



Making Self-Care a Priority for Women At Risk of Breast Cancer–Related Lymphedema

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Abstract

Estimates suggest that between 41% and 94% of breast cancer survivors may develop the chronic condition of secondary lymphedema at some point during their lifetimes. Self-care is critical for effective lymphedema management and risk-reduction. At the same time, women in general have been characterized as engaging in self-sacrificing behaviors in which they choose other-care over self-care. This study explored the self-care experiences of women with breast cancer within the contexts of complex and demanding familial and work-related responsibilities. Participants ($N = 14$) were enrolled in a behavioral-educational intervention aimed at lymphedema risk-reduction. This feminist family theory-informed secondary analysis of qualitative data focused on women's familial roles and the balance or lack of balance between self-sacrifice and self-care. Findings included participants' struggles with time management and prioritizing self-care over care of others as well as making a commitment to self-care. Findings have implications for patient and family-level education and research with regard to gender role-based barriers to self-care and self-care within complex social contexts.

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The National Cancer Institute offers the most recent estimates of approximately 2.9 million women who have had a history of breast cancer (Howlader et al., 2013). At the same time, the American Cancer Society estimates that there will be 232,240 new cases of breast cancer and 64,640 new cases of in situ (i.e., early stage) breast cancer that are likely to develop in 2013 (American Cancer Society, 2013). Between 41% and 94% of breast cancer survivors are at lifetime risk for developing secondary lymphedema (American Cancer Society, 2007; Armer & Stewart, 2010; Ferlay, Bray, Pisani, & Parkin, 2004). This chronic condition involves the accumulation of protein-rich fluid that affects physical, functional, and psychosocial health and well-being (Pyszel, Malyszczak, Pyszel, Andrzejak, & Szuba, 2006; Radina & Armer, 2004; Voogd et al., 2003). For many breast cancer survivors, secondary lymphedema (hereafter lymphedema) is the second most dreaded outcome of breast cancer treatment—the first being breast cancer recurrence (Bernas, Askew, Armer, & Cormier, 2010).

Some research suggests that there are cancer treatments that may increase the risk of developing breast cancer–related lymphedema. Such treatments (e.g., surgical removal of lymphatic vessels and nodes and the development of tissue fibrosis that sometimes follow radiation treatments, infection, or surgery) tend to damage and potentially weaken the lymph nodes and the vessels carrying lymph fluid. This process may then compromise the effectiveness of the valves in the lymph vessels. The result is the accumulation of lymph fluid in the tissues of the arm, hand, chest, back, and neck (Fu & Rosedale, 2009; Rockson & Rivera, 2008). Although researchers have explored surgical (e.g., auxiliary lymph node dissection versus sentinel lymph node biopsy, see Cormier et al., 2010), physiological (e.g., body mass index [BMI], see Ridner, Dietrich, Stewart, & Armer, 2011), and genetic explanations (e.g., Miaskowski et al., 2013), the etiology of breast cancer–related lymphedema remains unclear (Aldrich et al., 2012). Women with lymphedema commonly report arm swelling as a physical symptom but may also experience other symptoms as well, such as pain, heaviness, tenderness, numbness, limited range of motion, and stiffness (Armer, Radina, Porock, & Culbertson, 2003; Thomas-MacLean, Miedema, & Tatemichi, 2005).

Lymphedema Self-Care

Lymphedema self-care, sometimes referred to as “risk-reduction techniques” and the “self-management of lymphedema symptoms,” involves specific

behaviors and activities undertaken on a regular basis by the individual, with or without the assistance of others. The involvement in self-care by those with lymphedema is necessary to manage swelling and other symptoms and to reduce the risk of infection (Ridner, Bonner, Deng, & Sinclair, 2012). In 2002, the National Lymphedema Network (NLN) offered 18 risk-reduction guidelines aimed at reducing the factors (e.g., infection, injury/trauma, damage to the venous and/or lymphatic systems) that may contribute the development of lymphedema and/or the flare-up of existing lymphedema (NLN Medical Advisory Committee, 2012; Ridner, 2002). According to both the NLN and the American Lymphedema Framework Project, many of these risk-reduction guidelines involve lifestyle changes and require self-care behaviors on the part of the individual (e.g., keeping the arm clean and protected from sunburn, abrasions, and insect bites; maintaining healthy weight, resting; Armer et al., 2013; Bernas, 2013; NLN Medical Advisory Committee, 2012).

The recommended self-care behaviors can be time-consuming and labor-intensive (Ridner, Bonner, et al., 2012; Ridner, Fu, et al., 2012). These include, for example, weight reduction, whole body exercise, wearing compression garments, intensive skin care, infection risk-reduction, simple manual lymph draining (MLD), and complete decongestive therapy (CDT; Ridner, Fu, et al., 2012). Simple MLD is the practice of a special kind of massage whose purpose is to reduce and control swelling associated with lymphedema. CDT involves two phases. A trained physical or massage therapist administers the first phase. The second phase involves lifelong self-care. This second phase of CDT includes a combination of MLD, wrapping the arm with several layers of elastic bandages (i.e., compression bandaging), exercise, skin care, and wearing an expensive custom-made compression sleeve and/or glove (Petrek, Pressman, & Smith, 2000). This self-care behavior, which is the standard of care for lymphedema, can be burdensome in terms of restricting range of motion, having to set aside time during the day to perform MLD, having to ask others for help, and avoiding getting the wrapping wet (Meiklejohn, Heesch, Janda, & Hayes, 2013; Radina & Armer, 2001; Ridner, Fu, et al., 2012). Women who use compression bandaging for self-care must remove the wrapping and rewrap the arm for bathing or other water activities (e.g., swimming, washing dishes). Last, the compression sleeve and gloves are often prohibitively expensive. Thus, they must be washed by hand everyday and the woman with lymphedema must be careful not to stain or otherwise damage the sleeve (Rourke, Hunt, & Cormier, 2010).

Coping With Lymphedema in Daily Life

Changes in physical appearance created by lymphedema can affect physical and psychological health as well as interpersonal relationships (Passik &

McDonald, 1998; Radina, Watson, & Faubert, 2009; Thomas-MacLean et al., 2005). Those coping with this chronic condition can be subject to frustrating physical limitations (e.g., being unable to lift heavy objects; reducing activities that require repetitive motions with the arm; keeping the arm elevated) that can reduce their perceived or actual ability to participate in normal, daily activities (Meiklejohn et al., 2013; Radina, 2009; Radina & Armer, 2001; Ridner, 2002). Similar to other chronic conditions such as asthma or diabetes, these physical limitations may require these women to renegotiate family roles and modify how the family function as a unit (Heisler, Cole, Weir, Kerr, & Hayward, 2007; Horne, 2006; Radina & Armer, 2001, 2004; Thomas-MacLean et al., 2005). This may include a redistribution of household responsibilities (i.e., asking her husband to do the grocery shopping because the bags are too heavy, employing a maid service to handle housework that is too taxing) or the modification of such responsibilities (i.e., lowering standards of household cleanliness; Fu, 2005; Radina & Armer, 2001). Previous studies by the authors (Radina, 2009; Radina & Armer, 2001, 2004; Radina et al., 2009) of how women with lymphedema describe coping with this chronic condition in the context of their families, identify the need for further investigation of the challenges that women with breast cancer–related lymphedema face in the context of their family life and the associated responsibilities.

Psychosocial Outcomes of Coping With Lymphedema

Women who live with breast cancer–related lymphedema are unique as they have successfully coped with the physical and emotional distress of cancer (Passik & McDonald, 1998) only to face this often-disabling complication of their cancer treatment (Radina & Armer, 2001). The preponderance of research suggests that people with lymphedema and associated symptoms experience poorer well-being and health-related quality of life. At the same time, these individuals are also likely to experience a greater incidence of distress related to their symptoms in the form of depression or anxiety (Fu et al., 2013). With regard to gender, Lam, Wallace, Burbridge, Franks, and Moffatt (2006) found that among people with all known types of lymphedema, women were more likely than men to report feelings of depression and resentment related to the compression garment they must wear for self-care.

Sensitizing Perspectives on Women and Family Life

Feminist Family Studies

The secondary analysis of qualitative data presented here is informed by several central tenets of feminist family studies. The first central tenet is that a

family is a social group that is subject to and reflects the social and political systems within which it exists. That is, families are microcosms where larger social processes, like power and privilege, which are based on the social construction of gender, are played out and often perpetuated (Walker & Thompson, 1984). Based on this assumption of feminist theory as it relates to family, the present study seeks to understand how women with lymphedema manage their familial roles, either successfully, or unsuccessfully, with self-care. Specifically, these roles may be influenced by expectations about responsibilities and behaviors that are inherent in the large social and political contexts in which they live (e.g., self-silencing, self-sacrificing). For example, this may lead some women to struggle with managing these expectations while also finding the time, space, and energy to engage in self-care. Similar to the first central tenet, feminist family scholars recognize that families often are not a locus of safety and security for many women and that families can be both a site of struggle and a source of support (Allen, Lloyd, & Few, 2009). Given this assumption, this study also recognizes that, for women with lymphedema, family life can be a place where there may be struggles and/or support for self-care. The third central tenet is the awareness that a large portion of research regarding women in the context of family life focuses on what they *do* for the family and the impact these actions have on other family members. Walker (2009) argued that little research attention has been paid to “women’s own needs, desires, and abilities” (p. 22). This argument that informs the present study in that the focus is not on the tasks or responsibilities that women fulfill for the family or its members. Rather, the focus is on how women experience the potential struggle to take care of their own needs for self-care within family contexts. Finally, the fourth central tenet that informs this study is that of feminist praxis as a “disciplinary essential” (Allen et al., 2009, p. 12). That is, feminist family scholars must not only challenge the assumptions of current knowledge but must also engage in scholarly work that calls for social change. One way that this can be done, as suggested by Walker, is to focus on the daily life experiences of women within the context of family life. In so doing, and by informing nurses and other helping professionals of its findings and implications, the work presented here seeks to enact change that will enable all women with lymphedema to remove potential barriers to their self-care within the context of their familial roles.

Self-Silencing and Self-Sacrificing

To understand some of the social and potentially political forces that may influence the role of women in family life, as well as to focus on how women manage what they do for family members and their own self-care, we turn to

the work of Jack (1991) and Jack and Ali (2010). The concepts of self-silencing and self-sacrificing emerged from work conducted by Jack, who studied the relationship between women with depression and the important others in their lives. *Self-silencing* includes behaviors that are based on the belief that to gain and maintain psychosocial intimacy with important others, one must deny their own needs and desires. Similarly, *self-sacrificing* involves behaviors that place the needs and desires of important others above one's own. Both of these concepts can be viewed as a relational tool that, when used, ensure connections to important others.

Gilligan (1982) and Jack (1991) have argued that women are socialized within family and community life to embrace this concept of self-sacrifice in the service of others. Gilligan specifically equates women's ideal of goodness as being linked to their desire for/sense of conformity to gendered social norms and values about their roles in relation to others (e.g., mother, spouse/partner). Jack later suggested that women learn through their interactions within their families of origin that pleasing others, taking care of others, and giving to others is morally and socially rated as better or of greater importance than attending to one's own needs or desires. To behave in such a way that prioritizes one's own needs is considered selfish and therefore bad. Jack also argues that this act of caring, which can at times be self-sacrificial caring, is a relational tool that women are socialized to use to "cement connections to others" (p. 120). Thus, caring for others, and doing so in an unselfish way or at the expense of one's own needs, is the currency that women are socialized to use to create and maintain relationships with others. Interestingly, some have argued that the concept of self-sacrifice in the context of family life is one that, when combined with the concept of gender, becomes pathology for women and source of praise for men (Bahr & Bahr, 2001).

Self-sacrifice for women can have far-reaching consequences for women, both physically and psychologically. Physically, women who endorse ideals of self-sacrifice may neglect important self-care such as rest, exercise, eating a healthy diet, or attending to health concerns.

Psychologically, these women are at greater risk for experiencing low self-esteem, repressed anger at unmet needs, and depression (Jack, 1991).

Self-sacrificing may be relevant to lymphedema management, which requires engaging in self-care that requires some degree of commitment to and prioritizing of the self over self-sacrificing. Research has suggested that for people with chronic conditions adherence to necessary self-care is often associated with depression (DiMatteo, Lepper, & Croghan, 2000). That is, those who experience greater depression are less likely to engage in self-care activities. At the same time, engaging in self-sacrificing behaviors and living with lymphedema have both been associated with depression (Fu et al., 2013;

Jack, 1991; Lam et al., 2006). Therefore, both having lymphedema and engaging in self-sacrificing behaviors may in turn lead to depression, and thus, reduced adherence to self-care. Therefore, it is important to understand the experiences of women with lymphedema as it relates to negotiating their self-care within family contexts that may require or expect self-sacrificing behaviors. By understanding this process for women, nurses and other helping professionals may be able to provide prevention education aimed at helping these women adhere to self-care that would reduce the risk of lymphedema flare-up and depression.

Aims of the Present Study

To better understand what may be needed to successfully manage lymphedema risk, this study explores breast cancer survivors' experiences of self-care within the contexts of complex and demanding social responsibilities (e.g., paid work, family responsibilities) that may elicit gendered self-sacrificing behaviors. In particular, we explore the possible relationships between socially constructed and gender-base behavior associated with self-sacrificing among women with breast cancer-related lymphedema. Given that both breast cancer-related lymphedema and self-sacrificing behaviors have been found to be associated with poorer psychological health in women (e.g., depression), we have focused our exploration of these individuals' accounts of how the either do, or do not successfully make their self-care a priority within their family contexts. Our ultimate aim is to gain understanding of the factors that may help or hinder compliance with self-care behaviors related to the management of lymphedema symptoms to provide guidance for patient education for nurses and other helping professionals.

For our exploration, we relied on data collected in connection with a feasibility study of a nursing intervention aimed at the instruction of self-care techniques for breast cancer patients as part of their postoperative care (Armer et al., 2009). We used these data for secondary analysis with the purpose of understanding traditional gender role-based influences (i.e., expectations for prioritizing care of others) on self-care versus self-sacrifice for these individuals.

Method

Study Design

The data analysis reported here is a secondary analysis of data generated in a larger study that was conducted between 2006 and 2008 and was funded by

the Lance Armstrong Foundation (Armer et al., 2009). Specifically, the researchers engaged in retrospective interpretation of the original data to explore a research question that had not been a part of the initial data collection and analysis (Hinds, Vogel, & Clark-Steffen, 1997; Radina & Downs, 2004). The research question was as follows: For women with breast cancer-related lymphedema, who were engaged in a behavioral-educational intervention (i.e., modified-MLD, deep breathing, exercise, skin care) aimed at lymphedema risk-reduction, what gender-role based influences were cited by participants related to their participation in self-care and/or self-sacrifice?

Behavioral Intervention

Initially, 27 newly diagnosed breast cancer survivors who were scheduled for surgery were recruited into a bundled intervention that included individual education on lymphedema risk-reduction and modified-MLD (MMLD). This intervention involved MMLD, which is

a behavioral-educative self-care action consisting of deep breathing, abdominal massage, axillary clearance, and gentle lymphatic manipulation of the limb, coupled with standard LE education. The education component included information about the appropriate use of compression garments, skin care and avoiding injury to the skin, lifestyle modification, and caution about limb constriction. Increasing self-care agency through motivational interviewing and solution-focused therapy via the supportive-educative nursing system may help patients engage in self-care actions to reduce the risk of developing LE. (Armer et al., 2009, p. 7)

MLD has been shown to reduce limb volume and flare-ups in individuals with lymphedema and has been recommended to reduce the risk of developing lymphedema (Moseley, Carati, & Piller, 2007). Deep breathing, although its efficacy is debated among researchers and practitioners, is thought to improve lymphatic clearance in the thoracic and abdominal cavities and has been shown to reduce lymphedema in the arm (Moseley, Piller, & Carati, 2005; Piller, Craig, Leduc, & Ryan, 2006).

Primary findings from this companion study are reported elsewhere (Armer et al., 2009). As the parent study progressed, nurse researchers noticed that some participants were not routinely performing self-care measures as instructed. This led to conversations with and observations of the participants by the nurse researchers. Participants cited several reasons for not performing the self-care they were taught in the intervention including low energy, fatigue, and lack of motivation.

Data Collection

Based on these findings from a larger study, a questionnaire was developed based on Orem's (2001) power components. This questionnaire consisted of 19 open-ended interview questions aimed at exploring the essential capabilities of study participants to engage in self-care actions related to health care deviation requisites specific to risk-reduction of lymphedema (see the appendix). For more information regarding the larger study and the development of the questionnaire instrument, see Armer et al. (2009).

The questionnaires were mailed to the 27 participants who were either currently enrolled in or who had recently completed the 18-month intervention. Participants were provided with self-addressed stamped envelopes to return their questionnaires. For those who did not complete and mail back the questionnaires, a research nurse or a trained graduate student completed the questionnaire with participants via telephone. A total of 14 participants returned the surveys by mail or participated in a telephone interview.

Description of Participants

Respondents' ages ranged from 35 to 81 years ($M = 60$ years). The average participant was 13 months beyond breast cancer surgery at the point of the completion of the survey. All participants were treated for breast cancer using surgery and chemotherapy. Half ($n = 7$) of the participants also received radiation as part of their treatment. As this was a feasibility study that piloted an intervention, and the goal was to reduce individuals' lifetime risk of developing lymphedema, data were not available during this study regarding indicators of the development lymphedema in these participants. Eleven participants identified as Caucasian while three identified as African American. All participants were in traditional, heterosexual family forms. Six participants reported being married, four were divorced, three described themselves as single, and one participant reported being widowed. No data were collected regarding participants' employment status.

Data Analysis

Analysis of these data involved thematic analysis (Braun & Clark, 2006) that was informed by the central tenets of feminist family studies and the concepts of self-silencing and self-sacrifice as outlined earlier (Allen et al., 2009; Jack, 1991; Walker, 2009; Walker & Thompson, 1984). First, based on the assumption that family life is influenced by and also reflects larger social contexts, including power struggles that result from the social construction of gender

(Walker & Thompson, 1984), we focused on the portion of the available data that specifically referred to family and family life. Second, we approached data analysis with an understanding that families can be both a site of struggle and a source of support (Allen et al., 2009). Third, given Walker's (2009) call for research on "women's own needs, desires, and abilities" (p. 22), we focused analysis on how women experience the potential struggle to take care of their own needs for self-care within family contexts. Finally, we used Jack's (1991) concepts of self-silencing and self-sacrificing to focus our attention on the potentially gender-based behavior choices and/or expectations of these participants.

Given feminist family theory (Allen et al., 2009; Walker, 2009; Walker & Thompson, 1984) and the concept of self-sacrificial caring (Jack, 1991), we expected to find that women would express varying degrees of ease and frustration with managing family life/family members' needs and their own self-care needs. Specifically, we anticipated that one possible barrier to engaging in self-care would be the prioritizing of the care of others. In general though, we were interested in putting the daily lives of women with lymphedema at the center of our analysis to better understand how women do or do not balance self-care with self-sacrificial caring in the contexts of family life.

Data analysis procedures. The data from the 14 participants were transcribed and de-identified prior to the secondary analysis process. The data were then organized according to participants' responses to each question in the survey. For example, all the participants' responses to Question 1 were placed together and so on. A summary of the stem of the survey question is provided in brackets for data presented in the results section as a means of providing context for the participants' responses.

Data analysis proceeded with the first author then reading through the data multiple times to become familiar with the data set as a whole. This was followed by the development of a coding scheme aimed at focusing coding on data that was relevant to the research question. For example, the concept of housework as one aspect of other-care was used as a code. Discrete phrases, sentences, and/or responses across interview questions and across interview were then coded that related to housework (e.g., "At the end of the day I am a bit tired, housework, cooking."). Next, codes across the interview questions were collapsed into larger codes surrounding similar ideas. For example, codes such as time or time management that arose across questions were combined. Finally, these larger codes were evaluated as to their relevance to the research question (Emerson, Fretz, & Shaw, 1995). Those that corresponded to the research question were retained, and those that did not were discarded.

The data and coding scheme were then shared with a graduate research assistant who was asked to code the data according to the coding scheme. After her initial coding, the first author and the research assistant met and discussed areas of agreement and disagreement and clarified the coding scheme. Both the first author and the research assistant then returned to the data and adjusted their coding according to the revisions. At that time, initial Cohen's kappa values were calculated. These values were interpreted according to those presented by Viera and Garrett (2005). Initial Cohen's kappa values ranged from .264 (fair agreement) to .875 (almost perfect agreement). The first author and the research assistant further refined the coding scheme and returned to the data to make one last round of adjustments. Final Cohen's kappa values were then calculated. These ranged from .779 (substantial agreement) to 1.0 perfect agreement. The end result was the identification of three overarching themes related to women's self-care and self-sacrifice.

Results

The result of this data analysis was the identification of three interrelated themes surrounding participants' reports of how they either do, or do not make self-care a priority in the context of caring for others. These three themes were (a) making the time, (b) struggles with putting myself first, and (c) making a commitment to self-care. Together these themes point to the ways in which the participants engaged in self-sacrifice or "others-sacrifice" given their family contexts and their roles within their families. These three themes are discussed in turn below. In an effort to provide context for participants' responses, the question root has been added in brackets where appropriate.

Making the Time

All the 14 participants talked about how managing time was an important factor in ensuring they engaged in self-care. This included how time management was a struggle as well as how they had successfully managed their time to incorporate self-care. Nine of the participants described how they often experienced difficulties in making the time to fit self-care into their daily routine among their other obligations (e.g., housework, taking care of spouses/grandchildren). For example, Sandra stated, "[I make the decision about whether or not to practice the self-care measures based on] how tired I am, how much time I have." Similarly, Debbie stated, "[The factor that influences my decision-making about choosing to practice self-care behaviors is] how much time it takes if I have a busy day. If I get too busy [it gets in the way of my practice of self-care measures]."

Two of the nine participants who mentioned struggling with time management specifically discussed how their obligations to paid work outside the home kept them from engaging in self-care. Elaine stated, “Since starting this program I have not really done any of these things [risk-reduction techniques]. I work two jobs and did not have the time to do these things.” Barb expressed similar concerns,

My work schedule has a way of taking over my life. Right now I work 16-hour days—6 days a week. I have fallen into the same patterns as before my cancer, and I can’t get out! I have the energy. I just don’t have the discipline to stick to a routine. Working always seems more important.

Although work outside the home may not be directly related to self-sacrificing caring for family members, certainly the financial support for the family provided by paid work, and prioritizing that work over important self-care could be considered self-sacrificial caring. When asked about the factors that influence her decision making about choosing to practice self-care behaviors, Barb simply stated time management. Thus, it seems that for at least some women who are at risk of breast cancer–related lymphedema, work outside the home can be a significant barrier to self-care.

In contrast to time management being a barrier to self-care, all the 14 participants discussed how they have successfully been able to make time to take care of themselves despite their busy days. Comments about this success revolved around “try[ing] to make a habit” (Sandra) and also, when during their daily schedules, they were able to perform MLD or deep breathing/relaxation. For example, Carol explained how she manages to incorporate self-care into her routine,

I meditate first thing in the morning and last thing at night. I exercise before and after work for at least 30 min. I schedule a massage the week after my cancer treatment to ensure my body is flowing, particularly my lymph system.

Nancy described how important it is for her to maintain a regular schedule so she can make sure she engages in self-care,

It’s not easy, remembering [to do the massage] is best when you have any type of schedule at all. It’s important, and I try to do [the massage] first thing in the morning, mid-day when I’m relaxing . . . I try to do it while in bed or getting up. Some days, not as often, I do [the massage] only once . . . I have noticed if I don’t do these things I have heaviness in that arm, I have swelling and discomfort. And, so I need to keep it up

Three of the 14 participants mentioned how, although they have made efforts to make self-care a part of their daily routines, they still struggle with this. For example, Nancy said “It’s not easy” and Anne stated “I am still trying to do [make self-care activities a part of daily life].”

Based on the statements presented above, we can see that all the participants reported ways they have used to make sure they engage in self-care regularly. At the same time, the majority of participants (9 of 14) described struggling to find the time in their daily lives to engage in self-care.

Struggles With Putting Myself First

Six of the 14 participants described struggling at times with managing their self-care activities in the context of caring for others or their other responsibilities related to family life. Although this theme only appeared in the statements of 43% of the participants, its clear focus on aspects of the research question make theme an important focus of these results. Statements included specific references to “taking care of others” and other obligations such as housework. For example Linda stated, “Definitely external things in life [get in the way of my practice of self-care measures]—mostly taking care of others.” Similarly, Mary explained,

Well, just daily living [gets in the way of my practice of self-care measures], my husband, and pets. My husband is handicapped and always wanting something and my little doggies want rubbing. I think you take care of everyone else first and then yourself.

Barb explained that making self-care a priority is a struggle for her because

My work [gets in the way of my practice of self-care measures]. I’m a lazy person when it comes to taking better care of my body. Between the office and keeping up with housework, I don’t seem to have enough time. Seems like my priorities are out of whack, doesn’t it? I lack the self-discipline to place my health first in my life. I was taught from a very early age that work is most important and I guess that lesson stuck. I need a way to rearrange my life.

Similarly, Nancy has an active lifestyle and busy family. She said,

If I am not at home or on a vacation [it gets in the way of my practice of self-care measures, and] that can distract me. If other things are going on around me . . . if my . . . family has changed. I can be distracted from doing that. You must think of others’ need a lot.

For these six participants their struggles with self-care revolved around trying to balance self-care to reduce their risk of developing breast cancer–related lymphedema with taking care of others (e.g., family, pets, housework, work outside the home).

Five of the 14 participants mentioned how the responsibilities related to their familial roles as wife or mother specifically took time away from doing self-care activities or made them too tired to do so. For example, Patty stated, “At the end of the day I am a bit tired—housework, cooking.” Similarly, Linda stated how “mostly the time required [keeps me from engaging in self-care]—and [I] seem to be tired after all other obligations.” For Susan it was, “Having my husband around [gets in the way of my practice of self-care measures].” Susan prefers her privacy and doesn’t like to do the massage in front of him. Thus, she avoids doing the necessary massage and other activities if her husband is at home.

These participants’ statements point to the very real nature of how some women with breast cancer–related lymphedema can struggle with making self-care a priority in the context of familial obligations that require their time, attention, and energy. Rather it seems that these women choose, or feel obligated to choose, self-sacrificing behaviors over self-care to meet the needs of others in their lives (i.e., family members, pets, employers).

Making a Commitment to Self-Care

While participants reported struggling to balance their various familial obligations, many participants (11) expressed a strong desire or commitment to make their self-care a priority. Specifically, when asked about their goals with regard to self-care, these participants mentioned how their engagement in self-care on a regular basis was important to reducing their risk of development breast cancer–related lymphedema. Such statements included responses similar to Kathleen’s “I believe 100% self-care measures mentioned above will prevent development of lymphedema.”

Three of these 11 participants described ways in which their family members actually facilitated their commitment to self-care. For example, Debbie said, “My family helps me take the time to do it.” Others talked about how family members took over household chores that would have normally been the participants’ responsibility (e.g., carrying heavy things, housework).

These findings suggest that although there is a commitment to engage in self-care by most of the participants, all of them expressed struggles with making the time to follow through with those commitments. The

three participants who specifically mentioned struggling to make a habit of self-care (see “Making the Time” section above) made statements that reflected strong desires to reduce their risk of breast cancer–related lymphedema. For example, Nancy said,

I think it is very important because if I become lax and not do it I can tell the difference. I tell the difference in the heaviness of my arm. I try to take care of myself in a way so I don't have to deal with the heaviness.

Similarly Linda stated, “[My goal is] to do whatever I can to prevent lymphedema.” The same was true for Anne who said, “Well I'd like to certainly prevent it from happening.” Thus, it seems that making a commitment to self-care, and even understanding the importance of self-care, some participants still struggled in finding a balance between self-care and self-sacrifice.

Discussion

This study explored the concept of self-sacrifice within the context of family functioning among women at risk of breast cancer–related lymphedema. The findings suggest that many of these women struggled with making their self-care a priority despite being enrolled in an intervention study aimed at teaching them techniques for self-care to reduce their risk of developing breast cancer–related lymphedema. Often the major barrier to self-care was *not* being unaware about how to perform the self-care techniques as suggested by others (Fu, Axelrod, & Haber, 2008; Sherman & Koelmeyer, 2011), but rather the pull the participants felt to put others' needs first. The majority of participants (9 of 14) described struggling to find the time in their daily lives to engage in self-care. This finding is consistent with findings identified by Ridner, Dietrich, and Kidd (2011) who found that a fifth of their participants with both mild and severe breast cancer–related lymphedema reported time management to be a barrier to self-care.

This study and its findings also highlight the role that so many women play in their families in terms of care of others. This focus on their gendered social roles reflects a feminist theoretical lens that puts women's daily-life experiences of family life and their personal needs at the center of analysis (Walker, 2009; Walker & Thompson, 1984). The finding that women must negotiate self-care in terms of their varied obligations to others is consistent with findings specifically related to breast cancer–related lymphedema (Radina & Armer, 2001, 2004). The present study focuses more broadly

than the authors' prior work with regard to lymphedema and family life in that it includes both women with breast cancer–related lymphedema and breast cancer survivors who are at risk of developing lymphedema. At the same time, this study moves the empirical understanding of the impact of breast cancer–related lymphedema risk and related self-care activities forward with regard to considering the woman as a gendered being living in a society in which gender expectations may influence self-care behaviors. The majority of these participants expressed motivation to engage in self-care behaviors and even the knowledge about how to do so, which they attributed to the intervention in which they were enrolled. Others have found a link between self-care knowledge, motivation, and behavior (e.g., Fu & Rosedale, 2009). Although this matrix of variables offers important clues to improving patient after-care from breast cancer treatments, it assumes that the patient exists within a social vacuum that is void of other very real barriers to self-care (i.e., the socially constructed expectations for women's familial behaviors). Thus, the present study introduces a new and nuanced variable of social context to the exploration of strategies for reducing risk for developing breast cancer–related lymphedema—that of the social construction of gender roles that may make self-care particularly challenging for women. Specifically, highlighting this variable demands the consideration of factors related to gender, and the social and political implications of gender both within and outside the family, when developing self-care interventions for women with lymphedema or other typically gender specific chronic conditions (e.g., chronic pelvic pain).

Limitations and Directions for Future Research

This study is not without limitations. First, although the use of secondary analysis of qualitative data is not atypical, we did find ourselves limited in the breadth and depth of participants' responses. In the future, a more focused collection of primary data that explore the concepts that were the focus of the study may help researchers to better understand the role of gender in self-care. Second, the study population was not very ethnically or geographically diverse. As gender roles and the emphasis placed on family life is tied to cultural meanings, it would be interesting to explore if these findings hold among more diverse populations. Last, the data used for analysis were gathered from the women themselves and not from partners or other family members. The collection and analysis of such data would help researchers to better understand the various interfamilial perspectives on family roles and expectations. This understanding has direct implications for

family-level interventions aimed at helping families adjust and cope with lymphedema as a chronic condition.

Implications for Family Nursing Practice

These findings have implications for family nursing care with regard to patient education that considers gender role-based barriers to self-care and furthering understanding of self-care within complex social contexts. Interventions aimed at self-care for women with lymphedema should move beyond the instruction of MLD and other techniques aimed specifically at physical self-care and include psychosocial aspects of self-care. These psychosocial aspects should focus on how to make self-care a priority, how to manage self-care in the context of competing demands, and how to talk about and negotiate the space and time for self-care within relational contexts. The goal of such interventions is to raise awareness of gender-based role constraints in families as well as to provide both motivation and skills for ensuring that the women's self-care is viewed as a priority, not only by the woman but her loved ones as well.

As discussed by Cooper, Loeb, and Smith (2010), primary care nurse practitioners (PCNP) often oversee lifestyle changes not only related to managing risk of reoccurrence but also complications related to cancer treatment such as lymphedema. PCNPs, as well as other professionals engaged in family nursing care, thus, serve an important role in helping breast cancer survivors manage their quality of life. One aspect of that quality of life is helping individuals and their families navigate changes to the family system that may be related to necessary lifestyle changes (e.g., self-care for managing lymphedema risk and symptoms; Radina, 2013).

The participants in this study described both challenges and successes with negotiating their own self-care within the contexts of expectations for self-sacrificial care in their families. Family nursing care professionals may wish to use the experiences of these women as examples upon which to develop future interventions with this population. Interventions should be aimed at helping those loved ones in the woman's life to understand the importance of the physical self-care to reduce lymphedema risk and manage lymphedema, if it does occur. This could include psycho-educational programs, webinars, instructional videos, and family life education about gender-based relational dynamics in families for couples and/or families. Nurses may provide some of this patient/family instruction but should also consider obtaining referrals to marriage and family therapists or medical family therapists who may be best positioned to help navigate changing family roles.

Appendix

Interview Guide

These questions refer to the self-care practice information regarding deep breathing, specialized body massage, and other measures to reduce the risk of lymphedema, which you received at the beginning of this study.

1. To what extent do you believe you are at risk of developing lymphedema?
2. What are your goals in relationship to reducing your risk for lymphedema?
3. To what extent do you believe practicing these self-care measures (such as deep breathing, specialized body massage, and other measures) will prevent or reduce the development of lymphedema? Describe.
4. How do you go about making a decision about whether or not to practice the self-care measures to prevent or reduce lymphedema?
5. What factors influence your decision-making about choosing to practice self-care behaviors of deep breathing, specialized body massage, and other self-care behaviors to prevent or reduce lymphedema?
6. How do you fit these self-care practices of specialized body massage, deep breathing, and other self-care measures into your daily routine of your overall self-care?
7. What is your physical capability to perform the self-care actions?
8. How would you describe the level of energy you have to perform self-care activities on a continuous basis to prevent or decrease lymphedema?
9. What gets in the way of keeping your attention and focus on practicing self-care measures to prevent or reduce lymphedema? (This could be what you are thinking and/or external things in your life.)
10. How do you manage crisis situations that interfere with your self-care in lymphedema risk-reduction?
11. What resources are available to aid you in carrying out deep breathing, specialized massage, and other self-care activities? Which of these have you used?
12. What resources are lacking for you to adequately carry out these self-care activities?
13. What self-care practices to prevent or reduce lymphedema might be confusing for you?
14. What information or support would help you understand and practice self-care behaviors to prevent or reduce lymphedema?

15. How would you describe your ability to care for yourself amid changing conditions within and around you?
16. How do actions by your family or others facilitate your self-care in lymphedema risk-reduction?
17. How do actions by your family or others interfere with your self-care for lymphedema risk-reduction?
18. Tell about issues you face in performing self-care activities to reduce the risk of developing lymphedema, such as time required, effort required, lack of help, or other.
19. Is there anything else you would like to tell us about the education and/or self-care practices related to lymphedema risk-reduction you have learned about in this study?

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