

## Quality of Life of Latina Breast Cancer Survivors: From Silence to Empowerment

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**Abstract:** *Breast cancer is the most common form of cancer among Latinas living in the United States. This article reports the findings of a qualitative study aimed at understanding the experiences of 25 Latinas, between the ages of 28 and 83, who are long-term (at least five years post diagnosis) breast cancer survivors. The findings revealed three key issues and concerns: (a) fear of being stigmatized and being treated differently if they talked about their breast cancer experience; (b) overcoming the perceived negative effects that breast cancer has on their femininity; and (c) the effects of breast cancer recovery and survivorship on social relationships of family and community. Family support and peer advocacy helped survivors in several areas: (a) to cope with the fear of recurrence; (b) to combat the fear of social stigma; (c) to become stronger as they dealt with the permanent life changes as a Latina breast cancer survivor; (d) to support them in the struggle for the provision of culturally sensitive health care; and (e) to provide social support in the form of advocacy for other Latina breast cancer survivors.*

**Keywords:** *Latina, breast cancer, survivorship, social support, health*

While breast cancer affects many individuals, particularly women, studies on breast cancer survivorship focus on describing how women experience many processes and problems after their breast cancer treatment has ended. For example, women experience the fear of recurrence and permanent changes to their bodies, their social roles, their intimate relationships, and their families (Ashing-Giwa, Rosales, Lai, & Wietzel, 2013; Ashing-Giwa et al., 2004; Ferrell & Dow, 1996; Fobair et al., 2006). Breast cancer survivors report that although family, friends, and health care professionals perceive their experience to be over, they experience new challenges as a result of complex changes such as living with the fear of recurrence, uncertainty, social stigma, disruption of intimacy, changes in self-perceptions, altered bodily appearance, and function (Ashing-Giwa et al., 2004; Carver, Smith, Vida, & Antoni, 2006; Cimprich, Ronis, & Martinez-Ramos, 2002; Fobair et al, 2006; Sammarco & Konecny 2010).

Women's individual experiences of health and illness potentially transform them, bringing new meanings about themselves, their bodies, their health, and their future. Living through and surviving breast cancer can be a catalyst for social change; provide a greater appreciation of time, life, and social relationships; and can lead to a healthier lifestyle and behavior (Vickberg, 2001; Zebrack, 2000). For some women, the process of

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surviving breast cancer includes a search for meaning in their lives, the construction of a new sense of self and role responsibilities, and self-transformation (Breadan, 1997; Carpenter, Brockopp, & Andrykowski, 1999; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Some breast cancer survivors describe their struggle for self-transformation happening as a result of connecting with their family and friends. Carpenter et al. (1999) reported that perceptions of personal awareness, mortality, coming of age, and life reassessment were described as positive changes, because they led women to become more aware of themselves. As a result, they reported changing various aspects of their social relationships and their work to help them feel stronger, more courageous, and more satisfied with themselves as breast cancer survivors. In some cases, Pelusi (1997) noted that breast cancer survivors managed the stigma they experienced by “mediat[ing] the expectations of others” (p. 1348). In other words, they had to control how others were affected by their breast cancer, particularly their husbands’ responses to their mastectomy scar, and the side effects of chemotherapy. However, for some women, the breast cancer diagnosis was not a stressful event. In cases where women did not feel an intense awareness about their breast cancer experience, they reported very little or no changes with their self-perception after breast cancer. These women were less apt to engage in a process of self-examination and introspection, and did not report increased self-awareness. Carpenter et al. (1999) identified key psychological and social factors that contributed to the inability of breast cancer survivors to experience self-transformation, which included lack of courage or strength related to mental and physical stamina; lack of information and support from health care providers; not having social support from family and friends; lack of income; and age. In addition, she noted that breast cancer survivors reported psychosocial problems such as coping with the death of one or more family members, the imprisonment of a child, loss of a job, divorce, or relocation. These obstacles interfered with the ability to devote the time and energy necessary to examining the self and moving toward making desired changes for self-transformation and self-empowerment.

Researchers have found that breast cancer survivors report a variety of family-related concerns. For example, women tend to report concerns about not being able to see their children grow up, the emotional impact that their breast cancer has on their children, feeling isolated, problems with fertility, and intimate sexual relations (Cimprich, Ronis, Martinez-Ramos, 2002; Dunn & Steginga, 2000; Fobair et al., 2006). Resources such as peer social support do have a positive impact because people can access the information to learn how to cope with the changes and uncertainty after breast cancer and how to communicate with health care providers (Sammarco, 2001; Zebrack, 2000).

Studies on Latina breast cancer survivors have reported that Latina breast cancer survivors experience different outcomes compared to non-Hispanic White women. In a study conducted by Carver et al. (2006) on long-term breast cancer survivors, Latinas reported more negative feelings about having been diagnosed with breast cancer, more social avoidance, more distress about their families’ futures, and more distress about the possibility of recurrence compared to white non-Hispanic women. In another study by Lopez-Class et al. (2011), Latina breast cancer survivors reported secrecy and shame about their breast cancer diagnosis, feelings of isolation, the need for family and social

support, challenges with developing social relationships, challenges with navigating the U.S. medical care system, and language barriers when interacting with health care professionals. Similarly, Ashing-Giwa et al. (2004) found that Latinas reported greater concerns relating to fear of death, pain and suffering, body image and sexual relations, and financial burdens when compared to other racial and ethnic groups who were breast cancer survivors. Uncertainty is an important factor shaping a persons' ability to make sense of the meaning of illness-related events such as their disease process, treatment, or hospitalization (Mishel, 1988). When an individual lacks information or experiences the unexpected or unfamiliar, they may experience uncertainty; and for breast cancer survivors, uncertainty can cause stress (Mast, 1998). Sammarco and Konecny (2008) researched the relationship between quality of life and uncertainty and found that Latinas with less formal education (less than a college education) reported greater uncertainty. In a follow-up study, Sammarco and Konecny (2010), seeking to understand quality of life, social support, and uncertainty, found that Latinas had higher levels of spousal support and slightly greater family social support than their counterparts; but they also reported lower quality of life and higher levels of uncertainty related to breast cancer. Furthermore, Latinas who perceived receiving less social support, or who lacked access to resources such as information in Spanish or support groups in Spanish, reported greater uncertainty and lower quality of life compared to Latinas who reported feeling supported.

Understanding how social well-being and quality of life is impacted by breast cancer survivors aids professionals in understanding how social roles and social relationships affect women's adjustment to breast cancer. Ferrell, Grant, Funk, Otis-Green, and Garcia (1997) define social well-being as "a way to view not only the cancer or its symptoms, but also the person surrounding the tumor; it is the means by which we recognized people with care, their roles, and relationships" (p. 400). More research is needed that focuses on how social and cultural values shape Latina breast cancer survivors' social well-being and quality of life. This study examines the perceptions of Latina long-term breast cancer survivors (five years or more since diagnosis) and aims to understand their breast cancer survivorship experiences. Lastly, this study generates findings useful for the provision of culturally sensitive health care and support services to benefit breast cancer survivors and their families.

## **Literature Review**

### **Latina Breast Cancer Survivors in the United States**

In 2010, the U.S. Census estimated 50.5 million Latinos were living in the United States, comprising approximately 16% of the U.S. population (Ennis, Rios-Vargas, & Albert, 2011), and the Latino population continues to grow in the United States. Although the incidence of breast cancer is lower for Latinas compared to Whites (non-Latinas), Latinas diagnosed with early stage breast cancer are 20% more likely to die from breast cancer than White non-Hispanic women (American Cancer Society, 2010).

Extensive research in health care shows that Latinas experience many barriers to health care treatment and diagnosis such as poverty, lack of health insurance, lack of a regular source of health care, lack of breast cancer prevention information in Spanish,

racial discrimination, and misconceptions about the disease (Ramirez et al., 2005; Schiller, Lucas, Ward, & Peregoy, 2012; Soni, 2007). Studies on the use of screening mammography for early prevention and detection show that older women who speak primarily Spanish are less likely to adhere to mammography screening guidelines compared with non-Hispanic White women (Borrayo et al., 2009).

Some studies have noted that being undocumented, low-income, low in English proficiency, and uninsured negatively impact Latinas' abilities to access quality health care (Documet, Green, Adams, & Weil, 2008; Vega, Rodriguez, & Gruskin, 2009). Researchers Campesino, Ruiz, Uriri Glover, and Koithan (2009) found that Mexican American breast cancer survivors reported that immigrant women tend to lack insurance, which resulted in limited access to treatment and neglect by medical staff. These problems are often reproduced in health care settings structurally because of the lack of culturally and linguistically sensitive health care. For example, physicians tend to rely on untrained individuals and family members or friends to translate and help discuss breast cancer treatment options for patients with limited English-proficiency. This practice contributes to disparities in the delivery of breast cancer care (Ashing-Giwa et al. 2006; Campesino et al., 2009; Rose et al., 2012), and may put many women at risk of being diagnosed with advanced stage tumors requiring mastectomy and chemotherapy (American Cancer Society, 2010; Li, Malone, & Daling, 2003; Singh, Miller, Hankey, & Edwards, 2003). For example, a study that examined ethnic differences between Hispanic women and non-Hispanic women with equal access to health care found that differences existed in the size, stage, and grade of breast cancer. Hispanic women were more likely to be diagnosed at a younger age; at a later stage of disease; present with larger, higher grade tumors; and with less treatable estrogen and progesterone negative tumors than non-Hispanic women (Watlington, Byers, Mouchawar, Sauaia, & Ellis, 2007).

Juarez, Ferrell, and Borneman (1998) found that Latino/a cancer patients experiences are embedded in culturally-based values of family life and religious beliefs that are interrelated and culturally bound. They concluded that, "Culture influenced all domains; physical, psychological, social and spiritual of quality of life...and no issue is exclusively a physical, psychological, social or a spiritual one" (p. 318). The study also identified that the most difficult changes to psychological well-being included anxiety, uncertainty, a lack of acceptance of the illness by family members, loss of independence, changes in family roles, and the financial impact of illness on the family. Napoles-Springer, Ortiz, O'Brien, Diaz-Mendez, and Perez-Stable (2007) found that one third of Latina breast cancer survivors never utilized support groups; mainly because they had no knowledge of existing support groups and instead received support primarily from their family. However, when family members encouraged them to attend a support group, they were seven times more likely to attend a support group than women who received very little or no encouragement. Galvan, Buki, and Garces (2009) found that Latinas reported the following as important: needing support from family (primarily spousal support), professionals (doctors and nurses), peers, and spiritual sources. In this study, participants who participated in social support groups valued exchanging their personal experiences about cancer with other women, reported feeling emotionally supported, and had an optimistic outlook compared to those who did not.

Conducting interviews with Latina breast cancer survivors about the long-term impact their breast cancer experience has had on their lives is important to capture their interpretations of those experiences with being a Latina breast cancer survivor. It is recommended by the National Cancer Policy Board that:

The psychosocial needs of women with breast cancer must be understood in the context of other issues that affect women's coping, quality of life, and well-being, such as socioeconomic factors and cultural factors, the quality of social support, access to health care, and the presence of other chronic illness or life crises. (National Cancer Policy Board, 2004, p. 23)

In this study, qualitative methodology lends well to understanding women's perceptions and responses about the significance of breast cancer in their lives and the cultural values and beliefs that impose unique meanings. Ethnicity and gender socially and culturally shape Latinas' experiences with breast cancer. Qualitative in-depth studies of Latina breast cancer survivors provide a unique opportunity to understand how Latinas link their past experiences of breast cancer with their present concerns and future possibilities. The documentation of their experiences is important in understanding the implementation of cultural and linguistic sensitivity in breast cancer services and advocacy.

### **Methodology**

Grounded theory, as a research method in qualitative research, was utilized to develop a well-integrated set of concepts leading to a thorough theoretical explanation of social phenomena under study (Glaser & Strauss, 1967). Feminist qualitative research asserts that women's life experiences are embedded in the particular historical forms of social relations that shape their experience. When women's perspectives are at the center of inquiry, we learn how social structures influence women's experiences with breast cancer (Kasper, 1994; Langellier & Sullivan, 1998). These principles informed the researchers to conduct a qualitative study of 25 Latina long-term breast cancer survivors (beyond five years of diagnosis) living in California who were interviewed in Spanish or English depending on the preference of the participant. The interviewer and one of the researchers developed a survey instrument containing basic demographic questions and various quality of life questions related to breast cancer, which were approved by the University Institutional Review Board. Over an 18-month period, respondents were recruited through advertisement flyers (in Spanish and English), from contacts at community organizations, and from breast cancer support groups in California. The recruitment flyer, which described the purpose of the research and included information and contact details of the researcher, was posted at health care organizations. Respondents contacted the researcher over the phone, and when they agreed to participate in the study, the researcher mailed the informants a packet consisting of a letter introducing the study, a copy of the English and Spanish (LTBCS) version of the questionnaire, a copy of the Institutional Review Board (IRB) approval, an English and Spanish consent form, and the researcher's Certificate of Completion of the National Institute of Health Human Subjects Protections Education. Respondents contacted the interviewer after they had received the packet and read the materials. The respondent determined the location of the interview, either at the researcher's office or a location

convenient to the respondent, as well as provided a date and time to meet for the interview. Respondents were informed of confidentiality and anonymity, and, with their permission, interviews were tape-recorded. Most of the interviews were conducted in English, one third were in Spanish, with the majority occurring in the home of the respondent. Interviews ranged between 60-90 minutes. During the initial part of the interview, respondents were asked if they experienced any social, psychological and/or physical side effects as a result of having breast cancer. Most women began telling their story from the point when they were first diagnosed. Then they discussed the type of treatment that they received. They were specifically asked, "After having had breast cancer, how would you describe your quality of life socially?" Initially, respondents reported that they were doing fine, but when asked if breast cancer had affected their relationships, the women began to discuss how breast cancer had changed them. The second part of the interview entailed questions that asked survivors to identify what, if any, were the positive effects of being diagnosed with breast cancer, as well as key demographic background information.

After the interviews were completed, they were transcribed by the researcher and a research assistant who are bilingual Spanish and English speakers. Interviews conducted in Spanish were translated into English, and then coded. Each interview was read twice before it was coded. The initial coding process involved coding for topical categories relating to the social aspects of quality of life. The initial codes served to summarize and sort out many issues relating to coping with diagnosis; surgery, including breast reconstruction; treatment relating to chemotherapy and radiation; and the long-term physical and social side effects. The coded "conglomerates" of data were sorted into categories of recurring patterns and issues: health status, relationships, body image, family, friends, and communication. Then, utilizing Kathy Charmaz's (1983) focused coding method, the researchers analyzed each new category systematically, utilizing line-by-line in-vivo coding, sorting out a series of repetition in statements, patterns, or inconsistencies relating to an issue in the topical categories, which provided more detailed codes relating to talking and expressing their fears, their feelings about their bodies, femininity, sexuality, and the need for social support. This method of analysis does have limitations because the process involves discarding a lot of the data during the coding process and presenting only parts, or slices of the narrative. However, this qualitative analysis allows for a nuanced understanding of the meaning-making process in coping with the long-term effects of a breast cancer.

### **Sample Demographics**

Latinas' average age of diagnosis was 47 years old, with mean age of 57 at the time of the interview. Most of the Latinas were first-generation bilingual, in Spanish and English, but one third of the women were Spanish monolingual. Sixty percent of the Latinas interviewed were college-educated, with 40% reporting incomes higher than \$60,000; 44% of the sample reported earning less than \$30,000. Most Latinas (80%) identified themselves as being of Mexican origin and other Latinas (20%) identified themselves as being from Guatemala, Honduras, Peru, and Argentina. Sixty percent of the women interviewed were not born in the United States, but were raised in the United

States. The other 40% were born in the United States. Most Latinas stated that they received a mastectomy, but more than a third of the women had breast reconstruction (See Table 1).

Table 1 *Demographics of Sample (n=25)*

	<b>n</b>	<b>%</b>
<b><i>Have Health Insurance</i></b>	24	96
<b><i>Type of Treatment</i></b>		
Mastectomy	21	84
Lumpectomy	6	24
Chemotherapy	15	60
Radiation	4	16
Hormone Therapy	8	32
<b><i>Breast Reconstruction (yes)</i></b>	10	40
<b><i>Nativity</i></b>		
Born in the United States	9	36
Not Born in the United States	16	64
<b><i>Education</i></b>		
High School Graduate or Less	10	40
Some College or College Graduate	15	60
<b><i>Employed (yes)</i></b>	15	60
<b><i>Household Income</i></b>		
Less than \$15,000	3	12
\$15,000 but less than \$30,000	8	32
\$30,000 but less than \$60,000	4	16
\$60,000 or more	10	40
Note: Mean Age = 57 (34-84 years old); Mean Age at Diagnosis = 47 (27-75 years old); Mean Years Post Diagnosis = 10 years		

There are limits to this sample because referrals were made nonrandom, primarily from a snowball sample. Recruitment patterns may reflect similar social ties, and respondents were similar to each other in their age, education, class, and ethnicity. Neither the women's narratives nor the researchers' observations and interpretations can be generalized to represent the experiences of all Latina breast cancer survivors.

## Results

Most of the respondents in the study reported that being diagnosed with breast cancer was a major life event that brought about new meaning in their life and their health. Key concepts identified by the respondents were the difficulty of being able to talk about the loss, fear of recurrence as a recursive mindset, stigma, and uncertainty about their futures. They also reported that, although they received social support, they needed more assistance with being able to cope with the fear of recurrence. Another key concept that emerged was that breast cancer made them more aware of their health, their roles in their families, their body images, and their femininity. They reported needing more support coping with the impact that breast cancer had on their body and their social relationships, particularly, their intimate relationships. Some of the women reported that sharing ideas and opinions with others who had similar or comparable experiences helped them understand their own illness. Lastly, the respondents reported that surviving breast cancer was a process of having to face new challenges, yet when they were supported by a friend, a family member, or someone who shared a similar experience, they were able to adapt. In some cases, women discussed feeling “empowered,” mainly because they became more empathetic toward other women like themselves who had been diagnosed with breast cancer.

### The Long-term Impact of Having a Breast Cancer Diagnosis and Treatment

Subjects reported that they found it difficult to discuss with others how their diagnosis impacted them. Many of them reported a fear of recurrence, a fear of stigma, and a fear of being treated differently. Most of the women stated that they had to socially negotiate their self-disclosure about the emotional impact that breast cancer had for them.

*My friends, my family, and my husband are very supportive. I still measure how much I let them know, because you don't want to upset them.*

*Y te puedo decir que nunca se acaba porque siempre tienes el miedo que regresa [cancer] verdad? Pero yo seguí luchando porque yo soy una mujer que siempre me dediqué a mis hijos y a mi esposo. [I can tell you that it never ends; because I can tell you that you always have fear that it (cancer) will return, right? But, I continue to fight because I am a woman who has always been dedicated to my children and my husband].*

*El cáncer te cambia toda tu vida. Cuando a mi me preguntan “Y a ti como te ha ido?” Pues tú tienes que ser positiva si tú quieres seguir aquí. Eso es lo que yo siempre les digo. Pero tampoco les digo que es la maravilla y que vas a regresar a tu vida. Yo no mas digo “tienes que ser positivia si quieres estar aqui.” Pero la verdad es que para mi ha sido una hebra que nunca he podido acabar de jalar... para mí ha sido traumática. Sigo con el temor de cancer. [Cancer changes all of your life. When they ask me, “How did it go for you?” Well you have to stay positive if you want to survive. That is what I always tell them. But, at the same time, I don't tell them everything is marvelous and that you are going to return to your previous life. But the truth is, for me, it has been like an unwinding thread*

*that I have never been able to stop pulling. I pull, and pull and pull...It has been a traumatic experience for me. I continue to fear cancer].*

*You feel. Wow, I made it to five years, but all you feel so fearful. You know, I am numb from going from the perception of myself as a healthy person to now, I am dealing with cancer, and there is a stigma to it. There is a lot of different things, even the way people look at you at work. I get asked more often, when I am going to retire.*

Often respondents stated that they were very cautious how they speak about having breast cancer to their spouses or family members and about their fear of recurrence because they did not want to “burden” them with negative emotions or “worry” them. They did not want to bring other people “down,” upset them, or be treated differently because they had breast cancer. Most women stated that they often concealed and did not share or express their emotions about breast cancer out of fear that people would perceive them negatively. A majority of the respondents stated that they had never been approached by anyone to discuss the impact that breast cancer had on them initially and the continued suffering from the long-term effects of their breast cancer treatment and surgery.

### **Perceptions of the Impact That Breast Cancer Has on Femininity**

The women who had a mastectomy or a permanent procedure on their bodies reported no longer “feeling the same” after breast cancer. Many of the women reported that the changes to their body affected their femininity and sexuality. Latina women who had mastectomies reported that breast cancer treatment and surgery had a negative effect on their body image, which also had a negative effect on their social relationships.

*Si, la recuperación si fue duro pero lo más difícil fue la aceptación de que cuando vi que yo no tenía el pecho porque yo he sido una mujer que siempre me gusta arreglarme, lucirme y una de las cosas que más me gustaba usar eran mis vestidos, a sentirme atractiva y para mi fue muy difícil cada vez que yo salía y miraba una mujer así como yo me vestía. [Yes, the recovery was hard, but what was more difficult was the process of accepting that I did not have a breast because I was the type of woman who liked to get dressed up, to show off (my beauty), and one of the things that I liked most was to wear my dresses to feel attractive. So, for me, it was very difficult every time I would go out and see a woman dressed the way I used to dress].*

*I think I had two very nice looking breasts. I am sorry that is not the case now. I do a lot of ballroom dancing, and some of the Latin dancing dresses that are cut low in the front, you know that it looks nice, but I will never be able to wear a dress like that. So, there is a degree of grieving that went along with losing my breasts. I am saddened that my body has had to look different and I feel it is part of the sacrifice that one makes to get well. The grief period, the thought of losing your breast or the possibility of losing the breast is very traumatic to all women.*

*Mira cuando me hicieron la lumpectomia, para mi era desagradable verme. Porque... veía deforme mi seno. ¿Si? En primera significó una herida en mi cuerpo. Una deformación en mi cuerpo. [sighs] En segunda imaginate si me hubieran quitado el seno. Hubiera sido una mutilación. Para mi eso es, una mutilación. Si una mutilación ya que es una parte que falta de tu cuerpo que todas las demás mujeres tienen. Look, when I had the lumpectomy, for me, it was unpleasant to see myself because I saw my breast deformed. Yes, [at] first, it meant a scar [would be] on my body... a deformation on my body... a mutilation. It would have been a mutilation. Imagine if they had removed my breast. For me, what it's a mutilation -a mutilation to your body! A part of your body, that all women have, is missing].*

The women reported that they did not discuss their sadness, loss, and anxiety about their body image with others because they feared being stigmatized and they were reluctant to discuss how breast cancer impacted their body. Some women said that they did not want to be perceived as being vain or “too much into her body image.” They were concerned that if they spoke about their experience, they would also be inviting insensitive comments from others, particularly family, friends, co-workers, and health care providers.

*Some people made some insensitive comments; they were often women. One teacher, when she learned that I had reconstructive surgery said, “how fortunate you are; how lucky you are; you know, you got to pick your size.” And I said, “You know what? I much rather have the ones God gave me, thank you very much,” and I walked out of the room. And another one, I tried to explain to her that I was grieving and that I was sad about the loss of my breast, and she said, “I didn't think you were into your body that way.” And I said, “Well, it wasn't the defining factor of my being, but it's still a loss of your body.” It's just not the same. Let alone people just do not understand it when you have reconstructive surgery. You lose. All the nerve endings are shot, so that sense of touch is gone. It is a whole other ball game. That is a big loss. Or, I thought that is a big loss.*

### **Need for Social Support and Information**

Latinas found themselves having to negotiate a new social landscape and often stated that they sought out the support of close friends and family, followed by clergy (or their religious group), and social support groups. Most Latinas stated that the health care system fell short of providing and assisting them in understanding the impact that breast cancer has in their lives and their well-being.

*My sisters were very supportive and people at my church prayed for me. I remember calling around to see if there was a church base support group, and there wasn't one. And I had a visit from the priest; he basically told me, “life's rough get over it.”*

*Siento que allí [grupo de apollo] aprendes. O sea, aprendes porque una dice una cosa y a lo mejor a la misma vez te esta pasando a ti. Y a lo mejor la misma duda que tu tienes la otra persona la... la hizo y ya sabe la respuesta. O sabe*

*expresar ese sentimiento y uno no lo sabe expresar o no lo dice. Entonces allí aprendes bastante. Aprendes que tu no eres la única que sufres. Sino que, hay otras mujeres que son completamente distintas a ti que vienen de otra familia. Que es la misma cultura y que lo sienten [igualmente]. Y no te sientes tan culpable tampoco. ¿No? Entonces aprendes bastante. [I feel that at the support group, you learn. I learn because one person may say one thing that you are experiencing. The same doubt that you have, another person may have or have experienced it, and they have the answer. They know how to express their feelings [when] one does not know how to express those feelings. So, you learn a lot. There are some women who have very unique experiences from different family backgrounds. They come from the same cultural background and can feel similarly. You do not feel guilty. Right? Thus, you learn a lot].*

In this sample, a majority of the women stated that information and communication about life after breast cancer should be improved for bilingual and Spanish-speaking Latinas. When asked how a doctor or health care provider can be sensitive to Latinas needs, one survivor stated:

*If you don't have dialogue with your doctor, then he is not sensitive to all of your needs that you might have, and you are unable to tell him what is actually transpiring in your body and your mind.*

Most women, particularly women who spoke limited English, stated that their communication with their doctor was poor, and they lacked information on how to adapt to the long-term side effects of breast cancer.

*Yo le preguntaba al doctor, y el me preguntaba, y el me ignoro, me ignoro. El no me dio la informacion. [I would ask the doctor, and he would question me, and he would ignore me. He ignored me. He did not give me information].*

The women in the sample stated that bilingual social support groups were needed to assist long after their breast cancer surgery and treatment were completed, to assist in coping with the challenges they faced as breast cancer survivors. When asked how social support groups helped after their treatment was over, they reported that they attended support groups to talk about how breast cancer affected their status as women, and they identified the need to build a community of support. Women utilized various forms of social support, including their families, church members and clergy, trained therapists or counselors, and support groups to help them cope.

*I dealt with some things I haven't dealt with from my past, like my folks, my place in the family, my value as a woman, and my culture. My sisters and I told my folks that it is not ok that the men in our family seemed to be much more valued than the women in the family. I am better affirming my own value and my own worth in different arenas. I am better able to just stand up for myself. I think my husband had the perspective "once we get through it, she can go on and be the same person that she was." You know, my attitude toward house cleaning changed, my attitude towards the way I spend my energy has changed, and my ability to say "no" got stronger. I remember telling a friend that [when they]*

*took my breast, my heart opened; because everybody was looking at my breast, nobody could look at my heart.*

*I have shown my body (to), I don't know to how many women. I wouldn't like another woman to go through that because it was horrendous; because even though I have a wonderful family and friends, but it is like they just hear the word "cancer" and it's like a death sentence.*

Talking to others and sharing their experiences helped women understand how to cope with the long-term social and physical effects of breast cancer. The respondents stated that, as they became more engaged when listening to other women's experiences, they were able to talk more about the impact of breast cancer in their own lives, seek out more information about breast cancer, and were likely to see their future as surviving breast cancer instead of a death sentence.

### **Perceptions of the Impact That Breast Cancer Has on Intimate Relationships**

When asked about the long-term effects on their quality of life, they connected it to body image and femininity, but found it difficult to talk about. Most stated that they thought about the impact that breast cancer surgery and treatment would have on their sexual intimacy. The women reported that they rarely spoke about how breast cancer compromised their sexual intimacy. The issue of sexuality and intimacy became apparent when they engaged in intimate social relationships. Their main concern was the fear of being rejected or being stigmatized by their partner's or by their spouse's perception of them as being disfigured or deformed. In a few cases, women said that they did not engage with another person intimately because they felt ashamed of how they looked.

*I have not liked having relationships with another person. Even when I have had suitors, well, I feel, I feel bad, do you understand me? Because a man, when he sees one like this they say, "No, you are no longer complete." They make you [feel] ugly and it hurts oneself. You are no longer complete.*

*My fiancée, he started coming less around and calling me less and I knew that this was going to be the end. I remember one day confronting him, and I said, 'I know what is happening, and I think I know why, but I just want you to tell me. Tell me in my face that you don't want me because I am missing a breast.' And, he didn't have the guts to say that. I said, "I just want you to tell me." He finally admitted, "Yes, I am having a terrible time, and maybe, if they [had] cut off your foot instead of your breast, maybe that may [would] have been different."*

Although many women were supported by their spouses, Latinas reported that breast cancer surgery and treatment has had long-term effects on their ability to experience intimacy.

*I have been able to talk to him and say, "I don't have my breasts now, so I feel half of my joy is gone, but why don't we make up this way? More stimulation in other areas." Sometimes, he says, "I am not very creative, but you tell me what to do." Which is good. You know, a lot of women, they cannot even speak of it, or mention anything.*

### **Perceptions of Self Transformation and Empowerment**

In this study, Latinas reported that breast cancer made them become more introspective about their futures. They stated that being diagnosed with breast cancer made them think about their lives, their health, and well-being. The process coincided with rethinking and becoming more conscious about their roles in their families as mothers, wives, sisters, and grandmothers. Some women said that breast cancer made them think about their gender and cultural roles in their communities as well.

*When you get the diagnosis of cancer, you realize that your time is limited. I started focusing more on the quality of my life. I changed my diet, and it's changed the way I value relationships.*

Many women reported that talking to and connecting with other women, especially Latinas who could relate to them culturally and who had breast cancer helped them to adapt to the challenges and changes of breast cancer. However, most women reported that they were aware that breast cancer support, which addresses the unique needs of Latina breast cancer survivors, was lacking in the health care system. Most Latinas perceived a lack of outreach and sensitivity by the health care system and felt that women who feel unsupported may feel helpless or alone. Over half of the Latina women became involved in breast cancer prevention advocacy efforts and engaged in public speaking by sharing their personal stories with other Latina breast cancer survivors. Many of the women said that they became involved in raising awareness and breast cancer education and prevention to help break down the stigma of shame and silence and to promote the message that being diagnosed with breast cancer doesn't mean that a woman has to die from breast cancer. As one Latina stated, "I am a survivor. I tell everybody. I tell them [other breast cancer survivors] so that they'll know that there is a second chance." Being diagnosed with breast cancer was perceived as a turning point in the women's lives. In discovering their authenticity, the women reported focusing on their present living conditions, changing their values and beliefs, and achieving more self-confidence and self-empowerment.

*People have told me, and I think it's somewhat like a light was turned on inside me and I'm radiating. Well, you know, I just consider myself as a survivor. What changed is how I live my life, you know. I always thought I was a good person. I learned to live more one day at a time. I learned to live to make the best of my days. You don't do things that are foolish or needless anymore.*

### **Discussion and Conclusion**

The long term effects of breast cancer made it difficult, and in some cases impossible, to return "back to normal" and feel fully embodied. This study describes key social and cultural issues that Latina breast cancer survivors experience. After their surgery and treatments, these Latinas faced many challenges, including communicating their needs and concerns, especially the fear of recurrence of their breast cancer, and the long-term effects and changes to their body, femininity, sexuality, and personal empowerment. Furthermore, Latinas reported that their quality of life, after being diagnosed with breast cancer, depended on their relationship with their family and friends

and access to resources including social support. However, it was difficult for them to talk about their concerns because they did not want to burden their families. Family values and roles, the expectations as a mother and wife, and ideas about femininity shaped their breast cancer survivorship experiences. In some cases, breast cancer permanently changed their bodies and their social identities, including how they related to their families and friends. The findings in this study add to understanding the relationship between family relationships and social relationships, including gender roles and expectations that have not been addressed by previous research. In this study, Latinas reported that being a breast cancer survivor included coping with the challenge of having to negotiate their social roles and social identities.

Prior research has found that *familism*, or having a strong identification and attachment with one's family, is a key factor for providing social support, but also can hinder a woman's ability to share her experience (Lopez-Class et al., 2011). A key theme that emerged in this study is that Latina breast cancer survivors live with fear and the stigma of discussing their breast cancer with others because they are afraid of being treated differently. Many of the women stated that they did not share the emotional impact that breast cancer had on them because they did not want to "burden" their families or friends, or simply because they thought others would not be able to provide the emotional support that they were seeking. This finding is consistent with the findings of Lopez-Class et al. (2011) also found that Latinas reported feeling supported by their families, but did not share their emotional responses with them; or they had difficulty communicating with their spouses and their health care professionals about their illness experiences. Yet, most Latinas in this study reported seeking social support from family, friends, and clergy before participating in formally-organized support groups or working with a therapist. Furthermore, they reported that although nurses and doctors were supportive, communication, information, and educational services about breast cancer and survivorship were inadequate and needed to be improved for bilingual and Spanish-speaking Latinas. Studies on Latina breast cancer survivors have noted that they have different needs, and the lack of access to social support results in Latinas' having a decreased awareness of information and less access to information needed to reduce isolation and promote healthy breast cancer adjustment (Buki et al., 2008; Campesino et al., 2009; Galvan et al., 2009; Zambrana & Thornton Dill, 2006).

The process of becoming empowered did emerge as a result of reflective thinking and self-transformation. Many respondents reported that becoming an advocate helped them gain a sense of empowerment in facing their personal challenges as breast cancer survivors. Ten of the women reported that they became involved in providing social support and advocacy to help other Latinas understand that breast cancer is not a death sentence and that there is life after breast cancer. According to Gutierrez (1994), empowerment is a process of increasing self-efficacy; developing a critical consciousness; skill building that allows the individual to develop resources to be more powerful on an individual, interpersonal, or political level; and involvement with similar others. This empowerment process is a "continual process of growth and change which can occur throughout the lifecycle" (p. 205). Gutierrez (1994) argues that, if social workers are to create structures and programs to mediate the effects of stress and

encourage empowerment, they should consider the empowerment process perspective; particularly, she notes, when working with marginalized groups who are likely to experience stress due to societal injustice and inadequate access to resources (Gutierrez, 1994). Personal empowerment is difficult to measure, but researchers have found it to be effective in promoting lay health education programs that go beyond providing access to health care to provide culturally appropriate health education programs to underserved communities (Booker, Robinson, Kay, Najera, & Stewart, 1997).

This research has generated useful information about the social and cultural context and nuances of breast cancer survivorship among Latinas. There are not enough studies that have examined Latinas' perceptions on how breast cancer affects their social relationships. In this study, Latinas reported that being diagnosed with breast cancer made them rethink their social roles. Moreover, having access to social support helped them talk about their experiences and become advocates for other breast cancer survivors. Studies have shown that social support such as the provision of information and peer group support can help cancer survivors change their perceptions of the threat of cancer and reduce stress (Zebrack, 2000).

Social support can help women and their families find meaning, minimize fears when facing breast cancer, mobilize resources to aid them in adapting to the changes, and feel more "in control" and empowered (Hilton, 1988; Lee, 1997). Klawiter (2008) noted that breast cancer survivors experienced positive changes by becoming pro-active in their well-being and health care. The perception of social support improved their quality of life (Sammarco, 2001), while social support, in the form of financial assistance, counseling, and support services, facilitated effective coping skills, enhanced socioeconomic resources, and motivated breast cancer survivors to engage in adaptive behaviors (Galvan et al., 2009).

Several caveats should be considered in evaluating our results, including the sampling approach, the clinical diagnosis, and the participants. The sample was primarily from California and recruited from various community health care organizations, and many do not reflect the experiences of women who have not connected to or utilized community-based health care facilities. In addition, this sample does not reflect a nationally-represented sample of diverse Latinas living in the United States; thus the results of this study cannot be generalized to all Latinas. The experiences of the women in this sample reflect women who had some access to health care since health care facilities were the locations utilized to recruit participants. Despite these limitations, our study builds upon and adds to the existing literature about Latina breast cancer survivorship. This qualitative study shows how social and cultural values shape the experiences of breast cancer survivors and how breast cancer survivors redefine and are resilient in the face of societal constraints and barriers. Latina breast cancer survivors prefer care-giving, social support, and educational interventions by Latinas who can relate to their survivorship experience. It is in this way that Latina breast cancer survivors can begin the process of recovery and healing and become empowered through building community.

Interventions should be designed to address cultural needs specific to Latina women. While this study utilized a small sample, it offers a glimpse into breast cancer survivorship experiences and how they are shaped by a variety of factors including the importance of family, immigration, language, outreach and education, and social support. Overall, a heightened awareness of cultural differences in program and policy development is critical in the development of interventions to include Spanish and English inter-cultural communication social support programs. Doing so will allow women to speak freely about how breast cancer affects their bodies, femininity, social relationships, and sexuality without anxiety or shame. Another option includes utilizing Latina breast cancer survivors in staffing and program development, as they seem to be more compassionate toward women and their families when discussing breast cancer.

At the familial level, social role conflict can be addressed by educating spouses and family members about the long-term effects of breast cancer to facilitate their learning about how they can communicate and provide social support. For Latinas, the process needs to include an open dialogue about their social and cultural roles in the family, their femininity, and sexuality. Interventions that address sexual intimacy may best be implemented with individual and couples counseling, and with support groups led by therapists sensitive to ethnicity, diverse cultures, and gender (Buki et al., 2008; Documet et al. 2008).

At the community level, interventions are necessary to educate the Latino community about cancer survivorship. More specifically, interventions should address how to access health care and develop grassroots community initiatives that promote cancer awareness and social support. The effectiveness of different forms of social support should be explored such as religious support, recreation and leisure support, self-help, and cultural empowerment support. Additional research will provide a better understanding of how culturally and linguistically sensitive services are beneficial resources that promote empowerment for Latina breast cancer survivors. Agencies, policy makers, organizations, and individuals must be creative in the development of resources when considering Latinas, their perceptions, health care, health providers, and in developing and designing research. Identifying cultural differences and discussing those differences openly, while holding the dominant health care systems accountable, is crucial to educating those systems. Equally critical is the need to examine the multiple systems of oppression that affect Latinas and integrate supportive interventions to overcome those barriers.

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