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Physical activity in the lives of those living with lymphoedema following cancer treatment

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Abstract

Background: Despite recent evidence demonstrating that exercise neither increases risk of nor exacerbates lymphoedema, lymphoedema prevention and management advice cautions against 'repetitive use' or 'overuse' of the affected arm. It is plausible that this advice creates a barrier to participation in exercise and, more generally, physical activity (any daily activity [PA]). This study explored the relationship between lymphoedema and PA among people following cancer treatment. *Methods:* Social constructionist grounded theory guided study design, development of interview questions and the qualitative data analysis approach undertaken. Data were collected via focus groups and telephone interviews. *Results:* Five focus groups (n=16 participants) and 13 telephone interviews were completed. Participants (women n=26, men n=3) were aged 39-80 years and were experiencing mild to severe lymphoedema following treatment for a variety of cancers. Participants varied in how they defined PA. Its perceived importance was mostly associated with the ability to partake in daily activities, with only some participants highlighting its importance for lymphoedema management or more general health benefits. Most participants' PA decreased after diagnosis, a consequence of confusion around appropriate PA and fear that PA could worsen lymphoedema symptoms. *Conclusions:* Lymphoedema guidelines need to be more clear and specific when discussing the role of PA and exercise in the prevention and management of lymphoedema. It may be more appropriate to discuss ways to optimize safety when engaging in specific tasks rather than to highlight the need for avoidance of participating in certain activities.

Keywords

Cancer, experience, secondary lymphoedema, physical activity, exercise, impact

Introduction

There is a growing body of evidence that supports promotion of physical activity ('significant movement of the body and limbs' [PA]) [1], including exercise (planned activity to improve or maintain fitness), following cancer. Those who accumulate at least 150 minutes of PA per week post-cancer are considered sufficiently active [2] and report fewer and less severe treatment-related side effects and higher function, quality of life and potentially survival, compared with those who are insufficiently active or sedentary [3-7]. Preliminary evidence suggests that these benefits extend to cancer survivors with lymphoedema [8-10]. Furthermore, exercise intervention studies of people with, or at risk of, lymphoedema demonstrate that exercise neither exacerbates nor initiates lymphoedema [9,11-14]. However, most cancer survivors do not engage in sufficient levels of PA for health and disease-related benefits [7,15-17].

Lymphoedema prevention and management guidelines have traditionally taken a risk management approach. Guidelines caution against 'repetitive use' or 'overuse' of the affected limb and have failed to provide practical implications of this advice to individual's PA levels, including exercise. As such, there is suggestion that adherence to guidelines may have the unintended consequence of discouraging use of the affected limb [14,18] and thus contribute to reduced PA.

To better communicate risk reduction and management guidelines, it is important to understand how those with lymphoedema perceive PA, including how they define it, what they perceive its benefits to be and how having lymphoedema has changed their participation in PA. Therefore, the aim of this study was to examine the relationship between PA and lymphoedema in the context of everyday life, from the perspective of people diagnosed with lymphoedema following cancer treatment.

Participants and Methods

The overall research process was informed by the tenets of social constructivist grounded theory. Social constructionism acknowledges individual choices; highlights the powerful influence of contexts on human behaviour; and theorizes how norms, routines, and patterns of practice develop within those contexts and over time [19]. This theoretical approach is therefore relevant to exploring how people with lymphoedema construct their experiences with PA. Ethical approval for this qualitative study was sought and received (Queensland University of Technology [HREC #0900001069]).

People who had received a diagnosis of lymphoedema by a health professional (e.g., oncologist, general practitioner or physiotherapist) were recruited through study advertisements placed in the Lymphoedema Association of Queensland's state-wide newsletter (300 members) and in urban community newspapers (circulation 140,000 households in central Brisbane). Interested participants contacted study staff, at which time verbal confirmation of cancer and lymphoedema diagnosis was ascertained. Study information packages were then sent to eligible participants and scheduling of data collection was made.

Following informed consent, data were collected via focus groups for those who could travel to the university and via telephone interviews for those who could not meet face-to-face. An interview guide with open-ended questions was formulated to assist in

exploring specific research questions, although an informal and flexible approach was maintained to allow deep exploration of experiences. Participants were first asked about their experiences with lymphoedema and its consequences to their daily lives, and were then asked questions about their definitions of PA, its importance to daily life and descriptions of any changes in their PA since diagnosis with lymphoedema.

Audiotapes were transcribed verbatim immediately following focus groups and telephone interviews and then the data were imported into NVivo 8 (QSR International, Melbourne) for organising and coding. Deductive data analysis was conducted to enable conclusions to be drawn from the specific questions asked. During each step of coding, constant comparison of data, codes and concepts was conducted to compare and contrast statements, incidents, actions and experiences to previously coded data. Data saturation was determined when the categories accounted for all variations in the data collected.

Results

Twenty-nine people diagnosed with lymphoedema following cancer treatment participated in this study. Sixteen each participated in one of five focus groups, and 13 participated in individual telephone interviews. Three participants were men and 26 were women. The median age was 63 years (range 39–80 yrs), and the median time since lymphoedema diagnosis was 8 years (range 6 months–16 yrs). Six participants lived in regional and 23 participants in urban areas. Twenty participants had developed lymphoedema following breast cancer, seven following gynaecological cancer, one following prostate cancer and one following Hodgkin's disease.

Definition of PA: *“You don't realise until you have to avoid it...every single thing that you do is actually physical activity”* (female, lower limb lymphoedema [LLL], 52 yrs). While PA was broadly described as any action that requires movement, some participants conceptualised PA as exercise or the lymphoedema exercises prescribed by health professionals.

Importance of PA: *“You've got to stay physical; there's no doubt”* (female, LLL, 80yrs). Regardless of the definition attached to PA, participants agreed that PA is a vital aspect of everyday life. They spoke of its importance for performing daily activities, including independently caring for themselves and doing light house work. Some extended its importance to include being able to care for their family, undertake paid employment and participate in recreational and social activities. Only a few participants spoke about the importance of exercise (rather than PA more generally) for overall health, fitness or its lymphoedema-specific benefits. Being able to exercise gave some participants a sense of freedom from the limitations typically imposed by having lymphoedema.

Impact of lymphoedema on PA: *“My approach to it [PA] has changed”* (male, upper limb lymphoedema [ULL], 56 yrs). Three main concepts emerged during discussions about the impact of lymphoedema on PA: 'confusion', 'barriers' and 'perceived ability'.

Confusion: *“Believing from what I'd read and heard that you know, don't do repetitive work, don't carry heavy things, don't do heavy work....and that was like saying well instead of having a whole cake you could perhaps just have a crumb”* (female, ULL, 62 years). Participants expressed confusion both before and after their lymphoedema

diagnosis about appropriate PA for someone with lymphoedema. Many participants commented that the advice received from health professionals, written cancer care materials and lymphoedema prevention guidelines contributed to this confusion, with mixed messages being received about appropriate types and amount of PA, its safety and importance. For example, they reported one source saying that repetitive arm movements are considered safe, yet lymphoedema guidelines suggest avoiding repetitive arm movements.

Barriers: *“It [lymphoedema] has definitely been an impediment to me being more public in exercise”* (female, ULL, 60 yrs). Participants described being embarrassed about exposing the affected limb, and as a consequence, limited their recreational activities with family and friends and/or their participation in exercise. Comments such as *“more awkward...looking like an idiot”* (female, ULL, 52 yrs) and *“I would never go swimming in public”* (female, LLL, 59 yrs) typify these experiences. Participants also noted that they were hypersensitive to the current state of their affected limb as well as any changes in size and symptoms experienced, and consequently they were highly protective of their limb (e.g., avoided use) whenever possible. Compression garments worn by many were described as uncomfortable, hot and restrictive. Several participants highlighted that the challenges encountered when removing and reapplying compression garments during certain activities such as going to the beach or when swimming, reduced their participation in such activities. For example, *“if I take my garment off to go for a swim, it’s very hard to get it back on”* (female, LLL, 58 yrs). Fear of injury or of aggravating symptoms associated with lymphoedema was another clear barrier to PA. This fear often resulted in protective behaviours, such as avoidance of use of the affected limb: *“I was afraid to do too much with the leg; I didn’t want to do...damage or overwork it or anything in case it swelled up to the point where I couldn’t manage it”* (female, LLL, 80 yrs).

Having lymphoedema also influenced the desire or commitment to become or stay physically active. For some, having lymphoedema reduced their PA participation. They reported that the time and financial costs associated with managing lymphoedema as well as other co-morbid health conditions and/or maintaining care-giving and other societal roles took priority over PA. Some held the perception that exercise was not essential for recovery from cancer or for management of lymphoedema. One participant spoke about inactivity being beneficial for his lymphoedema and said, *“I know that [on] my quieter days [my arm] seems to be a lot better; if I’m sort of just sitting around just laying on the couch... or something, then lymphoedema seems to be better”* (male, ULL, 57 yrs). However, a few participants viewed PA as a means of preventing function losses and therefore made PA a core component of their lymphoedema management

Perceived ability: *“I had to start all over again”* (Laura, ULL, 63 yrs). Many participants perceived their ability to be physically active changed following a diagnosis of lymphoedema. Lymphoedema was viewed by some as a disability that prevented participation in PA (e.g., *“I want to be back to normal...I haven’t found a way to get there”* [female, ULL, 60 yrs]). Participants reported experiencing losses in physical fitness and feeling unbalanced (as one limb was larger and heavier than the other) due to their lymphoedema. For many, these changes meant their perceived ability to do their regular PA, including gardening, housework, bushwalking and horseback riding, was reduced. A participant confided, *“It’s [physical activity] gone from huge to nothing; well, that’s how I see it, nothing”* (female, ULL, 58 yrs). For others, these changes were

viewed as a stimulus or motivator to participate in PA. Nonetheless, even for those participants who wanted to be physically active, the need for support and advice about appropriate PA from health professionals knowledgeable about lymphoedema was clearly expressed. Participants felt such guidance would increase their confidence in their ability to do health-enhancing PA without aggravating their lymphoedema. One participant said, *“I’d feel a lot safer in that respect because so many people do not understand lymphoedema and they don’t understand the limitations of it”* (female, ULL, 71 yrs).

Discussion

When injured or wounded, the natural behaviour is to restrict movement of the affected limb, and this is largely reflected in current lymphoedema guidelines as well. Experiences of the participants interviewed for the present study shows that many follow this natural instinct and reduce their PA out of fear of ‘making things worse’ or ‘for their limb to become unmanageable’. Given accumulating evidence for benefits of remaining physically active even if affected by lymphoedema, this study highlights practical aspects that need to be addressed to support people with lymphoedema to stay or become again physically active.

Participants’ definitions of PA varied widely, with some considering all daily activities to be PA and others considering only exercise to be PA. Most participants, however, did perceive PA to be vital to all aspects of daily life, although only a few considered it important for lymphoedema management or long-term health benefits. Given the short and long-term health benefits associated with being regularly active following a cancer diagnosis, this is of public health concern. Educating people with lymphoedema of the relevant benefits that can be realized through participation in regular PA seems the likely first step in improving their knowledge and subsequently their behaviour. However, it will also be necessary to address the practical, day to day issues of living with lymphoedema that adversely impact PA.

The barriers to PA associated with having and managing lymphoedema in this study included physical, emotional, social and time constraints, all of which contributed to protective and avoidance behavior of the affected limb. Guidelines that encourage participation in PA need to acknowledge these barriers (e.g., difficulties associated with finding the right clothing for a certain situation; difficulties with putting on a compression garment after swimming; avoiding use of the affect limb to avoid harm) and suggest possible solutions (e.g., using scarves or loose fitting garments to cover the affected limb; swim prior to showering to avoid putting the garment on twice during the day; carry light loads to start [e.g., weight of grocery bag] and slowly increase weight of loads overtime). To address reductions in perceived ability, guidelines need to highlight strategies that can be used to optimize safe engagement in PA and exercise, irrespective of baseline fitness and function, for example, the importance of starting ‘low’ and progressing slowly. With respect to exercise, guidelines could suggest walking half the distance that people think they could walk without becoming fatigued or creating a change in lymphoedema symptoms and to then slowly increase the distance walked over time. Extra attention also needs to be given to the wording of lymphoedema prevention and management guidelines with a view to reducing confusion in the practical implementation of the guidelines. Confusion may be avoided or at least reduced if greater emphasis were placed on how to participate in certain activities safely rather than on

which activities to avoid. There would need to be a consistent message that participation in PA is appropriate, but that for specific tasks, changes need to be made to optimize safe participation. For example, instead of recommending to ‘avoid gardening without gloves’, guidelines could state, ‘when gardening, it is advisable to wear gloves’. There remains much to learn about the role of PA in the prevention and management of lymphoedema. While care and caution is recommended in attempts to prevent onset or exacerbation of lymphoedema, it is also important to recognize that the promotion of overly cautious or protective behavior may also have significant, adverse physical, emotional and/or social ramifications.

In summary, this was a qualitative study and the findings reflect the experiences of the participants involved. Participants shared a range of experiences about lymphoedema and PA that highlight the importance of societal and individual factors in influencing PA. The findings also suggest issues that need to be considered in the review of lymphoedema prevention and management guidelines, while also providing a platform from which further survivorship research can be built.

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