

## Breast Cancer-Related Lymphedema: Implications for Family Leisure Participation

*An estimated 20% of breast cancer survivors face the chronic condition of breast cancer-related lymphedema. This study explored the ways in which women with this condition experienced changes in their participation in family leisure as one indicator of family functioning. Participants (N = 27) were interviewed regarding lifestyles before and after lymphedema, perceptions of personal independence, relationships with others, and personal coping. Data were analyzed using a cooperative, inductive format. Participants described a heightened sense of caution regarding participation in family leisure activities. Participants coped with lymphedema by either modifying the way they participated or not taking part in family leisure activities. Professionals may use these findings to assist women and their families in modifying leisure activities and exploring new activities.*

The National Cancer Institute estimated that approximately 2.5 million women living in 2004 had a history of breast cancer. The most recently available estimates regarding new cases indicate that 178,480 new cases of breast cancer are likely to have developed in 2007 (Ries et al., 2007). Despite the fact that fewer women appear to be facing new

diagnoses of breast cancer (American Cancer Society, 2007), those who have already been diagnosed and those who will be diagnosed in the future are faced with important quality of life issues (Passik & McDonald, 1998). One issue challenging women's quality of life following breast cancer treatment is lymphedema, a condition characterized by the chronic and abnormal swelling of the arm, chest, neck, or back that results from breast cancer treatments that involve the removal of or damage to the lymph nodes located under the arms and chest (Passik & McDonald). Estimates suggest that 20% of breast cancer survivors experience lymphedema (Clark, Sitzia, & Harlow, 2005).

The physical appearance and limitations created by breast cancer-related lymphedema (hereafter lymphedema) can affect physical and psychological health as well as social and sexual relationships (Casley-Smith, 1992; Passik & McDonald, 1998; Passik, Newman, Brennan, & Tunkel, 1995; Thomas-MacLean, Miedema, & Tatemichi, 2005). Thus, lymphedema can influence breast cancer survivors' posttreatment quality of life. In their studies of breast cancer survivors, Radina and Armer (2001, 2004) have identified the need for further investigation of changes in relationships with family members (e.g., spouses or partners, children, grandchildren) that occur because of functional limitations and social stigma created by lymphedema.

The focus of this article is on one aspect of quality of life, family leisure activities, as an indicator of how women's interactions and relationships with family members have been affected by the onset of lymphedema.

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Specifically, the purpose of this article is to explore the ways in which women with breast cancer-related lymphedema experienced changes in their leisure-based interactions with family members. In order to accomplish this, we have employed the use of the Core and Balance Model of Family Leisure Functioning (Zabriskie, 2000). Findings from this study may be used to influence the ways helping professionals, who work with this population and other populations with physical disability and chronic conditions, consider the patient as an individual who is a member of a family. Specifically, affected individuals and their families may need concrete suggestions for how to minimize disruptions to family leisure activities, an important aspect of family functioning.

#### BREAST CANCER-RELATED LYMPHEDEMA

Lymphedema can result from successful cancer treatments that have eliminated cancer but leave the survivor with physical, emotional, and social effects that can diminish quality of life. Although the exact cause of breast cancer-related lymphedema is unknown, evidence suggests that some cancer treatments may increase the risk of developing lymphedema; risks include the surgical removal of lymphatic vessels and nodes and the development of tissue fibrosis that sometimes follow radiation treatments, infection, or surgery (Kwan et al., 2002). Common breast cancer treatments damage and potentially weaken the lymph nodes and the vessels carrying lymph fluid, and they can compromise the effectiveness of the valves in the lymph vessels (Smith, 1998). The result is the accumulation of lymph fluid in the tissues of the arm, hand, chest, back, and neck (Berne & Levy, 1996). Lymphedema symptoms can arise between hours and years after breast cancer treatment (Markowski, Wilcox, & Phala, 1981). Although women with lymphedema report a variety of physical symptoms, including pain, heaviness, tenderness, numbness, limited range of motion, and stiffness, arm swelling is the most common (Armer, Radina, Porock, & Culbertson 2003; Coster, Polle, & Fallowfield, 2001; Thomas-MacLean et al., 2005).

Lymphedema and its sequelae impose limitations on women's lives. Limitations reported in previous research include difficulty or the inability to lift heavy objects such as groceries, camping equipment, or grandchildren,

as well as difficulty performing activities that require repetitive motions with the upper body or arms such as sweeping the floor, painting, or typing (Radina & Armer, 2001; Ridner, 2002). In addition, women report limitations resulting from recommended strategies for managing lymphedema. For example, women are advised to keep the affected arm elevated to reduce swelling or to protect themselves from sunburns, insect bites, injections, or cuts that can produce cellulitis (Radina & Armer, 2001; Ridner). Cellulitis is an acute infection that can be caused by any break in the skin where bacteria can grow. Symptoms include redness, pain, and warmth to the touch (Medline Plus, 2006). Persons with lymphedema are especially at risk for cellulitis because of the presence of stagnant lymph fluid in the limbs creating ideal conditions for bacteria to thrive (Lymphnotes, 2006). Furthermore, to reduce and control swelling associated with lymphedema, women are encouraged to practice a special kind of massage called manual lymph drainage (MLD), wrap the arm with several layers of elastic bandages or wear an expensive custom made compression sleeve. Not only is this treatment restricting in terms of range of motion, but it also imposes other restrictions. For example, a woman must set aside time during the day to perform MLD and may have to ask others for help. She must also avoid getting the wrapping wet and therefore has to remove the wrapping and rewrap the arm for bathing or other water activities. Finally, because the compression sleeve is so expensive and must be washed by hand everyday, she has to be careful not to stain or otherwise damage the sleeve (Casley-Smith, 1992).

In addition to limitations, women with lymphedema are subject to potential psychosocial problems including depression, anxiety, poor adjustment to illness, and low self-esteem (Maunsell, Brisson, & Deschenes, 1993; Thomas-MacLean et al., 2005). The limitations and psychosocial difficulties frequently require the individual and her family to renegotiate family roles and modify how they function as a unit (Radina & Armer, 2001, 2004). This may include a redistribution of household responsibilities (e.g., asking her adult son to help her husband move furniture that she would have otherwise done herself or employing a maid service to do the vacuuming) or the modification of how and if such responsibilities are undertaken

(e.g., lowering standards of household cleanliness, learning to use the other arm to paint the bathroom) (Radina & Armer, 2001).

#### *Family Leisure and Women with Lymphedema.*

The colloquial phrase “the family that plays together stays together” implies that family interaction in the context of leisure (i.e., play) enhances the family’s ability to remain stable (Orthner & Mancini, 1990). There is a positive relationship between family leisure engagement, family satisfaction, and family quality of life (Zabriskie & McCormick, 2003). A useful way to understand the impact of lymphedema on family leisure and ultimately family functioning is the Core and Balance Model of Family Leisure Functioning (Zabriskie, 2000; Zabriskie & McCormick, 2001). The Core and Balance model, like the Circumplex Model of Marital and Family Systems (Olsen, 1986) on which it is based, posits that families are self-regulating systems whose goal is to establish and maintain balance in response to changes occurring both within and outside the family system (White & Klein, 2002). Specifically, these models suggest that positive family functioning is achieved through a balance of family cohesion (i.e., closeness, emotional bonding) and family adaptability (i.e., the family’s ability to be flexible and change), and is maintained through family communication. The Core and Balance model argues that family adaptability, cohesion, and communication are facilitated through family members’ joint engagement in family-based leisure activities (Zabriskie & McCormick, 2001).

The Core and Balance Model further categorizes distinct types of family leisure activities that contribute to family functioning. Core leisure activities are “common everyday, low-cost, relatively accessible, and often home-based activities that families do frequently” (Zabriskie & McCormick, 2003, p. 168). For example, core activities may be watching a movie, playing a game, family dinners, e-mailing or instant messaging with family members, grandparents babysitting for or playing with grandchildren, making dinner together, and informal and spontaneous conversations (Zabriskie & McCormick, 2001). Families who perceived themselves as having high levels of emotional closeness tend to engage in more of these types of activities (Zabriskie, McCormick, & Austin, 2001). By contrast, balance leisure activities are “less

common, less frequent, more out of the ordinary, and usually not home based thus providing novel experiences” (Zabriskie & McCormick, 2003, p. 168). These may include family travel, outdoor activities (e.g., water skiing, hiking, camping), family reunions, and special events (Zabriskie & McCormick, 2003). Families’ engagement in these kinds of activities is related to perceptions of family adaptability (Zabriskie et al.). According to the Core and Balance Model, families who participate in both core and balance activities have healthier family functioning because of increased levels of communication that enhances family cohesion and adaptability (Zabriskie & McCormick, 2003).

Leisure time with family also contributes to individual experiences of mood, life satisfaction, and quality of life. Engaging in a variety of leisure activities helps in encapsulating and facilitating companionship, improved perception of sense of control, reciprocity and exchange, intellectual stimulation, and buffers against health-related effects of aging (Purcell & Keller, 1989; Rowe & Kahn, 1998). Social participation and connection to others allow for the development of emotional connections or emotional support networks (Rowe & Kahn). For example, Stone (1987) found that engaging in family leisure activities is a predictor of individuals’ reports of positive mood.

The role that family leisure plays generally also applies to families in which there is a chronically ill or disabled member. Guerin and Dattilo (2001) found that, for these families, participation by family members in shared leisure time is associated with enhanced family communication and stability. Despite this relationship, taking part in balance activities (e.g., outdoor recreational activities) has been found to be less likely in families with a disabled member (38%) compared to families without a member with a disability (52%) (Jo, Kosciulek, Huh, & Holecek, 2004). Certainly, the physical and time limitations of managing the often disabling condition of lymphedema can have an impact on nonleisure-based daily activities (e.g., housework, personal care) (Radina & Armer, 2001); however, for individuals with disabilities, the benefits of leisure activities have been well established (Jo et al.). These benefits include increases in self-confidence, social networks, and one’s sense of accomplishment and satisfaction (Lloyd, King, Lampe, & McDougall, 2001).

For women in particular, participation in leisure activities in general, whether engaged in individually or with their families, may act as a buffer against stressful life events such as breast cancer and breast cancer-related lymphedema (Pondé & Santana, 2000). Thus, the continued participation of women with lymphedema in family leisure activities appears valuable for sustaining women's quality of life after breast cancer treatment. It should be noted, however, that research regarding women and leisure indicates that family members can actually function as impediments to women's individual leisure choices (Stalp, Radina, & Lynch, 2008). For example, women as wives and mothers are often responsible for family management, which includes the creation of time and space for other family members' independent leisure activities (e.g., doing the grocery shopping for her husband's football party, driving children to dance lessons). Because of these other responsibilities, women's independent leisure is often sacrificed so that they can accomplish these other tasks for their families (Henderson, Bialeschki, Shaw, & Freysiner, 1999).

Family leisure is important for understanding family functioning (Zabriskie & McCormick, 2001), particularly in the context of chronic health conditions and health-related disabilities (Jo et al., 2004). Lymphedema can create serious limitations that can affect both family functioning and participation in leisure. Examining the specific impact of family leisure activities is just one way in which family functioning in the context of lymphedema can be explored. Thus, the focus of this article is on the lived experiences of participants who described changes in their participation in family leisure as one of the many ways the development of lymphedema has affected their daily lives in the context of their families.

## METHOD

### *Participant Recruitment and Rationale*

Participants who had been diagnosed and treated for lymphedema resulting from breast cancer treatment were recruited via (a) breast cancer and lymphedema support and advocacy groups, (b) Internet discussion board postings, (c) articles and recruitment notices in newsletters circulated to breast cancer survivors, and (d) referrals from participants who had taken part in this study.

Women were intentionally sought who lived throughout the United States and who represented various ages and lengths of time living with lymphedema. Data were not kept as to the source of recruitment for each individual participant. Despite this, an estimated 70% were recruited through Internet discussion boards and referrals from other participants. All those who expressed an interest in participating met the eligibility criteria and were invited to participate. No participants expressly refused to participate after being invited. Approximately five to seven women who initially were invited to be interviewed did not participate. This was primarily because of personal time constraints on the part of the participant or the participant having moved and not provided the researchers with updated contact information.

### *Participants*

Participants ( $N = 27$ ) were primarily White ( $n = 26$ , Hispanic = 1) and ranged in age from 40 to 78 years ( $M = 59.5$  years). Participants were geographically dispersed, with five living in the South (FL, KY, MD, NC), four living in the Northeast (CT, MA, NJ, PA), nine living in the West (AZ, CA, ID, NM, SD, WA), and nine living in the Midwest (IA, IN, MI, MO, OH). Twenty-four were married, two were divorced, and one was single. All were well educated, with an average of 15.8 years of formal education (range = 12–25 years). All but one participant had children; two had minor-aged children living at home, whereas the remaining participants' adult children lived independently from participants' dwellings. Two participants were providing in-home care to their aging parents. On average, all participants were 5.7 years past their breast cancer diagnosis (range = 7 months to 20 years) and 4 years past their diagnosis of lymphedema (range = 3 months to 16 years).

### *Research Team*

Data collection and analysis took place over a 4-year period. During this time, the author served as the principal investigator and enlisted the participation of undergraduate ( $n = 11$ ) and masters level graduate students ( $n = 3$ ), two of whom had mothers or grandmothers or both who were breast cancer survivors. The undergraduate students were between the ages of 18 and 22 and all were from the fields of family studies/services,

women's studies, or psychology. All student coinvestigators completed coursework in basic research methods, and the author provided specialized training regarding data collection and analysis methods, including how to deliver the interview protocol. The author is a doctoral-trained qualitative researcher with a background in human development and family studies, nursing, and family and community medicine and has conducted research and volunteered with breast cancer and breast cancer-related lymphedema populations for 9 years.

### *Data Collection*

Each participant took part in one interview lasting between 45 and 60 minutes. For nine participants, face-to-face interviews were conducted, whereas for the remaining 18, interviews took place over the telephone. Interviews were conducted by either the author or student members of the research team. Each interview was recorded and transcribed before data analysis. The interviews were designed to explore five topics regarding the participants' experiences as they made the transition from family caregivers to, quite often, the recipient of family care. These topics were as follows: (a) personal information, (b) descriptions of participants' lifestyles before and after the onset of lymphedema symptoms, (c) perceptions of functional and psychological independence, (d) relationships with others, and (e) personal coping (see the Appendix).

### *Data Analysis*

Although a total of 14 student research assistants contributed to data collection and management over the course of this study, only five participated in data analysis for this article. Data were analyzed using a cooperative, inductive approach that began with the research team (the author and five student research assistants) individually reading through the entire data set and making note of recurrent ideas expressed by multiple participants (Hill, Thompson, & Williams, 1997; Patton, 2002) with specific focus on the influence lymphedema has on familial relationships. More specifically, the research team read through each transcript, considering how the participant talked about her lymphedema and its implications for her family relationships. This use of consensual qualitative research (CQR), involving data collection and analysis by a team

of researchers, provided triangulation and thus enhanced the dependability of the data analyses (Hill et al.). In addition, this approach to data analysis was chosen to accomplish two goals that allowed for (a) the emergence of important aspects of how participants' perceived changes in their interactions with their family members related to lymphedema and (b) the author to work collaboratively with students of qualitative research to provide them with hands-on research experiences.

Consistent with the description of CQR by Hill et al. (1997), the research team individually read through the data set and then met so that members could present their thoughts about recurrent ideas to the rest of the team. Through these presentations and subsequent discussions, consensus was reached among the research team on dominant themes about lymphedema and implications for family leisure activities. Once themes were identified, specific team members returned to the data to clarify subthemes by identifying evidence within the data.

### *Data Quality*

Several steps were taken both before and during data collection and analysis to ensure the trustworthiness and quality of the data and its analysis. First, because the approach to data collection for this study involved the use of a semistructured interview guide, some variability in the structure of the interviews across research assistants is to be expected. To encourage as much uniformity as possible, the author provided all research assistants with the same training on how to complete the interview. Throughout data collection, the author periodically reviewed the transcripts for these interviews to ensure that relative consistency in the interviews existed and provided retraining with research assistants when necessary. Second, the research team acknowledges, as is consistent with qualitative research philosophy, that no research is entirely objective (Morrow, 2005). The credibility of these data and findings was enhanced because of the research team's ability to establish rapport with participants. This was at least partially based on the participants' awareness of the author's extensive experience with women living with breast cancer-related lymphedema and work with local breast cancer communities (e.g., volunteer work with a local breast cancer lymphedema support and advocacy group).

In addition, the findings for this study were reviewed by a qualitative health researcher who was not involved in the study to provide feedback and verify the findings.

Transferability (i.e., external validity or generalizability) was established using detailed descriptions in the presentation of these findings (Morrow, 2005). This includes the clear and detailed description of the research team, data collection, analysis processes, and participants. It is inappropriate in qualitative research for researchers to claim far-reaching generalizability of their data (Morrow). Thus, great care has been taken to avoid overgeneralizing in the presentation of the findings. Accordingly, readers are encouraged to judge whether and how these findings generalize to other populations, contexts, or situations (Gasson, 2004).

Dependability (i.e., reliability) was achieved in two ways (Morrow, 2005). First, this criterion of data quality was addressed during data analysis through the inclusion of a multilevel and multidisciplinary research team representing family services/studies, women's studies, and psychology (i.e., the author and graduate and undergraduate students). The composition of this team allowed for triangulation of researchers and the perspectives they brought to data collection and analysis. The same is true for the inclusion of research team members with and without personal experience with breast cancer in their families. Following their independent reading of the entire data set, the author and five student members of the research team met to discuss areas of agreement and disagreement regarding themes and subthemes and to resolve any conflicts that arose. The result was clarification of themes and subthemes that each researcher then elucidated by returning to the data set to find examples and nonexamples of the themes and subthemes. Second, dependability of these data and findings was established by continuing to collect data from participants until, through the author's concurrent examination of the data, it was determined that data saturation was reached (Morrow). That is, the author periodically examined the transcripts of completed interviews with special attention to interview consistency across research assistants and degree of redundancy by participants in response to interview questions. When it was determined that few new data (i.e., new ideas, variability in responses) were being generated by the interview guide, data collection was stopped.

## RESULTS

Two issues arose from the analysis of these data. First, participants expressed a keen sense of their physical limitations related to lymphedema. This theme, titled Embodied Limitations, consists of two subthemes: (a) Being Cautious and Aware and (b) Frustration with Physical Dependency. The second issue involved the ways in which participants coped with these embodied limitations. This theme, entitled Patterns of Coping with Limitations during Family Leisure Activities, consists of two coping strategies: (a) stopping participation in family leisure activities that might be dangerous or difficult and (b) making modifications in participation to continue their leisure time with their families.

### *Embodied Limitations*

One aspect of dealing with any chronic or disabling condition is becoming aware of one's physical limitations. The participants described being aware of how their physical abilities had changed as a result of developing lymphedema. We have thus borrowed this term for the purposes of encompassing both awareness and cautiousness about physical limitations but also frustrations with these limitations that these participants expressed.

*Being cautious and aware.* Participants described having a general heightened sense of caution regarding their daily lives and leisure activities in that they did not want to place their bodies in harm's way (i.e., aggravating the swelling, being at risk for developing life-threatening infections). For example, Betty (66, married, 2 years with lymphedema) explained:

I know that I had, I felt like I had to *be careful*. I know that I had limits as to what I could do. And I know that my arm would get tired. For example, if I were doing yard work or raking . . . I don't know what you call it, the worry or the . . . I think it was just tacked on with all the emotional things I had gone through with the breast cancer.

Betty's statement illustrates a common struggle for many women with breast cancer-related lymphedema—the lingering concerns of breast cancer that are connected to the lymphedema. For many women, developing and managing lymphedema served as constant reminders of having gone through breast cancer treatment

and concerns about possible reoccurrence. Thus, it was often difficult for women to see the two illnesses as distinctly separate. Sharon (60, married, 9 months with lymphedema) also explained:

There are some days that my hand bothers me if I am using it a lot. It swelled a lot in the beginning because I do a lot computer work and gardening, that can be kind of painful . . . I do have to be *pretty careful* that I don't get too tired. Sometimes if I do too much, I just kind of have a little meltdown and spend a couple days really resting. That's new to me and I do not particularly like that either. I don't like to pace myself.

In addition, both Betty and Sharon mentioned having to be careful about not becoming overly fatigued.

*Being frustrated with limitation.* This heightened sense of awareness and cautiousness was coupled with general frustration with their embodied limitations. Below, Carol and Kathleen discuss their frustrations with having to engage in self-care that can take their time away from other activities including family leisure. Both women also refer to having to complete massage as part of their self-care routine. This specialized type of massage is called MLD and can either be performed by a physical therapist (preferably a certified MLD therapist) or the individual. Carol (57, married, 2½ years with lymphedema) explained:

There are mornings that I just resent having to do the massage in order to put the sleeve on before I can start my day. There are times that I would just like to hop out of bed and be on the go. But I have to allow time to, to attend to my arm and get the sleeve on . . . I can't just start something without having done that first.

Kathleen (55, married, 2 years with lymphedema) expressed a comparable sentiment regarding having to do the MLD, "It gets to be a little bit bothersome when most people can take a shower and read or go to bed and or watch TV and go to bed and I've got to sit here and do this 20–30 minute massage." Betty and Kathleen expressed their frustration with the time they must put in to self-care that they could otherwise spend doing other things (i.e., starting the day, watching TV). This is time that they

perceive others without lymphedema would be able to devote to other pursuits.

In addition to being time consuming, participants also expressed frustration with the cumbersome nature of the supplies and equipment need for their self-care. For example, Susan (50, married, 3 years with lymphedema, minor children in the home) explained:

One thing I noticed is that flying is difficult with lymphedema. You know, going to visit relatives on the West Coast, because of the lymphedema, has been difficult. You have to package and carry all that extra stuff with you, and the equipment. It's really time consuming. To pack you up and wrap you, and do the massage and the machine and all that stuff. It's just a lot more time out of my life to take care of it. I like things simple [laughs]. It's complicated, wrapping it up and everything.

In addition to this frustration with self-care, participants also discussed how their need to be careful had spilled over into their leisure activities with their family members. Specifically, this meant having to make such accommodations as asking for help from others. Participants described how this new need to depend on others was especially frustrating. Mary's (60, married, 3½ years with lymphedema) experience was that her concerns about aggravating her condition have limited her activities in that she does not want to ask for help or be a burden to others:

I used to scuba dive, and I don't anymore. Even though I know scuba diving would help my lymphedema I just have a hard time asking my husband to not only lug his big heavy equipment, but my very heavy equipment too, because that's a lot of work. It is also hard for me to get in and out of boats. If they have a ladder its fine, but if I have to hoist myself up, I just can't do it.

Donna (63, married, 6 years with lymphedema) expressed similar concerns about having to be dependent on others to be able to participate in leisure activities with her granddaughter:

I was trying to get back into driving [following a rotator cuff injury] just before my lymphedema hit and that's probably the worst thing it's done for me because I can't drive and I can't pick her [granddaughter] up at nursery school. I can't drive her to different places. I can't do my own shopping. I am dependent on pretty much on my husband to do almost all of my . . . to drive me

around or go shopping or take me to doctor's and things like that.

With regard to the Core and Balance Model of Family Leisure, many of the participants who described being cautious and aware expressed frustration with being dependent on others for help with core activities (e.g., yard work, shopping, driving) more so than with certain balance activities (e.g., scuba diving and traveling).

### *Patterns of Coping With Limitations During Family Leisure Activities*

For many participants, this struggle with embodied limitations carried over to leisure activities, particularly those who previously engaged in these activities with family members (e.g., golf, backpacking, water skiing, traveling, lifting grandchildren during play). Participants appeared to cope with their limitations in two ways: modifying how they participated in the activity or no longer doing the leisure activity. These two subthemes are described below.

*Modifying participation in leisure activity.* Participants who did not want to or did not perceive the need to stop participating in certain family leisure activities as a result of their lymphedema described ways in which they modified their participation. These modifications involved changing or rethinking their participation (i.e., getting different equipment, planning how they will participate more carefully). Patricia (56, married, 1 $\frac{3}{4}$  years with lymphedema) explained how her love of camping and outdoor activities prompted her to rethink how she could still participate and accommodate for her limitations:

I do just about the same things, only I have to be very careful . . . I have to plan things more carefully, like I am going to be going on a backpacking trip for a week in the end of September and I have to really be careful about how much I carry in my pack. I've spent quite a lot of money getting light weight sleeping bags, real state of the art light stuff, because I really worry about the possibility that my arm could, my lymphedema could be made worse.

Nancy (60, single, 13 years with lymphedema) was also an avid camper and, like Patricia, has looked toward the use of special equipment to help her continue to participate.

I do [sigh] . . . I have done a lot of camping and outdoor activities with my kids as they were growing up and with friends as my kids have left. I like hiking and . . . I was just a single parent with several kids around so I did a lot of activities around doing things with the kids. I just do things differently [now]. I have an over-sized fanny pack instead of a backpack that I use . . . That's probably the biggest difference is that I just don't carry a pack at all. And I'm more careful about what I lift. [long pause] I was not able to do some of the activities such as backpacking trips as an adult advisor with their group. Because I couldn't carry a backpack. So I switched to being involved in different kind of activities with them . . . I was troop treasurer instead of backpacking.

Modifications of how participants engaged in leisure activities with their families extended to the realm of grandparenting. When Carol (57, married, 2 $\frac{1}{2}$  years with lymphedema) takes care of her grandson, she has learned how to still play with and take care of him and avoid aggravating her condition at the same time:

I've tried to not let it [lymphedema] influence the other things that we would normally do. And I'm fortunate enough. I have a new grandson that I provide some daycare occasionally. And I just make sure I have my sleeve on to be able to attend to him and not adversely affect my arm.

Carolyn (59, married, 7 years with lymphedema) was also a grandmother and has determined that even though she can no longer lift her grandchildren, she can still cuddle with them. She just has to cuddle a little differently than she used to.

I'm still playing the same roles [in the family]. Maybe I've modified those roles just a little bit. I like to be a loving grandmother. I'd like to reach down and lift up my little granddaughters, but I do not do that. I modify my actions. I go down to their level and give them or a hug or a squeeze. I just explain to them that I cannot lift them up and they seem to be fine.

*Not doing the leisure activity.* The second way that the participants talked about coping with limitations to their participation in family activities was to stop participating in specific activities they found difficult or felt aggravated their condition. Donna (63, married, 6 years with lymphedema) explained how being unable to travel had limited her ability to visit her



children and grandchildren. This was something that Donna perceived as being a new barrier to her relationship with her family.

I can't carry luggage. I can't, in fact, getting in plane would aggravate the situation. They're saying you have to bring all your stuff with you on the plane. If you are ever going to fly you have to be very careful because it [the swelling] can get much worse just being on a plane [due to changes in cabin pressure]. . . . I can't really travel anymore.

Judith (56, married, 6 years with lymphedema) expressed her feeling that because she can no longer do certain athletic activities with her family, she is missing opportunities for interaction.

The lymphedema's negative impact has been; we used to play volleyball all the time, my husband and I, and now I'm afraid to play volleyball, for fear I will hurt my arm. I don't play volleyball, and now I found out that I can't water ski. . . . [laughing] That was something that I didn't do very often, but it does make me angry that I can't, you know that I lost.

Susan (50, married, 3 years with lymphedema, minor children in the home) explained that because she can no longer walk for long distances or carry heavy things, like shopping bags, her interactions with her children have been limited.

I can't walk long distances or carry anything. Like shopping with the kids and everything, I can't do all that. Can't play the games and stuff like that that they'd like me to do. Plus, for some reason, I thought it was the cancer, but people have told me it's probably more the lymphedema than anything that is tiring me out . . . We go camping a lot, and I don't like to go camping because I can't do that stuff. We used to go boating and all kinds of outdoor activities. Even if we go for a hike in the woods, my arm swells up from being down. I feel like, it's weird, but I'll have to hold my arm up in the air when I go. You know, take the kids like to Disney World, I have to have my arm propped up a lot. Or if it's down all the time while we're doing things, it's just really bad, it's just swelling up.

Two participants described having removed themselves from the physical aspects of family activities they once enjoyed because of limitations from lymphedema. Carol (57, married, 2½ years with lymphedema) described

how she has taken herself out of activities she once enjoyed because of the lymphedema.

There are times that I decline invitations to do certain things. I don't hike when we're camping. People do, and there's always a hike planned, and so forth, and I don't feel comfortable being exposed to the sun and the heat that much. And knowing at the end of the day, my . . . my arm would be real fatigued . . . The lymphedema has of course, affected what I do as far as outdoor activities . . . I no longer water ski. I was doing well at water skiing for my age. [laughing] And uh, to know that I probably shouldn't put that extra exertion on the arm. I just have to say "okay, that's as good as I'm I'll get." That's the end of my participation in that activity.

In contrast to Carol, Carolyn (59, married, 7 years with lymphedema) described a situation in which she could not participate in an activity but rather than not participate at all, she had her daughter stand in as a proxy for her. In this way, she was not actually doing the activity but the activity was able to be completed.

One of the things I like to do, my husband likes to make flour tortillas and he rolls them out. I used to do that too. One time when I did that I noticed the lymphedema would be worse immediately after that. The pressure from pushing down with the palm of my left hand seemed to cause the swelling to reappear. Since then I've decided I'm just never going to do that again at least not with that hand. In a real minor way that has affected our ability to invite guests over and maybe fix an entire meal where we would both help with the preparations. More recently, last weekend, we had a party for the high school wrestlers at the end of the season and we were invited to come and make chimichangas for the whole bunch. Where normally he and I would be the one rolling these out, I could not do that so, we had to hunt around and find somebody else which turned out to be our daughter volunteered as a replacement for me because I could not do the rolling because of the lymphedema. I know that's a real minor thing, but it's an example of how it's affected the people around me.

## DISCUSSION

Up to 20% of women who are treated for breast cancer develop breast cancer-related lymphedema. This chronic and often disabling condition has been found to have an impact on both individual and family quality of life (Radina & Armer, 2001, 2004; Stalp et al., 2008).

Because the prevention, treatment, and physical limitations of lymphedema are time consuming and cumbersome, many women find their lifestyles must be modified in some way to cope (Radina & Armer, 2001). The findings from this study suggest that lifestyle modifications extend beyond daily activities such as dressing, bathing, cooking, and housekeeping into the realm of family leisure. Research has established the important role that individual and family leisure play in personal and family coping, especially for those who are coping with a disabling or chronic illness (Guerin & Dattilo, 2001). Thus, the exploration of family leisure in the context of lymphedema as a chronic illness delves into areas of both family leisure and quality of life with lymphedema that have not been addressed empirically before. In exploring family leisure engagement as one indicator of family functioning, this study expands current knowledge about how families may be affected by this specific condition. At the same time, these findings may also provide insight into the role that family leisure can play for families coping with other chronic conditions and potentially disabling conditions (e.g., fibromyalgia, multiple sclerosis).

Using a cooperative, inductive approach to the analysis of qualitative data, two themes were identified. *Embodied limitations*, the first theme, consists of a heightened sense of awareness and caution among these women concerning their physical activities as well as a sense of frustration with the limitations women face as a result of the lymphedema. Ferrans (1997) described this aspect of quality of life as embodied limitations. This term has also been used by Bethune-Davies, McWilliam, and Berman (2006) to describe women coping with chronic and disabling conditions. These findings are consistent with those identified elsewhere using these data (Radina & Armer, 2001, 2004) but provide more in-depth exploration into how these feelings specifically affect self-perception of physical abilities, with specific emphasis on how these self-perceptions may related to opportunities to engage in leisure time with the family.

*Patterns of coping with limitations during family leisure activities*, the second theme identified in this research, took two primary forms. The first of these involved continuing to participate in family leisure activities but with extra care (e.g., purchasing lightweight hiking equipment) and also being creative about how to participate (e.g., becoming the scout troop

treasurer rather than accompanying children on backpacking trips). Those participants who reported coping in this way appeared to take the lifestyle changes in stride. The attitude was more, "So what? I will just have to do it another way" rather than "That is the end of that." The second strategy for coping with changes in lifestyle was to withdraw from family activities. Specifically, the Core and Balance Model would argue (Zabriskie et al., 2001) that withdrawing from family leisure activities could jeopardize overall levels of family functioning by eliminating opportunities for building or improving family adaptability, cohesion, or communication.

Regardless of how participants chose to cope with their embodied limitations, be it modifying the family leisure activities or by disengaging from them, most described experiencing limitations with regard to core family leisure activities (e.g., travel, waterskiing, camping, cooking for special occasions). These can be considered core activities because, on the basis of the stories of these participants, it can be assumed that engaging in these types of activities were pretty typical for their families. Zabriskie et al. (2001) argued that those families who engage in core activities have greater capacity for adaptability. Thus, one interpretation of how the limitations on core activities may affect family functioning is that those who have this greater capacity for adaptability may be more resilient with regard to coping with changes brought on their lymphedema. In fact, many of these participants appear to be rather resilient in the ways they cope with their embodied limitation. One explanation for this resiliency is offered elsewhere by Radina & Armer (2004), who examined the outcomes of women with breast cancer-related lymphedema, within the context of their families using the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993; McCubbin, Thompson, & McCubbin, 1996). They found instances where participants described themselves and their families as either adjusting (i.e., making small changes in family patterns of functioning to cope with lymphedema), adapting (i.e., making major changes in family patterns of functioning to cope with lymphedema), or living in crisis. Specifically, those families who were resilient had a family appraisal of the limitations brought on by lymphedema as manageable and something that could be incorporated into patterns of daily living. At the same time, the more resilient families

pulled together as a family to make necessary changes (e.g., the entire family focusing on the lymphedema and supporting the patient, the patient or her spouse changing jobs, using humor and inside jokes). Thus, although Radina & Armer (2004) offered some explanation of how resiliency in these families might be understood, this study describes a unique focus on family leisure as one specific aspect of family functioning. Certainly, for the women described in this study, those who made changes in the way they participated in family leisure could be classified as either adjusting or adapting rather than in crisis. This ingenuity and perseverance demonstrates how women with breast cancer-related lymphedema can be resilient in coping with their conditions not only in their daily family lives but in specific family activities involving leisure.

This study extends Zabriskie and McCormick's (2001, 2003) Core and Balance Model of Family Leisure Functioning by focusing on family leisure experiences in the context of chronic illness. Previous research has found that participation in balance activities (e.g., water skiing, camping, traveling) was less likely in families where a family member has some sort of physical disability (Jo et al., 2004). Although there is a wide range in the degree to which lymphedema presents as a physical disability, it appears from these data that women with lymphedema experience strains on both balance and core activities (e.g., gardening, grandparents babysitting for or playing with grandchildren, making dinner together). Specifically, participants described being more aware of and cautious with their bodies and the impact activities may have with regard to core activities, many of which they continued to do in modified or limited ways. With regard to balance activities, participants described stopping or limiting their participation in these activities. This suggests that findings by Jo et al. (2004) may transfer to families who are coping with a member's lymphedema.

Study findings may also extend Zabriskie and McCormick's (2001, 2003) argument that there is a relationship between families' participation in balance activities and family members' perceptions of family adaptability. For these participants, the most frequently cited activities for which they needed to consider their participation were balance activities. Future research could address how women in families where participation in balance activities is related to more positive perceptions of family

adaptability are affected by changes in their ability to take part in those types of activities. Although this issue is beyond the scope of the data collected here, it is deserving of additional research attention.

### *Implications for Practice*

It seems that for some women who participated in this study, management of their lymphedema resulted in either reducing or eliminating their participation in family leisure. As a consequence of this, family functioning was potentially compromised. Thus, allied health professionals (e.g., family life educators, social workers, family therapists, and physical therapists) interacting with women with lymphedema and their families need to stress not only prevention and treatment but also the important role of family leisure activities in maintaining family cohesion and adaptability. Certainly, this is an opportunity for family life educators and family therapists to help these families work together to continue participating in family leisure despite one family member's new physical limitations. This may include educating the woman and her family members on how to deal with family crisis such as learning to make changes to family roles and responsibilities not only in terms of leisure activities but in daily family life as well. In addressing the needs of this population, physical therapists may also be important resources for women and their families, given that breast cancer survivors cite physical therapists as their greatest source of information about lymphedema (Bosompra et al., 2002). Physical therapists should help women develop solutions for adapting equipment and teaching how to make necessary physical adjustments. At the same time, physical therapists need to consider the social context in which women may be engaging in leisure and help the women and their families develop ways they can adapt as a group to encourage continued participation. Social workers can also play a role in assisting these families by helping them connect to programs that can help families cope including family life education programs, finding adaptive equipment, and identifying recreational therapy programs that the family can take part in together. For example, studies have found that recreational therapy programs (e.g., family camps) that involve family members have a positive effect on family quality of

life (Zabriskie, Lundberg, & Groff, 2005). It may be beneficial for some women and their family members to participate in specific camps that can help them not only enjoy the shared leisure activity of camping and other outdoor activities but learn how to adjust to limitations on those activities. Such experiences have been shown to improve family interaction and nurture relationships among family members (Agate & Covey, 2007).

#### *Limitations and Directions for Future Research*

These results, of course, should be considered with regard to several potential limitations. First, the greatest limitation is that data were not collected regarding the severity of the woman's lymphedema and specific symptoms they regularly experienced. Knowledge of this information is certainly relevant for understanding potential relationships between the woman's degree of physical limitations, their ability to participate in certain family leisure activities, and their motivation for coping with changes in leisure activities with their family members. Future research would benefit from clinical observations (e.g., measurements of arm circumferences), use of symptom measurement instruments (e.g., Lymphedema Breast Cancer Questionnaire; Armer et al., 2003), and in-depth interviewing regarding women's participation in family leisure activities and coping with changes in their ability to participate.

Second, the majority of the participants for this study were middle-aged, White women. Given that family leisure activities and expectations for women's participation in these activities may differ in terms of cultural and subcultural values (Walker, Deng, & Dieser, 2001), future research should seek to investigate these issues with a more culturally and ethnically diverse sample. At the same time, no male participants with lymphoma were included in this study. The main reason for this was that less than 1% of men are diagnosed with breast cancer. This small number combined with the fact that roughly 20% of individuals who are diagnosed with breast cancer even develop lymphedema would make finding sufficient numbers of male participants challenging. Despite this, future research may want to explore how the lives and families of males with breast cancer-related lymphedema are affected.

Third, the focus of this study was on the perceptions of women with breast cancer-related lymphedema within the context of their families. To gain a more complete understanding of the ways in which families are affected by lymphedema, future studies should investigate the perspectives of family members. Finally, this study did not address types of lymphedema (e.g., leg or trunk lymphedema) other than those resulting from breast cancer treatment. This is a concern as women with breast cancer-related lymphedema have commented that it is difficult to separate lifestyle changes resulting from breast cancer from those resulting from lymphedema (Radina & Armer, 2001). Thus, it maybe unclear as to why these women experienced changes in their participation in family leisure activities, despite the fact they there specifically asked about changes they attribute to the onset of lymphedema. Future research with primary lymphedema of the arm (i.e., congenital) or secondary lymphedema (i.e., resulting from some trauma to the lymph system) in other areas of the body will help further elucidate relationships between lymphedema and family leisure activities.

#### CONCLUSION

These findings further empirical understanding of the ways in which lymphedema can influence women's familial relationships in terms of the leisure time spent with family members. These findings may be used by family life educators and health care professionals to assist women and their families in modifying how they engage in leisure activities and exploring new such activities that will allow them to continue participating in this way with their families.

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## APPENDIX

Topic	Questions
Personal information	<ul style="list-style-type: none"> <li>• Demographics (age, marital status, education, racial/ethnic background, number and ages of children, number and ages of others who are co-residing, years since breast cancer diagnosis, years since lymphedema diagnosis).</li> <li>• To begin, tell me about your experience with lymphedema.</li> <li>• What current treatment are you undergoing to control/manage your lymphedema?</li> </ul>
Descriptions of participants' lifestyles before and after the onset of lymphedema symptoms	<ul style="list-style-type: none"> <li>• What activities/responsibilities did/do you participate in (e.g., employment/volunteering/hobbies)?</li> <li>• Did you work outside the home? If yes – [What did you do?] What did your job entail?</li> <li>• What roles did/do you play in the lives of others (e.g., mother/caregiver/sister/ group leader)?</li> </ul>
Perceptions of functional and psychological independence following the onset of lymphedema	<ul style="list-style-type: none"> <li>• Do you feel that having lymphedema has created situations for you in which you have to ask others for help to complete tasks that you would otherwise have completed on your own? If yes – How do you feel about having to make these changes?</li> <li>• What changes, if any, have you made in order to complete your daily activities (e.g., housework, paid work, etc)? If yes – How do you feel about having to make these changes?)</li> </ul>
Relationships with others	<ul style="list-style-type: none"> <li>• How do you feel changes in your ability to complete daily tasks has affected [the lives of] others in your life, if at all (e.g., are you able to do more or less for them)?</li> <li>• Some women with lymphedema that we have talked to say they feel like a burden on others because of their increased need for assistance. How do you respond to this?</li> <li>• How has lymphedema impacted your sexual relationship with your partner/spouse? Why?</li> </ul>
Personal coping	<ul style="list-style-type: none"> <li>• What things do you do/have you done that help(ed) you in adjusting to living with lymphedema?</li> <li>• What advice would you give to other women who either have lymphedema or have just been diagnosed?</li> </ul>