

Experiences of Living With Non-Cancer-Related Lymphedema: Implications for Clinical Practice

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Lymphedema is a chronic medical condition caused by lymphatic insufficiency that can lead to extreme swelling and susceptibility to infection. Physical and psychosocial effects of the condition can have a significant impact on an individual's life and level of participation. Research about experiences of individuals living with lymphedema has focused primarily on women with breast cancer, yet individuals with non-cancer-related lymphedema are a distinct group. In this study, the authors used qualitative description to explore the experience of 7 individuals living with advanced and complicated cases of lymphedema who had been treated in an inpatient setting. Findings reveal the extensive impact lymphedema has on those who live with it. Participants spoke of difficulty finding a correct diagnosis and effective treatment, the importance of their inpatient experiences, and the challenges of daily self-management. The authors make recommendations to increase lymphedema awareness, promote inpatient treatment programs, and create effective self-management techniques.

Keywords: *rehabilitation; disability; qualitative research*

Lymphedema is a chronic medical condition that results in swelling of an extremity or other body parts that can reach striking proportions. Lymphedema arises from an insufficiency of the lymphatic system and is classified as either primary or secondary depending on the cause of lymphatic dysfunction. Primary lymphedema results from intrinsic abnormalities of the lymphatic system due to atypical development of lymphatic tissues in utero (Lerner, 2000) that causes lymphatic vessels to be either missing or impaired. Symptoms might be present at birth or develop later in life, and familial patterns are sometimes present (Szuba & Rockson, 1998). Secondary lymphedema is more common and occurs when lymph vessels are damaged or removed as a result of extrinsic causes like trauma, infection, or cancer treatments such as surgery or radiation. Estimates of the incidence and prevalence of lymphedema vary widely (Moffatt et al., 2003; Williams, Franks, & Moffatt, 2005) and are difficult to estimate for the general population. The prevalence rate for all types of chronic edema, including lymphedema, has been estimated at 1.33 per 1,000 (Moffatt et al.,

2003). Less is known about the rates for primary lymphedema. One study focusing on patients of lymphedema treatment centers found that primary lymphedema was the diagnosis for 8% of all new referrals to the clinics (Sitzia et al., 1998), with 65% of the those referrals experiencing symptoms of lymphedema for more than 5 years prior to diagnosis. In all forms, lymphedema is likely more common than usually thought (Weiss & Spray, 2002) because of missed diagnoses and a lack of standardization in diagnostic criteria and measurement practices (Logan, 1995).

Swelling is the most prominent feature of lymphedema (Figure 1). In addition, lymphedema is characterized by poor skin condition and an increased risk of infections such as cellulitis (Lerner, 2000).

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Figure 1
Man With Extreme Left Leg Lymphedema,
Prior to Complete Decongestive
Therapy as Part of Inpatient Treatment



Figure 2
Same Man as in Figure 1
Following Inpatient Treatment
Procedures



Individuals often experience recurrent infections that cause further damage to the skin, exacerbate existing swelling (Szuba & Rockson, 1998), and might require hospitalization for treatment with intravenous antibiotics. Physical symptoms of pain (Passik, Newman, Brennan, & Tunkel, 1995), limb heaviness and discomfort (Woods, Tobin, & Mortimer, 1995), and decreased physical mobility (Sitzia & Sobrido, 1997) can be present and contribute to functional limitations in both the home and work environments (Woods et al., 1995). Indeed, Moffatt et al. (2003) found that 8% of individuals with lymphedema had to give up working altogether.

Treatment for lymphedema focuses on reducing swelling and improving skin condition. The Consensus Document (2003) released by the Executive Committee of the International Society of Lymphology advocates complete decongestive therapy (CDT) as the treatment of choice for patients with lymphedema.

Despite a long history as the gold standard of treatment in Europe and Australia, CDT is relatively new in the United States (Szuba & Rockson, 1998) and has only recently emerged as the standard of care (Cheville et al., 2003). CDT is a two-phase manual therapy program. The intensive phase consists of daily sessions of a specialized massage technique known as manual lymph drainage (MLD) and compression bandaging by a trained therapist, along with exercise and skin care (Figure 2). This is followed by the maintenance phase, when responsibility for self-management is shifted to the individual with lymphedema. This phase, which typically consists of daily compression garment wear, nighttime compression, and continued exercise and skin care, lasts for the remainder of the person's life.

Although lymphedema is categorized as primary or secondary for diagnostic purposes, a more meaningful distinction might be whether it is or is not cancer related. Treatment for cancer is the most common

cause of lymphedema in the Western world (Lerner, 2000), a fact that has likely led to the current focus on cancer-related lymphedema in the research literature. However, it has been suggested that individuals with cancer-related lymphedema and those with non-cancer-related lymphedema (i.e., primary lymphedema and non-cancer-related secondary lymphedema) form two distinct groups. Individuals with non-cancer-related lymphedema typically experience the condition longer prior to diagnosis, have greater severity of swelling, and are more likely to have bilateral and lower limb swelling, leading to considerable management problems made more complex by late referral (Sitzia, Woods, et al., 1998). Despite the unique challenges they face, Moffatt et al. (2003) described the care provided for individuals with non-cancer-related lymphedema as poor and highlighted the disparity between their care and the level of care experienced by individuals with cancer-related lymphedema.

There is also less known about the experiences of individuals with non-cancer-related lymphedema. Studies of the impact of lymphedema on quality of life have generally concentrated on breast cancer-related lymphedema. Psychological distress, depression, social inhibition, and sexuality concerns have been identified in this population (Passik & McDonald, 1998). However, Carter (1997) has warned that separating the experience of surviving breast cancer from the experience of living with lymphedema might be difficult. Similarly, it is difficult to determine the specific effects of non-cancer-related lymphedema on quality of life in studies with mixed groups (Pereira de Godoy, Braille, de Fatima Godoy, & Longo, 2002). It appears that persons with primary lymphedema might experience greater difficulty with diagnosis and self-image, more trouble finding clothing and shoes that fit, and more problems with depression and anxiety (Williams, Moffatt, & Franks, 2004).

To provide appropriate care for those with non-cancer-related lymphedema, it is important to have firsthand knowledge of how living with a chronic illness affects the lives of these individuals (Gerhardt, 1990). The experiences of those dealing with the life-long responsibilities of self-maintenance following a CDT program are of particular interest. The purpose of this study was to gain insight into the perspective of individuals with non-cancer-related lymphedema to increase understanding of their experiences and, thereby, enhance treatment and guidance by health professionals.

Method

We used fundamental qualitative description, a research method based on the principles of naturalistic inquiry (Lincoln & Guba, 1985), to learn more about the experience of individuals living with non-cancer-related lymphedema. The goal of this qualitative approach is to describe an event or experience to enhance understanding. In contrast to research designs that use narrative data as a source for the construction of conceptual theories or present findings in abstract terms, fundamental qualitative description is distinguished by being low inference and presenting findings in everyday language (Sandelowski, 2000). Fundamental qualitative description leads the researcher to concentrate on preserving the voices of the participants by presenting their experiences in their own words to the greatest extent possible, with minimal inferences by the investigator.

Recruitment of Sample

All study participants were recruited from the pool of individuals with non-cancer-related lymphedema who had completed a lymphedema rehabilitation program at a regional hospital in the Pacific Northwest of the United States. Each was treated in an inpatient setting for 2 to 3 weeks, followed by 4 to 6 weeks of outpatient treatment at the same institution. Only those individuals with the most debilitating and severe cases of lymphedema are managed in an inpatient setting (Foldi, 1994; Thiadens, 2003); therefore, we used purposive sampling of these extreme cases to provide information-rich experiences to illuminate both the unusual and the typical (Patton, 2002).

Once we had obtained approval from the institutional review boards of the regional hospital and the University of Washington, the study was first introduced to potential participants by a third party liaison from the regional hospital. The liaison was a staff member familiar with the lymphedema rehabilitation program's population of clients, as well as with this study and the inclusion criteria. Qualifying individuals who expressed interest in the study were then contacted by the researcher, who explained that on consent, prospective participants would take part in an interview ranging from approximately 1 to 2 hours with a 30 minute follow-up telephone call about his or her experience of living with lymphedema. Confidentiality was assured, as was the individual's right to refuse to answer any question and to terminate the interview at any time.

Participants

All individuals with non-cancer-related lymphedema who had been treated since the inpatient program's inception in 1998 and who met the study inclusion criteria agreed to be interviewed. Of these 7 participants, 4 were women. Five participants were White, 1 was Black, and 1 reported her ethnicity as Alaskan Indian. Participants either had primary lymphedema or lymphedema secondary to noncancer causes, including trauma, spider bite, or infection. One participant had unilateral lower extremity lymphedema, 5 had bilateral lower extremity lymphedema, and 1 participant had bilateral lower extremity lymphedema and lymphedema of one hand. The mean age of participants was 52 years (range 36 to 75). Time since onset of their symptoms ranged from 5 to 75 years with those individuals with primary lymphedema experiencing their symptoms the longest. The mean time between the completion of the participant's inpatient treatment and participation in this study was 3 years, ranging from 8 months to 5 years since discharge.

Data Collection

A semistructured interview guide was developed for this study and consisted of a series of open-ended questions with accompanying probes designed to elicit narratives about the participant's experience of living with lymphedema. The interview guide emphasized the broad themes of diagnosis, treatment, self-management, and the psychosocial effects of living with lymphedema. The questions and emphasis areas were based on the review of relevant literature (e.g., Williams, Moffatt, et al., 2004) and the primary author's clinical experiences as an occupational therapist treating patients with lymphedema.

Interviews took place in the participant's home, with the exception of one interview conducted over the telephone. The first author presented herself to participants as a researcher interested in learning about the participant's experiences of living with lymphedema. She revealed she had clinically treated individuals with lymphedema but stressed that the participants were the subject matter experts about their own histories and that she was there to learn from them. Interviews were audiotaped and later transcribed verbatim. Field notes taken during the interviews captured nonverbal behaviors, such as signs of fatigue, and environmental factors, such as external disturbances, and aided the process of reflective listening and summarization.

Additional general impressions and observations were noted on completion of the interview in a process of memo writing (Maxwell, 2005).

Approximately 2 weeks after each first interview, the participant was contacted on the telephone to provide an opportunity for clarification and elaboration on behalf of both the researcher and participant. These member checks (Lincoln & Guba, 1985) included sharing initial impressions and analysis with the participant for verification of accuracy. The follow-up telephone call was also audiotaped and then later transcribed verbatim for coding and thematic analysis.

Data Analysis

Data were analyzed using qualitative content analysis, a process that requires researchers to immerse themselves in the data and then organize their impressions so that a comprehensive and meaningful description of their findings is possible. The immersion and organization phases began during the data collection phase and recurred continuously throughout analysis.

Recordings of interviews were listened to prior to transcription with a special emphasis on listening for the big picture (Borkan, 1999). The process of transcription served as an additional avenue of immersion. Once transcribed, interviews were read for a deeper understanding. Passages that stood out as important were highlighted, erring on the side of over inclusion. The process of constant comparison was used initially to compare passages from different transcripts on a "look alike, sound alike" basis (Lincoln & Guba, 1985, p. 341), leading to the development of preliminary categories for coding. These categories were generated from the data to emphasize the experience of participants as represented in the interviews rather than a predetermined code set developed by the researchers.

The Ethnograph was used to assist in the coding process to organize data from multiple transcripts. Operational definitions of codes were developed and refined, with the rationale for each detailed in memos. Special attention was paid to negative cases (i.e., atypical case stories) and evidence that disconfirmed initial impressions. Patterns in the data emerged, and codes were grouped into themes based on their common descriptive elements and threads that appeared to connect them (Seidman, 1998). Themes were conceptualized by the researchers as representative of participant's collective experiences and labeled using participants' words or meanings.

Trustworthiness

Several steps were taken to enhance trustworthiness of study findings. All team members read each transcript and met to discuss and determine salient patterns and themes (Crabtree & Miller, 1999). Credibility efforts also included member checks conducted with the study participants to verify descriptive findings and meanings attributed to those findings. Development of operational code definitions aided in the internal consistency and stability of the code set and enhanced the thoroughness of the coding process (Lincoln & Guba, 1985). Finally, the study's audit trail included a field journal maintained by the primary investigator to record decision making practices during analysis, as well as personal feelings about the research process and preexisting beliefs or potential biases that might have influenced findings.

Findings

Three comprehensive themes emerged from interviews and subsequent coding, memo writing, and follow-up interviews with participants. Each participant reached a point in his or her life with lymphedema when they felt they had *Nowhere to Turn*. Correct diagnosis and referral for inpatient care was a *Turning Point* for them in terms of managing lymphedema, and all were now *Making Room* in their lives for the complex self-management routines needing to be followed.

Nowhere to Turn

The theme of *nowhere to turn* describes the experience of all 7 participants during the time when the symptoms of their lymphedema were seemingly out of control and exerting a significant negative influence on their lives. It is marked by a profound lack of recognition and resolution by the medical community and was described by the majority of participants as the most difficult period in their lives with lymphedema.

Missing out on Life

The most striking and disrupting commonality experienced by participants was difficulty finding a correct diagnosis and adequate treatment. Delayed diagnosis translated into progression of the swelling and subsequent susceptibility to infection, decreased mobility, and social isolation. One participant, who had consulted five doctors over the course of 14 years searching for a diagnosis, described the severity of her

swelling, "My legs were 36 inches around at the calf; both of them!" All 7 participants reported extensive histories of cellulitis. During the years prior to her diagnosis, one individual experienced recurrent infections that eventually led her to be hospitalized every 2 to 4 weeks, resulting in swelling and skin breakdown so extensive she could barely walk and was homebound. Crying, she explained, "I couldn't go to family functions, I couldn't do anything. I missed out on a lot. I didn't have a life at all."

Most participants described similar difficulties with walking and functional mobility, such as getting out of chairs, off the toilet, into cars, or into a bathtub. Decreased stamina and energy were reported by all. "I couldn't even walk five feet without getting out of breath," stated one individual, whereas another described the impact on her recreational participation; "I used to love to fish, but my legs got so bad I couldn't go fishing . . . I didn't have the stamina." Five of the 7 participants reported falling frequently during this time period because of the heaviness and immobility of their limbs.

Weight of the limb(s) and reduced mobility also meant a loss of independence for some individuals. One individual required assistance to get into the bathtub and stated, "It was all we could do just to lift [my legs] and get them in there." Another individual described her dependence on family members to help her go to the bathroom and get into bed as "embarrassing" and "depressing."

Alone and Hiding From the World

Unwanted attention from strangers was another source of embarrassment and depression, leading to social isolation. One individual explained, "It's depressing to have lymphedema because people really don't understand it . . . they stare and make fun. I started wearing long dresses and I wouldn't go out much." Another individual described the following event as illustrative of the experiences that led her to become a "recluse":

I was in a store . . . and a little girl says, "Hey lady, what's wrong with your legs?" And I couldn't say anything. I just sat there and cried . . . But I didn't *know* what was wrong with my legs. And I got really depressed.

Such feelings of depression were prominent in the stories of 4 individuals. One stated, "Before I knew what I was even dealing with, it was very devastating. I just wanted to crawl in a hole and live in it." Another

explained, "They could tell me everything I didn't have. But they couldn't tell me what was wrong. I hit depression because there wasn't an answer anywhere."

Searching for Answers

Stories of limited knowledge by the medical profession defined this time period for most participants. "'We don't know what's the matter.' That's all I ever got told," recounted one individual. Others reported doctors making statements that ranged from dismissive, "I don't know what else to do for you, so don't bother to come back" to insensitive, "Did they have to cut your leg off yet?" Four individuals reported being told to simply "go on a diet." Initial reactions of feeling "brushed off" and "frustrated" led to more severe feelings of hopelessness.

When you have this, and you have no clue what it is, and you go to *medical doctors* for help and they tell you *nothing* . . . and say you're just obese and the only answer is to lose weight . . . where's the hope?

A striking example of longstanding limited knowledge about the condition was that from an older participant born with primary lymphedema. He reported first hearing the term *lymphedema* only 20 years ago, after living with the condition for more than 50 years. However, in contrast to participants who described the experience of not knowing what was wrong as "traumatic" and "unbearable," he maintained that as a young child with lymphedema, he "never thought of it as a handicap" and explained, "I knew I had big legs, but it's like having a big nose, it's just there." However, he experienced the first of many severe infections when he was a junior in high school and said it was "the first time I really found out that lymphedema was something that was not good to have." The lack of adequate treatment to control his lymphedema and the repeated infections eventually had a negative impact on his self-confidence. He described his lymphedema during this time period as "a real disadvantage," thinking "nobody will ever want to marry me" and "if I got a job, I'd probably get sick and lose it anyway."

Four of the 7 participants reported having to give up working because of uncontrolled lymphedema. One explained that although he continued to work, the long hours on his feet required by his job negated the effects of his outpatient treatment. The swelling in his leg progressed to sizeable proportions despite 6 long years of therapy 3 to 5 days a week. The ineffectiveness of his treatment left him feeling as if he had nowhere to turn and fearing amputation: "It doesn't take a rocket

scientist to figure out . . . if I can't control my leg, somebody else is going to control it. And they're going to take it off."

In addition to fears of amputation, participants reported feeling "scared" of going into a wheelchair, becoming bedridden, and/or having a negative impact on their family. However, participants lacked the requisite information to better their situations. The eventual discovery of a correct diagnosis and viable treatment options sparked a sense of determination in participants to do "whatever it took." For most, the diagnosis and treatment experiences it led to signaled turning points in their lives with lymphedema.

Turning Point

This period is marked by the return of hope and drastic improvements in participants' conditions due to successful treatment. A correct diagnosis after years of searching signified the first change for the better for some participants. Often it was chance events, such as seeing someone with lymphedema on a talk show or a hospital's commercial for a lymphedema treatment program that provided the clues these participants needed. An offhand remark by an acquaintance led one participant to a lymphedema therapist in a nearby city. Despite being told by the therapist "You're the worst case I've ever worked with," the participant stated, "There was more hope, because I knew what I was dealing with." Another participant, whose searching on the Internet aided in her self-diagnosis, said, "I was so relieved when I found out that I had lymphedema. I mean, it's not something to be happy about, but I was happy. That I wasn't going crazy, that there really was something wrong with my legs." Her sense of relief was followed by questioning "Where do I go, what do I do, how do I get the kind of help I need?" Her research revealed there were no lymphedema therapists in her state, and she made the difficult, but determined, decision to move: "It was not exactly something I wanted to do, but I had to."

All 7 participants faced similar challenges finding effective treatment. Each had unsuccessful outpatient experiences before inpatient treatment. Although inpatient care was the turning point that all participants had in common, participation in an inpatient program required additional dedication and determination in terms of effort, finances, and a willingness to commit to treatment. The scarcity of inpatient lymphedema rehabilitation programs meant that many individuals had to travel long distances. The rarity of the programs also translated into prolonged and

sometimes unsuccessful disputes with insurance companies for coverage. The length of inpatient programs required a significant investment of time and extended absences from friends and family.

One individual described the "battle" with his insurance and the belated approval that gave him only 4 days' notice before he was to arrive for inpatient treatment. He hurriedly arranged for the extended time off work and drove 2,000 miles to the hospital. The extent of his swelling forced him to drive his van with his body positioned at an angle and his leg "pressed up against the door." Yet he describes his inpatient experience as "incredible" and "the best thing I ever did."

The positive impressions of their inpatient experience shared by all participants appeared to reflect both confidence in their health care providers and satisfaction with the drastic improvements in the symptoms of their lymphedema. Because of the severity of swelling, volume reduction of affected limb(s) typically resulted in significant weight loss for most participants during inpatient treatment. One participant, who lost more than 100 pounds (45 kg) over 3 months of treatment stated, "It was great. I mean these people, that's what they do, lymphedema." Another participant, who lost about 140 pounds (64 kg) during 10 weeks of successive inpatient and outpatient treatment, described the staff as "fantastic" and remarked, "They knew exactly what was going on . . . they viewed working on my legs as a challenge."

The objective measures of volume reduction and weight loss translated into rapid gains in mobility for participants. One individual described her excitement when she first bent her knee while standing during therapy, "That for me was a big accomplishment . . . I couldn't do that before." The participant whose leg barely fit in his van on the drive to the hospital shared that after weeks of inpatient therapy, "I went out and got in my van. It was like night and day . . . I jumped in and was like 'Wow.' . . . That was the biggest deal."

Most participants emphasized the value of the range of specialists they met with during their inpatient experiences, including physiatrists, occupational and physical therapists, dieticians, and rehabilitation nurses. For many participants, meeting with a psychologist, as well as hearing the stories of fellow patients, was an important aspect of their inpatient treatment. One individual shared, "Knowing there were others that had the same problem and were going through the same type of struggle that I was made a big difference because I felt I wasn't alone anymore." Another participant stated that prior to talking with a psychologist

and others with lymphedema, "I knew it could get real serious, but I didn't know there was a way you could cope with it and live with it."

Talking to others with lymphedema at the hospital "gave me hope it would be okay" reported one individual, who described feeling "overwhelmed" when she first started her inpatient treatment. She explained, "They kept saying you're going to be doing this for the rest of your life, but I didn't know how we were going to do that." However, after a few days of treatment, "they had taught me how, and I finally could see the benefits of being able to maintain."

Most participants also reported feeling prepared to manage their lymphedema at home. They described having to bandage themselves during therapy, being taught self-manual lymph drainage, and being instructed in skin care and exercise. If family members were present, they were included in the instruction. Many participants were given handbooks to take home with pictures of step-by-step directions of compression garment application and bandaging techniques to use as a reference and "troubleshooting guide."

Armed with the necessary knowledge and tools for self-management, participants returned home to begin the next stage in their lives with lymphedema. For some, the euphoria of the results of treatment was tempered by the extent of the self-management procedures and the reality that lymphedema was chronic. The lifelong endeavor of self-management forced all 7 participants to make room in their lives and minds for continuing to live with lymphedema.

Making Room

The theme of making room illustrates the substantial effort required of participants to make room in their lives for lymphedema, from the physical effort of daily self-management to the mental effort of staying motivated for that self-management and coping with a chronic illness. Participants' descriptions of those efforts highlighted how, despite successful treatment, living with lymphedema continued to affect their lives in substantial ways.

The advanced stage of their conditions necessitated extensive and sometimes complex self-management practices. One individual, who chose to use compression bandages during the day as well as at night, described how he had to allow plenty of time to get ready for work every morning, "I've got to get up, take a shower, roll my bandages I've taken off, get re-bandaged . . . put everything back on. It's a pain in the neck; it's up to two hours a day, extra." Similarly,

most participants reported spending between 1 and 2 hours a day engaged in self-management. One individual reported that it took him 30 minutes every morning to put on the combination of five compression garments in various lengths and levels of compression. Because of the high level of compression their garments required, 3 of the participants required assistance in their application, with 1 describing having to wake up at 4:30 every morning so that her husband could assist her before he left for work.

All participants stressed the importance of consistency in their self-management procedures. One stated, "You've got to keep an eye on it and work with it because it can swell back up on you real fast." Another individual, who emphasized, "It's real important to keep up with it," described how she learned the significance of consistency after the first of two inpatient hospitalizations:

My mom got real sick. So I gave up what I was doing (for myself) to take care of her. I should have just put my stockings on . . . but you don't think of things like that when somebody needs you right now. . . . So my legs got worse again.

Participants also stressed the importance of having a routine and the right tools as critical to the success of their self-management. One individual, who said that "a routine makes a big difference," had missed only 2 days of wearing her compression garments in the 3 years since her inpatient treatment. Another participant stressed the importance of having the right tools and credited a change in the type of compression he wore at night for aiding in his consistency and success.

Participants gauged the success of their self-management procedures in various ways. A few recorded periodic measurements at home and compared them to measurements taken during treatment. Some tracked frequency of infections, whereas others used more subjective measures, such as how their clothing fit, energy level, mobility, participation, and independence. One individual stated, "My success was being able to do those things I had been unable to do. Seeing that I was getting back to the world I had left." Another participant's comments illustrated the social implications of the increased stamina he used as an indicator of the success of his self-management, "You're able to walk longer distances without stopping. I'm with the group, not just trailing behind."

The various measures of success detailed by participants also appeared to serve as motivators for compliance with their self-management programs.

Many participants reported periods of 2 years or longer without a case of cellulitis since their inpatient treatment and successive self-management. One individual listed avoiding infection as his primary motivator. Many participants described a fear of regression as a motivation.

I don't want to do anything to jeopardize and send my leg going backwards. . . . If I don't do it, I'll be right back up to [the inpatient program] or I'll be over in a hospital somewhere with somebody amputating my legs.

One participant stated simply, "If you do what you are told to do, you can have life." The social implications of successful self-management and the lingering feelings of embarrassment are illustrated by one individual's story: "Being able to wear real clothes again was the main motivation. Who wants to wear sweats forever? By being able to wear regular clothes, people don't see the big legs."

About the ongoing maintenance phase of self-management, a participant shared, "You kind of felt you were getting back to normal . . . as normal as you can get and still aware of what you had to do." Another stated, "If you can keep it managed, you can live a pretty well normal life." Still, participants stressed the need to be "careful" and "cautious." One participant, who described the continued need to elevate her feet, rest, and be vigilant with her self-management, warned, "You can't just think that you can do anything that you want without having some kind of repercussions." Another participant said, "With my legs and feet, I have to be very careful I don't get cuts because they're so infection prone."

Lymphedema continued to affect participants' lives in other ways as well. One man described the limitations in both prolonged standing and prolonged sitting in a working environment as reasons "why they say I'm disabled." The impact on employment was also illustrated by a participant's story of feeling "guilty" when he tried to restrict the time on his feet at work: "You want to pull your share of the weight, you know?"

In addition to employment, lymphedema continued to affect some participants' physical appearance, ability to buy clothing, and self-image. One individual, who described her legs as "ugly" and "distorted," said she hated to touch them because, "They're not like real legs . . . they're purplish colored and dry and scaly." She reported having to make her own clothes even after treatment and stated, "It would be so nice

to just go into a department store and buy something off the rack."

The impact on self-image is demonstrated by one participant, who shared, "In the back of my mind . . . people are looking at me and probably talking about 'What's wrong with that guy?'" His reluctance to participate was illustrated by his reaction to being invited out by his friends to socialize with women. He stated, "I'm sorry, that's not going to happen for me. . . . I may be the nicest guy in the world, but, to them, it's like I'm a freak of nature probably."

The myriad of ways in which lymphedema affected their lives caused participants to describe living with it as "a constant battle," "restricting," "limiting," "stressful," "painful," "time-consuming," "a drag," and "no fun." Frustration was emphasized by 6 of the 7 participants. Some described the process of self-management as "a daily reminder . . . I have something wrong with me." With having to depend on her husband to assist her with self-management, one worried, "What if anything happened to [my husband]? How will I get along, what will I do? That uncertainty is always there."

Participants described a number of ways in which they dealt with living with emotions such as uncertainty and frustration. Six individuals listed support from their family and friends as central, and 5 stressed the importance of their faith. A positive attitude was emphasized by most participants.

Participants used different strategies to make sense of living with lymphedema. One participant, whose family history included several members with primary lymphedema, stated, "I'm thankful it's me and not one of my brothers or sisters. I don't think they would cope as well as I do. . . . God only gives us what we can handle . . . so that's why I got it." In what seemed to be an effort to place themselves in a larger context of individuals living with disabilities, individuals commented, "There's always somebody out there that's got it worse than you." One individual stated,

The guy that doesn't have any legs at all would kill to wrap his legs every day . . . He probably wouldn't like having lymphedema, but he would sure as heck like to have that leg that he needed to take care of.

The fact that lymphedema is chronic was difficult for many participants to come to terms with. One participant claimed she "had to just get over that I had something that I'd have to deal with for the rest of my life," and said, "I stated over and over in my mind: You either live with it or die with it." Another participant stated he made room in his life for living with lym-

phedema because "You don't have a choice . . . there's no pill, there's no miracle cure." He continued, "I'm not happy about it, I don't like it, but I've got to do it. I've got to get wrapped and go to work." Some participants initially struggled with questions such as "Why me?" although all appeared to agree with one participant, who said, "It's something I know I have to live with and deal with and I've accepted that."

Even after successful treatment and self-management, this phase of living with lymphedema is marked by continued frustration with medical professionals. Several participants described instances of having to teach emergency room doctors about lymphedema to receive treatment for cellulitis. One participant focused her frustration with her doctor into a desire to educate others with lymphedema:

There are a lot of people here that have lymphedema, but they don't know what it really is. They don't have anywhere to go. . . . I really need to get out and find these people and talk to them because I'm sure they're living a nightmare, too.

Several participants described making room in their lives to educate others about lymphedema. "I talk to anybody I can find that'll listen, because I was in awe when I found out all that it entailed and all that no one knew," stated one individual. Another shared, "I am constantly telling people 'Oh, I have lymphedema' and telling them what it is" and included medical professionals in her efforts. "I'm educating doctors every chance I get," she said, adding, "Maybe other people will not go through what I've gone through . . . that's what I hope for."

Despite the extensive impact lymphedema has on those who live with it, all 7 participants claimed to live lives that were "fairly normal." One participant, who had lived with lymphedema for more than 70 years, stated, "You need to be on top of it . . . it's part of your life, but it doesn't need to be all-consuming." His parting advice to others was simply, "Lymphedema is as much of a handicap as you let it be."

Discussion

The experiences detailed in this study illustrate the broad impact of living with non-cancer-related lymphedema within the diverse contexts of the participants' lives, offering health care professionals insight into the challenges these individuals face. The relevance of such insights should not be underestimated, as they not only

contribute to our understanding of individuals' experiences but suggest ways in which health care advice and instruction might be improved. The experiences of the participants in this study highlight the need for increased awareness of lymphedema; more comprehensive rehabilitative approaches to lymphedema management, as typified by inpatient lymphedema programs; greater focus in treatment programs on those outcomes most meaningful to patients; and deeper understanding of what influences individuals' compliance with long-term self-management.

One of the most important findings of this study was what a delay in diagnosis and treatment meant to participants in terms of the impact on their lives. From feelings of depression to being forced into early retirement, each participant described the far-reaching consequences of living with uncontrolled lymphedema without knowing where to turn. Although an increase in the severity and progression of the symptoms of lymphedema as a consequence of late referral is well documented (Casley-Smith, 1995; Sitzia, Woods, et al., 1998), the extent of the functional and psychosocial implications of that progression was greater than expected and clearly distressing to participants.

The typical experience of spending years searching for a diagnosis and treatment reveal a clear need for increased public awareness of lymphedema and, in particular, the need for increased attentiveness and education among medical professionals. Specific strategies are needed, as references to limited medical knowledge of the condition are pervasive in the literature, and yet the problem persists. Educational efforts must include the entire spectrum of medical professionals, as individuals with non-cancer-related lymphedema are initially more likely to be seen in the emergency room for treatment for cellulitis or by a general practitioner than by specialists such as oncologists, who might be more familiar with lymphedema. Even in the case of lymphedema therapists, increased awareness of inpatient programs as a resource for referral of extreme cases is needed.

The uniformity of participants' failed outpatient experiences and their unanimous view of inpatient treatment as a significant turning point in their lives highlight the importance of inpatient lymphedema rehabilitation for individuals with severe lymphedema. The intensity of the program, combined with the opportunity it provided to focus completely on treatment in a setting removed from the demands of everyday life, appeared to be crucial to participants' success. In addition, as all participants had lower extremity

lymphedema, the opportunity inpatient treatment provided to elevate their legs and avoid prolonged standing likely contributed to their positive treatment results. Furthermore, the emphasis participants placed on the value of the comprehensive nature of their inpatient care appears to validate the relevance of a more interdisciplinary, rehabilitative approach to lymphedema management as suggested by Mason (2000) and support the views of those who believe that more inpatient programs are needed (Thiadens, 2003).

The findings highlighting the importance of using outcome measures in treatment programs that are meaningful to patients have important implications for goal setting by health care providers (see also Weiss & Spray, 2002). For instance, study participants tended to recount the physical effects of their treatment in terms of weight loss rather than the more common clinical measure of volume reduction. Weight loss appeared particularly meaningful to participants, who reported numerous unsuccessful attempts to lose weight after being told by physicians to "go on a diet" prior to specific treatment for lymphedema. The additional measures of success detailed by participants, including decreased frequency of infections, increased mobility, increased social participation, and fitting into regular clothes, illustrate the importance in goal setting of understanding what limb reduction means to individuals with lymphedema in terms of the impact on their lives.

Study participants reported an extremely high rate of compliance with prescribed self-management programs, a finding that is particularly striking, as the self-management procedures they described following were often complex, required good judgment, and called for a substantial investment of time. Understanding what is important to each individual is also critical in understanding what motivates each person to comply with such demanding tasks over lengthy periods. Participants spoke of the importance of a routine, availability of the right tools (e.g., compression garments), ongoing support of the staff where they received inpatient care, and the support of family and friends as critical to their consistency in self-management. The high rate of compliance reported by study participants also appeared to be influenced by their satisfaction with inpatient care. The affect of providers, participants' confidence in their expertise, and the thoroughness of preparation for self-management were mentioned as elements that contributed to their satisfaction. These findings are important, as patient satisfaction has been shown to have a direct effect on compliance (Cameron, 1996; Sitzia & Wood, 1997). However, the single greatest rea-

son for compliance with self-management procedures detailed by participants in this study was their history of living with lymphedema. The extent of the impact that uncontrolled lymphedema had on their lives was so great, and the consequences of noncompliance so threatening, that most participants appeared to view compliance as their only option. Once more, the importance of discovering and seeking to understand each individual's unique history of living with lymphedema is demonstrated, with those histories vital to health care providers as they collaborate with individuals in their treatment and instruction in self-management.

Limitations of this study include a small sample size and lack of racial diversity. In addition, the high rates of compliance described by participants might be related to the relatively short period since their inpatient treatment, as most participants had completed their inpatient treatment within the previous 5 years. Finally, the role of their histories of living with severe and debilitating lymphedema over many years as a motivation for compliance with self-management is unlikely to represent what would inspire individuals with less complicated and less advanced presentations of the condition. More research into what leads those individuals toward successful self-management is needed.

The experiences of the participants in this study add to our knowledge of how non-cancer-related lymphedema affects the lives of those who live with it. These findings provide insights relevant to health care providers in their efforts to provide appropriate care for people with lymphedema. In addition, they highlight the need for attention to a wide spectrum of issues from multiple stakeholders, including third-party payers, educators, researchers, and clinicians. Of particular importance is the need for identification and implementation of concrete strategies to improve lymphedema awareness by the public and the medical community to reduce the time between onset and diagnosis. In addition, postdiagnosis, there is a need for better understanding of the role of inpatient care for individuals with severe lymphedema. In the long term, there is need for further understanding of the complexities of maximizing adherence with demanding, long-term self-management programs. Efforts such as these will, we hope, result in individuals with lymphedema having a place to turn early on, receiving effective treatment that results in fewer complications, and needing less room in their lives to manage this complex condition.

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