

# Chapter 15

## A Vision for Improving Quality of Life Among Spanish-Speaking Latina Breast Cancer Survivors



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### Introduction

Latinas are at higher risk than non-Latino white women of psychosocial and physical sequelae of breast cancer. Latinas report higher rates of anxiety, depression, fear of recurrence, fatigue, and pain; they also have worse health-related quality of life (HrQoL) and shorter disease-free survival [1–3]. Spanish-speaking Latina immigrant breast cancer survivors, in particular, experience worse quality of life and emotional well-being than their English-speaking and White counterparts [2]. Multiple synergistic factors place many Latinas with breast cancer at increased risk of chronic elevated stress; these factors include limited English proficiency (LEP), low literacy, lack of access to culturally and linguistically appropriate clinicians and information about their illness and treatment, limited employment and insurance coverage, lack of transportation, unfamiliarity with the health care system, greater existential concerns and fear, more symptoms, and later stage at diagnosis and more aggressive disease [4–6]. Compared to White, African American, and English-speaking Latinas, Spanish-speaking Latinas are significantly more likely to report difficulty understanding treatment information and to need help with written materials they receive from their treatment team [5].

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## **State of the Science on Behavioral Interventions to Improve Health-Related Quality of Life Among Latino Cancer Survivors**

Among White women with breast cancer, stress management interventions improve health-related quality-of-life (HrQoL), reduce stress and anxiety [7], and may reduce chances of recurrence by decreasing inflammation and improving immune responses [7, 8]. However, a limited number of studies of the effectiveness of stress management programs have included Latinas with breast cancer and rural populations. Furthermore, stress management programs for cancer patients are primarily delivered by mental health professionals in large cancer centers. Widespread adoption of stress management programs could be enhanced if they were translated for more vulnerable, ethnically diverse patient groups and for delivery in community settings by trained peers. Similarly, physical activity interventions have resulted in improved mood among women with breast cancer [9].

A comprehensive systematic review identified 15 intervention studies designed to improve HrQoL among Latino cancer survivors; most of these studies were pilot or feasibility studies, and nine were randomized controlled trials (RCTs) [3]. Half of these studies involved mixed ethnic groups and, thus, were not specifically tailored for Latinos, and very few engaged community partners. Interventions were largely psychosocial (6), followed by educational (4), exercise/dietary (4), and navigational (1). The authors concluded that the science of interventions among Latino cancer survivors is nascent and in great need of further development. Although this review found that interventions are feasible and acceptable among Latinos and that early results are promising, there is insufficient evidence on which to base further translation and dissemination efforts to reduce psychosocial health disparities and improve HrQoL among Latinas with breast cancer.

## **The Nuevo Amanecer Program and Translation Methods**

### ***Rationale***

Our research program focuses on developing community-based interventions to equip Spanish-speaking Latina breast cancer survivors with the information and tools to manage their disease. This research aims to reduce psychosocial and symptom disparities experienced by underserved cancer survivors. We focus on community-based self-care approaches for several reasons. First, many underserved communities have limited access to cancer support services and oncology specialists, especially in rural areas [10]. Second, a shortage of cancer specialists, including psycho-oncologists, is projected to worsen with the growth of the older population [11]. Third, two influential reports by the National Academy of Sciences have led to recommendations by several regulatory and advocacy bodies that cancer

care address survivors' comprehensive needs including surveillance, late effects of treatment, distress screening, psychosocial care, and healthy lifestyles, as well as attention to the transition from active treatment to survivorship [12, 13]. Fourth, over 75% of cancer patients are followed up in primary care, but primary care physicians often lack the necessary training and confidence that they possess the specific expertise required to manage the health care needs of cancer survivors [14]. Finally, as health care in this country moves to accountable care organizations responsible for managing the health of populations, integration of cancer support services with health care systems will be critical, including establishing linkages among oncologists, primary care providers, and community-based cancer support services.

### ***Translation of the Nuevo Amanecer Program***

Working with community partners, we developed an extensive research program to address these gaps. We conducted extensive formative research and developed Nuevo Amanecer (A New Dawn), a new 8-week, peer-delivered cognitive-behavioral stress management (CBSM) program for Spanish-speaking Latinas. Using community-based participatory research methods, we applied an innovative translational process model appropriate for minority and underserved populations (we integrated an evidence-based intervention, a community best-practices program, and formative research results) resulting in a program that could be delivered by trained breast cancer survivors (peers) [15]. We tested Nuevo Amanecer in a randomized controlled trial (RCT) of urban Latinas who were newly diagnosed with breast cancer; results indicate that it effectively improved several quality-of-life domains and decreased breast cancer concerns and depressive and bodily symptoms [16]. In the words of a participant, "The program changed me. It made me happier and helped me think positive thoughts so I could push forward and fight."

Cognitive-behavioral stress management interventions such as Nuevo Amanecer and culturally tailored physical activity interventions have tremendous value for giving disenfranchised patient populations the tools to help manage their cancer and gain control over what many perceive as an untenable situation. CBSM skills training delivered early in the cancer care trajectory can reduce the most common symptoms experienced by Latinas with limited access to culturally and linguistically appropriate psychosocial services [16].

Throughout rural California, Latinos are concentrated in communities with agricultural jobs; in these communities, we find more Latinos living in poverty, fewer with a high school degree or some college, and lower per capita community revenues and expenditures [17]. Cancer patients in rural areas suffer greater disparities related to lack of access to cancer supportive services, including informational and psychosocial support [18]. Barriers to cancer support services among rural women with breast cancer include distance, lack of transportation, low income, and low literacy. In the Central Valley of California, geographic isolation, distance to health care providers, and language barriers are risk factors for poor health [19]. Effective

psychosocial health programs for rural Latinas with breast cancer could reduce these disparities. Because the broader Latina population in California includes many in rural settings and with limited literacy, a necessary step prior to full-scale dissemination is to adapt *Nuevo Amanecer* for more vulnerable subgroups and test it in these new populations. In addition, community organizations need resources to facilitate incorporating such programs into their settings. Thus, we embarked on *Nuevo Amanecer-II*, a study in which we are translating and testing the program in three rural, low-income communities in California. We trained a new set of community health workers (CHWs) to deliver the program. Recruitment for the study has closed, and intervention delivery and follow-up assessments should be completed by September 2018.

Baseline breast cancer-specific quality-of-life data from our *Nuevo Amanecer* and *Nuevo Amanecer-II* RCTs demonstrate that compared to norms based on white breast cancer survivors, Latinas do worse on every domain. Using the Functional Assessment of Cancer Therapy measures that include a subscale on breast cancer concerns (FACT-B), we found that urban and rural Spanish-speaking Latinas reported worse overall quality of life, physical well-being, emotional well-being, social/family well-being, and functional well-being compared to norms from a sample of 400 White women with breast cancer. Spanish-speaking Latinas scored about 60% lower (indicating poor quality of life). These results are consistent with prior studies, although these studies are few in number [1, 2].

Development of these programs occurs in partnership with community organizations, Latina breast cancer survivors, and clinicians using an integrative approach that synthesizes scientific evidence with community knowledge, while taking into account the local context [15]. We utilize mixed methods to obtain data that informs program development (e.g., semi-structured interviews and surveys with survivors, clinicians, and social service providers). We embed these programs in the community by training community-based organizations to deliver them in a fashion that they have determined works with the populations they serve. We have described this implementation model and the features that make it especially suitable for translation of programs for delivery in health disparity communities [15].

## **A Conceptual Framework to Guide Research on Behavioral Interventions for Latino Cancer Survivors**

Based on this program of community-based participatory research (CBPR), we developed a conceptual framework of survivorship needs, types of programs that would address these needs, and the hypothesized mediators and outcomes that would be affected by these programs [20]. According to Spanish-speaking breast cancer survivors, their needs focus on four general areas: symptom management, psychosocial health, coordination of post-treatment care including the transition from immediate diagnosis to survivorship, and healthy lifestyles. Based on the

literature, the types of interventions that help include (1) skills training on symptoms, stress management, and communication with family and clinicians; (2) information on symptoms and treatment side effects, recommended follow-up care, signs of recurrence, healthy lifestyles (physical activity and nutrition), and community resources; and (3) social support. These types of interventions have been shown to improve self-efficacy for managing symptoms, stress, and communication; improve knowledge; and increase perceptions of social support. Improvements in these mediators lead to decreased stress and distress and improved health-related quality of life [20].

Spanish-speaking Latinas experience limited access to culturally and linguistically appropriate cancer survivorship care. Cancer centers are often ill-equipped to meet the needs of cancer patients who are limited-English proficient and low income, especially in rural areas. Such women often fall through the cracks and may not receive high quality care for breast cancer into the acute and survivorship phases. Community-based models that utilize CHWs and peers are proven methods for reaching underserved populations, resulting in improved health outcomes [21]. CHW-delivered cancer support programs could be a low-cost, effective method for meeting the psychosocial needs of underserved Spanish-speaking cancer survivors.

## **Gaps and Opportunities for Future Research**

Clearly, we need stronger evidence for the effectiveness of behavioral interventions for improving the HrQoL of Latino cancer survivors. Once culturally appropriate cancer support programs are found to be effective in diverse populations, we will need effective methods for disseminating these evidence-based programs. Although there are platforms for dissemination of evidence-based behavioral interventions, including cancer-related programs, these are largely only known to and used by researchers. Researchers can address such service delivery gaps by developing an integrated program of research focused on translation and dissemination of evidence-based behavioral interventions for underserved cancer survivors.

Importantly, in our *Nuevo Amanecer-II* study, we added the collection of biospecimens (hair and saliva samples) to examine the effects of the program on cortisol levels (a biomarker of stress). Minority populations in the United States are less likely than Whites to donate biospecimens [22], and there is almost no evidence on the effectiveness of methods employed by researchers to collect biospecimens among Latinos. In the context of this study, our CHWs successfully collected the biospecimens. However, we were unable to secure the cooperation from one partner community-based organization; thus, we were not able to offer women from that community the choice of providing saliva and hair samples. To inform future efforts, we will report on the unique issues we have faced with collection of biospecimens among Spanish-speaking Latina breast cancer survivors. Such evidence is critical so that vulnerable populations can accrue the benefits of precision medicine. Deployment of targeted resources will be necessary to include minority populations

in large, multicomponent cohort studies that require biospecimens, such as the “All of Us” program, a national initiative to enroll a diverse and representative cohort of one million Americans to advance precision medicine for all diseases [23]. Inclusion of vulnerable populations in all phases of this research is imperative, if we are to reduce health disparities and assure communities that the results will be relevant for and accessible to them.

A promising avenue for delivering behavioral interventions to minority communities, including Latinos, is technology-assisted community health worker interventions. In other translation efforts, we recently developed and conducted a pilot test of a Spanish-language mobile phone application to provide women with breast cancer survivorship planning and physical activity promotion tools. We combined the mobile phone application with telephone-delivered health coaching. Data analyses are in process, but preliminary results suggest that the tool was acceptable to women, increased their self-efficacy to manage their illness, and increased their daily average steps. In another study, we developed a prototype of an English and Spanish mobile phone application that adapted the core stress management components of the *Nuevo Amanecer* program for use among low-income women undergoing chemotherapy for breast cancer. We hope to test this mobile phone application in a future RCT that will incorporate telephone health coaching as well. Finally, we are providing technical assistance to another investigator-community stakeholder research team on a project that is translating our program for use among underserved, rural white women using a telehealth modality delivered by peers (rural breast cancer survivors). Thus, we are translating effective programs for new populations and delivery methods that have potential for broad-based dissemination.

## Conclusions

As cancer centers strain to meet the needs of the burgeoning cancer survivor population, alternative service models that capitalize on community resources and integrate CHWs and families into the health care delivery system will be needed. Working with disparities communities, investigators can integrate evidence-based programs with community knowledge and best practices to test and disseminate co-developed programs to meet the needs of vulnerable cancer survivors. Working together, academic-community partners can develop acceptable, effective, and potentially more sustainable programs to reduce disparities. With such an approach, the intervention development process is incomplete “until an intervention is optimally efficacious and implementable with fidelity by practitioners in the community” [24].

Through *Nuevo Amanecer-II* we are testing whether the program meets the needs of vulnerable and low literacy Latinas in rural areas. This will ensure that the program is appropriate for rural and urban Latinas and results in a transportable program and implementation guide for community-based organizations prior to widespread dissemination. Because of the extensive involvement of community

advocates, survivors, and cancer care providers throughout translation, broad program dissemination should reduce ethnic disparities in psychosocial health. Our Nuevo Amanecer process evaluation indicates that it was precisely this careful integration of community input that resulted in a program that effectively reduced disparities in the psychosocial health of vulnerable Latinas in the study by meeting their needs and anticipating implementation barriers [25]. On study completion, we will post our program products on Internet sites to further disseminate them and to maximize the community benefit derived from these studies. Our vision is to see this practical, culturally relevant program widely adopted to eliminate psychosocial health disparities in vulnerable Latinas with breast cancer.

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