Experiences of men with non-cancer related lymphoedema UK-based online survey. Part two: findings and discussion

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Abstract

This article is the second instalment in the series. The preceding article detailed the background, methodology and methods, while the current article delves into the study's findings and alignment with the broader literature. The study aimed to explore the research question: 'how do men perceive their engagement in the self-management of non-cancer-related lymphoedema?' Upon completing an online survey based on the validated lymphoedema quality of life tool (LYMQoL), the gathered data underwent narrative thematic analysis. Three themes emerged: Theme 1 explored the strategies men use to address the psychological impact of self-care, including physical concealment. Theme 2 focused on the use of physical control as a method for managing perceived vulnerability. Theme 3 centred on relationships within self-care. The findings shed light on the intricate nature of self-care in the context of lymphoedema and its impact on masculinity. These insights resonate with existing literature, emphasising the use of available resources driven by the perceived vulnerability men experience in their lives.

Introduction

In the preceding article, the rationale for undertaking the research was elucidated, focusing on the dearth of research focusing on men diagnosed with non-cancer related lymphoedema in the United Kingdom and Ireland (Cooper-Stanton et al, 2024; 2022). As discussed earlier, lymphoedema is a persistent condition characterised by fluid accumulation in any part of the body, that can lead to tissue changes, and increased risk of infection (Wounds UK, 2023; Rankin, 2016). A prior systematic meta-aggregation review (Cooper-Stanton et al, 2022) highlighted the limited research and supported the qualitative approach adopted to address the research question: How do men perceive engaging in self-management of non-cancer related lymphoedema? This article will present and elaborate on the findings, incorporating direct quotes from the

participants. Subsequently, a discussion on the broader literature, an assessment of the study's strengths and weaknesses, and a concluding section will follow.

Findings

Data gathered from participants and the subsequent analysis led to three themes that collectively encompass the perceptions of men (*Table 5*). Pseudonyms were used to maintain confidentiality and were shown in *Table 4* in the previous article (Cooper et al, 2024). The themes were contextualised against hegemonic masculinity through its expression by men in the form of traits and behaviours and within the Health, Illness, Men and Masculinities (HIMM) framework discussed in the theory section.

Table 5 – Survey Themes

Theme 1 – Psychological impact of self-care and the renegotiations of hegemonic masculinity – Lymphoedema and the required self-care psychologically leads men to question their masculinity and the commencement of re-negotiations within their hegemonic masculinity by using their remaining capital.
Theme 2 – Physical control and its influence within hegemonic masculinity – Men face multiple levels of vulnerability to their hegemonic masculinity that requires them to strengthen and increase their existing capital through the acquisition of skills, expertise and knowledge within the physical management of lymphoedema.
Theme 3 – Support networks and renegotiation of hegemonic masculinity – Self-care can be strengthened by existing support networks and relationships within the man's social world. To embrace them as supportive, men must re-negotiate their hegemonic masculinity by using their capital to incorporate these changes within their male identity.

Theme 1 – Psychological impact of self-care and the renegotiations of hegemonic masculinity

In this theme the focus is upon the psychological impact of men self-managing their lymphoedema and the use of coping strategies aligned to their perception of hegemonic masculinity in the form of traits and behaviours. All men in the study indicated lymphoedema affected their masculinity in some way, such as physical strength and relational styles (friendships through shared activities):

> *'Since being diagnosed, I have given up my regular physical activities (military fitness, 5-aside football, surfing). I also have a lot of difficulty with other activities such as running, cycling, swimming and hiking.' (Alfie)*

Difficulties in undertaking sports or other recreational activities can cause a decline in physical and mental health and limits their ability to express themselves as a man through these activities. All men mentioned varying degrees of perceived vulnerability caused by lymphoedema, either in the present or in the past:

> *'I hate the fact that I am afraid of go for a swim or wearing shorts for self-consciousness reasons (…) this bugs me so much.'* (Harry)

> *'I constantly feel worthless, as I feel that I am not able to contribute to either my household or society.'* (Jake)

Coping strategies employed by men when self-managing their lymphoedema were varied, when considered against the expected hegemonic traits and behaviours. The dominant expressions were stoic:

> '*I try not to let it get me down.'* (Joe)

> '*I learned to cope.'* (Ben)

While some men indicated that the potential stoicism supported them in self-management, it does not factor in how men and their perceptions may have changed over time. This is in terms of the historical impact of lymphoedema when they first began to self-care and to their present perceptions:

> *'Lymphoedema has impacted me greatly, but it is now well-managed.'* (Andy)

> *'These are all good questions that can be scored differently depending on my feelings close to my original diagnosis 10 years ago compared to today.'* (Chris)

Andy and Chris assigned the changes that occurs to men over time to a more positive outlook, while other men who were at the beginning of their journey reflected the sentiment shared by Luke:

> *'I find it mad that I am dealing with this at my age.'* (Luke)

The quotes collectively indicated changes in perceptions that men have about themselves. However, the changes required to accommodate the condition and self-management involved trying to work around the limitations and/or to hide it from others. Thus the condition was never truly visible and men choose what was to be seen by others:

> *'I've had it so long that I have learned to work around it.'* (Harry)

> *'Other people are not aware that there is anything wrong with me. I no longer wear shorts as I don't want my compression garments to be visible. I have changed the style of trousers I wear due to my lymphoedema; I prefer loose fitting clothes.'* (Alfie)

By concealing their lymphoedema, men provided a curated version making them less vulnerable to themselves and others. However, this was not always possible due to the cause, severity, or management of the condition:

'I feel self-conscious because of my leg. I can't always find trousers that fit, which makes me both sad and angry.' (Matt)

Some men chose not to hide their condition and instead reframed it within their lives. The reframing was based upon the acceptance of the condition, set against their own and others' perceptions regarding the role of lymphoedema in their lives. This approach was different to concealment (to hide vulnerabilities) as strength was derived from their situation:

'I am not so worried about my image, mainly because I generally don't care what other people think.' (Will)

'I have grown to love being me after living with this condition for over 20 years.' (Ryan)

'Dealing with lymphoedema has been a source of strength.' (Arthur)

Men indicated the alterations within their perceptions of masculinity by expressing it through actions, such as concealment, avoidance, or challenging perceptions. The use of traits and behaviours can be supportive coping strategies for some men as they navigate the effect of their condition and can mitigate their perceived losses. The use of these strategies also extends to men who are attempting to physically control the impact of their lymphoedema.

Theme 2 – Physical control and its influence within hegemonic masculinity

In this theme, men focused upon the ability to physically control their lymphoedema, which is essential for the self-management of their condition. Its relevance to their masculinity and its expression is through formation of coping strategies that allow them to engage in self-management.

All men in the study engaged in some form of self-reliance, even adapting to the condition's changeable daily presentation:

'I am generally managing quite well at the moment.' (Arman)

'*My swelling is completely controlled by my stockings.'* (Ben)

'I am less mobile than others but adapt as the condition allows.' (Noel)

Words such as 'completely controlled' or 'generally managed quite well' indicate the internalisation of their masculinity and the use of supporting traits or behaviours such as self-reliance and independence. By Pursuing control can indicate a man's level of uncertainty and even fear about not being in control of their health condition.
All men experienced some form of physical complications associated with lymphoedema. For some men, these complications enabled them to gain experience and knowledge that they used when required:

'The condition can vary hugely depending on the day and even the weather. It can take its toll by the end of the day with a larger swelling and a heavy feeling.' (Luke)

'After a hard day's activities, my leg will feel uncomfortable but I try to manage it the best I can by elevating where possible.' (Arman)

The way men employed this knowledge and experience was by testing their endurance when engaging in past and current activities. This allowed them to anticipate and accommodate possible outcomes, thus enabling them to mitigate possible vulnerability:

'I cannot drive for longer than 90 minutes without taking a break.' (Chris)

'I learned where my breaking point was with lymphoedema.' (Ryan)

The quotes focus on the physical aspects in terms of establishing a 'breaking point'. Not all men perceived their compression in the same way, or accepted it fully within their lives, leading to potentially unmet needs:

> '*I do have days when I just want the lymphoedema to disappear. The stockings remind me every day that I have something wrong with my legs.'* (George)

> *'I have learnt how to manage my condition; most issues I face are internal.'* (Ryan)

Whether the quotes indicate the potential for internal stigma to be present, especially when engaging in the physical management of lymphoedema, is not explicitly clear in the findings. The tentative existence of stigma may indicate the potential complexity that is present when men engage in the physical control of their lymphoedema. This is especially relevant when they engage in activities that may be considered risky to establish what they perceive as a 'breaking point'. Equally, risk may lead men to avoid existing or potential support networks that have the potential of forming another coping strategy.

Theme 3 – Support networks and renegotiation of hegemonic masculinity

In this theme, the presence of support networks was perceived as another coping strategy, depending upon men's perception of masculinity at that time. A number of men reflected on the challenges that were faced in forming and maintaining relationships due to a limited understanding of the condition. A majority of men avoided groups-based activities in the past or present. It further isolated them and diminished their ability to socially connect with other men:

> *'The risk of infection prevents me from swimming and walking.'* (Noel)

'I have torn a meniscus due to weight gain and loss of fitness, which I believe is due to loss of interest in sport after the lymphoedema. This makes it very difficult to reverse things.' (Mike)

While the majority of men disengaged with the activities that gave them a form of social connectedness, a small number continued with the activities that they enjoyed, despite the possibility of complications:

'I have been involved in sports and exercise from a young age. I stay very active by going to the pool 3–4 times a week, the gym and a nine-mile walk.' (George)

Engagement in support networks, such as sports or relationships, was a rarity amongst the men. In most accounts, men avoided them owing to the potential perceived vulnerability and possible physical complications. Three men sought support from those closest to them, which in certain accounts extended to others:

'My wife is very supportive. Most people are very understanding, including my workplace and I do still volunteer.' (Will)

'I have a great marriage, but I do require a bit more support from my wife.' (Ted)

'My boyfriend is very supportive if I need it on a mental level and my employer is aware of my condition and has been great.' (Luke)

While some men sought support, which ultimately did not undermine their perceptions of themselves, others did not share the same perception:

'*I rely heavily on my wife to help clean, moisturise and apply dressings to my legs.'* (Jake)

The shifting of expectations within existing relationships can present as a challenge for men, when they perceive themselves as becoming dependent. A number of men did not

have any close support networks or found it hard to form new ones, in terms of finding a partner. This was due to the significance of self-managing the condition and its impact on appearance. It added a further dynamic to those relationships:

> *'Relationships can be hard with lymphoedema.'* (Arman)

> '*As a homosexual man, I think other men find my swollen leg unattractive. A few have commented and it has added to my feelings of rejection. I am conscious of how my legs look and this has stopped me from taking an initiative with relationships.'* (George)

Physical changes represent an alteration in a man's ability to be secure in their gender expression, but also how that expression leads to connection. While men avoiding connecting with others is a coping strategy in response to perceived vulnerability, it can also represent a form of self-stigma that leads to men self-isolating from groups that may offer support and gender identity.

Collectively, the findings indicated the varied negotiations men undertook when self-managing their condition and how they framed the involvement of social support in their lives. However, renegotiations around masculinity form part of a transition that men complete at their own pace. It is influenced by perceptions of vulnerability and whether the coping strategies strengthen their expression as a man. This feeds into the notion that masculinity is a spectrum, one that is not fixed across a man's course of life due to significant events.

Discussion

To the best of our knowledge, this is the first qualitative study to explore hegemonic masculinity and its influence within the experiences of men diagnosed with non-cancer related lymphoedema, who are undertaking self-care. The study offers an exploration and examination of the transition men undertake in response to lymphoedema upon their hegemonic masculinity and the coping strategies they employ. Flurey et al's (2018)

work offers insight into these transitions men undertake in response to their lymphoedema and the subsequent consequence of engaging in self-care.

Psychological impact of self-care and the renegotiations of hegemonic masculinity

Men experience psychological vulnerability because of their lymphoedema and the loss of self as an identity (Charmaz, 1983; Demain et al, 2015), but more specifically the identity formed by their masculinity (Flurey et al, 2018). While men who participated in the study illustrated various aspects of their illness narrative (Kleinmen, 1998), there was also biographical disruption (Bury, 1982) caused to their hegemonic masculinity or masculine script (Flurey et al, 2018). Disruption, specifically biographical, focuses on the man's 'loss of confidence in the body that leads to loss of confidence in social interaction' due to lymphoedema, with its presence in their lives having 'meaning' and 'significance' (Bury, 1991).

The actions men took were to minimise its impact upon their perceived vulnerability, using associated male traits, behaviours and gender-based coping strategies, such as stoicism (Flurey et al, 2018; Connell and Messerschmidt, 2005; Connell, 1993). Stoicism has been associated with a masculine trait that can lead to negative outcomes in terms of men not seeking help (Karl et al, 2022), compared to women who will seek help more readily (Lindon and Barry, 2021). While stoicism is also present in women, it is to a lesser degree as compared to men (Pathak et al, 2017).

Men's responses aligned to Flurey et al's (2018) work where men wished to retain their masculinity and engaged in re-negotiation of their hegemonic masculinity over a period. These negotiations resonate with the work by Spector-Mersel (2006) and can signify 'disrupted hegemonic gender scripts' caused by a loss of 'harmony' with social expectations of male performance. The transition between the retaining and negotiating may involve men inhabiting both points, which illustrates the disruption men experience as shown in the study by Hohne (2022).

Men engaging in coping strategies aligned to hegemonic masculinity, such as self-reliance and withdrawal, acts as an expression of their masculinity (Flurey et al, 2018).

It also provides them with the means to re-establish certainty within their lives as a protective factor caused by the uncertainty of their ill-health (Zanchetta et al, 2017; Zinn, 2004; 2005) and resonates with the notion that men wish to return to their gender script to be able to perform according to the expectations from their gender (Eguchi, 2009). Gender or masculine scripts are seen as socially derived to provide men and women ways of thinking and acting (Gast and Peak, 2011). Not engaging in expected behaviours marks men as different (Michael, 2016) and this can lead to the experiences of stigma, either by men themselves or perceived from others (Stangl et al, 2019; Goffman, 1963). Stigma has been noted in studies that have focused upon the treatment burden of having a long-term condition (Demain et al, 2015), such as wearing compression therapy, and the biographical disruption men experience (Bury, 1991).

Equally, men manifest this stigma (Stangl et al, 2019) by withdrawing from activities, or concealing their condition due to perceived vulnerability (Arnell, 2014). This has connections to the chronic disease management study by Merdsoy et al (2020) where men actively engaged in 'managing self-perceptions' and 'evading emotions' as coping strategies. The disruption itself focused on a man's inability to produce and reproduce expected behaviours of hegemonic masculinity, such as emotional control, leading to disruption that is biographical and connects to the stigma, but also loss of freedom (Demain et al, 2015). Despite the reasons for their use, coping strategies may also represent resources (Bury, 1991) that men employ to mitigate the impact of lymphoedema and the burden it represents (Demain et al, 2015). Rome (2021) suggests these responses relate to a perceived violation of men's normal hegemonic masculinity. This violation leads men to attempt to restore a version of their masculinity (Courtenay, 2009). The efforts to restore or negotiate the changes within pre-held perceptions of masculinity align to the systematic review findings about establishing a 'new norm' in response to the presence of lymphoedema and changing masculinity (Cooper-Stanton et al, 2022). The changes to hegemonic masculinity also indicate that masculinity is not fixed, but one that can change in response to situation over a period of time (Rome, 2021; Connell and Messerschmidt, 2005).

Physical control and its influence within hegemonic masculinity

In response to psychological aspects of their condition, men focused on the ability to physically control lymphoedema to frame it as a 'heroic struggle' in response to their perceived vulnerability (Gough, 2013). Men undertake this journey to regain a sense of control over their bodies, the disease and its relationship to their 'masculine identity' (Flurey et al, 2018). They also represent 'strategies to protect and adapt their identities' (Wilde et al, 2020) by becoming experts in their condition.

In a study by O'Rourke et al (2022), men were reported to have a higher use of adaptive coping (active stress coping) compared to women. This was also observed in a study by Zanchetta et al (2017) where men become actively interested in gaining knowledge about their body to support themselves within their masculine expression. Further still, the acquiring of knowledge can imbue the notion of accruing more masculine capital, to use in mastering, managing, and compensating for non-masculine behaviour (Arnell, 2014; de Visser et al, 2009). Thus they embody a sense of independence by becoming even more self-reliant and concealing any sense of vulnerability (Courtenay, 2009) in response to the perceived losses in their hegemonic masculinity (Wilde et al, 2020). Pursuing independence and expertise within the management of lymphoedema can be beneficial when the emphasis is upon self-management, such as self-application of compression therapy in lymphoedema (Cooper-Stanton et al, 2022). However, an overall focus on self-reliance can delay access to support (Zanchetta et al, 2017), and perpetuate the notion of that men do not seeking help as often as women and the invisibility of men's health and their needs (Courtenay, 2009; Liddon & Barry, 2021).

A study by Zanchetta et al (2017) stated that some men 'believed that society expects men to be less sensitive to their own health issues and needs than women'. Men are adapting their masculinity, or gender scripts, in response to the physical changes and performative expectation through re-negotiation (Flurey et al, 2018) by acquiring new resources to manage the disruption of having a long-term condition (Courtenay, 2000; Evans et al, 2011), and in response to fluctuating biographical disruption due to the physical factors (Locock et al, 2009).

Support Networks and Renegotiation of Hegemonic Masculinity

Partner and/or spousal involvement in care has been seen as being positive (Arnell, 2014), despite concerns that as men progress across their life course, relationships may become impoverished leading to diminished and altered masculinity (Evans et al, 2011; Willis and Vickery, 2022). While social support is seen as a protective factor (Frank, 1998), most men in the study by Arnell (2014) stated that their spouses or partners (80%) were their main social support, with this figure lower for women (59%) owing to a wider support network. As indicated in other studies, spouses can encourage health-enhancing behaviours (Willis and Vickery, 2022) and discourage health-harming activities (Arnell, 2014) in men, as compared to those without social support networks.

The accepting of support from spouses or partners requires men to negotiate and perceive support as not undermining their masculinity and its expression (Flurey et al, 2018). Women were noted as seeking social support more readily than men (O'Rourke et al, 2022). Men need to reframe support (Gough, 2013) as a form of masculine capital that compensates for changes in their masculinity (Arnell, 2014; de Visser et al, 2009).

Variable engagement within the available support networks or its perception, such as spouses, may resonate with the study by Zanchetta et al (2017) that focused on stigma and shame, leading men to become marginalised (Flurey et al, 2018). Marginalisation was noted in the work by Connell and Messerschmidt (2005) and Courtenay (2009), due to men not being able to fulfil their determined hegemonic masculinity identity. Wilde (2020) called this 'dual identity'—between the man's perceived masculinity and their dependence upon others. Merdsoy (2020) linked this vulnerability in men leading to 'emotional self-management' within relationships to avoid further deterioration of their masculinity. Arnell (2014) suggests that men use their masculine capital to negotiate these changes by assessing their ability to contribute to a relationship, such as money and occupational status, as a means of exchange. Using masculine capital as compensation for non-masculine behaviours (Arnell, 2014; de Visser et al, 2009) must be re-framed as capital, such as reliance on others, to mitigate their own perceived stigma (Gough, 2013).

Our findings show that men experienced vulnerability caused by the disruption in their hegemonic masculinity. They used associated traits and behaviours (hegemonic masculinity) as coping strategies to reduce further erosion of their masculinity. While the use of these coping strategies as resources, or masculine capital, helped men to renegotiate their masculinity, it may perpetuate their marginalisation and invisibility because of concealment of lymphoedema in society.

Strengths and Limitations

The current study adds to the literature in relation to men diagnosed with non-cancer related lymphoedema. The study was based upon building qualitative elements into a validated quality of life tool [LymQol] that offers a level of credibility, dependability and transferability to other groups and settings. The analysis used documented approaches in the form of thematic analysis. Representation of men with lymphoedema being majority White and aged over 45 years correlates with national and international studies within developed westernised countries at the present time (Moffatt, et al 2019a; 2019b). Those who participated in the study also provided a life course view of the condition, due to the variance in ages.

The limitations of the study related to the number of men who participated in it, which was 22 in total. It has been noted that research with men is challenging and may result in lower levels of participation (Markanday et al, 2013; Slauson-Blevins & Johnson, 2016). However, the number of men who participated correlates to similar or higher numbers within specific lymphoedema research (Cooper-Stanton et al, 2022). The application of the findings outside the UK (all four nations) and the Republic of Ireland needs to be considered against the variety of healthcare provision and access, and the cultural context and differences within other countries. The level of details men provided within the free text may have an impact upon the results, in terms of developing a deeper understanding. As there was only one Black participant and the rest were White, the application of this study beyond this group is limited. A total of 19 participants identified as heterosexual, with three identifying as gay.

The study indicates the relationships men have with their condition and how this can be affected by several factors, such as diagnosis duration, and how the developed coping strategies may support them in managing the condition.

Conclusion

This study focuses on men and their perception of self-management after being diagnosed with non-cancer related lymphoedema. Men experienced disruption in their lives and their perception of masculinity due to lymphoedema. In response, men used associated hegemonic masculinity behaviours to reduce their perceived level of vulnerability and increase the perception of control. This initial response upholds their original concept of masculinity, prior to engaging in its re-negotiation through existing or new forms of masculine capital. This was seen across the men in the study, with re-negotiation taking place over a given period. The insights from this article creates opportunities to understand a man's response to self-managing their lymphoedema within their lives.

Key points

- The study offered an understanding into the enquiry presented in the preceding article: how do men perceive their engagement in the self-management of non-cancer-related lymphoedema?
- The three key findings revolve around the psychological impact of non-cancer-related lymphoedema on men and their sense of masculinity.
- Men strive for control over their health as a result of this condition. This may result in their withdrawal from social connections.
- The responses and strategies used by men are linked to the disruption that lymphoedema introduces into their lives and the negotiations they undergo in response.

CPD reflective questions

1. In what ways can the findings be applied to bolster your work with men experiencing lymphoedema?
2. How has the study broadened your personal understanding of masculinity?

3. Which aspects of the article do you believe necessitate additional investigation?

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