

Post-Breast Cancer Lymphedema: Understanding Women's Knowledge of Their Condition

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Purpose/Objectives: To investigate chronic condition representations and treatment choices among women with post-breast cancer lymphedema (LE) to understand their receipt and use of accurate medical information.

Design: Qualitative, template analysis.

Setting: Midsized midwestern city and surrounding rural areas.

Sample: 18 Caucasian women aged 37–87 years ($\bar{X}$ = 58.8 years) with LE.

Methods: Telephone and face-to-face interviews, lasting 45–60 minutes, were conducted by research students and graduate nursing students. Interviews were audiotaped, professionally transcribed, and verified for transcription accuracy. Self-regulation theory as a template was applied to (a) understand participants' use of health information to cope with LE and (b) evaluate the accuracy of participants' health information that may have influenced participants' abilities to make appropriate prevention or treatment choices.

Main Research Variables: Participants' illness representations and coping strategies.

Findings: Participants were aware of the fundamental cause of their LE—breast cancer treatment. They also were conscious of other causes of symptom onset. These causes are supported by existing empirical evidence. Participants' treatment choices were consistent (e.g., use of compression treatment, massage, elevation, pumps, therapists and therapy centers, and positive attitude and faith) and inconsistent (e.g., effectiveness of exercise and medication in management of LE) with empirical evidence.

Conclusions: Future research and practice should target the role of exercise as a cause of LE and as a treatment option, investigate allergic reactions as a possible catalyst of LE symptoms, work to improve diagnosis of LE and patient education, and examine the effectiveness of medications as a treatment method.

Implications for Nursing: Review of LE risk factors in the postoperative period and continued assessment and education are vital to a comprehensive approach to post-breast cancer LE care.

Key Points . . .

- Ignorance about the symptoms of lymphedema (LE) among medical professionals has led to the use of inappropriate or inadequate courses of treatment; this is evident because not enough treatment centers, certified LE therapists, and other medical professionals are prepared to treat LE.
- Among patients with breast cancer, those who receive radiation therapy or surgical resection of axillary lymph nodes are at the greatest risk for developing upper-extremity LE.
- Patients may not be knowledgeable about effective LE treatment, such as complex decongestive physiotherapy, which involves manual lymphatic drainage, skin care, compression, and exercise to decrease limb volume.

use of inappropriate or inadequate courses of treatment (Földi, 1998). Presently, the United States does not have enough treatment centers (currently 158), certified LE therapists (currently 357), and other medical professionals who are prepared to treat LE (Lymphology Association of North America [LANA], 2002; National Lymphedema Network [NLN], 2002b; Rinehart-Ayers, 1998). Others have argued that patients' unawareness about LE is a result of the method and timing of post-breast cancer LE risk communication (Passik & McDonald, 1998).

The focus of the present study is the accuracy of patient knowledge about LE. Specifically, research has suggested that many women with LE do not know or understand the risk of LE, what caused their LE, and how to treat LE (Radina & Armer, 2001; Thiadens et al., 2002). Self-regulation theory guided the development of the research question for this study: What do the chronic condition representations and management choices of patients with LE indicate about their knowledge of accurate medical information and their use of this information?

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Increasing numbers of women are surviving breast cancer as a result of innovations in technologies for breast cancer detection and treatment (Ganz, 1999). However, an estimated one-third of women who undergo breast surgery involving the removal or irradiation of the axillary lymph nodes develops secondary lymphedema (LE) of the arm (Chu et al., 1996; Ganz).

Studies have shown that many women who are at risk for developing post-breast cancer LE perceive that they did not receive adequate education about LE at the time of surgery (Thiadens, Armer, & Porock, 2002; Woods, 1993). Runowicz (1998) argued that this might occur because most healthcare providers do not receive formal training about LE risk, prevention, and treatment. This has resulted in worldwide ignorance about LE symptoms, leading to late diagnosis and the

Background

What Is Lymphedema?

Upper-extremity LE following breast cancer develops as a result of a mechanical disruption of lymphatic drainage, causing lymph fluid to collect in the subcutaneous tissues of the affected extremity (Olszewski, 1991; Whitman & McDaniel, 1993). A blockage in the transport of lymphatic fluid results in the buildup of fluid in the surrounding tissue and along the length of the arm (Lockhart, 1999; Passik, Newman, Brennan, & Holland, 1993). Among patients with breast cancer, women who receive surgical resection of axillary lymph nodes or radiation therapy are at the greatest risk for developing LE (Passick et al.). LE may develop within weeks or up to many years following breast cancer treatment.

Women typically notice swelling in the arm or fingers, which may progress to a pitting edema or develop into firm, thickened skin (Paskett & Stark, 2000; Whitman & McDaniel, 1993). Other symptoms include numbness, stiffness, or pain in the affected area (i.e., hand, arm, shoulder, neck, chest, or back) and reduced range of motion (Davis, 1998; Passik et al., 1993). LE often results in frustrating physical limitations and subsequent psychosocial obstacles for those who are affected (Armer, 2002; Radina & Armer, 2001).

Current medical literature contains many possible, but few definitive, treatment options for patients suffering from LE (Board & Harlow, 2002). Some of the most widely prescribed and used LE treatment options include a special massage and the use of bandages and compression garments. The type of massage most frequently prescribed in the treatment of LE is known as manual lymphatic drainage (MLD) or manual lymphatic therapy. MLD is a gentle massage designed to increase lymphatic flow in the affected limb and move excess fluid into the trunk (Casley-Smith, Boris, Weindorf, & Lasinski, 1998; Földi, 1998). Bandages often are used as a component of the intensive phase of LE therapy to control and reduce acute swelling, and compression garments are used for control of chronic LE (Brennan & Miller, 1998). One method that currently is accepted as an effective treatment by practitioners and patients alike is that of complex decongestive physiotherapy (CDP), which decreases limb volume by using MLD and compression (bandaging and compression garments) strategies in addition to specialized skin care and exercise techniques. The skin care techniques are performed to help reduce the possibility of fungal and bacterial infections, and the specialized exercises are designed to restore mobility to the joints and rebuild muscle in the affected limb (Casley-Smith et al., 1998; Földi). Potterton (1998) reported that 86% of 299 CDP-treated patients maintained at least a 90% reduction in bilateral limb volume difference over an average of nine months.

Self-Regulation Theory

Self-regulation theory (Leventhal & Johnson, 1983; Leventhal, Leventhal, & Schaefer, 1992) provides a framework for understanding factors that may influence individuals' perceptions of the causes of a chronic condition, the relationship between perceived causes and reporting of symptoms, and how perceived causes influence decision making about self-care behaviors that influence either reporting or ignoring symptoms of chronic conditions. Self-regulation theory, depicted in Figure 1, consists of three stages: representation of

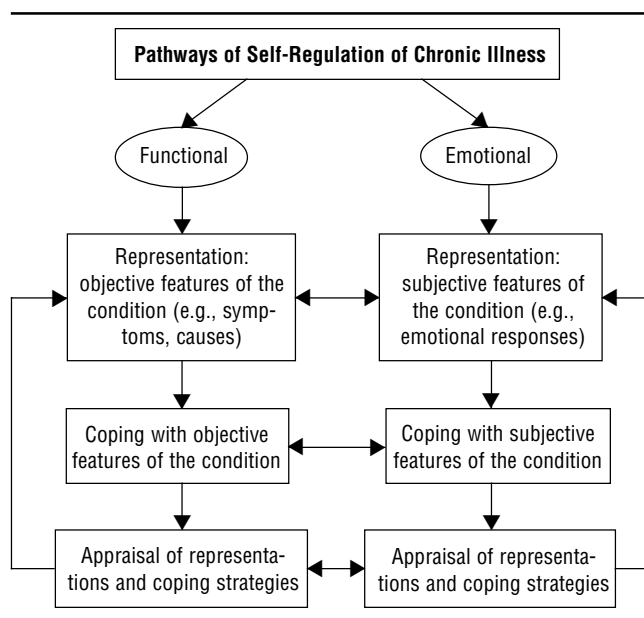


Figure 1. Self-Regulation Theory

Note. Based on information from Jayne & Rankin, 2001; Johnson, 1999.

a chronic condition, coping with a chronic condition, and appraisal of a chronic condition. Representation of a chronic condition includes the experience of symptoms, perceived causes, and beliefs about the duration and severity (e.g., acute, chronic, recurring). Coping involves making plans about how to deal with the chronic condition in response to the person's representations of the condition. Appraisal is the individual's assessment of the chronic condition and his or her strategies for coping (Sebern, 1996).

These stages can be experienced via two pathways: emotional and functional. The emotional pathway is concerned with achieving emotional comfort when coping with a chronic condition. The functional pathway, which is the focus of the present study, involves the minimization of disruption to typical activities that might be caused by the chronic condition (Johnson, Fieler, Wlasowicz, Mitchell, & Jones, 1997).

Johnson (1999) incorporated information processing theory into self-regulation theory, allowing for an improved understanding of how individuals use the information that they receive about the chronic condition. Included in this approach are two assumptions relevant to the present study. First, individuals are motivated to pursue treatment based on their beliefs about their health. In the present study, patients' beliefs about what caused their LE are examined with regard to their choices of LE treatments. Second, individuals' knowledge of concepts and information related to their chronic condition are organized into schemata. These schemata then are used to anticipate and interpret new health information. Experiences that confirm schemata give individuals confidence in their understanding of the chronic condition leading to the retention of those schemata—unconfirmed schemata are rejected (Johnson). The present study investigates participants' confirmed schemata and the experiences that give rise to them. Specifically, the focus is on participants' schemata about LE causes and choices regarding LE treatment options, as well as their appraisal of these schemata.

Methods

Larger Study

The present investigation used data from a larger study, Patient Perceptions of Chronic Illness, that explored health perceptions and coping with specific chronic conditions within diverse racial, ethnic, and ethno-religious groups (e.g., African American, religious elders, Amish) in the Midwest (Armer, 2000; Armer, Conn, Rogers, Clawson, & Tripp-Reimer, 1998). The larger study investigated perceptions regarding self-management behaviors among adults and elders experiencing common chronic conditions, including hypertension, diabetes, arthritis, cancer, and post-breast cancer LE. The result was a number of subgroups within the larger study consisting of participants with either specific chronic conditions or racial, ethnic, and ethno-religious backgrounds. For example, Hispanic and African American participants with hypertension were included as two of the subgroups.

The interview protocol used with each of the groups was developed from self-regulation theory. Questions explored participants' general health beliefs and behaviors, beliefs and experiences specific to the chronic condition, ways in which individuals coped with the condition, and functional limitations that participants believed were caused by the condition. Interviews generally lasted 45–60 minutes and were conducted via telephone or in person. Nurse interviewers (i.e., nursing students completing undergraduate research requirements and graduate nursing students) were trained in the conduct of the research interview through demonstration and return demonstration of the appropriate interview techniques by the second author, with ongoing review of completed audiotapes and transcriptions. All interviews were audiotaped and professionally transcribed. Interviewers verified the accuracy of all transcriptions.

Present Study

The present study investigated the perceptions and experiences of a subgroup of participants from the larger study—women with post-breast cancer LE. These participants were recruited using snowball sampling from two local LE support groups and the referrals of healthcare professionals. The interview protocol used in the larger study was employed with this sample of women with post-breast cancer LE. Sample interview questions are shown in Table 1.

Data Analysis Procedures

Data analyses began with initial coding procedures in the form of line-by-line readings and coding of the 87 pages of data from the interviews with participants with post-breast cancer LE (Emerson, Fretz, & Shaw, 1995). Coders were the primary author and two baccalaureate life sciences research interns who were trained and supervised by the primary author. Comparisons were made between emergent codes identified by the coders to determine and establish consistency in coding. Agreed-upon codes were merged into a codebook containing more than 300 specific codes. The primary author then completed a series of memos to clarify thoughts about the codes and to formulate connections among them. Data analyses continued with the development of larger focused codes determined by sorting codes into categories and identifying themes within the categories (Emerson et al.).

Table 1. Interview Protocol Domains and Sample Interview Questions

Domain	Sample Questions
General health beliefs and behaviors	What does being healthy mean to you? Tell me about a time when you were sick and you did something to help yourself get better.
Beliefs about lymphedema	How did you learn you had lymphedema? What do you believe caused your lymphedema?
Ways of coping with lymphedema	Tell me about a time when you sought help for problems from lymphedema. What kinds of things do you do to manage the effects of lymphedema?
Functional limitations believed to be caused by lymphedema	What kinds of problems do you notice since you have had lymphedema?

Two strategies were used to interpret the meaning of these focused codes. First, the major concepts of self-regulation theory were used in the creation of a template a priori codebook (Crabtree & Miller, 1999) that focused the researchers' attention on participants' chronic condition representations and chronic condition knowledge related to LE causes, prevention, and treatment. The second strategy involved the concept of appraisal from self-regulation theory regarding participants' representations and knowledge. The participants' individual appraisals of the accuracy of their chronic condition representations and the effectiveness of their coping strategies were identified and compared to current medical knowledge to highlight consistencies and inconsistencies in their understanding of LE and identify key areas where improved health education for LE patients may be necessary.

The sample consisted of 18 Caucasian women ranging in age from 37–87 years ($\bar{X} = 58.8$ years). Thirteen (72%) participants were married at the time of the interview. All participants were breast cancer survivors (stages I–IV) with post-treatment LE. All participants had been assessed professionally by their physicians and a trained therapist prior to enrollment in the study. LE had developed from weeks to years following cancer treatment (surgery, radiation, and chemotherapy, alone or in combination). LE ranged in gradation from mild to severe and was chronic (not acute) in nature. The ipsilateral limb was involved in all cases; in some, the affected breast and trunk also were involved. The majority of participants had completed intensive therapy for LE management, whereas some were still engaged in intensive treatment (including bandaging) at the time of the interviews.

Results

Self-regulation theory concepts guided the identification of two predominant themes: participants' representations of LE and methods for managing LE. Participants' most common chronic condition representations were their beliefs about what caused their LE. These believed causes included treatment for breast cancer, exercise, skin damage, and allergic reactions. Participants also discussed ways of coping with LE in terms of their LE management experiences, including the use of compression treatments, physical activities, pumps,

medications, and therapists and therapy centers, as well as maintaining a positive attitude.

Perceived Causes of Lymphedema

Treatment for breast cancer: Several women believed that their LE was caused by breast cancer treatment (e.g., removal of lymph nodes, radiation therapy). For example, Delores, whose beliefs were based on her understanding of her breast cancer treatment, explained, “I would suspect the radiation [caused the LE], because they really took very little of my lymph glands; I had a lumpectomy. I did not have a breast removed, and it was followed by radiation.” Similarly, Mary, who was treated for breast cancer prior to the introduction of sentinel lymph node biopsy, entered into breast cancer treatment knowledgeable about LE risks.

I just consider the whole process [axillary lymph node dissection] just barbaric as hell. [My surgery was] just two years [before they started offering] the sentinel trick [sic]. I tried to talk the surgeon out of taking out all of my lymphs [sic] because I read in an alternative book, “Don’t let them take your lymph”—I’m sorry, but I think the book was right. I’m living evidence.

Both of these examples highlight the common belief among most participants, regardless of breast cancer treatment, that some aspect of their treatment was responsible for causing LE.

Exercise: Lois and Sarah reported believing that their LE was caused, at least in part, by exercise and overuse of their affected arms. Lois explained, “I thought it was because I started back to the gym and I was doing some weight training. I think I was lifting too heavy a weight. Thinking back on it, that may have worsened it.” Similarly, Sarah recalled being aware of restrictions on arm use and feeling that, had she been more careful, she may have been able to prevent the onset of LE. “I overexercised my arm—lifted three table leaves. They were heavy, and I had to reach to put them on a shelf. I can’t reach with that arm. All the lifting and reaching did it.”

Skin damage: Although less frequently mentioned, the theme of skin damage (e.g., sunburn, insect bites, cuts) also was prevalent in these data. For example, Martha explained experiencing the onset of LE during an outdoor vacation.

It was really humid that day and I was wearing a real light jacket. It got kind of hot so I took off the jacket and I got a sunburn. The next thing I knew, it [her arm] was just like a great big old bubble. When it swelled up and turned bright red, I got real concerned and went to the hospital . . . and that’s when I found out that I had [LE].

Beyond sunburn, other participants described insect bites and abrasions as possible causes of their LE.

Allergic reactions: Participants’ experiences with allergic reactions were reported less frequently than other related outdoor skin damage discussed earlier. Participants like Mary mentioned allergic reactions as a possible cause of LE.

I was out gardening with long sleeves and gloves in the spring. I’ve always been allergic to something that emerges in the spring. The sleeve and the glove became separated, just a very narrow strip, and . . . there went my arm [swelling].

Despite the scarcity in the data, this patient belief appeared important to note because it provides added understanding.

Management of Lymphedema

Compression treatments: Many women discussed their use of a variety of compression treatments to manage LE. The use of off-the-shelf or custom-fit compression garments in an attempt to curtail and even reduce swelling was one of the most widespread treatments when combined with MLD. Frequently, women reported that the compression treatments were uncomfortable and unsightly but nonetheless effective. For example, Sophie explained her early attempts at self-care and her later experiences with compression treatment.

At first I used an [elastic] bandage, which I applied to my arm myself, and that helped . . . keep the swelling down. But, then I was told about the [compression] sleeve. These are never comfortable. I wore them, but I sure didn’t like them.

Sophie’s use of an elastic bandage as a compression device instead of the two-way stretch compression bandage recommended for LE is not unusual, especially in women who are confronted with uninformed care providers or inappropriate healthcare information. Linda also recalled her experience with compression treatment.

[The compression sleeve is] better than having to do the wrapping. . . . At the lymphedema clinic . . . they were showing us how to wrap and I felt like the Michelin Man™ when I came out of there. The [compression sleeves] are better, but they’re still restraining.

Other women who used compression garments reported more positive experiences. For example, Tammy said, “I have been wearing the newest [compression] sleeve, and it is very, very good because it gives a massage effect as I wear it during the day. I [also] have a garment that I sleep in at night.” The sleep garment Tammy referred to was a soft, flexible glove and sleeve resembling a large, quilted oven mitt. Known as a directional flow device, the garment is intended to support the continued flow of the lymph fluid from the distal to proximal limb, flow that is achieved using MLD, wrapping or bandaging, and compression sleeves. Frequently, women who have used this type of compression treatment describe it as being more effective than other nighttime methods, such as elevation of the affected arm.

Physical activities: The three most common physical activities reported by these participants to manage chronic LE are massage, elevation, and exercise. All of the women in the present study who used MLD did so in conjunction with a therapist. Participants’ appraisals of the effectiveness of this method varied. For example, Margaret expressed her frustration with this method. “I started treatment last year. I used MLD, which was a total waste of time.” In contrast, Tammy said, “I started MLD . . . and that has been one of the most wonderful things to have happened. We were able to reduce the [bilateral] arm [limb volume difference] by 52%.”

Elevation and exercise were other physical activities commonly mentioned by participants. For the participants who tried it, elevation appeared to be met with mixed results. For example, Mary explained, “Before I started treatment, I slept with five [pillows]. . . . I even tried tying my arm up to the headboard. . . . I woke up in the middle of the night with red marks all over my wrist.” A few participants, like Tammy, described their belief in the utility of exercise as an appropriate

method for treatment. Tammy said, “If I would ride the bicycle and walk every day, I’m sure that I’d be a lot better because I’m convinced the exercise, the pressure against the bandages, does force the fluid out and up.”

Pumps: In addition to compression garments, compression pumps have a long history of prescription and use in the United States (Brennan & Miller, 1998). Almost half of the participants described their use of compression pumps. For example, Delores explained her trial-and-error experiences.

[I started by] using [a compression machine]. It has 12 chambers and a sequential pump. . . . It did reduce my arm appreciably. . . . More recently, a more sophisticated pump has been developed called the biocompression sequential . . . and it has six chambers. It helped control [the LE], but . . . it’s very arguable whether it’s good or bad, truthfully. Sometimes I have used it and I’ve felt better, at least temporarily, but then other times I’ve kind of wondered about it.

Medications: Another common theme was the women’s access to and use of a variety of medications (e.g., antibiotics such as tetracycline and penicillin, pain medicines) as effective LE treatment methods. For example, Sophie explained, “[Whether the LE gets worse] depends on whether I pick up any new infections. [The doctor] knows that when I telephone and say I have an infection . . . he just sends me some penicillin.” Linda reported that the swelling caused by LE created pain that has made sleeping difficult for her, so she had to use pain medications to maintain her physical comfort. “[The doctor] has given me some pain meds this time, and that’s kind of helped me just to get to sleep . . . through just part of the night, and then I seem to be able to work through the rest of it.”

Therapists and therapy centers: Because LE as a chronic condition requires daily self-care, patients must learn self-care methods. Because these methods typically are learned with the help of therapists or therapy centers (Logan, 1995), that these women reported choosing such resources for treatment is not surprising. Mary explained her experience.

I can assure you that, after going to the physical therapist, having the massage therapy [MLD], all the wraps [compression therapy], and learning how to do the wraps myself, it’s obviously under much better control than [using the technique of elevation].

Also, Lois recalled,

The program at [the rehabilitation center] and the therapist that I deal with have been very helpful and very supportive. I haven’t got much help from the doctors. I really should say the doctor did the best thing he could have done for me in referring me to [rehabilitation center]. I just don’t feel like [doctors] know so much about it.

Similar to Lois, the women who received therapy at therapy centers frequently mentioned how this method was an effective LE management option for them.

Positive attitude: A number of women mentioned keeping a positive attitude or relying on their faith as a strategy for managing LE. Statements such as, “Faith gives you a better attitude. People are always praying for me” and “I try to have a positive attitude . . . mind over matter” are characteristic of

this theme. Not all of these women, however, believed a positive attitude and faith were effective. For example, Carol said, “I prayed a lot with my lymphedema, even though it did not help.” Similarly, Martha revealed,

I feel religious. . . . I believe in God, and I trust Him, and I know what’s going to happen to me is what’s going to happen to me, and there is nothing I can do about it. There’s [sic] things I can do about it, but if things go bad, that’s the way things are going to be.

These appraisals indicate that women are using their faith to simultaneously deal with the uncertainty of their cancer outcomes and cope with their LE.

Discussion

Accuracy of Condition Representations

The precise causes of LE following breast cancer treatment in selected individuals are not entirely understood. However, events that trigger LE in the affected arm include damage to the lymphatic system as a result of breast cancer treatment, infection, skin damage, fatigue or overuse, and repeated blood draws or pressure measurements (Rinehart-Ayers, 1998; Romero, 1999). In general, the women in the present study were aware of the fundamental causes of their LE, especially with regard to beliefs about breast cancer treatment, exercise, and skin damage.

First, several women reported the belief that their LE was caused by breast cancer treatment (e.g., removal of lymph nodes, radiation therapy), consistent with Paskett and Stark’s (2000) findings. These beliefs also are accurate with regard to current medical knowledge regarding the likely causes of LE (Kocak & Overgaard, 2000; Lymphatic Research Foundation, 2002; NLN, 2002a; Passik et al., 1993).

Second, the belief that physical activity is a possible trigger of LE is consistent with current medical knowledge regarding overuse of the affected arm (NLN, 2002a; Romero, 1999). For example, generally accepted prevention guidelines exist for women at risk for post-breast cancer LE (NLN, 2002a; Ridner, 2002). Three of the main guidelines are to avoid heavy lifting, typically not more than 10 pounds with the affected arm; reduce repetitive movement with the affected arm; and avoid excessive strain while exercising. However, exercise also is recommended in these same guidelines (Klose Norton Training and Consulting, LLC, 2002), which may cause confusion among patients about how much and what type of exercise is appropriate or inappropriate.

Third, any sort of trauma to the affected limb, however slight, has been found to be associated with increased LE risk. Thus, situations involving abrasions, cuts, pinpricks, insect bites, and even cracked cuticles on the affected limb—any breakdown in the skin, the body’s first line of defense against infection—are considered serious events that may increase LE risk (Rinehart-Ayers, 1998; Romero, 1999). In addition to the prevention guidelines mentioned previously, recommendations for those at risk for LE also include avoiding sunburns or insect bites that may lead to infection, avoiding blood pressure measurements or injections in the affected limb, and using gloves when washing dishes or gardening (Klose Norton Training and Consulting, LLC, 2002; Rinehart-Ayers).

In addition to chronic condition representations that reflect current medical knowledge, participants also were aware of

other incidents that may have facilitated LE symptom onset. For example, beliefs about the causal relationship between allergic reactions and LE are examples of patients' chronic condition representations that precede scientific knowledge. Research has not yet shown evidence to support the belief that an allergic reaction may cause the onset of LE. However, other possible explanations for outdoor experiences, such as allergic reactions, that have been supported empirically include repetitive movements, sunburns, insect bites, and skin abrasions (Rinehart-Ayers, 1998; Romero, 1999).

Evaluation of Lymphedema Management Choices

Despite following all of the LE precaution recommendations, patients may develop LE at some point following breast cancer treatment. After the onset of LE, a variety of treatment options are available, ranging from physical activities (e.g., exercise, MLD) to the use of specialized compression garments and pumps to surgery and drug therapies. Consistencies and inconsistencies exist between the experiences of these women and current scientific evidence regarding treatment options. These women reported the use of compression treatment, massage, elevation, pumps, therapists and therapy centers, and positive attitude and faith, all of which are consistent with treatments recommended in the current literature. Inconsistencies include the effectiveness of exercise and medication in the management of LE. Also, none of the participants specifically mentioned the name of a widely recommended management strategy, CDP (Földi, 1998), although they did mention components of CDP (MLD, compression, and exercise).

One method commonly chosen by participants was the use of compression treatments. Studies suggest that these techniques are successful for managing LE (Bertelli, Venturini, Forno, Macchiavello, & Dini, 1992; Johnson, Kupper, Farrar, & Swallow, 1982), although the underlying physiologic mechanisms are not yet well understood and data-based guidelines largely are absent. For example, the use of compression garments during air travel to counteract the effects of decreased external air (cabin) pressure on arm swelling has been recommended (Romero, 1999), although relatively little research has addressed the best practices related to air travel and LE. One explanation as to why these women may have experienced variations in the effectiveness of these treatments is a lack of consistency in the type of compression garments used (e.g., pressures, materials, design) and guidelines (e.g., number of hours per day) for use of the product (Brennan & Miller, 1998).

Participants also described using various physical activities, such as MLD and elevation, to manage their LE that were met with mixed results. One explanation for variations in experiences with MLD may be that using MLD alone is not considered sufficient to treat LE (Földi, 1998). Studies have shown that MLD can reduce swelling effectively in the affected limb when used in conjunction with other treatments such as bandaging (Brennan & Miller, 1998). Another explanation for the mixed reports may be related to the training of therapists, the treatment regimen, and patient compliance. The use of arm elevation by these participants is supported by empirical evidence that suggests elevation is an effective treatment technique for early (acute) LE (Casley-Smith, 1992); indeed, grade I LE is defined by its reversibility when the limb is elevated. Unfortunately, as some of these participants discovered, the interference of continuous elevation

with daily activities makes it an impractical solution (Brennan & Miller).

Participants described their experiences with the use of mechanical pumps to manage their LE. Although some evidence exists to support pumps as a successful method for treating LE (Bunce, Mirolo, Hennessy, Ward, & Jones, 1994), healthcare providers have many reservations about their use. Improper prescription and use of these pumps leading to tissue injury (lymphatic damage) in the past has caused many practitioners and patients to rule out compression pumps as a treatment option (Brennan & Miller, 1998). Although many third-party payors reimburse for pumps as durable medical equipment, NLN and other LE advocacy groups currently do not recommend them as a first line for treatment (Thiadens & Cole, 1996). When pumps are used, patients are cautioned to follow therapists' guidance closely and incorporate the pumps only as a component of a therapy program that also includes MLD and bandaging.

The use of trained therapists is an important aspect of successful treatment of LE (LANA, 2002). Until relatively recently, training therapists about LE and its management has received little attention in the United States (Runowicz, 1998). Also, anecdotal evidence suggests that the lymphatic system typically has received little attention in nursing and medical schools. However, through the North American Certification Project, LANA has created a national public forum aimed at uniting lymphologists and therapists from multiple disciplines on the fundamentals of treatment to address this disparity. In doing so, LANA expects to identify LE treatment as a specialty requiring advanced training (LANA). Thus, improved treatment by therapists and therapy centers and more widespread access to appropriate LE treatment for consumers may be expected in the coming years.

Some of the women in this study discussed the use of positive attitude and faith to manage their LE. This approach to chronic condition management is supported empirically as a method for coping with LE as a chronic condition. Gordon et al. (2002) found that women living with chronic conditions may describe having an external locus of control that places their health in the hands of a higher power. They also found that the women who appeared to be coping well with their chronic condition also were those who reported strong religious beliefs. Further, Koenig et al. (1999), Koenig and Larson (2001), and Musick, Koenig, Hays, and Cohen (1998) conducted research with women and patients with cancer that substantiated the role of spirituality and religiosity in improving health outcomes (e.g., fewer complications, shorter hospital stays). Further investigation of the connection among positive attitude, faith, and management of the psychosocial aspects of LE is warranted.

Two areas where participants described treatment choices have inconsistent support in current medical knowledge: exercise and medications. Empirical evidence regarding the physiologic impact of exercise on LE thus far has been inconclusive. Some studies have shown that exercise increases overall lymphatic flow (Mortimer, 1990, 1995) and the reabsorption of proteins (Leduc, Bourgeois, Peeters, & Leduc, 1990). Also, exercise of the limb while under compression is recommended in the widely accepted guidelines regarding safety measures for patients with LE and predisposed individuals (Klose Norton Training and Consulting, LLC, 2002; NLN, 2002a). Exercise is supported by these research findings;

however, little empirical evidence conclusively links exercise regimes specifically to decreases in limb swelling (Brennan & Miller, 1998). Although exercise is believed to influence LE positively, specific research-based guidelines related to the degree of repetition and maximum weight allowed do not exist.

The role of medications in the management of LE similarly is unclear. Participants also discussed reliance on medications to control symptoms associated with LE. The swelling that results from LE can cause pain in the joints and along the length of the arm (Paskett & Stark, 2000), necessitating the use of pain medication for some patients. Patients also reported early use of antibiotics in combating LE-related infections such as cellulitis. However, drug therapy beyond antibiotics and analgesics is not used widely because of the lack of data concerning long-term effects and their relative risk for complications (Brennan & Miller, 1998; Savage, 1985).

Conclusions

An evaluation of LE chronic condition representations and management choices reveals that these women have a fairly clear understanding of LE. One possible reason for this is that the sample was generated in an area where local access to health care and information was abundant. Thus, these participants' knowledge may not represent all patients with LE in the United States accurately, particularly in areas where access to LE treatment centers is limited.

Implications for Nursing Research and Practice

Despite the high knowledge level of these participants, some areas indicate cause for concern. First, consistent with empirical evidence, participants seemed confused about the simultaneous role of exercise as an LE cause and management strategy. Thus, future research should target the role of exercise in prevention and treatment. Also, patient education by nurses should seek to provide patients with consistent exercise guidelines related to the degree of repetition and maximum weight allowed. Second, allergic reactions as a possible cause of LE have not yet been supported empirically. These reactions should be investigated as a possible etiology of LE. Third, several women reported using over-the-counter and makeshift devices (e.g., elastic bandages, tying arm to bedpost to elevate arm while sleeping) to manage LE. Improved diagnosis of LE and patient education about appropriate and effective management techniques likely will improve women's treatment experiences. Fourth, the use of medication to cope with the symptoms associated with LE (e.g., swelling, pain, infection) has been studied little to date, largely because one class of drugs, benzopyrenes, has not received U.S. Food and Drug Administration approval. The majority of research involving the use of drug therapies in the treatment of LE has focused on those that either break down proteins or work as

diuretics. Benzopyrenes are purported to reduce the volume of high-protein edema fluid by stimulating proteolysis (Casley-Smith, 1986; Casley-Smith, Morgan, & Piller, 1993; National Cancer Institute, 2002). Similarly, diuretics have been found to be ineffective because they simply create systemic water loss and not the loss of the protein-rich fluid associated with LE swelling (Loudon & Petrek, 2000). Thus, continued investigation of the effectiveness of medications and the development of new medications are vital. Overall, future LE research should address these gaps in medical and patient knowledge. In addition, improvements need to be made in patient education regarding LE risks and treatments (Paskett & Stark, 2000).

To more fully understand the need or desire of patients with LE for accurate healthcare information, future research also should address the influence of patients' level of accurately understanding LE on their choices of effective and appropriate treatment techniques. Second, directly investigating the state of LE knowledge among medical professionals and their patients would allow for the determination of possible discrepancies in patient education. Finally, future research also should explore patients' sources of LE information and the content of that information (Coward, 1999) to better understand the complexities of information and areas where nurses and other healthcare professionals might best serve their patients.

As with many chronic conditions, the focus of much LE research has a management rather than preventive focus. Much of the focus of education deals with recommendations for prevention that are not yet based on empirical evidence. Probably the most important preventive measure is providing patients with information through pre- and post-treatment education about the possibility of developing LE (Casley-Smith, 1996; Paskett & Stark, 2000; Runowicz et al., 1998). Specifically, during the stressful and often chaotic post-breast cancer diagnosis and preoperative phase of adjustment and decision making, women are taught about the potential risk of LE related to breast cancer treatment. However, when facing what is perceived as a critical and potentially life-threatening decision regarding cancer treatment, less immediate, less urgent, and less life-threatening information may not be well appreciated or even recalled. Therefore, review of LE risk factors in the pre- and postoperative periods and continued assessment and education are vital to a comprehensive approach to post-breast cancer care. Also, measurement of arm volume and circumferences preoperatively is a strategy that may provide patients with more memorable preoperative education and have the added benefit of serving as a baseline measurement for later calculation of limb volume change.

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