Living with lymphoedema and obesity: Implications for training, communication, and management considerations

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Key words

Lymphoedema, Obesity, Management, Medical training, Patient–provider communication, Qualitative

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Abstract

Background: Excess weight is associated with an increased risk of lymphoedema in patients with breast cancer. Studies are lacking about the experiences of patients with comorbid lymphoedema and obesity. **Aims:** This study aimed to examine lymphoedema knowledge, management barriers and impact on wellbeing in those with lymphoedema and obesity. **Methods**: Twenty-six patients (10 male and 16 female) with a mean body mass index of 35.89 and secondary lymphoedema participated in focus groups. Using a grounded theory approach, transcript data were coded individually and compared. **Results:** Four themes were identified: (1) excess weight exacerbates lymphoedema and there were struggles to lose weight even though it would help manage symptoms; (2) patients were upset that physicians lacked lymphoedema knowledge and/or oncologists did not communicate with them about the risk of lymphoedema; (3) physical therapists were the main source of information; and (4) patients used multiple coping strategies to address challenges. **Conclusion:** Physicians need more training about lymphoedema and should be willing to refer patients for lymphoedema and weight loss treatment. Oncologists should communicate with patients about the risk of lymphoedema before cancer treatment.

Lymphoedema is a chronic condition in which excess lymphatic fluid collects in the body, usually in the extremities (Bogan et al, 2007). A higher body mass index (BMI) is associated with a greater likelihood of developing lymphoedema and faster lymphoedema progression in patients with breast cancer (Johannson et al, 2002; Mak et al, 2008). Once diagnosed, lymphoedema requires daily management to reduce the possibility of disability (Ogawa, 2012). Effective management depends on complex decongestive therapy (CDT: manual lymphatic drainage, compression, skin care and exercise), which are taught during the decongestive phase (Ogawa, 2012; Kim et al, 2007). Once swelling stabilises, the patient moves to the management phase, which is often most challenging for patients, as it requires them to perform self-massage and compression wrapping on their own or with the assistance of a family member or friend.

Qualitative studies with patients who have lymphoedema have focused primarily on those diagnosed after receiving treatment for breast cancer (Meiklejohn et al, 2013; Thomas-MacLean et al, 2005; Tsuchiya et al, 2012). Two recent studies conducted in the US and UK found patients report lymphoedema to be difficult because of: health professionals' limited knowledge of lymphoedema; difficulty accessing effective treatment and supplies; low social support; and feeling that healthcare professionals ignore their emotional needs (Barlow et al, 2014; Ridner et al, 2016). To our knowledge, previous qualitative studies have not examined the impact of lymphoedema on the lives of patients who are also struggling with excess weight. Understanding the specific challenges reported by patients with these comorbid conditions could be helpful for practitioners as they communicate with and assist patients and develop treatment plans.

The purpose of this focus group study was to determine what and how patients living with both lymphoedema and excess weight learned about lymphoedema and its management, the barriers to lymphoedema management and the impact of lymphoedema on wellbeing.

Methods

This study was approved by the Beaumont Health System Institutional Review Board. Patients were required to have a diagnosis of lymphoedema, be ≥18 years of age, have a BMI ≥25 and speak English to be eligible to participate. They could not be pursuing medical litigation, as we were concerned about the impact of this process on the data content we collected. The second author (Isbell) and another physical therapist (PT) searched the medical records to find patients who had received PT for lymphoedema in the past 2 years and met the age and BMI criteria. All patients had been referred to a PT after being diagnosed

Table 1. Demographic characteristics of participants.

Characteristic	*n* (%)
Sex:	
Female	16 (61.5)
Male	10 (38.5)
Ethnicity:	
Caucasian	20 (76.9)
African-American	6 (23.1)
Body mass index:	
Overweight (25.0–29.9)	7 (26.9)
Class I obese (30.0–34.9)	6 (23.1)
Class II obese (35.0–39.9)	6 (23.1)
Class III obese (≥40)	7 (26.9)
Marital status:	
Married	15 (57.7)
Divorced	4 (15.4)
Widowed	4 (15.4)
Separated	2 (7.7)
Single	1 (3.8)
Education:	
Bachelor's degree or higher	15 (57.7)
Associate's degree or some college	5 (19.2)
High school diploma	6 (23.1)
Employment status:	
Retired	16 (61.5)
Employed	6 (23.1)
Unemployed	2 (7.7)
Retired and employed	2 (7.7)

with lymphoedema by a physician on the basis of a history of cancer surgery with lymph node removal or radiation treatment for cancer or a family history of lymphoedema. Seventy-three potential participants were contacted by phone and invited to attend a focus group. Of these, 14 declined to participate and 33 did not call back to learn more about the study, did not show for a focus group or had died. All 26 individuals who showed for a focus group met the eligibility criteria.

Participants completed the informed consent process on arrival at the physiotherapy clinic. Height and weight were measured using equipment available at the clinic (Seca digital wheelchair scale and a Seca wall-mounted stadiometer). Participants were asked about any current medical litigation and completed demographics and health questionnaires.

Kozak was lead facilitator and was assisted by Isbell and typically another PT. Kozak and Isbell had no prior interactions with participants. Each focus group was audio-recorded and one undergraduate research assistant took notes to help create accurate transcripts, which were checked by Metzer.

Questions from an Institutional Review Board-approved list were asked. Follow-up questions were used as needed for the purposes of clarification and exploration of topics brought up by participants. Focus group questions can be obtained from Kozak. Data saturation occurred after five focus groups.

Data analysis was completed by hand using grounded theory and the constant comparative method (Glaser and Strauss, 1967). Grounded theory is an inductive approach that provides the opportunity to identify a theory or core category/theme (Glaser and Strauss, 1967; Braun and Clarke, 2006; Corbin and Strauss, 2014). All four authors participated in the analysis by independently noting potential themes/accompanying text for each transcript, discussing their lists of themes/text, and developing a final list of themes and subthemes. All five transcripts were reviewed one last time using the final list of themes to identify additional relevant text (Miles and Huberman, 1994).

Results

Sample description

A total of 26 individuals (mean age 63.2 years, mean BMI 35.89) participated in focus groups. Over 65% (*n*=17) were currently trying to lose weight, with self-help (eg exercising at home, calorie reduction) being the most common method. The majority of participants (69%, *n*=18) reported attempting to lose weight three or more times over the course of their lifetime.

All participants had developed lymphoedema in adulthood; 14 after cancer treatment. The remaining 12 had non-cancer-related diagnoses, such as injuries and surgeries; some were unable to identify a cause. *Table 1* provides the demographic characteristics of participants.

Qualitative results

Four main themes emerged from the five focus group discussions, see *Table 2*. First, some participants described a struggle with weightloss even though it would help manage their lymphoedema symptoms. Second, many spoke about their unpleasant experiences with physicians who had little knowledge about lymphoedema. Further, a number of participants who had received treatment for cancer stated they had not been told about their risk of developing lymphoedema. Third, participants described learning about lymphoedema primarily through PTs. The main knowledge topics included self-management skills, negative consequences of lymphoedema and what makes lymphoedema worse. Finally, participants discussed the challenges of lymphoedema self-management (financial, time, emotional) and coping strategies used (planning and instrumental support).

Weight struggles in patients with lymphoedema

Some participants discussed their struggles with excess weight. They talked about efforts to exercise and change their diet and their difficulty reducing their weight. A few commented that medications have been additional contributors to weight gain and have made it very hard to lose weight. Participants stated that excess weight makes lymphoedema and other medical conditions, such as heart failure, worse and that their weight issue makes it harder to manage symptoms of lymphoedema.

Implications of limited physician knowledge and inadequate communication with patients

According to many participants, physicians do not have adequate knowledge about lymphoedema, which has caused a number of frustrating and upsetting problems. For example, participants described struggling to receive the correct diagnosis and subsequently having delayed access to self-management skills training. They spoke about treatment options suggested by their physicians, such as taking aspirin, using a compression pump or taking a diuretic; these treatments are not recommended by lymphoedema experts as they are not effective. Further, a number of participants diagnosed with lymphoedema secondary to cancer treatment talked about medical staff (particularly oncologists) not communicating the possibility of cancer treatment leading to lymphoedema. They spoke about feeling upset they now had another medical problem that could possibility have been prevented.

Table 2. Themes and representative quotes.

Theme	Representative quotes
Weight struggles in patients with lymphoedema	"I can't drop an ounce! I have not been able to lose a pound. The more I diet, the more I gain." "Umm, my weight interferes as I am trying to wrap my stomach, it's so big and everything… I know that if I could lose the weight this would help with the whole process, so I don't know what's the matter with the mind there." "When I was first diagnosed with lymphoedema I think I had [a] stage where I was just eating anything and everything and I knew that wasn't the answer either. But being at home and having it available to do, I just did it. And then all of the sudden something hit me over the head and said: 'Hey, you know what, you're not going to get any better if you don't change some of these lifestyles.'"
Implications of limited physician knowledge and inadequate communication with patients	"There was never one conversation with anybody on that staff. I had no idea that I was at risk for it and that it could be an effect of the surgery, and when I called the surgeon he said my arm is really swollen up but 'I'm not really sure what's going on.'" "I can't tell you how many doctors I've talked to who didn't know anything about it…" "I have had swollen feet since I was 20 years old. And I went to different doctors and they didn't recognise what it was." "I was misdiagnosed. My doctor said I have fibromyalgia. She said, 'Go see a pain specialist', and I did my own research. She didn't refer me to anybody. And I found Dr X and I walked in and said, "I have severe pain. I supposedly have fibromyalgia." He looked at me and said: 'You don' have fibromyalgia. You have lymphoedema complicated with lipoedema.'" "I talked to my oncology and my primary care physician. They knew it was lymphoedema but they didn't know what to do about it." "Yeah, because aspirin will take away the swelling and I told them, 'I can't, I'm allergic to aspirin.'"
Patient knowledge about lymphoedema: How and what	"I think they [physicians] kind of just leave it up to the therapists who deal with patients every day and [have] worked out the answers to almost any question they can be asked." "Now I know what can bring it on." "I was diagnosed initially after my bilateral and I thought I had a grip on it until I came here [the physical therapy office]! And then they taught me truly how to maintain it [...]. You know, having to wrap all the time, but they had a lot of information." "Well they [the physical therapist] said to bring in my partner so they could show him how to do the massage. So he came in here a couple of times and they worked with him so that he knew what he was doing." "We're welcome to come back here [to the physical therapy clinic] at any time to see anybody."
Lymphoedema self-management challenges and coping strategies	"The procedures and things that my therapists have taught me how to do [...] you know I fall short sometimes. I'm being perfectly honest of not wrapping my legs and things in that nature but I'm only hurting myself because I've already been told by the therapists it's an ongoing everyday process." "Don't you all feel like you're pushing a rock up a hill? And you're just never going to get to the top? But if you let go of the rock it's gonna crush you so you have to just keep pushing and pushing… and that's how I feel about it. I'm not pleased to have yet another medical complication to worry about and deal with. [...] when you get right down to it you just have to do what's been instructed, educate yourself about your condition as much as you can and go forward from there… but you're still pushing a rock up a hill." "I was having my own self-pity parties…" "I was quite surprised with the expense that's involved with the applications that you have to purchase for lymphoedema. The doctors didn't explain that either about those things. But, um, when I got my grand total I almost passed out at how much I had to purchase, but I knew I had to get it in order to correct and change my lifestyle around somewhat." "It's definitely a commitment to make sure you do this every single day and, um, it does take a lot of time. It takes a lot of time to go through the lymphoedema massage and then to um, wrap and do those other things that you do for that." "Well yeah, when you're dealing with a sickness the biggest issue is feeling support so you can get through it. If you feel like you're in it all on your own the outcome is not likely to be very good because you just kind of start shutting down."

Patient knowledge about lymphoedema: How and what

The majority of participants explained that they learned about lymphoedema from PTs. They mentioned that physicians who know what lymphoedema is typically refer patients for physiotherapy and leave it to PTs to explain all aspects of the condition and to answer any questions. Participants stated that PTs were not only lymphoedema experts but were willing to provide self-management guidance via post-treatment follow-up appointments if needed.

Other sources of lymphoedema knowledge included the internet, one specific physician in the area with lymphoedema expertise, and the experience of living with lymphoedema.

Participants spoke about:

- Learning self-management skills, ie lymphatic massage, proper wrapping/

wearing of compression garments, exercising, elevating legs and appropriate lotions to protect the skin
- Negative consequences of lymphoedema, eg cellulitis, pain, swelling, being unable to engage in usual activities
- What makes lymphoedema worse, eg exposure to hot water or weather, not following self-management recommendations.

Lymphoedema self-management challenges and coping strategies

Participants discussed the challenges involved in lymphoedema self-management, given that it is a chronic condition. They spoke about the necessity of PTs to teach the patient and family members (e.g. spouse) proper massage techniques and appropriate wrapping of affected areas of the body.

Some participants talked about how insurance companies typically place a limit on the number of physical therapy sessions patients can receive. Some mentioned that wraps and compression garments are not covered by insurance, so there is a continual cost burden for them.

Many discussed how time-consuming self-management techniques are. Others spoke about the emotional burden of this condition; they have felt 'overwhelmed', 'exhausted', 'frustrated' and 'helpless'.

Some talked about the importance of accepting that there will be set-backs at times and how planning for relapses and knowing how to get back on track are important. They also discussed the importance of establishing a routine from the start, making self-management a priority, and knowing their 'limits' as essentials for good self-management. Further, participants said that family members (primarily spouses) providing massages and putting on compression wraps was helpful.

Some individuals expressed an interest in attending a lymphoedema support group to share information and provide support. No one was aware of any available groups.

Discussion

This qualitative study enrolled patients with two difficult medical conditions, lymphoedema and overweight or obesity. Most participants in previous focus group studies had lymphoedema secondary to cancer treatment (Thomas-MacLean et al, 2005; Tsuchiya et al, 2012; Meiklejohn et al, 2013; Barlow et al, 2014; Ridner et al, 2016). We enrolled patients regardless of the cause of lymphoedema. We are not aware of any other qualitative study examining the impact of lymphoedema on patients also struggling with excess weight.

Weight-related discussions happened during the focus groups, even though none of the questions were focused on this topic. It is well-documented that weight loss is difficult for many people (Harvey-Berino et al, 2010), so it is not surprising that participants also brought up this challenge. However, it is noteworthy that some described excess weight as not only interfering with lymphoedema self-management, but also making lymphoedema and other medical conditions worse. Practitioners working with patients who have lymphoedema need to communicate about the possibility of excess weight making lymphoedema worse so patients who are normal weight can work to prevent weight gain. Patients who already have lymphoedema and are overweight or obese should be referred for appropriate weight-management assistance, as our data suggest self-help was the most prevalent method used for weight loss attempts and excess weight exacerbates lymphoedema.

Two issues reported by participants were the lack of physician knowledge regarding lymphoedema and oncologists not communicating about the possibility of lymphoedema onset after cancer treatment. The fact that some participants stated they had not received information about the risk of lymphoedema is in line with other studies. It is problematic because patients might not have the opportunity to truly make an informed decision about their cancer treatment plan (Thomas-MacLean et al, 2005; Tsuchiya et al, 2012).

Participants identified a number of implications of physicians' lack of knowledge, including delayed diagnosis, delayed treatment and ineffective treatment recommendations. Some said they were given recommendations for ineffective treatment options, which is problematic and could be fixed if medical education was changed. In the UK, focus group participants with lymphoedema resulting from different causes reported interacting with physicians who lacked knowledge, which subsequently delayed diagnosis and treatment (Watts and Davies, 2016). Vuong et al (2011), who conducted a review of medical training for lymphoedema, found that US medical schools teach about the lymphatic system under the umbrella of the cardiovascular system and that the total time spent on the lymphatic system is typically under 30 minutes. They consider that lack of physician knowledge could be remedied by medical schools and state that physicians should be trained to identify lymphoedema, be knowledgeable about differential diagnoses and be aware of effective treatment options. Our data suggest physicians do not need to be well-versed in treatment, but do need to:
- Be willing and able to communicate with patients generally about complex decongestive therapy (CDT)
- Know that PTs are qualified to teach patients self-management skills
- Be willing and able to communicate with patients about the connection between lymphoedema and obesity
- Be willing to provide possible referral sources for CDT and weight management, both of which will involve different specialists.

Given that receiving a cancer diagnosis and going through treatment is stressful, it is possible patients might not recall the provision of lymphoedema-related information by oncologists. However, as so many participants stated they had not received any information, it is likely they were not told about their risk of developing lymphoedema. Therefore, at a minimum, oncologists need to educate patients about lymphoedema before a cancer treatment plan is solidified. It might also be useful to have more than one conversation about this important issue.

Participants were very clear about the necessity of PTs for successful management of lymphoedema. They described learning CDT techniques from PTs and PTs as being not only lymphoedema experts but approachable even after CDT was completed.

Possessing self-management skills does not mean that living with lymphoedema is easy, as there is an emotional burden and treatment has out-of-pocket costs and is time-consuming. Participants in other focus group studies have also spoken about treatment cost issues. For example, in one study multiple participants admitted to using compression sleeves that were stretched out because of a lack of insurance coverage or limits set by insurance companies regarding the number of supplies that can be purchased (Thomas-MacLean et al, 2005).

Strengths and limitations

A strength of this study is that we were able to recruit men. This is important for two reasons. First, women are more likely to be diagnosed with lymphoedema due to much more frequent breast cancer treatment, but men can also have lymphoedema as there are multiple causes. Second, it is common for obesity-related studies to only enrol women. This is problematic given that men can also struggle with excess weight. Therefore, we thought it was important to interview both women and men.

This sample was recruited from patients who had received CDT, which could be viewed as a limitation because their responses to questions might be different from individuals who had not received treatment. However, the authors of a study in Australia advertised for participants and these individuals spoke about some similar themes to our participants, such as not being told about the risk of lymphoedema and treatment being both costly and time-consuming (Meiklejohn et al, 2013).

Conclusion

Focus groups identified that overweight and obese individuals find living with lymphoedema difficult, particularly as they are also struggling with excess weight, which many are aware exacerbates lymphoedema and makes it harder to manage symptoms. Those with lymphoedema secondary to cancer treatment are often not made aware of the risk of lymphoedema by their oncologists. Many physicians have insufficient knowledge of lymphoedema to recognise and refer patients for CDT early in the disease process, when lymphoedema can more easily be managed.

Physicians should refer patients for professional weight management as needed. Although it might not be possible to prevent lymphoedema, unnecessary distress could be avoided if oncologists spent time educating patients about lymphoedema prior to deciding on a cancer treatment plan.

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