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Progress in Community Health Partnerships: Research, Education, and Action, Volume 13, Special Issue 2019, pp. 49-59 (Article)

Published by Johns Hopkins University Press DOI: https://doi.org/10.1353/cpr.2019.0038

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# WeCanConnect: Development of a Community-Informed mHealth Tool for People with Disabilities and Cancer

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Submitted 07 September 2018, revised 30 December 2018, accepted 29 January 2019

#### Abstract

Background: Cancer care for people with disabilities (PWD) is rife with uncertainty and obstacles. Not only do PWD have to contend with cancer and treatment-related sequelae, but also its impact on disabling conditions and functional capacity, as well as a health care system lacking accessibility and disability competence. Peer support can address important needs for emotional and informational support. mHealth tools for smart phones, tablets, or laptops hold promise to deliver such support in an accessible and scalable manner. This concept is unexplored for use among PWD with cancer.

**Objectives:** To describe a community-based participatory study that 1) identifies consumer-reported support needs and priorities among PWD and cancer and 2) integrates consumer perspectives into the design of an mHealth cancer support tool to address these needs and priorities.

**Methods:** Part 1 is a thematic analysis of semistructured, qualitative interviews with a purposive sample of experts in health and cancer care for PWD (n = 7) and a convenience

sample of cancer survivors with preexisting disabilities (n = 9). In part 2, results were integrated to develop an mHealth peer support tool to addresses identified needs.

**Results:** Themes included 1) barriers across the cancer care continuum, 2) strengths within the disability community, and 3) recommendations for mHealth and peer support. Based on the qualitative findings, we designed a mHealth tool for peer support and information sharing among PWD with cancer.

**Conclusion:** Consumer-informed mHealth tools hold great potential to leverage strengths in the disability community to address emotional and informational needs created by a lack of disability competence across the cancer care continuum.

#### Keywords

Cancer, people with disabilities, mHealth, community-based participatory research, health disparities

ifty-seven million Americans (or 22% of adults over the age of 18 years) live with disabilities, making PWD one of the largest minority groups in the country.¹ Compared with their nondisabled peers, PWD live with a thinner margin of health.² Despite myths that "lightening won't strike twice,"³ cancer is the second leading cause of death among PWD.⁴ Cancer and its treatment can trigger an array of negative psychosocial responses such as social withdrawal and isolation, depression, and anxiety and can

significantly impact a person's health-related quality of life, including physical, emotional, cognitive, social, functional, and spiritual well-being.<sup>5,6</sup> Cancer and its treatment has been called a "double whammy" for PWD and can lead to the development of secondary medical conditions as well as the exacerbation of the disabling condition itself.<sup>7-9</sup> Notwithstanding, PWD are an "unrecognized health disparity population"<sup>10</sup> and are largely absent from the cancer disparities agenda.

PWD encounter a variety of unique challenges during cancer diagnosis and treatment, including physical inaccessibility of examination and treatment equipment, concerns over injury, and poor quality examinations owing to unsafe transfers, and inappropriate positioning and handling in response to some patient's uncontrollable and/or restricted movements during examination.11 Treatment decisions for PWD are complicated by the uncertain impact that surgical approaches and chemotherapy may have on their existing disability, functional status and mobility, capacity to live independently at home, and overall ability to manage side effects or consequences of treatment in the midst of preexisting comorbidities, such as pain and fatigue. 12,13 The need to self-advocate for accommodations adds to the stress of navigating the cancer care system.<sup>13</sup> The lack of disabilitycompetent care contributes to treatment delays, inadequate follow-up care, and nonadherence, all of which can negatively impact outcomes.14,15

The disparities in the quality of cancer care for PWD prompted disability health advocates and academic researchers in the Chicago area to work together to find a solution. With National Cancer Institute funding support, a project team of disability community and health policy leaders and academic researchers with expertise in health care justice for PWD, psychosocial and behavioral support for people with cancer, health communications, and peer support, have come together to design and develop a community-informed mHealth (i.e., mobile health) tool for peer support and information sharing to address the needs of people with preexisting disabilities and cancer.

mHealth is the use of mobile technologies, such as smart phones and tablets, to support medical and public health practices. The past decade has seen a proliferation of mHealth apps to help people across the cancer care continuum, including, for example, apps focused on addressing cancer-related fatigue, 17 quality of life and well-being, 18 and depression and pain. 19 Although PWD own smartphones at the same rate as nondisabled adults (71% and 68%), they are one-half as likely to report using mHealth apps. 20 Given the potential for mHealth interventions to positively impact cancer and health outcomes, it is important to understand and address PWD' identified needs and priorities, as well as perceived barriers to the use of mHealth apps. 20

Evidence supports the efficacy, accessibility, and acceptability of peer support interventions (both face to face and online) as a source of information sharing and social support for people with cancer.21-25 Peers offer expertise that is substantially different from that offered by health care providers. Peer support is also a central tenant of the independent living movement for PWD and is grounded in the personal experience of confronting the day-to-day challenges of living with a health condition, such as cancer or a disability. Peer support can help bridge information gaps and allay some of the fear and uncertainty associated with this disease.26-28 mHealth technologies are uniquely suited to offer a viable solution to address barriers to face-to-face peer support, such as lack of time, lack of transportation, lack of local resources, and limited social networks<sup>29,30</sup>; yet, access to culturally tailored, technology-enabled peer support interventions are lacking for people with cancer and disabilities. In this article, we reveal the actions taken and findings from the project team's design phase of an mHealth tool that removes barriers to support for this target population.

#### **OBJECTIVES**

The goal of the design phase of app development was to leverage best practices of qualitative, community-based participatory research (CBPR) to:

- Determine patient and provider identified needs and priorities for social support and information sharing, and
- 2. Determine community perceived benefits and concerns for mHealth peer support interventions.

## **METHODS**

# Study Design

Cross-sectional, semistructured, qualitative interviews were conducted as part of a CBPR process to inform collaborative mHealth app development.

## Target Community

For this project, we defined the disability community as a group of people who share the lived experience of having a body or mind that functions differently from the norm and who frequently experience barriers to full and equal social participation owing to socially constructed factors in the built, social, economic, and political environment.<sup>31</sup> Within this community, we targeted people who experience the "double whammy" of cancer and preexisting disabilities.<sup>13</sup> Consistent with the priorities of our community partners, we sought to be broadly inclusive and welcomed participation by people with physical, cognitive, mental health, and sensory disabilities.

## Research Partnerships

As part of the National Cancer Institute-funded Chicago Cancer Health Equity Collaborative, this project was built on several long-standing research partnerships. Academic researchers with expertise in mHealth, psychosocial and behavioral cancer support and health communications (J.B., D.V., B.H.) had previously worked with members of the Latina community on an National Cancer Institute-funded project to develop an mHealth peer support tool called Maestra for Latinas with breast cancer survivors.<sup>32</sup> Simultaneously, the lead author (S.M.) and members of the disability community (J.P.R., T.W.) have had more than a decade-long history of collaborative research across multiple federal and foundation grants focused on understanding and addressing health and cancer care disparities among PWD (e.g., Magasi et al.,33 in this issue). Our community partners, who have a lived experience with disability, were members of the health care policy team at a local center for independent living at the time of the study.

Centers for independent living are part of a network of disability rights organizations run by PWD for PWD. Centers for independent living have a mandate to serve the cross-disability community. This focus on the cross-disability community helped to inform the scope and target population for this study.

From its inception, our work has been intensively participatory and collaborative. As a team, we decided to capitalize on our strengths and experiences to design and develop a mHealth tool modeled on *Maestra*'s peer-to-peer support platform to address the unmet needs of the disability community. We used a CBPR approach for this work because it (1) is compatible with the disability community's mantra "Nothing about Us without Us," which articulates the community's demands for inclusion, shared decision-making and leadership, 34-36 and 2) represents best practices in user-centered

design app development, which increasingly recognize the value of stakeholder input in all stages of app development.<sup>37</sup> Community partners have been involved in all stages of the research process from the formative research that identified the community need, up through the grant writing, data collection and analysis, and app design. They (J.P.R., T.W.) are co-authors of this article.

#### Recruitment and Data Collection

The study team purposively sampled seven experts in disability research, advocacy, cancer rehabilitation, and health policy. Experts provide a broad perspective on cancer care owing to their clinical, research, and policy work. 38 Our experts were selected from across the United States for their breadth of knowledge on issues facing the disability community across the cancer care continuum. Experts where recruited via an introductory email sent by the lead author (S.M.) explaining the scope of the study and inviting them to participate. All agreed to participate. Interviews were conducted over the phone by the lead author who has extensive experience in CBPR and qualitative research with the disability community. Interviews lasted approximately 1 hour and were audio-recorded and transcribed verbatim with identifiers removed.

In collaboration with our community partners, we also recruited a convenience sample of cancer survivors with preexisting disabilities. Cancer survivors with a disability are recognized for their ability to provide an in-depth view into their lived experience.<sup>39</sup> Interested individuals were screened for eligibility. Eligible individuals were scheduled for individual interviews. After obtaining informed consent, research team members with experience in qualitative interviewing with PWD (S.M., K.T., D.V.) conducted interviews in person or by phone per the participant's preference. Emphasis was on understanding PWD's cancer care experiences and their recommendations regarding peer support and app development. Interviews lasted approximately 90 minutes and were audio-recorded and transcribed verbatim with identifiers removed for analysis. Institutional review board approval was obtained at the academic researchers' participating institutions, including Northwestern University (the institutional review board of record), University of Illinois at Chicago, and Northeastern Illinois University.

## Data Analysis

Deidentified transcripts from both sets of interviews were analyzed using a thematic two-phase process, 40,41 proceeding from descriptive to conceptual coding using an iterative coding dictionary. Two coders (S.M., J.B.) independently coded all of the interview transcripts to develop a list of descriptive codes. Then, in collaboration with the academic and community partners, codes were organized into conceptual categories based on extensive team discussion and debate. In this report, we focus on the conceptual categories that helped us to understand the experiences of PWD across the cancer care continuum and informed our design of an mHealth tool.

#### **RESULTS**

We present our findings in two parts. First, we present the findings from our qualitative interviews. Second, we apply these findings to the conceptualization, architecture, features, and framing of a new consumer-driven peer-to-peer social support and connection app for PWD with cancer.

## Part I: Qualitative Interviews

A total of seven experts participated in the study from varied professional backgrounds, including health services researchers (n = 3), disability health policy and advocacy (n = 3), and cancer rehabilitation (n = 1). Six of the experts have conducted research and policy work that directly explores the intersection of disability and cancer prevalence, diagnosis, and/or care. Five of the experts self-identified as a person with disability, three of whom were cancer survivors. The cancer survivors included in this study were predominantly White (n = 7 of 9), female (n = 7 of 9), and with a history of breast cancer (n = 6 of 9), as well as a variety of congenital and acquired disabilities, including spina bifida, cerebral palsy, muscular dystrophy, spinal cord injury, traumatic brain injury, multiple sclerosis and intellectual/developmental disabilities. All participants were cancer free at the time of the interview. Based on the thematic analysis of the qualitative data, we identified three broad themes: 1) barriers across the cancer care continuum, 2) strengths within the disability community, and 3) recommendations for mHealth and peer support as adjuncts to cancer treatment. Each theme is described below and supported by descriptive quotations from participants.

Theme 1: Barriers Across the Cancer Care Continuum. The cancer survivors described with some satisfaction that they had received the "able-bodied" version of cancer care that aims to aggressively treat the cancer while also offering supportive services in a welcoming environment. As the following quotation indicates, this "Cadillac" version of integrated care contrasted with their usual health care experiences as PWD.

It was very interesting being a part of the cancer treatment and the whole process because there's so much support through—for women with breast cancer available in general for patients with breast cancer . . . I almost had to laugh, I thought, gee, I feel like I joined a great club, so, yeah, I mean it's like everyone is so nice and supportive and there's all these services that are available to you. I was just like wow, I wish they had a club for disabilities like this or MS. (Cancer survivor with multiple sclerosis)

There was, however, a consensus that the cancer care system was not accessible or accommodating to the needs of people with a range of physical, functional and cognitive impairments.

I was totally unaware until I got thrown into the whole cancer system how inaccessible it is. (Expert and cancer survivor with a physical disability)

Participants provided numerous examples of inaccessible treatment environments and equipment, as illustrated by the following quotations:

They are not equipped in the hospitals; they don't know how to lift . . . I had a couple of tests run . . . the scanning process would require me being transferred . . . it took like an hour longer to find somebody else in the hospital who could lift . . . It all adds . . . frustration, a whole other layer of stress. (Cancer survivor with MD)

and

We gave up on change rooms just because they're not too accessible. For a variety of reasons like too much hassle for me with leg braces and mobility impairments . . . I just stripped completely everyday [for my treatment]. (Cancer survivor with spina bifida)

Participants recognized that the existence of a preexisting disability complicated their treatment experiences owing in part to providers' lack of training in disability, in general, and the limited research to support evidence-informed decision making at the intersection of disability and cancer. As one expert indicated:

Little has changed in the last 30 years regarding how disability is taught in medical school . . . So when you are disabled and get cancer there is just a tremendous amount of uncertainty and confusion on how to proceed. (Expert and person with a physical disability)

This perspective was supported by several examples from other participants, such as,

[A friend with post-polio] was diagnosed with colon cancer and her colon cancer surgery resulted in almost total loss of muscle function. She is this older person who had polio and had very significant muscle function in her back and abdomen and that's what allowed her to sit in a wheelchair and function quite well. She lost all of that function as the result of the surgery . . . Her docs had no idea what to do with her . . . The outcome was totally devastating from a disability standpoint and not from cancer standpoint. (Expert and cancer survivor with disability)

Cancer survivors also reported that providers often failed to recognize the realities of living day to day with a physical disability and that "standard" recommendations and treatments may lead to additional functional limitations for people with preexisting disabilities.

After the outpatient surgery [lumpectomy], they say shit like you're not supposed to lift anything over ten pounds, I'm like, you don't understand how I lift myself . . . How do you think I transfer (move from wheelchair to bed, toilet)? I don't float . . . I was like a unicorn . . . I live in Chicago, Illinois, I should not be a unicorn in a major metropolitan area. (Cancer survivor with a spinal cord injury)

The lack of accessibility and disability competence within the cancer care system complicated care, added stress to an already emotionally demanding time, and created a sense of isolation among people with preexisting disabilities.

Theme 2: Strengths within the Disability Community. When confronted with a cancer diagnosis and barriers within the cancer care system, people with preexisting disabilities mobilized their internal and external resources, as described in the following quotations:

[PWD] start their experience with cancer armed with a set of coping strategies and a way of looking at impairment and disability that is gonna help them. (Expert)

[The cancer diagnosis] didn't faze me much at all... It was really no big whoop.... because of my reference point... I didn't sit around like worrying about if I was going to die or not because frankly, I should've already... I was more interested in the pragmatics. (Cancer survivor with a spinal cord injury)

However, given the lack of disability competence within the cancer care system, many of the participants recognized peer support was a way to mobilize the strengths within the disability community. Peer support also provided opportunities to break down some of the isolation and uncertainty they were experiencing as PDW in the cancer care system.

You must have peer support. Use technology and they can contact someone . . . with a similar disability for peer support or further knowledge. (Expert and person with a physical disability)

People feel they are the only ones going through a certain situation. Peer-to-peer approaches would have a tremendous potential to break down isolation. (Expert and person with a physical disability)

Unfortunately, many participants indicated that they hardly ever encountered other PWD when they were in treatment.

I've never met someone else and my friends have said they've never met someone who's had both cancer and TBI [traumatic brain injury] . . . [It would be helpful] that someone knows about the side effects of both cancer and TBI, and someone that—that—for the TBI, someone that doesn't talk down to me." (Cancer survivor with a traumatic brain injury)

When I was going through treatment, . . . I never saw anybody with a physical disability . . . I think I would've felt a little bit better just to have somebody to talk to . . . The Cancer Society offered peers, but I just didn't feel comfortable. (Cancer survivor with MD)

Although there was no consensus on what makes for the ideal peer, participants offered their perspectives on what they would like in a peer,

Someone who's positive, . . . has coped and adjusted to their disability . . . It doesn't have to be the exact same type of disabilities and somebody who probably has breast cancer because, other cancers are just so different." (Cancer survivor with MD)

Someone with my similar type of disability and someone who also is as active as me and someone who . . . lives in the big city . . . and has the same feelings with missing out on stuff . . . For me age I think would matter . . . I'm thinking young men have worries that are specific to them about romance, about fitting in, about different stuff. (Cancer survivor with cerebral palsy)

As indicated in the previous quotations, participants recognized value in connecting not only around disability and cancer type, but also based on specific areas of interest or concern.

Participants did, however, express some skepticism about the limits of peer support and the need for accurate evidenceinformed information from trusted sources.

I think that a peer, they would just increase my anxiety honestly. I think I would much rather talk to a professional . . . I just think it would increase my anxieties because somebody who's a lay person they're gonna have fears even if they've gone through it. Like I feel everyone is an individual . . . I like experts . . . I only like to rely on people that actually know what they're talking about." (Cancer survivor with spina bifida)

Theme 3: Recommendations for mHealth and Peer Support. Although participants saw some value in connecting PWD and cancer, some were skeptical that a mHealth tool exclusively for PWD was the best approach. Instead, they suggested

partnering with existing cancer support organizations and integrating disability content.

I feel like there'd be usefulness to something, there'd be innovation in an app that is useful and productive ... I don't necessarily see us looking at a disability-specific app . . . why can't it just be a category . . . or that partners with an organization . . . I feel like the power lies in the combining . . . We just need to get the community at large to see how everyone can get served versus keeping the camps discrete and they don't know what the other people's issues are because they don't have to look at it. (Cancer survivor with a spinal cord injury)

Participants also discussed the importance of accessibility when designing mHealth tools for people with a range of physical, sensory and cognitive abilities.

Accessibility needs a lot of attention. (Expert and cancer survivor with a disability).

I have a really hard time with apps . . . I can't use a touchscreen phone . . . So that kind of limits the amount of apps I use. So something that has a web interface that I can access on the web. (Cancer survivor with CP).

Participants also emphasized that accessibility should not compromise design quality and that creation of a welcoming, esthetically appealing user experience was important to counteract disability-related stigma.

You not only feel disadvantaged because you don't go anywhere that serves your needs 'cause they don't know what they are. But also you're also feeling like a second-class citizens because your medical brochure looks like a fifth grader made it on Microsoft Paint and then you got slick brochures that resonates . . . And there's ways to do that [so] that doesn't alienate the people that are scared of us. But wouldn't you be scared of the community that got ugly brochures? (Cancer survivor with a spinal cord injury)

Given the abundance of information available about cancer, there is a need to guard against information overload

and many participants reported that they were advised not to search for cancer information online.

You know, with the uncertainty, you're confused, you're being bombarded by information. . . . We all go through that with that diagnosis. So, I would try to help and say how I coped with that information overload . . . [by choosing] not to read on the Internet. That's just commonality stuff that doesn't have to do with disability. (Cancer survivor with MD)

# Part II: Envisioning and Assembling WeCanConnect App

Based on the qualitative findings, we used a collaborative, user-centered design process to design a mHealth support tool for peer support and information sharing among patients with cancer with disabilities called WeCanConnect (WCC). "We" represents the concept of community and togetherness, "can" represents both cancer and ability, and "connect" is the purpose of the tool.

WCC is explicitly designed to help patients with cancer with disabilities form connections with people with shared experiences via their smartphones and mobile devices. This is important given PWD's perceptions about the lack of disability competence within the cancer care system as well as people's lack of access to peers within their social networks and local communities.

Rooted in the concept of peer support and information sharing based on experiential knowledge, WCC offers users multiple circles of support that can help address their support needs, including one-to-one peer support, as well as topically focused community forums and an evidence-informed virtual library. Careful attention has been given to creating an esthetically appealing, disability friendly landing page (underscoring the importance of seeing oneself reflected in the app design and features) and an accessible design that meets or exceeds international web accessibility standards (WCAG 2.0). WCC's primary features are People like Me (one-to-one matching), community forums, and a virtual library.

People Like Me (One-to-One Matching). WCC will facilitate the matching of members based on a variety of cancer and demographic variables collected in member profiles, subject to each member's privacy and disclosure preferences. Matched members will be able to reach out to one another to form

connections. Information and social connection needs will not be determined by any single variable but can change over time, depending on the stage in the cancer journey, cancer type, and treatment side effects, as well as individual roles, responsibilities, and relationships. Therefore, members can perform customized searches based on their individual information and support needs

Community Forums. WCC will provide users with opportunities to engage around topical focus areas. This feature responds to research participants' discussions of the complexity of their cancer experiences and recommended discussion topics ranging from the pragmatics of managing transfers and adaptive equipment during treatment to social participation and work to sex and fertility. Community forums will allow the user to decide how they want to engage at any particular time, for example, actively reaching out for support or information, silently following conversation threads, or sharing their own expertise. Users will be able to post questions, join existing conversation threads, and search old conversations for relevant information. Conversations can be tagged with key words to allow information to be easily filtered, thus helping to mitigate some of the information overload experienced in traditional internet searches

Virtual Library. WCC will provide evidence-informed educational content from trusted sources that users can download or read online. The virtual library is being developed in response to participants' expressed concerns about the reliability of peer delivered information. Content for the virtual library will come from reputable evidence-informed sources, but will be formatted to be accessible and understandable (e.g., using plain language formats). We will use a limit and layer approach so that users who want more information on a topic can follow the links to primary sources. We will identify the best available evidence to develop content to address the information needs of PWD.

## DISCUSSION

There is a paucity of research on the cancer experiences and cancer care needs of PWD. Moreover, there is little to no research that shows how a peer-support mHealth app can support those needs. Our findings support the evidence that people with preexisting disabilities have complicated treatment experiences and altered treatment choices.<sup>42</sup> By

gathering data from multiple stakeholder perspectives, we were able to identify both strengths and opportunities for PWD across the cancer continuum of care who might benefit from a mHealth peer support tool.

Although participants were generally satisfied with their cancer care provider's knowledge and attention to treating the cancer itself, they identified a need for greater person-centered care that recognizes the functional and impairment issues that PWD bring to cancer treatment process. Increased provider training and disability competence have been identified as important for health care providers in general, 43 and our findings point to their salience within care cancer in particular. Working groups across the United States are developing curricula for health care providers to increase awareness about the physical, social, and attitudinal factors that shape PWD's health care experiences. 44,45 Building a disability-competent cancer care workforce to provide accessible and appropriate services will increase quality of care for all patients with cancer, including those with preexisting disabilities and those who acquire disabilities and functional limitations as a result of their cancer and its treatment.

There is a critical need to increase the accessibility of cancer treatment facilitates to ensure that PWD have equal access to quality cancer care. Unfortunately, while federal laws (the Americans With Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973) mandate that health care settings be accessible to patients with disabilities, these laws are inadequately enforced in both public and private health care settings. There is a need for increased compliance among health and cancer care providers and for increased oversight by regulatory agencies.

As disability rights advocates work to increase accessibility and disability competence, there also is a need to develop services that ensure PWD's information and support needs are met across the cancer continuum of care. In an increasingly under-resourced cancer care system, with a growing number of survivors to attend to each year, efforts have been made to engage peer volunteers in offering emotional and informational assistance to newly diagnosed individuals. <sup>47,48</sup> Although social support from family and friends has been shown to help mitigate cancer-related distress, <sup>49</sup> patients with cancer and disabilities have specific needs that often go unmet. These

support needs can be more readily addressed by peers who have had similar personal experiences.<sup>50</sup> Several systematic reviews of one-to-one peer support programs in oncology have reported significant benefits to support recipients, including increased knowledge, self-management self-efficacy, and psychological adjustment; improved decisional support; lower emotional distress; and a greater sense of empowerment.<sup>24,51–54</sup> Positive outcomes have also been reported for peer support providers, such as empowerment, personal growth and satisfaction.<sup>55,56</sup>

As a part of the Chicago Cancer Health Equity Collaborative infrastructure, we shared the findings of our research at community forums. This provided opportunities for both formal presentation of findings as well as informal conversation with community members and cancer care providers. We have also partnered with community partners at local disability right organizations, including centers for independent living to discuss study findings in a town hall setting. Finally, we have engaged members of the disability community in the process of developing the WCC app. Further participatory design activities are planned as we continue to move this work forward to implementation and commercialization.

Other under-served communities can build on our participatory design approach by seeking to truly understand and respond to community needs. The participants' emphasis on the need for integration and visibility within the broader context of cancer care and cancer support is a call to action for the providers to acknowledge and respond to the requests of the disability community. This includes the recognition of PWD within their own communities, clinics and cultural groups. Disability is a great equalizer cutting across racial, economic, and social boundaries. It is the one minority group that anyone can join; therefore, this study's findings can empower communities to promote access and inclusion of all member regardless of disability status.

#### LIMITATIONS

Given the diversity of both the disability and cancer care communities, one major limitation of this study is its relatively small sample size, even for a qualitative study. We were not able to recruit people living with all types of disabilities or all types of cancer. We were also restricted to

cancer survivors rather than people in different stages along the cancer care continuum. As survivors, participants were able to reflect back on their experiences of cancer care, but they may not have had the immediacy or urgency they did at the time. They also had the benefit of knowing that theirs was a positive outcome, people in the uncertain phases of new diagnosis and active treatment may offer different insights into their needs and priorities. The WCC app is still being developed and has not yet seen widespread implementation; therefore, we can speak only to its promise not its adoption, acceptability, or impact.

#### CONCLUSION

This research provides deep insights into PWD cancer care experiences and highlights the needs for greater attention to accessibility and disability competence across the cancer care continuum. For people with preexisting disabilities and cancer lack of accessibility and disability competent care complicate their treatment and recovery processes and lead to isolation, uncertainty and unmet needs. Although it is critically important to change the cancer care system to better meet the needs of PWD, systems change is slow and people need services and supports now. Peer support is an important adjunct to disability competent cancer care. mHealth tools, such as WCC, may provide an opportunity to form peer connections beyond their immediate social circles. There are still unresolved questions whether a standalone mHealth tool for PWD or broad reaching mHealth tool that integrates and embraces disability has the greatest potential impact on the target population of people with disabilities and cancer.

## **ACKNOWLEDGMENTS**

Support for this project was provided in part by The National Cancer Institute through the Chicago Cancer Health Equity Collaborative (U54CA202995, U54CA202997, and U54CA203000) and The American Cancer Society, Illinois Division (266888).

# **REFERENCES**

 Brucker DL, Houtenville AJ. People with disabilities in the United States. Arch Phys Med Rehabil. 2015;96:771–4.

- Institute of Medicine. Disability in America: Toward a national agenda for prevention. Washington, DC: Institute of Medicine; 1991.
- Merten JW, Pomeranz JL, King JL, Moorhouse M, Wynn RD. Barriers to cancer screening for people with disabilities: A literature review. Disabil Health Journal. 2015;8(1):9–16.
- Forman-Hoffman VL, Ault KL, Anderson WL, et al. Disability status, mortality, and leading causes of death in the United States community population. Med Care. 2015;53(4):346–54.
- WHOQOL. The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric procedures. Soc Sci Med. 1998;46:1569–84.
- Cella DF. Quality of life: Concepts and definition. J Pain Symptom Manage. 1994;9(3):186-92.
- 7. Iezzoni LI. Blocked. Health Aff. 2008;27(1):203-9.
- Iezzoni LI. Public health goals for persons with disabilities: Looking ahead to 2020. Disabil Health J. 2009;2(3):111–5.
- Iezzoni LI. Eliminating health and health care disparities among the growing population of people with disabilities. Health Aff. 2011;30(10):1947–54.
- Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. Am J Public Health. 2015;105(Suppl 2):S198–206.
- Iezzoni LI, Kilbridge K, Park ER. Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments. Oncol Nurs Forum. 2010; 37(6):711-7.
- Iezzoni LI, Park ER, Kilbridge KL. Implications of mobility impairment on the diagnosis and treatment of breast cancer. J Womens Health (Larchmt). 2011;20(1):45–52.
- Volker DL, Becker H, Kang SJ, Kullberg V. A double whammy: Health promotion among cancer survivors with preexisting functional limitations. Oncol Nurs Forum. 2013;40(1):64–71.
- Molina Y, Beresford SA, Espinoza N, Thompson B. Psychological distress, social withdrawal, and coping following receipt of an abnormal mammogram among different ethnicities: a mediation model. Oncol Nurs Forum. 2014;41(5):523–32.
- Ashing-Giwa KT, Gonzalez P, Lim JW, et al. Diagnostic and therapeutic delays among a multiethnic sample of breast and cervical cancer survivors. Cancer. 2010;116(13):3195–204.
- Kay M, Santos J, Takane M. mHealth: New horizons for health through mobile technologies. World Health Organization. 2011; 64(7):66–71.
- 17. 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):1239–53.
- 18. Rincon E, Monteiro-Guerra F, Rivera-Romero O, Dorronzoro-Zubiete E, Sanchez-Bocanegra CL, Gabarron E. Mobile phone apps for quality of life and well-being assessment in breast and prostate cancer patients: Systematic review. JMIR mHealth and uHealth. 2017;5(12).

- Agboola SO, Ju W, Elfiky A, Kvedar JC, Jethwani K. The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials. J Med Internet Res. 2015;17(3).
- Jones M, Morris J, Deruyter F. Mobile healthcare and people with disabilities: Current state and future needs. Int J Environment Res Public Health. 2018;15(3):515.
- 21. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. Patient Educ Counsel. 2008;70(3):315–37.
- Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. BMJ. 2004;328(7449):1166.
- Macvean ML, White VM, Sanson-Fisher R. One-to-one volunteer support programs for people with cancer: A review of the literature. Patient Educ Counsel. 2008;70(1):10–24.
- Bouma G, Admiraal JM, de Vries EGE, Schröder CP, Walenkamp AME, Reyners AKL. Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: A literature analysis. Crit Rev Oncol Hematol. 2015; 95(1):26–37.
- Huber J, Muck T, Maatz P, et al. Face-to-face vs. online peer support groups for prostate cancer: A cross-sectional comparison study. J Cancer Surviv. 2018;12(1):1–9.
- Hartzler A, Pratt W. Managing the personal side of health: How patient expertise differs from the expertise of clinicians. J Med Internet Res. 2011;13(3):e62.
- 27. Sillence E. Seeking out very like-minded others: exploring trust and advice issues in an online health support group. Int J Web Based Communities. 2010;6(4):376–94.
- Rubenstein EL. "Things my doctor never told me": Bridging information gaps in an online community. Proc Am Soc Inform Sci Technol. 2012;49(1):1–10.
- Nosek MA, Robinson-Whelen S, Hughes RB, Nosek TM. An Internet-based virtual reality intervention for enhancing self-esteem in women with disabilities: Results of a feasibility study. Rehabil Psychol. 2016;61(4):358–70.
- Leykin Y, Thekdi SM, Shumay DM, Muñoz RF, Riba M, Dunn LB. Internet interventions for improving psychological wellbeing in psycho-oncology: Review and recommendations. Psychooncology. 2012;21(9):1016–25.
- Magasi S. Infusing disability studies into the rehabilitation sciences. Top Stroke Rehabil. 2008;15(3):283-7.
- 32. Banas JR, Victorson D, Gutierrez S, Cordero E, Guitleman J, Haas N. Developing a peer-to-peer mHealth application to connect Hispanic cancer patients. J Cancer Educ. 2017;32(1):158–65.
- 33. Magasi S, Panko Reis J, Wilson T, ROsen A, Ferlin A, VanPuymbrouck L. ScreenABLE: Breast cancer screening among women with disabilities from community identified challenges to community-based programs. Progress in Community Health Partnerships. 2019; 13, 61–69.

- Werner D. Nothing about us without us: Developing innovative technologies for, by and with disabled persons. Palo Alto, CA.: Health Wrights; 1998.
- Charlton JI. Nothing about us without us: Disability oppression and empowerment. Berkeley: University of California Press; 1998.
- 36. Scotch RK. "Nothing About Us Without Us": Disability Rights in America. OAH Magazine of History. 2009;23(3):17–22.
- 37. McCurdie T, Taneva S, Casselman M, et al. mHealth consumer apps: The case for user-centered design. Biomed Instrum Technol. 2012;46(s2):49–56.
- Magasi S, Ryan G, Revicki D, et al. Content validity of patientreported outcome measures: Perspectives from a PROMIS meeting. Qual Life Res. 2012;21(5):739–46.
- 39. Saldana J. The coding manual for qualitative researchers, 2nd ed. Los Angeles: Sage; 2013.
- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
- 41. Varcoe C, Habib S, Sinding C, Fitch M, Gullatte MM, Cummings GG. Health disparities in cancer care: Exploring Canadian, American and international perspectives. Can Oncol Nurs J. 2015;25(1):73–81.
- 42. Iezzoni LI, Long-Bellil LM. Training physicians about caring for persons with disabilities: "Nothing about us without us!" Disabil Health J. 2012;5(3):136–9.
- 43. Minihan PM, Robey KL, Long-Bellil LM, et al. Desired educational outcomes of disability-related training for the generalist physician: Knowledge, attitudes, and skills. Acad Med. 2011;86(9):1171–8.
- 44. Shakespeare T, Iezzoni LI, Groce NE. Disability and the training of health professionals. Lancet. 2009;374(9704):1815–6.
- Lagu T, Griffin C, Lindenauer PK. Ensuring access to health care for patients with disabilities. JAMA Intern Med. 2015; 175(2):157–8.
- 46. Meyer A, Coroiu A, Korner A. One-to-one peer support in cancer care: a review of scholarship published between 2007 and 2014. Eur J Cancer Care (Engl). 2015;24(3):299–312.
- 47. Pistrang N, Jay Z, Gessler S, Barker C. Telephone peer support for women with gynaecological cancer: Benefits and challenges for supporters. Psychooncology. 2013;22(4):886–94.
- 48. Luszczynska A, Pawlowska I, Cieslak R, Knoll N, Scholz U. Social support and quality of life among lung cancer patients: a systematic review. Psychooncology. 2013;22(10):2160–8.
- 49. Giese-Davis J, Bliss-Isberg C, Carson K, et al. The effect of peer counseling on quality of life following diagnosis of breast cancer: an observational study. Psychooncology. 2006;15(11):1014–22.
- 50. Campbell HS, Phaneuf MR, Deane K. Cancer peer support programs-do they work? Patient Educ Couns. 2004;55(1):3–15.
- 52. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. Patient Educ Couns. 2008;70(3):315–37.

- 52. Macvean ML, White VM, Sanson-Fisher R. One-to-one volunteer support programs for people with cancer: a review of the literature. Patient Educ Couns. 2008;70(1):10–24.
- 53. Kirk S, Milnes L. An exploration of how young people and parents use online support in the context of living with cystic fibrosis. Health Expectations. 2015:n/a-n/a.
- 54. Chambers SK, Schover L, Halford K, et al. ProsCan for Couples: a feasibility study for evaluating peer support within a controlled research design. Psychooncology. 2013;22(2):475–9.
- 55. Skea ZC, MacLennan SJ, Entwistle VA, N'Dow J. Enabling mutual helping? Examining variable needs for facilitated peer support. Patient Educ Couns. 2011;85(2):e120–5.