

Developing a technology-based intervention for empowering cancer patients from low-income backgrounds: a lifecycle approach

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Abstract: Despite significant advances across the cancer continuum from prevention through survivorship, achieving uniform high-quality, patient-centered care for all remains a challenge. We have entered the era of precision medicine and multi-modal treatment where the promise of cure is great. Yet fragmented care and disparities in cancer outcomes persist, especially among those individuals from low income and under-resourced backgrounds. Thoughtful, mindful, and purposeful implementation of technology-based innovations have the potential to empower cancer patients and improve long-term outcomes and overall quality of life. These innovations have the potential to provide access to early detection and treatment and to extend and streamline cancer care coordination efforts by complementing and enhancing provider roles throughout the cancer continuum. Technology can be leveraged to mitigate limited resources and in turn improve long-term cancer outcomes for low-income cancer patients. While innovations in technology span a broad spectrum of advancement, we focus here on a technology-based intervention that serves the end goal of empowering patients throughout the cancer continuum as an example of what can be done to support cancer care and management through technology-based innovations.

Keywords: cancer, low income, technology, innovation, intervention, empower

Background

Significant progress has been achieved in treating and caring for cancer patients since the signing of the United States National Cancer Act in 1971.¹ Novel treatment modalities coupled with earlier detection have improved the outcomes for cancer patients.² The number of cancer survivors in the USA is projected to reach 20.3 million by 2026.³ As the population ages, the number of new cancer cases is estimated to increase from 1.6 to 2.3 million cases per year or by 45% in the 20-year period from 2010 to 2030.⁴ Globally, at a minimum, the number of new cancer cases is anticipated to reach 21.7 million by 2030.⁵ The increased incidence and prevalence of cancer married with soaring cancer-related needs and costs and a projected decrease in the number of cancer-specific health professionals, including oncologists, puts an increasing burden on the cancer care delivery system in the United States and abroad.¹

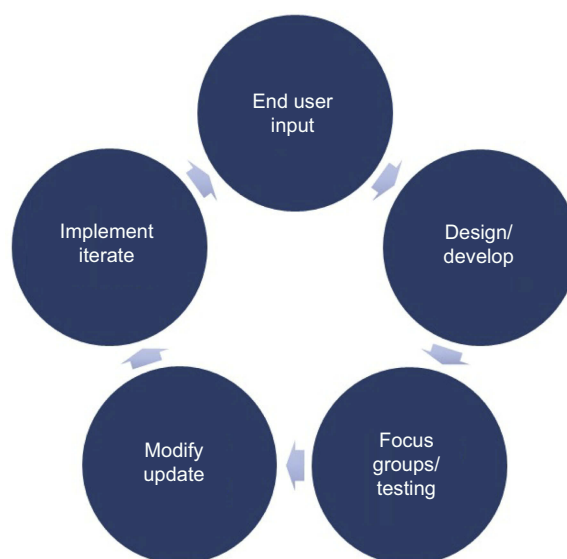
Achieving patient-centered high-quality cancer care for all remains elusive. This is particularly pronounced in populations that are traditionally underserved and experience cancer health disparities in screening, diagnosis, treatment, and outcomes related to their socioeconomic status, racial/ethnic background, or

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geographic location.^{6–10} Technology-based innovations rooted in acceptability, utility, and sustainability offer promise to address disparities in care across these populations.

Technology-based innovations potentially can facilitate patient-provider interaction and empower patients and their caregivers to ultimately achieve and sustain high-quality, patient-centered cancer care. These innovations span the cancer continuum ranging from preventive approaches to digital health solutions to diagnostics to devices. For sustained empowerment and impact, these innovations must meet the needs of the concerned patients and be supported by their communities. In other words, as noted by Kuijpers et al, the innovation must “provide cancer survivors with the skills, knowledge, and motivation to positively influence their health status, which is commonly referred to as patient empowerment”,¹¹ a key element in self-management and improved outcomes.¹² This approach makes intuitive sense, but the realities of implementation and scalability are far more challenging. Thus, the first step in developing or considering an existing innovation for use in an under-resourced setting is determining the buy-in and uptake of the proposed innovation.

Several frameworks, including the IDEAS (integrate, design, assess, and share) framework and the lifecycle approach, exist for modeling the implementation of technology-based solutions.^{13,14} Each of these frameworks emphasizes “assessment” as a step in the process. This lifecycle approach described here is modeled after the technology development lifecycle which is defined as a progression through a series of differing stages of development.¹⁴ The lifecycle starts with end-user input followed by design and development, then focus groups and testing, subsequently by modifications and updates, and finally implementation and future iterations based on additional end-user input (Figure 1). An evidence-based design is the result of this iterative process and input from the patient and provider end users through focus groups and testing. The nature of involving the patient in the lifecycle from the beginning inherently empowers them.^{12,15} The idea with the lifecycle approach is to enable experiences that inform the lifecycle and subsequently yield information on how care and resources are used and optimized. This information on care and resource optimization in turn provides a measure of patient empowerment. Additionally, wrapped around any framework should be a thoughtful, mindful, and purposeful mindset



LIFECYCLE: Evidence-based design with iterative input from patient and provider end users through focus groups and testing.

Figure 1 Lifecycle approach to developing technology-based innovations.

that places the cancer patient at the center. This patient-centric approach ensures that the perspective of the patient is paramount and under consideration at all times. Within this mindset, any innovation that is introduced will have greater chances of acceptability, utility, and sustainability.

An ideal way to illustrate this approach is through a case study of empowering patients through technology-enhanced navigation using a lifecycle approach. The benefits of patient navigation in alleviating barriers to treatment initiation and adherence have been well documented.^{16–18} Patient navigation is an outgrowth of observations by surgical oncologist, Dr Harold Freeman in 1990. Trained as a surgeon, Dr Freeman noted that he was seeing far too many women with late-stage breast cancer in the operating room. He felt the cancers should have been caught earlier and sought to address barriers to cancer screening, diagnosis, treatment, and supportive care. Patient navigation was born at Harlem Hospital. The first cancer patient navigation program demonstrated an increase in the 5-year breast cancer survival rate at Harlem Hospital from 39% to 70%.¹⁷ Since 1990, patient navigation has become a part of the cancer care continuum with patient navigators helping patients and their families weave through the complexities of a cancer diagnosis and beyond.^{19–27} Numerous studies have highlighted the benefits of cancer care coordination, including patient navigation and survivorship care planning, in achieving high-quality cancer care.^{28–32} As an evidence-based

approach to managing treatment and care through the cancer care continuum, cancer patient navigation offers a sustainable solution to addressing the increasing costs of cancer care and for empowering patients.^{33,34} Extending navigation services to all groups and settings remains a challenge. Technology-based innovations offer one approach to meeting the challenge.

Case study

Rationale

The case study described here is rooted in the question: “Can technology be leveraged using a lifecycle approach to empower cancer patients while optimizing care and resources?”. It challenges the reader to think about resources the health community can leverage to empower cancer patients and optimize care and resources through technology-based innovations.

The case study recounts the design and results of the Technology Enhanced NavigationSM Trial (TENSM Trial).^{35,36} The randomized clinical trial stemmed from the motivation to find ways to better support low-income women going through breast cancer treatment. Progress in cancer treatment has resulted in improved survival but with an increasing complexity of treatment presenting more challenges for optimum cancer care delivery. Treatment delays, failure to take medication regularly, visit cancellations, missed appointments, and poor symptom management can prevent getting the right dose at the right time and affect cancer outcomes. These issues are more likely to happen among poor, underserved women, including racial and ethnic minorities, who often face limited psychosocial support, financial challenges, and physical and mental health comorbidities.^{20,35,36}

Data from cancer patients and research studies have shown that the poor and underserved have poor cancer outcomes.^{6,37–42} Socioeconomic and racial disparities in receipt of appropriate adjuvant therapy for breast cancer are well documented.^{8,9} The completion of treatment regimens for breast cancer that often include a combination of radiation, chemotherapy, and hormonal therapy is particularly challenging for low-income patients who commonly present with comorbidities, endure financial constraints, have limited psychosocial support, and are care for in under-resourced communities.^{6,9,35} This situation leads to disparities related to race, age, geography, which are more than often tied to income level.^{37,42} Additionally, this creates

both an information gap and information overload along with social isolation and an increasing reliance on self-care.⁶ The pillars of long-term survival post-diagnosis, including initiating and completing appropriate treatment, receiving supportive care addressing their psychosocial needs, and accessing information and resources to keep them informed from diagnosis through survivorship, are often limited in low-income cancer patients.^{6,35}

As noted earlier, navigation programs offer a potential solution to overcome disparities in treatment, improve receipt of treatment and thus improve cancer outcomes, but few studies have rigorously explored the impact of technology-enhanced patient navigation models on long-term treatment adherence.^{17,19,35,36,43–45} Thus, the goal of the TENSM Trial was to determine if “virtual” interaction with a navigator, who was a trained health professional, versus information alone would improve adherence, symptom management, and quality of life among low-income breast cancer patients undergoing adjuvant breast cancer treatment.^{35,36}

Application design

The design of the TENSM application was based on evidence and need as vocalized by breast cancer care providers and breast cancer patients. The statement “TENSM is part of my medical team” summarizes the sentiments expressed by focus group participants convened to evaluate the feasibility and acceptability of the TENSM application.^{35,36} The focus group was comprised of low-income breast cancer patients with varying computer expertise. A common theme raised by the group was the isolation they experienced during treatment and the advantage of being connected to information that was filtered and tailored for them. Thus, there was overwhelming support for the face-to-face interaction with the navigator through video chat.^{35,36} Most significantly, the women viewed the TENSM application as a “medical tool” that should be part of their medical team and as their friend.^{35,36}

The TENSM application was designed as a readily accessible, cost-efficient, web-based knowledge and communication portal designed to support women in navigating through the complexities of cancer treatment and to get the right treatment and information at the right time. The TENSM application offers a novel and innovative approach to provide personalized support to individuals by including opportunities for a virtual chat

between the patient and the navigator, tailored information, and most importantly, limits feelings of isolation which in turn empowers the patient. Features of the TENSM application include a simple, secure login, and easy-to-use interface with topics identified by icons.^{35,36} The topical areas connected users to specific, vetted Internet links and team-produced videos and documents. Intervention participants had access to video chat and messaging capabilities.^{35,36} The application included areas to include information on staging, recommended treatment, and provider contact information.^{35,36} Lastly, the questionnaire module supported questionnaire administration and tracking for both health/quality of life assessments and usability.^{35,36} As part of the lifecycle approach, end-user (ie, patients and providers) input was obtained prior to designing the application user interface and after the end user-informed user interface was designed.

Study design

The virtual navigation program supported by the TENSM application was evaluated in a simple non-crossover randomized clinical trial comparing the technology-enhanced navigator program to Internet access alone.^{35,36} Eligible patients were low income and newly diagnosed with stage 0–III breast cancer, for whom adjuvant therapy with chemotherapy, hormone therapy, and/or radiation therapy were part of the recommended treatment plan.

Recruitment and enrollment

Recruitment was facilitated through breast cancer treatment insurance-type programs managed by the Maryland Department of Health and Mental Hygiene and through a network of oncology care providers across the state of Maryland. To eliminate any bias related to technology access, all study participants were provided with a netbook computer and Internet access for the durations of the study. Participants were enrolled from across the state of Maryland where adequate wireless broadband service was available. All patients met low-income level criteria as defined by the Housing and Urban Development Guidelines at the time of the study.⁴⁶ Informed consent and randomization to the navigator arm (intervention) or the Internet-access only arm (comparison) occurred during the enrollment visit, a majority of which took place in the study participant's home. The patient empowerment process began during the enrollment visit. Study participants were given the computer along with a Quick Start Guide and a longer User Guide with

detailed instructions on connecting to the Internet and using the netbook computer and the navigation application. They also received hands-on training on how to use the device and web-based application, including completion of the online questionnaires. Many of the patients had little to no computer experience and they were able to master the tool during the 2-hr enrollment and training session conducted by the study coordinator.

Implementation

The trial was designed to compare access to a navigator plus information vetted and tailored for breast cancer patient to providing access to information alone. A week after enrollment, the study coordinator contacted the participants to assess any problems they may have with the computer. Within 2 weeks of enrollment, participants on the navigator intervention arm were assigned and contacted by a nurse or social worker navigator. Contact was either by telephone or videoconferencing using the computer. Ultimately, the novelty of videoconferencing disappeared and a majority of the interactions were via telephone.^{35,36} The navigators attempted to contact study participants approximately every 2 weeks or more often as needed (Helzlsouer 2016a, Helzlsouer 2016b). Assessments included patient-reported outcomes based on validated questionnaires for functionality, quality of life, self-efficacy, and usability of the application. Status of treatment completion, hormone initiation, unscheduled outpatient visits, emergency room visits, and hospitalizations were obtained from medical records. Key study outcomes included treatment adherence, fatigue, quality of life, satisfaction with care, and technology feasibility and usability.

Results

From a total of 150 interested individuals screened, 102 were enrolled and 98 (49 on each study arm) included in the final analysis.^{35,36} The presence of comorbidities at baseline was assessed and found that almost half of the women in both study arms at four or more reported diseases.^{35,36} Further, about half of those had either anxiety or depression. This speaks to the challenges of addressing cancer treatment in a complex environment where women are dealing with multiple disease burdens at the same time. All of the study participants on the intervention (navigator) arm completed recommended chemotherapy and initiated recommended hormone therapy, whereas four study participants on the control arm did not complete one or more recommended adjuvant treatments.^{35,36}

A high level of use and agreement on ease-of-use and confidence in using the portal was observed.^{35,36} The usability assessment of the web-based application obtained 3 months after enrollment was similar between the two groups with approximately 75% reporting that they used the program frequently and that it was easy to use.^{35,36} Notably, none of the study participants reported having access to navigator services beyond initial diagnosis and surgery.^{35,36} This reality mimics what often occurs in cancer care and clearly illustrates the need for a technology-based approach to providing the needed support and access to services during cancer treatment and beyond.

In summary, adherence to treatment was better with the addition of a navigator compared to control. End-user involvement and iterative development supported the high degree of usability. More significant is that computer competence was achievable after brief training (~2 hrs) even among those with no prior computer experience. The use of the application and overall confidence in the ability to access reliable information was high thus assisting into patient empowerment.^{35,36}

Lifecycle: experiences that inform

With the TENSM case study in mind, it is apparent that the lifecycle is made up of experiences. These experiences inform and extend and feed into a larger lifecycle. Further, the outcomes from the lifecycle determine what happens next. In the lifecycle approach, we look to 1) sustain impact, 2) continue the lifecycle, and 3) add relevant components based on the experience of the lifecycle. Collectively, the lifecycle experiences inform and empower. The lifecycle approach inherently ties into the optimization of care and resources, which involves the following five steps: 1) identifying the issue; 2) assessing the situation; 3) taking action; 4) evaluating the impact; and 5) sustaining the solution (Figure 2). Further, this approach involves the human and the technology working together hand-in-hand. Building further on care and resource optimization is being able to incorporate findings and new information into the lifecycle. For example, through our TENSM lifecycle, we found challenges to sustainability to include: connectivity costs, compliance with questionnaires among the control group who had no personal interaction with a navigator transition to survivorship care, independent navigation versus direct line of care, hours of operation, mobile population, intermittent phone service, length and multiplicity of treatments, and transition to survivorship care. Despite these challenges, the

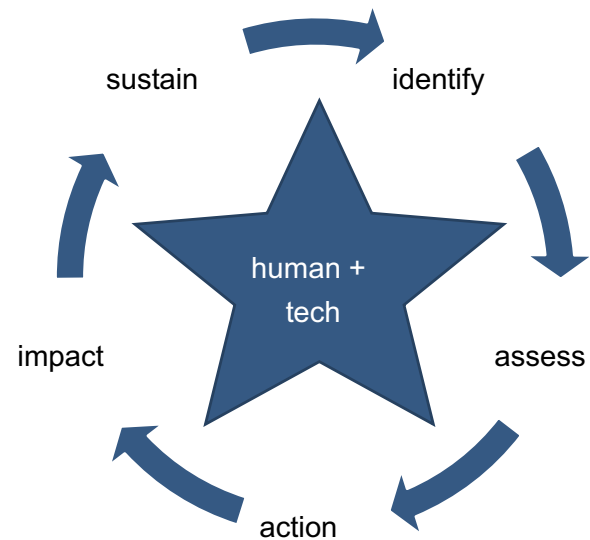


Figure 2 Care and resource optimization.

decreasing costs of electronic devices, such as tablets, phone, and portable computers, and improved accessibility to connectivity open a new avenue for patient empowerment with the lifecycle approach providing a framework for optimizing care and resources by leveraging human capital and technology.⁴⁷ Ultimately, technology-based innovations can be used to empower low-income cancer patients and optimize care and resources using a lifecycle approach that actively engages patients and values their input as part of the process.⁴⁸

Conclusions

Together the case study and lifecycle approach described here provide an example of a framework for developing, evaluating, and implementing technology-based innovations for low-income cancer patients across the cancer continuum. There are an increasing number of evidence-based approaches to improving the cancer experience from prevention through survivorship. Davis and Oakley-Girvan (2017) outline key elements of patient empowerment and user-centered application design, development, and testing to ensure that applications will meet the needs of cancer survivors.⁴⁸ Although the innovation described in the case study is a digital health-based solution, innovations can be solutions ranging from a process to a device that ultimately result in a paradigm shift from the status quo to a new approach to addressing the growing cancer burden, especially in under-resourced settings. Innovations with low cost are needed to address disparities among low-income and low-resourced communities. The ultimate test of implementation and sustainability is having the correct alignment of resources and buy-in. For example, with the advent of the human papillomavirus vaccine and novel approaches to

screening and treatment, cervical cancer incidence and prevalence has the potential to be drastically reduced.^{49–51} White Tsu notes that “We already know what causes cervical cancer, how to prevent it, and how to treat it, even in resource-constrained settings”, and yet the solution is “in large part, sustained political commitment”.⁵⁰ The challenge is to think and look outside of the proverbial box and begin from the patient perspective considering their lifestyles and available resources to identify innovations with high impact and relatively low cost. These innovations fill gaps in care and ultimately serve to empower the cancer patient beyond their initial diagnosis and positively impact their long-term outcomes.

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Disclosure

The authors report no conflicts of interest in this work.

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