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Developing a Culturally Competent Peer Support Intervention for Spanish-speaking Latinas with Breast Cancer

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Abstract

Little research exists on the need for, barriers to, and acceptability and effectiveness of psychosocial support services among Latinas with breast cancer, despite their increased risks of psychosocial distress. This formative research study identifies barriers to and benefits and components of an effective peer support counselor intervention for Spanish-speaking Latinas recently diagnosed with breast cancer. Analysis was based on interviews of 89 Latino cancer patients referred to psychosocial services; 29 Spanish-speaking survivors of breast cancer; and 17 culturally competent advocates for Latinos with cancer. Results indicate that interventions should begin close to diagnosis; build self-care skills; be culturally competent and emotionally supportive; provide language appropriate cancer information; encourage self-expression; and address lack of access to and knowledge of services. Creating such psychosocial programs with input from survivors and advocates who have similar self-identities to patients would improve quality of life in diverse and underserved populations.

Keywords

Breast cancer; Latinos; peer counselors; psychosocial support; mixed methods

INTRODUCTION

Breast cancer is the most frequently occurring cancer and the leading cause of cancer death among Latinas (1–3). One in every 11 Latinas will develop invasive breast cancer over her lifetime (3). In 2002, over two million people were living with breast cancer in the United States; over 65,000 of them were Latinas (4). By the year 2050, Latinos will constitute 25% of the U.S. population (5). Thus, as the Latino population continues to grow, so will the cohort of Latina women living with breast cancer and its consequences.

Thirty to 45% of women with breast cancer experience substantial psychological morbidity in the first two years of survivorship,(6–9) making psychosocial support an important aspect of cancer care (10). Data on the prevalence of breast cancer–associated psychosocial morbidity among Latinas is limited; yet Latinas may be at increased risk of psychosocial sequelae of breast cancer due to unique socioeconomic and cultural factors. Latina breast cancer survivors experience greater concerns over recurrence, pain, death, complications of adjuvant therapy, (11) body image, sexual functioning, job disruptions, financial hardships,

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weight gain, and being rejected by their husbands after treatment compared to white women (12). Among Latinas, limited English proficiency, part-time or no employment, limited insurance coverage, lack of transportation, and unfamiliarity with the health care system may elevate their risk of distress (12, 13). Language barriers which prevent Spanish-speaking patients from fully understanding their diagnosis or treatment and from becoming involved in patient centered decision making may result in increased anxiety (13). Factors specific to Latino culture also exert powerful influences. *Familismo*, for example, a value system that places great importance on relationships within the immediate and extended family, may provide Latina breast cancer patients with a strong support network. However, it may also cause increased emotional distress as women attempt to protect the family from the consequences of their illness, especially the inability to carry out household responsibilities (14).

Despite these increased risks, Latinas have limited access to culturally and linguistically appropriate psychosocial support services (15). Limited availability and awareness of such services are key barriers to their use among ethnic minority and underserved women (16). Cultural issues, such as reluctance to discuss emotional problems with strangers and views that psychosocial support services are for the mentally ill, may further prevent the psychosocial needs of Latinas from being identified and addressed (12, 17). Evidence among ethnically diverse women with breast cancer indicates that cultural factors, such as cancer-associated stigma, fatalism, and spirituality may influence how women adapt to being diagnosed with breast cancer (18). These factors may also affect their attitudes and use of cancer support services. Transportation and childcare needs also can prevent Latinas from participating in group support programs (19). Furthermore, language differences may prevent physicians from engaging in a discussion of psychosocial needs and services with their Spanish-speaking patients. These unique cultural factors must be considered in the design and delivery of effective support services.

Cancer peer support programs have demonstrated positive effects on cancer survivors, including informational, emotional, and instrumental benefits, (20) possibly mediated by several mechanisms, such as enhanced coping skills, increased self-efficacy, normalization of the cancer experience, and role modeling of health promoting behaviors. Peer support can take many forms, but most programs consist of in-person, one-to-one or group support. Most participants in these programs, however, are highly educated and middle class, (20) unlike the average Latina woman in our study.

Little has been done to assess the acceptability and effectiveness of psychosocial interventions among Latinas. The use of peer cancer survivors to deliver support interventions is a promising avenue for increasing access to cancer support services in community settings, (21, 22) especially for Latinas. Latina breast cancer survivors view other Latinas as engendering hope and as excellent sources of information about how to talk to their physicians and make better treatment decisions (23, 24). Peer health educators have worked effectively among Spanish-speaking Latinas to promote cancer screening, (25, 26) but the feasibility of tailored peer-delivered cancer support interventions for Latina breast cancer survivors needs to be investigated. We sought to determine how such interventions could be accomplished in a population of underserved women.

In this study, our goal was to collect formative data to evaluate an existing cancer support program for Spanish-speaking Latinos and to obtain community input on the design of a peer support counselor (PSC) intervention that could be tested in a randomized controlled trial in a subsequent study. Specifically, the aims of this study were to: 1) identify the barriers to and benefits of Spanish-language cancer psychosocial support services among Spanish-speaking Latinos with cancer; 2) identify the psychosocial needs of Spanish-speaking Latinas with breast cancer; and 3) identify key components of a cancer PSC intervention with input from community advocates and Spanish-speaking Latinas living with breast cancer.

METHODS

With the guidance of a community advisory board consisting of community-based organizations and Latina breast cancer survivors, a pilot study was conducted by a Latina researcher at the University of California San Francisco partnered with Círculo de Vida Cancer Support and Resource Center (Community Partner or CP), a community-based provider of Spanish-language cancer psychosocial support services. The CP's program includes a PSC component called "Las Angelitas" or the angels, which consists of training Latinas who have had cancer to provide emotional and informational support to newly diagnosed Latinas.

Sample

Three sources of data were used in this study: telephone surveys of Spanish-speaking Latinos referred to the CP (n=89); semi-structured interviews (group and individual) with Spanish-speaking Latinas living with breast cancer (n=29); and semi-structured interviews with community advocates (n=17).

Spanish-speaking Latinos with Cancer Referred to the CP—The CP receives referrals from San Francisco Bay Area hospitals and community organizations. The sampling frame for the telephone survey consisted of all persons referred to the CP in the 5 years prior to the survey (N= 189), which took place between February and May, 2006. Inclusion criteria were: self-identifies as Latino, speaks primarily Spanish, diagnosed with cancer in the past 5 years, and age 18 years or older. Forty-seven percent (n=89) completed the interview, 32% (n=60) had incorrect contact information, 11% (n=20) was unable to be reached after 15–30 attempts, 5% (n=10) refused, 4% (n=8) was deceased, and 1% (n=2) was too sick or disabled to participate. All participants elected to do the survey in Spanish.

Specific characteristics of the telephone survey sample are provided in Table 1. In summary, the majority of the sample consisted of immigrant women with breast cancer, who spoke primarily Spanish, had public health insurance, and had a high school education or less. The sample appeared to have a low acculturation level as all except for two were foreign-born, about three-fourths of the sample spoke English less than well, and 82 percent preferred to receive their health care in Spanish.

Spanish-speaking Latinas Living with Breast Cancer—We completed 29 group or individual semi-structured interviews with Spanish-speaking Latina breast cancer survivors recruited through community-based organizations. Inclusion criteria were: self identifies as Latina, diagnosed with breast cancer in the past 5 years, speaks primarily Spanish, resides in San Mateo or San Francisco County, and age 18 years or older. Twenty-four women participated in focus groups (two groups of 8 women each who had used support services and one group of 8 women who had not). Another 5 women who had not used services were interviewed individually at their request. The majority had been diagnosed within the past 2 years; their mean age was 53 years; 35% rated their health as poor or fair; 55% had a high school education or less; and 59% reported having MediCaid insurance. Most (90%) preferred receiving their medical care in Spanish. All were foreign-born, with a mean of 16.7 years (SD=13.0) residing in the United States. Most (93%) spoke English less than well. The most frequent source of social support reported was children (45%); spouse or partner, a female relative, friends, and cancer support groups tied for the second most often mentioned source of social support (31%).

Community Advocates—We interviewed 17 Latino cancer care advocates, including providers of cancer support services (n=8), patient navigators (n=4), social service providers (n=3) and oncology social workers (n=2), identified through word-of-mouth and cancer resource directories. Inclusion criteria were: lives in the San Francisco Bay Area and has direct experience working with Spanish-speaking Latinos who have cancer. The majority was of Latino ethnicity (76%) and about half was foreign-born (47%). All had at least some college education. Only one was a man, and the majority was older than 40 years of age. On average, 63% of their caseload consisted of Spanish-speaking Latinos (range=20% to 100%).

Procedures

All contact with potential or actual study participants was conducted by experienced bilingual-bicultural study personnel from the University of California San Francisco (UCSF). The UCSF institutional review board approved the study procedures.

For the telephone survey, potential participants received an initial contact letter in English and Spanish written at a 6th-grade reading level that included a postage-paid refusal postcard to decline participation prior to any further contact. Those who did not return the postcard were telephoned by an interviewer who obtained verbal consent prior to the interview, which lasted about 30 minutes. Participants received $10 for the survey.

For the semi-structured interviews with Latinas living with breast cancer, women were recruited in person at community sites and then contacted by telephone and stratified into two groups, previous users of cancer support services and non-users. Community advocates were contacted by telephone at their place of employment to invite them to participate. All in-person interviews were held in convenient community settings or participants' homes and lasted about one hour. We obtained written consent and interviews were audiotaped and transcribed. Participants were paid $25.

Measures

Translation—Survey items that were not available in Spanish and the semi-structured interview guides were rigorously translated using forward and backward translation methods with team review and reconciliation of discrepancies. New and newly translated survey items were pretested in both Spanish and English with community residents meeting eligibility criteria (who were not included in the final sample), using cognitive interviews.

Telephone survey instrument—In addition to standard demographic questions, the survey asked about preferred language for receipt of health care and self-assessed English-speaking ability on a 1–5 scale (1=not at all to 5= very well). Clinical questions included cancer site, years since diagnosis, stage at diagnosis, whether they were in treatment at the time of the survey, whether they had experienced a recurrence of their cancer, and self-rated health on a 1–5 scale (1=poor to 5=excellent). Two items asked patients to rate how much encouragement to seek support services respondents received from their family and from their oncologist on a 1–4 scale (1=none to 4=a lot).

Respondents who had never used the CP's services were asked to answer yes or no to a list of 15 possible reasons for not using services (e.g., transportation issues, lack of physician recommendation), how to increase awareness of services, and if they would have been more likely to use support services if their doctor had talked to them about it. Respondents who had used the CP's services but had stopped were asked their reasons for discontinuing use of services using a list of reasons similar to the one asked of non-users.

Users of services were asked to rate the overall quality of services, the benefits derived, and the usefulness of diagnostic and treatment information provided by their cancer physicians and by the CP on a 1–5 scale (1=poor to 5=excellent).

The outcome variable was assessed with a single-item asking, "Have you ever used any of the services at Círculo de Vida?" with a response option of yes or no.

Semi-structured interviews—Latina breast cancer survivors were asked open-ended questions about their reactions and concerns at the time of diagnosis; sources of support; unmet support or informational needs; potential barriers to support services; and when and how newly diagnosed Latinas should be offered support services. Those who had used support services were also asked about how they had learned of services; how they decided to use services; benefits obtained; and potential improvements to services. Those who had not used services were also asked about their reasons for not using them and barriers to their use.

Community advocates were asked about outreach and support methods they used with Spanish-speaking women with breast cancer; the effectiveness of their methods; recommended skills, training, and content for a PSC program; and the psychosocial needs of Latinas with breast cancer.

Analysis—Means and proportions were used as descriptive statistics. For the telephone survey, we used simple logistic regression to identify group differences between Latinos who had and had not used cancer support services. Due to small cell sizes, multivariate analyses were not conducted.

For the semi-structured interviews, the transcripts in their original language were the data. Accuracy of the transcripts was verified against the audiotape. Transcripts were content analyzed using a constant comparative method to compare as many similarities and differences as possible in the data to generate the coding categories for psychosocial and other needs described in Table 3 (27). The reliability and validity of the coding categories were assured through a five-step process. First, each transcript was independently coded into categories (inductive approach) by two bilingual-bicultural research team members with previous experience analyzing qualitative data. Second, discrepancies in coding were discussed and reconciled by the two coders. Third, after the transcripts had been coded into the categories, the text coded within each category was again reviewed by each coder (deductive approach) to ensure that the text represented the category. Fourth, the research team held meetings to verify the codes and emerging themes, identify illustrative quotes, and frame implications for improving PSC interventions for Latinas with breast cancer. Finally, results of the study were reviewed by the Community Advisory Board for accuracy since many of the members were interviewed for the study in their role as community advocates. Coding of the transcripts was performed using QSR's NVIVO qualitative data analysis software (28).

RESULTS

Results for all three data sources are presented together, organized by thematic category. The psychosocial and other concerns of Spanish-speaking Latinas with breast cancer and their implications for designing a PSC intervention are presented in Table 3.

Themes About Cancer Psychosocial Support Arising from the Interviews

Barriers to Using Psychosocial Support Services—In the telephone survey, of 84 people who had heard of the CP, 73 (82%) reported they had ever used the CP's services and 16 (18%) said they had not (Table 1), with gender and cancer site being the only significant differences between users and non-users on demographic or clinical variables. Men were less likely to use services than women (odds ratio, OR=0.18; 95% confidence interval, CI, 0.04, 0.79). Persons with cancers other than of the breast were less likely to use services than those with breast cancer (OR=0.21; CI 0.06, 0.76). Respondents who reported that they received quite a bit or a lot of encouragement from their family to seek support services were significantly more likely to use services than those who had not (OR=6.21; 95% CI 1.55, 24.95). Although not significant, those who received quite a bit or a lot of encouragement from their oncologist to seek services were more likely to use services than those who had not (OR=7.89; 95% CI 0.97, 64.56).

Among the 16 people who had not used services, the most frequently cited reasons for non-use were being too busy (n=6), feeling too ill (n=5), and never having heard of the CP (n=3). Of these 16 people, 10 (63%) indicated that if their oncologist had talked to them about the CP, they would have been more likely to use the services. Of the 16 people who had not used services, 12 (75%) suggested that more information about cancer support services needs to be disseminated by oncologists, hospitals, and clinics to increase awareness of services.

In the semi-structured interviews with survivors, for those who had never used support services, the three most commonly cited barriers were lack of transportation, lack of familiarity with the nature of support services, and being unaware that services were available in their local area.

Among participants in the phone survey, for the 29% that were no longer using services, the most frequently cited reasons for discontinuing services were distance to the center (n=10), lack of transportation (n=5), and receiving enough support from other sources (n=3).

Benefits of Psychosocial Support Services—Of the 73 respondents who had used the CP's services, 51 (71%) were using them at the time of the interview. Both in-person and telephone support appeared to be acceptable, as these were the most heavily used services (86% for women's support groups and 56% for telephone support), which received mean ratings of 3.7 (SD=0.69) and 3.8 (SD=0.47), respectively, on a 1(not helpful) to 4 (very helpful) scale.

Among those who had used the CP's services, the average overall rating of services was 4.3 (SD=0.88) on a 1–5 scale (1=poor to 5=excellent); 97% (68 of 70) rated services overall as "good," "very good," or "excellent" (Table 2). The benefits of services that received the highest ratings were helping them express their feelings (mean=4.3, SD=0.81); helping them feel that someone really understood their cancer experience (mean=4.3, SD=0.83); helping them feel less anxious and depressed (mean=4.1, SD=1.01); and learning how to ask questions of and express their needs to physicians (mean =3.9, SD=1.04). The usefulness of diagnostic and treatment information provided by the CP was rated higher on average than that of physicians (3.8 vs. 3.3; scale=1–5). Eighty-four percent of people indicated that the information provided by the CP helped them to understand "quite a bit" or "very much" (versus "not at all" or "somewhat") the information their physicians provided.

In response to open-ended items, telephone survey respondents identified the most helpful aspects of the CP's services as the emotional and informational support provided. Other helpful aspects included being able to talk about the cancer experience, educational presentations, and listening to the experiences of others. The one aspect that emerged as least helpful was discussing the effects of cancer on their lives, as it sometimes led to feelings of depression and fear. In the focus groups of women who had received support services, the most frequently mentioned benefits were, in order of importance: 1) the ability to discuss cancer related issues with a fellow cancer survivor; 2) the support and compassion received; and 3) information on cancer and its treatment.

Informational Needs of Spanish-speaking Latinas with Breast Cancer—Advocates recommended the provision of simple and culturally appropriate information in Spanish focused on two general areas: 1) breast cancer, treatments, treatment side effects, and management of side effects; and 2) community resources to reduce trauma and improve the patient's sense of well-being, hope, and ability to cope. One advocate stated that providing information "…changes a Latina's sense of well-being, that there are treatments available, that there are chances of surviving this, that treatments have advanced considerably, that even though it may be hard, she needs to go through with it, and that there are support services available."

Cancer survivors described being confused by the terms "radiation" and "chemotherapy" and out of frustration, turning to their friends and acquaintances for more information. In the words of one of the women, "You ask your friends, a neighbor, half the world, and your mind becomes like a tossed salad. But, when you are confronted with reality, you are no better off. You have no idea what the treatment consists of, the side effects, and what to expect."

Cancer information to dispel myths was also important. One of the advocates stated, "I had questions like, 'Is cancer contagious? My son doesn't want to wash my clothes because he thinks he is going to catch it.' I mean just heart wrenching questions. So getting the FACTS is very helpful." Most of the advocates reported working with Latino clients who tended to be of low socioeconomic status, which tends to be associated with a sense of fatalism. The provision of information that is comprehensible served to dispel such fatalism. One of the oncology social workers stated, "The majority of Latino patients I have seen are NOT sophisticated. These are people who are doing manual labor, housekeeping, in the fields. They hear myths ALL of the time. 'Oh, she had breast cancer and she died.' I ask them, 'What kind of breast cancer, what stage?' 'I don't know, but she has the same thing I have.' They just hear the umbrella category, 'cancer,' and they immediately put themselves there, which then automatically gives them immense fear sometimes to the point that they're immobilized because they are so scared about that person who died."

The need for low literacy materials on cancer was also evident in both survivor and advocate interviews. Several survivors commented that the Spanish language treatment brochures they were provided were difficult to understand. One woman described going over a brochure on breast cancer treatment many times and thinking, "People will never understand this and they NEVER explain it to you."

Knowledge of Community Resources and Advocacy—In addition to cancer information, advocates believed that knowledge of community resources is vital for peer educators and patients because patients' needs may include financial assistance, housing, mental health services, transportation, meals, housekeeping, and childcare. One advocate stated: "A lot of my clients call me for other resources. I'm almost a clearing house for information because I know a lot of them don't have a lot of people like that that they can call." The advocates frequently described the extreme hardship associated with lack of funds to cover treatment, especially for undocumented immigrants. This required that advocates secure assistance from state and private programs to cover costs of treatments and medications.

Advocates stressed the need to advocate on behalf of their clients due to language, socioeconomic factors, immigration status, and lack of familiarity with the health care system. As further described, advocacy on behalf of patients involved navigating county health care systems, obtaining more timely appointments, working on-on-one with physicians to obtain answers to patients' questions, and guiding patients so that they understand their diagnostic and treatment processes.

Psychosocial Needs of Spanish-speaking Latinas with Breast Cancer—Although informational support was viewed as a critical need, psychosocial support around the time of diagnosis to alleviate fear and anxiety appeared to be equally important. In the period immediately following confirmation that they had cancer, the majority of women described an intense fear that they were dying. One woman said, "You have the idea in your head that cancer is synonymous with death." Another woman stated that support is especially important for Latinos because they are accustomed to seeing women die of breast cancer in their home countries due to the shortage of mammography facilities.

Difficulty expressing their feelings was another common psychosocial issue. For many of the women, their primary concern when diagnosed was for their families. The idea of having peers who have gone through breast cancer treatment to talk to was very reassuring to the Latina survivors, as it meant an opportunity for communicating about their cancer without, as they saw it, burdening their family members. Some described a process of withdrawal from social contact that diminished over time through the provision of support services. As one woman stated, "When I started the program, I was very closed off, even to myself. I began the support process and it helped me to express myself better, bit by bit." Another survivor stated that many Latinas are not familiar with cancer support services and need to see that, "Yes, we do talk about cancer. We can openly talk about our feelings."

Advocates recommended that a PSC have active listening skills, which they described as being "supportive, a good listener, non-judgmental, and questioning yourself constantly." They stressed that advocates should present available options without telling the patient what to do. One advocate said, "So you need to question yourself, 'Am I really imposing my own beliefs or my own issues on the patient or am I respecting their wishes, am I supporting them even if I don't agree with what they are doing.' "

Powerlessness and Patient Empowerment—Another dominant theme among the Latina breast cancer survivors was a sense of powerlessness during the diagnostic and treatment phases, largely due to the lack of information in Spanish. This powerlessness was associated with the perception that they were unable to ask questions during their medical encounters, largely due to physicians' time constraints.

A complementary theme espoused by advocates was the importance of providing Latinas with skills to manage their own needs subsequent to cancer. Advocates stressed that Latino culture is characterized by a general sense of humility and deference to health care professionals. This humility makes it critical for peer educators to teach patients self-advocacy skills by pointing out their inherent strengths and how to identify resources in their immediate environment. The advocates commented that it is important for PSCs to resist the urge to fix the patient's problems, but rather support the patient's efforts to address their own needs. Thus, advocates recommended skills-building for the patient in relation to accessing resources and information, asking their physicians for second opinions, being involved in their treatment, and asking for help when they need it. "Leadership training based on the premise that all beings are created equal," was viewed by one of the advocates as a necessary component of empowering Latinas to take care of themselves.

Cultural Competence—Comments by the survivors and advocates indicated the multidimensional nature of cultural competence. Sensitivity to culture involved awareness of: 1) the advantages of a shared cultural background between the PSC and her client; 2) cultural beliefs and attitudes; and 3) unique considerations associated with being of a lower socioeconomic status. Both survivors and advocates felt that the PSC and her client needed to share a similar background to facilitate a sense of mutual trust. When asked if she thought it was necessary to be Latino to be a PSC for Latinas, one advocate responded: "I think it is very important because then they see that there is a connection. My experience has been that I think it helps to have that cultural connection. There's a fear factor that is eliminated when you're part of the same community. I can understand how my aunts would react, or my mother, or my sister, so it becomes very personal for me."

Based on their experience working with Spanish-speaking Latinas with breast cancer, advocates advised about the need to incorporate and be sensitive to cultural beliefs in the provision of support. For example, advocates commented that peer educators needed to practice *simpatía* (cultural script of positive interpersonal relations), respect patients' beliefs about folk medicine, recognize that Latinos tend to be reserved about their feelings until trust is developed, and assist patients with feelings of fatalism. As one advocate stated, "One of the things that is really challenging is that this culture is not a culture that likes to talk about things, and so they really guard themselves as far as how they're feeling and what they're thinking. It takes them awhile to really open up. They're embarrassed. They don't think they need to talk to anybody about these problems, and then the issues come into play."

Although advocates described their Latina clients as facing substantial barriers due to their low socioeconomic status, they also viewed them as resilient in many respects. For example, one of the advocates stated "Latinos are usually poor because they are recent immigrants. They are just getting going, they don't have an education, they are undocumented so they can't really get good jobs, but I always had the sense that they were more functional because they had overcome all those obstacles to get themselves here, and even if their families weren't here, they were still connected to their families in their countries of origin so there was much less isolation."

The Central Role of the Family—Advocates stressed the importance of assessing family factors and involving family members in the provision of support since, as one of the advocates states, "what I've really found out in working with the Latina population, is that they don't want to cause any hardship to their family." They stressed that assisting families with information and support could help alleviate the stress on the patient. Advocates reported having to respectfully negotiate with a client's spouse to obtain permission from the husband for the woman to attend support programs. Often, the advocate's role was seen as one of encouraging the family to provide instrumental and emotional support even though the client may appear to be functioning well. As one of the advocates describes, "Unfortunately, I've seen a lot of Latinas, they're suffering, they're going through treatment, but they're still trying to cook and take care of the kids, and do everything and the husband's not viewing it in the sense that she needs help and that she needs support during this time."

Spirituality—Spirituality and religious beliefs were mentioned often by both the survivors and advocates. Many survivors mentioned their faith in God as a source of strength and hope. However, as in the case of family roles, advocates alluded to both positive and negative aspects of Latinas' religious beliefs. While many felt that faith was an important resource for Latinas coping with their diagnosis and treatment, the sense of acceptance that their fate was to get cancer sometimes meant that advocates had to work with the women to mobilize self-care behaviors. The advocates described a delicate balance between respecting women’s religious beliefs and illustrating the benefits of medicine and self-care.

Building Trust between the Support Service Provider and the Client—As described by advocates, establishing trust with clients was a process that occurred over time and required PSCs to be sensitive to the client’s readiness to accept support. Therefore, they suggested that the intensity of services be tailored to the client’s expressed needs. A resounding theme in the survivor and advocate interviews was the fundamental importance of personal contact in delivery of a support intervention. One of the patient navigators described the best way to build trust: “It’s really about the one-to-one contact. Each client is assigned a care navigator and they work with clients making sure that they just check in and see how things are going, as well as seeing if they want someone to come with them to their doctor’s appointments, or if they need us to follow-up with other services. But mainly it’s about emotional support and just checking in to see how they are doing.” The most effective service delivery model as described in the interviews appears to be one in which the physician makes a referral to the support provider, who then initiates a phone call and a home visit with the patient. Some advocates added that building trust leads to better patient adherence to treatment and increased self-disclosure.

DISCUSSION

In this mixed methods study, we found that Spanish-speaking Latinas with breast cancer are characterized by unique sociocultural factors that must be taken into account to provide effective cancer support services. These factors make navigating the health care system more difficult, especially when convergence in language and sociocultural understanding do not exist between patients and physicians or providers of psychosocial services. This divide results in insufficient and low-quality cancer information for patients and magnification of the already existing barriers to accessing medical and psychosocial cancer care.

Although we did not measure acculturation directly in this study, most women were immigrants who spoke English less than well and preferred to receive their health care in Spanish; therefore, they appear to represent a less acculturated sample. The unique sociocultural factors and language issues that emerged in this study may be especially important for less acculturated women, thus putting them at increased risk of difficulty in adapting to their cancer diagnosis. For example, they may experience greater difficulty in raising psychosocial concerns with their physicians, and thus, may be especially likely to derive benefit from a culturally tailored PSC program. A study of a peer-delivered intervention to assist Spanish-speaking Latinas with breast cancer treatment decision making provides evidence of the usefulness of these types of interventions for less acculturated Latinas. Investigators in that study found that their intervention successfully addressed cultural factors that included living well for their children’s sake, reticence to ask physicians questions out of respect, lack of fluency in English, fatalism, spirituality, and early intervention to dispel fear and misconceptions (24).

An essential component of an effective intervention, therefore, must include cultural competence, which is shared community and cultural identity, beliefs, and attitudes; experience of the effects of immigration and low socioeconomic status; and facility in the patient’s primary language. Peer counselors with these attributes in our study had familiarity with unique cultural, socioeconomic, family, and religious factors, such as fear of death, immigration stress, traditional sex roles, religiosity, and literacy. They also demonstrated the ability to address the emotional and informational needs of these patients, as well as advocate for them, assist with problems of access, and help negotiate with family and community members. PSCs should be trained to be sensitive to traditional Latino sex roles, family obligations, and taboos in talking about cancer.

Among our participants who had used psychosocial services, there was strong belief in the benefits of such interventions. The greatest benefits were seen as emotional support in helping them express their feelings, knowing that someone understood their cancer experience, and reduction of their anxiety and depression. Thus, the identity of peer counselors as cancer survivors is an important component of support services. Also important is training in active listening skills to ensure the assistance provided is nonjudgmental, supportive, and tailored in content and intensity to the client's needs (i.e., participants define their level of involvement).

Providing cancer information that the women did not believe could be obtained from their physicians and personal skills building are components approximately equal in importance to emotional support. Participants and community advocates believed that PSCs were more able to provide understandable and useful information about cancer because of their ability to present it in Spanish and low-literacy formats. Information should include specific explanations of breast cancer treatment and management and available community resources. Information should also include training, specifically, self-efficacy skills training to offset the sense of powerlessness that results from the diagnosis. Specific skills-building would involve learning how to manage anxiety and express their feelings; write down their questions and seek information from credible cancer information sources; and access local community resources. That the PSC is a Latina cancer survivor who models and endorses self-care behaviors, such as asking family members for help with household tasks when necessary or asking questions of her oncologist, should serve to normalize these behaviors for other Latinas with cancer.

To be most effective, both emotional and informational support should begin as soon after diagnosis as possible. This support can be provided in person or by telephone, both of which were acceptable to the Latinas in our study. Personalized contact promotes the patient's trust in the peer counselor and reduces feelings of anxiety.

Findings from this study are consistent with previous studies that have shown that Latinas with cancer disproportionately experience hardships associated with language barriers, poverty, limited transportation, complex family issues, and lack of familiarity with the health care system (14, 29). Prior studies suggest that Latinos and other minorities are more likely than whites to desire increased information and access to cancer-related support (30, 31). Many Spanish-speaking Latinas undergo cancer diagnosis and treatment without ever seeing a physician who speaks their language or an interpreter due to limited availability of language concordant clinicians and language assistance services. Because Latinas may be at higher risk of distress subsequent to a cancer diagnosis, (16, 29, 32, 33) they may be among the groups most likely to benefit from cancer support services. This study confirms the importance of *familismo*, spirituality, and fear of death among Spanish-speaking Latina cancer survivors (14). It also supports the previously reported unique benefits, including increased self-efficacy, of peer support provided by cancer survivors (20, 34, 35).

Limitations of this study include small sample sizes and a high non-response rate among the telephone survey respondents. However, demographic characteristics of cancer survivors included in the study reflect well the characteristics of Spanish-speaking Latinos in the San Francisco Bay Area. The generalizability of these findings to other geographic areas and diseases merits further investigation.

This study makes several unique contributions in identifying the psychosocial and informational needs of Latinas with breast cancer and the key components of a psychosocial, peer-delivered cancer support intervention. Our results indicate that strong community-based peer support programs are a viable model to address effectively the need for more accessible and relevant cancer support services. They also indicate that by drawing on the expertise of community advocates and Spanish-speaking Latinas living with breast cancer, our ability to develop programs that are responsive to the psychosocial needs of this growing population is improved. Rigorous testing of cancer support service models designed for ethnically and linguistically diverse women with breast cancer should be performed to address the current significant gap in the literature and inform the development of interventions. Furthermore, our results draw attention to the need to better understand the psychosocial needs of increasingly diverse cohorts of cancer patients and to offer potential solutions for maximizing their quality of life.

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Table 1

Characteristics of Spanish-speaking Latino cancer patients referred to the Círculo de Vida Cancer Support and Resource Center

Characteristic	Total Sample (N=89)	Used Services (n=73)	Did Not Use Services (n=16)	Odds Ratio (95% Confidence Interval)
Sex, N (%)				
Women	78 (87.6)	68 (93.1)	10 (62.5)	1.0
Men	11 (12.4)	5 (6.9)	6 (37.5)	0.18 (0.04, 0.79)
Birthplace, N (%)				
United States	2 (2.3)	1 (1.4)	1 (6.2)	1.0
Foreign-born	86 (97.7)	71 (98.6)	15 (93.8)	5.15 (0.30, 87.8)
National origin, N (%)				
Mexico	31 (35.2)	23 (31.9)	8 (50.0)	1.0
Central America	45 (51.1)	38 (52.8)	7 (43.8)	2.0 (0.59, 6.75)
Other Latino origin	12 (13.7)	11 (15.3)	1 (6.2)	3.67 (0.40, 33.71)
Age in years, mean (SD)	55.1 (11.0)	54.4 (1.25)	58.1 (3.14)	0.98 (0.93, 1.04)
English-speaking ability, N (%)				
Not at all/poorly	25 (28.4)	19 (26.4)	6 (37.5)	1.0
Fairly well	40 (45.5)	34 (47.2)	6 (37.5)	1.22 (0.31, 4.90)
Well/very well	23 (26.1)	19 (26.4)	4 (25.0)	0.94 (0.20, 4.39)
Education in years, N (%)				
0–6	23 (26.1)	15 (20.8)	8 (50.0)	1.0
7–12	41 (46.6)	37 (51.4)	4 (25.0)	3.75 (0.92, 15.34)
> 12	24 (27.3)	20 (27.8)	4 (25.0)	2.04 (0.48, 8.60)
Health insurance, N (%)				
None	8 (9.6)	6 (8.7)	2 (14.3)	1.0
Public	47 (56.6)	38 (55.1)	9 (64.3)	1.37 (0.24, 7.95)
Private	28 (33.8)	25 (36.2)	3 (21.4)	2.78 (0.38, 20.50)
Marital status, N (%)				
Married	37 (42.1)	29 (40.3)	8 (50.0)	1.0
Not married	51 (57.9)	43 (59.7)	8 (50.0)	2.03 (0.63, 6.49)
Cancer site, N (%)				
Breast	61 (68.5)	54 (88.5)	7 (43.8)	1.0
Other	28 (31.5)	19 (67.9)	9 (56.2)	0.21 (0.06, 0.76)
Years since diagnosis, N (%)				
< 1	18 (20.5)	14 (19.4)	4 (25.0)	1.0
1–4	50 (56.8)	40 (55.6)	10 (62.5)	0.59 (0.11, 3.03)
5 or more	20 (22.7)	18 (25.0)	2 (12.5)	1.31 (0.16, 10.56)
Knows stage at diagnosis, N (%)				
No	48 (53.9)	43 (58.9)	5 (31.3)	1.0
Yes	41 (46.1)	30 (41.1)	11 (68.7)	2.73 (0.83, 9.04)
Currently in treatment, N (%)				
No	41 (47.1)	31 (43.1)	10 (66.7)	1.0

Characteristic	Total Sample (N=89)	Used Services (n=73)	Did Not Use Services (n=16)	Odds Ratio (95% Confidence Interval)
Yes	46 (52.9)	41 (56.9)	5 (33.3)	1.82 (0.52, 6.35)
Current cancer is a recurrence, N (%)				
No	77 (88.5)	63 (88.7)	14 (87.5)	1.0
Yes	10 (11.5)	8 (11.3)	2 (12.5)	0.44 (0.08, 2.58)
Self-rated health, mean (SD) *	2.84 (0.91)	2.93 (0.92)	2.50 (0.82)	2.10 (0.98, 4.51)
Family encouragement to seek support services				
None/a little	36 (43.4)	24 (35.3)	12 (80.0)	1.0
Quite a bit/a lot	47 (56.6)	44 (64.7)	3 (20.0)	6.21 (1.55, 24.95)
Oncologist encouragement to seek support services				
None/a little	56 (63.6)	42 (57.5)	14 (93.3)	1.0
Quite a bit/a lot	32 (36.4)	31 (42.5)	1 (6.7)	7.89 (0.97, 64.56)

*Response options range from 1=poor to 5=excellent.

Note: cell sizes may not add up to total N due to missing data.

Table 2

Ratings of services received from Círculo de Vida Cancer Support and Resource Center

Benefit	Total N	Mean (SD)	Percentage Rating[*] Services at 3 +
Overall quality of Círculo de Vida services	70	4.3 (0.88)	97
Helped you to express your feelings	71	4.3 (0.81)	99
Helped you to feel that someone really understood your experience with cancer	72	4.3 (0.83)	97
Helped you to feel less depressed	72	4.1 (1.01)	94
Taught you how to ask your doctors questions about your cancer and cancer treatment	62	3.9 (1.04)	94
Taught you how to tell your doctors what you want or need	61	3.9 (1.04)	94
Helped you to feel less afraid and anxious	71	4.1 (1.04)	92
Information you received from Círculo de Vida about your diagnosis and treatment choices or options	65	3.8 (1.20)	88

[*] Response scale: 1=poor; 2=fair; 3=good; 4=very good; 5=excellent

Table 3

Psychosocial and other support needs of Spanish-speaking Latina breast cancer survivors and their implications for the design of a peer support intervention

Psychosocial and Other Support Needs	Illustrative Example	Implications for Intervention Design
Need for information on cancer, its treatment, treatment side effects, and community resources	"We need information, information, and more information, because we hear so many things that are not true. I imagine many people have incorrect information about their treatment because we have no other choice but to ask our friends, relatives, and neighbors." *Latina breast cancer survivor*	Provide information on cancer and treatment that is culturally and linguistically appropriate; low literacy materials; information to dispel myths; information on community resources to assist with basic living needs
Advocacy	"Especially if the person does not speak English, in addition to interpreting, one has to constantly advocate on their behalf because hospitals are a reflection of larger society and we have racism and class differences here just as we do in the rest of society." *Community advocate*	PSC needs bilingual skills to assist client with navigation of health care and community resources, and obtain answers from client's cancer care team to client's questions/concerns
Need to raise awareness of psychosocial services	Spanish-speaking Latinos referred to Círculo de Vida Cancer Support and Resource Center and Spanish-speaking Latinas with breast cancer cited lack of awareness of cancer psychosocial services as a key barrier to use of services	Personal contact from a PSC; outreach to cancer care providers, and cancer patients and their families; families and physicians can encourage the use of support services
Fear of impending death	"When you are diagnosed you feel completely lost. You have the idea that cancer is synonymous with death. They tell you its cancer and you feel as if you've already died. At that point, I even saw the coffin, the color of the inside of the coffin, and I was in it." *Latina breast cancer survivor*	Relieve fears and anxiety; encourage hope; invoke religious beliefs if appropriate
Need for emotional support, especially from a peer cancer survivor	"When you are diagnosed it is very important to have support because you feel as if your world collapses…It is best to have that person there at the hospital (peer support counselor). When you are in the waiting room, she is there telling you not to worry, that they will help and support you no matter what. It's a reassurance." *Latina breast cancer survivor*	Early intervention to provide compassionate, caring support; active listening. PSC shares her experiences while acknowledging that each person's experience is unique
Difficulty expressing feelings and needs	Spanish-speaking Latinos referred to Círculo de Vida Cancer Support and Resource Center and Spanish-speaking Latinas with breast cancer cited help with learning how to express feelings as a primary benefit of psychosocial support services	Modeling of expressive behaviors by PSC; PSC provides encouragement and empathy
Sense of powerlessness; need for building self-care skills	"We are here to support them and to have that belief that they have it in themselves to access the information. They may need help or encouragement, but that they have the capacity. So it's more about empowerment." *Community advocate*	PSC focuses on patient empowerment; builds self-efficacy; models and teaches skills for cancer self-care
Cultural competence and language assistance	"There are communities all over the country who need peer educators who are Spanish-speaking, but they don't know how to reach them, just like they don't know how to reach Latinos to do clinical trials. If they don't know how to speak to them in their language, at their level, with the understanding of how to reach their hearts, their value system, then it doesn't matter." *Community advocate*	PSC shares culture and language of patient; addresses unique cultural and socioeconomic factors; interprets and translates (with adequate training)
Consideration of the central role of the family	"The way I've found that's most effective to treat Latina breast cancer patients is to involve the family. Because once the family is involved, it cuts down on a lot of the cultural barriers. They understand. They understand that the disease is not contagious. They understand that it can be treated. We try to get them to understand that the woman herself needs emotional support." *Community advocate*	PSC encourages involvement of family members in the provision of support to patient; conducts home visits to become familiar with the home environment; identifies family issues; provides informational and emotional support to family; maintains primary focus on needs of client
	"It is good that the family is with you, but they are also going through a difficult time. They are also scared. Family members should also be included, perhaps by having a meeting with the family to give them information."	

Psychosocial and Other Support Needs	**Illustrative Example**	**Implications for Intervention Design**
	Latina breast cancer survivor	
Spirituality	“I’ve had a client say, ‘I don’t want treatment because God gave me this disease and He will take care of me.’ And that was kind of difficult because this woman’s disease was progressing so I had to get across, ‘Okay, I understand that you believe that God gave you this disease, but he also created tools, like treatment options that can help you. SO you might want to consider it.’ No matter what, you can’t force anyone to do anything, and I believe it’s the person’s own choice. But, definitely, there’s a lot of belief that God has given a person this disease for a reason.” *Community advocate*	PSC respects women’s religious beliefs, reinforces the strength and solace faith provides; reinforces the positive aspects of accepting one’s illness as a way of moving forward, while simultaneously modeling positive self-care behaviors, e.g., seeking information about treatment options and side effects
Building trust between the support service provider and the client	“The first time I contact them, they might be in shock because of their diagnosis or they might not trust me yet, so I just say that we have some services and I just ask if it would be possible to send her some materials. So I’ll do that and I will follow-up a week later, and some of them will want you to tell them a little more about the program, and say ‘I want you to come to my doctor’s visit with me.’ So it definitely depends on the person and most of them start getting engaged more and more once we build kind of a system of trust.” *Community advocate*	PSC tailors intensity of services to client’s readiness to accept services and needs; uses in-person contact to build relationship and trust
Transportation needs	Transportation was identified as a key barrier to initiating or continuing cancer support services among Spanish-speaking Latinos referred to Círculo de Vida Cancer Support and Resource Center	PSC travels to patient and provides additional support via telephone

PSC = Peer Support Counselor.