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ORIGINAL ARTICLE

How people construct their experience of living with secondary lymphoedema in the context of their everyday lives in Australia

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Abstract
Purpose The purpose of this work was to explore how men and women construct their experiences living with lymphoedema following treatment for any cancer in the context of everyday life.
Methods The design and conduct of this qualitative study was guided by Charmaz' social constructivist grounded theory. To collect data, focus groups and telephone interviews were conducted. Audiotapes were transcribed verbatim and imported into NVivo8 to organize data and codes. Data were analyzed using key grounded theory principles of constant comparison, data saturation, and initial, focused, and theoretical coding.
Results Participants were 3 men and 26 women who had developed upper- or lower-limb lymphoedema following cancer treatment. Three conceptual categories were developed during data analysis and were labeled "accidental journey," "altered normalcy," and "ebb and flow of control." "Altered normalcy" reflects the physical and psychosocial consequences of lymphoedema and its relationship to everyday life. "Accidental journey" explains the participants' experiences with the health care system, including the prevention, treatment, and management of their lymphoedema. "Ebb and flow of control" draws upon a range of individual and social elements that influenced the participants' perceived control over lymphoedema. These conceptual categories were interrelated and contributed to the core category of "sense of self," which describes their perceptions of their identity and roles.
Conclusions Results highlight the need for greater clinical and public awareness of lymphoedema as a chronic condition requiring prevention and treatment, and one that has far-reaching effects on physical and psychosocial well-being as well as overall quality of life.

Keywords Cancer · Secondary lymphoedema · Quality of life · Qualitative research · Grounded theory · Social constructionism

Introduction

Secondary lymphoedema is one of the most feared and problematic sequelae of cancer treatment [1, 2]. It is characterized by swelling from excess accumulation of fluid in body tissues, predominantly affecting the limbs, although it can present in the trunk or other areas of the body [3]. It is a common outcome of cancer treatment, with at least 20 % of those diagnosed with melanoma, prostate, breast, or gynecological cancer developing lymphoedema following treatment [4]. The incidence of these cancers is increasing in developed countries [4], and consequently, lymphoedema is a growing public health concern.

Lymphoedema impacts physical and psychosocial well-being. Physical consequences include limb swelling, heaviness, tightness, fatigue, pain, and recurrent episodes of infection or inflammation [1, 5, 6]. Psychosocial consequences include distress, depression, anxiety, frustration, changes in role function, lack of social support, reduced body image, and social avoidance [7–9]. The consequent impact on health-related quality of life can exacerbate other cancer

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treatment-related side effects, such as depression, anxiety, and reduced physical function [2, 9, 10].

To date, qualitative research has been conducted to understand patient perceptions of lymphoedema [11–16], psychosocial effects of the condition [17], knowledge and management of the condition [19, 20], and its impact on work and the family [18, 21–23]. Key findings are that cancer patients often feel ill-informed about the risk of lymphoedema and that knowledge about lymphoedema within the community and health professional settings is lacking. Limited knowledge may contribute to the common patient experience of receiving inaccurate or inconsistent advice about diagnosis and management of the condition [12, 13, 15, 17]. Additionally, patients report that lymphoedema limits participation in daily activities, such as caring and home duties, leisure activities, and employment or, at least, requires major changes in the way these activities are undertaken [13, 22, 23].

Prior qualitative research has explored the impact of lymphoedema on quality of life using descriptive or phenomenological approaches. In doing so, lymphoedema and individual subjective experiences with lymphoedema have been described; however, these approaches do not acknowledge that people exist and act within a social environment and do not exist and act in isolation from external influences [24]. A deep understanding about the role of social context in shaping beliefs, meanings, and actions of those with lymphoedema over time is lacking. Further, women with upper-limb lymphoedema (ULL) following breast cancer have been the focus of previous lymphoedema research, yet lymphoedema is an issue for men and women and may present as ULL or lower-limb lymphoedema (LLL). The purpose of this study was to apply a social constructivist approach to explore how men and women construct their experiences living with lymphoedema following treatment for any cancer in the context of everyday life.

Method

Theoretical framework

Social constructionism theorizes that knowledge of everyday life exists as individual interpretation and is subjectively meaningful to people in a real and logical sense [24]. This framework further proposes that people are able to exercise individual choice and also react to social and contextual influences. It also acknowledges that individuals' actions influence others, and in turn, individuals are influenced by other's actions. This study applied a social constructivist framework to collect information about personal experiences with lymphoedema, including its impact on their daily lives, experiences with diagnosis and treatment, and related experiences involving family, friends, the health care system, and the broader society.

Sample

Following ethical approval (Queensland University of Technology HREC no. 0900001069), we sampled people who had received a diagnosis of lymphoedema by a health professional (e.g., oncologist, general practitioner, or physiotherapist) following cancer treatment, in order to obtain information-rich cases relevant to our research question in accordance with qualitative methods [25]. We included both men and women, but did not purposively sample to make gender comparisons. Participants were sought by placing advertisements in two editions of the Lymphoedema Association of Queensland newsletter (300 members) and in three community newspapers (circulation 140,000 households). Following expression of interest and verbal confirmation of cancer and lymphoedema diagnosis, participants were sent an information package and written informed consent was collected.

Data collection

The principal researcher (JM) conducted focus group interviews to collect data from participants who lived near the university campus and telephone interviews with all other participants. The focus groups were conducted in a private and accessible location at the university. There were two to four participants in each group, and an informal and flexible approach was maintained to allow deep exploration of experiences in a relaxed environment. The research questions were addressed using an interview guide with open-ended questions (Table 1). Open-ended questions allowed participants to reflect upon issues, past events, and contexts that significantly affected their experiences with lymphoedema. These

Table 1 Interview guide

Think back to when you were initially diagnosed with cancer, before you developed lymphoedema
How was lymphoedema portrayed to you?
How did you feel about the condition?
Since diagnosis with lymphoedema, can you describe your experience with it?
How has lymphoedema impacted on your daily life?
Is there anything that exacerbates symptoms of lymphoedema?
Is there anything that alleviates symptoms of lymphoedema?
Is there anything that influences how you treat or manage lymphoedema?
What other issues do you have with living with or treatment of lymphoedema?

questions and additional prompting questions (e.g., How did others treat you?; How do you think people perceived the condition?; How did it change your social situation, work situation, caring for your children?; How has lymphoedema changed your daily activities?) were formulated to encourage participants to share their personal understanding of the condition prior to diagnosis and their experiences of its onset; to share their understanding of how others perceived and portrayed the condition; and to share how the condition impacted their daily life, particularly on their work, family, and societal roles. An informal and flexible approach was maintained during interviews to allow deep exploration of experiences in a relaxed environment. All interviews were audio-recorded and notes on initial thoughts, ideas, and codes were written to supplement the recordings.

Data analysis

Interviews were transcribed verbatim and transcripts were imported into NVivo8 qualitative software. This software was used to organize and code data. In accordance with the constructivist grounded theory, initial, focused, and theoretical coding were performed [26, 27]. For initial coding, labels that reflected actions were applied to a word-by-word or line-by-line segment. Focused coding was then conducted to synthesize and explain initial codes. Lastly, theoretical coding was undertaken to specify relationships among categories to build a theory [26, 27]. Concept maps were used extensively to connect ideas and to consolidate into major categories.

Results

Twenty-nine people with secondary lymphoedema following cancer treatment participated in this study (Table 2). Sixteen participants took part in focus groups and the remaining 13 participants completed telephone interviews.

Table 2 Participant characteristics

Participants	$n=29$
Gender	Female, $n=26$
	Male, $n=3$
Age	Median, 63 years
	Range, 39–80 years
Residence	23 from Brisbane Metro area
	6 from regional areas
Cancer diagnosis	
Breast cancer	$n=20$
Gynecological cancer	$n=7$
Other	$n=2$
Duration since lymphoedema	Median, 8 years
Diagnosis	Range, 6 months–16 years

The intent of the analysis was to gain an insider perspective from those living with lymphoedema. The social constructivist framework allowed us to examine the meanings participants attached to the condition, particularly meanings over time and within a social context. Categories and concepts were derived directly from participants' accounts of their experiences prediagnosis, in the early stages of treatment with lymphoedema, and over the longer term. These accounts provided context to their experiences, with many referring to lymphoedema in relation to their cancer experience, themselves, their families, broader social situations, the workplace, and the health care system.

Three conceptual categories were developed from the data. The first, "altered normalcy," draws upon participants' accounts of the physical and psychosocial effects of lymphoedema and their impact on everyday life. The second category, "accidental journey" explores the "secret society" of a lymphoedema diagnosis and the importance of finding a health professional with knowledge and experience with lymphoedema and its treatment and management. The final category, "ebb and flow of control," reveals the elements that influenced participants' perceived control over lymphoedema.

The core category of "sense of self" was developed to explain relationships among the three categories (Fig. 1). Diagnosis with lymphoedema was described by most participants as a traumatic life-changing event that altered their "sense of self." Activities and roles participants previously enjoyed, the way in which they perceived their identity, and their capacity to care for themselves characterized their sense of self. Likewise, their sense of self influenced their sense of normalcy, their journey through the health care system, and their perceived control over their lymphoedema.

Altered normalcy

Participants' sense of normalcy was altered after receiving a lymphoedema diagnosis. Their view of normalcy was defined by roles and activities undertaken prior to developing lymphoedema or by the abilities and disability of others with and without lymphoedema. While some participants adjusted their perceptions of what was normal after their diagnosis, many felt unable to achieve what they perceived as normal. As one woman said, "I want to be back to normal and I haven't found a way to get there" (ULL, 60 years). Others talked about the importance of being seen as normal rather than as someone with a debilitating and visible chronic illness. One woman said, "Your body wasn't your body anymore, it was becoming this strange disability that you had to accommodate in your life" (ULL, 65 years).

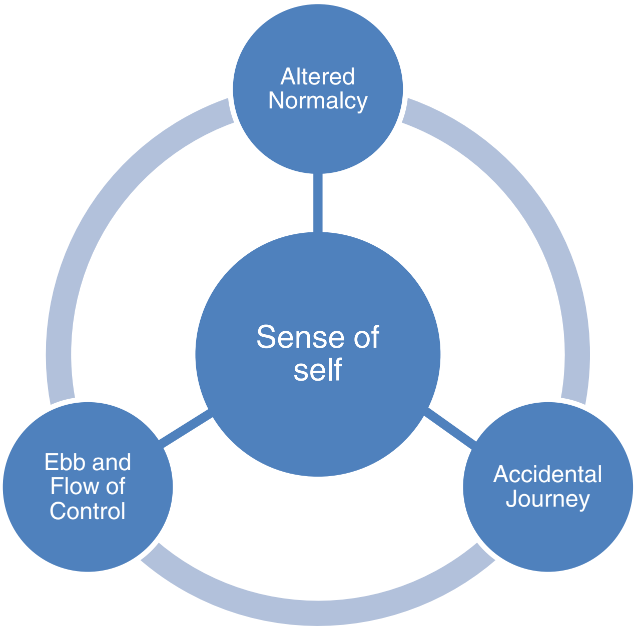

Fig. 1 Conceptual categories for how people construct their experience living with secondary lymphoedema in the context of everyday life

"It's not just a limb, it's a holistic thing"

The altered sense of normalcy reflected the all-consuming nature of lymphoedema. One woman said, "It's not just one limb; it's a holistic thing about how it affects your body" (LLL, 58 years). Consequently, some participants reported feeling disabled and not owning their own bodies or being labeled disabled by other people. Other participants reported that they were changed from an independent, fully functioning individual to dependent and disabled, altering their sense of normalcy and sense of self.

Participants described how lymphoedema affected their physical, emotional, and social well-being. Physical effects they described included sleep disturbances, cellulitis, pain, discomfort, loss of limb strength, loss of range of movement and coordination, tightness, heaviness, and heat radiating from the inside of the limb. Participants further described how the physical effects impacted them emotionally and their interactions with family, friends, and the broader society. Participants described shock, anger, and fear upon learning about their diagnosis of lymphoedema. During treatment and in the longer term, they spoke about their frustration, sense of loss, hopelessness, guilt, and depression. Combined with the physical effects, many described significant consequences to their job satisfaction, sense of achievement, independence, and quality of relationships with partners, family, and friends. For example, some participants described how a loss of physical function lowered their self-esteem, which resulted in their participating in fewer social and recreational activities with family and friends. One participant, describing her fear of some public situations, said, "I don't go down the supermarket; I just got scared somebody would bump me" (female, ULL, 77 years). Others reported that they felt embarrassed by their affected limb or by their compression garment, which served as a visible representation of the condition and led them to wear clothes that concealed the affected limb or compression garment. Comments such as "weight of depression" (male, LLL, 64 years); "I was ashamed" (female, LLL, 80 years); and "I'm not attractive and I guess incompetent" (female, ULL, 60 years) exemplify their emotions. The psychosocial changes that were occurring while participants were living with the chronic condition were highlighted when a participant said, "I suppose it's like a grieving process, you've got to go through different stages" (female, ULL, 67 years).

"It affected every aspect of your life"

The effects of lymphoedema were described in the context of daily living, recreational or physical activity, social activity, and employment. Most participants reported significant effects, which compelled them to limit, modify, or avoid various activities. One woman said, "You felt like you were running a race and you weren't quite keeping up with everyone" (LLL, 58 years). Participants described difficulties in undertaking normal daily activities, such as writing, driving, hanging out washing, opening bottles, carrying shopping, housework, and gardening, and many reported that repetitive activities, including vacuuming and ironing, were challenging and, for some, were avoided. Some participants shared stories about challenges to their roles as caregivers, which in turn, altered their sense of self through a change in role identification. For example, many spoke about difficulties in performing simple nurturing acts, such as simple household chores, cuddling, carrying, or holding hands with a small child or grandchild. Participant comments included "they want to sit on your lap and have a cuddle, that can be really difficult because, they don't understand" (female, ULL, 44 years); "pegging out clothes or doing the washing … I might do it in three goes instead of one go" (male, ULL, 56 years); "I can't vacuum the house" (female, ULL, 61 years).

Many described reducing work hours, modifying their work space, or being forced to resign from their career. One woman reported, "I was told to seek another career … it's a change that was forced on me" (ULL, 52 years). Several participants also described being unable to participate in activities spontaneously because lymphoedema required planning and preparation. Such limitations impacted participants' abilities to develop and engage in close relationships and to fulfill plans and aspirations, contributing to stress and disappointment within relationships and again impacting their sense of self. Participants also discussed their increased reliance on partners, family, friends, or community support for assistance with the lymphoedema management or with daily activities. In general, participants longed to participate uninhibited in everyday activities, including dressing without considering the affected limb, to reclaim their pre-lymphoedema sense of self.

"Accidental journey": experiencing the health care system

Interactions with the health care system were portrayed as an "accidental journey." Many participants reported that the condition was under-recognized and underestimated within all areas of the health care system. Thus, they were often not informed that they could develop lymphoedema and either stumbled upon or had to seek out information about diagnosis and treatment themselves. One woman said, "Am I in for some sort of secret society and I accidentally fell through the door and now I'm getting some information?" (LLL, 64 years). Many accounts were shared of health care professionals' inability to facilitate diagnosis, treatment, and management of lymphoedema. Participants also reported negative and condescending attitudes from health care professionals and discussed the lack of readily available information or the conflicting and inconsistent advice that was received. Men and people with cancers other than breast cancer were particularly ill-informed. One man said, "Everything was aimed at women … you [men] were more or less ignored" (ULL, 71 years). This contributed to the "accidental journey" whereby some participants, faced with no clear guidance, experimented with lymphoedema management strategies on their own.

In contrast, when participants found a health care professional knowledgeable in lymphoedema, that person was described as a "lifeline", crucial in the long-term management of the condition. This health care professional was typically a physiotherapist with specialist training in lymphoedema management. However, all participants noted that treatment came with considerable financial, time, physical, and emotional costs. The strength of the relationship with a lymphoedema specialist, along with the feasibility and perceived benefits of undertaking treatment in the context of daily life, influenced treatment uptake and adherence.

Ebb and flow of control

This category reflects the perceived control participants had over their lymphoedema, which contributed to their sense of self. Participants' perception of control was shaped by individual and social influences and the context in which they lived and worked as well as the period of time since diagnosis.

Most participants reported initially denying or avoiding accepting a lymphoedema diagnosis, and some struggled to progress past this point. A woman said, "I kept thinking somebody's going to re-diagnose me and I haven't really got lymphoedema" (ULL, 61 years). Control over lymphoedema was challenged due to difficulties in remaining physically active or performing lymphoedema treatment and management strategies. A man said, "I can't exercise too much on my right arm because it becomes too tired; I have a set of exercises I can do … I don't do those probably as much as I should" (ULL, 56 years). Some described difficulty maintaining lymphoedema management alongside other daily commitments. Others described fluctuations in their lymphoedema regardless of their commitment to its treatment and management. One woman said, "Lymphoedema seemed to be something like an incoming tide; … there didn't seem to be anything you could do about it" (ULL, 63 years). Participants who were elderly, living alone, or living with comorbidities also reported being challenged in gaining control over the condition.

Maintaining a positive outlook and sense of humor, accepting ownership of the condition, actively seeking information, and being persistent with treatment were described as strengthening participants' sense of control. Comments such as "everything ultimately is possible" (female, LLL, 63 years); "you've got to get out there and think for yourself" (female, LLL, 63 years); and "through knowledge … control is gained of it" (female, LLL, 66 years) illustrate these elements. A social force that participants described as influencing their sense of control was that of giving and receiving support. Support was expressed as psychosocial support from family friends and the broader public as well as physical support through the provision of resources to treat and manage lymphoedema. Comments such as "My partner's very supportive" (male, 57 years); "My friend and I give encouragement to each other" (female, 67 years); and "The school were wonderful … they put air-conditioning in … I had a special desk so you could put your foot up underneath" (female, 58 years) typify these descriptions. When confronted with a lack of support and understanding, participants spoke about trying to reduce the significance of the condition and limiting their involvement with lymphoedema management strategies. They also described their frustration, depression, and feelings of being lost or alone. As one participant said, "People don't understand what it is and I look fine … I still sometimes have to explain to people why I do what I do, and I don't know if everybody really understands" (female, 61 years). Conversely, remaining physically active and adapting daily routines and activities to accommodate lymphoedema management were described as strengthening a sense of control over lymphoedema. Participants remarked, "We're very lucky that we've been able to change our lifestyle" (male, ULL, 56 years); “After I knew that I could exercise, I could do things and take control of it; it wasn’t controlling me … it was a period of years though” (female, ULL, 63 years); “My husband has supported me all the way” (female, LLL, 82 years); and “Being in a support group really helps you to stay focused” (female, LLL, 60 years). Although some participants considered themselves active players in the control of their lymphoedema, many also believed that “luck” was involved. One woman said, “I’m pretty lucky, it’s not that bad” (ULL, 63 years). Participants also described comparing their condition to others with lymphoedema of similar extent, rather than their pre-lymphoedema self or people without lymphoedema, as a way to maintain perspective on their level of control over lymphoedema. One man remarked, “It doesn’t get to the extent of the swelling that some of the women experience” (ULL, 70 years).

Discussion

Participants’ “sense of self” following a lymphoedema diagnosis was clearly challenged by experiences of an “altered normalcy,” the “accidental journey” travelled in diagnosis and longer-term management of lymphoedema, and the perceived “ebb and flow” of their control over lymphoedema. While “sense of self” evolved over time, it was clear that the experiences of living with lymphoedema extended well beyond the diagnosis period and also beyond those living with the condition to partner, family, social, and employment contexts. Participants also described the physical and psychosocial implications of dealing with an enlarged limb, as well as reported how managing lymphoedema negatively impacted relationships with partners, family, friends, and work colleagues. These important findings highlight the need for a comprehensive approach to the management of lymphoedema that encompasses attempts to minimize swelling and progression and optimize physical and psychosocial function.

Findings from this study also highlight areas of lymphoedema management that require improvement. Our participants reported that information available on lymphoedema is most relevant to women with ULL following breast cancer. The relevance of this information to men or people with ULL or LLL following other cancers is unclear. Patient assessment of their lymphoedema severity and its impact on their lives may not reflect clinical judgment of severity, which is typically guided by the size of the limb. Furthermore, based on our findings, patients’ adherence to prescribed lymphoedema treatment is a consequence of comparing perceived treatment benefits and costs, and for some people, even when treatment can lead to significant benefits, the financial and time costs make treatment unattainable. Thus, there is a need to improve patient-directed education material and account for patients’ perceptions of lymphoedema severity in the diagnosis of their condition. Also, our findings suggest that prescribed treatment requires consideration of patients’ various roles, time constraints, and lymphoedema needs and may benefit from integrating family or other support people into diagnosis and treatment sessions.

Within the health care system, participants reported a lack of awareness about lymphoedema and its appropriate treatment, inadequate provision of timely and relevant information about lymphoedema, and a lack of understanding and support from health care professionals. Such issues have been reported previously [11, 13, 15, 19, 28] and are likely not unique to people with lymphoedema. A 2011 survey compared the health care experiences of patients with complex needs treated in various countries [30]. Overall, 55 % of Australian patients reported gaps in hospital discharge planning and 19 % reported that neither their medical specialist nor regular doctor were informed about their specialist needs. These findings, particularly when considered in light of our findings that knowledgeable health care professionals are “lifelines,” draw attention to the need for greater awareness of and education about lymphoedema within the health care system. This would assist in the provision of relevant and timely information and would strengthen recognition from the broader health care system that lymphoedema is a chronic condition requiring ongoing attention. Increasing the focus of the lymphatic system and its associated disorders within medical and allied health undergraduate and postgraduate degrees would be one strategy to achieve this, and the promotion of lymphoedema-specific courses by professional associations as continuing education would be another. Such actions would lead to significant improvements in the “accidental journey” through the health care system that is currently experienced by people with lymphoedema.

In an effort to improve public recognition of lymphoedema, lessons could be learned from the breast cancer experience. As recent as the 1980s, breast cancer was shrouded in secrecy and it was not until individual women and well-known identities began to publicly share their stories that the silence broke [29]. The success of breast cancer advocacy has been further accredited to a rise in public education and fundraising, the uptake of political action for change, and sufficient support from business, government, and scientific communities [29]. Similar action could help to bring lymphoedema “out of the closet.”

Other key findings in this study are that both social and individual factors influenced participants’ changing perceptions of control of lymphoedema over time. These findings extend what has been learned from previous research on coping mechanisms of women with lymphoedema following breast cancer treatment [11, 13, 20, 23]. Specifically, women cope by taking ownership, having a positive outlook, being committed to treatment, having strong support, and adapting one's daily life. Our findings combined with these previous findings draw attention to the need to understand how best to achieve a balance between self-management and care from specialists in lymphoedema treatment. To do this, lymphoedema prevention, treatment, and management guidelines must be revised to compliment, not compete with, a person's lifestyle, and they must be sensitive to the social contexts in which the condition is experienced.

The major strength of this study is that it is the first qualitative study to explore the role of social context in how people understand and experience everyday life living with lymphoedema. Unlike previous qualitative analysis of the lymphoedema experience, our use of this approach recognizes the important influence of both individual choice and social context in how people interact with and respond to situations after a lymphoedema diagnosis. The main study limitation is that, despite attempts to recruit broadly, all except one participant were members of the Lymphoedema Association of Queensland. As members, they may have been more likely to be information seekers, to receive support, or to have more severe lymphoedema than nonmembers, which could have influenced the experiences reported in this paper. Nonetheless, this study was able to capture experiences of men and women with ULL and LLL following treatment for various cancers, including participants who resided in metropolitan and regional areas, and the study provides the first in-depth account of peoples' experiences living with secondary lymphoedema in Australia. It could be argued that data saturation was not reached among subgroups such as men or those with lymphoedema following cancer other than breast cancer; however, the objective of qualitative research is to reach data saturation among the participant sample and not of subgroups. There was no intent in this study to separately analyze responses between male and female participants or participants with ULL versus LLL, and during analysis, the experiences of all participants were captured and included in the breadth and depth of the categories. Moreover, while the study was advertised to groups that include men and women with lymphoedema, as is often the case with studies in this field, women more readily participated in this study than did men, and as a result, the experiences of women dominated the current work. The experience of men with lymphoedema is a distinct area for the focus of future research. Participants brought to the study a broad range of experiences that related to their "sense of self." The "altered normalcy," "accidental journey," and "ebb and flow of control" represented the processes people used to construct their experiences living with secondary lymphoedema in the context of their everyday lives. In summary, their experiences demonstrated that lymphoedema impacts all aspects of daily life, requires experienced health care professionals in its diagnosis and treatment, and a comprehensive approach to longer-term management that addresses both the physical and psychosocial needs of people with lymphoedema.

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