interaction. You know, with the coach giving reminders, as opposed to having an email message kind of a reminder coming from a program. You know, if you have that more personal...Someone that's interested in what you're accomplishing, I think that's a better motivator. [Participant 1, level 4, aged 56 years, years since diagnosis not reported]

The promise of a coach is somebody who can celebrate with you when you've reached your goals...and can also listen to you when you're struggling and be empathetic. [Participant 2, level 4, aged 53 years, 1 year since diagnosis]

Ideally, the coach should provide both functions. He should have deep expertise and be a motivator, just like a football coach. [Participant 5, level 4, aged 78 years, 16 years since diagnosis]

Community

An overwhelming majority of participants appreciated having others with similar experiences to relate with:

...when I was first diagnosed with prostate cancer, I went to a local support group of meetings and it was really terrific. The ability to interchange information, there's no substitute for it as far as I'm concerned and if there was a way you could enable that I'd be all for it. [Participant 5, level 1, aged 80 years, 8 years since diagnosis]

I think [Community of Wellness] is perfect because there's so many different...some people are doing active surveillance, some people are doing radiation, some people are just...there's so many different things but does anybody have the real answer of what worked for them or what is working for you, that's hard to do. [Participant 4, level 1, aged 71 years, 1 year since diagnosis]

[Community of Wellness] is just a way to interact with people who are going through the same thing, and sometimes get support and sometimes receive it through that kind of community. [Participant 1, level 3, aged 75 years, 7 years since diagnosis]

One of the things I really liked about [Community of Wellness] was that I felt like I was part of a community. Not only was it in the name, but it was nice to feel like there was some help more than just going to the doctor. So that was very valuable to me. Obviously, there were a lot of benefits that I got from it. You know, maybe they'll come out during the discussion. I just thought it was really good being a part of something that at least acknowledged, "Hey,

we're alive. We have cancer, but somehow, we're getting through it," and that sort of thing was emotionally quite beneficial. [Participant 1, level 3, aged 75 years, 7 years since diagnosis]

Impressions and Habits

Ideally, lifestyle interventions help participants develop lifelong habits. In this quotation, one participant offers his thoughts on the long-term impacts of this intervention. This quotation and others reflect the participants' impressions of the program; these impressions add to their collective experiences with technology and health:

six months later...I have really changed. [The program] kind of kicked it off. But if I look back from where I am right now, and what I'm eating now, and how I'm eating, it's dramatically different than how I was before I entered the program, and even when I finished the program because I continued on that trajectory, and been able to really, to do that. So, I think as far as coaching goes, everybody's different. And I'm not sure that the program's long enough to be able to really drive the kind of...You know, to be able to see the sustained change, or even get to the sustained change, maybe. [Participant 2, level 4, aged 53 years, 1 year since diagnosis]

Intuitive Interventions

Each code generated in this study represents a unique mechanism for designing a more intuitive, web-based lifestyle intervention for prostate cancer survivors. By addressing the environment, we may transform factors that already exist in participants' lives as obstacles to reinforcing factors for improved engagement with the web-based program. By addressing participants' motivation, we may improve our ability to tailor web content and web-based communications. Understanding participants' preconceived attitudes based on past encounters with the health care system will allow us to actively address concerns and improve program adherence. We may influence preparedness when we assess and consider each

participant's unique level of health and technological literacy, readiness to change, and trust and bolster these whenever possible through program content. Program design and program support are the most easily affected; we can increase intuitiveness through tailored communication, materials, and feedback, providing quality educational content, serving as allies, and generating community.

Noting the ways in which certain codes presented in the different intervention levels helped contextualize feedback. For example, participants in level 1, who received only web access to educational content, requested more communication, whereas participants in levels 2 to 4, who received increasing levels of behavioral support, provided details on ways in which the multiple forms of communication they received might be tailored. Participants in levels 3 and 4 received more types of behavior support and were also more likely to request more instructions or reminders orienting them to the program, as their interventions had more components. Conversely, some codes were commonly expressed across groups, such as competing priorities, readiness for change, flexibility, education, and community.

The relationships among these codes (Figure 4 [41]) represent iterative, actionable pathways by which designers may increase program intuitiveness for prostate cancer survivors engaging in web-based interventions often via multiple mechanisms at once. For example, we might influence motivation (accountability and discordance) by improving program design in the following ways: (1) using Health on the Net [43] transparency and quality principles (quality, confidentiality, neutrality, transparency, community, and visibility) for certification, (2) communicating with clinical providers about participants' involvement in the program, (3) remaining sensitive to participants' guilt with failures to modify behaviors, and (4) leveraging participants' familiarity with existing lifestyle programs to optimize engagement. These and other grounded theory-based solutions (Table 2) may result in a more accessible and integrated intervention for prostate cancer survivors.

Figure 4. Grounded theory-based approaches to increasing prostate cancer survivors’ engagement with web-based Community of Wellness lifestyle intervention: relationships among barriers and motivators related to engagement with web-based behavioral support, with potential solutions (green, ie, Health on the Net).

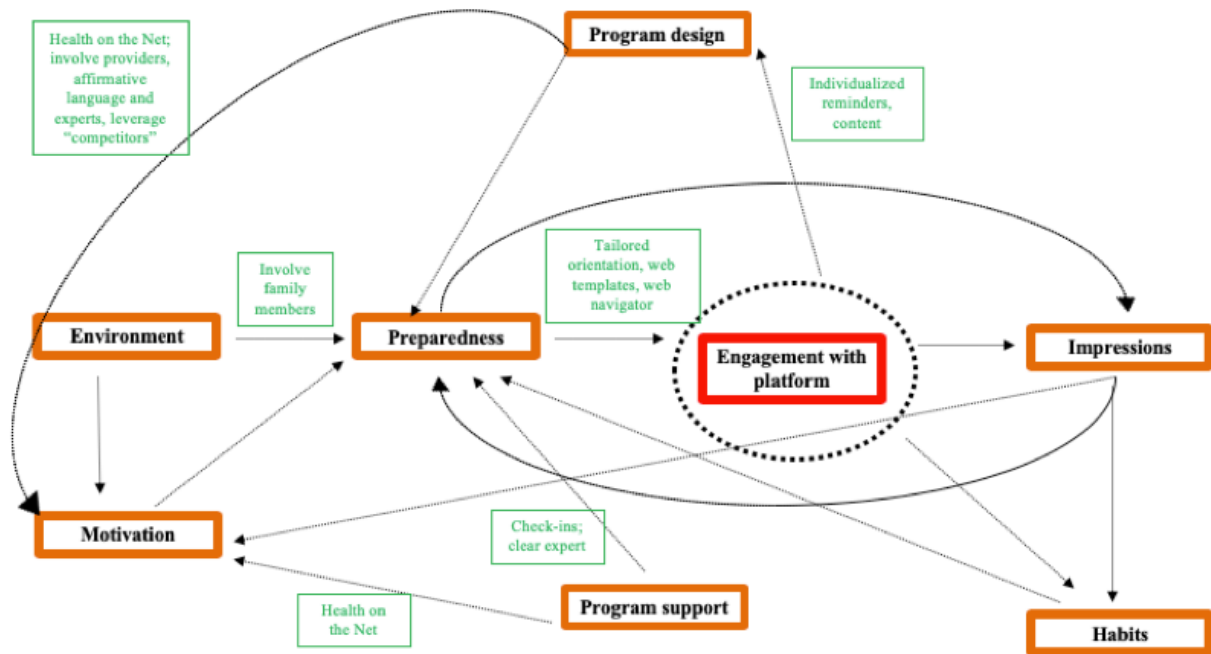


Table 2. Participant-inspired recommendations to improve intuitiveness and engagement with remotely delivered behavioral interventions for men with prostate cancer.

INSERT	Issue	Solution	Recommendations for improvements
Environment	<ul style="list-style-type: none"> Home environment Competing priorities Other lifestyle programs 	<ul style="list-style-type: none"> Anticipate and leverage potential sources of friction preventing participation Involve providers Involve family members 	<ul style="list-style-type: none"> Send letters framed toward stakeholders’ unique role in the patient’s program involvement Leverage existing programs (eg, partner with meal delivery services and/or gyms with discounts for patients with cancer)
Motivation	<ul style="list-style-type: none"> Accountability Discordance 	<ul style="list-style-type: none"> Provide longitudinal support Minimize stigma 	<ul style="list-style-type: none"> Provide quality feedback or monitoring Continue to use judgment-free language
Preparedness	<ul style="list-style-type: none"> Health literacy Technological literacy Trust Readiness for change 	<ul style="list-style-type: none"> Assess patient comfort level with technology Assess health literacy Assess readiness to change 	<ul style="list-style-type: none"> Use tailored web templates based on technological and health literacy Incorporate customizable web interfaces Customize orientation to program Incorporate website navigator Use motivational interviewing techniques to assess baseline readiness and subsequent progression
Program design	<ul style="list-style-type: none"> Communication (instructions and reminders) Materials Customization (flexibility and tailored feedback) 	<ul style="list-style-type: none"> Maximize relevant information Minimize extra information 	<ul style="list-style-type: none"> Construct and use individual profiles per baseline, performance, and other time commitments Add individualized reminder content and frequency Create various versions of the site to match health and technological literacy of the user
Program support	<ul style="list-style-type: none"> Education Ally Community 	<ul style="list-style-type: none"> Improve transparency Increase ally availability 	<ul style="list-style-type: none"> Add Health on the Net certification Emphasize “coach’s” role as expert and support person Allow for updates to profile Add ability to filter resources

Discussion

Implications

Men with prostate cancer find themselves in an era of seemingly limitless access to medical information via the web. Technological advances impact their daily lives, and as technology and health care delivery are increasingly intertwined, their ability to maintain health may inevitably be influenced by their willingness to engage with technological interfaces [44,45]. We learned that prostate cancer survivors within this study were sensitive to discrepancies related to clinical evidence and practice. They developed heuristics for navigating copious information, they described an interest in transparent sources, and they voiced a desire for continuity and ongoing care. They discussed the emotional impact of their participation within the health care system; these cumulative experiences (including newer experiences with technology-based care) underlie all experiences with health-promoting interventions.

Qualitative Methodology

We used the grounded theory methodology because no comprehensive theory of web interventions for behavior change in prostate cancer survivors has been developed before. This methodologic approach is a strength because data-driven open coding is most equipped to interrogate the inherent assumptions held by study participants and researchers alike [40]. Another strength of the study was the interpretation of data across groups receiving progressive levels of lifestyle interventions.

Comparison With Prior Work

An intuitive, web-based interface is not a novel concept. In 1993, Nielsen [46] coined the term *usability engineering*, where the usability of a system is defined by (1) learnability, (2) efficiency, (3) memorability, (4) low error rate, and (5) satisfaction. Usability heavily overlaps with intuitiveness, although we believe intuitiveness emphasizes tailoring and program responsiveness, shifting the burden of anticipation on program designers rather than program users. The interest in temporal and user tailoring beyond usability is also illustrated by the growing literature on *just in time* adaptive interventions, which are designed to adapt according to changes in an individual's contexts over time. These interventions provide the most appropriate and timely support to their users (usually enabled by mobile and sensing technologies); their applications in health promotion are of particular interest [47].

Our findings suggest that intuitiveness will likely depend on both the context and the intended user. This qualitative study elucidates some of the key areas that can be optimized for intuitive use of an internet-based lifestyle intervention among well-educated, White prostate cancer survivors. Although we used a grounded theory approach and generated data-driven codes, many of the resulting codes and their relationships to one another (Figure 4) are corroborated by existing theories in public health, as described below.

The environment code (applied in instances where participants mention environmental factors impacting their program engagement) is corroborated by the idea of a multilevel intervention based on the social ecological model. The social

ecological model by Bronfenbrenner and Morris suggests that the individual is enveloped and influenced by interpersonal, organizational, community, and public policy networks [48]. *Readiness to change* is supported by the transtheoretical model stages of change (with the stages of precontemplation, contemplation, preparation, action, maintenance, and termination) [49]. The idea that self-efficacy and agency influence how accountability is achieved (social cognitive theory) is highly consistent with motivation (accountability and discordance) [50]. Finally, the health belief model [51], which differentiates between behaviors in health and illness, is especially interesting when applied to lifestyle interventions in prostate cancer survivors. Prostate cancer survivors are in a unique position of having a chronic illness but also being in a position to engage in preventative health behaviors to deter recurrence or disease progression. The various components of the health belief model (perceived benefits vs perceived threat, self-efficacy, and cues to action) are impacted by the large majority of codes in our grounded theory model.

Limitations

Limitations of the study include the small subgroup sample size and lack of a theoretical sampling process parallel to the analyses. Overall, 10% (20/200) of eligible men were both interested and available to participate in the focus groups at the scheduled times. Although the smaller sample size is acceptable as our objectives were to explore themes using a grounded theory approach, this introduces a possible selection bias. In addition, not all participants fully participated in the web intervention as indicated, and the focus groups took place a median of 7 months after the interventions. Some men participated in multiple TrueNTH programs or were involved in other clinical trials. Although the longer follow-up period and competing priorities contributed valuable, realistic insight into the participants' lasting impressions and their habit formation, participants may not have recalled all the details of the intervention. In addition, although this was a multi-institutional study, the participants' experiences may primarily reflect viewpoints of educated, White men in the West and Mountain regions of the United States, where there may be disproportionately greater exposure to technology and overall better physical activity rates [52]. The lack of theoretical sampling and smaller subgroup sample size limits our ability to confidently comment on data saturation. In response to these limitations, we had a low threshold to include open codes in grounded theory, even if they were introduced by just 1 or 2 participants (ie, preparedness: trust, impressions, and habits); data-driven codes were also more likely to be elevated to axial or selective code status if the concepts they represented were supported by previous well-supported theories in public health. This qualitative study does not provide insight into which level of intervention performed best for this group of end users; however, it does provide researchers with important insights into the challenges of creating web-based approaches to support survivorship care that is both high tech and accessible. Further quantitative studies are needed to confirm the validity and directionality of these associations. Further work is needed to explore how our proposed theory applies to men with different sociodemographic characteristics.

Conclusions

Our study demonstrates that a web-based lifestyle intervention for men with prostate cancer can become intuitive and encourage adherence. These include addressing technological and health literacy, motivation, and environmental factors. In addition, flexible and transparent web design, integration of key stakeholders (ie, providers, family members), and effective coaching may improve the usability and intuitiveness of a web-based intervention to support prostate cancer survivorship. Men with prostate cancer tend to be older, have comorbidities, and balance multiple priorities; this may limit their ability to

engage with a web-based lifestyle platform. A web intervention's potential to affect long-term change will depend on the intuitiveness of its components, allowing integration within an individual's daily life (eg, clinical support, familial involvement, preparedness for program participation). This grounded theory-based analysis may help guide future web intervention designs for cancer survivors. The convergence of our findings with well-established theories in public health suggests that certain aspects of our theory are broadly applicable to lifestyle intervention design, although this will require further study.

Acknowledgments

The authors would like to acknowledge the Movember Foundation; the Steven & Christine Burd-Safeway Distinguished Professorship (University of California, San Francisco); the Helen Diller Family Chair in Population Science for Urologic Cancer (University of California, San Francisco); Kimi Daniel (Oregon Health and Sciences University); Greta Macaire (University of California, San Francisco); Carol-Ann Mullin, MSPH, operations manager (University of Colorado Cancer Center); Jade Moon, BS, research assistant (Oregon Health and Sciences University); Kellie Paich (University of Colorado Cancer Center; the Movember Foundation); NIH P30DK098722; P30 CA069533-21; K07CA197077; UL1TR002369; and their study participants (University of California, San Francisco; Oregon Health and Sciences University; University of Colorado Cancer Center).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus group guides for Community of Wellness.

[[PDF File \(Adobe PDF File\), 244 KB - cancer_v6i2e19362_app1.pdf](#)]

References

1. American Cancer Society. ACS Cancer Facts and Figures. *Cancer Pract* 2000 May;8(3):105-108. [doi: [10.1046/j.1523-5394.2000.83001.x](https://doi.org/10.1046/j.1523-5394.2000.83001.x)]
2. Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin* 2019 Sep;69(5):363-385 [FREE Full text] [doi: [10.3322/caac.21565](https://doi.org/10.3322/caac.21565)] [Medline: [31184787](https://pubmed.ncbi.nlm.nih.gov/31184787/)]
3. Winters-Stone KM, Moe E, Graff JN, Dieckmann NF, Stoyles S, Borsch C, et al. Falls and Frailty in Prostate Cancer Survivors: Current, Past, and Never Users of Androgen Deprivation Therapy. *J Am Geriatr Soc* 2017 Jul;65(7):1414-1419 [FREE Full text] [doi: [10.1111/jgs.14795](https://doi.org/10.1111/jgs.14795)] [Medline: [28263373](https://pubmed.ncbi.nlm.nih.gov/28263373/)]
4. Chang D, Joseph DJ, Ebert MA, Galvão DA, Taaffe DR, Denham JW, et al. Effect of androgen deprivation therapy on muscle attenuation in men with prostate cancer. *J Med Imaging Radiat Oncol* 2014 Apr;58(2):223-228. [doi: [10.1111/1754-9485.12124](https://doi.org/10.1111/1754-9485.12124)] [Medline: [24118850](https://pubmed.ncbi.nlm.nih.gov/24118850/)]
5. Galvão DA, Taaffe DR, Spry N, Joseph D, Turner D, Newton RU. Reduced muscle strength and functional performance in men with prostate cancer undergoing androgen suppression: a comprehensive cross-sectional investigation. *Prostate Cancer Prostatic Dis* 2009;12(2):198-203. [doi: [10.1038/pcan.2008.51](https://doi.org/10.1038/pcan.2008.51)] [Medline: [18852703](https://pubmed.ncbi.nlm.nih.gov/18852703/)]
6. Iadeluca L, Mardekian J, Chander P, Hopps M, Makinson GT. The burden of selected cancers in the US: health behaviors and health care resource utilization. *Cancer Manag Res* 2017;9:721-730 [FREE Full text] [doi: [10.2147/CMAR.S143148](https://doi.org/10.2147/CMAR.S143148)] [Medline: [29238222](https://pubmed.ncbi.nlm.nih.gov/29238222/)]
7. Leach CR, Bellizzi KM, Hurria A, Reeve BB. Is it my cancer or am i just getting older?: Impact of cancer on age-related health conditions of older cancer survivors. *Cancer* 2016 May 09;122(12):1946-1953. [doi: [10.1002/ncr.29914](https://doi.org/10.1002/ncr.29914)]
8. Finlay A, Wittert G, Short CE. A systematic review of physical activity-based behaviour change interventions reaching men with prostate cancer. *J Cancer Surviv* 2018 Aug;12(4):571-591. [doi: [10.1007/s11764-018-0694-8](https://doi.org/10.1007/s11764-018-0694-8)] [Medline: [29770953](https://pubmed.ncbi.nlm.nih.gov/29770953/)]
9. Richman EL, Kenfield SA, Stampfer MJ, Paciorek A, Carroll PR, Chan JM. Physical activity after diagnosis and risk of prostate cancer progression: data from the cancer of the prostate strategic urologic research endeavor. *Cancer Res* 2011 Jun 01;71(11):3889-3895. [doi: [10.1158/0008-5472.CAN-10-3932](https://doi.org/10.1158/0008-5472.CAN-10-3932)] [Medline: [21610110](https://pubmed.ncbi.nlm.nih.gov/21610110/)]
10. Kenfield SA, Stampfer MJ, Giovannucci E, Chan JM. Physical activity and survival after prostate cancer diagnosis in the health professionals follow-up study. *J Clin Oncol* 2011 Feb 20;29(6):726-732. [doi: [10.1200/JCO.2010.31.5226](https://doi.org/10.1200/JCO.2010.31.5226)] [Medline: [21205749](https://pubmed.ncbi.nlm.nih.gov/21205749/)]

11. Wang Y, Jacobs EJ, Gapstur SM, Maliniak ML, Gansler T, McCullough ML, et al. Recreational Physical Activity in Relation to Prostate Cancer-specific Mortality Among Men with Nonmetastatic Prostate Cancer. *Eur Urol* 2017 Dec;72(6):931-939. [doi: [10.1016/j.eururo.2017.06.037](https://doi.org/10.1016/j.eururo.2017.06.037)] [Medline: [28711382](https://pubmed.ncbi.nlm.nih.gov/28711382/)]
12. Friedenreich CM, Wang Q, Neilson HK, Kopciuk KA, McGregor SE, Courneya KS. Physical Activity and Survival After Prostate Cancer. *Eur Urol* 2016 Dec;70(4):576-585 [FREE Full text] [doi: [10.1016/j.eururo.2015.12.032](https://doi.org/10.1016/j.eururo.2015.12.032)] [Medline: [26774959](https://pubmed.ncbi.nlm.nih.gov/26774959/)]
13. Bonn SE, Sjölander A, Lagerros YT, Wiklund F, Stattin P, Holmberg E, et al. Physical activity and survival among men diagnosed with prostate cancer. *Cancer Epidemiol Biomarkers Prev* 2015 Jan;24(1):57-64. [doi: [10.1158/1055-9965.EPI-14-0707](https://doi.org/10.1158/1055-9965.EPI-14-0707)] [Medline: [25527697](https://pubmed.ncbi.nlm.nih.gov/25527697/)]
14. Winters-Stone KM, Dobek JC, Bennett JA, Maddalozzo GF, Ryan CW, Beer TM. Skeletal response to resistance and impact training in prostate cancer survivors. *Med Sci Sports Exerc* 2014 Aug;46(8):1482-1488 [FREE Full text] [doi: [10.1249/MSS.0000000000000265](https://doi.org/10.1249/MSS.0000000000000265)] [Medline: [24500540](https://pubmed.ncbi.nlm.nih.gov/24500540/)]
15. Winters-Stone K, Dieckmann N, Maddalozzo G, Bennett ?, Ryan C, Beer T. Resistance Exercise Reduces Body Fat and Insulin During Androgen-Deprivation Therapy for Prostate Cancer. *ONF* 2015 Jul 1;42(4):348-356. [doi: [10.1188/15.onf.348-356](https://doi.org/10.1188/15.onf.348-356)]
16. Winters-Stone KM, Dobek JC, Bennett JA, Dieckmann NF, Maddalozzo GF, Ryan CW, et al. Resistance training reduces disability in prostate cancer survivors on androgen deprivation therapy: evidence from a randomized controlled trial. *Arch Phys Med Rehabil* 2015 Jan;96(1):7-14 [FREE Full text] [doi: [10.1016/j.apmr.2014.08.010](https://doi.org/10.1016/j.apmr.2014.08.010)] [Medline: [25194450](https://pubmed.ncbi.nlm.nih.gov/25194450/)]
17. Winters-Stone KM, Lyons KS, Dobek J, Dieckmann NF, Bennett JA, Nail L, et al. Benefits of partnered strength training for prostate cancer survivors and spouses: results from a randomized controlled trial of the Exercising Together project. *J Cancer Surviv* 2016 Aug;10(4):633-644. [doi: [10.1007/s11764-015-0509-0](https://doi.org/10.1007/s11764-015-0509-0)] [Medline: [26715587](https://pubmed.ncbi.nlm.nih.gov/26715587/)]
18. Fornusek CP, Kilbreath SL. Exercise for improving bone health in women treated for stages I-III breast cancer: a systematic review and meta-analyses. *J Cancer Surviv* 2017 Oct;11(5):525-541. [doi: [10.1007/s11764-017-0622-3](https://doi.org/10.1007/s11764-017-0622-3)] [Medline: [28639157](https://pubmed.ncbi.nlm.nih.gov/28639157/)]
19. Chan JM, Holick CN, Leitzmann MF, Rimm EB, Willett WC, Stampfer MJ, et al. Diet after diagnosis and the risk of prostate cancer progression, recurrence, and death (United States). *Cancer Causes Control* 2006 Mar;17(2):199-208. [doi: [10.1007/s10552-005-0413-4](https://doi.org/10.1007/s10552-005-0413-4)] [Medline: [16425098](https://pubmed.ncbi.nlm.nih.gov/16425098/)]
20. Richman EL, Stampfer MJ, Paciorek A, Broering JM, Carroll PR, Chan JM. Intakes of meat, fish, poultry, and eggs and risk of prostate cancer progression. *Am J Clin Nutr* 2010 Mar;91(3):712-721. [doi: [10.3945/ajcn.2009.28474](https://doi.org/10.3945/ajcn.2009.28474)] [Medline: [20042525](https://pubmed.ncbi.nlm.nih.gov/20042525/)]
21. Richman EL, Carroll PR, Chan JM. Vegetable and fruit intake after diagnosis and risk of prostate cancer progression. *Int J Cancer* 2012 Jul 01;131(1):201-210 [FREE Full text] [doi: [10.1002/ijc.26348](https://doi.org/10.1002/ijc.26348)] [Medline: [21823116](https://pubmed.ncbi.nlm.nih.gov/21823116/)]
22. Richman EL, Kenfield SA, Stampfer MJ, Giovannucci EL, Chan JM. Egg, red meat, and poultry intake and risk of lethal prostate cancer in the prostate-specific antigen-era: incidence and survival. *Cancer Prev Res (Phila)* 2011 Dec;4(12):2110-2121. [doi: [10.1158/1940-6207.CAPR-11-0354](https://doi.org/10.1158/1940-6207.CAPR-11-0354)] [Medline: [21930800](https://pubmed.ncbi.nlm.nih.gov/21930800/)]
23. Peisch SF, Van BEL, Chan JM, Stampfer MJ, Kenfield SA. Prostate cancer progression and mortality: a review of diet and lifestyle factors. *World J Urol* 2017 Jun;35(6):867-874. [doi: [10.1007/s00345-016-1914-3](https://doi.org/10.1007/s00345-016-1914-3)] [Medline: [27518576](https://pubmed.ncbi.nlm.nih.gov/27518576/)]
24. Pettersson A, Kasperzyk JL, Kenfield SA, Richman EL, Chan JM, Willett WC, et al. Milk and dairy consumption among men with prostate cancer and risk of metastases and prostate cancer death. *Cancer Epidemiol Biomarkers Prev* 2012 Mar;21(3):428-436. [doi: [10.1158/1055-9965.EPI-11-1004](https://doi.org/10.1158/1055-9965.EPI-11-1004)] [Medline: [22315365](https://pubmed.ncbi.nlm.nih.gov/22315365/)]
25. Chavarro JE, Stampfer MJ, Hall MN, Sesso HD, Ma J. A 22-y prospective study of fish intake in relation to prostate cancer incidence and mortality. *Am J Clin Nutr* 2008 Nov;88(5):1297-1303 [FREE Full text] [doi: [10.3945/ajcn.2008.26419](https://doi.org/10.3945/ajcn.2008.26419)] [Medline: [18996866](https://pubmed.ncbi.nlm.nih.gov/18996866/)]
26. Dickerman BA, Giovannucci E, Pernar CH, Mucci LA, Hernán MA. Guideline-Based Physical Activity and Survival Among US Men With Nonmetastatic Prostate Cancer. *Am J Epidemiol* 2019 Mar 01;188(3):579-586 [FREE Full text] [doi: [10.1093/aje/kwy261](https://doi.org/10.1093/aje/kwy261)] [Medline: [30496346](https://pubmed.ncbi.nlm.nih.gov/30496346/)]
27. Rock CL, Doyle C, Demark-Wahnefried W, Meyerhardt J, Courneya KS, Schwartz AL, et al. Nutrition and physical activity guidelines for cancer survivors. *CA Cancer J Clin* 2012;62(4):243-274 [FREE Full text] [doi: [10.3322/caac.21142](https://doi.org/10.3322/caac.21142)] [Medline: [22539238](https://pubmed.ncbi.nlm.nih.gov/22539238/)]
28. Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, et al. Exercise Guidelines for Cancer Survivors. 2019;51(11):2375-2390. [doi: [10.1249/mss.0000000000002116](https://doi.org/10.1249/mss.0000000000002116)]
29. Hayes SC, Newton RU, Spence RR, Galvão DA. The Exercise and Sports Science Australia position statement: Exercise medicine in cancer management. *Journal of Science and Medicine in Sport* 2019 Nov;22(11):1175-1199. [doi: [10.1016/j.jsams.2019.05.003](https://doi.org/10.1016/j.jsams.2019.05.003)]
30. Kuijpers W, Groen WG, Aaronson NK, van HWH. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. *J Med Internet Res* 2013;15(2):e37 [FREE Full text] [doi: [10.2196/jmir.2281](https://doi.org/10.2196/jmir.2281)] [Medline: [23425685](https://pubmed.ncbi.nlm.nih.gov/23425685/)]
31. Kenfield SA, Van Blarigan EL, Ameli N, Lavaki E, Cedars B, Paciorek AT, et al. Feasibility, Acceptability, and Behavioral Outcomes from a Technology-enhanced Behavioral Change Intervention (Prostate 8): A Pilot Randomized Controlled Trial in Men with Prostate Cancer. *Eur Urol* 2019 Jan 09. [doi: [10.1016/j.eururo.2018.12.040](https://doi.org/10.1016/j.eururo.2018.12.040)] [Medline: [30638635](https://pubmed.ncbi.nlm.nih.gov/30638635/)]

32. Golsteijn RHJ, Bolman C, Volders E, Peels DA, de Vries H, Lechner L. Short-term efficacy of a computer-tailored physical activity intervention for prostate and colorectal cancer patients and survivors: a randomized controlled trial. *Int J Behav Nutr Phys Act* 2018 Oct 30;15(1). [doi: [10.1186/s12966-018-0734-9](https://doi.org/10.1186/s12966-018-0734-9)]
33. Golsteijn RHJ, Bolman C, Volders E, Peels DA, de VH, Lechner L. Development of a computer-tailored physical activity intervention for prostate and colorectal cancer patients and survivors: OncoActive. *BMC Cancer* 2017 Jun 26;17(1):446 [FREE Full text] [doi: [10.1186/s12885-017-3397-z](https://doi.org/10.1186/s12885-017-3397-z)] [Medline: [28651586](https://pubmed.ncbi.nlm.nih.gov/28651586/)]
34. Mohamad H, Ntessalen M, Craig LCA, Clark J, Fielding S, N'Dow J, et al. A self-help diet and physical activity intervention with dietetic support for weight management in men treated for prostate cancer: pilot study of the Prostate Cancer Weight Management (PRO-MAN) randomised controlled trial. *Br J Nutr* 2019 Sep 14;122(5):592-600. [doi: [10.1017/S0007114519001090](https://doi.org/10.1017/S0007114519001090)] [Medline: [31177994](https://pubmed.ncbi.nlm.nih.gov/31177994/)]
35. Trinh L, Arbour-Nicitopoulos KP, Sabiston CM, Berry SR, Loblaw A, Alibhai SMH, et al. RiseTx: testing the feasibility of a web application for reducing sedentary behavior among prostate cancer survivors receiving androgen deprivation therapy. *Int J Behav Nutr Phys Act* 2018 Jun 07;15(1):49. [doi: [10.1186/s12966-018-0686-0](https://doi.org/10.1186/s12966-018-0686-0)] [Medline: [29880049](https://pubmed.ncbi.nlm.nih.gov/29880049/)]
36. Winters-Stone KM, Kenfield SA, Van Blarigan EL, Moe EL, Ramsdill JW, Daniel K, et al. Effect of Increasing Levels of Web-Based Behavioral Support on Changes in Physical Activity, Diet, and Symptoms in Men With Prostate Cancer: Protocol for a Randomized Controlled Trial. *JMIR Res Protoc* 2018 Nov 15;7(11):e11257 [FREE Full text] [doi: [10.2196/11257](https://doi.org/10.2196/11257)] [Medline: [30442638](https://pubmed.ncbi.nlm.nih.gov/30442638/)]
37. Corbett T, Cheetham T, Müller AM, Slodkowska-Barabasz J, Wilde L, Krusche A, et al. Exploring cancer survivors' views of health behaviour change: "Where do you start, where do you stop with everything?". *Psychooncology* 2018 Jul 01;27(7):1816-1824. [doi: [10.1002/pon.4732](https://doi.org/10.1002/pon.4732)] [Medline: [29645327](https://pubmed.ncbi.nlm.nih.gov/29645327/)]
38. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007 Dec;19(6):349-357. [doi: [10.1093/intqhc/mzm042](https://doi.org/10.1093/intqhc/mzm042)] [Medline: [17872937](https://pubmed.ncbi.nlm.nih.gov/17872937/)]
39. Charmaz K. *Constructing Grounded Theory*. Sage Publications 2006. [doi: [10.4135/9781446212165.n27](https://doi.org/10.4135/9781446212165.n27)]
40. Vollstedt M, Rezat S. An Introduction to Grounded Theory with a Special Focus on Axial Coding the Coding Paradigm. In: Kaiser G, Presmeg N. eds. *Compendium for Early Career Researchers in Mathematics Education*. ICME-13 Monographs. Springer International Publishing; 2019:81-100.
41. Rennie DL, Fergus KD. Embodied Categorizing in the Grounded Theory Method: Methodical Hermeneutics in Action. *Theory Psychol* 2006;16(4):483-503. [doi: [10.1177/0959354306066202](https://doi.org/10.1177/0959354306066202)]
42. Boeije H. A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews. *Qual Quant* 2002;36(4):391-409. [doi: [10.1023/A:1020909529486](https://doi.org/10.1023/A:1020909529486)]
43. URL: <https://www.hon.ch/en/> [accessed 2020-01-04]
44. Shahrokni A, Loh KP, Wood WA. Toward Modernization of Geriatric Oncology by Digital Health Technologies. *Am Soc Clin Oncol Educ Book* 2020 Mar;40:1-7. [doi: [10.1200/EDBK_279505](https://doi.org/10.1200/EDBK_279505)] [Medline: [32243198](https://pubmed.ncbi.nlm.nih.gov/32243198/)]
45. Fallahzadeh R, Rokni SA, Ghasemzadeh H, Soto-Perez-de-Celis E, Shahrokni A. Digital Health for Geriatric Oncology. *JCO Clin Cancer Inform* 2018 Dec;2:1-12. [doi: [10.1200/CCI.17.00133](https://doi.org/10.1200/CCI.17.00133)] [Medline: [30652581](https://pubmed.ncbi.nlm.nih.gov/30652581/)]
46. Nielsen J. *Usability Engineering*. Nachdr. Kaufmann 2010.
47. Nahum-Shani I, Smith SN, Spring BJ, Collins LM, Witkiewitz K, Tewari A, et al. Just-in-Time Adaptive Interventions (JITAs) in Mobile Health: Key Components and Design Principles for Ongoing Health Behavior Support. *Ann Behav Med* 2016 Sep 23. [doi: [10.1007/s12160-016-9830-8](https://doi.org/10.1007/s12160-016-9830-8)] [Medline: [27663578](https://pubmed.ncbi.nlm.nih.gov/27663578/)]
48. Gauvain M, Cole M. eds. *Readings on the Development of Children*. 4th ed. Worth Publishers 2005.
49. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. *Am J Health Promot* 1997;12(1):38-48. [Medline: [10170434](https://pubmed.ncbi.nlm.nih.gov/10170434/)]
50. Bandura A. Social cognitive theory: an agentic perspective. *Annu Rev Psychol* 2001;52:1-26. [doi: [10.1146/annurev.psych.52.1.1](https://doi.org/10.1146/annurev.psych.52.1.1)] [Medline: [11148297](https://pubmed.ncbi.nlm.nih.gov/11148297/)]
51. Rosenstock IM. The Health Belief Model and Preventive Health Behavior. *Health Educ Behav* 1974 Dec 01;2(4):354-386. [doi: [10.1177/109019817400200405](https://doi.org/10.1177/109019817400200405)]
52. Centers FDC. Adult Physical Inactivity Prevalence Maps. Published online 2020. URL: <https://www.cdc.gov/physicalactivity/data/inactivity-prevalence-maps/index.html#overall> [accessed 2020-01-04]

Edited by G Eysenbach; submitted 14.04.20; peer-reviewed by D Lin, H Evans; comments to author 12.06.20; revised version received 08.08.20; accepted 22.09.20; published 10.11.20.

Please cite as:

Wang EY, Graff RE, Chan JM, Langlais CS, Broering JM, Ramsdill JW, Kessler ER, Winters-Stone KM, Van Blarigan EL, Kenfield SA

Web-Based Lifestyle Interventions for Prostate Cancer Survivors: Qualitative Study

JMIR Cancer 2020;6(2):e19362

URL: <http://cancer.jmir.org/2020/2/e19362/>

doi: [10.2196/19362](https://doi.org/10.2196/19362)

PMID: [33170126](https://pubmed.ncbi.nlm.nih.gov/33170126/)

©Elizabeth Y Wang, Rebecca E Graff, June M Chan, Crystal S Langlais, Jeanette M Broering, Justin W Ramsdill, Elizabeth R Kessler, Kerri M Winters-Stone, Erin L Van Blarigan, Stacey A Kenfield. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 10.11.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Assessment of Data Usage of Cancer e-Interventions (ADUCI) Framework for Health App Use of Cancer Patients and Their Caregivers: Framework Development Study

Natalie Heynsbergh^{1*}, PhD; Seung Chul (Eric) O^{1*}, MMM; Patricia M Livingston¹, PhD

Faculty of Health, Deakin University, Geelong, Australia

*these authors contributed equally

Corresponding Author:

Natalie Heynsbergh, PhD

Faculty of Health

Deakin University

1 Gheringhap Street

Geelong

Australia

Phone: 61 3924 68225

Email: n.heynsbergh@deakin.edu.au

Abstract

Background: Multimedia interventions can provide a cost-effective solution to public health needs; however, user engagement is low. Multimedia use within specific populations such as those affected by cancer differs from that of the general population. To our knowledge, there are no frameworks on how to accurately assess usage within this population to ensure that interventions are appropriate for the end users. Therefore, a framework was developed to improve the accuracy of determining data usage. Formative work included creating a data usage framework during target audience testing for smartphone app development and analysis in a pilot study.

Objective: The purpose of this study was to develop a framework for assessing smartphone app usage among people living with cancer and their caregivers.

Methods: The frequency and duration of use were compared based on manual data extraction from two previous studies and the newly developed Assessment of Data Usage of Cancer e-Interventions (ADUCI) Framework.

Results: Manual extraction demonstrated that 279 logins occurred compared with 241 when the ADUCI Framework was applied. The frequency of use in each section of the app also decreased when the ADUCI Framework was used. The total duration of use was 91,256 seconds (25.3 hours) compared with 53,074 seconds (14.7 hours) when using the ADUCI Framework. The ADUCI Framework identified 38 logins with no navigation, and there were 15 discrepancies in the data where time on a specific page of the app exceeded the login time. Practice recommendations to improve user engagement and capturing usage data include tracking data use in external websites, having a login function on apps, creating a five-star page rating functionality, using the ADUCI Framework to thoroughly clean usage data, and validating the Framework between expected and observed use.

Conclusions: Applying the ADUCI Framework may eliminate errors and allow for more accurate analysis of usage data in e-research projects. The Framework can also improve the process of capturing usage data by providing a guide for usage data analysis to facilitate evidence-based assessment of user engagement with apps.

(*JMIR Cancer* 2020;6(2):e18230) doi:[10.2196/18230](https://doi.org/10.2196/18230)

KEYWORDS

multimedia; user engagement; cancer; smartphone; framework; usage data; eHealth technology; e-intervention; data analysis; efficiency; e-research; apps

Introduction

Background

Within the health care context, electronic health (eHealth) technologies such as smartphone apps can assist people in managing their health by providing information, support, communication, and resources to track the progression of well-being or illness [1]. In 2017, over 318,000 health apps were available to download [2]. Evidence-based apps and formal evaluations are growing in chronic disease areas such as for diabetes and mental illness, including anxiety and depression [2]. However, there is little evidence on app usage within the adult cancer population [3-5].

Worldwide, there is a need for supportive eHealth technology in the cancer field as the provision of cancer care has shifted toward an outpatient setting [6]. The adoption of human-computer interaction and user-centered design principles can guide intervention development to inform user needs [7]. User-centered design approaches have been adopted to develop two apps: one for people living with cancer [5] and one for caregivers [4]. User-centered design enables developers to identify the unique needs and behaviors of population groups to ensure that technology accurately reflects users' requirements [7]. Previous technology-based strategies have been used in the cancer field to promote emotional well-being such as audio-visual techniques, and have used a similar approach of seeking user engagement to guide the development of new interventions [8].

Many adults living with cancer and their informal caregivers are managing cancer in the community; thus, the need for cost-effective supportive interventions is vital to inform patient and caregiver care needs. Smartphone app interventions have the potential to be more cost-effective than face-to-face interventions; however, this can depend on adherence and use [9]. Positive engagement of users directly impacts users' motivation and intention to use multimedia platforms and apps [10]. There is no single definition or concept of user engagement; rather, its complexity involves the investment of a person into using a program and encompasses satisfaction, ability to engage, and sustained engagement [11]. Within the general population, user engagement with eHealth interventions is low; over an 18-month surveillance period, engagement with self-guided apps ranged between 13% and 26% [12]. In the adult cancer setting, usage of apps is relatively unknown with few evaluations having been completed [4,5]. App usage among this population may also differ from that of the general population as patients and caregivers are usually highly burdened, distressed, and lacking in time [13,14]. Therefore, it is unknown what constitutes "active engagement" in this group. Therefore, frameworks to measure use and engagement in the adult cancer setting are required to facilitate the accurate evaluation of interventions for informing the feasibility and cost-effectiveness of evidence-based apps. To our knowledge, no frameworks addressing this topic exist. We performed a scoping review of the literature and consulted leading eHealth specialists across the state of Victoria in Australia, and no similar frameworks or guidelines were identified.

To fill this gap, the Assessment of Data Usage of Cancer e-Intervention (ADUCI) Framework was developed and validated using a three-step approach. Step one involved creating a framework for user testing during development [15]. In step two, the framework for app use and engagement was developed by analyzing findings of a pilot study to determine the feasibility of app interventions [4]. We here report the results of step three, in which the framework from the pilot study [4] was corroborated by applying it to another study in a randomized controlled trial [5].

Study 1: User Testing

An app usage framework was developed during the planning, design, and evaluation phases of an app for cancer caregivers. This comprised two phases, user acceptance testing and user experience testing, during app development [15]. Participants were provided with scenarios and were required to find the corresponding information within the app. Each scenario was timed and a cutoff of 20 seconds was applied to guide the time necessary to complete tasks. The timeframe of 20 seconds was used as a guide from the general population and was amended to inform use of an app among older adults [16]. Tasks that took participants over 20 seconds to complete or were incomplete resulted in corresponding content and design changes to the app.

Study 2: Pilot Study Usage Data Analysis

Adult caregivers of people with colorectal cancer receiving chemotherapy in the outpatient setting were approached and invited to participate in the feasibility pilot study. Caregivers who participated in the study were provided with access to the "Carer Guide" smartphone app for 30 days. Carer Guide included access to information and resources to help manage the needs of people with colorectal cancer as well as the caregivers' own needs. Caregivers were required to log in to access any information within the app. Data tracking was recorded using Google Analytics, and included the frequency of login, length of login, and number of pages visited. The ADUCI Framework was validated in this study by applying data cleaning methods to analyze and report usage data. On average, caregivers used the app for 22 minutes each time they logged in [4].

Ethical Concerns

Both studies were approved by the Human Research Ethics Committees at the relevant health care organizations and at Deakin University. Participants were informed in writing that usage data would be monitored to determine which pages were visited.

Objectives

The aim of this study was to corroborate the ADUCI Framework by applying it to data usage from a randomized controlled trial (study 3) involving a smartphone app for people diagnosed with cancer [5].

Methods

Study 3: Applying the ADUCI Framework to a Randomized Controlled Trial

Patients receiving chemotherapy in an outpatient setting in Melbourne, Australia were approached and invited to participate in the study. Following recruitment, participants were randomly allocated to either the intervention or control group. Participants in the intervention group had access to a smartphone app ("ACE" app), which provided static information and support resources to participants [5]. ACE app resources included the ability to view and change hospital appointments and record notes in a notebook. Over a 4-month period, participants could access ACE when needed, and received monthly reminders to complete distress thermometer scores. Participants could access information and support freely; however, they had to log in to the app to change appointments and complete distress thermometer scores. Participant usage data were tracked internally through the ACE app. Tracking information included login frequency, duration of login, and number of pages visited.

Assessment of Data Usage With the ADUCI Framework

The ADUCI Framework comprises two components: assessment of duration of use and frequency of use. Duration of use was measured as the length of use in seconds for each app login, as well as the amount of time spent in each section of the app. Frequency of use included the number of logins overall and the number of times each section of the app was visited.

Framework for Duration of Use

Based on the findings of the pilot study [4], a 22-minute cutoff was applied for each login of the ACE app after page navigation had ceased. The purpose of this cutoff was to standardize the

usage data that were manually extracted and to remove or reduce situations where people may have the app running in the background on their phone without actively using the app. Similarly, app usage less than 1 second was not included in the analysis, as 1-second use often had no navigation and may have been a user error in clicking on the wrong app icon.

Framework for Frequency of Use

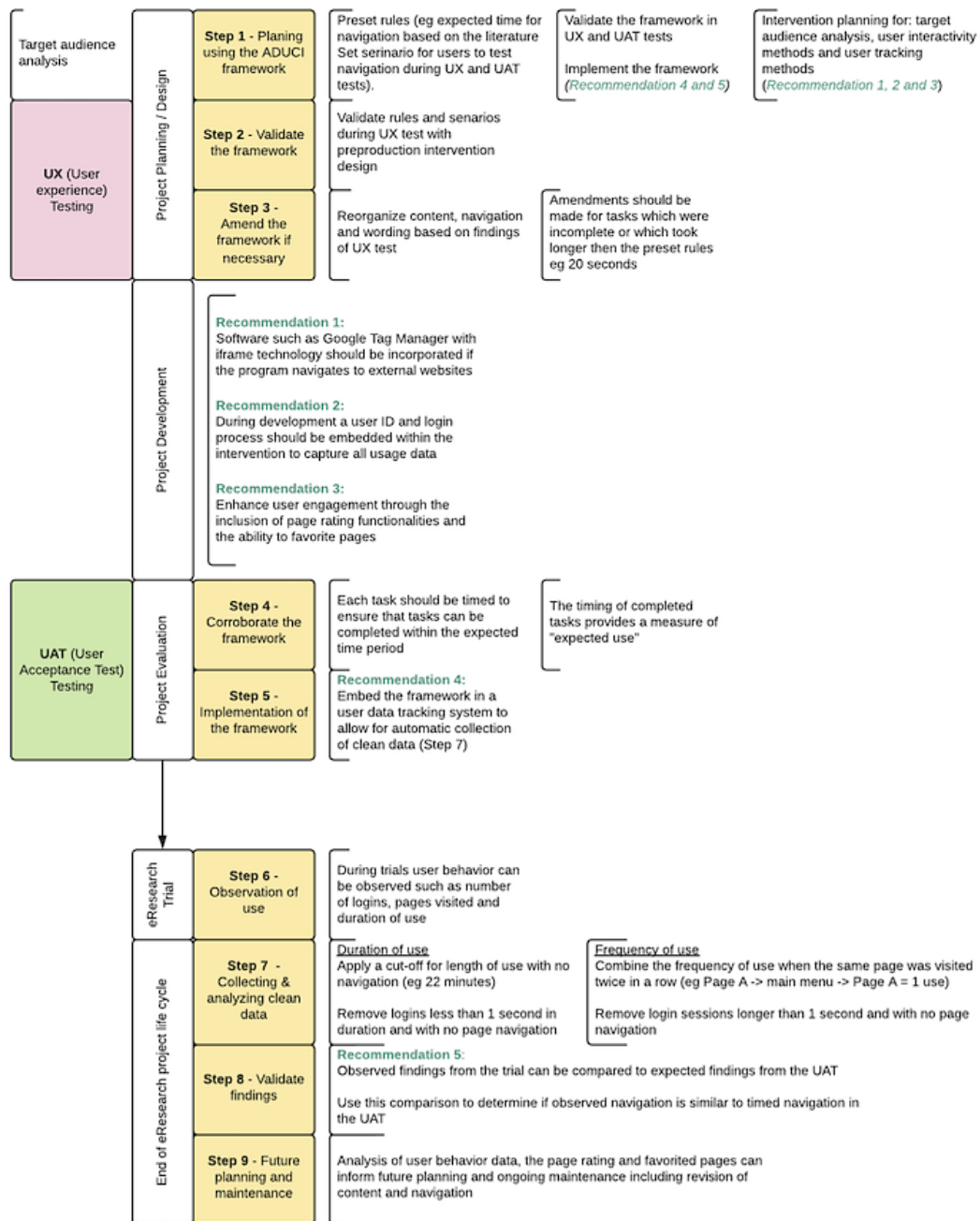
The frequency of page visits was cleaned and analyzed in the following format. When navigation moved from a content page to the main menu and back to the same content page (eg, *Cancer Information, Main Menu, Cancer Information*), the frequency of use of the *Cancer Information* page was interpreted as 1 (Scenario 1). When navigation moved between several pages but page visits were repeated, the page visits were tallied (Scenario 2). For example, when navigation followed the order *Cancer Information, Main Menu, Wellbeing, Main Menu, Cancer Information*, this was interpreted as 2 views for *Cancer Information* and 1 view for *Wellbeing*.

These rules were applied since in Scenario 1 there was no information as to whether this navigational pattern was intentional or accidental, whereas in Scenario 2, as another page had been visited in between the two times that the *Cancer Information* page was visited, subsequent use of this section of the app was most likely intentional.

In the event that users logged into the app for longer than 1 second but had no navigation beyond the main menu, this event was removed from the analysis as no use of app content occurred.

The ADUCI Framework includes nine steps to guide intervention planning, development, user testing, data cleaning, and analysis. Future recommendations outlined in the Results section below have also been incorporated into the process. See [Figure 1](#) for an overview of the framework.

Figure 1. The Assessment of Data Usage of Cancer eInterventions (ADUCI) Framework and future recommendations for eInterventions.



Data Analysis

Descriptive statistics were used to summarize the duration and frequency of use of each login and each section of the app used. Data were analyzed by comparing results from the manual extraction and when the ADUCI Framework was applied.

Results

Frequency of Use

A total of 279 logins were recorded in the manual extraction of data compared to 241 when using the ADUCI Framework. The

mean difference in number of logins was 6 (range 0-13) when comparing manually extracted data with the ADUCI findings (Table 1). The most frequently used sections of the ACE app had the highest number of discrepancies between manual data extraction and when the Framework was applied. Frequency of use was similar between the manual extraction and the ADUCI Framework; however, the Framework showed a reduction in frequency of use in each section of the ACE app (Table 1).

Table 1. Frequency of use of the ACE app and each section within the app over a 4-month period.

App feature accessed	Manual extraction (n)	ADUCI ^a Framework (n)	Difference
Cancer information	70	57	13
Navigation	40	33	7
Allied health	21	13	8
CCV ^b support service	29	28	1
Clinical trials	28	23	5
Appointments	165	159	6
Need help	7	3	4
About us	0	0	0
Notepad	42	35	7

^aADUCI: Assessment of Data Usage of Cancer Electronic Interventions.

^bCCV: Cancer Council Victoria.

Length of Use

The manual extraction highlighted that, on average, the ACE app was used for 328 seconds at each login, and for a total of 91,256 seconds over the 4-month intervention period (Table 2). When the ADUCI Framework was applied, the mean length of

use was 224 seconds and total use was 53,074 seconds. Across the different sections of the app, the total length of use ranged from 0 seconds to 213,930 seconds (3566 minutes or 59.4 hours) in the manually extracted data compared to 0 to 52,074 seconds (230 minutes or 3.8 hours) when the ADUCI Framework was applied.

Table 2. Length of use of the ACE app in seconds.

App feature accessed	Manual extraction		ADUCI ^a Framework		Difference	
	Mean	Total	Mean	Total	Mean	Total
All uses	328	91,256	224	53,074	104	38,182
Cancer information	3450	213,930	266	13,813	3184	200,117
Navigation	2376	80,784	74	2897	2302	77,887
Allied health	56	1190	56	890	0	300
CCV ^b support service	22	559	125	2996	-103	-2437
Clinical trials	1358	38,018	25	628	1333	32,390
Appointments	1142	161,010	71	10,434	1071	150,576
Need help	25	178	30	150	-5	28
About us	0	0	0	0	0	0
Notepad	1243	45,976	81	2686	1162	43,290

^aADUCI: Assessment of Data Usage of Cancer Electronic Interventions.

^bCCV: Cancer Council Victoria.

Application of the ADUCI Framework resulted in a reduction of time spent in each section of the app, with the exception of the Cancer Council Victoria (CCV) support service. During data cleaning, additional time was recorded in the CCV support service section (Table 2).

In the manual extraction, there were several errors in the data recorded. Errors showed that the duration of use of a specific section of the app exceeded the duration of login. For example, the *Cancer Information* section was recorded as having been used for 16,072 seconds, whereas the total login duration of the app for that session was recorded as 4 seconds. Similar discrepancies occurred 15 times in the manually extracted data.

These discrepancies were eliminated when the ADUCI Framework was applied.

Future Work

This analysis informed the development of a framework for analyzing user usage data during the project planning/design and evaluation stages. In addition to the proposed ADUCI Framework, there are four recommendations for future eHealth interventions, which can provide a more effective approach to handling usage data as well as implementing user engagement methods to reduce the time needed for manual data cleaning. The ADUCI Framework offers a more accurate approach of analyzing usage data; however, there were gaps present in the

data collected, and additional features and functionality would ensure that complete data are available for analysis. These features and functionalities are listed below as future recommendations.

Recommendation 1: Track All Usage Data if Possible

Due to the sensitive nature of health information and its potentially huge storage and maintenance requirements, most eHealth mobile apps cannot contain all of the information required by end users. Quite often, apps use linking methods to specific information outside the app. Researchers and developers should consider all possible issues with tracking usage data during the planning and design stage of project development to apply a suitable solution to avoid missing usage data. In the development stage, internal and external testing should be conducted at various times with small groups of end users to ensure that the system collects all intended usage data.

An example of this situation within the ACE app is the feature that linked patients to external CCV webpages. In both the pilot study [4] (study 2) and the ACE app trial [5] (study 3), the tracking system was unable to continue monitoring data usage once users navigated out of the app ecosystems to external websites. This issue can be solved by using a technical solution such as Google Tag Manager with iFrame technology to link and track usage outside the app.

Using a solution such as Google Tag Manager with iFrame technology will address two gaps in user engagement analysis. First, it will provide full coverage of end user data usage and behavior, allowing for more accurate assessment of usage data. Second, it will provide developers with a complete understanding of what the end user needs and be able to provide tailored content in current or future projects.

Recommendation 2: Link User ID to Tracking Record

Similar to the ACE app, across other health conditions, it is common to find that user IDs are not incorporated into the development of apps [17]. A login should be present to enable tracking of all of a user's usage. This may be achieved via the functionality of having people log in once and enabling a "remember me" function on the app. This function should be considered in the planning stage. In addition, if the app does not have prior logins recorded to use, it should request that the user log in before continuing to access the app.

However, this functionality needs thorough internal and external testing during the app development and evaluation stages to ensure that it is working properly, and that all relevant data are being captured.

Similarly, the decision of whether or not to implement a user login process within apps is an important consideration. A limitation of the ACE app was the loss of user data throughout the trial, as users were only required to log in to change appointments and record distress thermometer readings [5]. Minimizing security requirements such as logins can increase the accessibility of apps as users are not required to remember login details; however, without these security measures, it is not possible to definitively track user data. Incorporating user

IDs should be balanced between the characteristics of the end users, the purpose of the app, and the need to provide accurate usage data.

Recommendation 3: Enhance User Engagement

E-interventions and e-research projects are often developed for specific end users. Therefore, it is essential to undertake target audience analysis to understand the audiences' needs, and to design user engagement tools based on concepts of human-computer interaction.

User-centered design is closely aligned with human-computer interaction to ensure that programs are developed to meet the needs and capabilities of users [7]. Both apps in this study were iteratively tested using a user-centered design approach to ensure that the content, functionality, and usability were suitable. Findings between studies were similar where the majority of participants were female, in their 50s, held a tertiary-level qualification, and used a smartphone. Based on these demographic characteristics, we suggest designing a user interface with similar characteristics to popular social media platforms, and providing functions that give users the ability to fully control and personalize program content to enrich their experience [18-20].

User engagement with interventions and app popularity may be enhanced using the following tools: (1) star rating functionality, as a useful measurement of content and interactive media presence [21]; (2) interactive media favorite functionality, for building an individual end user's custom interactive content and media library [22]; (3) counting the star rating when observing other users' activities; and (4) providing a familiar interface such as consistent design with current social media and networking web content so that engagement strategies (eg, star rating) are familiar [23,24].

These engagement tools will provide strong evidence-based guidelines for program content development in the future by highlighting which content is most highly rated, most favorited, and most respected. Such tools may also provide evidence as to which existing content needs attention from the program content developers. Developers should evaluate the engagement strategies with users at the end of the project life cycle to build better engagement tools for future studies.

Recommendation 4: Implementation of the ADUCI Framework in the System

Usage data findings presented in the data collection and data analysis phase of ADUCI Framework development emphasize the importance of having frameworks to properly assess and manage usage data throughout the life cycle of development and testing of e-interventions. If implemented in the evaluation stage of an e-research project development life cycle, usage data can be more effectively analyzed. For example, it required approximately 40 hours to manually extract data from the ACE app study to determine a more accurate and useful dataset. By implementing the practice recommendations and ADUCI Framework, the final analysis of returned usage data will be performed much more efficiently, with both time and cost advantages.

Recommendation 5: Validate Findings and Provide Opportunities to Map User Behavior

This paper provides an overview of the ADUCI Framework by comparing findings between manually extracted data and data obtained using the Framework. However, there was limited ability to assess the accuracy of user behavior and pathways data from this study. In future studies, developers and designers could conduct more specific target audience analysis to understand specific behaviors for building a tailored framework in the planning stage. The Framework could be validated by comparing expected use in different stages of the project. In the project planning stage, user acceptance testing and user experience testing could include scenarios and measurement methods for expected use. In the design, development, and evaluation stages, use could be observed and measured during user testing. After the launch of the project, usage data could be obtained through clinical trials. This comparison of expected versus observed use may also provide more opportunity to assess user mapping and determine pathways of user behavior.

Recommendation 6: Ethics and Transparency With Users

To ensure that vulnerable populations such as people with a cancer diagnosis are protected, users should be informed of the intent to collect usage data as proposed in this Framework. Clear identification of the type of data intended to be collected and the purpose for data collection is vital in promoting trust between users and app developers. Particularly within clinical trials, this can be achieved during the information and consent process to ensure that users are providing informed consent. In both of the studies used to develop this Framework, ethics approval was obtained and participants were informed of usage data tracking prior to providing consent. Usage data were collected to inform the evaluation of and engagement with the app interventions in line with a user-centered design approach, allowing for future iterations to build upon findings. To protect users' privacy, only coded data were extracted that were linked to user IDs. No personal or identifying information was obtained or used.

Next Steps for the ADUCI Framework

The ADUCI Framework facilitates the extraction of accurate usage data and informed approaches to reduce the burden of lengthy manual data extraction. However, the Framework has limitations because it is in the early stages of development. The proposed recommendations create the next opportunity to test and refine the Framework, and to assess user engagement based on tailored comprehensive target audience analysis. Recommendations 1 and 2 will prevent usage data leakage while allowing developers to understand target audience behavior, thereby providing more accurate usage data for analysis. Recommendation 3 will give target audiences enriched personalization to engage with the program. The collectable data from personalization methods, including star rating, favorite, and counting star rate functionalities, will supply evidence-based future planning sources. Recommendations 4 and 5 will allow for the development of a more robust framework for projects and will provide the opportunity to validate the Framework.

Discussion

Principal Findings

Applying the ADUCI Framework can reduce errors and allow for a more accurate analysis of usage data. The ADUCI Framework describes how to incorporate and analyze usage data at each stage of the research life cycle, including development during user testing, pilot testing, and applying findings to a randomized controlled trial. This provides future research with a framework for measuring and testing functionality, usability, and user engagement.

The importance of precisely reporting usage data is to provide an accurate representation of user engagement with e-interventions. Consideration of user engagement begins during the planning and design stages, and continues through the development and evaluation stages of an e-research project's life cycle. Enhancing user engagement includes developing programs that are quick, easy, and intuitive to use [25]. This process was achieved and addressed during user testing, and included having a cut-off time of 20 seconds to complete actions. This cut-off time allowed for any changes to be made to ensure that the content was easily navigated and functionality was usable by the targeted audience.

User engagement continues to be monitored and assessed throughout the life of interventions. Satisfaction with interventions can have a positive impact on user engagement, by which people with high satisfaction may be more likely to continue using interventions [26]. There is a strong imperative to accurately analyze satisfaction and app intervention use to determine the suitability of intervention content for meeting end users' needs. Recommendations, including page rating functionality, the ability to record favorite pages within apps, and the use of technical solutions such as Google Tag Manager with iFrame technology, provide the opportunity to accurately assess users' satisfaction with interventions and to link satisfaction with corresponding usage data. This is particularly important in the cancer field owing to the changing nature of information and resources available for people living with cancer and their caregivers. Adequate usage data will inform how to design and maintain e-interventions to meet the needs of people affected by cancer.

The ADUCI Framework was developed by applying the method to the ACE app study for adequate data cleaning. Data cleaning frameworks have been applied to other areas of health care technologies such as electronic medical records [27] to ensure accuracy in the data extracted. In this study, we compared manually extracted data automatically generated from usage tracking platforms and data obtained after the ADUCI Framework was applied. Manually extracted data showed a 16% increase in the number of logins compared to that identified by the ADUCI Framework. Applying the ADUCI Framework to duration of use provided strong evidence for the need to thoroughly clean and analyze manually extracted data. App usage when the ADUCI Framework was applied showed much less variance in duration of use. This was due to the removal of logins with no use and the standardization of lengthy uses with no navigation. For example, application of the framework

resulted in a difference of approximately 55.5 hours of use of the *Cancer Information* section of the ACE app, with no navigation. Total duration of use of the app for the intervention period was 53,074 seconds when the ADUCI Framework was applied, which was recorded as approximately 72% higher (91,256 seconds) without the Framework. Combined with discrepancies evident in our report in which the duration of use in a specific app section exceeded the duration of login on several occasions, these findings highlight the inflation of results that can occur without the use of a framework. The use of the ADUCI Framework during development and testing highlight areas where data cleaning and analysis can be improved for future interventions.

Within the psycho-oncology setting, there is a need for cost-effective assessments of interventions [28] that meet users' needs. Assessing usage data with the ADUCI Framework and applying the recommendations for practice outlined in this report may help to more accurately assess user engagement throughout the life cycle of an intervention and allow for a thorough analysis of cost-effectiveness [9]. This approach can continue after translating research into practice, which facilitates the ongoing upkeep of interventions and potential cost savings in being able to amend existing interventions rather than the cost of developing new interventions or undertaking audits.

Limitations

This study was limited as the ADUCI Framework was developed from a sample of 43 participants who received the e-intervention. However, usage (over 250 logins) allowed for the Framework to be thoroughly tested in this cohort. A larger sample would enable verification of the Framework and a thorough comparison of observed use and expected use during user testing. With a larger sample, it may be possible to assess users' behavior and provide additional information about the navigation patterns users follow.

Conclusion

Accurate data usage analysis is vital in the growing eHealth environment to ensure that e-interventions are promoting engagement. In this study, we have proposed a framework to support the assessment of apps guided by user-centered design and human-computer interaction. This first iteration of the ADUCI Framework highlights how data can be accurately extracted, the potential for resource savings in a project life cycle, and provides recommendations for future studies to incorporate in their project design to enhance the usage data captured.

Acknowledgments

This study is supported by the National Health and Medical Research Council (Grant/Award Number: 1094831); Eastern Health, Epworth Healthcare, Barwon Health, North Eastern Metropolitan Integrated Cancer Service (ICS), Western & Central Melbourne ICS, Barwon South Western Regional ICS, North Eastern Melbourne ICS, Peter MacCallum Cancer Centre.

Conflicts of Interest

None declared.

References

1. Lupton D. Apps as Artefacts: Towards a Critical Perspective on Mobile Health and Medical Apps. *Societies* 2014 Oct 29;4(4):606-622. [doi: [10.3390/soc4040606](https://doi.org/10.3390/soc4040606)]
2. The Growing Value of Digital Health Evidence and Impact on Human Health and the Healthcare System. IQVIA Institute for Human Data Science. 2017. URL: <https://www.iqvia.com/insights/the-iqvia-institute/reports/the-growing-value-of-digital-health> [accessed 2019-08-28]
3. Heynsbergh N, Heckel L, Botti M, Livingston PM. Feasibility, useability and acceptability of technology-based interventions for informal cancer carers: a systematic review. *BMC Cancer* 2018 Mar 02;18(1):244 [FREE Full text] [doi: [10.1186/s12885-018-4160-9](https://doi.org/10.1186/s12885-018-4160-9)] [Medline: [29499663](https://pubmed.ncbi.nlm.nih.gov/29499663/)]
4. Heynsbergh N, Heckel L, Botti M, Livingston PM. A Smartphone App to Support Carers of People Living With Cancer: A Feasibility and Usability Study. *JMIR Cancer* 2019 Jan 31;5(1):e11779 [FREE Full text] [doi: [10.2196/11779](https://doi.org/10.2196/11779)] [Medline: [30702432](https://pubmed.ncbi.nlm.nih.gov/30702432/)]
5. Livingston P, Heckel L, Orellana L, Ashley D, Ugalde A, Botti M, et al. Outcomes of a randomized controlled trial assessing a smartphone Application to reduce unmet needs among people diagnosed with CancEr (ACE). *Cancer Med* 2020 Jan;9(2):507-516. [doi: [10.1002/cam4.2718](https://doi.org/10.1002/cam4.2718)] [Medline: [31769226](https://pubmed.ncbi.nlm.nih.gov/31769226/)]
6. Bertucci F, Le Corroller-Soriano A, Monneur-Miramón A, Moulin J, Fluzin S, Maraninchi D, et al. Outpatient Cancer Care Delivery in the Context of E-Oncology: A French Perspective on "Cancer outside the Hospital Walls". *Cancers (Basel)* 2019 Feb 14;11(2) [FREE Full text] [doi: [10.3390/cancers11020219](https://doi.org/10.3390/cancers11020219)] [Medline: [30769858](https://pubmed.ncbi.nlm.nih.gov/30769858/)]
7. Rogers Y, Preece J, Sharp H. The process of interaction design. In: *Interaction design: beyond human-computer interaction*. United Kingdom: Wiley; 2011.
8. Cullinan C, Agamanoli S, Roche D, Hegarty F. Open Window: Reducing Isolation for Patients. 2004 Presented at: UbiComp 2004 Sixth International Conference on Ubiquitous Computing; 2004; England URL: <http://web.media.mit.edu/~stefan/hc/publications/Cullinan04OpenWindowUBICOMP.pdf>

9. Iribarren SJ, Cato K, Falzon L, Stone PW. What is the economic evidence for mHealth? A systematic review of economic evaluations of mHealth solutions. *PLoS One* 2017;12(2):e0170581 [FREE Full text] [doi: [10.1371/journal.pone.0170581](https://doi.org/10.1371/journal.pone.0170581)] [Medline: [28152012](https://pubmed.ncbi.nlm.nih.gov/28152012/)]
10. Webster J, Ahuja JS. Enhancing the Design of Web Navigation Systems: The Influence of User Disorientation on Engagement and Performance. *MIS Quart* 2006;30(3):661-668. [doi: [10.2307/25148744](https://doi.org/10.2307/25148744)]
11. O'Brien H, Cairns P, Hall M. A practical approach to measuring user engagement with the refined user engagement scale (UES) and new UES short form. *Int J Human-Comput Stud* 2018 Apr;112:28-39. [doi: [10.1016/j.ijhcs.2018.01.004](https://doi.org/10.1016/j.ijhcs.2018.01.004)]
12. Baumel A, Kane JM. Examining Predictors of Real-World User Engagement with Self-Guided eHealth Interventions: Analysis of Mobile Apps and Websites Using a Novel Dataset. *J Med Internet Res* 2018 Dec 14;20(12):e11491 [FREE Full text] [doi: [10.2196/11491](https://doi.org/10.2196/11491)] [Medline: [30552077](https://pubmed.ncbi.nlm.nih.gov/30552077/)]
13. Lambert S, Levesque J, Girgis A. The impact of cancer and chronic conditions on caregivers and family members. In: Koczwara B, editor. *Cancer and chronic conditions: addressing the problem of multimorbidity in cancer patients and survivors*. Singapore: Springer; 2016:159-203.
14. Sklenarova H, Krümpelmann A, Haun MW, Friederich H, Huber J, Thomas M, et al. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* 2015 May 01;121(9):1513-1519. [doi: [10.1002/cncr.29223](https://doi.org/10.1002/cncr.29223)] [Medline: [25677095](https://pubmed.ncbi.nlm.nih.gov/25677095/)]
15. Heynsbergh N, Heckel L, Botti M, Livingston PM. Development of a Smartphone App for Informal Carers of People With Cancer: Processes and Learnings. *JMIR Form Res* 2019 Apr 11;3(2):e10990 [FREE Full text] [doi: [10.2196/10990](https://doi.org/10.2196/10990)] [Medline: [30973346](https://pubmed.ncbi.nlm.nih.gov/30973346/)]
16. How Long Do Users Stay on Web Pages? Nielsen Norman Group. 2011. URL: <https://www.nngroup.com/articles/how-long-do-users-stay-on-web-pages/> [accessed 2018-09-12]
17. Iribarren SJ, Schnall R, Stone PW, Carballo-Diéguez A. Smartphone Applications to Support Tuberculosis Prevention and Treatment: Review and Evaluation. *JMIR Mhealth Uhealth* 2016 May 13;4(2):e25 [FREE Full text] [doi: [10.2196/mhealth.5022](https://doi.org/10.2196/mhealth.5022)] [Medline: [27177591](https://pubmed.ncbi.nlm.nih.gov/27177591/)]
18. Most popular social networks worldwide as of April 2020, ranked by number of active users. Statista. 2020. URL: <https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/> [accessed 2020-06-25]
19. Mohsin M. 10 Social media statistics you need to know in 2020. Oberlo. 2020. URL: <https://au.oberlo.com/blog/social-media-marketing-statistics> [accessed 2020-06-25]
20. Chen J. Social media demographics to inform your brand's strategy in 2020. Sprout Social. 2020. URL: <https://sproutsocial.com/insights/new-social-media-demographics/> [accessed 2020-06-25]
21. Churchill E, Sarma A. Data design for personalization: current challenges and emerging opportunities. 2014 Presented at: Proceedings of the 7th ACM international conference on web search and data mining; 2014; New York. [doi: [10.1145/2556195.2556211](https://doi.org/10.1145/2556195.2556211)]
22. Eagan J. Designing interfaces to enrich personalization. 2006 Presented at: Proceedings of the 6th Conference on Designing Interactive systems; 2006; University Park. [doi: [10.1145/1142405.1142460](https://doi.org/10.1145/1142405.1142460)]
23. Guidelines in HCI. Tutorials Point. URL: https://www.tutorialspoint.com/human_computer_interface/guidelines_in_hci.htm [accessed 2020-05-26]
24. Kimani S. Design rules. URL: http://www.dis.uniroma1.it/~catarci/HCIslides/HCIDesignRules_April2012.pdf [accessed 2020-06-25]
25. Davis FD. Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. *MIS Quart* 1989 Sep;13(3):319-340. [doi: [10.2307/249008](https://doi.org/10.2307/249008)]
26. Kim Y, Kim D, Wachter K. A study of mobile user engagement (MoEN): Engagement motivations, perceived value, satisfaction, and continued engagement intention. *Decis Support Syst* 2013 Dec;56:361-370. [doi: [10.1016/j.dss.2013.07.002](https://doi.org/10.1016/j.dss.2013.07.002)]
27. Dziadkowiec O, Callahan T, Ozkaynak M, Reeder B, Welton J. Using a Data Quality Framework to Clean Data Extracted from the Electronic Health Record: A Case Study. *EGEMS (Wash DC)* 2016;4(1):1201 [FREE Full text] [doi: [10.13063/2327-9214.1201](https://doi.org/10.13063/2327-9214.1201)] [Medline: [27429992](https://pubmed.ncbi.nlm.nih.gov/27429992/)]
28. Tuffaha H, El-Saifi N, Chambers S, Scuffham P. New challenges in psycho-oncology: Economic evaluation of psychosocial services in cancer: Challenges and best practice recommendations. *Psychooncology* 2019 Jan;28(1):3-10. [doi: [10.1002/pon.4933](https://doi.org/10.1002/pon.4933)] [Medline: [30440112](https://pubmed.ncbi.nlm.nih.gov/30440112/)]

Abbreviations

CCV: Cancer Council Victoria

eHealth: electronic health

ADUCI: Assessment of Data Usage of Cancer Electronic Interventions

Edited by G Eysenbach; submitted 13.02.20; peer-reviewed by M Kanis, E Winkler; comments to author 20.04.20; revised version received 05.06.20; accepted 14.06.20; published 15.09.20.

Please cite as:

Heynsbergh N, O SC, Livingston PM

Assessment of Data Usage of Cancer e-Interventions (ADUCI) Framework for Health App Use of Cancer Patients and Their Caregivers: Framework Development Study

JMIR Cancer 2020;6(2):e18230

URL: <http://cancer.jmir.org/2020/2/e18230/>

doi: [10.2196/18230](https://doi.org/10.2196/18230)

PMID: [32930666](https://pubmed.ncbi.nlm.nih.gov/32930666/)

©Natalie Heynsbergh, Seung Chul (Eric) O, Patricia M Livingston. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 15.09.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study

Teresa A'mar^{1*}, PhD; J David Beatty², MD; Catherine Fedorenko¹, MMSci; Daniel Markowitz², MD; Thomas Corey¹, MS; Jane Lange¹, PhD; Stephen M Schwartz¹, PhD; Bin Huang³, DrPH; Jessica Chubak^{4*}, PhD; Ruth Etzioni^{1*}, PhD

¹Public Health Sciences, Fred Hutchinson Cancer Research Center, Seattle, WA, United States

²Swedish Cancer Institute, Seattle, WA, United States

³College of Medicine, University of Kentucky, Lexington, KY, United States

⁴Kaiser Permanente Washington Health Research Institute, Seattle, WA, United States

*these authors contributed equally

Corresponding Author:

Ruth Etzioni, PhD

Public Health Sciences

Fred Hutchinson Cancer Research Center

1100 Fairview Avenue North

Seattle, WA

United States

Phone: 1 206 667 5000

Email: retzioni@fredhutch.org

Related Article:

This is a corrected version. See correction statement: <https://cancer.jmir.org/2020/2/e23821/>

Abstract

Background: There is a need for automated approaches to incorporate information on cancer recurrence events into population-based cancer registries.

Objective: The aim of this study is to determine the accuracy of a novel data mining algorithm to extract information from linked registry and medical claims data on the occurrence and timing of second breast cancer events (SBCE).

Methods: We used supervised data from 3092 stage I and II breast cancer cases (with 394 recurrences), diagnosed between 1993 and 2006 inclusive, of patients at Kaiser Permanente Washington and cases in the Puget Sound Cancer Surveillance System. Our goal was to classify each month after primary treatment as pre- versus post-SBCE. The prediction feature set for a given month consisted of registry variables on disease and patient characteristics related to the primary breast cancer event, as well as features based on monthly counts of diagnosis and procedure codes for the current, prior, and future months. A month was classified as post-SBCE if the predicted probability exceeded a probability threshold (PT); the predicted time of the SBCE was taken to be the month of maximum increase in the predicted probability between adjacent months.

Results: The Kaplan-Meier net probability of SBCE was 0.25 at 14 years. The month-level receiver operating characteristic curve on test data (20% of the data set) had an area under the curve of 0.986. The person-level predictions (at a monthly PT of 0.5) had a sensitivity of 0.89, a specificity of 0.98, a positive predictive value of 0.85, and a negative predictive value of 0.98. The corresponding median difference between the observed and predicted months of recurrence was 0 and the mean difference was 0.04 months.

Conclusions: Data mining of medical claims holds promise for the streamlining of cancer registry operations to feasibly collect information about second breast cancer events.

(*JMIR Cancer* 2020;6(2):e18143) doi:[10.2196/18143](https://doi.org/10.2196/18143)

KEYWORDS

cancer registries; medical claims; cancer recurrence event; statistical learning; breast cancer; medical informatics; data mining

Introduction

Population-based cancer registries are indispensable for tracking the evolving burden of cancer in the population. In the United States, the Surveillance, Epidemiology, and End Results (SEER) Program [1] of the National Cancer Institute (NCI) is a national resource for population-based information on cancer incidence, mortality, and survival. SEER provides curated, quality-controlled information on demographics, disease characteristics at diagnosis, and primary treatments for newly diagnosed patients in 18 geographically defined catchment areas around the country.

While SEER is a primary source of information about the population cancer burden, it currently focuses on primary diagnoses of cancer and the first course of treatment. Mortality information is added via annual linkages to vital status records from the National Center for Health Statistics and State Health departments. Beyond the date and cause of death, information on postdiagnosis outcomes such as cancer recurrence or progression is not collected, except for subsequent primary tumors. A prospective system for recording recurrences in the SEER registries would require expanded reporting by health care facilities and providers and the requisite financial support to extract and process the necessary information. The absence of such an infrastructure in SEER has driven efforts to harness administrative claims data for recurrence identification.

Claims-based approaches use a patient's pattern of medical claims to identify the recurrence event at the individual level. Initial claims-based breast cancer recurrence algorithms were "clinically intuitive," (ie, based on beliefs about what diagnosis or procedure codes would be used at the time of a recurrence) [2-5]. Recently, more automated statistical learning and data mining approaches have been harnessed to predict recurrence events from claims histories. Chubak et al [6] used classification and regression tree analysis to predict whether a patient had experienced a breast cancer recurrence or second breast cancer diagnosis. Ritzwoller et al [7] used a combination of logistic regression and changepoint detection to identify the presence and timing of recurrence events. Both of these contributions focused on identifying outcomes for research studies; in this study, we focus on a surveillance application, motivated by the lack of recurrence information in cancer registries and the consequent absence of recurrence in registry-based assessments of population disease burden.

In this article, we present a statistical learning algorithm to predict second breast cancer event (SBCE) occurrence and timing using a cancer information registry linked with medical claims among women with localized breast cancer diagnosed in the Puget Sound SEER cancer registry (Cancer Surveillance System) and treated at Kaiser Permanente Washington (KPWA), formerly Group Health. Our work differs from that of Ritzwoller et al [7] and Chubak et al [6] in several ways. First, we use a gradient boosting algorithm which generally provides improved performance over logistic regression or single trees as used in

these previous studies. Our definition of the learning problem (as a month-based classification problem) and our use of gradient boosting permitted the inclusion of a large number of predictors, including some novel predictors that leveraged our learning problem definition and improved performance over the Chubak algorithm in this data set. Additionally, in contrast to prior studies which focused on research applications, our entire focus is on the augmentation of cancer registries; this guides our evaluation of predictive performance and recommendations for practical applications of our work.

Methods**Definitions and Overview**

The standard definition of cancer recurrence is the return or rediagnosis of disease after an apparently disease-free interval. In contrast, cancer progression is any transition to a more advanced disease state without a disease-free interval. In this manuscript, we focus on SBCEs, which we define as a resurfacing of the original breast cancer (ie, recurrence) or a diagnosis of a new breast cancer. We focus on the first SBCE after the primary breast cancer diagnosis. Our goal was to use the entire record of claims for a patient to predict whether (and when) a recurrence has occurred, not to predict imminent or future recurrence for real-time clinical care, which would only be able to use claims up to the time of prediction.

Resolution of the defined prediction problem rests on the following: (1) the availability of a large enough sample of patients with claims histories and gold standard SBCE data; (2) claims histories that are adequately rich so that features predictive of SBCE can be extracted; (3) a prediction algorithm that outputs a prediction of both the presence of an SBCE within an individual patient and the timing of the event; and (4) a set of metrics for assessment of the performance of the prediction algorithm. We discuss each of these below.

Study Population and Gold Standard

The study population was female KPWA patients aged 18 and older with a first primary, unilateral, stage I-II breast cancer between 1993 and 2006. We used Cancer Surveillance System, the SEER registry for the Puget Sound area, to identify these cases. Only patients who remained enrolled at KPWA for 1 year after their breast cancer diagnosis (unless they died) were included. Additional eligibility criteria have been described previously [6]; a total of 3152 patients were eligible.

Through structured medical record abstraction of KPWA charts (both paper and electronic), we confirmed eligibility and collected gold standard data on breast cancer recurrence and second primary breast cancers. Abstractors had access to the full medical record, which included clinician progress notes, imaging reports, surgical reports, and pathology reports. Based on this information, a recurrence was defined as an invasive tumor in the ipsilateral breast or lymph nodes, or a distant tumor, occurring at least 120 days after definitive surgery for the index breast cancer. A second breast primary was defined as a

contralateral breast tumor, occurring at least 120 days after definitive surgery for the index breast cancer. Additionally, a second breast cancer in the ipsilateral breast after breast-conserving surgery is considered a second primary in SEER if it is confirmed by histological evaluation and tumor markers to be distinct from the index primary; or occurs over 5 years from the date of diagnosis of the index primary breast cancer. Chart-abstracted data were considered the gold standard in algorithm development. The KPWA Human Subjects Research Committee approved study activities.

Deidentified data only (with all dates stored as days since diagnosis of the first primary) were available for the current analysis. Patient-level data were augmented to include a randomly generated month and day of diagnosis and fractional year for age on the day of diagnosis. These changes allowed us to include the time since diagnosis and age in real numbers as month-level predictor variables, as well as summarize the claims information by calendar month.

Predictor Variables

Candidate predictors for algorithm development included registry variables summarizing demographic (eg, age) and disease characteristics (eg, site, stage, grade, hormone receptor status) at diagnosis and variables defined on the basis of the health care utilization (henceforth called “claims,” though most codes resulted from health care within the KPWA system and not from external providers who submitted actual claims for reimbursement). Procedures and diagnoses were identified using standard coding systems (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM], Current Procedural Terminology [CPT], and Healthcare Common Procedure Coding System [HCPCS]).

Valid claims were defined to be claims after the analysis start date (6 months after the primary breast cancer diagnosis) until the end of follow-up. For patients with a nonbreast second primary cancer, the end of follow-up was set to 3 months before the registry-based diagnosis date. For patients with more than one SBCE, we included all claims before and after the event but censored the data 1 month before the first subsequent breast cancer event. For patients without an SBCE we included all claims recorded until the end of follow-up.

For each individual, we consolidated claims by days since primary breast cancer diagnosis so that any diagnosis or procedure code occurred at most once per day. Additionally, all diagnosis codes included in the analyses had to occur at least twice (ie, on two separate days) for at least one individual. Codes were then summed by calendar month for each individual to create a monthly count total for each code.

We grouped codes that were similar or that captured the same clinical condition or medical procedure type using code groupings specified in Chubak et al [6], which implemented both coarser and finer grouping systems. The coarser groups had 11 diagnostic code groups and 22 procedure groups, and the finer scale groups had 77 diagnostic code groups and 156 procedure code groups. In our analysis, we used these finer level groups ([Multimedia Appendix 1](#)).

Prediction Problem Definition and Feature Engineering

We formulated our prediction objective as a classification problem on a person-month level. The goal was to classify months as either pre- or post-SBCE (including the month of SBCE). In this way, we transformed the problem of predicting a person-level time to event into a binary classification problem at the level of a person-month. Features used to predict the SBCE status for each month included baseline registry variables, months since diagnosis, age of the patient in the month, and a set of counts representing the number of occurrences of each code group within the month. In addition, we counted the number of months since the last occurrence of each code group as well as the number of months until the next occurrence. A default value of -1 was used when no instance of the code group was observed before or after the current month. An additional set of features consisted of the fraction of the prior months containing at least one instance of each code group.

We adopted a gradient-boosting algorithm (function XGBoost in R; R Foundation for Statistical Computing) [8] for the predictive analysis. Gradient boosting is an iterative, ensemble algorithm that incorporates multiple classification models; XGBoost is an optimized, distributed gradient boosting library designed by Chen et al [8]. The data for both the non-SBCE and SBCE patients were each split 80:20 and combined into training and test sets, respectively. The training set was split into 5 groups for cross-validation in a stratified fashion, to identify flexibility parameters that produced optimal out-of-sample performance.

Performance Metrics

All performance metrics were calculated on the test data set. We evaluated predictive performance at both a person-month level and a person level. Person-month-level accuracy was captured via receiver operating characteristic (ROC) curves and area under the curve (AUC) statistics.

For person-level predictions, we defined a grid of threshold probabilities between 0.10 and 0.75, and defined a person as having an SBCE if any of their month-level predictions exceeded the threshold. The predicted time of an SBCE was set to be the first month for which the month-level prediction exceeded the threshold. The sensitivity and specificity of the person-level predictions were assessed along with person-level positive and negative predictive values.

We assessed the accuracy of the predicted time of SBCE by calculating the mean and median difference between the predicted and actual time of the event for persons correctly predicted to have an SBCE. We also graphed a Kaplan-Meier curve of the predicted time to an SBCE and compared it against the Kaplan-Meier curve of the observed time among all patients with an SBCE. Thus, person-level accuracy of the SBCE prediction and its timing were calculated for each threshold probability.

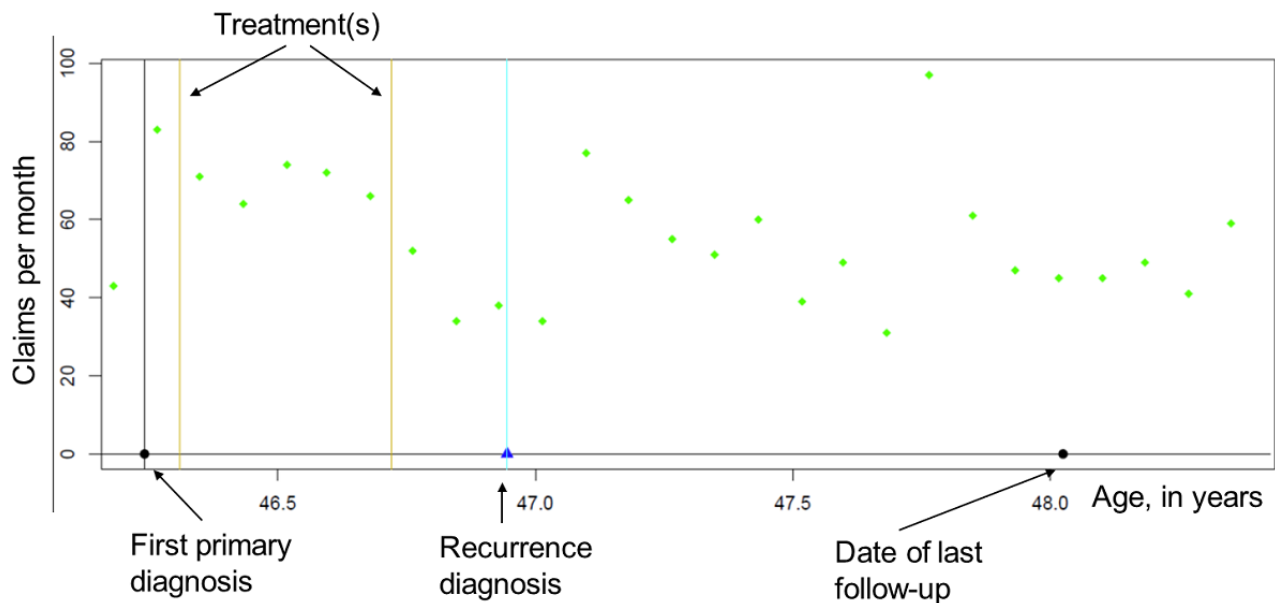
Results

There were 3152 eligible patients. Baseline demographic and clinical characteristics of these cases have been previously summarized [6]. SBCE patients were more likely to have been diagnosed in an earlier calendar year, to have regional rather than localized disease, to have tumors that are not as well-differentiated, and to have negative estrogen or progesterone receptor status. The cumulative net

(Kaplan-Meier-based) probability of an SBCE was 25% over 14 years follow-up.

Of the 3152 initially eligible patients, 3102 had at least one month of claims starting 6 months after the initial date of diagnosis up to a maximum of 159 months, 2698 without an SBCE and 404 with an SBCE. Figure 1 shows an individual-level profile of the number of claims per month for a hypothetical SBCE case.

Figure 1. Sample plots for a hypothetical case showing a typical pattern of recorded claims each month before and after a second breast cancer event (SBCE).



Of the 404 patients with an SBCE, 394 had at least one month of claims after the date of the second event. Predictive analyses excluded the 10 recurrent cases with no claims after their SBCE date, yielding a final sample size of 3092 patients. In the monthly claims data for the 3092 patients included in the analysis, there were 543 unique diagnostic codes and 992 unique procedure codes.

The training set included monthly claims data for 2160 patients without an SBCE and 315 with an SBCE. The test set included monthly claims data for 538 patients without an SBCE and 79 with an SBCE.

The number of months of available claims was slightly longer in patients with an SBCE (range 3-138, mean 44.7, median 39.5, SD 26.2 months) compared to those without an SBCE (range 1-149, mean 31.5, median 28, SD 19.2 months). SBCE cases had claims for a median of 21.9 months before and 19 months after the SBCE.

Table 1 displays the 20 features with highest importance identified by the gradient boosting algorithm. The features with highest importance are those most commonly present in the submodels that constitute the final algorithm. They primarily include secondary malignancy, imaging tests, diagnostic tests, and salvage treatments.

Table 1. Top 20 features identified by the gradient boosting algorithm.

Order	Description
1	Fraction of prior months with diagnosis code for secondary malignant neoplasm of other specified sites
2	Fraction of prior months with procedure codes for biopsy or excision of lymph nodes
3	Months since last procedure code for needle biopsy
4	Fraction of prior months with diagnosis codes for secondary malignant neoplasm of respiratory and digestive systems
5	Months since last procedure code for bone scan
6	Months since last procedure code for other tumor markers
7	Months since last diagnosis code for carcinoma in situ of breast and genitourinary system
8	Fraction of prior months with diagnosis code for cancer of breast
9	Time until next diagnosis code for secondary malignant neoplasm of respiratory and digestive systems
10	Fraction of prior months with procedure code for fine needle aspirate
11	Number of instances of diagnosis code for cancer of breast in the current month
12	Months since procedure code for biopsy or excision of lymph nodes
13	Fraction of prior months with procedure code for chemotherapy
14	Months since diagnosis
15	Months since last procedure code for chest computed tomography
16	Fraction of prior months with procedure code for bone scan
17	Age in current month
18	Fraction of prior months with diagnosis code for benign mammary dysplasias
19	Time until next diagnosis code for secondary malignant neoplasm of other specified sites
20	Time until next diagnosis code for cancer of other and unspecified sites

The AUC for month-level ROC curve in the test data set was 0.986 (Figure 2). Multimedia Appendix 2 shows the monthly SBCE status (0 for pre-SBCE; 1 for post-SBCE, including month of SBCE), along with predicted probabilities of being post-SBCE for a randomly selected set of 12 non-SBCE cases

in the test set; Multimedia Appendix 3 presents similar results for 12 SBCE cases. The predicted probabilities generally tracked well with the observed outcomes, but performance in SBCE cases degraded over time in some cases after the month of the event.

Figure 2. Month-level receiver operating characteristic (ROC) curve based on the test data set corresponding to the prediction model derived using the training data set. The area under the curve (AUC) is 0.986.

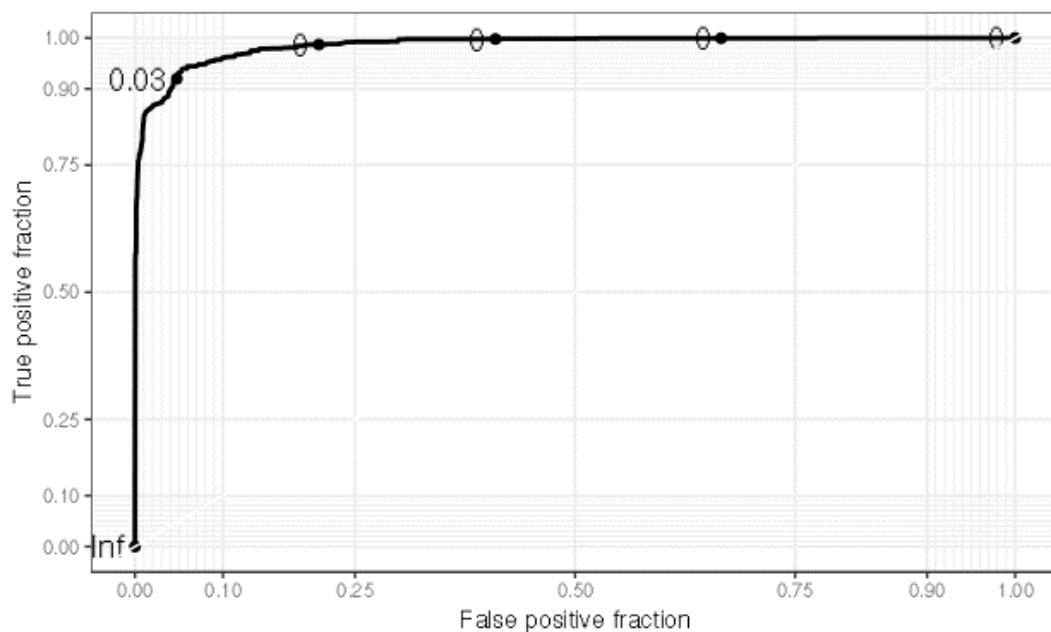


Table 2 provides the person-level performance for various thresholds for classifying an individual as having an SBCE. For each threshold, an individual was classified as having an SBCE if at least one of the monthly predicted probabilities (of being post-SBCE) exceeds the threshold. Lower thresholds are associated with greater sensitivity but lower specificity and

positive predictive value (PPV). The sensitivity, specificity, PPV, and negative predictive value (NPV) corresponding to a threshold of 0.5 are 88.6%, 97.8%, 85.4%, and 98.3% respectively. As the threshold increases, the PPV improves, and as the threshold decreases, the NPV improves.

Table 2. Person-level performance (sensitivity, specificity, and positive and negative predictive values) corresponding to various probability thresholds for classifying an individual as having a second breast cancer event^a.

Threshold	Sensitivity	Specificity	Positive predictive value	Negative predictive value
0.10	0.962	0.942	0.710	0.994
0.15	0.937	0.950	0.733	0.990
0.20	0.924	0.955	0.753	0.988
0.25	0.911	0.957	0.758	0.987
0.30	0.886	0.959	0.761	0.983
0.35	0.886	0.963	0.778	0.983
0.40	0.886	0.972	0.824	0.983
0.45	0.886	0.976	0.843	0.983
0.50	0.886	0.978	0.854	0.983
0.55	0.886	0.980	0.864	0.983
0.60	0.886	0.980	0.864	0.983
0.65	0.886	0.981	0.875	0.983
0.70	0.873	0.983	0.885	0.981
0.75	0.861	0.987	0.907	0.980

^aFor each threshold, an individual is predicted to have a second breast cancer event if at least one of the monthly predicted probabilities exceeds the threshold. There were 538 cases without and 79 cases with a second breast cancer event in the test set.

Table 3 summarizes the accuracy of the predicted timing of SBCE at each threshold probability. For a threshold of 0.5, the mean difference in months between the predicted and observed month of recurrence for correctly classified recurrent cases is 0.04 months (SD 3.5 months) and the median difference is zero.

Figure 3 plots a Kaplan-Meier curve of the observed time to SBCE among SBCE cases in the test data set, overlaid with a similar curve of the predicted time to SBCE (defined as the first month for which the predicted probability of being post-SBCE

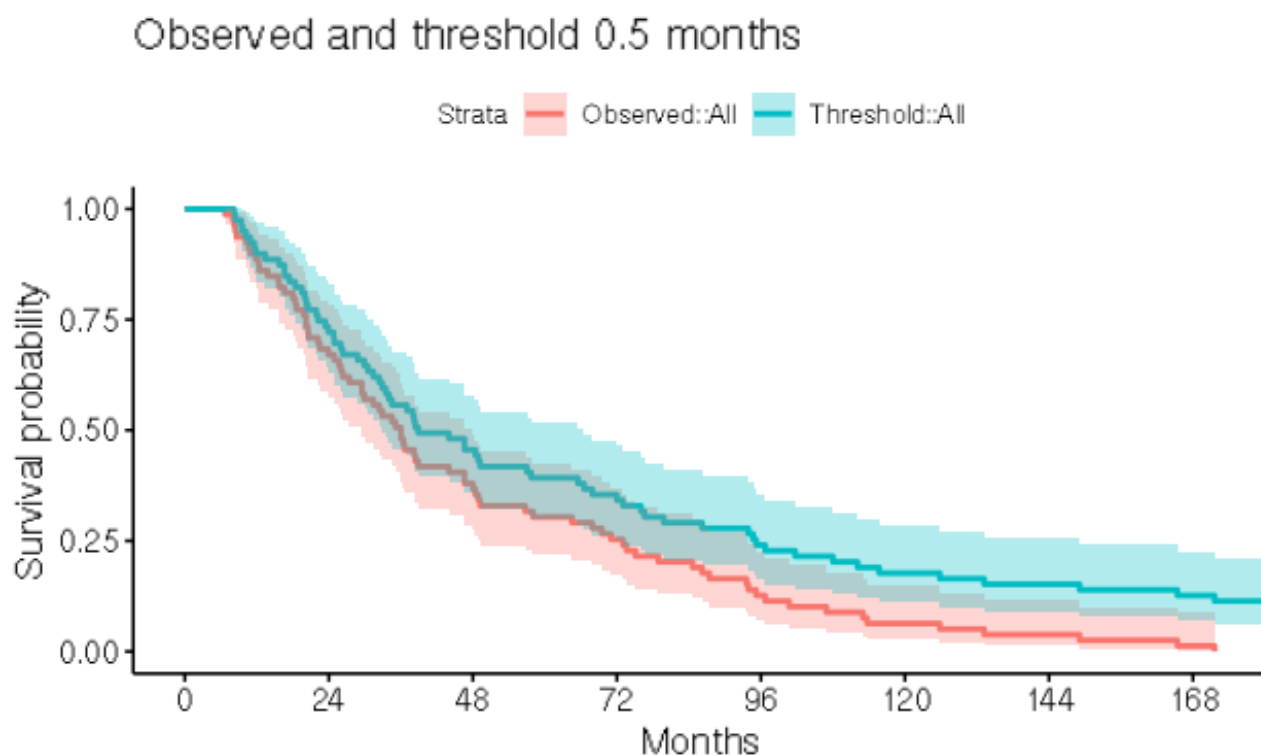
exceeds 0.5). In the predicted curve, cases for which no SBCE is predicted are censored at their last follow-up time. The observed and predicted curves confirm the favorable performance of the prediction algorithm in terms of both person-level diagnostic performance and timing. Note that these results may vary slightly depending on the random number seed/initialization used to split the data into the training and test sets and perform the cross-validation subselection used in the XGBoost algorithm.

Table 3. Accuracy of the predicted timing of a second breast cancer event at each of a set of threshold probabilities^a.

Threshold	Predicted number of second breast cancer events	Mean difference in months	Median difference in months	Minimum difference in months	Maximum difference in months
0.10	76	-1.5	0	-36	19
0.15	74	-0.8	0	-27	19
0.20	73	-0.3	0	-24	19
0.25	72	-0.3	0	-24	19
0.30	70	-0.5	0	-24	5
0.35	70	-0.5	0	-24	5
0.40	70	-0.3	0	-24	5
0.45	70	-0.2	0	-24	5
0.50	70	-0.04	0	-24	5
0.55	70	0.01	0	-24	5
0.60	70	0.1	0	-24	5
0.65	70	0.1	0	-24	5
0.70	69	0.3	0	-24	9
0.75	68	0.4	0	-24	9

^aThe table shows the mean, median, maximum, and minimum of the difference between the observed and predicted time of a second breast cancer event given the threshold for each of the individuals correctly predicted to have a second breast cancer event. A negative value indicates that the predicted time of a second breast cancer event precedes the observed time. For each threshold, an individual is determined to have had a second breast cancer event if at least one of the monthly predicted probabilities exceeds the threshold. There are 79 individuals with a second breast cancer event in the test data.

Figure 3. Accuracy of predicted timing of recurrence expressed via a comparison of Kaplan-Meier curves for observed (red) versus predicted (blue) time to SBCE among test set cases with a SBCE, where the predicted time to SBCE is based on a threshold probability of 0.5. Cases for whom no SBCE is predicted (monthly predicted probabilities never exceed 0.5) are censored at their last follow-up time. SBCE: second breast cancer event.



Discussion

This study tackles the overarching question of how best to harness electronic health data to inform cancer registries about disease recurrence events and to augment them to add this information. The core of our contribution centers on data mining of medical claims histories using a relatively established gradient boosting algorithm. The algorithm and the accompanying features expand on and complement published data mining approaches that use claims histories to learn about the risk of disease recurrence. Furthermore, our focus on surveillance, which drives our learning problem definition, performance evaluation, and recommendation, differs from existing work that focuses on clinical prognostication.

Our approach yields a continuous prediction per each valid claims month, to which a threshold can be applied to yield a level of diagnostic performance that is most consistent with a prespecified performance. A higher threshold raises sensitivity and lowers specificity. A lower threshold has the opposite effect. If achieving high NPV is the primary objective, then a lower threshold might potentially be preferred. With a NPV of 99.4% at a changepoint threshold of 0.10, our algorithm could be offered to registries as a tool for ruling out an SBCE [9]. Indeed, in the test data set with sample size of 617, a threshold of 0.10 classified 510 individuals as not having an SBCE. Therefore, if an NPV of 99.4% was deemed to be adequate, use of the algorithm would mean that the registry could focus recurrence-identification resources on 17% (107/617) of the case population.

Our approach has one feature in common with that of Ritzwoller et al [7], who predicted cancer recurrence based on medical claims among cases with lung and colorectal cancer. Their two-step procedure first predicted individual-level recurrence status and then predicted its timing by identifying the month of greatest change in the count of each code grouping, and reconciling the months so identified across the groupings. Our procedure merges the prediction of the presence of recurrence and the timing of recurrence, and applies a similar changepoint idea, but to the single series of monthly predicted probabilities of being post recurrence. This avoids the need to reconcile different predictions, and accommodates a large number of

novel features that leverage the month-based definition of the statistical learning problem.

Any method that uses medical claims to predict SBCE status will ideally require continuous and complete claims histories on all registry cases. In practice, there are likely to be gaps in coverage and some claims histories may be partially missing. Further, claims histories will not be available for uninsured cases, limiting the representativeness of the population for which recurrence information will be made available via our approach. In the KPWA data used here, most patients retained health system coverage over time, reducing the extent of this problem in the current analysis.

We foresee offering this algorithm as part of population-based center cancer registries' data capturing process. One critical reason that recurrence data are not well captured is that abstractors do not have enough time to look over all cancer cases periodically to identify any recurrence. Utilizing our algorithm, a subset of probable recurrences can be marked for further abstraction to verify the occurrence and timing of a recurrence. The threshold can be adjusted based on the resources available in the individual registry.

There are other limitations that arise from reliance on medical claims data as an approach for augmenting cancer registries. Diagnosis and procedure coding systems change over time and so claims-based algorithms will need frequent review and updating to remain current [10]. Even for those patients who are insured, gaps in coverage will inevitably arise as patients lose coverage or transition between insurance plans. Some insurance plans may not agree to participate in a linkage with the cancer registry. In any registry catchment area, there will be multiple payers; agreements will have to be executed with all of them for maximum coverage and linkages across plans will have to be implemented. These logistical issues are important but secondary to the critical first step showing that the linkages are likely to provide valid, useful, and useable information to inform health care professionals about disease recurrence. Further work is ongoing to investigate how the performance of our data-mining approach transfers to a setting in which there are multiple payers and coverage gaps or nonuniversal availability of claims linkages within a registry catchment area.

Acknowledgments

We thank Denise Albano and Noelle Noble (Fred Hutchinson Cancer Research Center) and Lisa Ross, Monica Fujii, and Onchee Yu (Kaiser Permanente Washington) for their assistance.

This work was supported by the National Institutes of Health (UG3CA218909, R21CA143242, R01CA120562, and R01CA093772) and by the American Cancer Society (CRTG-03-024-01-CCE). The collection of cancer incidence data used in this study was supported by the Cancer Surveillance System of the Fred Hutchinson Cancer Research Center, which is funded by Contract Number N01-CN-67009 and N01-PC-35142 from the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute with additional support from the Fred Hutchinson Cancer Research Center and the State of Washington. RE's work is partially supported by the Rosalie and Harold Rea Brown Endowment.

Conflicts of Interest

JC is Principal Investigator of a contract from Amgen Inc awarded to the Kaiser Foundation Health Plan of Washington to evaluate the accuracy of using electronic health record data to identify individuals with reduced ejection fraction heart failure. The other authors declare no conflicts.

Multimedia Appendix 1

Diagnostic and procedure code groups and types.

[[DOCX File, 23 KB - cancer_v6i2e18143_app1.docx](#)]

Multimedia Appendix 2

Monthly SBCE status along with predicted probabilities of being post-SBCE for a randomly selected set of 12 non-SBCE cases in the test set.

[[DOCX File, 33 KB - cancer_v6i2e18143_app2.docx](#)]

Multimedia Appendix 3

Monthly SBCE status along with predicted probabilities of being post-SBCE for a randomly selected set of 12 cases with an SBCE in the test set.

[[DOCX File, 44 KB - cancer_v6i2e18143_app3.docx](#)]

References

1. Surveillance, Epidemiology, and End Results Program. URL: <https://seer.cancer.gov/> [accessed 2020-02-05]
2. Warren JL, Yabroff KR. Challenges and opportunities in measuring cancer recurrence in the United States. *J Natl Cancer Inst* 2015 Aug;107(8) [[FREE Full text](#)] [doi: [10.1093/jnci/djv134](https://doi.org/10.1093/jnci/djv134)] [Medline: [25971299](https://pubmed.ncbi.nlm.nih.gov/25971299/)]
3. Earle CC, Nattinger AB, Potosky AL, Lang K, Mallick R, Berger M, et al. Identifying cancer relapse using SEER-Medicare data. *Med Care* 2002 Aug;40(8 Suppl):IV-75. [doi: [10.1097/00005650-200208001-00011](https://doi.org/10.1097/00005650-200208001-00011)] [Medline: [12187172](https://pubmed.ncbi.nlm.nih.gov/12187172/)]
4. Lamont EB, Herndon JE, Weeks JC, Henderson IC, Earle CC, Schilsky RL, Cancer and Leukemia Group B. Measuring disease-free survival and cancer relapse using Medicare claims from CALGB breast cancer trial participants (companion to 9344). *J Natl Cancer Inst* 2006 Sep 20;98(18):1335-1338 [[FREE Full text](#)] [doi: [10.1093/jnci/djj363](https://doi.org/10.1093/jnci/djj363)] [Medline: [16985253](https://pubmed.ncbi.nlm.nih.gov/16985253/)]
5. Hassett MJ, Ritzwoller DP, Taback N, Carroll N, Cronin AM, Ting GV, et al. Validating billing/encounter codes as indicators of lung, colorectal, breast, and prostate cancer recurrence using 2 large contemporary cohorts. *Med Care* 2014 Oct;52(10):e65-e73 [[FREE Full text](#)] [doi: [10.1097/MLR.0b013e318277eb6f](https://doi.org/10.1097/MLR.0b013e318277eb6f)] [Medline: [23222531](https://pubmed.ncbi.nlm.nih.gov/23222531/)]
6. Chubak J, Yu O, Pocobelli G, Lamerato L, Webster J, Prout MN, et al. Administrative data algorithms to identify second breast cancer events following early-stage invasive breast cancer. *J Natl Cancer Inst* 2012 Jul 20;104(12):931-940 [[FREE Full text](#)] [doi: [10.1093/jnci/djs233](https://doi.org/10.1093/jnci/djs233)] [Medline: [22547340](https://pubmed.ncbi.nlm.nih.gov/22547340/)]
7. Ritzwoller DP, Hassett MJ, Uno H, Cronin AM, Carroll NM, Hornbrook MC, et al. Development, Validation, and Dissemination of a Breast Cancer Recurrence Detection and Timing Informatics Algorithm. *J Natl Cancer Inst* 2018 Mar 01;110(3):273-281 [[FREE Full text](#)] [doi: [10.1093/jnci/djx200](https://doi.org/10.1093/jnci/djx200)] [Medline: [29873757](https://pubmed.ncbi.nlm.nih.gov/29873757/)]
8. Chen T, He T. xgboostXtreme Gradient Boosting. cran.r-project. 2019. URL: <https://cran.r-project.org/web/packages/xgboost/vignettes/xgboost.pdf> [accessed 2020-02-05]
9. Chubak J, Pocobelli G, Weiss NS. Tradeoffs between accuracy measures for electronic health care data algorithms. *J Clin Epidemiol* 2012 Mar;65(3):343-349.e2 [[FREE Full text](#)] [doi: [10.1016/j.jclinepi.2011.09.002](https://doi.org/10.1016/j.jclinepi.2011.09.002)] [Medline: [22197520](https://pubmed.ncbi.nlm.nih.gov/22197520/)]
10. Carroll NM, Ritzwoller DP, Banegas MP, O'Keeffe-Rosetti M, Cronin AM, Uno H, et al. Performance of Cancer Recurrence Algorithms After Coding Scheme Switch From International Classification of Diseases 9th Revision to International Classification of Diseases 10th Revision. *JCO Clin Cancer Inform* 2019 Mar;3:1-9. [doi: [10.1200/CCI.18.00113](https://doi.org/10.1200/CCI.18.00113)] [Medline: [30869998](https://pubmed.ncbi.nlm.nih.gov/30869998/)]

Abbreviations

AUC: area under the curve
KPWA: Kaiser Permanente Washington
NCI: National Cancer Institute
NPV: negative predictive value
PPV: positive predictive value
PT: probability threshold
ROC: receiver operating characteristic
SBCE: second breast cancer events
SEER: Surveillance, Epidemiology and End Results

Edited by K Eddens, D Vollmer Dahlke; submitted 11.02.20; peer-reviewed by G Rao, AR Razavi, N Miyoshi; comments to author 03.06.20; revised version received 16.06.20; accepted 18.06.20; published 17.08.20.

Please cite as:

*A'mar T, Beatty JD, Fedorenko C, Markowitz D, Corey T, Lange J, Schwartz SM, Huang B, Chubak J, Etzioni R
Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study
JMIR Cancer 2020;6(2):e18143*

URL: <http://cancer.jmir.org/2020/2/e18143/>

doi: [10.2196/18143](https://doi.org/10.2196/18143)

PMID: [32804084](https://pubmed.ncbi.nlm.nih.gov/32804084/)

©Teresa A'mar, J David Beatty, Catherine Fedorenko, Daniel Markowitz, Thomas Corey, Jane Lange, Stephen M Schwartz, Bin Huang, Jessica Chubak, Ruth Etzioni. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 17.08.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Original Paper

Evaluation of a Remote Symptom Assessment and Management (SAM) System for People Receiving Adjuvant Chemotherapy for Breast or Colorectal Cancer: Mixed Methods Study

Lisa Whitehead¹, PhD, MA, BSc, RN; Laura Emery¹, MMedSc, PGDip, BSc; Deborah Kirk¹, DNP, FNP-BC, NP-C, AOCN, FAANP; Diane Twigg¹, PhD, MBA, BHLthSc (Nsg) (Hons), RN, RM, FACH, FACHSM; Deborah Brown², DipRN; Joanna Dewar², FRACP, MRCP, MBBS

¹Edith Cowan University, Joondalup, Australia

²Sir Charles Gairdner Hospital, Perth, Australia

Corresponding Author:

Lisa Whitehead, PhD, MA, BSc, RN

Edith Cowan University

270 Joondalup Drive

Joondalup, 6027

Australia

Phone: 61 63042641 ext 2641

Email: l.whitehead@ecu.edu.au

Abstract

Background: The Symptom Assessment and Management (SAM) program is a structured, online, nurse-supported intervention to support symptom self-management in people receiving adjuvant chemotherapy post surgery for breast or colorectal cancer.

Objective: The objective of this study was to describe the development, implementation strategy, and evaluation of the SAM system.

Methods: The development of the SAM program involved 3 phases. In phase 1, the web app was developed through consultation with consumers and clinicians and of the literature to ensure that the system was evidence-based and reflected the realities of receiving treatment and supporting patients through treatment. In phase 2, 7 participants recorded the severity of 6 symptoms daily over the course of 1 cycle of chemotherapy. In phase 3, 17 participants recorded their symptoms daily over the course of 3 cycles of chemotherapy. Once symptoms were recorded, participants received immediate feedback on the severity of their symptoms and self-management recommendations, which could include seeking immediate medical attention. Data on quality of life, symptom burden, anxiety and depression, distress, and self-efficacy were collected during treatment; participants' perceptions of the SAM program were evaluated following participation via interview.

Results: The outcomes of the SAM project include the development of a system that is reliable and easy to use and navigate. Participants reported benefits related to using the SAM program that included feeling more in control of managing their symptoms and feeling reassured. Engagement with the system on a daily basis was variable, with some participants completing the symptom tracker daily and others engaging some of the time. The feedback from all participants was that the system was easy to navigate and the information was relevant and supportive.

Conclusions: The SAM program has the potential to enhance the management of symptoms for people receiving chemotherapy treatment. The system creates an accurate repository of symptoms that can be accessed easily and highlight patterns in symptom experience. These can be shared with clinicians, with patient permission, to inform and support treatment plans. The potential to predict the risk of developing severe symptoms can be developed to anticipate the need for care and support. Further considerations on how to increase engagement with the system, the value of the system for people diagnosed with other tumor types and treatment regimes, and the incorporation of the system into everyday clinical practice are needed.

(*JMIR Cancer* 2020;6(2):e22825) doi:[10.2196/22825](https://doi.org/10.2196/22825)

KEYWORDS

self-management; intervention; symptom management; breast cancer; colorectal cancer; cancer; symptom; monitoring; online intervention; development; implementation; evaluation

Introduction

Chemotherapy is a core component of cancer care for many people diagnosed with cancer and can be used as an adjuvant treatment, which means chemotherapy is an additional cancer treatment given after the primary treatment, usually surgery, to lower the risk that the cancer will return. There are a range of symptoms commonly experienced by people receiving chemotherapy, including pain, fatigue, trouble sleeping, nausea, vomiting, distress, anxiety, and depression [1]. The experience of symptoms can have an impact on the ability to adhere to treatment regimens and on quality of life [2,3]. In addition, the toxic effects of chemotherapy can be serious and life-threatening; for example, dehydration following vomiting and/or diarrhea and infection following leukopenia. Chemotherapy is most often delivered in the outpatient setting and the majority of associated side effects are managed in the community setting. The ability to communicate with health care providers in a timely way about symptoms that are impacting daily functioning, have become moderate or severe, or are prolonged is important to promote effective self-management and prevent hospitalization, or, in the case of severe or prolonged symptoms, advise on the need for urgent attention [1,2,4].

Technology can facilitate both the monitoring of symptoms and communication between patients and health care providers, and there has been a rapid increase in the number of systems in development; however, many require further development in order to enhance their usability and clinical integration [5], and few studies have been conducted in cancer settings [6].

An increasing number of mobile apps have been designed to support cancer care. Charbonneau et al [7] found 123 digital health options specific to cancer patients. These apps provide a variety of services for those in the cancer community. The apps support self-reporting and home monitoring of symptoms associated with cancer treatment [2,8-14] and report toxicities directly to the provider [2,8-12,14], as well as provide disease-specific monitoring [10,11], monitoring during active phases of cancer care [2,8,9,14] or during hospice stays [12], evidence-based education or self-care advice based on patient input to the system [2,12], and/or community cancer resources [2,15].

The web app developed and implemented in this study, the Symptom Assessment and Management (SAM) system, combined all of these features with the addition of an alert system. Based on patient scores, or levels of toxicity, alerts were generated ranging from evidence-based education to contact with providers to emergency assistance. We believe that the web app, developed in collaboration with consumers and health care providers, provides a comprehensive platform for people receiving adjuvant chemotherapy for breast or colorectal cancer to access information, assess and chart a range of symptoms, and receive real-time self-care advice.

Methods

Study Aim

The aim of the pilot study was to develop and implement a SAM web app for patients receiving chemotherapy as adjuvant treatment after surgery for breast or colorectal cancer. Participants did not have a diagnosis of active cancer. Participants were prompted by the mobile, web-based system to assess symptoms during treatment and they were provided with evidence-based real-time recommendations to support their self-management.

Study Design

A mixed methods design was employed involving 3 phases: (1) phase 1, development of the web app, (2) phase 2, pilot involving one cycle of chemotherapy, and (3) phase 3, intervention over 3 cycles of chemotherapy.

Phase 1: Development Phase

In the development phase, a review of the literature related to best practice of symptom management was conducted to develop alert levels for symptom severity and self-care messages. The guidelines and self-management documents highlighted the most commonly reported symptoms, when patients need to contact a clinician for advice or seek emergency support and self-management advice on managing symptoms. Following the review, consultation with consumers who had experience of breast or colorectal cancer and meetings with clinicians were held to further inform the selection of symptoms to be included in the system, the development of the alert algorithms and the content of the self-care messages. The symptoms of nausea, vomiting, diarrhea, constipation, temperature, mouth and throat sores (mucositis), neuropathy (numbness in hands and feet), fatigue, and distress were selected. An external company was employed to design and create the interactive web platform, the SAM platform. Three meetings were held with the developers to discuss the content to be included as supplied by the research team, usability features of the web app, presentation of the web app and pretesting. In addition to tracking symptoms on a daily basis, the web app provided participants with relevant phone numbers, self-care advice, access to evidence-based resources, and a summary page of symptoms (my symptom history). Participants were also reminded that the site was “not monitored 24/7 and should not be used as a replacement for medical appointments.” An advisory committee was established and included clinicians from the medical oncology team, nursing representatives, the research team, and three consumer representatives who had experienced cancer and received chemotherapy. Two meetings were held to report on progress and seek advice on recruitment strategies.

Phase 2: Pilot

In Phase 2, 7 participants were asked to record their symptoms daily on the web app for 1 chemotherapy cycle using either a personal computer, iPad (Apple Inc), or smartphone. Participants were invited to record their temperature using a thermometer provided by the research team to check whether they had a raised temperature, which could be indicative of an infection. Participants completed questionnaires at baseline (prior to the

chemotherapy cycle) and again at the commencement of cycle 2 (approximately day 14 for colorectal cancer patients or approximately day 21 for breast cancer patients) to evaluate quality of life, symptom burden, mental health, and self-efficacy. Participants completed an interview at the end of the cycle of chemotherapy. The key aim of this phase was to ensure that the web app was functional from a user perspective, data were collected and stored as planned, and the alert system did not create undue distress for participants or additional and unnecessary demands on health care staff.

Phase 3: Intervention

In phase 3, 17 participants recorded symptoms on the web platform over 3 chemotherapy cycles. Participants were also invited to record their temperature using the thermometer provided to check whether they had a raised temperature, which could be indicative of an infection. During this phase, participants completed questionnaires at baseline (prior to the chemotherapy cycle) and at the commencement of cycles 2, 3, and 4. Interviews were conducted at the end of cycle 3. The aim of this phase was to explore the usability and utility of the site over a longer period of time, including the number of alerts generated and the actions taken as a result of the alerts generated.

Ethics

The study received approval from the human research ethics committee at the hospital as well as the university ethics committee.

The SAM System

The web-based system comprised four functions: (1) to monitor symptoms experienced on a daily basis or anytime a participant wanted to assess their symptoms, (2) to provide immediate feedback on self-care actions to be taken based on the data entered, (3) to map symptoms on a graph over time that could be reviewed by the participant or provided to clinicians to review, and (4) to provide a repository of evidenced based information on key symptoms for further reading and consultation.

The decision to build a web-based app over a native app was driven primarily by the goals of the system and secondly by cost. The web-based app was able to meet all of the study needs and was able to be viewed and used across a range of devices (desktops computers, laptops, iPads, and smartphones). The research team believed that a native app would not add any benefit in relation to aesthetics or functionality but would risk compromising accessibility and would cost substantially more to create. A screenshot of the log-in page as it appears on a smartphone and a tablet are presented in [Multimedia Appendices 1 and 2](#), and additional screenshots, including examples of self-care messages, are presented in [Multimedia Appendices 3-5](#).

Daily Symptom Monitoring

The system allowed for real-time symptom monitoring and management of nausea, vomiting, diarrhea, constipation, mouth and throat sores (mucositis), neuropathy (numbness in hands and feet), fatigue, and distress in patients who had surgery for

early breast or colorectal cancer. A scale from 0 to 10 was created for each symptom, allowing participants to slide a cursor up and down the scale. On completion of the scales, a series of self-care messages were sent back to guide self-care, and within these messages was the alert level that the scores had generated. The algorithms differed by symptom, but self-care advice was either green (no or mild symptoms), amber (indicating an area of concern), or red (indicating serious concern and the need to take action). For example, an amber alert would advise participants to contact their medical oncology team or general practitioner during business hours or, if the participant was concerned, to visit their closest emergency department after hours; a red alert would suggest that the participant go to their closest emergency department for immediate assistance. As per the study protocol, red alerts were forwarded to the medical oncology clinical nurse manager (CNM) within 1 to 3 days of being received by the research team, in case additional follow-up was required. The symptoms were mapped onto graphs accessible on a separate page on the site and these allowed participants to view the trajectory of symptoms over time.

Library of Resources

A library of resources was generated to include links to one or more evidence-based sites for each symptom. The resource page was referred to in the self-care messages where appropriate and was accessible at all times to participants to access when necessary. The contact numbers of key personnel and groups were displayed in two places on the site: on the home page and on the self-management report page following the entry of symptoms.

Population and Setting

Participants were individuals who had received a diagnosis of breast or colorectal cancer, completed surgery, and were scheduled to receive adjuvant chemotherapy at a tertiary hospital in a metropolitan area. Additional inclusion criteria were that participants were aged 18 years or older; receiving a minimum of 3 cycles of chemotherapy on an outpatient basis; able to read, write, and speak English sufficiently well to participate in data collection; deemed by a member of the health care team to be physically and psychologically fit to participate in data collection; able to provide written consent (hard copy or electronic); and willing and able to use their own computer, iPad, or smartphone with internet access to complete the study.

The exclusion criterion was a prior experience of chemotherapy.

Participant Recruitment

Participating medical oncologists and the CNM identified eligible participants by screening patient referrals and medical history prior to chemotherapy clinics each week. Those eligible to participate were given information about the study by the participating medical oncologists or CNM and offered a copy of the participant information and consent form to review. For patients who agreed, their details (name, phone number, date of first chemotherapy cycle) were forwarded to the research assistant and contact was made following a chemotherapy education session. Consenting participants were shown face to face how to access and navigate the site and/or emailed information to help them access the SAM website and a link to

complete the surveys at each time point. Prior to the start of phase 1, medical oncology and nursing staff were invited to attend a short training session on the recruitment process and how the SAM web portal would be used by participants. The goal was to recruit up to 10 people in phase 2 to test the system across one cycle of chemotherapy and to recruit up to 40 people in phase 3. Because this was a feasibility study without a comparison group, the figures were based on how many participants it seemed reasonable to recruit within the study time frame and based on a review of the outpatient list of potentially eligible patients over the preceding month.

Participant Questionnaires

Participants completed the Functional Assessment of Cancer Therapy-Breast (FACT-B) [16] and Functional Assessment of Cancer Therapy-Colorectal (FACT-C) [17] cancer scales to measure quality of life, the Rotterdam Symptom Checklist (RSCL) to measure symptom burden [18], the Hospital Anxiety and Depression Scale (HADS) to assess mental health [19,20], and the Strategies Used by Patients to Promote Health (SUPPH) [21,22] to measure self-efficacy. The FACT-B has been assessed as appropriate for use in oncology clinical trials, as well as in clinical practice. Ease of administration, brevity, reliability, validity, and sensitivity to change have been reported [16]. Significant sensitivity to change in the performance status rating was demonstrated for the FACT-B total score, the physical well-being subscale, the functional well-being subscale, and the breast cancer subscale. An alpha coefficient (internal consistency) for the FACT-B total score has been reported to be high ($\alpha=.90$), with subscale alpha coefficients ranging from .63 to .86. There is evidence to support test-retest reliability, as well as convergent, divergent, and known groups validity. The reliability and validity of the FACT-C was reported across three samples that differed based on the extent of disease and ethnicity [17]. Across the samples, adequate reliability and validity were demonstrated for the FACT-C. Internal consistency analyses across the samples yielded alpha coefficients above .85 for the FACT-C total score. The FACT-C was able to distinguish among patients of different functional categories, particularly between ambulatory patients and patients who required bed rest for some period of time during the day. For patients whose functional status worsened, their quality of life worsened compared with patients whose functional status stayed the same or got better, indicating that the FACT-C is sensitive to changes in functional status.

For the RSCL, the reliability of the three subscales is high, with alpha coefficients ranging from .80 to .87 on the physical symptom distress scale, .85 to .94 on the psychological symptom distress scale, and .86 to .95 on the activity level scale [23]. The clinical validity of the RSCL is reported as satisfactory. The physical distress scales, subscales, and individual physical items differentiate between disease and treatment states as well as moments of treatment process. The psychological scale differentiates between cases and noncases [23].

The HADS has demonstrated satisfactory psychometric properties across a range of groups: in primary care [20], with cognitively intact patients in nursing homes [24], with inpatients with cancer [25], and in the general population [20,26].

The SUPPH was developed to measure patients' confidence in carrying out self-care strategies [21]. Good initial psychometric properties were found in patients receiving either cancer chemotherapy or hemodialysis. The alpha coefficients were well above the desired criterion of .70. Test-retest and generalizability estimates for the SUPPH were high [22].

Measures were completed at baseline and at the commencement of cycle 2 (phases 2 and 3) and cycles 3 and 4 (phase 3 only). Participants were emailed a survey link at each time point, which allowed them to complete the questionnaires through the Qualtrics online survey platform [27]. This ensured that participants received their questionnaires independent of clinic visits and it allowed questionnaires and reminders to be emailed directly to participants by the research team without the need to involve clinical staff. If requested, paper questionnaires were mailed to participants who preferred to complete the questionnaires in hard copy.

Interviews

Participants were invited to participate in a semistructured phone interview to explore their experiences using the web platform. The question guide used in the interviews was developed by the research team in consultation with the consumer advocates and advisory committee. Interviews were transcribed and analyzed using content and thematic analysis to identify common themes. Questions addressed the relevance of items in the scale (symptoms), the self-care messages, the resources section, and the symptom graphs; the experience of any symptoms not included in the scale; and feedback on the layout of the site and navigation and recommendations to improve the site.

Data Analysis

Data from the demographic questionnaire and questionnaires retrieved from Qualtrics were saved for analysis using SPSS software (IBM Corp). Data analysis explored changes over time in relation to quality of life, symptom burden, mental health, and self-efficacy. Phone interviews were transcribed using NVivo software (QSR International) and analyzed using content and thematic analysis. Content analysis of the comments created within the system were undertaken where they were generally short and supported the reason for recording a certain symptom severity. Thematic analysis [28] was undertaken with the interview data involving the stages of familiarization, coding, generating initial themes, reviewing themes, designing and naming themes, and writing up.

Results

Sample Characteristics

In total, 44 individuals were approached to participate in the study and 24 of them consented to participate. The sample comprised 12 women who had been diagnosed with breast cancer (phase 2, $n=3$; phase 3, $n=9$) and 12 people diagnosed with colorectal cancer (phase 2, $n=4$; phase 3, $n=8$). No participant had active disease or was scheduled to receive adjuvant chemotherapy. Table 1 sets out the demographic details.

Table 1. Sociodemographic characteristics of study participants.

Characteristics	Phase 2 (n=7)	Phase 3 (n=17)	Total (N=24)
Age (years)			
≤29, n (%)	0 (0)	1 (6)	1 (4)
30-49, n (%)	2 (29)	4 (24)	6 (25)
≥50, n (%)	5 (71)	12 (71)	17 (71)
Mean (SD)	57.4 (11.7)	55.2 (14.8)	55.8 (13.8)
Cancer diagnosis, n (%)			
Breast	3 (43)	9 (53)	12 (50)
Colorectal	4 (57)	8 (47)	12 (50)
Gender, n (%)			
Male	0 (0)	5 (29)	5 (100)
Female	7 (100)	12 (71)	19 (100)
Marital status^a, n (%)			
Married/partnered	4 (57)	10 (59)	14 (58)
Not partnered (single/separated/divorced)	2 (29)	7 (41)	9 (38)
Country of birth, n (%)			
Australasia	5 (71)	10 (59)	15 (63)
Europe	1 (14)	5 (29)	6 (25)
South Africa	1 (14)	0 (0)	1 (4)
Asia	0 (0)	2 (12)	2 (8)
Highest level of education, n (%)			
Completed high school	4 (57)	5 (29)	9 (38)
Trade or technical and further education certificate	0 (0)	4 (24)	4 (17)
Tertiary qualification/s	3 (20)	8 (47)	11 (46)
Employment status^b, n (%)			
Full-time	1 (14)	5 (29)	6 (25)
Part-time/casual	2 (29)	6 (35)	8 (33)
Homemaker	1 (14)	1 (6)	2 (8)
Retired/not working	3 (43)	5 (29)	8 (33)

^aValues do not always total 100% due to missing responses for some variables.

^bWithin 12 months prior to diagnosis.

Engagement with the Web Platform (SAM)

Visits to the Website and Completion of the Symptom Tracker: Phase 2

The web analytics allowed tracking of the number of visits to the website, pages visited, completion of the symptom tracker, and dates for each. The number of times the symptom tracker was completed in phase 2 ranged from 9 to 33 (days enrolled in SAM ranged from 15 to 67 days). The number of missed days ranged from 0 to 34 days, a completion rate that ranged from 51% to 100% of days symptoms were recorded using the symptom tracker, with an average completion rate of 78% of days enrolled.

Based on feedback from the consumer group, we included an option for participants to click a button on the homepage if they had no symptoms to record—effectively a score of 0 across all symptoms. Four participants in phase 2 used this option and recorded 2, 3, 7, and 9 days, respectively, where they had “no symptoms to record.”

Recording of Symptoms as Severe: Phase 2

Symptoms were recorded as being severe (8 or above) on individual symptoms a total of 22 times: nausea (n=2), vomiting (n=1), diarrhea (n=2), constipation (n=4), mucositis (n=1), fatigue (n=8), and distress (n=4). In phase 2, 16 red alerts were recorded: constipation (n=2), diarrhea (n=2), distress (n=5), nausea (n=2), vomiting (n=5). The red alerts were generated by 5 of 7 (71%) phase 2 participants. Four people generated

multiple red alerts: 1 participant generated 5 separate red alerts for vomiting (n=3), constipation (n=1), and distress (n=1); 1 participant generated 4 separate red alerts for vomiting (n=2), constipation (n=1), distress (n=1), and nausea (n=1); 2 participants generated 2 red alerts for distress (n=3) and diarrhea (n=1); and one participant generated 1 red alert for vomiting (n=1). In addition, 7 (44%) of the 16 reported red alerts also contained at least 1 or 2 amber alerts for other symptoms, including constipation (n=2), distress (n=4), fatigue (n=3), and mucositis (n=1).

Generation of Red Alerts: Phase 2

The number of days between treatment and symptom severity triggering a red alert varied between 0 (ie, the same day as chemotherapy) and 11 days. Two of the red alerts also included a report of the participant being admitted to hospital. In addition, 2 hospital admissions were reported following the generation of an amber alert.

Visits to the Website and Completion of the Symptom Tracker: Phase 3

In phase 3, the number of times the symptom tracker was completed ranged from 21 to 106 times and days enrolled in SAM ranged from 45 to 117 days. The number of missed days ranged from 0 to 87 days, and completion rate ranged from 21% to 100%, with an average of 59%. Nine participants used the “no symptoms to report” button in phase 3 on between 1 and 10 days: 10 days (n=1), 5 days (n=2), 4 days (n=2), 3 days (n=1), 2 days (n=1), and 1 day (n=2).

Recording of Symptoms as Severe: Phase 3

Symptoms were recorded as being severe (8 or above) on individual symptoms a total of 78 times: nausea (n=6), vomiting (n=5), diarrhea (n=8), constipation (n=3), mucositis (n=8), neuropathy (n=16), and fatigue (n=32). Three participants did not record any symptoms of 8 or above and 4 participants only recorded 1 symptom at one time point as 8 or above.

Generation of Red Alerts: Phase 3

The number of valid red alerts generated during phase 3 was 38: constipation (n=2), diarrhea (n=13), distress (n=5), nausea (n=7), neuropathy (n=2), high temperature (n=2), and vomiting (n=7). As per the study protocol, these red alerts were forwarded

to the medical oncology CNM within 1 to 3 days of being received by the research team in case additional follow-up was required. Two additional red alerts were excluded after being identified as incorrect entries (ie, temperature recorded as 367 instead of 36.7 and 63.8 instead of 36.8).

The 38 red alerts were generated by 12 participants. Seven participants generated multiple red alerts: 6 alerts (n=2), 5 alerts (n=2), 4 alerts (n=2), and 3 alerts (n=1). The remaining 5 participants each generated 1 alert. In addition, 15 (39%) of the 38 reported red alerts also contained between 1 and 3 amber alerts for other symptoms: constipation (n=2), distress (n=6), fatigue (n=5), mucositis (n=4), neuropathy (n=3), and vomiting (n=3).

The number of days between treatment and symptom severity triggering a red alert ranged between 0 (ie, the same day as chemotherapy) and 26 days. Three participants also reported a hospital visit and/or stay at the same time as their red alert. Two of these participants also advised that their chemotherapy cycles were delayed by 1 to 2 weeks due to neutropenia. Four hospital admissions were reported following the recording of amber alerts.

Use of Resource Pages

The resource pages were not accessed regularly by participants. In phase 2, 4 participants accessed resource pages and in phase 3, 6 participants accessed resource pages. The participants who accessed resource pages visited a variety of pages rather than one or two pages. No link between symptom experience or severity of symptoms and accessing resource pages was found.

Questionnaire Data for Phase 3 Participants

Mental Health: Anxiety and Depression

The frequency of self-reported levels of anxiety and depression (Table 2) show that at each time period, the majority of phase 3 study participants were experiencing a clinical level of anxiety and a borderline clinical level of depression, which increased (from 53% to 70.5%) and decreased (from 80% to 47%), respectively, over time. The statistical significance of these changes in anxiety and depression could not be reliably determined due to low frequencies across each of the 4 time points.

Table 2. Frequencies for mental health categories and median scores for physical and psychological symptom burden and self-efficacy at each time point for phase 3 participants (n=17).

Variables	Time point			
	Baseline	Pre cycle 2	Pre cycle 3	Pre cycle 4
Mental health, n (%)				
Anxiety				
Normal range	3 (18)	2 (12)	1 (6)	2 (12)
Borderline clinical	5 (29)	7 (41)	3 (18)	3 (17)
Clinical	9 (53)	8 (47)	13 (76)	12 (71)
Total	17 (100)	17 (100)	17 (100)	17 (100)
Depression				
Normal range	2 (13)	3 (18)	3 (19)	6 (35)
Borderline clinical	12 (80)	14 (82)	9 (56)	8 (47)
Clinical	1 (7)	0 (0)	4 (25)	3 (18)
Total	15 (100)	17 (100)	16 (100)	17 (100)
Symptom burden, median score				
Physical symptom distress	36.0	40.0	44.0	48.0
Psychological symptom distress	13.0	11.5	12.0	13.0
Overall valuation of life	2.0	2.5	2.5	2.0
Self-efficacy, median score	92.1	105.1	117.1	113.6

Symptom Burden

Median scores at each time point for physical symptom distress, psychological symptom distress, and overall valuation of life indicate that participants reported a relatively low level of symptom distress and a good overall valuation of life across the time points (Table 2). The level of physical symptom distress did significantly increase over time (Friedman $\chi^2_3=19.1$, $P<.001$; n=14) while the level of psychological symptom distress (Friedman $\chi^2_3=7.4$, $P=.06$; n=16) and valuation of life (Friedman $\chi^2_3=2.7$, $P=.44$; n=16) did not vary significantly over time.

Self-Efficacy

Reports of self-efficacy were relatively high among the phase 3 participants at each time point (Table 2). However, the increase in median self-efficacy scores from baseline over the treatment cycle was not statistically significant (Friedman $\chi^2_3=0.4$, $P=.94$; n=12).

Quality of Life

Data on the participants' quality of life, as measured by the FACT-B (version 4) and FACT-C (version 4), were not reported, as full scale scores for approximately 60% of participants at each time point could not be calculated because of missing values. Missing values were spread across a number of scale items, although the item with the highest number of missing responses concerned the participant's satisfaction with their sex life. Up to 58% of respondents opted not to respond to this item. This may be because participants considered the issue too personal to disclose or because they considered a response to the item to be unrelated to their illness. Future studies of the

self-reported quality of life of persons undergoing cancer treatment might consider using an alternative, shorter validated and reliable measure and ensure that participants cannot opt out of responding to items (eg, use a forced-choice survey format).

Interview Data

Fifteen interviews were completed: 4 in phase 1 and 11 in phase 2. The findings from phase 1 were comparable with those identified in phase 2 and the combined data. The key findings were ability to use technology and benefits of using the system and recommendations.

Ability to Use Technology

Participants received training in accessing and using the site. All described the training as adequate and the site as straightforward and easy to use:

Oh definitely. Just basic. That was good. Yes. And just so it was quick to go through it as well. And for me with no computer skills that's saying something.
[P204]

Participants accessed the site on a range of devices—computer, smartphone, or tablet—and nearly all participants used the same device throughout the study. Participants reported being able to connect to the site easily, although many reported having trouble activating the option to remain logged into the webpage. Once this was explained, no further issues were reported.

No, nothing major. I forgot the passwords a couple of times and got myself into a bit of a muck. But that was my problem. But no I managed to get there.
[P218]

Participants reported that the site was well designed, straightforward, and easy to use. All participants described the scale (0-10) as easy to navigate, and all participants stated that they felt a scale was the best way to measure symptom severity, rather than a method such as emojis.

I use them (emojis). I use them in my texts, and I use them, but I'm not sure they are completely medically appropriate. [P208]

Key Benefits of Using the System

All participants reported the key benefits of the system as being made aware of their symptoms and changes in symptoms over time, as well as being able to account for symptoms.

Basically it kept you where you were. What's going on, knowing all your symptoms, keeping up with things and keeping up with you know the side effects. Yeah that was important to me. I've noticed now because I haven't been using it. It's hard to keep track of where I'm at what's happening. [P204]

Participants were required to enter data on the SAM site once a day. Although data collected directly from the website suggests not all participants completed daily entries for the duration of the study period, everyone described a daily level of engagement as repetitive but acceptable.

It's repetitive of course but it is what it is. But I found it not too hard to fill in. No not at all. [P206]

Remembering to log in was sometimes an issue, with participants suggesting they either forgot or did not always feel well enough. Even so, using the system did not appear to have an impact on daily routines or cause distress.

Sometimes it was because I was feeling really rough and other times it was that I basically forgot. I should have done it...and I suppose if I hadn't done it one day I thought I might have thought 'did I do it'? I couldn't remember whether I'd done it as well sometimes. I suppose that sometimes I'd go in and I'd do it—put my symptoms in and then I don't think it logged it because it kinda logged me out and I had to log back in and then I'd repeat what I've just done. [P221]

Participants mostly described remaining engaged with the self-care messages that were returned and continued to see them as positive and to read them.

I can't remember the ones that popped up off the top of my head but they were useful. It was like, it was good to know. Oh yeah. Great I haven't been nauseous today. That's nice. Like that was good, like positive reinforcement that things are getting a bit easier. So that was good. [P211]

Overall, participants were positive about the alert facility of the system, reporting that they felt “secure” in the knowledge that their data were being tracked and they had a record. Participants were aware that their symptoms were not being monitored by clinicians; however, they were aware that alerts would be forwarded to the CNM, who in turn would make a note of the alert on the patient's file and follow them up as required. This

resulted in a follow-up call made to the participant or their family, which was received positively.

My husband got a call from the medical oncology nurse after I had been admitted to hospital. This gave him relief that I was being followed up. [Pilot, Respondent A]

As I say some people at the other end reacted when it flagged up a possible problem so I was quite impressed. [P206]

All participants interviewed described feeling reassured that their symptoms were being tracked.

I found that the whole thing was very useful keeping a track on myself as well as knowing where I'm at. [P204]

The information was you know that it sort of reassured me that things were going probably as they should do. [P205]

Participants described having information collated in one place and the ability to review patterns helpful.

Yes they were useful, they were a little bit um, what's the word. They would sort of ease your mind a wee bit when you went through them to say well things aren't quite as bad as you might think they are. [P205]

Yeah I'll go back and have a look and then I see the little patterns. When you are worse and such, when you come good you can follow it that way. [P207]

Several participants described following recommendations generated in the daily symptom tracker to contact a clinician or a medical oncology team member, or to visit the emergency department based on the feedback.

Even with the green, I was more like oh okay I'll take that in note and I'll suggest it to my specialist. [P204]

I think the three different colors (symptom tracker web page) was definitely good. Obviously orange was sort of like I've really got to pay attention. I did ring the nurses a few times if I was getting a randomly different side effect. [P211]

Yes. I had to go in—high temp...I think it did tell me like bang—This is high. Like consult. Don't wait for the next day or see how you are in the morning. [P207]

Once I hit the orange then it was like yeah I'll give them a call. So it was good to have that as a reference. [P211]

A number of participants described the system as supporting them to manage their symptoms more effectively:

Yes there would have been times where I went Ah don't worry I'll feel okay I just won't bother with my temperature. Yeah. And I think that was a big eye opener...So it made me go stop, rest and recheck myself. [P204]

I think yeah the color coding thing, definitely. So if I was in the orange or the red it definitely causes you

to do something. It definitely causes you to action something. So yes definitely in that sense. [P211]

The ability to assess symptoms over time was valued:

Just the fact that you can go back and just having a little bit of a good look at the history you know that sometimes you can't quite remember sometimes. When you had a bad day or something you can go back and go you can see your peaks and troughs—these things that you've selected. I've gone back and had a look and see how it goes up and down. [referring to graphs] cos you forget sometimes when your good days are and your bad days. [P207]

Recommendations

While many of the participants described the symptoms graphs as helpful, it was clear that the interpretation of the graphs became more difficult as data entry increased. One respondent also reported that the date of entry did not appear on the printout, while other participants found the graphs difficult to view on a smartphone. This is an area for attention in future versions of the program.

The pilot study found that the resources page was accessed at the beginning of the chemotherapy cycle but not much thereafter. In phase 3, to encourage continued engagement with the resources page, additional reminders were added to the daily summary page:

Well there were links and information that you could actually access direct from there. Sometimes I was just too tired to follow it through. But when I was able I appreciated the fact that the information was there. So I've actually kept the stuff in mind to take action. I've actually printed some of this stuff out so I know what to do if I get a um, what to watch out for. [P218]

Several participants referred to forgetting to enter data or feeling too ill to enter data. We added a button on the front page so that participants could indicate that they hadn't forgotten but did not feel like completing the scales. Some participants suggested the ability to enter data retrospectively would be valuable and this could be a feature in a future version of the program.

The thing that I actually found the most frustrating to be honest, was the fact that and especially initially um you couldn't go back. Like the first day I logged in and I couldn't actually go back to like the couple of days before that and put in, like I'd noted down what my symptom were but I couldn't go back because of it. Like you couldn't do it for a specific date. I think would've been helpful for you guys and for me. [P208]

During the pilot phase, we identified incorrect data entries when participants forgot to move the slider, which had a default setting of “5”, resulting in an amber alert. As a result, all sliders were set to 0 as a starting point. Some participants suggested that it would have been good if they had the ability to go back and edit entered data, as sometimes the slider would land on a number they didn't intend to submit:

But again—also being able to edit it because sometimes I accidentally pressed like it went to 10

because I scrolled up and I accidentally pressed it not realizing yet because it would look like I've hit a 10 but I can't go back and edit it. [P211]

Some participants asked for more information on specific issues, including the use of pain killers, a specific focus on the first week of treatment when symptoms were at their worst, and the use of supplements:

Yeah. And painkillers as well because at the moment I'm just going from one lot of pain killers to another lot of pain killers and they don't really tell you much on the side effects... Or other supplements that can be added like Sustagen and things like that. You know I've had to remind myself I can take that. [P204]

Some participants suggested providing different daily messages:

Yeah definitely. I can't remember what they say exactly but from memory it was just the first time I read it either. Yeah. And then I noticed after a few days was the same thing so I just I was okay with that. And when it changed color I read it again. Come on. OK it's like something different again. I think that, like I said before the more personable thing that's definitely something to look at. [P211]

Participants suggested that setting up the program as an app would be helpful in relation to accessing the program directly from their smartphone and the ability of the app to generate push notifications as reminders to complete the symptom tracker. Overall, participants reported positive experiences and many believed the system has great potential to be further developed.

Discussion

Principal Results

Our results demonstrated that participants involved in this study were positive about their experience of using SAM to monitor and manage their chemotherapy-related symptoms. Participants found SAM to be helpful in supporting them to manage symptoms and described feeling confident in accessing and using the site. Participants reported that using SAM increased feelings of reassurance and security related to awareness of symptoms and changes on a daily basis. The generation of an alert when symptoms were moderate or high was overwhelmingly viewed as positive by participants, who described acting on the advice given, and participants were impressed when the oncology team followed up with them. The interactive aspects of SAM highlight the ability of technology to be used for purposes beyond data collection. The system has established procedures to both generate feedback and promote early intervention. Based on their experiences, participants could see potential for the development of SAM, in terms of both the functionality of the system and developments within the health care system. Suggestions for developments include the addition of an alarm feature to remind participants to complete the symptom scales, the ability to enter missed data and edit data entered in error, and an option to allow the report of any additional symptoms experienced that were not covered by the core symptoms reported. The functionality of the system, positive feedback from patients, and refinements of the system

based on feedback from participants, consumers, and the advisory group support recommendations for the further development of the system and its use within health care services.

Limitations

The limitations of the study include that it was set up as a pilot study and as such the sample size was small and no comparison group data were collected. Nearly one-half of the individuals who were approached to participate declined. The most common reason given was feeling overwhelmed with their diagnosis and upcoming treatment. Data were collected over a limited time period, and the role of a system like SAM over a longer time period—even posttreatment—in the improvement in supportive care needs remains an area for exploration. Participation was restricted to 2 tumor groups and the applicability of the system to people with similar symptom profiles is likely but cannot be confirmed. Future research with a larger sample of patients receiving adjuvant chemotherapy following breast or colorectal cancer and a comparison group is recommended. Exploratory

studies to adapt the SAM system for people with advanced disease and those receiving other treatment modalities (eg, immunotherapy) are recommended.

Conclusions

This study indicated that people receiving postoperative chemotherapy for breast or colorectal cancer had positive perceptions of and experiences using SAM to monitor and manage chemotherapy-related toxicity. The remote monitoring of symptoms and an alerting system helped to ensure that people who were experiencing symptoms were identified early and that participants were facilitated to seek timely intervention. This has the potential to reduce both the severity and duration of the symptoms experienced, promoting a system of care that is anticipatory and preventative rather than reactive. This serves to enhance patient safety as a direct line of communication between the patient, cancer specialists, and the general practitioner, and provides patients with access to evidence-based, real-time feedback based on their experience of symptom severity as required.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Log-in screen on a smartphone.

[[PNG File , 234 KB - cancer_v6i2e22825_app1.png](#)]

Multimedia Appendix 2

Log-in screen on a tablet.

[[PNG File , 486 KB - cancer_v6i2e22825_app2.png](#)]

Multimedia Appendix 3

Self-care messages.

[[PNG File , 446 KB - cancer_v6i2e22825_app3.png](#)]

Multimedia Appendix 4

Symptom history.

[[PNG File , 490 KB - cancer_v6i2e22825_app4.png](#)]

Multimedia Appendix 5

Symptom tracker.

[[PNG File , 337 KB - cancer_v6i2e22825_app5.png](#)]

References

1. Beck SL, Eaton LH, Echeverria C, Mooney KH. SymptomCare@Home: Developing an Integrated Symptom Monitoring and Management System for Outpatients Receiving Chemotherapy. *Comput Inform Nurs* 2017 Oct;35(10):520-529 [[FREE Full text](#)] [doi: [10.1097/CIN.0000000000000364](https://doi.org/10.1097/CIN.0000000000000364)] [Medline: [28570285](https://pubmed.ncbi.nlm.nih.gov/28570285/)]
2. Maguire R, Fox PA, McCann L, Miaskowski C, Kotronoulas G, Miller M, et al. The eSMART study protocol: a randomised controlled trial to evaluate electronic symptom management using the advanced symptom management system (ASyMS) remote technology for patients with cancer. *BMJ Open* 2017 Jun 06;7(5):e015016 [[FREE Full text](#)] [doi: [10.1136/bmjopen-2016-015016](https://doi.org/10.1136/bmjopen-2016-015016)] [Medline: [28592577](https://pubmed.ncbi.nlm.nih.gov/28592577/)]
3. Brearley S, Stamataki Z, Addington-Hall J, Foster C, Hodges L, Jarrett N, et al. The physical and practical problems experienced by cancer survivors: a rapid review and synthesis of the literature. *Eur J Oncol Nurs* 2011 Jul;15(3):204-212. [doi: [10.1016/j.ejon.2011.02.005](https://doi.org/10.1016/j.ejon.2011.02.005)] [Medline: [21489873](https://pubmed.ncbi.nlm.nih.gov/21489873/)]

4. Breen S, Kofoed S, Ritchie D, Dryden T, Maguire R, Kearney N, et al. Remote real-time monitoring for chemotherapy side-effects in patients with blood cancers. *Collegian* 2017 Dec;24(6):541-549. [doi: [10.1016/j.colegn.2016.10.009](https://doi.org/10.1016/j.colegn.2016.10.009)]
5. Jensen RE, Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC, et al. Review of electronic patient-reported outcomes systems used in cancer clinical care. *J Oncol Pract* 2014 Jul;10(4):e215-e222 [FREE Full text] [doi: [10.1200/JOP.2013.001067](https://doi.org/10.1200/JOP.2013.001067)] [Medline: [24301843](https://pubmed.ncbi.nlm.nih.gov/24301843/)]
6. Kofoed S, Breen S, Gough K, Aranda S. Benefits of remote real-time side-effect monitoring systems for patients receiving cancer treatment. *Oncol Rev* 2012 Mar 05;6(1):e7 [FREE Full text] [doi: [10.4081/oncol.2012.e7](https://doi.org/10.4081/oncol.2012.e7)] [Medline: [25992209](https://pubmed.ncbi.nlm.nih.gov/25992209/)]
7. Charbonneau DH, Hightower S, Katz A, Zhang K, Abrams J, Senft N, et al. Smartphone apps for cancer: A content analysis of the digital health marketplace. *DIGITAL HEALTH* 2020 Feb 11;6:205520762090541. [doi: [10.1177/2055207620905413](https://doi.org/10.1177/2055207620905413)]
8. Abernethy AP, Herndon JE, Wheeler JL, Day JM, Hood L, Patwardhan M, et al. Feasibility and acceptability to patients of a longitudinal system for evaluating cancer-related symptoms and quality of life: pilot study of an e/ Tablet data-collection system in academic oncology. *J Pain Symptom Manage* 2009 Jun;37(6):1027-1038 [FREE Full text] [doi: [10.1016/j.jpainsymman.2008.07.011](https://doi.org/10.1016/j.jpainsymman.2008.07.011)] [Medline: [19394793](https://pubmed.ncbi.nlm.nih.gov/19394793/)]
9. Abernethy AP, Zafar SY, Uronis H, Wheeler JL, Coan A, Rowe K, et al. Validation of the Patient Care Monitor (Version 2.0): a review of system assessment instrument for cancer patients. *J Pain Symptom Manage* 2010 Oct;40(4):545-558 [FREE Full text] [doi: [10.1016/j.jpainsymman.2010.01.017](https://doi.org/10.1016/j.jpainsymman.2010.01.017)] [Medline: [20579839](https://pubmed.ncbi.nlm.nih.gov/20579839/)]
10. Basch E, Artz D, Dulko D, Scher K, Sabbatini P, Hensley M, et al. Patient online self-reporting of toxicity symptoms during chemotherapy. *J Clin Oncol* 2005 May 20;23(15):3552-3561. [doi: [10.1200/JCO.2005.04.275](https://doi.org/10.1200/JCO.2005.04.275)] [Medline: [15908666](https://pubmed.ncbi.nlm.nih.gov/15908666/)]
11. Basch E, Artz D, Iasonos A, Speakman J, Shannon K, Lin K, et al. Evaluation of an online platform for cancer patient self-reporting of chemotherapy toxicities. *J Am Med Inform Assoc* 2007;14(3):264-268 [FREE Full text] [doi: [10.1197/jamia.M2177](https://doi.org/10.1197/jamia.M2177)] [Medline: [17329732](https://pubmed.ncbi.nlm.nih.gov/17329732/)]
12. Dy SM, Roy J, Ott GE, McHale M, Kennedy C, Kutner JS, et al. Tell Us™: a Web-based tool for improving communication among patients, families, and providers in hospice and palliative care through systematic data specification, collection, and use. *J Pain Symptom Manage* 2011 Oct;42(4):526-534 [FREE Full text] [doi: [10.1016/j.jpainsymman.2010.12.006](https://doi.org/10.1016/j.jpainsymman.2010.12.006)] [Medline: [21458214](https://pubmed.ncbi.nlm.nih.gov/21458214/)]
13. Purswani JM, Dicker AP, Champ CE, Cantor M, Ohri N. Big Data From Small Devices: The Future of Smartphones in Oncology. *Semin Radiat Oncol* 2019 Oct;29(4):338-347. [doi: [10.1016/j.semradonc.2019.05.008](https://doi.org/10.1016/j.semradonc.2019.05.008)] [Medline: [31472736](https://pubmed.ncbi.nlm.nih.gov/31472736/)]
14. Snyder CF, Jensen R, Courtin SO, Wu AW, Website for Outpatient QOL Assessment Research Network. PatientViewpoint: a website for patient-reported outcomes assessment. *Qual Life Res* 2009 Sep;18(7):793-800 [FREE Full text] [doi: [10.1007/s11136-009-9497-8](https://doi.org/10.1007/s11136-009-9497-8)] [Medline: [19544089](https://pubmed.ncbi.nlm.nih.gov/19544089/)]
15. Walker DK, Hardeman A, Owen L, Frank JS. Information at the Point of Care: An Informational Application for Cancer Resources. *Comput Inform Nurs* 2015 Sep;33(9):390-5; quiz E1. [doi: [10.1097/CIN.000000000000171](https://doi.org/10.1097/CIN.000000000000171)] [Medline: [26176641](https://pubmed.ncbi.nlm.nih.gov/26176641/)]
16. Brady MJ, Cella DF, Mo F, Bonomi AE, Tulskey DS, Lloyd SR, et al. Reliability and validity of the Functional Assessment of Cancer Therapy-Breast quality-of-life instrument. *J Clin Oncol* 1997 Mar;15(3):974-986. [doi: [10.1200/JCO.1997.15.3.974](https://doi.org/10.1200/JCO.1997.15.3.974)] [Medline: [9060536](https://pubmed.ncbi.nlm.nih.gov/9060536/)]
17. Ward W, Hahn E, Mo F, Hernandez L, Tulskey D, Cella D. Reliability and validity of the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) quality of life instrument. *Qual Life Res* 1999 May;8(3):181-195. [doi: [10.1023/a:1008821826499](https://doi.org/10.1023/a:1008821826499)] [Medline: [10472150](https://pubmed.ncbi.nlm.nih.gov/10472150/)]
18. de Haes J, van Knippenberg F, Neijt J. Measuring psychological and physical distress in cancer patients: structure and application of the Rotterdam Symptom Checklist. *Br J Cancer* 1990 Dec;62(6):1034-1038 [FREE Full text] [doi: [10.1038/bjc.1990.434](https://doi.org/10.1038/bjc.1990.434)] [Medline: [2257209](https://pubmed.ncbi.nlm.nih.gov/2257209/)]
19. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983 Jun;67(6):361-370. [doi: [10.1111/j.1600-0447.1983.tb09716.x](https://doi.org/10.1111/j.1600-0447.1983.tb09716.x)] [Medline: [6880820](https://pubmed.ncbi.nlm.nih.gov/6880820/)]
20. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002 Mar;52(2):69-77. [doi: [10.1016/s0022-3999\(01\)00296-3](https://doi.org/10.1016/s0022-3999(01)00296-3)] [Medline: [11832252](https://pubmed.ncbi.nlm.nih.gov/11832252/)]
21. Lev EL, Owen SV. A measure of self-care self-efficacy. *Res. Nurs. Health* 1996 Oct;19(5):421-429. [doi: [10.1002/\(sici\)1098-240x\(199610\)19:5<421::aid-nur6>3.0.co;2-s](https://doi.org/10.1002/(sici)1098-240x(199610)19:5<421::aid-nur6>3.0.co;2-s)]
22. Lev EL, Eller LS, Kolassa J, Gejerman G, Colella J, Lane P, et al. Exploratory factor analysis: strategies used by patients to promote health. *World J Urol* 2007 Mar;25(1):87-93. [doi: [10.1007/s00345-006-0126-7](https://doi.org/10.1007/s00345-006-0126-7)] [Medline: [17066263](https://pubmed.ncbi.nlm.nih.gov/17066263/)]
23. Haes JD, Olschewski M, Fayers P, Visser M, Cull A, Hopwood P, et al. Measuring the quality of life of cancer patients with the Rotterdam Symptom Checklist: A Manual. 2012. URL: https://meetinstrumentenzorg.nl/wp-content/uploads/instrumenten/194_2_N.pdf [accessed 2020-11-30]
24. Drageset J, Eide GE, Ranhoff AH. Anxiety and depression among nursing home residents without cognitive impairment. *Scand J Caring Sci* 2013 Dec;27(4):872-881. [doi: [10.1111/j.1471-6712.2012.01095.x](https://doi.org/10.1111/j.1471-6712.2012.01095.x)] [Medline: [23072281](https://pubmed.ncbi.nlm.nih.gov/23072281/)]
25. Annunziata M, Muzzatti B, Altoè G. Defining hospital anxiety and depression scale (HADS) structure by confirmatory factor analysis: a contribution to validation for oncological settings. *Ann Oncol* 2011 Oct;22(10):2330-2333 [FREE Full text] [doi: [10.1093/annonc/mdq750](https://doi.org/10.1093/annonc/mdq750)] [Medline: [21339383](https://pubmed.ncbi.nlm.nih.gov/21339383/)]

26. Iani L, Lauriola M, Costantini M. A confirmatory bifactor analysis of the Hospital Anxiety and Depression Scale in an Italian community sample. *Health Qual Life Outcomes* 2014 Jun 05;12:84 [FREE Full text] [doi: [10.1186/1477-7525-12-84](https://doi.org/10.1186/1477-7525-12-84)] [Medline: [24902622](https://pubmed.ncbi.nlm.nih.gov/24902622/)]
27. Online survey software. Qualtrics. URL: <https://www.qualtrics.com/core-xm/survey-software/> [accessed 2020-11-18]
28. Clarke V. Thematic analysis. In: Lyons E, Coyle A, editors. *Analysing Qualitative Data in Psychology*. London: Sage; 2016:84-103.

Abbreviations

CNM: clinical nurse manager
FACT-B: Functional Assessment of Cancer Therapy-Breast
FACT-C: Functional Assessment of Cancer Therapy-Colorectal
HADS: Hospital Anxiety and Depression Scale
RSCL: Rotterdam Symptom Checklist
SAM: Symptom Assessment and Management
SUPPH: Strategies Used by Patients to Promote Health

Edited by G Eysenbach; submitted 24.07.20; peer-reviewed by T Alessa, P Chow; comments to author 17.08.20; revised version received 12.10.20; accepted 25.10.20; published 07.12.20.

Please cite as:

Whitehead L, Emery L, Kirk D, Twigg D, Brown D, Dewar J

Evaluation of a Remote Symptom Assessment and Management (SAM) System for People Receiving Adjuvant Chemotherapy for Breast or Colorectal Cancer: Mixed Methods Study

JMIR Cancer 2020;6(2):e22825

URL: <http://cancer.jmir.org/2020/2/e22825/>

doi: [10.2196/22825](https://doi.org/10.2196/22825)

PMID: [33284122](https://pubmed.ncbi.nlm.nih.gov/33284122/)

©Lisa Whitehead, Laura Emery, Deborah Kirk, Diane Twigg, Deborah Brown, Joanna Dewar. Originally published in *JMIR Cancer* (<http://cancer.jmir.org>), 07.12.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Cancer*, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Corrigenda and Addenda

Correction: Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study

Teresa A'mar^{1*}, PhD; J David Beatty², MD; Catherine Fedorenko¹, MMSci; Daniel Markowitz², MD; Thomas Corey¹, MS; Jane Lange¹, PhD; Stephen M Schwartz¹, PhD; Bin Huang³, DrPH; Jessica Chubak^{4*}, PhD; Ruth Etzioni^{1*}, PhD

¹Public Health Sciences, Fred Hutchinson Cancer Research Center, Seattle, WA, United States

²Swedish Cancer Institute, Seattle, WA, United States

³College of Medicine, University of Kentucky, Lexington, KY, United States

⁴Kaiser Permanente Washington Health Research Institute, Seattle, WA, United States

*these authors contributed equally

Corresponding Author:

Ruth Etzioni, PhD

Public Health Sciences

Fred Hutchinson Cancer Research Center

1100 Fairview Avenue North

Seattle, WA

United States

Phone: 1 206 667 5000

Email: retzioni@fredhutch.org

Related Article:

Correction of: <https://cancer.jmir.org/2020/2/e18143/>

(*JMIR Cancer* 2020;6(2):e23821) doi:[10.2196/23821](https://doi.org/10.2196/23821)

In "Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study" (*JMIR Cancer* 2020;6(2):e18143) the authors noted two errors.

The metadata erroneously listed only Teresa A'mar and Ruth Etzioni as having contributed equally; this has been corrected to reflect that Teresa A'mar, Jessica Chubak, and Ruth Etzioni contributed equally.

In addition, Jessica Chubak's affiliation was originally listed as:

Washington Health Research Institute, Kaiser Permanente, Seattle, WA, United States

This affiliation has been corrected to:

Kaiser Permanente Washington Health Research Institute, Seattle, WA, United States

The correction will appear in the online version of the paper on the JMIR website on September 24, 2020, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been submitted to those repositories.

Submitted 24.08.20; this is a non-peer-reviewed article; accepted 25.08.20; published 24.09.20.

Please cite as:

A'mar T, Beatty JD, Fedorenko C, Markowitz D, Corey T, Lange J, Schwartz SM, Huang B, Chubak J, Etzioni R

Correction: Incorporating Breast Cancer Recurrence Events Into Population-Based Cancer Registries Using Medical Claims: Cohort Study

JMIR Cancer 2020;6(2):e23821

URL: <http://cancer.jmir.org/2020/2/e23821/>

doi: [10.2196/23821](https://doi.org/10.2196/23821)

PMID: [32970603](https://pubmed.ncbi.nlm.nih.gov/32970603/)

©Teresa A'mar, J David Beatty, Catherine Fedorenko, Daniel Markowitz, Thomas Corey, Jane Lange, Stephen M Schwartz, Bin Huang, Jessica Chubak, Ruth Etzioni. Originally published in JMIR Cancer (<http://cancer.jmir.org>), 24.09.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Cancer, is properly cited. The complete bibliographic information, a link to the original publication on <http://cancer.jmir.org/>, as well as this copyright and license information must be included.

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org

<https://www.jmirpublications.com/>