

Chapter 13

Advancing E-health Interventions in Cancer Control and Survivorship for Hispanic/Latina Breast Cancer Patients



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E-health Interventions for Breast Cancer

Breast cancer is the most commonly diagnosed cancer among Hispanic/Latina women, and epidemiological data indicate that there are approximately 220,000 Hispanic/Latina breast cancer survivors (BCS) currently living in the United States

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A. G. Ramirez, E. J. Trapido (eds.), *Advancing the Science of Cancer in Latinos*, https://doi.org/10.1007/978-3-031-14436-3_13

[1]. Continued increases in the numbers of BCS are expected because of advancements in early detection and cancer treatments. As such, there has been a greater focus on health-related quality of life (HRQOL), which represents the impact of health on one's physical, functional, emotional, and social functioning. Compared to non-Hispanic/Latina BCS, Hispanics/Latinas report poorer HRQOL, worse symptom burden, and more cancer-related psychosocial needs [2–10]; Hispanic/Latina cancer survivors also report greater unmet needs than non-Hispanic/Latina White cancer survivors [11]. Furthermore, Hispanic/Latina BCS report greater unmet needs than both prostate and colorectal cancer survivors (OR 2.33–5.86 [1.27–14.01]), with the highest unmet needs existing in the domains of psychological, health system and information, patient care and support, and physical and daily living [11].

Despite these documented disparities, few psychosocial interventions [12–14] have specifically targeted Hispanic/Latina BCS [2, 8, 15]. Research has demonstrated the importance of culturally appropriate interventions, as they are more effective when tailored to a particular racial/ethnic group [16] and show moderate to large effects [17]. Specific Hispanic/Latina cultural beliefs and values such as *familismo*, *marianismo*, and *personalismo* may need to be considered, as they can indirectly impact health and well-being outcomes [18, 19]. Thus, there is a need for culturally and linguistically appropriate interventions that address the unique needs and specific concerns of Hispanic/Latina BCS.

E-health platforms are increasingly being used to deliver psychosocial and supportive care interventions to cancer survivors, with preliminary data indicating benefits for psychosocial outcomes and lifestyle behaviors [20, 21]. Broadly, e-health platforms refer to health services delivered through the use of information technology, including the Internet and mobile and wireless applications. Notably, Hispanic/Latino individuals in the United States seek health information online at similar or higher rates than other racial/ethnic groups [22], and the use of smartphone technologies has increased with eight out of ten Hispanics/Latinos now owning a smartphone [23]. E-health interventions reduce the need to travel for in-person cancer care and support, and they may be especially appealing to minority and underserved patients who may have more logistical barriers to accessing in-person cancer care. Therefore, harnessing technology-based interventions such as smartphone applications and additional e-health interventions has the potential to increase the accessibility of scalable, evidence-based supportive care interventions that are culturally and linguistically appropriate for Hispanic/Latina patient populations.

Despite the increasing use of e-health platforms to deliver programs for cancer patients and survivors, more studies are needed to evaluate their efficacy and effectiveness, especially for racial/ethnic minority and underrepresented cancer patients. A systematic review revealed that the majority of available smartphone applications for cancer patients still lack evidence for their effectiveness [24]. Another recent systematic review identified 24 e-health psychosocial interventions for improving HRQOL in BCS, including six e-health platforms for health management and four mobile applications for physical activity [25]. A majority of these studies demonstrated encouraging results, including improvement of health literacy, disease and

treatment knowledge, coping abilities, and social support [25]. However, some results were inconclusive, negative, or mixed. Furthermore, the feasibility and effectiveness of e-health platforms among Hispanic/Latina BCS have not been established, as only a handful of e-health studies have focused on Hispanic/Latina cancer patients and survivors [26]. Given the increasing focus on e-health platforms in the delivery of supportive care interventions, evaluating whether and how Hispanics/Latina BCS benefit from these programs is an essential step toward reducing documented cancer disparities.

To address this gap in the literature, our research team developed a culturally informed, evidence-based psychosocial smartphone application called *My Guide* to improve the HRQOL and symptom burden among Hispanic/Latina BCS who completed active treatment within the past 2 years. In this chapter, we briefly describe the development and evaluation of *My Guide* and discuss future directions for culturally tailored e-health intervention platforms for Hispanic/Latina BCS and patients.

My Guide

Intervention Development

A key aspect of *My Guide* development was our existing partnership with the Latina Breast Cancer Association of Chicago [27]. This community organization provides educational and emotional support programs for Hispanic/Latina BCS and their families in the Chicagoland area. The goal of our partnership was to identify the highest priority needs of Hispanic/Latina BCS in the Chicagoland area and address those needs via a bilingual and culturally tailored smartphone application [27]. Guided by principles of community-engaged research [28], our team developed the *My Guide* smartphone-based intervention through an iterative process that began with meetings with our community partner to identify specific concerns of this population and relevant topics to include within *My Guide*.

Our team used an iterative process of developing *My Guide* to ensure that both the content and delivery of the material were relevant to Hispanic/Latina BCS. Our first step was to conduct field interviews with nine Hispanic/Latina BCS to obtain thematic information on the experiences of Hispanic/Latina BCS, specifically related to aspects of emotional and physical HRQOL during the transition from active breast cancer treatment to breast cancer survivorship. Important themes identified included managing symptoms and side effects, coping with cancer, impact of cancer on friends and family, financial concerns, and additional cancer-related resources for Hispanic/Latina survivors. These themes were used to inform the content development within the *My Guide* application. Cultural issues such as the importance of family values within the Hispanic/Latina communities, perceived stigma regarding illness perceptions and cancer, and language barriers were also integrated within the application.

The second step in our iterative design process was to evaluate the usability of the initial prototypes of the *My Guide* application to ensure the appeal and ease of use among Hispanic/Latina BCS. We conducted two rounds of usability testing with 28 college students and 9 Hispanic/Latina BCS. Results indicated high usability feedback among the Hispanic/Latina BCS with an average response of 4.23 out of a maximum of 5 ($SD = 0.9$) on the usability questionnaire. Additionally, Hispanic/Latina BCS expressed a preference to be able to listen to the content within the application and to have less content or text in each section. Before transitioning to the next stage of development, participant feedback was integrated within application development [29]. Specifically, our team developed audio content that was embedded throughout the application, which allowed participants to choose to read or listen to the content in each section. The audio content also helped address concerns related to low literacy.

Our third step was to finalize the programming through a brief 4-week, single-arm field trial of the *My Guide* application with 25 Hispanic/Latina BCS [30]. Consistent with previous e-health intervention studies, we incorporated a weekly telecoaching protocol to enhance supportive accountability in using *My Guide*. From the initial trial, recruitment and retention rates exceeded 70%, participants used *My Guide* for an average of 9.25 hours across the 4 weeks (2.31 hours/week), and the mean score on the satisfaction survey was 65.91 out of a possible 70 points (range: 42–70), in which higher scores reflect greater satisfaction. Breast cancer knowledge significantly improved across time ($d = 0.59$), and there was a trend for improved HRQOL over the course of 4 weeks that did not reach statistical significance. There were several key lessons learned from our field trial. For example, we observed that most eligible patients had their own smartphones, with less than 20% of study participants relying on a study-issued smartphone. Additionally, approximately half of the study participants engaged with *My Guide* at the recommended levels of weekly use (2 hours/week). Based on this observation, our team recommended future use of a stepped-care telecoaching protocol to minimize calls for those meeting adherence goals and to provide more support for those struggling to meet study usage goals.

Pilot Randomized Controlled Trial (RCT)

Following the single-arm field trial, our team conducted a pilot RCT to evaluate the feasibility, acceptability, and preliminary efficacy of *My Guide* relative to an attention-control condition. Thus, we developed a second smartphone application titled *My Health* [31]. Both *My Guide* and *My Health* were web-based applications accessible on smartphones as well as computers and tablets, and available in English and Spanish. Similar to attention-control content used in other psychosocial intervention studies among cancer populations [32, 33], we designed *My Health* to provide easy-to-understand and evidence-based recommendations for promoting healthy lifestyles (e.g., nutrition, physical activity, prevention of chronic illness).

Study Procedures Participants completed a baseline (T1) survey of sociodemographic information, primary intervention outcomes (i.e., symptom burden, HRQOL), and secondary intervention outcomes (i.e., nutrition, physical activity). Participants were randomized 1:1 to *My Guide* or *My Health* for 6 weeks and were encouraged to use their assigned smartphone application for 2 hours/week. Follow-up surveys were administered immediately post-intervention (T2) and 2 weeks after the T2 assessment (T3). Similar to the single-arm field trial, we used a telecoaching protocol to encourage participants' weekly use of their assigned application [30, 34]. All participants received telecoaching calls in their preferred language before Week 1, Week 2, and Week 6 of the intervention. In the remaining weeks, a stepped-care approach informed the need for additional telecoaching, with 90 minutes of application use in a given week (out of the recommended 2 hours) used as the threshold.

Results and Discussion Of 80 participants enrolled and randomized, 2 were lost to follow-up (one from each condition) and 78 were analyzed (*My Guide*: $n = 39$, *My Health*: $n = 39$). Sociodemographic and clinical characteristics did not differ between study conditions. Participants were an average of 52.54 years old ($SD = 11.36$). Most participants were born outside the United States (71%), reported Mexican ancestry (64%) and preferred to communicate in Spanish (64%). More than half of the participants had a high school education or less (54%) and an annual household income of $< \$25,000$ (53%). Most participants had stage II disease (41%) and received chemotherapy (58%) and/or radiation therapy (71%).

Consistent with prior studies [32, 35–37], we considered a 70% recruitment rate and an 80% retention rate feasible. We also considered 90 minutes of application use per week feasible based on our single-arm field trial [30]. In this pilot RCT, we successfully recruited 79% of eligible women and retained 95% of enrolled participants through the T3 assessment, indicating good feasibility [38]. On average, participants used the *My Guide* and *My Health* smartphone applications for 86.58 minutes/week ($SD = 66.08$) and 72.80 minutes/week ($SD = 62.57$), respectively, neither of which reached the 90 minutes/week threshold to indicate feasibility. However, average use exceeded 1 hour/week for both applications, which is more time than a patient might expect to spend individually with an in-person counselor (typically 50-minute appointments once a week or less) [38]. Acceptability was evaluated at T2 with a survey assessing participant satisfaction with each smartphone application. The vast majority of participants were satisfied (*My Guide* = 97%, *My Health* = 92%) and would recommend their assigned application to another woman with breast cancer (*My Guide* = 100%, *My Health* = 95%). Specifically, one participant stated, “I would recommend *My Guide* because I no longer feel alone. It helped with my side effects and helped me realize that others are going through the same thing,” and another said, “Of course I would recommend *My Guide*! While using *My Guide* you learn so much about everything and things that you didn't even realize you didn't know. I would love if everyone could have access to this information.” Participants expressed that “*My Guide* is a form of support...” and “the videos

of other survivors and learning how to relax was so helpful to deal with my anxiety. How to manage my symptoms was very helpful as well.” In addition, most participants indicated that they would like to continue using the application for longer than the 6-week study period (*My Guide* = 92%, *My Health* = 84%) [38].

In terms of preliminary efficacy, we evaluated breast cancer symptom burden and HRQOL (primary outcomes) with the Breast Cancer Prevention Trial symptom questionnaire [39] and the Functional Assessment of Cancer Therapy-Breast [40, 41], respectively. We assessed differences in symptom burden and HRQOL domains between study conditions over time using linear mixed-effects models controlling for language preference, education, and application use (i.e., whether or not the participant used their assigned application for an average 90 minutes/week). Across both study conditions, breast cancer symptom burden declined from T1 to T2 ($d = 0.08$), breast cancer well-being improved from T1 to T2 ($d = 0.20$), and improvements in breast cancer well-being were maintained at T3 ($d = 0.17$) [38]. We also evaluated nutrition and physical activity (secondary outcomes) with the Brief Dietary Assessment Tool for Hispanics [42] and the International Physical Activity Questionnaire Short Form (IPAQ-SF) [43, 44], respectively. *My Health* participants reported a greater decrease in daily fat sources from T1 to T2 compared to *My Guide* participants ($d = 0.30$), and this was maintained at T3 ($d = 0.47$). In addition, participants in both conditions reported increased time spent walking from T1 to T2 ($d = 0.31$) [45].

To our knowledge, this was the first study to design and evaluate two culturally informed smartphone applications for Hispanic/Latina BCS, *My Guide* (intervention) and *My Health* (control). Results demonstrated that the study procedures were feasible and acceptability was high for both applications. Both *My Guide* and *My Health* reported improvements in breast cancer symptom burden and breast cancer well-being over time; however, there were no differential effects between study conditions. Additionally, improvements in symptom burden were not sustained at the two-week follow-up assessment. These results suggest that technology-based interventions may facilitate engagement in care post-treatment among Hispanic/Latina BCS.

My Guide for Breast Cancer Treatment

Throughout the field trial [30] and pilot RCT [38], many women reported that it would have been even more beneficial if they had access to their assigned application during active breast cancer treatment. Additionally, *My Guide* participants expressed wanting more information about general health and lifestyle behaviors, while *My Health* participants wanted more information specific to breast cancer and coping strategies. To address this feedback, our team developed a new smartphone application, *My Guide for Breast Cancer Treatment* [46], for Hispanic/Latina women in active treatment for breast cancer.

Given the high use of *My Guide* and *My Health*, both smartphone applications [31] were combined and content was adapted to be more relevant for Hispanic/Latina women currently receiving treatment for breast cancer. Notably, the *My Guide for Breast Cancer Treatment* intervention includes information specific to breast cancer and its treatment and symptom and stress management strategies, as well as content promoting healthy diet and physical activity for breast cancer patients during treatment. Additional notable differences between *My Guide* and *My Guide for Breast Cancer Treatment* include a longer study period of 12 weeks versus 6 weeks, tailored content, and gamification features. A 12-week intervention timeframe was selected as it is the expected length of adjuvant treatments, and prior behavioral interventions reported benefits in symptom burden and HRQOL after 10 weeks [47–49]. Additionally, this revised intervention highlights targeted content based on the participants' concerns and needs, which are assessed every 2 weeks. Finally, participant adherence and motivation to use the *My Guide for Breast Cancer Treatment* application are reinforced by virtual awards based on different levels of weekly use (e.g., ribbon for 30 minutes/week, medal for 45 minutes/week, and trophy for 60 minutes/week).

My Guide for Breast Cancer Treatment is currently undergoing evaluation among a sample of 60 Hispanic/Latina women in active treatment for breast cancer. Participants are randomized 1:1 to the intervention or enhanced usual care control condition, which in addition to care as usual includes educational materials regarding breast cancer and survivorship from the National Cancer Institute [50] and a list of supportive care resources and organizations in the Chicagoland area. Control participants will be given access to *My Guide for Breast Cancer Treatment* after the study completion.

Conclusion

With increasing technology access and use among Hispanics/Latinos in the United States [22, 23], e-health platforms provide an innovative opportunity to deliver more easily accessible, scalable, and tailored psychosocial and symptom management interventions to those with limited access to culturally and linguistically appropriate supportive care resources. Growing evidence indicates high acceptability of technology-based interventions among Hispanic/Latino cancer patients [26, 51, 52]. However, few e-health interventions have been developed specifically for Hispanic/Latina BCS [2, 8, 15] despite documented disparities in HRQOL and psychosocial outcomes [2–10]. Additionally, cultural and linguistic factors should be considered in terms of the design and delivery of e-health interventions for the Hispanic/Latino population [53]. For example, aside from language barriers, a number of cultural attitudes and beliefs may impact health behaviors and should be included in the intervention such as importance of family values, taking care of others, gender roles, and relationship with the provider [53]. And given their high use, smartphones may be the optimal technology platform to deliver English and Spanish

evidence-based resources to address the unmet psychosocial needs of this underserved population.

Using community-engaged approaches, our team developed a culturally informed, evidence-based psychosocial intervention, the *My Guide* smartphone application, which demonstrated feasibility, acceptability, and preliminary efficacy in improving breast cancer symptom burden and HRQOL over time. However, of note, there were no differential effects in outcomes between *My Guide* and the attention-control *My Health* application. Participants expressed wanting to have used their assigned application during active breast cancer treatment in addition to post-treatment. As such, our team expanded the scope and focus of *My Guide* to be relevant for Hispanic/Latina women in active breast cancer treatment. To the best of our knowledge, both smartphone applications (*My Guide* and *My Guide for Breast Cancer Treatment*) are among the first bilingual and culturally informed supportive care interventions for Hispanic/Latina women who completed or are currently undergoing active treatment for breast cancer. Technology-based supportive and behavioral interventions that focus on breast cancer treatment and self-management may improve patient engagement as well as patient-reported outcomes during active treatment for breast cancer and into survivorship. Additionally, the self-guided *My Guide* and *My Guide for Breast Cancer Treatment* applications may offer much needed patient support to Hispanic/Latina BCS. During patient interviews, some of our study participants expressed feelings of loneliness and difficulties obtaining or asking for support from their families, and often noted concerns of burdening their loved ones. Findings from other qualitative studies with Hispanic/Latina BCS have indicated family as the main source of support, but some have similarly noted feeling alone and wanting more emotional support [2].

Our studies are expected to contribute to the limited cancer survivorship research in Hispanic/Latino communities and establish whether e-health interventions are feasible and effective for delivering supportive oncology interventions to this under-represented patient population. Future studies should consider the inclusion of a social networking component, especially given the importance of and desire for more social support, as well as the integration of evidence-based, patient-centered tools into electronic health records. In addition, given the multiple components of these psychosocial interventions, the effect of each component should be individually evaluated in order to identify the most effective intervention elements on study outcomes. Finally, an additional area for future directions includes establishing the efficacy of *My Guide* and *My Guide for Breast Cancer Treatment* across a nationwide, diverse sample of Hispanic/Latina BCS. If found efficacious, future efforts will focus on disseminating the applications to Hispanic/Latino communities across the United States, increasing the public health impact among Hispanic/Latina women with breast cancer. And future research focused on implementing culturally appropriate interventions for Hispanic/Latina BCS should evaluate the cultural nuances at the system level as well. Given the lack of culturally tailored, evidence-based, e-health psychosocial interventions for Hispanic/Latina BCS, *My Guide* and *My Guide for Breast Cancer Treatment* may help bridge a gap in cancer care and

have the potential to reduce disparities in psychosocial outcomes among Hispanic/Latina BCS.

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