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## Quality of Life among Immigrant Latina Breast Cancer Survivors: Realities of Culture and Enhancing Cancer Care

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### Abstract

**Objectives**—Breast cancer is the most common cancer among Latinas. This study examined social, cultural, and health care system factors that impact quality of life and survivorship experiences of Latina immigrant breast cancer survivors.

**Design**—We interviewed Latina breast cancer survivors (n=19) and, based on the interview findings, conducted two focus groups (n=9). Research staff translated transcripts from Spanish into English. Two trained raters reviewed the content and identified themes. Thematic content analysis was used to categorize and organize data.

**Results**—Participants were largely mono-lingual in Spanish, predominantly from Central and South America and most (68%) had lived in the U.S. for 10 or more years. All women were diagnosed and treated in the U.S. and were an average of 3.1 years from diagnosis. Women’s survivorship experiences appeared to be shaped by cultural beliefs and experiences as immigrants such as secrecy/shame about a breast cancer diagnosis, feelings of isolation, importance of family support (familism), challenges with developing social relationships in the U.S. (less personalismo), and, for some, their partner’s difficulty with showing emotional support (machismo). Navigating the U.S. medical system and language barriers were additional challenges in participants’ health care interactions.

**Conclusion**—Latina breast cancer survivors adhere to certain cultural values and face unique issues as immigrants, potentially influencing overall quality of life and doctor-patient communication. Efforts to improve Latina immigrant breast cancer survivors’ quality of life could include increased assessment of psychosocial functioning and referral to social support services, culturally-sensitive navigation programs and consistent use of appropriately trained interpreters.

### Keywords

breast cancer; survivorship; Latinos; quality of life; qualitative

## INTRODUCTION

Breast cancer is the leading cancer among U.S. Latino women (referred to as “Latina”). The U.S. Latina population is rapidly growing [1,2] and thus the absolute number of Latina women likely to develop breast cancer is expected to increase in the coming decades [2].

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Greater use of mammography among Latinas and improved access to treatment will also increase the overall number of survivors [2].

Growing out of the initial research on quality of life conducted with largely homogenous samples of Caucasian non-Hispanic survivors [3], recent research literature highlights the role of culture and ethnicity in the experience of Latina breast cancer survivors [4-10]. Culture—or coherent and dynamic belief, lifestyle and value systems passed from generation to generation—contribute to people’s definition of health and well-being [11,12] and influence how people interpret and manage the world around them [13]. Multidimensional elements of culture, including language, environment, social structure, religion/world view, and economy [14], interact to influence health status, disease perception, and medical care [12]. Culture helps create meaning or structure with events that seem uncontrollable [12], like a breast cancer diagnosis. Moreover, cultural beliefs and traditions may impact symptom recognition, ability to communicate symptoms and/or understand treatment recommendations. Culture may also influence expectations about medical care, preferred amount of involvement with making decisions about treatment [15,16], patient-centered education efforts, communication and provision of coordinated care delivery [17-19].

Differences are evident between Latina and Caucasian breast cancer survivors in their illness and cancer survivorship experiences. For example, a number of negative post-treatment effects, including fatigue, depression and strained work and spousal relationships appear greater among Latina survivors compared to Caucasian survivors [4,6,20]. These ethnic-group variations in quality of life may have many explanations, including differences in access to, or quality of, cancer care [21,22]; culturally-based beliefs and/or consequences of immigration [2,5,6,23].

A number of cultural concepts are relevant to Latinos’ health. For example, certain Latino cultural values involving how people relate to one another are linked to patient-physician communication, recruitment into health-related research studies, and efforts to improve treatment-decision making [24]. One Latino cultural value, *personalismo*, is a script characterized by a warm, personal, and empathetic way of relating to others [24,25]. Similarly, *simpatia* is a relational style that emphasizes expressions of graciousness and charm [26], and *respect for individuals* reflects feelings of high esteem for a person and a willingness to be influenced by that person [27].

Another value, *familism*, relates to strong identification and attachment with one’s nuclear and extended family [28]. Prior work identified the influence of family as a key factor in women’s narratives about breast cancer prevention [29]. For example, family can be viewed both as a source of support [4] or as a deterrent to having open conversations about breast cancer, with the latter particularly influenced by *pudor* (embarrassment). *Pudor*, defined as a sense of humility, modesty or reserve related to self, has been linked with feelings of discomfort in exposing one’s body during physical exams [29]. A sense of reserve may lead to avoidance of information, which in turn, may contribute to fatalistic attitudes about cancer [30]. Cancer fatalism, or ideas related to not being able to prevent cancer or death from cancer, is associated with lower levels of acculturation [31]; however, whether greater fatalism is associated with worse health behaviors is unclear [32]. While fatalistic views have also been linked to religiosity (i.e., seeing cancer as God’s Punishment), other evidence indicates the interplay between fatalism and spirituality may yield benefits [32,33]. For example, religiosity and spirituality are associated with increased social and functional well-being of breast cancer survivors [9]. Some Latina breast cancer survivors pray for better symptom management or prevention of cancer recurrence [2,5,9].

Gender roles in Latino culture may also influence breast cancer survivors' experiences. For example, in a sample of Mexican Latinas, the loss of their traditional female gender role—characterized by responsibilities related to caregiving—was viewed by the survivors as being just as painful as receiving cancer treatment [34]. *Machismo*, a male Latino value, has both positive and negative attributes (e.g., aggression, pride, honor) and may be related to partner communication [35] and health and illness beliefs relevant to seeking health care [36].

Given the potential influence of cultural values on health and well-being outcomes in Latinas, we conducted a qualitative evaluation of cultural factors that influence quality of life in a sample of immigrant Latina breast cancer survivors predominantly from Central and South America. To date, prior research in this area has largely focused on Latinas of Mexican origin [2,6,9], with much less known about the unique cultural experiences of underserved Latina survivors from other countries. Further exploration of culture and its effect on health will help inform our efforts to create culturally-competent oncology healthcare teams to improve outcomes among diverse Latino subgroups [17-19].

## MATERIALS AND METHODS

### Setting

The researchers conducted a qualitative cross-sectional study within the Latin American Cancer Research Coalition (LACRC). The LACRC was a National Cancer Institute-funded regional Community Network Program (CNP). The goal of the LACRC was to conduct research in partnership with community clinics to promote cancer control in Latinos in the metropolitan District of Columbia area. All study procedures were approved by the Institutional Review Board at Georgetown University.

### Procedures

The researchers recruited Latina survivors age 21 and older within 10 years of their breast cancer diagnosis. Women were excluded if they were unable to provide written informed consent in English or Spanish or were < 1 year or > 10 years post-diagnosis. The researchers recruited women through fliers or by physician staff who reviewed medical charts and contacted eligible women from community clinics, local oncology practices, surgeons, hospitals, and a Latino-serving cancer support agency. Women were told that their decision to participate would not affect their medical care and were assured of the confidentiality of their responses. All women provided written informed consent.

The researchers collected data on survivors' experiences in two ways—individual interviews and focus groups. This dual approach to data collection was used for a number of reasons. First, the researchers conducted the individual interviews to learn more about individual Latina breast cancer patients' perceptions of their quality of life after completion of cancer treatment. Second, after reviewing the interview data and identifying initial themes, the researchers elected to seek additional insight into whether and how certain cultural influences impacted other Latina survivors' quality of life. Thus the researchers developed a focus group guide to expand upon the identified interview themes. Third, the researchers anticipated that these two complementary approaches could provide a broader representation of women's survivorship experiences than either approach alone. Specifically, interviews were conducive to collecting sensitive information and intensely personal insights – and the focus groups allowed us to use the group process to capture confirmation of and/or divergent perspectives. The researchers used structured interview guides for both settings.

**In-Depth Interviews**—The researchers conducted individual in-depth interviews in 2004 and 2005. Two trained bilingual interviewers collected participants' demographic information and then used structured interview guides to elicit information about general quality of life after breast cancer treatment, emotional and physical impacts, family and spousal relationships, resumption of work and daily routines, and engagement in social activities. Interviewers probed for the cultural context and beliefs that may have contributed to participants' survivorship experiences. The 60- to 90-minute interviews were conducted in Spanish in either a private room at a clinic or the participant's home. The researchers audiotaped interviews with participants' permission and then each interview was transcribed in Spanish, translated to English, and then back translated by separate study staff. Participants received a gift card valued at \$40.

**Focus Groups**—The researchers conducted two focus groups with Latina breast cancer survivors in 2007. The researchers explained issues regarding confidentiality and obtained written informed consent at the beginning of each group. Women completed brief demographic questionnaires prior to the discussion. The researchers held groups at a local Latino-serving cancer support agency (Nueva Vida), and provided participants with resources for transportation, parking and/or babysitting services. A trained bilingual moderator facilitated the groups using a semi-structured interview guide developed to expand upon emergent themes from the in-depth interviews (see Appendix). Several discussion prompts were used, as necessary, to elicit specific information about the impact of culture or Latino values on participants' survivorship experiences. Each focus group lasted 2 hours and was audiotaped with participants' permission. The researchers again transcribed audiotapes in Spanish and translated the transcripts into English by trained study staff. Participants received gift cards valued at \$30.

## Analyses

The researchers used the NVIVO 8 software package, a qualitative research analysis program (NVIVO Software, QSR International) to analyze the transcripts. The researchers used a thematic content analysis approach to categorize and organize content from both the individual interviews and focus groups [37]. First, trained research staff reviewed the content and separately identified preliminary themes found in the transcripts. Second, two trained raters independently identified a priori and data-driven themes to describe logical relationships among the participants' responses. Third, the researchers revised and refined identified themes using an iterative process until raters and study team members reached agreement about major coding categories. Although transcripts from the individual interviews and focus groups were analyzed separately, similar themes emerged, with data from the focus groups used to confirm and refine categories. As such, the researchers combined the results from the interviews and focus groups. The researchers organized our results by theme and extracted exemplary quotes.

## RESULTS

The study sample was comprised of 28 Latina breast cancer survivors: 19 completed in-depth interviews and 9 participated in the focus groups ( $n=5$  and  $n=4$  for the two groups). Saturation of identified themes appeared to be achieved following the interviews and two focus groups. Participants were, on average, 3.1 years ( $SD=1.5$  years) post-diagnosis and 47 years of age ( $SD=9.0$  years; Range 34-72 years; see Table 1). About two-thirds had lived in the United States for over 10 years (Range 1 to over 15 years) and all had immigrated to the United States. Women from El Salvador made up 25% of our sample. The researchers did not collect detailed information about stage of breast cancer at diagnosis since many women were unaware of their stage of disease. Notably, all women were living in the United States

at the time of their diagnosis and treatment for breast cancer. The majority reported undergoing mastectomies (68.4%) and adjuvant chemotherapy (79%). Almost half reported having radiation (52.6%) and a small number reported having a lumpectomy (4.2%). Most women (73.6%) reported still being on hormone therapy at the time of study participation.

### Cultural Influences on Quality of Life for Latina Breast Cancer Survivors

The researchers identified several themes relevant to cultural values and immigration issues that impacted quality of life for these Latina breast cancer survivors. Many women noted the importance of their relationship with God as a source of strength in dealing with their cancer diagnosis. Other values impacting survivorship included fatalistic beliefs about cancer; personalismo; secrecy/shame related to their diagnosis and its impact; a sense of self-reliance; and Latino machismo. Women also consistently reported linguistic barriers that impacted doctor-patient communication, treatment decisions, and follow-up survivorship care.

**Relationship with God/Spirituality/World View**—Most women in our sample reported that they relied on spirituality, specifically their relationship with God, to comfort them, although a few reported that their diagnosis made them question their faith. One woman who reported turning to God noted: “I give this to God; for me...he has supported me at all times, it has been less of a burden on my shoulders, he has been very helpful.” Not all women found immediate comfort in God at the time of their diagnosis, as one participant mentioned having a crisis of faith soon after diagnosis: “I had a little spiritual shock at the beginning of my disease. My relationship with my supreme being was affected a lot. I was hurt.... I understood that he is always there; yes, but I had a strong hit. I’m over it but I know that is normal, it’s normal in the human being.” Some participants emphasized a recommitment to their religion and/or church, while others stated they used religious practices to help them cope: “One of the things that is harder for me is the stress, and trying to control my stress through prayers. For me, that is quality of life.” For a few women, their views of God appeared to impact treatment-decision making. For example, one woman stated that she opted not to have breast reconstruction because it would be going against God and nature: “*If that* [a diagnosis of breast cancer and subsequent mastectomy] happened to you and you could live with that, why would you search beyond nature?”

**Fatalism**—Many of the women remarked that, among Latinos, cancer is often viewed as a fatal diagnosis. “I fear the death, because I thought that I was going to die when they diagnosed me.” Women indicated that the word cancer was often equated with death in their home countries. “Among Latinos the word cancer means that your life came to an end already.” Another woman commented “When I went to the oncologist to see the results about whether I had cancer anywhere else, I went with fear - I did not even want to enter [the building] for them to tell me anything...the results, I told myself, I’m going to die. I went with that thinking that I believed that I’m going to die.” Learning about cancer and various treatment options appeared to help some Latina survivors overcome initial worries about death: “Cancer is a synonym of death, but if we investigate a little more there are different types of cancer and levels....” Another noted, “I did not want to know anything. I did not want to read anything. When they told me that I need chemotherapy I said no. But some people informed me and help me a lot.”

Although many women noted significant anxiety at the time of diagnosis that extended to follow up appointments, for a number of women in our sample, fatalistic thoughts about cancer seemed to dissipate over time. For example, a few Latina survivors appeared interested in dispelling fatalistic attitudes about cancer. “I also advise other people who have been diagnosed with cancer and tell them that the world is not coming to an end.” In



reference to cancer recurrence, Latina survivors' experiences appear to be based on their emotional reactions to the initial diagnosis and individual responses to treatment. "*If I think it could come back I would not live.*" For example, a few women noted that because they suffered during chemotherapy, they would not opt for additional treatment if their disease recurred: "If it does come back I'm not going to get the treatment. Because I suffered a lot...." For these women, thoughts about a future diagnosis may have been less related to fatalistic beliefs but rather shaped by physical and emotional challenges they encountered during initial adjuvant treatment.

**Personalismo**—Several women described feeling isolated and lonely; these feelings appeared to be driven by both women's immigrant status and being cancer survivors. Commenting on the difference between her life before and after her cancer diagnosis, one survivor noted: "My life was beautiful. I was daring and did not fear anything. I was liberal minded and felt like nothing could stop me. Now it's not like that." One participant commented that her social life in the United States is different because she is more cautious about sharing her thoughts and feelings with others since her diagnosis. "You have fewer friends here. I used to have more friends back home. When I came to this country [having friends] *went down the drain*. [Back in my country] I felt my personality was more social and I would have more topics of conversation and would make friends right away.... Now I don't." Other women indicated that they were less likely to reach out to people or socialize following their breast cancer diagnoses. "It's terrible in this country because you don't have anybody," and "*Before I used to go out more than I do now.*" Participants reported a number of reasons for being less social, including not feeling as "*happy-go-lucky*" as they had felt before their diagnosis, not wanting to answer questions about their illness, and attending fewer parties because of not being able to wear the types of dresses/clothes worn before breast surgery.

Although a number of women in our sample reported feeling isolated, a few remarked that their illness experience actually improved the support they received from others, "I thank the Universe that everyone at my work supported me and after the chemo they were a lot more careful and still supported me." Remarketing on the strength of their friendships, two women noted, "*Positive things* [about my cancer experience] are the friends who were there for me in the good and bad times" and "People did not stop being my friends, and they became closer to me." For those women who commented that they felt isolated as a cancer survivor here in the United States, a few noted that one of the reasons they did not feel comfortable reaching out to others was that they had difficulty talking about their breast cancer.

**Secrecy/Shame Surrounding Breast Cancer**—Although most women in our sample felt supported by family members, some did not feel comfortable telling loved ones about their illness: "My mother does not know that I've had an operation for cancer yet." Likewise, one woman commented: "I hadn't told anything to my husband or my mom or my son until I went to get chemotherapy because [then] I could not hide it anymore because my hair was going to fall out...." Some women felt pressure from their partners not to tell other people, including family, about their illness or treatment. "My husband, when they said they'll give me chemotherapy..., he said, I don't want you to tell the kids...." Similarly, one woman noted that her husband "...did not want me to tell my friends what was happening to me, how I felt. When I wanted to talk with him about something I had read, he always told me that he was not up to [hearing about] *it then.*" Other women felt compelled to hide their emotional responses to their illness from their family, particularly children. "There's always the doubt and fear of the disease, but I don't tell them either. It's for me. Sometimes I cry on my own. My son asks me and I tell him I'm remembering my parents." Although the level of comfort in talking about their diagnosis and emotional responses varied from woman to woman, several women noted that they did not want to burden family or friends with their

fears related to the cancer coming back. For example, one woman commented, “*I did not tell my husband [about my fear] because I do not want to make anyone worry.*” The sense of not wanting to be a burden on others appeared influenced not only by women’s desire to take care of others, but also from feelings of self-reliance.

**Self-reliance**—Distinct from a more traditional cultural female role in which a Latina woman is seen as dependent or even subservient [38], women in our sample often remarked about their ability to be self-reliant. One woman said she was a very active person and never liked to depend on others and was bothered that she needed help due to lymphedema: “I didn’t like to have help carrying the bags and even now I am still silly and sometimes I carry the supermarket bags because I don’t want to feel that I depend on my husband or my son...” In addition, several women agreed that their ‘mental toughness’ may be due to learning how to be self-reliant and ‘fighting’ for themselves back in their home countries. “Maybe at home they taught us how to fight for things and to try to overcome any [challenges] *we faced.*” One woman commented that to her, quality of life was “*to be independent in the process of recovery.*” In addition to greater self-reliance, many Latina survivors indicated that working at their jobs during and after breast cancer treatment helped distract them from their illness. Participants often described work as being therapeutic for them. “I was undergoing chemotherapy, yet work was therapeutic for me because I did not want to be home depressed and have my children see me.” These sentiments may reflect some of the Latina survivors’ desire to maintain independence after going through a life-threatening experience. Self-reliance appeared to help many of the survivors identify themselves as strong and capable individuals, even in the face of illness. “I’ve always been an independent person who never liked to be dependent on others or my husband economically.”

**Machismo**—Several women noted their male partners had difficulty demonstrating support and coping with the emotional aspects of having a spouse with a cancer diagnosis. A few noted that Latino males may not readily show emotions or want their wives to be open about their cancer diagnosis with other people. In addition, several women commented that although they experienced a loss of libido following treatment, some felt obligated to engage in sexual activity because it was a “machismo thing.” For example, one woman commented “Obviously it is difficult because you don’t have a breast, despite that I had a lot of [reconstructive] *surgeries, then it is difficult to be able to [have sexual relations], but you need to work on that... for them.... It is our culture.*” Another woman noted that her husband told her that she “doesn’t love him anymore because I don’t feel the sexual desire.” Still, another felt that her husband had become quite jealous. “My husband has become extremely jealous; he does not like anyone to talk to me, no one, no. If they look at me, [he says] *why so much?*” Despite some challenges with their partners, several participants noted that their cancer diagnosis actually improved communication with their spouses: “Besides being married to each other, we’ve become good friends. I always tell him everything.”

**Familism**—Family support was a significant factor in determining survivors’ quality of life. Many of the Latina survivors’ emphasis on family relates to a cultural construct called familism, or the view of family as a supportive system within both immediate and extended family members [28]. Although the majority of women indicated that family members provided support, there were also challenges in these relationships. “It affects the family, my brothers, my mom. My mom is a 75 year old healthy lady. She doesn’t know what an illness is or anything.... In our family there is nobody that has had cancer, I am the first.” Several women commented that cancer affected their children. As one woman noted, “*It affects [things] a lot, especially our kids .... [My son] shows [himself as] so strong but at the end it affects him a lot in school....*” One woman noted the impact of not having her large

extended family live close to her: “That affects me a lot, not having all my family – that is 10 brothers and sisters, my mother, and a lot of nephews. I had emotional distress...because I don’t have them here.” A few women mentioned that family members came from far away to provide them with care. One woman commented specifically on weight gain as a consequence of a visit from family members: My mother came from El Salvador to take care of me – they gave me a lot of things [to eat] *that made me fat.*” Another mentioned that separation from family was more worrisome to her than her health: “At that moment I was passing a difficult situation, I don’t have my son here and that worries me more than my own health.” In addition, women commented that their families tried to protect them by not sharing upsetting news or information about other family issues – to protect the survivors while they dealt with their illness. “Well now those who are in Colombia must try to protect me... they try to be selective in what information I receive.”

**Factors Associated with Immigration**—Participants noted problems associated with being in a foreign country at the time of diagnosis. Frequently, women reported that one challenge in the United States is that the perceived “pace of life” is much faster here than in their countries of origin. Several women commented that this cultural change impacted their quality of life, as they often felt rushed and perceived a sense of urgency in terms of making medical decisions. Women also reported differences in their networks and employment in the United States compared to their home countries: “Being here is very difficult compared to living in my country of origin, because if you have trouble finding work here, you are not able to provide for yourself and/or rely on family or friends for financial support.” Another woman noted challenges related to under-employment, as she was unable to find a job related to the graduate school training she obtained in her home country. Finally, several women noted that they did not have any built-in support systems here as they had in their countries of origin, making coping with cancer that much more difficult. The concept of personalismo, as described above, seems particularly relevant for Central and South American Latino immigrants living in United States. Distance from the built-in support systems of their home country—systems typically defined by warmth, empathy and ongoing social connections-- may have created additional challenges for women diagnosed with breast cancer.

**Communication with Health Care Professionals**—For most participants, even those who spoke English, language challenges complicated their survivorship care, “To me it was stress – the language, totally caused stress.” Although several women mentioned the utility of having interpreters, many experienced problems with the interpretation process. For example, women felt that their concerns or questions were not accurately conveyed to health care providers: “Sometimes they put you with an interpreter but I understand a little bit and the interpreter does not say what you are saying. He says another thing.” Central to these issues was a sense that many women felt they were not always able to make themselves understood, even if they spoke English. For women who did not have access to either a trained or lay family member interpreter, communication difficulties resulted in both delays in treatment and increased patient frustration related to follow-up care: “I have pain in the breast all the time....Here it hurts me constantly, and I bless the doctor but the truth is that I do not know why he made another [surgery] there....” In some cases, communication difficulties appeared to impact survivorship care. One woman indicated that she did not begin Tamoxifen until a year after her diagnosis due to a misunderstanding of the risks and benefits of taking Tamoxifen to help prevent recurrence. Other women indicated they experienced a time delay in receiving follow up care after completing their adjuvant therapy because they did not know when to schedule follow up appointments with their oncologists. One woman mentioned that although there were times when she had someone available to interpret for her, on “*other occasions* [there was] not, and there was nobody to tell me there



are other options, or you can do this, or nothing....That was my big issue, not being able to communicate exactly and not knowing how to express myself – and [express] *all that I felt so that they understood me....*” Another woman, who relied on her daughter to serve as an interpreter during medical appointments, indicated she did not want her daughter to know about problems related to sexual functioning; as such, this participant did not share these concerns with her physician.

## DISCUSSION

Our sample of predominately Central and South American immigrant Latina breast cancer survivors reported a number of culturally-held beliefs and values that impacted their overall quality of life. Several results from the present study provide key targets for educational efforts to improve cancer care to the growing number of Latina breast cancer survivors. First, to our knowledge, our study is among the first to note how participants’ descriptions of feeling lonely, isolated and not being able to make friends in the United States (less personalismo) impacted their overall quality of life. Separation from family is a significant stressor for many immigrants [39], and our results indicate that a breast cancer diagnosis, along with language barriers and changes in social habits, may exacerbate this stressor for some Latina survivors. In prior investigations with Mexican-American Latina breast cancer survivors, changes in social experiences have not been reported as having a prominent impact on survivors’ quality of life. Perhaps this distinction is due to the geographic distance from family members of most of our sample (Central and South America), the high rate of being mono-lingual in Spanish, or the greater insularity of first-generation Latino immigrant communities in the Washington, DC area compared to second generation Latinos [40]. Together, these novel results indicate the importance of assessing Latina survivors’ perceived support, feelings of isolation and other potential psychosocial stressors as an important component of high-quality survivorship care [8].

Second, several of the Latina immigrant survivors in our study reported a strong sense of self-reliance versus adherence to more traditional Latina roles. Perhaps this sense of self-reliance can be used as a tool to further engage women in the process of their cancer care in a way that accounts for the cultural construct of respect for physicians. For example, active participation in treatment decision making and adherence to surveillance recommendations could be reframed as a way for women to help their physicians provide them the best care possible [41]. Third, certain cultural beliefs the researchers identified expand upon prior research with Latina survivors [4,5]. For example, a number of participants indicated that religiosity, fatalistic beliefs, secrecy about cancer, and familism all impacted their current quality of life. The ways in which the Latina survivors in our sample described the impact of these beliefs/views on their experiences as cancer survivors and their sense of self were nuanced. Some women appeared to shift their beliefs over time—when initial fatalistic views about cancer became less fatalistic after gaining knowledge about treatment—and other women mentioned the strengthening of their convictions through their cancer experience. Interestingly, many of these cultural factors were salient in the survivorship experiences of the women in our sample even though the majority of them had lived in the United States an average of 10 years.

Our findings on cancer fatalism suggest that, similar to prior findings [23], women initially endorsed fatalistic beliefs; however, survivors appeared to be less fatalistic over time. Prior research into interventions to reduce cancer fatalism appears promising [42] and may be useful to help newly diagnosed Latina women cope with anxiety about their illness.

Some Latina women reported feelings of shame and secrecy related to their breast cancer and/or sexual functioning – feelings that at times extended to partners of patients, perhaps in

part due to Latino machismo. For example, machismo may impact both men and women's level of comfort discussing emotional aspects of cancer and/or some women's perceived sense of obligation related to engaging in sexual activity. In addition to the potential impact of gender roles in expressing thoughts and feelings about a breast cancer diagnosis, feelings of secrecy or shame may be further exacerbated if women are relying on an interpreter (professional or lay) to communicate their concerns to an English-speaking oncology professional. As such, Latinas may be hesitant to bring up certain issues with their health care providers.

For all cancer survivors, follow-up care is often fragmented, with no single physician serving as the coordinator of care following the completion of treatment [19]. Latina breast cancer survivors, particularly immigrant survivors, face additional challenges within an already complex system, including language and health literacy barriers that make medical information even more difficult to navigate [18]. These barriers may result in delayed initiation of or problems with adherence to medical treatment. For example, our data correspond with earlier work with Latinos in which patients' inability to speak English compromised effective communication with their physician [6,23]. Training of oncologists in cultural competence has the potential to improve the quality of communication and care for Latina survivors so that sensitive issues can be appropriately addressed [43]. Further, utilization of trained interpreters, although not a panacea, may help ease worries over using family members as translators [18]. In future research, empirical evaluation of patient navigation programs that address the needs of recent immigrants will help determine whether these types of programs improve the quality of life of Latina breast cancer survivors [6,23,44].

Several caveats should be considered in evaluating our results, including the convenience sampling approach, the length of time many of our participants had lived in the U.S. and the lack of detailed clinical data on disease stage. Our convenience sample of women was recruited from community-based agencies and clinics and hence may not reflect the experiences of women not connected with these types of services. The sample did, however, include diverse Latinas from a variety of Latin American countries, levels of education, and ages. Given this diversity – including likely distinctions between women based on their countries of origin and age at diagnosis – results cannot be generalized to all immigrant Latina breast cancer survivors. Despite being largely monolingual in Spanish, the majority of our participants had lived in the U.S. for over a decade. As such, the experiences of the women in the present sample could also differ from those of more recent immigrants. Finally, data was collected a number of years ago and thus survivorship experiences of women diagnosed more recently may differ given advances in treatment or growing attention to the impact of culture on quality of life and cancer care [41,43].

Despite these limitations, our study builds upon and adds to existing literature about Latina breast cancer survivors as one of the first exploratory studies of predominantly Central and South American low-income immigrant women with breast cancer. Interestingly, regardless of the number of years living in the U.S., factors associated with immigration (isolation, lack of familiarity with the medical system) and culturally-held beliefs remained salient for many women in our sample. Future research can focus on more homogenous samples of Latina breast cancer survivors—exploring survivorship issues among women from specific countries and/or determining the impact length of time in the United States. The relevancy of specific cultural values denote specific targets for education programs and development of patient-centered services for immigrant Latina survivors to improve the experiences in this underserved, but resilient, population.

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## Appendix

### Focus Group Discussion Guide

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- 1 What does the term "quality of life" mean to you?  
Possible probes:
    - a. Physical functioning
    - b. Psychological functioning
    - c. Spiritual functioning / religion
    - d. Social Relationships: deepening of connection with family or friends
    - e. Functional: Ability to work, provide for family
  - 2 What impacts your current quality of life?  
Possible probes:
    - a. Physical changes since treatment
    - b. Weight gain / weight loss
    - c. Relationships: family, friends
    - d. Intimate Relationships: changes in sexual functioning
    - e. Work stress
    - f. Attitude
  - 3 What symptoms (or side effects) do you currently experience because of your cancer treatment?  
Possible probes:
    - a. Loss of functioning in arm
    - b. Weight gain / weight loss
    - c. Change in sexual desire; Menopause
    - d. Changes in Attitude
    - e. Cognitive changes (memory, word finding ability)
  - 4 How does your family impact your quality of life?  
Possible probes:
    - a. Spouse/partner
    - b. Children; Parents
    - c. Siblings

- d. Extended family – here and back home
- 5 How has language ability impacted your quality of life?
- Possible probes:
- a. Communicating with health care team
  - b. Communicating about insurance
- 6 How have your values impacted your quality of life?
- Possible probes:
- a. Spiritual beliefs / attitude (optimism)
  - b. Family-orientation
  - c. Not wanting to burden others
  - d. Keeping health concerns private

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**Table 1**

Demographic Characteristics of Latina Breast Cancer Survivors by Data Collection Mode (N=28)

Characteristic	In-depth interviews (n=19) N (%)	Focus groups (n=9) N (%)
Age		
≤50 years	12 (63.1)	8 (88.9)
>50 years	7 (36.8)	1 (11.1)
Years in U.S.		
≤ 10 years	6 (31.6)	3 (31.3)
> 10 years	13 (68.4)	6 (66.7)
Country of Origin		
Central America		
El Salvador	5 (26.3)	2 (22.2)
Guatemala	3 (15.8)	1 (11.1)
South America		
Peru	3 (15.8)	1 (11.1)
Colombia	1 (5.2)	4 (44.4)
Paraguay	1 (5.2)	0 (0.0)
Chile	1 (5.2)	0 (0.0)
Bolivia	2 (10.5)	0 (0.0)
North America		
Mexico	2 (10.5)	1 (11.1)
Caribbean		
Dominican Republic	1 (5.2)	0 (0.0)
Education		
< High School degree	6 (31.6)	2 (22.2)
HS degree	8 (42.1)	5 (55.6)
> High School degree	5 (26.3)	2 (22.2)