

“I never heard anything about it”: Knowledge and psychosocial needs of Latina breast cancer survivors with lymphedema

Women's Health
Volume 17: 1–11
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/17455065211002488
journals.sagepub.com/home/whe



Lydia P Buki^{1,2} , Zully A Rivera-Ramos^{3,4},
Marlen Kanagui-Muñoz^{5,6}, Puncky P Heppner⁵, Lizette Ojeda^{5,7},
Emaan N Leahardy^{1,8} and Kari A Weiterschan^{1,9}

Abstract

Objective: Breast cancer is the most commonly diagnosed form of cancer and the leading cause of cancer-related death among Latina women in the United States. One aspect of recovery that has been underrepresented in the English-language literature is the recovery of Latina women who have developed lymphedema, a debilitating condition characterized by persistent swelling of the arm, hand, chest, and/or breast. To fill this research gap, a study was conducted to examine the lived experiences of Latina women with breast cancer-related lymphedema.

Methods: Given the limited scholarship on this topic, qualitative methods were used to obtain a foundational and nuanced understanding of Latina women's experiences. Semi-structured interviews were conducted with a sample of 10 Latina survivors with breast cancer-related lymphedema. Data were analyzed through thematic analysis and constant comparison methodology.

Results: The data analysis yielded three major themes: knowledge of lymphedema, impact of lymphedema diagnosis, and coping with lymphedema. Participants had limited knowledge of lymphedema and its risk factors upon diagnosis, in addition to barriers accessing quality care. They also noted psychological distress related to a significant financial burden as well as social anxiety related to interacting with others while wearing compression gloves or sleeves. A major coping strategy was receiving social support from friends, family, peers in structured support groups, and spiritual/religious groups or practices.

Conclusions: Our findings bring to light contextual factors that may place Latina breast cancer survivors at increased risk for lymphedema and for experiencing a high burden managing their condition. Recommendations are provided for primary, secondary, and tertiary prevention.

Keywords

access to care, coping, Latina women, lymphedema, social support

Date received: 16 February 2021; revised: 16 February 2021; accepted: 17 February 2021

¹Department of Educational and Psychological Studies, University of Miami, Coral Gables, FL, USA

²University of Illinois, Champaign, IL, USA

³Department of Educational Psychology, University of Illinois, Champaign, IL, USA

⁴Counseling & Wellness Center, University of Florida, Gainesville, FL, USA

⁵Department of Educational, School & Counseling Psychology, University of Missouri, Columbia, MO, USA

⁶Department of Psychiatry, Kaiser Permanente Medical Center, Richmond, CA, USA

⁷Department of Education and Human Development, Texas A&M University, College Station, TX, USA

⁸Department of Behavioral Health, University of Nebraska Medicine, Omaha, NE, USA

⁹Rush University Medical Center, Chicago, IL, USA

Corresponding author:

Lydia P Buki, Department of Educational and Psychological Studies, University of Miami, Coral Gables, FL 33146, USA.
Email: l.buki@miami.edu



In this article, we explore Latina women's unique experiences living and coping with lymphedema. Among Latina women, breast cancer is the most commonly diagnosed form of cancer and the leading cause of cancer-related death.¹ With improved survival rates, 96% of Latina women with local cancers, and 85% of Latinas with regional cancers, will survive at least 5 years following diagnosis.¹ Considering Latinxs comprise the largest ethnic minority group in the United States, with predictions for dramatic increases in the aging population,² the number of Latina survivors will rise significantly in the coming years. In addition, estimates suggest that 30% to 40% of women who have undergone breast cancer surgery develop breast cancer-related lymphedema (BCRL).³ Thus, it is critical to understand the experiences of Latina women living with this disabling condition in the United States.

The American Cancer Society defines lymphedema as a chronic condition resulting from lymph fluid build-up under fatty skin tissue.⁴ Women with BCRL may experience persistent swelling of the arm, hand, breast, and/or chest; feelings of heaviness or fullness; decreased mobility; aching or tingling; and skin tightness or hardening in the affected region.⁴⁻⁶ There is no cure for BCRL; therefore, it requires diligent consistent care to manage the condition.⁴ Research on women's experiences with BCRL has been conducted primarily with White non-Latina women in the United States and internationally. Findings show that breast cancer survivors have limited knowledge of the existence of the condition and its risk factors, placing them at further risk.^{5,7,8} This is concerning given the ways in which BCRL influences quality of life. BCRL may result in physical, occupational, psychological, and interpersonal difficulties. Physical limitations include restricted arm movement, increased breast pain and swelling, fatigue and difficulty sleeping, feelings of weakness, and achiness.^{6,9,10} Symptom management requires significant time and energy, such as engaging in physical therapy, bandaging, wearing visible gloves or compression sleeves, avoiding heavy lifting and strenuous activities, limiting the use of the affected arm, and modifying or withdrawing from activities at home (e.g. housework, childcare), work (e.g. heavy lifting), or leisure (e.g. exposure to the sun) that exacerbate swelling.^{4,10} Having to rely on others for help can interfere with the timely completion of tasks and result in feelings of aggravation and distress.¹¹

Additional psychological sequelae may include body image concerns and low quality of life.^{9,10,12} To avoid the appearance of having a disability, and to prevent others from staring and asking questions, women may try to hide their compression sleeves or not wear them in public.^{5,12} Given the challenge of finding clothes that fit, women also may spend considerable time dressing.^{5,6} Some women have reported that BCRL serves as a reminder of their breast cancer diagnosis and treatment,¹⁰ triggering fears of recurrence and worry.⁵ Studies conducted with a majority of non-Latina White women in the United States and

abroad show that women with BCRL have better psychological outcomes when drawing on social support, engaging in faith-based practices, and using active coping strategies.^{5,7}

Even though several factors place Latina women at risk for lymphedema, there is a dearth of information about their experiences with BCRL. Compared to non-Latina White women, Latinas are more likely to be diagnosed with larger tumors,¹³ at later disease stages,¹³ and with more aggressive cancer types;^{13,14} to have mastectomies;¹⁵ to receive unnecessary axillary surgery;¹⁶ to be diagnosed before the age of 50;¹⁷ to have limited access to healthcare, and to have lower levels of income and formal education.¹⁸ These factors place Latinas both at higher risk of developing lymphedema and at a disadvantage in terms of access to post-treatment rehabilitative care, especially if they are Spanish monolingual speakers.¹⁹⁻²¹ Psychosocial risk factors such as employment in labor-intensive occupations that require heavy lifting or greater use of hands,²² may further contribute to disparities in the development and experience of BCRL among Latina women.

Although research is limited, Black, Indigenous, and People of Color with BCRL have reported more severe symptoms than non-Latina White survivors.²³ This is important to note, as it suggests a need to further investigate those factors that contribute to, and maintain, these disparities, as well as to identify ways to ameliorate them. In particular, Latina women have reported significantly higher rates of swelling, pain, depression, and fatigue from BCRL than their non-Latina White peers.²¹ In addition, Latina women have reported (a) receiving limited information about their risk of developing BCRL, (b) feeling a sense of loss related to changes in their level of independence, and (c) difficulty coming to terms with the chronic, lifelong nature of the condition. These findings are consistent with a growing body of research showing that, overall, Latina women report more negative outcomes related to mental health, physical health, and quality of life than non-Latina breast cancer survivors.^{17,20} Despite their disproportionate burden, in our review of the literature we only identified one study focused exclusively on the lived experiences of Latina women with BCRL,²⁴ and another that included Latinas within a multiethnic sample.²¹ Given the limited data about this population and current data suggesting great needs within the population, we designed a qualitative study to examine the lived experiences of Latina women with BCRL.^{25,26} The study was modeled after a similar study conducted with non-Latina White women by Heppner et al.¹¹

Methods

Methodological approach and design

In the current study, qualitative methods were utilized to examine the lived experiences of 10 Latinas with BCRL

living in the United States. This sample size is consistent with that of similar studies reporting on understudied health-related topics.^{11,27} These methods are indicated for studies exploring and generating a nuanced understanding of understudied areas of human behavior and experience.²⁵ Following an interview guide, individual interviews were conducted to capture a description of the cultural, social, and psychological aspects of the participants' experiences. Thematic analysis and constant comparison methodology were used to analyze and develop interpretations of the interview data.²⁶

Measures

Demographic questionnaire. Data were obtained about women's demographic factors such as age, immigration history, formal education attainment, and marital status.

Interview guide. An interview guide was modeled after a protocol created by Heppner et al.¹¹ To develop the items, the authors drew from the extant literature on lymphedema and coping, as well as from their expertise on nursing aspects of lymphedema and psychosocial aspects of problem solving. After conducting a pilot interview, they refined the wording of the questions and incorporated additional questions to assess the desired content. Using their interview protocol as a starting point, we reviewed each question's relevance to Latina women and added some specific questions to elicit cultural and language issues. The updated protocol was pilot tested by the first author with one Latina breast cancer survivor with BCRL who worked as a staff member for a cancer support organization. With her feedback, we made minor edits to make the language easier to understand. The final interview guide consisted of 31 questions that focused on (a) the participant's history of BCRL, including lymphedema-related difficulties, stressors, and symptoms (e.g. "How did you find out that you had lymphedema?" "What changes to your body or symptoms did you experience due to lymphedema?"), (b) psychosocial issues such as coping, social support, and the impact of lymphedema (e.g. "What has been for you the most difficult part of having lymphedema?" "Who or what has been the greatest help in dealing with lymphedema?"), and (c) cultural and language issues (e.g. "Do you think your cultural background or religion affects in any way how you take care of your health, especially the care of lymphedema?" "In what language do you prefer to receive information regarding your health?"). The complete interview protocol is available from the first author.

Procedure

We recruited participants through gatekeepers in several nonprofit organizations that serve the needs of Latina

breast cancer survivors in Florida, New York, and Washington, DC. Our intention was to recruit a sample that would yield a variety of experiences. Specifically, we contacted gatekeepers at each of these organizations and gave them information to publicize the study to clients diagnosed with lymphedema. Those women who indicated interest in the study were subsequently contacted by a research team member to ascertain their intent to participate and to schedule the interview. The study had Institutional Review Board approval #05203 from the University of Illinois, and approval #1039429 from the University of Missouri-Columbia. Participants provided verbal informed consent, which contained all the elements of written informed consent, prior to the start of the interview. Oral consent was obtained to lower potential barriers to participation, as women from immigrant communities may not feel comfortable providing written documentation of their full names and signatures. At the beginning of the interview, women were read an informed consent script with opportunity to ask questions. After they agreed to participate and provided verbal permission to audiotape the interview, the interview started. Acknowledgment of participants' verbal consent was recorded on file with their interview. For their participation, they received an informational package on health promotion topics.

Of the 10 interviews, one was conducted by the first author, a bilingual and bicultural Latina scholar with extensive training and experience conducting qualitative studies with Latina breast cancer survivors. The remaining nine interviews were conducted by a fully bilingual Latina graduate student who obtained training and supervision from the first author. Participants had the option of completing the interview in Spanish or English; six participants elected to have the interview in Spanish. Each interview lasted 60 to 90 min, was conducted by phone, audiorecorded, transcribed, and reviewed for accuracy by a bilingual research team member.

Data analysis

Two graduate student researchers conducted the thematic analysis with training and supervision from the first author. The analysis involved a systematic, iterative process of coding transcripts to identify conceptual categories that captured participants' lived experiences.²⁶ First, the coders independently engaged in open coding of two transcripts, identifying salient aspects of women's experiences. Next, they discussed their coding process with the first author, and consensus was established on the most appropriate preliminary conceptual categories that fit the data. Subsequently, each coder was assigned two different transcripts in English and Spanish to code individually, followed by a third transcript coded by both, to continue ensuring consistency across coders. After reviewing

coding of the third transcript, the remaining transcripts were distributed across the two researchers for coding. As the coding evolved and was refined, team members returned to previously coded transcripts to ensure the coding scheme was consistently applied across all transcripts. Thus, the credibility and trustworthiness of the findings were enhanced by carefully training the coders, documenting every step of the analytic procedures, and holding consensus meetings to establish agreement on thematic categories.²⁵ To further promote the trustworthiness of the study, the Results section includes thick description, providing context for the participants' comments and quotes. In cases where the original quotes were in Spanish, they were translated by fully bilingual researchers using the back-translation method. Given the potential to identify participants, research data are not shared.

Results

Participants

A national and diverse sample of 10 Latina women participated in the study. All identified as White. Nine out of 10 participants were immigrants and had lived in the United States for 3 to 36 years ($M=18.67$; $SD=11.51$). Regions represented include the Caribbean, Central America, and South America. A diverse sample is important when attempting to explore varied experiences. Participants' ages at the time of the interview ranged from 40 to 68 ($M=52.60$; $SD=9.65$). Six participants were currently married, and nine reported having children. Participants lived with their spouse and children ($n=4$), their spouse ($n=1$), their children ($n=1$), with roommates ($n=2$), and alone ($n=2$). Formal education levels ranged from no formal education ($n=1$), middle school ($n=1$), high school ($n=1$), and some college ($n=5$), to college graduation ($n=2$). In terms of access to healthcare, four participants did not have any type of medical coverage, four had Medicaid or Medicare, and two had private insurance. Only four participants were employed outside the home.

Participants' ages at diagnosis ranged from 38 to 64 years ($M=49.00$; $SD=10.04$). The surgeries they underwent included lumpectomy ($n=4$), simple mastectomy ($n=1$), lumpectomy and simple mastectomy ($n=1$), radical mastectomy ($n=3$), and simple and radical mastectomy ($n=1$). All participants reported experiencing recurring symptoms, such as arm swelling. Six participants reported comorbid conditions such as depression, anxiety, asthma, arthritis, high blood pressure, and osteoporosis.

Qualitative findings

Data analyses yielded three major themes: knowledge of lymphedema, impact of lymphedema diagnosis, and coping with lymphedema. Each of the themes is discussed in the subsequent sections.

Knowledge of lymphedema. Participants reported that knowledge was critical in managing this condition. However, many of them did not learn about BCRL until they were diagnosed. Given their lack of information, many engaged in behaviors that enhanced their risk of developing BCRL. Also, women reported inaccurate information about BCRL, and when they were given information by healthcare professionals, at times it was hard to process. In the following paragraphs, we present these findings in more detail.

Learning about BCRL. Six out of the 10 women did not know that lymphedema was a side effect of breast cancer treatment, and only learned about the condition after experiencing symptoms. One participant reported being unaware of the condition's name even though she had seen the doctor:

[The doctors] did not mention the word "lymphedema" to me at all; they only told me . . . that I was retaining liquid in that arm . . . but I never heard the word "lymphedema" from the doctors' mouths; rather, I learned it when we started talking in the support group . . .

Another participant explained: "[When I went to the doctor, it] was the first time I heard of that illness because I did not know that a mastectomy could lead to it." Despite their need for information and the fact that some participants had complicating comorbid conditions, only three women reported having regular access to healthcare information. The six participants who chose to be interviewed in Spanish reported a preference for Spanish-language materials, and the four participants who chose to be interviewed in English reported a preference for English-language materials. However, all participants agreed that it was more difficult for Spanish monolingual Latina women than for English-speaking women to find quality information about BCRL.

Engaging in risk behaviors. Lacking knowledge of the condition, many participants inadvertently engaged in various risk behaviors. One participant reported,

No . . . I did not know anything at all [about lymphedema] because nobody talked to us about that, no. I learned about it when my arm was already very swollen. Because I traveled to [country] . . . and once I got there, I noticed after a few days that my wrist was [swollen] . . . I was washing clothes by hand [when I saw the swelling]. My daughters asked me "What is going on? You are washing clothes by hand? Stop doing it." So I stopped . . . Truthfully, [we] thought [washing clothes caused the swelling].

The fact that this participant carried a suitcase, was not wearing compression sleeves on the flight, and washed clothes by hand, likely contributed to her worsening symptoms. The participant further shared that only after she

returned to the United States and attended a breast cancer support group, did she learn these were lymphedema symptoms; the group facilitator, who was a healthcare professional, recommended she seek medical care and begin treatment.

Reported information about BCRL. During the interviews, participants reported inaccurate information about the condition. Four participants believed that lymphedema could be cured: “I want it to disappear, for the swelling to be gone from my hand in two or three years.” Similarly, another participant said: “Well . . . that’s why I am taking care of myself, I hope . . . that it does not return, because who knows how it will be later, no, no, I can’t imagine it.” One participant, in fact, reported that her healthcare provider suggested the swelling would go away:

I told him, “Look at my hand, it’s swollen.” And he said, “Oh yeah, it’s a little swollen.” He wasn’t surprised, it wasn’t that big anyway. But for me, it looks *big*, and he said, “Yes, it is lymphedema, that’s okay. It will disappear after chemo is over,” that’s what he said. And now chemo is over and still I have it.

One participant did recall being told about lymphedema as a side effect of breast cancer surgery. For her, obtaining this information during the critical time of breast cancer diagnosis and treatment implicated cultural and psychological complexities:

Being raised in a third world country, cancer means dying . . . [The doctors told me I was going] to have a surgery where they remove your lymph nodes from your arm . . . [and I thought], just do the surgery, do what you have to do to keep me alive. They said: “We took 18 lymph nodes.” I was like “Ok . . . what is that?” Whatever, I mean; it’s too hard [dealing with a breast cancer diagnosis]. I mean, I didn’t understand it, lymph nodes and all this. And I had my surgery, and everything went smoothly . . . So, she [the doctor] did mention [lymphedema] when she was talking about all the things. [But] it’s a lot of information that they give to you for somebody who doesn’t have the knowledge skills.

Another woman reported,

. . . you have to do research on your own because there is nothing out there . . . [the doctor said:] “By the way, you may get this [condition] called lymphedema.” Oh yeah! I am going to remember after having chemo and . . . 6 months of radiation? You want me to remember something about lymphedema?

Overall, women reported acquiring a dearth of information about lymphedema risk factors, symptoms, and prognosis. Some participants did not have access to this information even after showing symptoms. It was clear, however, that lymphedema would eventually have a significant influence on their daily lives.

Impact of the lymphedema diagnosis. Being diagnosed with BCRL affected participants in various ways. Experiencing new physical symptoms resulted in a significant burden for them and influenced their psychological well-being as well. Their experiences in these two areas are presented next.

Burden of lymphedema symptoms. Participants reported symptoms that included swollen and/or firm arms, swollen wrists and fingers, numbness in the fingers, elbow discomfort, and pain in the affected areas. They experienced these symptoms as a great burden, and as a result were unable to fully engage in daily activities as they had prior to diagnosis. They reported experiencing limitations when carrying heavy objects, getting dressed, and engaging in housework; they also noted feeling easily fatigued and uncomfortable while sleeping. One participant shared,

[lymphedema] does cause stress. It limits me, it means that I have to ask others to stop what they’re doing to come and help me . . . If my arm is too swollen and I’m in too much pain, I can’t do things that I want to do.

Psychological well-being. Given that many symptoms of lymphedema are visible, women reported changes in their body image, which in turn influenced their psychological well-being. One participant reported: “When I would see that one hand was thicker than the other . . . that made me depressed.” One woman explained that she felt self-conscious about others noticing she was different when wearing a compression glove: “one develops a psychological hang-up.” Being out in public was particularly bothersome for participants. One woman explained that people would ask about her arm, making her self-conscious:

When I’m out in public and when people see my arm or see me with the stockings on my arm . . . they stop and ask me what it is . . . and why am I wearing that? Why is my arm big? Some people become persistent and then they want you to explain and . . . not all the time do I have the time nor feel inclined [to explain it].

To avoid raising curiosity, some participants changed their habits and dress. For example, one participant sacrificed a great deal of her social life, reporting that she “would stay away from people” to avoid being asked questions.

Women also experienced financial burdens and related stressors that influenced their psychological well-being. Due to their symptoms, four participants were unable to continue working and one worked on call, experiencing loss of income and additional stress to make ends meet. One participant was greatly affected by her inability to continue in her profession, given the need to use her arm when working:

But this goes beyond what one thinks or what one wishes . . . in the sense that life has changed . . . I was a cook . . . and now I can't do it . . . So I have not earned a penny since this happened to me . . . It has affected me physically, spiritually, emotionally . . . because it was my best time ever [when I was working], when I was the happiest.

Because lymphedema is expensive to treat, participants' additional financial burden was particularly stressful: "When I have to . . . buy the wraps . . . every time is like \$70 something dollars. When you're not on a stable income, it becomes very difficult . . . [the treatment] is very costly; products for lymphedema are very costly." Similarly, another participant reported ". . . [It] is very expensive, I mean just the sleeve that you use . . . it cost me \$125 dollars." Thus, women bore the additional psychological burden of facing these unanticipated expenses, which came after undergoing costly breast cancer treatment.

Participants noted additional factors that enhanced, and that hindered, their psychological well-being. On the one hand, for a participant who was aware of the condition before developing it, knowing her risk and being able to control the symptoms was a protective factor. Another participant who was given information and understood the risk of developing the condition reported,

I didn't feel negative about [being diagnosed with BCRL] . . . because, you know, because from the surgery I knew that something would happen . . . they explained to me that with massage therapy and with the different stockings . . . it was something that could be dealt with.

At the same time, she did not anticipate the chronic nature of the condition:

I wasn't prepared to know that [lymphedema] is going to be a life-long problem . . . So I'm just having to learn to deal with it . . . after a while, it depresses [you] . . . if I have had [the arm] swollen for say, three or four days straight . . . it cuts down on my activities, my ability to do things for myself; being able to pull the zipper up or do buttons or undo buttons, and open things. It bothers me because I live alone

Women also felt distressed to have a constant reminder of their breast cancer diagnosis. One participant made a distinction between willing and unwanted reminders she could not ignore:

You know, if I want to be reminded of having had the surgery or [breast cancer], because I, I'm dealing with it by helping others, that's fine, that's my choice . . . [Lymphedema] is a constant reminder, you know, getting up one morning and because it's draining, my fingers look like toads, they are so swollen. Overall, for participants, the far-reaching impact of living with lymphedema was a source of considerable functional, financial, and psychological burden.

Coping with lymphedema. As participants learned to control the chronic nature of lymphedema symptoms, they found them more manageable. Women reported using a variety of coping strategies: they received social support, engaged in downward comparison, and in passive and active coping. Each strategy is discussed next.

Social support. Emotional, informational, and instrumental support were critical to participants' coping process. Emotional support refers to interactions where support was conveyed through verbal and nonverbal expressions of caring. Informational support includes interactions where support was conveyed through the provision of information about the diagnosis, prognosis, and treatment of lymphedema, whereas instrumental support encompasses interactions where support was provided via material goods or services. Because of the distinct nature of each type of support, we describe women's perceptions about them in separate paragraphs.

Participants reported receiving emotional support from multiple sources: friends, family, peers in structured support groups, and spiritual/religious groups or practices. The benefits of emotional support for the participants included increased hope, strength, comfort, and the opportunity to vent frustrations. For example, one woman described how her friends' concern and actions increased her sense of well-being: "[My friends] have been the few closest [people whom] I tell what is going on, and they are concerned [about] what is going on with me . . . they pray and give me hope that things will be better for me and my kids." In addition, women often perceived religion and/or spirituality as a source of emotional support, both through participation in church groups and through prayer. One woman said, "I pray using the rosary and so that has comforted me much." Also, some women reported receiving emotional support from peers through their participation in structured groups. Hearing other women's stories was inspiring to them.

All participants reported receiving some type of informational support after the diagnosis. The information they received was critical because it exposed them to key signs and symptoms as well as strategies for managing the condition. Sources of information included health professionals (i.e. doctors, nurses, physical therapists) and peers. One woman stated, "[The massage therapist] taught me exactly what I should do and what I should not do . . . she referred me to a different place to go get a different glove and we got the right measurements." Furthermore, participants received referrals, recommendations, and tips that helped them manage their condition effectively from support group peers and facilitators: ". . . I found a woman who also had lymphedema in the arm . . . she was going to the same hospital . . . talking to other people is when you find out . . . what places are the best [for treatment]."

Women reported that instrumental support from family, friends, and health professionals was critical in their coping

process. Nonmedical sources of instrumental support ranged from help with household duties (e.g. cooking, caring for children) to assistance with treatment such as giving massages, coming along to medical appointments, serving as interpreters, checking on swelling, and paying medical bills. For example, one woman reported,

I have to be careful with [the laundry basket] if it is heavy. I have to turn around and ask all the time, “Can you do this for me?” “Can you carry this for me?” “Can you grab this for me?”

Among sources of instrumental support, participants perceived their immediate family members as the most consistent providers. Finally, several participants reported needing financial assistance, a type of instrumental support, beyond what was originally required for their cancer treatment, particularly given added costs not covered by insurance. Paying for services (e.g. massage) or equipment (e.g. sleeves) was difficult for them; they noted the complications that can arise from delaying these purchases with a condition like BCRL. For many participants, financial needs went unmet.

Downward comparison. Several women compared their experiences to those of others whose condition was more acute than their own. One woman reported using downward comparison to cope with breast cancer, and noted it was a helpful way to cope with lymphedema as well. She stated,

. . . I always remind myself that as bad as this may be, there are others that are going through a lot worse and there are others that are more limited. There are others, you know, that can’t do half of what I do.

Another participant reflected on the fact that she had more knowledge about the condition than one of her peers: “So, my hand didn’t get that big. I have it controlled and learned to [manage the condition] . . . and I went to the doctor, but [another] lady [had] lymphedema and she didn’t know . . .” Feeling that they were better off than others, these women expressed a sense of gratitude and comfort. One woman shared, “. . . My arm swells, but I know someone in my support group who is worse off than me. Truly, sometimes I think, ‘my goodness, thank God my symptoms are not like hers’.” Thus, through downward comparison, women appeared to contextualize the severity and impact of their symptoms.

Passive and active coping. Women used a variety of coping strategies to manage their lymphedema symptoms. These strategies included passive coping, such as efforts to avoid or “wish away” the situation; and active coping, such as deliberate efforts to manage or change the situation. Participants did not use one of these strategies

exclusively; generally, they used passive coping to alleviate the emotional toll of BCRL, and active coping to manage their symptoms.

Examples of passive coping included crying, feeling helpless, and being resigned to accept the condition or endure the symptoms. One participant expressed a wish to engage in a behavior (e.g. exercise the arm) without following through. Another said: “I cry a lot . . . I cry a lot. I try not to let people see me . . . I take a pill and go to sleep.” Active coping strategies included engaging in self-care behaviors (e.g. not putting strain on the affected arm), using medical equipment as recommended, and attending support groups and medical appointments regularly. For instance, a participant engaged in several activities to help manage BCRL: “I have become more spiritual, involved in church, reading, I listen to music, and do yoga.”

Discussion

To our knowledge, this is only the second published study focused specifically on the unique experiences of Latina breast cancer survivors living with BCRL in the United States. As presented in subsequent sections, many of our findings are consistent with those of previous studies with women of other ethnicities within the United States and abroad, which suggests the universality of many issues experienced by women with BCRL. Our major finding, however, is the unique burden faced by Latina women living with BCRL while experiencing limited access to healthcare as well as financial strain.

First, we found that participants’ access to information and quality care was severely restricted. High-quality information was especially difficult to obtain for women seeking materials in Spanish. Our participants had low incomes, some had limited English-language fluency, and 80% had Medicare or no health insurance coverage—all factors associated with low health literacy, low quality care, and poor health outcomes.²⁸ Lymphedema care requires having knowledge of the condition, identifying symptoms early, and having access to ongoing and coordinated care, much like other chronic conditions.⁴ Thus, to successfully manage BCRL, women must establish an ongoing relationship with a healthcare provider who will maintain their records, coordinate care, and be available for consultation between visits—all of which is hampered by financial strain, language barriers, and limited access to care.

Consistent with prior research with Latina and non-Latina samples in the United States, as well as with international samples, participants had limited knowledge of their risk for lymphedema.^{5,7,8,24} This is likely to have influenced their health outcomes, as knowledge is a major factor in empowering women to manage chronic cancer-related conditions.²⁹ Prior to their diagnosis, many women had never heard of the word lymphedema; two-thirds of

participants did not know they were at risk of developing the condition. Knowing about risk factors would have helped women lower their probability of developing BCRL, as well as prompt them to seek immediate medical care for emerging symptoms. Instead, the majority of participants learned about BCRL after their symptoms began to appear, and in many cases they had to research the condition on their own—an especially challenging task for patients with low levels of health literacy.

When noticing symptoms and approaching their doctors, many women reported feeling their concerns with swelling were trivialized. Also, although there is no cure, some women were told that symptoms would resolve on their own, creating false expectations and further eroding women's trust in their doctors. As a result, they turned to other BCRL patients for information regarding treatment, reflecting shortcomings in the quality of care they received. In previous research, Latina survivors have indicated feeling dismissed by their doctors, feeling like a "file," rather than a "patient."⁶ Together, these data point to structural issues that need attention if we are to enhance outcomes for Latinas with BCRL.

Despite their limited access to resources, participants reported that, generally, their management of BCRL improved over time. At the same time, significant challenges remained. Consistent with reports from research with Latina and non-Latina populations,^{6,24,30} continued swelling and other symptoms rendered participants less able to engage in activities independently than prior to the diagnosis. Their occupational lives were disrupted as well, consistent with previous reports in the literature about Latina and non-Latina White breast cancer survivors.^{26,31} In our sample, the burden was especially high for a participant whose occupation felt very fulfilling, but was no longer a vocational option for her given the areas of her body that were affected.

For many participants, the added financial burden of BCRL increased their psychological distress. Past research has documented Latinas' emotional toll related to the financial stress triggered by a breast cancer diagnosis;³² this was exacerbated by the added out-of-pocket costs required to manage BCRL.³³ In addition, Latinas experience greater financial repercussions given their disproportionate representation in occupations that require manual labor at the time of diagnosis.^{31,34} As such, they did not have some contextual supports reported in other studies by non-Latina White women with BCRL, such as generous sick leave policies that would allow them to rest and recover during crisis periods, flexible work hours without cuts in pay, and employer-based health insurance to cover the cost of the sleeves—all of which would ameliorate their financial burden.³⁵ Thus, the prohibitive cost of wraps and occupational limitations made it difficult for participants to afford the most basic and necessary treatment for BCRL.

Psychologically, wearing compression gloves and sleeves contributed to feeling self-conscious in social situations and served as a constant reminder of their breast cancer. Also, women reported a need to rely on family members to fulfill many household duties; all of these stressors have been noted by non-Latina women with BCRL as well.^{6,9,11,12} Thus, the diagnosis influenced various realms of women's lives, from their work life and body image, to their finances and familial life. Given their many challenges, women found various ways to cope.

Social support emerged as an important factor that helped women manage the stressors associated with lymphedema, consistent with reports from other studies.^{11,24} Participants reported finding comfort, hope, and strength when sharing their experiences with a social network of friends, family, support group members, and religious groups. Furthermore, women coped passively (e.g. crying, avoiding others) and actively (e.g. engaging in self-care, attending church). Consistent with findings in previous research with non-Latina White samples, participants reported that having a positive attitude helped them cope.¹¹

Contributions and limitations of the study

Through this study, we sought to expand our knowledge of Latina women with BCRL, a topic that is underrepresented in the English-language literature. Through qualitative inquiry, we gathered rich and nuanced information. Findings revealed important factors that influenced women's psychological and physical well-being and highlight the great need for focused intervention with this population.

As with any study, there are limitations. First, participants were recruited through organizations that offered supportive services to Latina survivors. As such, it is unclear if our findings would be transferable to women who do not have access to supportive services, who are likely to have even greater needs. In addition, our sample included women who had limited English proficiency; women fluent in English may have higher levels of health literacy and self-efficacy navigating the US healthcare system, resulting in different experiences. Finally, this was a cross-sectional sample. It is possible that women's needs and level of distress change over time. In the remainder of the article, we note implications and make recommendations for practice and future research.

Implications and recommendations

Given the progressive nature of BCRL, in the following sections we discuss implications and provide practice recommendations tailored for primary prevention (i.e. to lower the incidence), secondary prevention (i.e. to minimize the negative effects), and tertiary prevention (i.e. to

optimize survivors' quality of life). We also highlight areas for future research.

Primary prevention. Primary prevention efforts include strategies aimed at precluding the development of the condition. The National Comprehensive Cancer Network recommends that patients be (a) educated about lymphedema, (b) monitored for lymphedema, and (c) referred for lymphedema management when symptoms become apparent.³⁶ Yet, most study participants did not know what lymphedema was. It is imperative that during the treatment planning phase, healthcare providers educate Latina patients about potential BCRL symptoms while normalizing the condition. For Latina women with limited English proficiency and/or who may have low health literacy, medically trained interpreters should be used when needed. In addition, culturally relevant written or audiovisual information should be available in Spanish, written at a low literacy level, and presented in a format that is easy to understand.³⁷ Given the physical and emotional toll of breast cancer treatment, providing resources that women can access on demand (e.g. via a website or smartphone application) may also be beneficial. However, a review and evaluation of online Spanish health resources for lymphedema was consistent with women's perceptions; the authors found that most materials were at a ninth-grade reading level, showing deficiencies in understandability, actionability, and cultural sensitivity.³⁸ At the moment, two websites designed specifically for patients present high-quality information at a relatively low literacy level. These are the National Cancer Institute and Centers for Disease Control and Prevention Spanish-language websites "*linfedema*" pages, which provide an overview of the condition, the lymphatic system, risk factors, symptoms, treatment, and prognosis.^{39,40}

Through research, it would be possible to identify messages and delivery formats that are most effective for promoting early reporting of symptoms. Longitudinal studies are also needed to explore whether interventions at the primary prevention level affect the development of BCRL. It is also unclear whether comorbidities influence the development of BCRL in Latina women. There is some research suggesting that Black women who have undergone chemotherapy and have hypertension are at greater risk of developing the condition than women without these risk factors.⁴¹ Greater information about risk factors for Latina women will help tailor effective interventions.

Secondary prevention. Secondary prevention of lymphedema refers to strategies that reduce the condition's impact. First, it is important for women to feel respected as patients and to be given accurate information about ways to manage their condition. There is a growing body of research documenting the failure of doctor-patient communication with Black, Indigenous, and People of Color.^{42,43} Thus, health professionals should be cognizant of potential communication

barriers with Latina patients. In addition to doctors, support organizations play a major role in educating women. One pilot study found promising results from a support program for Latinas that provides information about lymphedema in the first of three sessions.⁴⁴ Additional psychoeducational programs that have empirical support are critically needed to maximize women's potential to manage BCRL.

Latina survivors manifesting symptoms of BCRL should be able to obtain care before symptoms worsen. Systemic changes are needed at the health system level to ensure women are monitored for lymphedema. Health *promotoras*, or community health workers, may help women navigate medical systems, obtain timely services, and identify sources of financial assistance to cover the costs of gloves, sleeves, and other equipment. Cultural factors should also be considered. For example, given the interdependence among family members in Latinx culture, and the fact that managing BCRL may require women to depart from expected roles, service providers should consider offering information sessions for women and their families on activities to avoid and how to care for a loved one living with BCRL (e.g. lift heavy objects for them).

Regarding research, longitudinal studies would provide information about ways in which women's support needs change over time, as well as the most appropriate points for individual and family intervention, with the goal of stopping the progression of the condition. It would also be critical to examine how the progression of BCRL may contribute to the development of, and may be influenced by, comorbid conditions in Latina breast cancer survivors. Women in our sample reported depression, anxiety, asthma, arthritis, high blood pressure, and osteoporosis. Their combined management has implications for outcomes related to BCRL. In addition, more research is needed to improve doctor-patient communication and relationship building, to facilitate early recognition and reporting of symptoms. Research focused on assisting health professionals in identifying any biases that may affect their ability to empathize and communicate effectively with patients is greatly needed, as well as studies focused on best practices on the use of medically trained interpreters.

Tertiary prevention. Tertiary prevention approaches aim to optimize quality of life. It is critical for women to have access to rehabilitation and mental health services. Mental health professionals should be knowledgeable of the ways in which BCRL influences women's psychological well-being. In particular, they should be prepared to help women: (a) become comfortable negotiating changing roles in their family, (b) address body image concerns and the process of living with a constant reminder of cancer, and (c) develop coping skills and strategies for reentering the workforce. Given the benefits of social support for Latina breast cancer survivors,⁴⁵ mental health professionals should help women identify possible sources of support. Overall, the goal of mental health treatment at this stage would be to normalize

their experiences with BCRL and facilitate the acquisition of skills and resources to enhance well-being. In this effort, more research is needed to understand the role of language and acculturation, and the efficacy of various therapeutic approaches, in the attainment of optimal mental and physical health outcomes. We hope that by implementing our recommendations for practice and research at all three levels of prevention, progress will be made in ameliorating cancer health disparities among Latina breast cancer survivors living with BCRL.

Acknowledgements

We thank Kali Knight and Berta Lewin for their assistance in preparing this manuscript for publication.

Author contributions

L.P.B. was involved in the conceptualization, methodology, formal analysis, investigation, and writing—original draft preparation, review, and editing—of the article. Z.A.R.-R. and M.K.-M. were involved in the formal analysis and writing—review and editing—of the article. P.P.H. was involved in the conceptualization, methodology, and writing—review and editing—of the article. L.O. contributed toward investigation and writing—review and editing—of the article. E.N.L. and K.A.W. were involved in the formal analysis and writing—original draft preparation.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Lydia P Buki  <https://orcid.org/0000-0001-5362-1511>

References

1. American Cancer Society. *Cancer facts and figures for Hispanics/Latinos 2018-2020*. Atlanta, GA: American Cancer Society, 2018.
2. Vespa J, Medina L and Armstrong DM. Demographic turning points for the United States: population projections for 2020 to 2060. *Current Population*, Report number P25-1144, February 2020, <https://www.census.gov/library/publications/2020/demo/p25-1144.html>
3. Dominick SA, Natarajan L, Pierce JP, et al. The psychosocial impact of lymphedema-related distress among breast cancer survivors in the WHEL study. *Psychooncology* 2014; 23(9): 1049–1056.
4. American Cancer Society. Lymphedema, www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/lymphedema (2020, accessed 1 February 2021).
5. Dönmez AA, Alici NK and Borman P. Lived experiences for supportive care needs of women with breast cancer-related lymphedema: a phenomenological study. *Clin Nurs Res*. Epub ahead of print 21 September 2020. DOI: 10.1177/1054773820958115.
6. Sleight A. Occupational engagement in low income Latina breast cancer survivors. *Am J Occup Ther* 2017; 71(2): 7102100020.
7. Barlow S, Dixey R, Todd J, et al. 'Abandoned by medicine?' A qualitative study of women's experiences with lymphoedema secondary to cancer, and the implications for care. *Prim Health Care Res Dev* 2014; 15(4): 452–463.
8. Deng J, Fu MR, Armer JM, et al. Self-reported information sources and perceived knowledge in individuals with lymphedema. *Lymphology* 2013; 46(4): 173–183.
9. Chachaj A, Malyszczak K, Pyszel K, et al. Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psychooncology* 2010; 19(3): 299–305.
10. Taghian NR, Miller CL, Jammallo LS, et al. Lymphedema following breast cancer treatment and impact on quality of life: a review. *Crit Rev Oncol Hematol* 2014; 92(3): 227–234.
11. Heppner PP, Tierney CG, Wang Y, et al. Breast cancer survivors coping with lymphedema: what all counselors need to know. *J Couns Dev* 2009; 87(3): 327–338.
12. Ridner SH, Dietrich MS and Kidd N. Breast cancer treatment-related lymphedema self-care: education, practices, symptoms, and quality of life. *Support Care Cancer* 2011; 19(5): 631–637.
13. Boone SD, Baumgartner KB, Joste NE, et al. The joint contribution of tumor phenotype and education to breast cancer survival disparity between Hispanic and non-Hispanic white women. *Cancer Causes Control* 2014; 25(3): 273–282.
14. Serrano-Gómez SJ, Fejerman L, et al. Breast cancer in Latinas: a focus on intrinsic subtypes distribution. *Cancer Epidemiol Biomarkers Prev* 2018; 27(1): 3–10.
15. Kouri EM, He Y, Winer EP, et al. Influence of birthplace on breast cancer diagnosis and treatment for Hispanic women. *Breast Cancer Res Treat* 2010; 121(3): 743–751.
16. Olaya W, Morgan JW and Lum SS. Unnecessary axillary surgery for patients with node-negative breast cancer undergoing total mastectomy. *Arch Surg* 2011; 146(9): 1029–1033.
17. Nahleh Z, Botrus G, Dwivedi A, et al. Clinico-pathologic disparities of breast cancer in Hispanic/Latina women. *Breast Dis* 2018; 37(3): 147–154.
18. Pew Research Center. Facts on U.S. Latinos, www.pewhispanic.org/2017/09/18/facts-on-u-s-latinos-current-data/ (2015, accessed 28 November 2020).
19. Kwan ML, Yao S, Lee VS, et al. Race/ethnicity, genetic ancestry, and breast cancer-related lymphedema in the pathways study. *Breast Cancer Res Treat* 2016; 159(1): 119–129.
20. Ashing-Giwa KT, Padilla G, Tejero J, et al. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psychooncology* 2004; 13(6): 408–428.
21. Eversley R, Estrin D, Dibble S, et al. Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncol Nurs Forum* 2005; 32(2): 250–256.
22. U.S. Bureau of Labor Statistics. *Labor force characteristics by race and ethnicity*, www.bls.gov/opub/reports/race-and-ethnicity/2018/home.htm (2018, accessed 28 November 2020).

23. Yanez B, Thompson EH and Stanton AL. Quality of life among Latina breast cancer patients: a systematic review of literature. *J Cancer Surviv* 2011; 5(2): 191–207.
24. Acebedo JC, Haas BK and Hermanns M. Breast cancer-related lymphedema in Hispanic women: a phenomenological study. *J Transcult Nurs* 2021; 32(1): 41–49.
25. Denzin NK and Lincoln YS. *The SAGE handbook of qualitative research*. Los Angeles, CA: SAGE, 2011.
26. Strauss AL and Corbin JM. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. 2nd ed. Thousand Oaks, CA: SAGE, 1998.
27. Rivera-Ramos ZA and Buki LP. I will no longer be a man! Manliness and prostate cancer screenings among Latino men. *Psychol Men Masculin* 2011; 12(1): 13–25.
28. Office of Disease Prevention Health Promotion. Health Literacy, www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/health-literacy (2020, accessed 28 November 2020).
29. Jørgensen CR, Thomsen TG, Ross L, et al. What facilitates “patient empowerment” in cancer patients during follow-up: a qualitative systematic review of the literature. *Qual Health Res* 2018; 28(2): 292–304.
30. Lopez-Class M, Perret-Gentil M, Kreling B, et al. Quality of life among immigrant Latina breast cancer survivors: realities of culture and enhancing cancer care. *J Cancer Educ* 2011; 26(4): 724–733.
31. Blinder VS, Patil S, Thind A, et al. Return to work in low-income Latina and non-Latina white breast cancer survivors: a 3-year longitudinal study. *Cancer* 2012; 118(6): 1664–1674.
32. Buki LP, Garcés DM, Hinestrosa MC, et al. Latina breast cancer survivors’ lived experiences: diagnosis, treatment, and beyond. *Cult Divers Ethn Min* 2008; 14(2): 163–167.
33. Dean LT, Moss SL, Ransome Y, et al. “It still affects our economic situation” long-term economic burden of breast cancer and lymphedema. *Support Care Cancer* 2018; 27(5): 1697–1708.
34. U.S. Bureau of Labor Statistics. *Labor force characteristics by race and ethnicity*, www.bls.gov/opub/reports/race-and-ethnicity/2018/home.htm (2018, accessed 29 November 2020).
35. Sun Y, Shigaki CL and Armer JM. The influence of breast cancer related lymphedema on women’s return-to-work. *Womens Health* 2020; 16: 1745506520905720.
36. National Comprehensive Cancer Network . Clinical practice guidelines in oncology, breast cancer version 5, 2020, www.arupconsult.com/reference/nccn-clinical-practice-guidelines-oncology-breast-cancer-version-5-2020 (2020, accessed 28 November 2020).
37. Buki LP, Salazar SI and Pitton VO. Design elements for the development of cancer education print materials for a Latina/o audience. *Health Promot Pract* 2009; 10(4): 564–572.
38. Johnson AR, Doval AF, Egeler SA, et al. A multimetric evaluation of online Spanish health resources for lymphedema. *Ann Plast Surg* 2019; 82(3): 255–261.
39. National Cancer Institute. *Linfedema (PDQ®)–Versión para pacientes*, <https://www.cancer.gov/espanol/cancer/tratamiento/efectos-secundarios/linfedema/linfedema-pdq> (2019, accessed 1 February 2021).
40. Centers for Disease Control Prevention. Los sobrevivientes de cancer. *Linfedema*, <https://www.cdc.gov/spanish/cancer/survivors/patients/lymphedema.htm> (2020, accessed 1 February 2021).
41. Togawa K, Ma H, Sullivan-Halley J, et al. Risk factors for self-reported arm lymphedema among female breast cancer survivors: a prospective cohort study. *Breast Cancer Res* 2014; 16(4): 414.
42. Diamond L, Izquierdo K, Canfield D, et al. A systematic review of the impact of patient–physician non-English language concordance on quality of care and outcomes. *J Gen Intern Med* 2019; 34(8): 1591–1606.
43. Pérez-Stable EJ and El-Toukhy S. Communicating with diverse patients: how patient and clinician factors affect disparities. *Patient Educ Couns* 2018; 101(12): 2186–2194.
44. Meneses K, Gisiger-Camata S, Schoenberger Y-M, et al. Adapting an evidence-based survivorship intervention for Latina breast cancer survivors. *Womens Health* 2015; 11(2): 109–119.
45. Galván N, Buki LP and Garcés DM. Suddenly, a carriage appears: social support needs of Latina breast cancer survivors. *J Psychosoc Oncol* 2009; 27(3): 361–382.