

**MALE MASK AND MONOLOGUE: VOICES FROM THE SILENT MINORITY
WITHIN LYMPHOEDEMA**

By

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ABSTRACT

Background

Men's perceptions of non-cancer-related lymphoedema are the basis of this thesis. Lymphoedema is a long-term physical condition which has multiple causes that lead to swelling in any part of the body. Lymphoedema can affect a person beyond the physical effects of swelling, to encompass the psychological and relational aspects within their lives. Men as a proportion of those affected by lymphoedema are a minority compared to women. A systematic meta-aggregation review was conducted which revealed that men affected by non-cancer-related lymphoedema are also underrepresented in the academic literature. The review indicated that theories of masculinity had not yet been used to explore men's experiences of lymphoedema, and nor had narrative inquiry has been utilised. The limited empirical literature and methodological approaches used in men with non-cancer related lymphoedema. Provided a unique opportunity to explore men's perceptions as outlined in the proposed research questions.

Research Questions

The existing literature was used in the formation of the main research question that was to be answered through the four sub-questions outlined below.

Main research question:

What are the perceptions of men diagnosed with non-cancer-related lymphoedema?

Sub-research questions:

1. How do men perceive engagement within their self-management of their non-cancer-related lymphoedema?

2. How do men perceive their non-cancer-related lymphoedema within their daily lives?
3. What are men's perceptions of support within their non-cancer-related lymphoedema?
4. What are men's perceptions of masculinity within their non-cancer-related lymphoedema?

Methods

Interpretivist qualitative methodology was applied throughout the thesis that supported the research questions outlined. As outlined in the background of the thesis was the limited exploration of the perceptions of men with non-cancer related lymphoedema and the use of narrative inquiry. The thesis used multiple methods and analytical approaches aligned to narrative inquiry across the three individual studies, such as online semi-structured interviews and the application of narrative linguistic analysis. The multiple approaches and reflexivity used across the three studies provided methodological triangulation that increased the trustworthiness and rigour of the work.

Findings

The findings of the thesis were formed across the four individual studies which included the systematic meta-aggregation review, narrative survey, solicited diaries and online semi-structured interviews. The systematic review identified four synthesised findings 1) the new norm, 2) the journey into the unknown, 3) access and 4) personhood. These findings were noted as being present in varying degrees within the narrative survey, solicited diaries and online semi-structured interviews. What was added to these findings was the way men may or may not align to varying

aspects of hegemonic masculinity in their gender expression within traits and behaviours, due to multiple masculinities and the disruption caused to men's masculinity due to lymphoedema. These aspects were noted across all themes and parts within the studies, for example, narrative survey theme psychological, diary theme vulnerability and semi-structured interview part disruption. In addition, the findings suggest that men use traits and behaviours as masculine capital within the negotiations surrounding their hegemonic masculinity, due to their disrupted masculinity and vulnerability. This was noted in the narrative survey through the theme of physical control, but also within the diary theme of solace in routine and the online interview part journey. Collectively the findings answered the overarching question of the perceptions of men with non-cancer-related lymphoedema.

Implications

Following the findings across the whole thesis has implications across policy, practice, research, and theory. Future policies were considered as needing to involve men within their production and to build upon previous projects that had focused on men. Whilst recognising that men as a group have differences and nuances. These nuances need to be present within practice through gender-based interventions, such as support or educational programmes that are co-produced, or gender transformative by challenging perceived unhealthy behaviours. The effectiveness of these interventions or approaches are possible future research implications that have relevance within the current national conversations surrounding men's health. The thesis has explored and applied the two theoretical concepts, 1) hegemonic masculinity and 2) HIMM framework. What was noted was the need in the findings to expand them to include other theories, such as biographical disruption, to explain

what was seen as disrupted masculinity, and typologies, such as renegotiating hegemonic masculinity, to interpret how men adapt their masculinities. The implications indicate the wide-ranging outcomes from the thesis that have relevance within both the area of lymphoedema and beyond.

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men with lymphoedema with new eyes, and knowledge and ultimately engage with kindness.

STATEMENT OF AUTHORSHIP

Chapters 2 to 5 have been written as manuscripts with one published (Chapter 2) with one submitted for publication (Chapter 3). The remaining chapters will be submitted to various journals related to lymphoedema, nursing and long-term condition management. As such, there would be overlapping background materials that were included in these chapters. Additionally, all these chapters were written with my supervisors Dr Nicola Gale, Dr Manbinder Sidhu, and Dr Kerry Allen, as they provided comments and feedback on the drafts. More specifically, I am the primary author for all these chapters and have led the design of studies as well as data collection, analysis and write-up.

List of papers and conference abstracts

Cooper-Stanton, G., Gale, N., Sidhu, M., Allen, K. (2022) 'A qualitative systematic review and meta-aggregation of the experiences of men diagnosed with chronic lymphoedema', *Journal of Research in Nursing*. Doi:10.1177/17449871221088791 (Published).

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1.0 Chapter 1 – General Introduction

1.1 - Chapter Summary

This chapter provides contextual information regarding the forthcoming chapters by introducing and discussing key aspects that informed the thesis and why it has focused on the perceptions of men with non-cancer-related lymphoedema. Outlined in the chapter is the background as to what is lymphoedema and the prevalence of the condition amongst men and women. It continues by introducing the theoretical concepts that were used throughout the thesis and their relevance which included hegemonic masculinity and the health, illness, men, and masculinities (HIMM) framework. This is followed by a discussion about the chosen qualitative methodological approach (narrative inquiry), methods (narrative survey, diary, interview), analysis (thematic, structural, linguistic) and where they were used in Chapters 3-5. Positionality and reflexivity are discussed and how they informed the thesis throughout. The final section outlines how the proposed research question was answered within Chapters 3-5 through the proposed four sub-questions. Followed by an outline of the structure of the thesis.

1.2 – Background

The thesis considered that both men and women developed long-term conditions that can be related to extrinsic factors, such as lifestyle and environment, or intrinsic factors, such as genetics (Galdas et al, 2015; NIHR, 2021). Despite extrinsic and intrinsic factors affecting both men and women, some disparities exist between the two genders (Robertson and Baker, 2017). Disparities at the time of the thesis included more women (50.1%) reported as having a long-standing health issue compared to men (45.7%), with more women (22.3%) reporting that the health condition limited them in some way compared to men (18.5%) (ONS, 2022c). More women reported being affected by common mental health conditions, such as anxiety and stress compared to men (Winchester, 2021), but this does not consider what has been suggested as an underestimation and recognition of the mental health needs of men (UK Parliament, 2023; Robertson and Baker, 2017). Whilst suicide rates were higher amongst men aged 45-49 years, the overall figure is 17.2 (men) compared to 5.4 (women) deaths per 100,000 of the population (ONS, 2022b). Equally, the life expectancy of men was four years shorter than women (ONS, 2022a), with the leading cause of death (65-79 years) being ischaemic heart disease (men) and cancer (women) in 2018 (ONS, 2020). Past explanations for disparities included gender differences in the behaviours of men and women, such as increased risk-taking amongst men compared to women, which may or may not align with perceived gender expressions within society, such as masculine or feminine (Lindon and Barry, 2018; 2021; Courtenay, 2009; 2000).

Despite potential explanations of gender disparities, gaps existed within the literature of men with long-term conditions, specifically lymphoedema. A specific gap

within the evidence base was identified in a systematic review conducted within Chapter 2 and which was published (Cooper-Stanton et al, 2022). Based on the review one main and four sub-research questions were created and are outlined in the thesis overview section. The questions focused on the perceptions of having non-cancer-related lymphoedema by men. The impact the condition had within their daily lives, but also their engagement in self-care, the available support, and their perception of masculinity. The research led to an increased understanding of the social world men inhabited with lymphoedema that had not been explored in previous studies (Cooper-Stanton et al, 2022).

1.3- Lymphoedema – Long-Term Condition

Lymphoedema is a long-term condition that affects both men and women with no known cure and limited success through surgical or pharmacological interventions (International Lymphoedema Framework [ILF], 2012; 2006). Lymphoedema is part of an overarching definition of chronic oedema that involves fluid and swelling being present in any part of the body and lasting over three months (Rankin, 2016). Included within lymphoedema are sub-categories which are primary and secondary lymphoedema (ILF, 2006). Primary lymphoedema has over 20 intrinsic causes due to abnormal development of the lymphatic system related to genetics or syndromic factors, such as Milroy's disease, klippel-trenaunay syndrome and Turners syndrome (Gordon et al, 2020; Mortimer and Rockson, 2014). Secondary lymphoedema is caused by extrinsic factors that affect the lymphatic system, for example, surgery or vascular disturbances (Mortimer and Rockson, 2014; ILF, 2006). In total, there are up to 30-40 distinct types of lymphoedema, with a variety of physical signs and symptoms, for example, oedema, lymphorrhoea, cellulitis (ILF, 2006), which can lead

to physical discomfort and even restriction (Cooper-Stanton et al, 2022). Restrictions are noted as reductions in quality of life that may lead to the development of depression or reduced mobility (Mercier, et al, 2019). Lymphoedema can occur at any point in a person's life course, either at birth or later in life and can lead to physical and mental health changes.

1.4 - Men and Lymphoedema

The decision to focus on men diagnosed with non-cancer-related lymphoedema was due to the limited research on their experiences and perceptions (Chapter 2). Non-cancer-related lymphoedema included primary or secondary lymphoedema (ILF, 2006). An international study indicated secondary lymphoedema was the main diagnosis of lymphoedema at 82.5% compared to primary lymphoedema at 17.5% (Keeley et al, 2019). In the same study, cancer-related causes of secondary lymphoedema represented 34% of lymphoedema service caseloads compared to non-cancer-related secondary lymphoedema 66% within the UK (Keeley et al, 2019). The proportion of men affected by lymphoedema was noted as variable amongst the available studies at that time. In an international study, across four countries and nine services established men represented 21% of those affected by lymphoedema (Keeley et al, 2019). It was noted that the figure was lower compared to another study conducted in the UK which estimated it was 28% (Moffatt et al, 2019c). A prevalence study within the West Midlands and Southwest of England stated the figure for men was 23% (Cooper and Bagnall, 2016). Across each of the figures, the main gender affected by lymphoedema was women.

Despite more women being affected based on gender there was also a consideration of age as a factor. As men age, there is an increased risk of the

development of lymphoedema, with the majority of men and women diagnosed with lymphoedema over the age of 45 years (Keeley, et al, 2019). Prevalence figures indicated that men's risk in the development of lymphoedema is 0.47 (under 65 years) to 2.48 (85 years plus) per 1,000 of the UK population with a higher prevalence figure noted amongst women (Moffatt et al., 2017; 2019c). Whilst age is a factor a cross-sectional study explored both prevalence and risk factors in the development of lymphoedema across Nottingham and Leicester, England (Moffatt et al, 2019b). The factors identified indicated that the majority of people with lymphoedema, have existing co-morbidities including diabetes or heart failure, and are White at 87.4% (Moffatt et al, 2019b). The study acknowledged that 'the pattern of ethnicity did not reflect the ethnic distribution within the general population', and that 'it is not possible to determine whether this indicates that these patients are not accessing care or whether ethnicity directly influences the prevalence of lymphoedema' (Moffatt et al, 2019b, p. 152). Those affected by lymphoedema can experience reduced Quality of life (QoL) but in the study by Mercier et al (2019) younger men reported improved QoL compared to older men. However, this comparison was limited due to the study not stating a definition of what encompassed the term younger men. Collectively, the evidence at that time indicated that the majority affected were women, white, over the age of 45 years and were related to secondary or non-cancer-related causes.

The figures failed to communicate the perceptions or experiences of men. What followed was a scoping review and then a systematic meta-aggregation review (Chapter 2). As highlighted in the scoping review and confirmed in the findings of the systematic review, there was a paucity of literature that focused on men. The paucity

of research was first acknowledged in the literature review by Cosgiff (2010). The review noted limited studies were focusing on men with cancer-related lymphoedema, and even more limited were studies on non-cancer-related lymphoedema. The systematic review (Chapter 2) identified a limited number of qualitative research studies that had focused solely on men, with one study noting the 'feminisation' of lymphoedema, with the majority focusing on women and cancer-related causes, such as prostate cancer (Cooper-Stanton et al, 2022). Included in the review were details of the methodology, study design, methods and theory that was undertaken across the studies (Chapter 2). It established that gender theory specifically masculinity was not considered, and neither was narrative inquiry (Cooper-Stanton et al, 2022). As an outcome of the limited research with men diagnosed with non-cancer-related lymphoedema and the need to consider the role of masculinity, this led to empirical research as described in Chapters 3-5.

1.5 - Hegemonic Masculinity

The influence of masculinity as a concept has been considered as both a factor and influence within the existence of health and social inequalities (Evans et al., 2011). Its presence has been noted in the work by Robertson and Baker (2017) as having either a positive and/or negative impact on the health of men. Masculinity has been associated with encouraging engagement with healthy activities, such as physical exercise to demonstrate strength and endurance, but can also reinforce risk-based behaviour, such as excessive alcohol intake or help-seeking avoidance to demonstrate independence (Liddon and Barry, 2021; Boulton, 2017; Robertson and Baker, 2017). Masculinity is considered an expression of socially constructed expectations surrounding gender and what is masculine or feminine (Courtenay,

2000; 2009). These expressions have involved traits and behaviours outlined in Table 1.0 but can also include the positions men hold and associated power, such as within work and family (Boulton, 2017; Courtenay, 2000; 2009). Despite traits and behaviours being considered as means of expressing masculinity as shown within Table 1.0. An overreliance on them to explain masculinity is considered an oversimplification and does not consider the differences that exist within men as a group (Connell and Messerschmidt, 2005). Connell's (1993) early work explored hegemonic masculinity as representing the dominant and idealised version within Westernised society. The presence of hegemonic masculinity offered a possible explanation of the power dynamics that exist within society, such as external hegemonic dominance over women, or internal hegemonic dominance over a group of men (Connell and Messerschmidt, 2005; Hearn & Hall, 2005; Demetriou, 2001). The term and use of hegemonic began in the 1970s but gained more prominence in the 1980s within educational and criminal applications, for example, social inequality within Australian high schools (Connell and Messerschmidt, 2005). Since its initial application, it has gained prominence within Westernised society, as a distinct and dominant masculinity compared to others, such as subordinate or inclusive masculinity (Anderson and McCormack, 2018; Connell and Messerschmidt, 2005). Hegemonic masculinity is considered the most 'honored way of being a man' and requires 'all other men to position themselves in relation to it', but it is noted that very few men meet this ideal (Connell and Messerschmidt, 2005, p. 832).

Table 1.0 Hegemonic Associated Traits and/or Behaviours

(Connell et al, 1993; 2005)	Assertiveness, aggressiveness, heterosexuality, dominance, competitiveness, control, self-reliance, perceived invulnerability, physical strength, and emotional restraint
Courtenay (2000; 2009)	Stoicism, denial of weakness or vulnerability, emotional or physical control, appearing strong or robust, not help-seeking, but also physical dominance, or aggression.
Boulton et al (2017) – 10 Positive Aspects of Masculinity	1) Relational styles (friendship through shared activity), 2) Male caring (protect others), 3) Action empathy (action in response to concerns), 4) Fatherhood (generative development over time), 5) Self-reliance (use own resources and problem solve), 6) Worker/provider (sense of purpose/meaning), courage (daring/risk taking), 7) Group orientation (source of identity/community), 8) Humanitarian activities, 9) Sense of humour (reduce tension/build relationships), 10) Heroism (overcoming obstacles/contribution to others).

Hegemonic masculinity and its relevance to the thesis were considered in the debates at the time the thesis was being written. It has been suggested hegemonic masculinity was outdated, due to social progress the inclusion of men regardless of their background, such as gay men, and the formation of new masculinities, such as inclusive masculinity (Anderson & McCormack, 2018). Other forms of masculinity are

considered as embracing matters their forefathers would have considered unacceptable, even if that led to men becoming marginalised, or subordinate to the dominant masculinity (Anderson and McCormack, 2018; O'Neill, 2015). Whilst the purpose of the thesis was not to compare masculinities, it can be suggested that different masculinities may reflect the 'configurations of practice that are constructed, unfold, and change through time', but still relate to hegemonic masculinity (Connell and Messerschmidt, 2005, p. 852). Alongside other masculinities, feminism was considered as a potential interpretive lens to view men within the study, specifically 3rd or 4th wave feminism, in which the oppression of anyone due to gender is considered unacceptable (Helmreich, 2017). Historically, there was a period in the 1970s titled the 'male liberation', in which groups of men supported feminism and the removal of roles that oppressed people based upon perceived gender roles (Connell and Messerschmidt, 2005; Messner, 1993). However, this mutual thinking did not last and led to feminism and masculinity studies going in different directions but have converged at varying times, such as 3rd and 4th wave feminism (Helmreich, 2017; Connell and Messerschmidt, 2005; Messner, 1993)

Whilst other theories were considered, hegemonic masculinity was selected due to its continued relevance and presence in society. The application of hegemonic masculinity has been used in several studies that were not related to lymphoedema, such as Oster et al, (2014) and Dale (2015), which focused on men with colorectal cancer and their diminished masculinity. The qualitative study by Michael et al (2016) focused on men treated for prostate cancer and noted that men's masculinity was affected, due to reduced sexual ability following treatment. The qualitative study by Flurey et al, (2018) considered men with rheumatoid arthritis which led to the

identification of three hegemonic masculinity-based typologies as described in Table 1.1. Men in the study moved back and forth between the three typologies to adjust to their long-term condition, such as masculinity being retained, negotiated, or rejected (Table 1.1). Hegemonic masculinity was also noted in the UK-based qualitative cross-sectional study by Willis and Vickery (2021) that explored older men, loneliness, and the way masculinity shaped men's perceptions. The exploration of hegemonic masculinity within this thesis acknowledged its continued presence within society and the limited exploration of this within men diagnosed with lymphoedema.

Table 1.1 - Hegemonic Masculinity Typologies

Retaining Hegemonic Masculinity	Focused on the man retaining and maintaining the ideals associated with hegemonic masculinity which was considered as important to men, such as activities and roles around sports activities or paid work as examples.
Renegotiate Hegemonic Masculinity	Focused on the man's adaptation that men undertake because of a loss of their masculine identity following their long-term condition. For example, being unable to take part in previous masculine activities, such as sports.
Rejection of Hegemonic Masculinity	Focused on a man becoming comfortable with their identity because of their long-term condition. Leading to the man's rejection of the need to conform to behaviours associated with hegemonic masculinity. This was considered as having a lower occurrence compared to the previous two typologies.

1.6 – Health, Illness, Men and Masculinities Framework [HIMM]

The HIMM framework by Evans et al (2011, p. 7) was applied to expand the lens of hegemonic masculinity and attempted to consider the ‘complex social relations and practices’ attached to gender and its influence upon men’s behaviour across their life course. Masculinity within the HIMM framework (Evans et al., 2011) viewed gender as a social construct that was present in the layers and structures of Western society, such as patriarchal, which also reflected the hegemonic masculinity view of gender (Connell and Messerschmidt, 2005). The HIMM framework acknowledged the presence of ‘multiple masculinities’ in society and intersecting elements, such as geography and education as shown in Figure 1.0 (Evans et al, 2011, p. 11). Gender-based social constructs include behaviours and traits that are demonstrated by an individual or group of men as described in Table 1.0. These behaviours are considered to affect the health outcomes of men as they age within their life course (Evans et al., 2011). Men aged 12-24 years are at increased risk of accidental death and injury, such as sports-related when compared to women (Evans et al, 2011, p. 11). Men aged 35-50 years focused on increasing levels of income resulting in some men experiencing fatigue, boredom, and depression (Evans et al, 2011). Those aged 50 years and above may become ‘invisible’ and isolated in society, due to transitions that are present in their career, such as retirement but also acquiring one or more long-term conditions (Evans et al, 2011, p. 12). The framework noted that as men age their ‘masculine ideals can be further eroded’ leading to ‘isolation’ (Evans et al., 2011, p. 11), which can be aligned with the findings of the study by Willis and Vickery (2021) regarding loneliness in older men. The framework

considered the need for masculinity to be recognised as a social determinant, due to health policies failing to consider this within their development and application.

Figure 1.0: Health, Illness, Men and Masculinities [HIMM] Framework (Evans et al, 2011, pp.11)



At the time of the thesis, there was no application of the HIMM framework within long-term conditions. There was one application within a scoping review that focused on men and smoking behaviours (Kodriati et al, 2018). The review established most studies in the area of smoking indicated men embedded a traditional or hegemonic view of their behaviours, leading to smoking being a projection of their 'control' and 'emotional stability' (Kodriati et al, 2018, p. 43). The projections or expressions within the review can be suggested as embodying what

Evans et al (2011) refer to as the socialisation of hegemonic masculinity ideals. Others have referred to this socialisation as forming a man's masculine identity or gender script that prescribes expectations of a given gender (Flurey et al, 2018; Seager et al, 2014). As a result, hegemonic masculinity and the HIMM framework have been used as a complementary approach to frame the study and interpret data within the thesis.

1.7 - Methodology

The underlying methodology in the thesis was a qualitative, inductive interpretive approach, as it focused on the subjective experiences of men within the context of non-cancer-related lymphoedema (Parahoo, 2014; Green, 2013; Caine et al., 2013). Inductive reasoning was applied within narrative inquiry to facilitate the establishment of patterns, relationships and meanings that were present within the stories expressed by men in the thesis (Caine et al., 2013; Green, 2013). Gavida and Adu (2022) referred to stories as ones that unfold and evolve (temporality) that are influenced by the person's unique background and circumstances (sociality), but also the environment in which events have occurred (place) (Gavida and Adu, 2022). Capturing the unique unfolding stories shared by men, led to the four dimensions suggested by Clandinin (2007) to be considered within the narratives presented across Chapters 3-5. The four dimensions involved: 1) living – live stories, 2) telling – sharing the story, 3) re-telling – repeating stories and thinking deeply, and 4) re-living – how transactions have shaped the individual. The dimensions provided a means for me to explore the meanings that are present within the autobiographical stories shared by men, but also to seek clarity at given points (Polkinghorne, 1995).

Narrative inquiry has a long and evolving history that focuses on a person's 'identity' and the meanings that are held within the stories they tell themselves and to others (Reissmann, 2008, p. 7). The contemporary use of narrative inquiry began in the 1960s with what was termed the 'narrative turn' and the move away from realism (Frost et al, 2010, p. 445; Reissmann, 2008). The move related to critiques in the use of positivist modes of inquiry, and increased cultural popularity of memoirs, identity movements, and the therapeutic use of life stories (Reissman, 2008). What followed the 1960s was the use of technology in the 1970s that allowed recordings of interviews, to allow both immersion and analysis of the text led to narrative analysis being developed (Frost et al, 2010; Reissmann, 2008), for example, structural analysis from Labov and Waletzky (1967). Narrative inquiry in the 1980s was influenced by the presence and influence of feminism and the notion that 'personal is political' (Reissman, 2008, p. 15). Despite an increased interest in narrative inquiry, criticisms have focused on the 'blurring' between the 'stories' that people 'tell', compared to what is lived and the 'authentic identity' within that story (Jarvinen and Mik-Meyer, 2020; p. 245).

However, some have referred to these criticisms as the 'messiness' within narratives that reflect the 'unique context' of a person's experience (Casey and Schaefer, 2016, p. 115). Clandinin (2006, p. 47) considered this as 'walking into the midst of stories', in which the researcher is an 'intermediary' within the interpretation of narratives (Gavida and Adu, 2022, p. 1). Interpretation of stories is through varied approaches within narrative analysis that are considered as a 'family of methods for interpreting texts that have in common a storied form' (Reissmann, 2008). Examples included thematic, structural, and linguistic analysis that were used in the thesis

(Frost et al, 2010). It is acknowledged that no one approach within the narrative analysis is the 'best', with any decision needing to be based upon the type of research being undertaken (Nasheeda, 2019, p. 2). Criticisms of narrative analysis focused upon the limited consideration of 'interactional' factors within thematic and structural analysis, due to a focus on the content and form of stories (Jarvinen and Mik-Meyer, 2020, p. 246). Despite these criticisms, others have suggested that narrative analysis has evolved due to increased knowledge of societal considerations, such as intersectionality, in which the researcher as an 'intermediary' can bring this out within each of the unique stories (Gavida and Adu, 2022, p. 1). To bring out this uniqueness within the narratives shared by men, led to the ontological and epistemological positions being considered in the thesis.

Ontologically the thesis focused upon the reality that men inhabit as being formed through a social construct, regarding gender and specifically the expression of masculinity within their behaviour and language as examples (Rodriguez, 2016; Connell & Messerschmidt, 2005; 1993). Constructivism used within the thesis acknowledged its continued relevance in Western society and the debates that existed regarding its objective and subjective consideration, following the work of Peter Berger, Thomas Luckmann and Pierre Bourdieu (Milos, 2021; Rodriguez, 2016). Men and their perceptions of the social world are formed through the production, reproduction, construction, and expression of their masculinity within their gender (Milos, 2021). Connell and Messerschmidt (2005) referred to this as the embodiment of the social practices that men undertake to demonstrate their masculinity and engagement within their social world. Narrative inquiry recognises the continual interaction, or 'production' that is present within the stories people tell,

and how they change over time (Caine et al, 2013; Polkinghorne, 1995). De-Fina (2015, p351) suggested that 'narratives are seen as the prime vehicle for expressing identity', and were used to explore the 'formation, reformulation and maintenance of identity' by men in the thesis (Frost et al, 2010, p. 445). Narrative inquiry enabled the exploration, interpretation and communication of the perceptions men held of their non-cancer-related lymphoedema and how this affected their masculinity within a socially constructed concept of gender (Rodriguez, 2016).

Epistemologically people interpret the world through the knowledge they have acquired, or created, which is influenced by constructivism as an external influence that men apply internally within their social world knowledge and perceptions (Milo, 2022; Connell and Messerschmidt, 2005; 1993). Knowledge generated by men within their social world is undertaken through participation in the production and reproduction of their masculinity (Milos, 2021; Courtenay, 2009; 2000). Engagement in narrative inquiry by men enabled them to begin to 'co-construct their understandings of the world' (Rodriguez, 2016, p. 126), and how they 'see the world' and the meanings given to their actions (Gavida and Adu, 2022, p. 1). Men sharing their narratives demonstrated what Caine et al (2013, p. 576) referred to as 'knowledge for the living' (Gavida and Adu, 2022) that goes beyond emotive expression to form a legitimate form of reasoned knowing (Bruner 1985). The creation of knowledge and reasoning takes time with the significance of events only occurring through varied forms of dialogue, such as written text and oral (Hunter, 2010).

In the thesis various methods were applied that allowed men to share their social worldview and the knowledge they held (Chapters 3-5). The meanings

attached to the words men used within their stories illustrated how they navigated their constructed world (Dale, 2015; Green, 2013). It is within this notion that gender should not be the 'a prior category that affects how people speak, but as a highly contextualised process of identification' (Swann, p19). It is within this context and shown within the thesis, that no man may construct the same meaning or perception of masculinity. The methods used to explore the narratives shared by men will be discussed in the next section.

1.8 - Methods

1.8.1 – Study Design

The thesis applied various study designs aligned to the narrative inquiry as outlined within the methodology section. Due to the thesis being an alternative format the study designs, data collection and analysis are discussed within each of the chapters (Chapters 3-5). Discussed below are the outlines of what has been undertaken in each chapter to answer the main research question and four sub-questions:

In Chapter 3 an online narrative survey was undertaken that used a validated lymphoedema quality of life tool (LymQoL) (Keeley et al., 2010) to answer the question as to how men perceive engaging within their self-care of lymphoedema. To provide further depth to the narrative survey the LymQoL was adapted to provide free-text space to allow men to reflect and provide further background to their answers (Appendix A). Free text comments by men were the focus of the narrative analysis, as the comments provided context to their responses, and enabled men to articulate their unique narratives (Rich et al, 2013; Shkedi, 2004). Men who participated in the survey reported that the questions and open text provided them

with the means to share their experiences. Surveys have been increasingly used within quantitative, or positivist paradigms, but have crossed multiple paradigms including qualitative or interpretivism (Shkedi, 2004). Surveys are used within narrative inquiry to explore a cross-sectional representation of people and their experiences (Tran et al., 2017; Shkedi, 2004). 'Narrative surveys' have been associated with being able to yield the benefits of 'nomothetic' (quantitative variables), and 'ideographic' (qualitative variables) by being able to combine the two aspects (Shkedi, 2004, p. 90-91). As Shkedi (2004) suggested the application of narrative surveys is based on what is already known about the phenomena and what is being explored within them (Shkedi, 2004). Due to the limited understanding of the experiences of men with non-cancer related lymphoedema following the systematic review (Chapter 2). The survey provided a means of establishing a baseline of knowledge that was used in the subsequent chapters (4-5). Each man who participated in the online survey was asked whether they wished to participate in the next two stages of the research (Chapters 4-5).

In Chapter 4 solicited diaries were undertaken by men, who had participated in the online survey, and who would go on to participate in the semi-structured interview. An example of the diary and guidance material is located within Appendix B. Solicited diaries are recognised within narrative inquiry as part of the 'toolbox' that is present within the narrative inquiry methods (Milligan, Bingley, Gatrell, 2005, p. 1882). The focus of the solicited diary answered the question as to the perceptions men had of lymphoedema within their daily lives. The solicited diary provided men with the means of being the authors of their own story. This approach aligned with the concept within narrative inquiry of being autobiographical and recognising the

power stories have in communicating meaning and understanding of a person's social world (Gavida and Adu, 2022; Polkinghorne, 1995). It has been suggested diaries can provide a 'cathartic' process, which was mentioned by men who undertook the diary and shared this within their interviews (Chapter 5). Diaries enabled an interpretive approach to be undertaken within the temporal aspects that are present within those stories, which was discussed in the methodology section (Caine et al., 2013; Clandinin, 2012). Despite the inability to explore statements further with individual men in the study, the patterns seen within the diary accounts provided insight into the stories men choose to tell themselves (Milligan, Bingley, Gatrell, 2005). The stories men told were used to inform the interviews that took place following the solicited diaries (Chapter 5).

In Chapter 5 narrative inquiry continued through the completion of online semi-structured interviews via Zoom which was a licensed product from the University of Birmingham. The questions being asked centred around the perceptions of support available to men and their masculinity. Narrative interviews provided a means of exploring the stories that are present within the experiences men shared within the online survey and solicited diary (Anderson and Kirkpatrick, 2016). Interviews provided a means of keeping men at the 'heart' of the study, by getting closer to their context and the meanings present within their narratives (Anderson and Kirkpatrick, 2016, p. 631; Freeman, 1998). Men in the interviews expressed that the interviews gave them a dedicated space to share their stories which had not been present before the study. By adopting this approach acknowledged that narratives are created in partnership rather than being found (Riessman, 2008). Working together, allowed the stories to go beyond listing events, to one in which narratives are linked

in both 'time and meaning' (Anderson and Kirkpatrick, 2016, p. 632). The interview schedule also known as a topic guide is located in Appendix C.

1.8.2 – Data Collection

The collection of data included a variety of approaches that were undertaken at varying parts of the thesis. It has been illustrated previously that the study design influenced the chosen data collection method. The chosen approaches taken were informed by ethical and data protection considerations, which are detailed in Chapters 3-5. Ethical approval with examples of the consent form and patient information leaflet is located in Appendix D. Throughout Chapters 3-5, any information that directly, or indirectly may have identified participants was removed and led to the use of pseudonyms (Heatin, 2021). The twelve-month promotion of the individual studies took place from September 2021 until August 2022, through a purposive approach (Parhoo, 2014). Specific organisations that represented or delivered care to men affected by lymphoedema were approached and included the British Lymphology Society, Lymphoedema Support Network and commissioned lymphoedema services.

In Chapter 3, twenty-two men participated in the online survey that had been created via Microsoft Forms, which was a licensed product provided by the University of Birmingham. Embedded in the survey was a video that detailed the research being undertaken from stages 1 to 3 and included specific details of the survey. Embedding the video received positive feedback from the men who participated in the study, but also from those who tested the survey before its launch. The use of embedded videos is not widely acknowledged but is seen as building 'rapport' between two people who share a common interest and understanding (Horsfall et al, 2021, p. 1).

Rapport and its relevance to research have been noted over sixty years and were relevant to this thesis (Kahn and Cannell, 1957). In addition to the video, the participant information and consent form were included in the survey (Appendix D). Before the completion of the survey men indicated by ticking a mandatory field (yes or no) that they had read the leaflet and consented to being part of the study. Online research at the time of the thesis had gained prominence (Sexia et al., 2017), especially during and following the COVID-19 pandemic saw more innovative means of undertaking research (Greenhalgh et al., 2020). The survey and thesis were undertaken during this period and used these approaches in response to global events.

In Chapter 4, twelve men completed the solicited diaries. Diaries were emailed to men who had indicated in the online survey that they wished to be part of the next stages of the study. Contact was made before the diary was sent, through individual emails to each man offering the option to meet to discuss the research further, following receipt of the diary and guidance materials (Appendix C). Men completed a further consent form and re-read the participant information leaflet (Appendix D). Solicited diaries are noted as varying in both the structure and the period allocated for their completion (Kenton, 2010; Meth, 2017). Based on the literature at the time, any diary and period are determined by the researcher and the research question being posed (Meth, 2017; Milligan, Bingley, Gatrell, 2005). Solicited diaries had not been used within lymphoedema or men at the time of the thesis (Cooper-Stanton et al, 2022). Upon reviewing guidance in the use of diaries and other studies, led to two weeks being undertaken, in which men recorded events either daily, on alternative days or could summarise their week (Meth, 2017; Milligan, Bingley, Reissmann,

2008; Gatrell, 2005). By allowing men to determine their level of engagement and depth in the completion of their diaries, was to recognise they are the owners of their story (Gawley, 2018; Reissmann, 2008). Completed diaries were emailed back and then subject to formatting and analysis within an Excel sheet.

In Chapter 5 twelve men took part in the semi-structured interviews and had been part of the online survey and diaries. Interviews were completed and recorded via Zoom. All men gave written consent to participate in the study after re-reading the participant information leaflet (Appendix D). As mentioned in the study design section, an interview schedule was developed and used in the interview to aid the data collection process (Appendix C). Online interviews negated geographical limitations, with men participating across the UK and Ireland, but also offered flexibility to men in the timing of the interview to fit around their lives (Greenhalgh et al, 2020; Sullivan, 2012). Interviews lasted between 45-90 minutes and aligned with the expected period for narrative interviews (Anderson, 2016; Reissmann, 2008). Each interview was recorded digitally via the Zoom facility, with the file saved within a password-protected OneDrive system licensed by the University of Birmingham, which was outlined in the data management plan (Appendix E). Each recording was transcribed verbatim (Reissmann, 2008) and then subject to analysis. The OneDrive system also housed the online survey results and solicited diaries as part of the data management plan.

1.8.3 – Data Analysis

Each Chapter from 3-5 used varying narrative analysis approaches that aligned with the chosen narrative inquiry and the methodology outlined earlier. Each Chapter gives specific details of the analysis approach taken. Analysis was also

considered against my positionality and reflexivity which will be discussed later in this chapter. An overview of the analysis undertaken is provided within this part of the thesis:

Chapter 3 applied thematic analysis within the open text provided within the online survey (Reissmann, 2008). The thematic analysis enabled the identification of patterns present in the survey data (Reissmann, 2008) with quotes used to illustrate the three themes that were created from the survey data. Mauthner and Doucet (2003) supported the approach with meanings created through interpretation within the analysis being undertaken. As part of the analysis, initial themes were shared with men who had participated in the survey to establish if they were reflective of their perceptions. Feedback from men was positive regarding the interpretation and relevance.

Chapter 4 applied thematic analysis as outlined in Chapter 3 after structural analysis had been undertaken (Labov, 1972). Whilst thematic analysis looked at the patterns within the text (Reissmann, 2008), structural analysis provided a means of deconstructing and identifying a greater depth in the meanings men shared within the study (Hunter, 2010; Labov, 1972). The deconstruction of the story follows the approach taken by Labov (1972) which is detailed within Chapter 4 and led to the creation of one main and two sub-themes. Using both approaches was unique due to it not being used within the existing literature on lymphoedema (Cooper-Stanton et al, 2022). Combining approaches allowed analysis and findings to go beyond the content in terms of the 'what', to one that considered the 'structure' or the way a story is told (Reissmann, 2008, p. 53, 78). As mentioned previously initial themes were shared with participants with feedback similar to the survey.

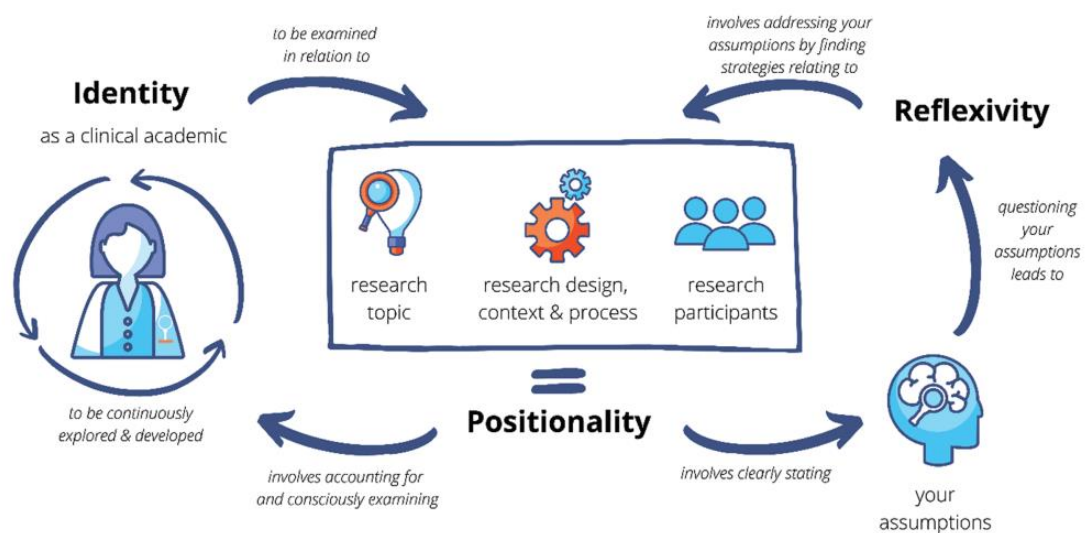
Chapter 5 employed a further narrative analysis tool that extended the analytical tools used in the previous chapters (3-4), from a focus beyond content and form to one that considered how they were told (Reissmann, 2008). Narrative linguistic analysis offered by Gee (1991), led to the analysis of the way men communicated their stories, through their pitch and tone which is referred to as paraverbal (Reissmann, 2008; Gee, 2007). Details of the analysis approach are contained within Chapter 5 and led to three parts being created from the stories men shared (Gee, 1991). The three parts revealed further details of the meanings men held within their social world gained through the analytical approaches detailed previously. To maintain trustworthiness and rigour in the findings, triangulation was achieved through various methodological approaches (Wilson et al, 2022; Chew-Graham et al., 2002). This included engagement with my positionality and reflexivity which is discussed in the next section.

1.9 – Positionality and Reflexivity

Positionality has been debated within research as to its purpose, application, and influence within the research process (Rushton, 2022; Wilson et al 2022; Bourke, 2014). Despite the debates, Hall (1990, p. 39) states ‘you have to position yourself somewhere in order to say anything at all’. By positioning myself as a researcher is to recognise my background and influence in the research that was undertaken, which is illustrated in Figure 1.1 offered by Wilson et al (2022, p. 44). Positionality considers the identity of the researcher, the position they have adopted in the research, and how this is presented throughout the research process (Savin-Baden and Major, 2013). By positioning myself recognised that positionality is ‘determined by where one stands in relation to the other’ (Merriam et al, 2001, p. 411). By considering my

position to the 'other' throughout the thesis, was to understand my cultural background (gender, race etc), beliefs, politics and how they are shaped by my surrounding sociopolitical and cultural context (Bourke, 2014). Considering my identity as a researcher within the wider context, is to consider their influence when forming the initial idea, question formation, methodological considerations, and the reporting of findings within the research process (Wilson et al, 2022; Bourke, 2014).

Figure 1.1 – Positionality within Identity and Reflexivity (Wilson et al, 2022, p. 44)



Positionality has varied perspectives on whether the researcher should be removed from the subject (Giorgi, 2012), or that the researcher is inseparable from the process (Moules et al, 2017). My position as a nurse specialist in lymphoedema provided a connection to the phenomena of interest (men with lymphoedema), which informed my position and approach which was considered beneficial (Wilson et al, 2022; Chhabra, 2020). However, it is acknowledged that personal connections can be a disadvantage, such as biases or expectations of outcomes by the researcher or participants (Kassan et al, 2020). My position aligns with the view that positionality provides a 'space' in which objectivism and subjectivism are present, due to the

inability to completely separate them from each other (Bourke, 2014, p. 3). It also recognises that this space is shared between me as a researcher and the men who participated in the study and that we each have individual identities which influenced the research process (England, 1994).

My identity as a researcher informed and influenced my positionality based upon the matters mentioned above, as my identity is one formed through my personal and professional background. I am a White cis-gender gay man from a working-class background who is a healthcare professional with over seventeen years of experience as a registered adult nurse. I have a dual role in being a nurse specialist in lymphoedema, which involves the diagnosis, management, and education of staff/patients for over ten years. My other role as a nurse academic within a higher education setting is the delivery of pre and post-registration courses for qualified nurses. I recognised my background and its potential influence within the research process, but also within whether I perceived myself as an 'insider' or 'outsider' (Bourke, 2014, p. 5). To be an insider is to be part of the community, such as having the same condition, or working in the area, with outsiders being those with no connections to the community being studied (Huberman and Miles, 2002). Others, see this binary approach as not being beneficial, and perceive these concepts (insider or outsider), as being on a continuum, in which a person moves back and forth, and even to a midway point called 'in-betweeners' (Wilson et al, 2022, p. 46; Arber, 2006).

My background as a man and a nurse specialist gave me an insider view of lymphoedema as part of my identity as a researcher. My 'professional identity' acknowledges my specialist knowledge, the functions within that specialism and its

recognition within nursing as a specialist field of lymphology (Wilson, 2022, p. 44; Neary, 2014). Being seen as an insider can have advantages, such as access to key stakeholders and participants, with participants being less 'guarded' (Wilson, 2022; p. 46). In the research process, my 'professional identity' (Wilson, 2022, p. 44) helped men to be less guarded with men expressing relief that they did not need to explain what is lymphoedema. Despite the advantages, I was mindful my insider view would have limitations and the assumptions men may have about my understanding of their condition. I considered that I may become an 'outsider', due to not having lymphoedema and my gender expression being potentially different from the men who participated in the study. Whilst these were important considerations, there was no noted effect upon the research within the two areas mentioned, which was based on my interactions with participants, both during and after data collection and analysis.

Another consideration was my background as a nurse specialist and working within a higher education setting (Rushton, 2022; Kassan et al, 2020) which may have influenced perceived 'power dynamics' (Bourke, 2014, p.6). Throughout the research process, I was aware of my assumptions of men with lymphoedema, and used this to avoid pre-empting the findings, due to my previous knowledge and experience (Wilson, 2022). I was aware that participants may give answers to questions they believed I wished to hear, due to my background as a nurse specialist (Chew-Graham et al., 2002). Despite these concerns and what some call the 'unseen cloak of power' (Beuthin, 2014. P. 489), men appeared to engage with me freely across the three stages within the thesis (Chapters 3-5).

Equally, I considered my position as one that perceives gender as a social construct with its expression in response to the social world (Connell and Messerschmidt, 2005). Narrative inquiry and the methodological approach applied within the thesis provided me with the ability to develop an understanding of how men shape, view and understand their social world (Riessmann, 2008; Rogers, 2007). Whilst I take this position, other men may have taken the view that being a man is an innate and biological position or may not align with the dominant concept being explored (Liddon and Barry, 2021). What became apparent in the findings (Chapters 3-4) of the study and especially within the interviews (Chapter 5) related to the embedded nature of gender within the social fabric of society. Whilst this insight was built throughout the thesis, I reflected upon its emergence within the findings, and my view of gender and its expression as a man. To this end and throughout the study I engaged in reflexivity, which has been suggested as being integral within the research process and when considering positionality (Wilson, 2022).

Reflexivity focuses on self-analysis of how the research has been undertaken, by critically examining the decisions made within my own identity and positionality (Lazard and McAvoy, 2017). As stated earlier, I am a nurse specialist who perceives that gender is socially constructed. Undertaking reflexivity, is to promote an 'honest' approach to the answers given to questions regarding my own beliefs and attitudes (Wilson et al, 2022, p. 47), and how this may have affected the decisions in the research process (Bolton and Delderfield, 2018). By recognising the importance of this at the beginning of the process, led to multiple points of reflexivity that were built into the thesis. For example, when reviewing the findings and analysis I used the reflexivity approach for narrative inquiry offered by Mauthner and Doucet (1998;

Table 3.0). Undertaking reflexivity included research diaries, sharing initial findings with men and my supervisors, but also the ability to undertake triangulation through methodological approaches, and wider sources of evidence (Wilson et al, 2022; Chew-Graham et al., 2002). Being reflexive provided me with the time for 'narrative imagination' that allowed other meanings to emerge, by releasing my pre-held meanings (Andrew et al., 2007, p. 489). By recognising my positionality through reflexivity, allowed my voice as a researcher to be present, whilst maintaining trustworthiness and rigour throughout the thesis.

1.10 - Thesis Overview

1.10.1 - Research Questions

The overall focus of the thesis was upon:

- a) locating, retrieving, and appraising the evidence that surrounds the perceptions of non-cancer-related lymphoedema across available qualitative research.
- b) explore the experiences and perceptions of men diagnosed with non-cancer-related lymphoedema; and
- c) to explore the relationship between lymphoedema and its effect on perceived masculinity.

Based on the overall focus, the thesis considered the following questions:

Main Research Question – What are the perceptions of men diagnosed with non-cancer-related lymphoedema?

To answer the overall arching question the following sub-research questions were included and formed chapters within the thesis:

1. How do men perceive engagement within their self-management of their non-cancer-related lymphoedema? (Chapter 3)
2. How do men perceive their non-cancer-related lymphoedema within their daily lives? (Chapter 4)
3. What are men's perceptions of support within their non-cancer-related lymphoedema? (Chapter 5)
4. What are men's perceptions of masculinity within their non-cancer-related lymphoedema? (Chapter 5)

1.10.2 - Sampling

The samples that are present in each of the studies, supported the exploration of the research questions, due to each stage providing an alternative approach to the gathering and analysis of data. Men who participated in stage 1, were offered the opportunity to continue into stage 2 and then into stage 3.

Online Survey (Chapter 3) - The online survey focused on obtaining the perceptions of men engaging in self-management of their non-cancer-related lymphoedema. Twenty-two men were recruited across the UK (four nations) and the Republic of Ireland.

Solicited Diary (Chapter 4) – The solicited diary involved twelve men who had been part of stage 1 and explored how men perceive their lymphoedema within their daily lives.

Semi-Structured Interview (Chapter 5) – The twelve men from stages 1 and 2, continued with the further exploration of their perceptions of support, but also masculinity related to their lymphoedema.

Overall, the stages allowed the recruitment of men from stages 1 to 3, which provided opportunities for greater depth and exploration with men affected by lymphoedema and their perceptions.

1.10.3 - Structure of the Thesis

The thesis is divided into six chapters. In Chapter 1 lymphoedema and its connection to men have been considered including the theoretical frameworks of hegemonic masculinity and the HIMM framework that I was used in this thesis. Chapter 2, was a systematic meta-aggregation review, that provided the background to the current evidence around men and their experiences of lymphoedema, such as diagnosis, impact upon daily lives, access to services and self-management adoption. The review informed the development of the qualitative studies that formed this thesis.

Chapters 3 to 5 are three qualitative studies focusing on different research questions that covered the experience of men engaging in self-management of lymphoedema, the effect this had upon their daily lives, the availability of support but also their perception of masculinity. Analysis was varied in each chapter to add depth and triangulation, from the application of thematic, and structural to linguistic narrative analysis. Each of the studies provided further understanding and insight into the lives of men affected by lymphoedema and their perception of masculinity. Chapter 6 provides an overall discussion of the thesis, by drawing together the findings of each qualitative study, to inform future directions of exploration and discussion.

10.1.4 - Chapter Contribution

Chapter 1 has provided the contextual background and how this is presented through the structure of the thesis. The Chapter has provided a discussion regarding the relevance of exploring the perceptions of men with non-cancer-related lymphoedema, and the application of the two theoretical approaches (hegemonic masculinity and HIMM framework). It has considered the qualitative methodological approach (narrative inquiry) and the methods that align with it, such as solicited diaries and structural analysis, but also the concept of positionality and reflexivity. The main research question and four sub-questions have been outlined within the structure of the thesis. The contextual background within this Chapter was expanded upon through the completion of the Joanna Briggs Institute (JBI) systematic meta-aggregation review within Chapter 2.

2.0 - Chapter 2 – A qualitative systematic review and meta-aggregation of the experiences of men diagnosed with chronic lymphoedema

2.1 - Chapter Rationale

Chapter 1 provided the contextual background as to why the thesis has focused upon the perceptions of men with non-cancer-related lymphoedema through the four sub-questions. To add further context to the background outlined in Chapter 1 led to the completion of a systematic meta-aggregation review offered by the Joanna Briggs Institute (JBI). The approach offered by the JBI continued the use of the proposed exploration of men's perceptions within a qualitative methodology as outlined in Chapter 1. Chapter 2 outlines the JBI approach within a defined search strategy and its application within agreed databases and the synthesis following appraisal of retrieved sources. No other systematic review that focused upon men with lymphoedema had been undertaken at the time of the thesis. The aim of the systematic review was the retrieval of primary qualitative research on the experiences of men with lymphoedema. The retrieval and subsequent analysis led to four findings that included 1) The new norm, 2) journey into the unknown, 3) access, access, access, 4) personhood. These findings were compared to the wider literature within the discussion.

Chapter 2 has been published and outlined in the list of submitted papers and conference abstract. The paper can be retrieved through the following reference: Cooper-Stanton, G., Gale, N., Sidhu, M., Allen, K. (2022) 'A qualitative systematic review and meta-aggregation of the experiences of men diagnosed with chronic lymphoedema', *Journal of Research in Nursing*. Doi:10.1177/17449871221088791.

2.2 - Abstract

Background

Lymphoedema is a chronic condition that is estimated to affect up to four people per 1000 of the UK population with this increasing with age. Men account for up to 20% of lymphoedema service caseloads with research focussing on women affected.

Aims

To retrieve primary qualitative research on the experiences of men with chronic lymphoedema.

Methods

A qualitative review was undertaken using the Joanna Briggs Institute (JBI) meta-aggregation method. A search strategy was applied to 12 databases, from inception to February 2021, with 22 studies identified and appraised. The findings were extracted and synthesised via the JBI approach.

Results

Four synthesised findings were identified: (1) The 'New Norm', how diagnosis led to men being faced with a 'new version' of themselves; (2) 'Journey into the Unknown' relates to the unforeseen diagnosis of the condition; (3) 'Access' – the challenge in receiving a diagnosis, and support; and (4) 'Personhood' – the impact of the condition upon external constructs and relationships. Conclusions: Men are faced with similar challenges as women coupled with societal expectations concerning gender identity and expression. This leads those wishing to engage with men to adopt 'gender-based tailoring' within healthcare services, information and support.

2.3 - Introduction

Chronic oedema is an umbrella term for what is a long-term condition (LTC), in which lymphoedema is a sub-category, with lymphoedema containing other categories, such as primary and secondary (Rankin, 2016). Primary (intrinsic) is due to developmental abnormalities within the lymphatics, such as Milroy's or Turners; this condition is estimated to affect between one in 2763 and up to one in 8000 people in the United Kingdom (UK) (Cooper and Bagnall, 2016; ILF, 2006; Rankin, 2016). Secondary (extrinsic) is linked to damage to the existing lymphatic system, such as infection, cancer or surgery, with this representing the most reported diagnosis within lymphoedema caseloads (Cooper and Bagnall, 2016; ILF, 2006; Rankin, 2016). It is estimated that between 140 and 250 million people across the world are affected by lymphoedema, with this figure being up to four people per 1000 of the UK population, with 20% of cases involving men, with incidence increasing with age (Cooper and Bagnall, 2016; Moffatt et al., 2019c). This qualitative systematic literature review aims to address an imbalance in the current evidence base between men and women diagnosed with lymphoedema.

2.4 - Methods

This qualitative systematic review utilised the meta-aggregation approach to synthesise the best available evidence (Lockwood et al, 2020; Table 2.0). This approach was adopted following a scoping exercise, that led to no other systematic reviews being identified within this subject area. It also led to the retrieval and review of primary research studies that lacked the depth and richness required for other approaches, such as meta-ethnography (Booth et al, 2013). Meta-aggregation has been described as having similarities with the Cochrane and Campbell guidance for

quantitative systematic reviews, which takes a pragmatic approach that is preferred by policymakers and clinicians (Lockwood et al., 2020).

Table 2.0 – JBI 5 Stage Approach to Meta-Aggregation

Stage	Details	Evidence
1	Critical Appraisal – All included studies were subject to critical appraisal before data extraction. This also included a review of the credibility and dependability of the studies included.	JBI Critical Appraisal Tool
2	Extraction - Study characteristics were extracted including study methods, phenomenon of interest, theme, and sub-themes (verbatim and illustrative quote)	JBI Qualitative Extraction Tool
3	Categorisation - the results of the studies (themes and subthemes) were initially grouped and then given a categorisation.	JBI Meta-Aggregation Approach
4	Synthesised Findings – the categories generated then lead to the creation of ‘synthesised findings’ that provide a comprehensive and representative conclusion to the categories.	JBI Meta-Aggregation Approach
5	Evidence Level – Each study that forms parts of the synthesised finding was given a designated evidence level of 1) Unequivocal (open to challenge), 2) Credible (interpretation) and 3)	JBI Meta-Aggregation Approach and ConQual

	Unsupported (no supporting evidence) – This relates to themes being supported by citations or interview excerpts provided by participants. This is then taken into account for the ConQual score regarding the confidence for each finding.	

2.4.1 - Search strategy and appraisal

The review applied a two-stage approach following question generation and construction as shown in Table 2.1. This built upon the previous scoping exercise, in terms of the search strategy, such as MESH terms, and identifying keywords from articles, which were applied within PEOT (population, exposure, outcome and type) (Bettany-Saltikov, 2016; Table 2.1). This approach led to multiple combinations via Boolean terms as shown in Table 2.2 within multiple databases and grey literature sources (Table 2.2). All retrievals were subject to the inclusion and exclusion criteria (Table 2.1) after duplication removal with these uploaded into Mendeley (2019) version 1.19.4 and presented in the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) (Lockwood et al., 2020: Figure 2.0). Twenty-two articles underwent the Joanna Briggs Institute (JBI) Critical Appraisal Checklist with information taken forward within the JBI Qualitative Data Extraction tool (Lockwood et al., 2020; Tables 2.3 and 2.4).

Table 2.1 – Review Question Breakdown, Inclusion/Exclusion Criteria for Retrievals

Question?	To establish the perceptions of male patients diagnosed with lymphoedema from a biopsychosocial perspective?	
Population	Adult men over the age of 18 years old	
Exposure	Diagnosed with lymphoedema	
Outcomes	Perceived impact of their conditions from a biopsychosocial perspective.	
Types	Qualitative Research and the varying research designs including meta-ethnography reviews.	
Details	Inclusion	Exclusion
Date Range	Any Year up until 2020	n/a
Gender	Men, or combined with females	Female only
Geography	Worldwide	n/a
Language	English Text	Non-English Text
Condition	Diagnosed with lymphoedema, primary, secondary, and chronic oedema	Not diagnosed with lymphoedema, or its sub-conditions
Types	Qualitative Research /Literature/reviews/meta-ethnography	Quantitative
Two Stage Process		

1)	Title and abstract review	Ascertain relevance based on keywords, inclusion, and exclusion criteria, set against the research question.
2)	Full-text review and duplication removal	Establish suitability based upon the inclusion and exclusion criteria, plus research question for further review/appraisal.

Table 2.2 – Search Strategy Table – Keywords, Boolean Combinations and Databases

Boolean	No	P	No	E	No	O	No	T
or	1	Male	12	Lymphoedema	27	Experiences	44	Qualitative
or	2	Man	13	Lymphedema	28	Life experiences	45	Qualitative research
or	3	Men	14	secondary lymphedema	29	Narratives	46	Qualitative approach
or	4	Man's	15	secondary lymphoedema	30	Stories	47	Qualitative Method?
or	5	Men's	16	chronic oedema	31	Perceptions	48	Qualitative Methodology?
or	6	Adult Male	17	chronic edema	32	Perception	49	Qualitative stud?
or	7	Adult men	18	Primary lymphoedema	33	Attitude	50	Qualitative inquiry
or	8	Adult Man	19	Primary lymphedema	34	Attitudes	51	Narrative inquiry
or	9	Adult men's	20	Cancer-related lymphoedema	35	Quality of life	52	Narrative research
or	10	Adult man's	21	Cancer-related lymphedema	36	well-being	53	Narrative stud?

or	11	AND	22	Non-cancer-related lymphoedema	37	View	54	Narrative analysis
			23	Non-cancer-related lymphedema	38	beliefs	55	Ethnography
			24	Lower limb lymphoedema	39	live experience	55	Auto Ethnography
			25	Lower limb lymphedema	40	perspective	56	Phenomenology
			26	AND	41	Findings	57	Grounded theory
					42	Accounts	58	Case stud?
					43	AND	59	AND
Combined			11+26+43+59 (AND)					
Databases	Cinahl, Medline, Nursing and Allied Health Database, Psychology Database, PTSD Pubs, Public Health Database available via ProQuest. APA PsychArticles, Journals@Ovid, Embase, Ovid Meline, APA Psych info available via Ovid. This extended to the retrieval of gray literature, sources from open grey EU and EThOS offered from the British Library, and Google Scholar							

Figure 2.0 - PRISMA flowchart indicating the phases that formed the systematic review.

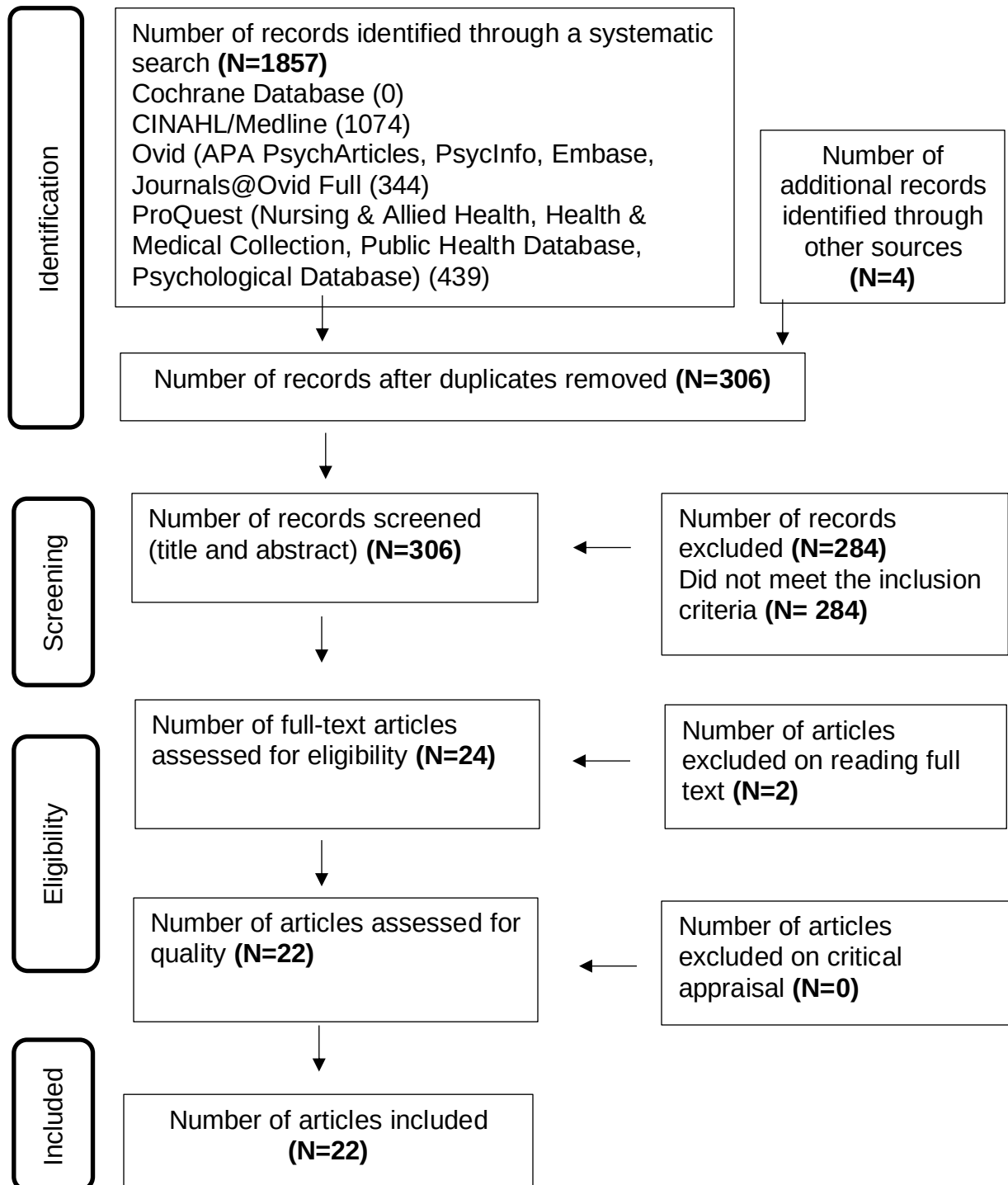


Table 2.3 - Data extraction Table for Included studies

Study	Country	Title	Phenomena of interest	Methodology/ Method	Setting/context /culture	Participant characteristics and sample size	Research Notes
Bogan et al (2007)	USA	Experiences of Living with Non-Cancer-Related Lymphedema: Implications for Clinical Practice	The purpose of this study was to gain insight into the perspective of individuals with non-cancer-related lymphedema to increase understanding of their experiences and, thereby, enhance treatment and guidance by healthcare professionals.	Qualitative – Qualitative approach within a naturalistic inquiry. Semi-Structure Interview with guide/open questions, broad themes with interviews audio recorded and transcribed with field notes. Analysis - was completed via content analysis and ethnography. Males and Females are integrated into one account.	Patients Own Home, diagnosed with non-cancer related lymphoedema or primary lymphoedema, who were or had received inpatient treatment in a regional hospital.	Purposive Sampling, 7 Participants (3 Male and 4 Female, 5 White, 1 Black, 1 Alaskan Indian), Bilateral Leg Oedema (5), Unilateral Leg Oedema (1), Bilateral Leg Oedema and Hand (1). Age (mean) 52 years, range 36-75 years, Inpatient involvement 3 years, and Discharge 8 months to 5 years.	No application to gender.

Results	Three comprehensive themes emerged with sub-themes identified: Three themes emerged - 1) Nowhere to turn - 2) Turning Point, 3) Making Room						
Borbasi et al (2004)	Australia	Getting it together: men's and their carers' experience of lymphoedema	The meaning and understanding of the experiences of men diagnosed and living with lymphoedema.	Semi-structured interviews which lasted between 30-60 minutes, which audio audio-taped and transcribed.	Men and their partners following the development of secondary lymphoedema related to surgery.	Over 18 years diagnosed with secondary lymphoedema following surgery and their spouses.	No application to gender.
Results	Four broad themes emerged from the data: 1) The nature of lymphoedema; 2) Sequelae of lymphoedema; 3) Scarcity of information about lymphoedema; 4) Spouses' perspectives.						

Crow (2020)	USA	Illuminating the experiences of growing up and living with primary lymphedema: a life history story	The purpose of the qualitative research study was to collect, preserve, and understand the life histories of young adults who grew up with and are living with primary lower limb lymphedema in the USA	Qualitative – Life histories related to interpretivist paradigm embedded within social constructivism. This led to the use of guided conversations as part of life history storytelling.	Men and women diagnosed with primary lymphoedema in the lower limbs.	Purposive sampling Participants - 5 (4 women and 1 man) Age range of 19-40 years, diagnosed with primary lymphedema.	Social Constructivism, mentioning a gendered lens (sociocultural /medica-historical contexts)
Results	1) Striving to Matter To and For Others and Self; 2) Complexities, Complications, and Confusions: Life Difficulties along the Journey; and 3) Lymphie Conundrums: Grappling with Normalizing/Othering. The first includes sub-themes about mattering to significant others, healthcare providers, others with primary lymphedema, and to self. The second includes subthemes about the complexities of decongestive therapy and self-management, schooling, other chronic diseases, and other priorities that push lymphedema to the background, the complications of biographical disruption and transformative brushes with cellulitis, and lingering confusions about cause and heritability. The third includes sub-themes about stigmatization, rejection, and discrimination, hiding to pass as “normal” and its costs, and straddling the lymphie conundrum with clothing.						

Deng et al (2016)	USA	Lymphedema self-care in patients with head and neck cancer: a qualitative study	Reporting head and neck cancer patients' perceived lymphedema: Self-care education: Self-care practices Self-care suggestions	Mixed methods - Semi-structured interviews which lasted between 30-60 minutes, were audiotaped and transcribed.	Men and their partners following the development of secondary lymphoedema related to surgery.	20 Participants - Male 65% (n=13) and women 35% (n=7), 100% White, Diagnosis and cancer were also present majority 50% were oropharynx location stage 4.	No application to gender.
Results	Themes generated related to the aims - Aim 1: perceived lymphedema self-care education Components - 1) Components of self-care education, 2) positive comments of self-care education, 3) insufficient or inappropriate information on self-care education Aim 2: reported lymphedema self-care practices Levels of engagement and methods, Aim 3: suggestions on lymphedema self-care						

Frid et al (2006)	Sweden	Lower Limb Lymphedema: Experiences and Perceptions of Cancer Patients in the Late Palliative Stage	The aim of this study was, therefore, to explore patients' experiences and perceptions regarding the influences of LLL, and how they manage this in the late palliative stage.	Qualitative – Phenomenology, Semi-structured Interviews, Open Ended Questions - experiences and thoughts about having lower limb lymphoedema (LLL). Analysis - phenomenographic approach using second order perspective rather than first.	Outpatient Clinic who were diagnosed with cancer related lymphoedema who were palliative.	Participants – 13 (9 Women and 4 Men), Diagnosed cancer-related lymphoedema and who were palliative (Pancreatic - 2, cervical - 2, Renal - 1, Breast - 1, Prostate 3, Adrenal - 1, Lung - 1, Unknown Origin - 1, Cecal - 1), Recruited from three different clinics in Stockholm and via 'maximum variation sampling strategy, Interview and death (12-168 days), Severity Mild - 4, Moderate - 3, Severe - 6.	No application to theory, or gender.
Results	Four main categories were identified: 1) The Future - Hope - The patients were aware that the LLL was permanent, but still they held hope for improvement, 2) The Physical Aspects - Discomfort and disgust – related to the appearance of the limb. 3) Interactions with Others - persons' reactions affected the way in which they perceived their limb. 4) Efforts - made by staff had a great influence on the patient's situation, 5) Dealing with Problems - To adapt oneself - or not – 6) Control through knowledge – but also avoidance strategies.						

Hamilton et al (2016)	Canada	Renegotiating hope while living with lymphoedema after cancer: a qualitative study	The purpose of the present analysis, then, was to assess the hope experiences of individuals living with SLC (including underrepresented groups such as men and those with lower limb SLC), an area which has been unexamined.	Qualitative – Qualitative approach - Semi-structured Interviews, Open Ended Questions - experiences and thoughts about having lower limb lymphoedema (LLL). Analysis - Phenomenography approach using second order perspective rather than first.	Clinic and people's homes via the telephone and who were diagnosed with cancer related lymphoedema and self-managing.	Participants – 13 from two sites in Fredericton and Ottawa which included 11 women and 2 men. The age range is between 31-77 years with a diagnosis of cancer ranging from 2-34 years with a mean of 10 years with CRL diagnosis being 1-11 years with a mean of 8.5 years. Cancer diagnosis, Cervical - 1, Breast 6, Melanoma 4, Endometrial 1, Prostate, and colorectal 1. Eight lived in an urban area with five working full-time.	Hope-based theory, No gender theory

Results	Four themes emerged: 1) Renegotiating Hope in the context of a chronic condition - One striking finding was that participants struggled to articulate what hope meant, even though the term is popular. 2) The Objects of Hope - When participants were asked generally about hope, they most often oriented towards a description of the objects of their hope. 3) Hope as an Outcome - While some participants struggled to define what hope was, they were much more capable of discussing hope as an outcome – or the factors that contributed to hope. 4) Hope as Action - While the distinction between coping and hope is subtle when exploring hope as action, it is important to note that participants talked about acting as a way of living hopefully

Jeans et al (2019)	Australia	Patient perceptions of living with head and neck lymphoedema and the impacts on swallowing voice and speech function.	This study aims to explore the experiences of patients with HNC who have HNL following treatment and examine their perceptions of the impact of HNL on their swallowing, voice, and speech function. The	Qualitative – Qualitative approach, Semi-structured - Face to face (6 people) and telephone (7 people), with a socio-demographic and illness questionnaire administered, followed by a series of open-ended questions. The answers to these questions were audio recorded. Analysis - led to the preliminary coding through NVivo 10 Reflexivity was considered through debriefing sessions	Secondary Setting/Hospital/Maxillofacial	12 Participants - Male 66.7% (n=8) and Female 33.3% (n=4), 50% had either neck dissection or not, with almost a 50% split between tumour and node staging.	No application to theory, or gender.

				to discuss and refine interpretations.			
Results	Four themes: 1) it feels tight; 2) it changes throughout the day; 3) it requires daily self-monitoring and management and 4) it affects me in other ways.						

Maree et al (2016)	South Africa	"Just live with it": Having to live with breast cancer related lymphedema	The objective of the study was therefore to explore how people living with breast cancer-related lymphedema experience this complication	Qualitative – Qualitative approach, Unstructured interview an opening question asked, "Please tell me what it is like for you to live with lymphedema", conducted in Afrikaans or English, and audiotaped. Teschs open coding was undertaken to reach data saturation. Reflexivity was mentioned as being continuous in the study.	Lymphoedema initiative at a university to explore breast cancer related lymphoedema in men and women.	Purposive sampling, eight women and one man. The age range was 43-61 years with the average being 61 years. Seven were Afrikaans, one was Greek, and one was Tswana. Six participants had stage two, one had stage two to three, and two had stage three lymphoedema. The presence of oedema was between two to sixty months.	Roy Adaptation Model of Nursing (biopsychosocial).

Results	Four themes emerged: Theme 1: “Just live with it”: Lymphedema the unknown and unspeakable, Theme 2: “My arm is painful”: Living with the physical consequences of lymphedema, Theme 3 - “You cannot hide it”: living with an altered body - Theme 4: “I am grateful”: Coping with the lymphedema.

McGarvey et al (2014)	Australia	Lymphoedema following treatment for head and neck cancer: impact on patients, and beliefs of health professionals	this study aimed to explore the relationships between How lymphoedema affects head and neck cancer patients. Beliefs of medical and health professionals regarding which patients might be more at risk of developing lymphoedema, How it affects patients, How lymphoedema might be effectively managed	Qualitative – Study Design Unclear - Semi-Structured Interview (one-on-one), Interview schedule/guide, Audio recorded (unclear), Transcribed verbatim (no software stated), Codes/themes (no mention of the framework applied), 2nd researcher involved in the code/theme generation.	Secondary Setting/Hospital/Maxillofacial	20 Participants, 10 Patients (8 Male and 2 Female), age range 32-75 years, mean age 60 years. 10 Healthcare Professionals - n=2 consultant maxillofacial surgeons, n= 1 dietitian, n= 1 speech pathologist, n=2 physiotherapist, n=1 radiation therapy nurse and n=1 head and neck co-coordinator. No statement of gender, age, experience, or qualifications.	No application to theory, or gender.

Results	The results 6 themes related to patients with a further 3 related to healthcare professionals: Patients: 1) physical effects of lymphoedema, 2) diurnal pattern, 3) Tightness and reduced cervical spine range of motion, 4) mucous secretions and swallowing, 5) psychosocial aspects (negative body image), 6) strategies to assist with facial lymphoedema. Healthcare Professionals: 1) Clinical features, 2) beliefs about the effects of secondary lymphoedema, 3) Management Strategies.

Meiklejohn et al (2019)	Australia	How people construct their experience of living with secondary lymphoedema in the context of their everyday lives in Australia.	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.	Qualitative – Qualitative approach, Focus group and telephone interviews with all other participants, with two to four participants in each group. Interview guide with open-ended questions (questions provided). Analysis - Interviews were transcribed verbatim and transcripts were imported into NVivo8 qualitative software, in accordance with the constructivist grounded theory, initial, focused, and	Secondary Setting/Hospital following cancer treatment	Participants were 29 in total with men (n=3) and female (n=26), Age median of 63 years (range 39-80 years). Majority (n=20) were breast cancer related diagnosis.	Social constructionism and social constructivist framework.

				theoretical coding were performed.			
Results	Three conceptual categories were developed from the data. 1) altered normalcy - physical and psychosocial effects of lymphoedema and their impact on everyday life. 2) accidental journey - explores the "secret society of a lymphoedema diagnosis and the importance of finding a healthcare professional 3) ebb and flow of control elements that influenced participants' perceived control over lymphoedema. Core category - sense of self						
Michael et al (2016)	Australia	The experiences of prostate cancer survivors: Changes to physical function and its impact on quality of life	The aim of this research is to help understand the experience of prostate cancer survivors in relation to physical function and how these changes impact on prostate cancer survivors' quality of life.	Qualitative – Phenomenology, Semi-Structured interviews, verbatim transcripts, thematic content analysis, reflexivity/member checking and 3rd part verification were stated.	Prostate Cancer Support Group for those who had received treatment	Purposive sampling - 7 men mean age 64.5 years (51-83 years, despite the work stating 41-80 years). Five men were married, one divorced and one widowed, with diagnoses ranging from 1993-2010. Radiotherapy was received by 3 men, with 4 receiving prostatectomy.	No application to theory, or gender. However, masculinity was mentioned, and related to other research studies.
Results	The main themes generated were 1) Masculinity - related to physical changes, 2) Loss of control over daily lives - related to incontinence and impotence, 3) age-specific perspectives - this considered employment						

Nixon et al (2018)	Australia	A mixed methods examination of distress and person-centred experience of head and neck lymphoedema	Examine distress and QoL in people undertaking a 22-week HNL treatment program following treatment for HNC Explore the person's experience of HNL and distress and the impact on day-to-day functioning following completion of HNL treatment	Mixed Methods, QoL: was assessed using EORTC QLQ and H&N43, with these subject to Friedman test, with pairwise comparisons and Bonferroni correction, Wilcoxon Signed Rank test, SPSS version 22. A single semi-structured interview was conducted 10–22 months after completion of the 22-week HNL treatment, once the data from. An eight-question interview guide and analysis of the interviews	Secondary Setting/Hospital/Maxillofacial	10 Participants - Male (n=9) and Female (n=1), Age 65.1 (mean) with a range of 42-89 years, Inclusion and exclusion criteria stated, convenience sampling appears to be present, due to the location, but is stated directly in this article.	No application to theory, or gender.

				were conducted using the model proposed by Braun and Clarke.			
Results	The five main themes were: (1) the psychosocial impact; (2) the physical experience and pattern/timing; (3) the experience of receiving treatment; (4) day-to-day distress; (5) support that helped manage distress; (6) adjustment to a “new normal”. The three sub-themes were: 1) emotional, 2) appearance changes, and 3) socialisations.						

Perera et al (2007)	Sri Lanka	Neglected Patients with a Neglected Disease? A Qualitative Study of Lymphatic Filariasis	The objective of the study was to inform future interventions and policies to help these vulnerable, neglected people. By doing so, it responds to the need for specific research identified in the most recent review of the sociocultural aspects of filariasis	Qualitative – Qualitative approach, Semi-structured, guided interviews in the local language, Sinhalese. Interviewers worked in single-sex pairs: one conducting the interview, the other recording the responses manually. Interview notes were transcribed and later translated into English for analysis. Analysis - An adaptation of the affordability ladder framework was employed to	The infection is currently endemic in Sri Lanka due to W. bancrofti and is presently confined to eight districts in the Southern, Western, and North-western Provinces [20]. Our study took place in three villages in Matara and one in Galle in 2004–2005. Reference to lymphoedema in Sri Lanka has been traced to the 13th century AD	Purposive sampling to select 60 (29 men and 31 women with filarial lymphoedema (45 with filarial elephantiasis and 15 men with filarial hydrocoele) from the south of Sri Lanka in 2004–2005. Participants were selected by poverty status, sex, and lymphoedema stage. Low income (Male 4 and 11 women), Middle income (Male 8 and Female 13), and high income (Male 2 and Female 7). A separate sample of 15 men with filarial hydrocele.	An adaption of the Healthcare affordability ladder framework, but no application to gender theory.

				organise and analyse the data.			
Results	Reference Ladder (Illness) – 1) Delayed diagnosis was common and had irreversible consequences 2) Household Economy Ladder - struggling to find work 3) Impact Ladder - The stigma associated with LF was a dominant theme						

Rio-Gonzalez et al (2018)	Spain	Living with lymphoedema—the perspective of cancer patients: a qualitative study	To illuminate the impact of LE on cancer patients' lives through their experiences, perspectives, challenges, and barriers	Qualitative – Phenomenology, Stage 1 - Unstructured interview with an "What is your experience with lymphoedema?" and stage 2 semi-structured interviews with a question guide developed following stage 1. All interviews were tape-recorded and transcribed verbatim. Researcher field notes were used. Analysis - thematic analysis was undertaken, and no data analysis	Two outpatient physiotherapy clinics focusing on people men and women diagnosed with cancer related lymphoedema.	Purposeful sampling, 11 participants were recruited between 2014-2016 (1 Male & 10 Female).	No application to theory, or gender.

				software was used. Rigour - Guba and Lincoln for establishing the trustworthiness of the data.			
Results	One main theme and four sub-themes emerged: 1) Living life with multiple barriers - Subthemes: 1a) Discovering physical and psychological barriers - 1b) Searching information, 1c) Uncomfortable moments, 1d) Building relationships - The social barriers, 1e) Controlling expenses.						

Shakespeare, L (2012)	Scotland	Lymphoedema in a remote and rural area: An investigation into the prevalence of lymphoedema and its effect on daily living and quality of life in a remote and rural area in the far north of Scotland.	To estimate the prevalence of lymphoedema/chronic oedema to investigate the characteristics of the condition in a very remote and rural area of Scotland and to explore the experience of a sample of people living with the condition in that area.	Mixed Methods – Stage 1 quantitative data collection (GP survey), Stage 2 – Individual survey with closed and open questions, Stage 3 – semi-structured interviews,	GP Practice Survey (Stage 1), with a survey sent to individuals via the GP (Stage 2). Telephone interview with participants (Stage 3).	Stage 1 – GP Lymphoedema Prevalence Survey = Total 17 GP Practices. Stage 2 – Patient Characteristics of Lymphoedema = Total 49 (10 Male & 39 Female). Stage 3 – Semi-Structured Interviews = Total 10 Male & 9 Female.	No application to gender theory
Results	In stage 3 (Interviews) this led to the identification of 5 themes: 1) Physical effects of lymphoedema on everyday life, 2) Psychological effects, 3) Treatments, 4) Knowledge about lymphoedema, 5) Provision of information about lymphoedema.						

Stolldorf et al (2016)	USA	A Comparison of the Quality of Life in Patients with Primary and Secondary Lower Limb Lymphedema: A Mixed-Methods Study	The purpose of this study was to describe and compare the impact of the symptoms of lower-limb lymphedema and the associated symptom intensity and distress on the quality of life of patients by lymphedema type.	Mixed methods - web-based survey (demographics, Lymphedema Symptom Intensity and Distress Survey-Leg (LSIDS-L), and one open-ended qualitative question). Participants' responses to the qualitative, open-ended question were analysed using ATLAS. ti, (Version 6.0; Dowling).	An online web-based questionnaire derived from a validated tool and followed by an open-ended question	Participants - 213 participants. Four categories of participants by lymphedema type emerged: primary lymphedema (n=96, 45%), secondary cancer-related lymphedema (n=37, 17%), secondary non-cancer-related lymphedema (n=45, 21%), and lymphedema of unknown causation (n=35, 17%). Lower-leg lymphedema of unknown origin was not included due to the ambiguity of lower-limb lymphedema. Participants were predominantly female	No application to theory, or gender.

						(n=159, 89.3%) male (n=54), employed full- time (n=75, 42.1%), and with lymphedema in both legs (n=72, 40.4%).	
Results	Qualitative Outcomes: 1) Impacting psychosocial well-being altering body image that impacts their psychological and social well-being, 2) Lacking resources - lack the financial resources, and availability of lymphedema practitioners. 3) Physical and functional impairments—physical consequences and functional impairments. 4) Treatment and care— care by others and self-care, problems, and challenges						

Thomas et al (2014)	Canada	Illustrating the (in)visible: Understanding the impact of loss in adults living with secondary lymphedema after cancer	To explore experiences of loss and hope in men and women living with SLC	Qualitative – interpretive descriptive design, A brief questionnaire (socio-demographics, cancer and SLC diagnoses, and treatment). Semi-structured interview guide. Analysis - Interpretive description draws on several methodological strands, including contemporary phenomenology (Thorne, 2008), within the software program, NVivo 10.	The project was based out of two research sites (Fredericton, NB, and Ottawa, ON).	Participants - 13 (11 women, 2 men) ranged from 31 to 77. Eight of the 13 participants lived in urban areas. Five participants were working full-time. Participants had been diagnosed with cancer from 2 to 34 years (mean 10 years) before being interviewed. Six participants had breast cancer, four had melanomas, and three had reproductive cancers. Participants had been diagnosed with SLC from less than 1 year to 11 years post-cancer diagnoses (mean 8.5 years). Seven participants had lower	No application to theory, or gender.

						limb SLC, while 6 were experiencing upper limb SLC.	
Results	Three key themes emerged: Theme 1 - (in)visibility and appearance, Theme 2 - (in)visibility and action, is connected to function and Theme 3 - (In)visibility of the present and future - loss of the present).						

Tidhar et al (2018)	Israel	The meaning of success in lymphoedema management	What do people with lymphoedema consider to be the meaning of success in the intensive phase of lymphoedema management? What do people with lymphoedema consider to be the meaning of success in the long-term phase of lymphoedema management?	Qualitative – Phenomenology, Semi-Structured Interviews and followed an interview guide.	Maccabi Healthcare System in the South district of Israel and with those diagnosed with cancer related lymphoedema who had received intensive treatment and now had moved to maintenance therapy.	Purposive sampling, Total 10 = 3 Male & 7 Female. The time since diagnosis is 1 to 35 years.	Biopsychosocial model (Armer). No application to gender theory.
Results	Two themes emerged from the data: 1) detachment and bad feelings/experiences immersed: 2) Lack of clarity as to moving to the long-term phase of treatment - The second aim meaning of success in the maintenance (long-term) phase. Two themes: 1) Empowerment - “not getting worse”, “stable”, and “maintain”. and the goal of maintaining, she said: Expectations - they talked about acceptance, about having no other choice but to deal with their condition.						

Towers et al (2008)	Canada	The psychosocial effects of cancer-related lymphedema	Seek further understanding of the psychosocial context of the suffering in those with cancer related lymphoedema.	Qualitative – Phenomenology, Semi-structured interviews with open-ended questions were used in the interview which followed the interview guide. Analysis - The content analysis approach was used once all verbatim transcription was completed.	To recruit and interview men and women with cancer-induced lymphoedema from hospital-based lymphoedema services, local therapists and lymphoedema associations and support groups.	Participants – 19 - 11 patients (10 female and 1 male) and 8 spouses, with diagnoses related to breast cancer (9), Melanoma (1) and Penile (1), affecting arm (9) and leg (3 with 1 unilateral and 2 bilateral). Age range 50-75 years with a mean of 63.7 years.	No application to theory, or gender.
Results	Four themes emerged from the data: 1) Frustration with the lack of financial support from government and insurance companies, 2) Being alone with this life-long problem: this related to conflicting information on the subject and treatment options and limited knowledge by physicians and society, 3) The burden of living with a swollen limb: this focused upon the realisation that the condition was chronic. 4) The importance of support systems: spouses, peer support groups, and exercise sessions.						

Viehoff et al (2015)	Netherlands	Functioning in lymphedema from the patient's perspective using the International Classification of Functioning, Disability, and Health (ICF) as a reference	This study aims to determine relevant aspects of functioning as well as relevant environmental and personal factors from the lymphedema patients' perspective and to quantify these, using the ICF.	Qualitative – Qualitative approach, Six different focus groups were used, each with 3–8 participants. These groups consisted of patients with (A) lymphedema with non-oncology background (mixed locations), (B) lymphedema with an oncology background (mixed locations), (C) lymphedema of the upper limb (mixed causes), (D) lymphedema of the lower limb (mixed causes), (E)	Outpatient location and with individuals that had been diagnosed with cancer or non-cancer related lymphoedema.	Patients were recruited from five different centres during 2012–2013. Stucki and Cieza. Thirty-one patients were recruited (men 10 and women 21), with a mean age of 55 years and locations ranging from upper limb (7), Lower Limb (11), midline (5), mixed locations genital (6) and breast/upper limb (2). Lymphoedema related to cancer (18) and non-cancer related (13) with 15 employed in work.	ICF Framework, but no application to theory, or gender.

				lymphedema in the genital region (mixed causes), and (F) lymphedema in the head and neck region caused by cancer treatment. Analysis - The data analysis was conducted in four steps and followed the method of 'meaning condensation' with step four, each MC was linked to one or more ICF categories.			

Results	Body Function - The top five frequently mentioned categories were 1) 'b435, Immunological system functions', (impairments in the lymphatic system); 2) b152, Emotional functions' (emotions such as fear, anger, joy); 3) b280, Sensation of pain'; 4) b126, Temperament and personality functions' (including psychic stability, confidence and optimism); and 5) 'b840, Sensations related to the skin'. Body Structures - the top five mentioned categories were 1) 's750, Structure of lower extremity'; 2) 's730, Structure of upper extremity'; 3) 's630, Structure of reproductive system'; 4) 's710, Structure of head and neck region'; and 5) 's760, Structure of trunk'. Activities and Participation - The top five categories identified were 1) 'd920, Recreation and leisure'; 2) 'd415, maintaining a body position' (lying, sitting, standing, etc.), 3) 'd570, Looking after one's health' (ensuring comfort, maintaining health, and managing diet and fitness); 4) 'd450, Walking'; and 5) 'd475, Driving'. In focus group C (upper limb lymphedema with mixed backgrounds), 1) 'd640, doing housework' occurred most frequently, whereas 2) 'd415, maintaining a body position' occurred most frequently in the genital lymphedema group (E). Environmental Factors - 1) 'e115, Products and technology for personal use in daily living' prostheses); 2) 'e580, Health services, systems and policies', 3) 'e355, Health professionals'; 4) 'e310, Immediate family'; and 5) 'e110, Products and substances for personal consumption'. Personal factors - can be broadly divided into sociodemographic factors (including gender and race), personal living situations and coping strategies.

Watts et al (2016)	Wales	A qualitative national focus group study of the experience of living with lymphoedema and accessing local multi-professional lymphoedema clinics.	What is it like to live with lymphoedema in terms of its effect on quality of life and well-being? In what ways has access to local lymphoedema clinics made a difference in their lives?	Qualitative – Qualitative approach, Convenience sampling via eight local lymphoedema clinics in Wales. Digitally recorded focus group interviews. Analysis - Content analysis (Coffey and Atkinson).	Local Lymphoedema clinic with men and women interviewed through focus groups that were mixed gender and causes (cancer and non-cancer related).	Total 59 = 10 Males & 49 women with an age range of 22-86 years. Twenty-four participants were diagnosed with cancer (7 men and 18 women) with thirty-four diagnosed with non-cancer related lymphoedema (3 men and 31 women).	No application or gender theory
Results	Themes: 1) It is a battle': Living with lymphoedema, 2) Delays in correct diagnosis – 3) The impact of the local specialist-led lymphoedema.						

Williams et al (2004)	United Kingdom	A phenomenological study of the lived experience of people with lymphoedema	Explore the lived experiences of people with various types of lymphoedema.	Qualitative – Phenomenology, Demographical data was gathered as a baseline from lymphoedema clinic Semi-structured interviews, open questions Analysis - via the 'open coding' offered by Strauss and Corbin, 1990).	Specialist lymphoedema clinic in London to explore the lived experiences of various types of lymphoedema.	Participants 15 - (12 women and 3 men with an age range of 35-89 years with a mean of 57 years. Lymphoedema presentation was 1-41 years old. Causes - breast cancer (3), Cervical cancer (2), Carcinoma Penis (1), Primary Lymphoedema (7), Venous Insufficiency	No application to theory, or gender.
Results	Three main themes were identified: 1) The experience of lymphoedema diagnosis - 1a) Uncertainty - 1b) Fishing in the Dark - 1c) Tension with healthcare professionals. 2) Experiencing and dealing with lymphoedema - 2a) Facing Others - the social, 2b) Keeping it hidden - difficulties with self-image, 2c) Rehearsing the story and learning to open, 2d) Making sense of it, 2e) Getting on with it - a variety of coping strategies. 3) Lymphoedema Treatment - 3a) Starting on a firm footing, 3b) Knowing what I need, 3c) Reading my body and judging the						
Total	22	Qualitative Approach = 9 Phenomenology = 6 Mixed Methods = 5 Unclear = 2		Total Male = 182 Total Female = 425		Gender Theory = 0 Gendered lens = 1 Biopsychosocial = 1 Social Construction = 2 Adaptation Model = 1 Adaption Framework = 1	

Table 2.4 – JBI Appraisal Tool and Scoring System

Studies/Citations	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
McGarvey et al (2014)	U	Y	Y	U	U	U	U	Y	Y	Y	5/10
Frid et al (2006)	U	U	Y	Y	Y	N	N	U	Y	Y	5/10
Perera et al (2007)	Y	U	Y	U	Y	N	N	U	Y	Y	5/10
Michael et al (2016)	U	Y	U	Y	Y	U	Y	Y	U	Y	6/10
Nixon et al (2018)	Y	Y	Y	Y	Y	U	U	U	Y	Y	7/10
Deng et al (2016)	U	Y	Y	Y	Y	N	U	Y	Y	Y	7/10
Río-González et al (2018)	Y	Y	Y	Y	Y	N	U	U	Y	Y	7/10
Stolldorf et al (2016)	Y	Y	Y	Y	Y	N	N	Y	U	Y	7/10
Towers et al (2008)	Y	Y	Y	Y	Y	U	U	Y	U	Y	7/10
Viehoff et al (2015)	Y	Y	Y	Y	Y	N	U	U	Y	Y	7/10
Williams et al (2004)	Y	Y	Y	Y	Y	N	N	U	Y	Y	7/10
Meiklejohn et al (2013)	Y	Y	Y	Y	Y	U	N	Y	Y	Y	8/10
Borbasi et al (2004)	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8/10
Jeans et al (2019)	Y	Y	Y	Y	Y	U	N	Y	Y	Y	8/10
Hamilton et al (2016)	Y	Y	Y	Y	Y	N	Y	U	Y	Y	8/10
Thomas et al (2014)	Y	Y	Y	Y	Y	U	U	Y	Y	Y	8/10
Tidhar et al (2018)	Y	Y	Y	Y	Y	U	Y	U	Y	Y	8/10
Watts et al (2016)	Y	Y	Y	Y	Y	U	Y	U	Y	Y	8/10
Bogan et al (2007)	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	9/10
Maree et al (2016)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	9/10
Shakespeare, L. (2012)	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	9/10
Crow, D. (2020)	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	9/10
%	82	91	95	86	95	14	36	55	87	100	%
Key:	Y (yes), N (no), U (unclear)										

Questions:	1. Is there congruity between the stated philosophical perspective and the research methodology? 2. Is there congruity between the research methodology and the research question or objectives? 3. Is there congruity between the research methodology and the methods used to collect data? 4. Is there congruity between the research methodology and the representation and analysis of the data? 5. Is there congruity between the research methodology and the interpretation of the results? 6. Is there a statement locating the researcher culturally or theoretically? 7. Is the influence of the researcher on the research, and vice-versa, addressed? 8. Are participants, and their voices, adequately represented? 9. Is the research ethical, according to current criteria, or for recent studies, and is there evidence of ethical approval by an appropriate body? 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

2.4.2 - Data synthesis

Data synthesis was completed through the completion of meta-aggregation supported by the JBI SUMARI (Lockwood et al., 2020; Table 2.0). After completing the appraisal process, each of the study's findings was included and then grouped into categories based on similarity, with an overall synthesised finding formed as a representative conclusion (Lockwood et al., 2020; Tables 2.0 and 2.5). Each of the synthesised findings was then given a designation based on the confidence of that finding, in terms of credibility and dependability which led to a ConQual being generated for each synthesised finding (Lockwood et al., 2020; Tables 2.0 and 2.6).

Table 2.5 - Synthesised Findings – Process for categorisation and synthesis formation

Study	Study Findings	Categories	Synthesises Findings
Crow (2020)	Lymphie Conundrums: Grappling with Normalizing /Othering	<i>Forced Normalcy</i>	The 'New Norm' (This refers to how those diagnosed with the condition are faced with a 'new version' of themselves, and how that is accommodated, and 'normalised' in their lives.)
Meiklejohn et al (2013)	Accidental Journey		
Meiklejohn et al (2013)	Altered Normalcy		
Nixon et al (2018)	Adjustment to a new normal		
Michael et al (2016)	‘An old man’s disease’: prostate cancer and the younger male		
Michael et al (2016)	‘Only half a bloke’: changes to self-perception		
Michael et al (2016)	‘It’s dictated my life’: disruption to function and its impact on daily life and life quality		
Crow, (2020)	Complexities, Complications, and Confusion: Life Difficulties along the Journey	<i>Psychological and Social Journey</i>	The 'New Norm' (This refers to the way in which those diagnosed with the condition are faced with a 'new version' of themselves, and how that is accommodated, and 'normalised' in their lives.)
Crow, (2020)	Striving to Matter To and For Others and Self		
Jeans et al (2019)	It affects me in other ways		
Meiklejohn et al (2013)	Ebb and Flow of Control		
Nixon et al (2018)	Supports that helped manage distress		
Nixon et al (2018)	Day-to-day distress		
Nixon et al (2018)	Psychosocial impact		

McGarvey et al (2014)	Psychosocial aspects of facial lymphoedema		
Shakespeare, L. (2012)	Psychological effects		
Deng et al (2016)	Suggestions on lymphedema self-care	<i>Management Process and Adoption</i>	Journey into the 'Unknown' (<i>This pertains to the journey taken by those diagnosed with lymphoedema. It also considers that the journey started alongside another journey, which has led a 'mystery tour' that is less than wanted.</i>)
Deng et al (2016)	Perceived lymphedema self-care education		
Deng et al (2016)	Reported lymphedema self-care practices		
Jeans et al (2019)	It requires daily self-monitoring and management		
Nixon et al (2018)	Experience of receiving treatment		
Shakespeare, L. (2012)	Treatments		
Shakespeare, L. (2012)	Knowledge about lymphoedema		
Shakespeare, L. (2012)	Provision of information about lymphoedema		
Jeans et al (2019)	It changes throughout the day	<i>Physical Journey</i>	Journey into the 'Unknown' (<i>This pertains to the journey taken by those diagnosed with lymphoedema. It also considers that the journey started alongside another journey, which has led a 'mystery tour' that is less than wanted.</i>)
Jeans et al (2019)	It feels tight		
Nixon et al (2018)	Physical experience and pattern/timing		
McGarvey et al (2014)	Physical effects of lymphoedema		
McGarvey et al (2014)	Diurnal pattern		
McGarvey et al (2014)	Tightness and reduced cervical spine range of motion		
McGarvey et al (2014)	Mucus secretions and swallowing		

Shakespeare, L. (2012)	Physical effects of lymphoedema on everyday life		
Maree et al (2016)	“I am grateful”: Coping with the lymphedema	<i>Affordability and Access - The few or the many?</i>	Access, Access, Access' (This pertains to the receiving of a diagnosis, information, and support. Set against the challenges in reaching this stage, and the benefits when it is achieved.)
Perera et al (2007)	Expenditure		
Perera et al (2007)	Household economy ladder		
Río-González (2018)	Controlling expenses		
Stolldorf et al (2016)	Lacking resources Patients		
Towers et al (2008)	Frustration		
Maree et al (2016)	“Just live with it”: Lymphedema the unknown and unspeakable	<i>Information and Knowledge Generation - sufficient vs insufficient</i>	Access, Access, Access' (This pertains to the receiving of a diagnosis, information, and support. Set against the challenges in reaching this stage, and the benefits when it is achieved.)
Río-González (2018)	Searching information		
Tidhar et al (2018)	Lack of clarity about moving to the long- term phase of treatment		
Towers et al (2008)	Being Alone		
Towers et al (2008)	Support Systems	<i>Support Networks - Knowing where to turn?</i>	Access, Access, Access' (This pertains to the receiving of a diagnosis, information, and support. Set against the challenges
Viehoff (2015)	Environmental Factors		
Watts et al (2016)	‘It has changed my life’: The impact of the local specialist led lymphoedema clinic		

			<i>in reaching this stage, and the benefits when it is achieved.)</i>
Perera et al (2007)	Illness	<i>Diagnosis - Lucky dip or serendipity</i>	Access, Access, Access' (This pertains to the receiving of a diagnosis, information, and support. Set against the challenges in reaching this stage, and the benefits when it is achieved.)
Watts et al (2016)	'Nothing was done until about a year ago': Delays in correct diagnosis		
Williams et al (2004)	Experience of lymphoedema diagnosis		
Frid et al (2006)	Interaction with Others	<i>Sociability, Status and Power - what are the returns</i>	Personhood' (This refers to the notion that a person exists as part of existential and relational constructs. How that is acknowledged by services and others is variable.)
Perera et al (2007)	Impact ladder		
Río-González (2018)	Building relationships		
Williams et al (2004)	Experiences and dealing with lymphoedema		
Hamilton (2016)	Hope as action		
Thomas (2014)	(In)visibility and appearance		
Bogan et al (2007)	Making Room		

Frid et al (2006)	The Future	Temporality - past, present, and future	Personhood' (This refers to the notion that a person a exists as part of existential and relational constructs. How that is acknowledge by services and others is variable.)
Hamilton (2016)	Renegotiating hope in the context of a chronic condition		
Thomas (2014)	(In)visibility of the present and future		
Tidhar et al (2018)	Hope		
Tidhar et al (2018)	Maintenance vs back to normal (acceptance vs hope)		
Bogan et al (2007)	Turning Point		
Frid et al (2006)	Dealing with problems		
Hamilton (2016)	The objects of hope		
Stolldorf et al (2016)	Impacting psychosocial well-being Patients		
Tidhar et al (2018)	Empowerment		
Viehoff (2015)	Personal Factors		
Bogan et al (2007)	Nowhere to Turn	Daily Life - Remembrance	Personhood' (This refers to the notion that a person a exists as part of existential and relational constructs. How that is acknowledge by services and others is variable.)
Frid et al (2006)	The Physical Aspects		
Maree et al (2016)	“My arm is painful”: Living with the physical consequences of lymphedema		
Río-González (2018)	Discovering physical and psychological barriers		
Stolldorf et al (2016)	Physical and functional impairments		

Stolldorf et al (2016)	Treatment and care		
Thomas (2014)	(In)visibility and action		
Towers et al (2008)	Burden		
Viehoff (2015)	Body Functions		
Viehoff (2015)	Body Structures		
Viehoff (2015)	Activities and Participation		
Watts et al (2016)	'It's a battle': Living with lymphoedema		
Williams et al (2004)	Lymphoedema treatment		

Table 2.6 - JBI ConQual Score – Determination of the study's credibility and dependability within the findings

Systematic Review Title	A Systematic Meta-Aggregation Literature Review of the male experiences of chronic oedema/lymphoedema				
Population	Men over the age of 18 years				
Phenomena	Experience and perceptions of chronic oedema and lymphoedema				
Context	Men living with lymphoedema across the UK and globally				
Synthesised Finding	Type of Research	Dependability	Credibility	ConQual Score	Comments
The 'New Norm' <i>(This refers to the way in which those diagnosed with the condition are faced with a 'new version' of themselves, and how that is accommodated, and 'normalised' in their lives.)</i>	Qualitative	Unchanged	Downgrade 1 level	Moderate	Downgrade 1 levels due to moderate credibility
Journey into the 'Unknown' <i>(This pertains to the journey taken by those diagnosed with lymphoedema. It also considers that the journey started alongside another journey, which has</i>	Qualitative	Unchanged	Downgrade 1 level	Moderate	Downgrade 1 level due to moderate credibility

<i>led a 'mystery tour' that is less than wanted.)</i>					
'Access, Access, Access' (<i>This pertains to the receiving of a diagnosis, information and support. Set against the challenges in reaching this stage, and the benefits when it is achieved.</i>)	Qualitative	Unchanged	Downgrade 1 level	Moderate	Downgrade 1 level due to moderate credibility
'Personhood' (<i>This refers to the notion that a person exists as part of existential and relational constructs. How that is acknowledge by services and others is variable.</i>)	Qualitative	Unchanged	Downgrade 1 level	Moderate	Downgrade 1 level due to moderate credibility

2.5 - Review findings

Four synthesised findings were identified. The first two findings, (1) The 'New Norm' and (2) Journey into the 'Unknown', had a high representation of men and their accounts, which were constructed from eight studies, 32 findings and four

categories. The remaining two findings, (3) Access and (4) Personhood, were constructed on 13 studies, 47 findings and seven categories. However, the sample of men and their accounts were smaller in representation or integrated into a single account.

2.5.1 - Synthesised finding 1: The 'New Norm'

The diagnosis of lymphoedema can have a negative impact on men, with the need to meet other men like themselves. The baseline that men form of themselves which represents their perception of normal, alters when this is challenged by a new diagnosis especially one that is long-term. One man stated, 'it's dictated my life', with another perceiving the condition as, 'an old man's disease', reinforced by their contact with men, 'You go to the support group...they are all elderly men, it felt old' (Michael et al, 2016, p. 326, 325). The baseline of men was affected by their perceived vulnerability, between physical strength and its projection of manhood, 'My legs ache,..., I don't have the strength in my legs that I used to have.', and its complications, 'the most distressing part of...was cellulitis' (Michael et al, 2016, p. 325; Nixon et al, 2018, p. 4). In the study by Crow (2020, p. 237) there was a perceived 'feminisation' of the condition by men, due to a perceived notion that body image was only a female concern, rather than being one that would affect both genders equally. This led to some men wishing to see, speak and interact with men like themselves, to lead to a 'life calibration', and to assist them in reconstructing their 'new normal' (Meiklejohn et al., 2013, p. 463; Nixon et al, 2018).

The psychological and social journey of men is not equal to the need for varied mechanisms to manage distress. It impacts the alterations to a man's physical appearance, such as facial oedema, affects their expression of their masculinity, and

how that leads to social avoidance, such as recreational activities (McGarvey, 2014; Nixon et al, 2018). However, this was not homogenous, with some stating the effects of lymphoedema were 'part and parcel of it', which has been described as the 'ebb and flow' but can perpetuate notions of stoicism (McGarvey et al, 2014, p. 321; Meiklejohn et al, 2013, p. 463). This has also been noted as a potential transitional process similar to a grieving process with some men wishing to be '...re-diagnosed.' (Meiklejohn et al., 2013, p. 463, Michael et al, 2016). Significant others were seen by men to play a key role in their lives, with this described as 'support that helped manage distress' (Nixon et al, 2018, p. 21). Men also drew strength from their occupational identity, but this strength could lead men to prioritise work over their health (Crow, 2020, p. 196–196; Nixon et al, 2018; Shakespeare, 2012).

2.5.2 - Synthesised finding 2: 'Journey into the unknown'

The physical manifestation of lymphoedema is the first challenge that men face but with limited knowledge and experience to manage it. This journey for some men occurs soon after treatment, such as cancer (Nixon et al, 2018). This led to experiences of physical discomfort and sensory changes, 'really tight around the bottom half of my chin' and 'It's much firmer...' (Jeans et al, 2019, p. 5). This rapid change did not allow time for preparation or even adaption for men, due to the reduced range of movement, facial oedema, but also thick and viscous secretions, with one man stating, 'It's certainly affecting [me]' (McGarvey, 2014, p. 320). The limited time led men to disengage from their recreational activities, due to limited knowledge and experience, of the 'diurnal patterns' within the presentation of their oedema (McGarvey, 2014, p. 320; Nixon et al, 2018). When this pattern was established, '...mainly there first thing in the morning...', it led to men employing

strategies to help them (Jeans et al, 2019, p. 5; McGarvey, 2014; Nixon et al, 2018; Shakespeare, 2012).

Self-management and the tools for educating men can be effective and empowering if tailored. The ability to undertake 'self-monitoring' and then implement strategies was seen as 'empowering' for men (Deng and Murphy, 2016; Jeans et al, 2019; Nixon et al, 2018). Expanding a man's knowledge in this area can be received positively by men, but must equally be balanced against their specific condition, education and even their level of acceptance (Deng and Murphy, 2016; Nixon et al, 2018). This has led to words, such as being 'fed up with it', related to their perception of self-management and having, 'no treatment at all, I just wear the elasticated stocking at work', despite compression therapy representing the mainstay treatment option (Shakespeare, 2012, p. 136). Tailoring education has been seen as requiring the understanding of the person's learning style, access to peer support and even technological support in terms of self-care reminders to achieve empowerment (Deng and Murphy, 2016; Nixon et al, 2018, p. 20).

2.5.3 - Synthesised finding 3: 'Access, Access, Access'

Access to knowledgeable healthcare professionals and services can improve biopsychosocial outcomes for patients. The level of access to those with knowledge and expertise was filled with challenges from diagnosis to treatment (Perera et al, 2007). This has led to multiple referrals to receive a diagnosis, with some receiving this outcome via serendipitous events, thus increasing levels of anxiety and risk of permanent physical changes (Perera et al, 2007; Watts and Davies (2016); Williams et al, 2004). Despite, reports of, 'I went through several diagnoses', this was compounded by the level of disinterest, but also observed lack of observed

compassion, by being told, 'just live with it' (Maree and Beckmann, 2016, p. 82; Perera et al, 2007; Watts and Davies, 2016; Williams et al, 2004, p. 282).

Access to resources and support is affected by occupation and level of income. The type of support offered after a diagnosis was perceived as being affected by the level of household income (Perera et al, 2007; Rio-Gonzalez et al, 2018). This was linked to the ability to purchase aids for the donning or doffing of garments, or to buy shoes as a result of the oedema as examples (Perera et al, 2007; Rio-Gonzalez et al, 2018). In addition to the household income, the type of occupation and the tasks involved within it were seen to affect patient outcomes (Rio-Gonzalez et al, 2018). For example, low-income households engaged in more precarious work, that had a direct impact on their condition, such as the increased risk of trauma, or an infection may lead to workplace disruption, such as sickness or absence (Rio-Gonzalez et al, 2018; Perera et al, 2007). This was associated with a level of 'frustration', due to the condition's impact but also the perceived lack of financial support, such as from the government to support as a result of their LTC (Stolldorf et al, 2016; Towers et al, 2008, p. 138).

Access to appropriate information can support a person to build their knowledge base surrounding lymphoedema. Limited access to appropriately tailored information led those affected to see information but came across some that were not appropriate, such as cancer-focused literature (Rio-Gonzalez et al, 2018).

Shakespeare's (2012) study connected with the notion that information needs to be understandable but also how it is related to its management (Tidhar, 2018; Towers et al, 2008). The absence of this being addressed led to feelings of loneliness, anger and disillusionment, '...haven't had someone tell me, to give me a straight answer'.

Whilst some suggest ‘the more I know, the more I will suffer’, acknowledges the individual concept of sufficient knowledge (Shakespeare, 2012, p. 139; Tidhar et al, 2018; Towers et al, 2008). Access to knowledge was also present when referring to effective support networks, such as significant others or peer support, who shared similar levels of knowledge and experiences to support their chosen strategies (Tower et al, 2004; Viehoff et al, 2016).

2.5.4 - Synthesised finding 4: ‘Personhood’

The diagnosis and development of lymphoedema were perceived as affecting the person’s past, present, and future. The altered baseline of individuals was seen as a biopsychosocial shift, with the presence of grief alongside varying ‘turning points’ and the perception of ‘making room’ for what had occurred (Bogan et al, 2007, p. 219). However, within the studies, this was not universal, with those that continued to ‘worry’, or were ‘waiting for a miracle to happen’, with the notion of ‘acceptance’ being a destination yet to be reached (Frid et al, 2006; Hamilton and Thomas, 2016, p. 826; Towers et al, 2008, p. 41). In ‘dealing with problems’, such as the use of donning tools, patient education or support, the ability to accept led to choices focussing upon the future (Frid et al, 2006, p. 9). This represented ‘objects of hope’ (Hamilton and Thomas, 2016, p. 826), but some were ‘not at that point yet’ (Bogan et al, 2007, p. 828; Stollendorf et al, 2016; Viehoff et al, 2016).

Lymphoedema affects the person’s perception of power and status within their lives. ‘Stigma’ was present within the study by Perera et al, (2007, p. 6), but also the reduced ‘social standing’ caused by the visibility and reaction to their lymphoedema. Williams et al. (2004) study commented on how the reactions and actions of those around them caused them distress. Thomas and Hamiton (2014) referred to the

problem of having a condition that was 'highly visible, while they live with a largely invisible or unknown condition', due to the limited social awareness (Rio-Gonzalez et al, 2018; Thomas and Hamiton, 2014, p. 4). The change in status and perception, altered existing relationships, such as caring duties, with others needing to be rebuilt even within themselves (Frid et al, (2006). Especially when it affected their occupational identity, 'The senior nurse took me off the ward and I was office-based. I decided then I had had enough, and I just retired. I feel grieved' (Watts and Davies, 2016, p. 3151). This led to the seeking of havens with those who held knowledge and experience to support them and to avoid feelings of loneliness (Thomas and Hamiton, 2014; Williams et al, 2004).

The presence of lymphoedema acts as a constant reminder within a person's daily life. The oedematous limb acted as a symbol, and a reminder of the changes that had occurred, but also led to a level of 'discomfort', beyond its physical appearance (Frid et al, 2006). This affected the person's constructed baseline (Viehoff et al, 2016), in which there was a focus on controlling the impact of the condition through strategies until this was challenged by external forces. '...in the summer when it is hot, you get the feeling that your leg is swelling and you can't move forward' (Viehoff et al, 2016, p. 415). This loss of control acted as a reminder of what had come to pass, with refuge sought through hiding the condition even from themselves, 'In winter it is a little better, I can hide it, but in summer it is very bad an emotional thing' (Maree and Beckmann, 2016, p. 81). The relationship between the conditions and its presence in their daily lives was one that is contentious, and hard to resolve.

2.6 - Discussion

The qualitative review provides one of the first collective insights into the daily lives of men diagnosed with lymphoedema. This resonates with the work by Moynihan et al, (2017) regarding men diagnosed with an LTC and the complexity that is added to a person's life when faced with another LTC diagnosis. This is relevant when other international studies suggest that lymphoedema often co-exists with another LTC condition (Cosgriff, 2010; Moffatt et al., 2019b). Moynihan et al, (2017, p. 1988) go on to suggest an LTC can cause a level of 'Ambiguity in a masculine world', in which vulnerability and weakness are associated with ill health by men and society (Moynihan et al., 2017: 1988). This feeds into the work by Leventhal et al, (2016) regarding a person's existing prototype of themselves (baseline) and how this develops into their 'illness representation'. This has been suggested as affecting masculinity and associated traits, such as older men and 'stoicism', but may also play a beneficial part in developing 'optimism' and even 'self-determination' (Moynihan et al, 2017, p. 1989). Masculinity is considered to have varying typology and expression, with some suggesting there are dominant versions (hegemonic) (Coles et al, 2012)

The changes to what is a perceived 'norm' and their masculinity is a challenging area for men, with them seeking a sense of control and empowerment to manage the LTC (Leventhal et al, 2016; Reigel et al, 2019; Zanchetta et al, 2017). This reflects other work regarding the need for appropriate access to information that is accurate and tailored (Deng and Murphy, 2016; Nixon et al, 2018). This not only considers how it is delivered, but also by whom, such as knowledgeable healthcare professionals, and the ability to interact with men similar to themselves (Flurey et al,

2018; Williams et al, 2004). This has the potential to change a man's prototype of themselves (baseline), but also the strategies for the management of their condition, thus altering their 'illness representation' (Leventhal et al, 2016). However, this requires men to allow a level of vulnerability in seeking support, linked to their internal beliefs surrounding being a man and ill health (Dale et al, 2015; Robertson and Baker, 2017). This may be magnified, due to the suggested inequity of service provision to those affected by lymphoedema in the UK (Moffatt et al, 2019a).

Multiple referrals and delays in the receipt of a diagnosis and treatment a documented issues, leading to complications (Dale et al, 2015; Perera et al, 2007; Stollendorf et al, 2016). For example, persistent infections and sickness, leading to men to place 'occupational demands' ahead of their health (Dale et al, 2015, p. 9). This was to project 'strength' within a workplace that considers ill health as unacceptable (Jönsson et al, 2020, p. 109; Zanchetta et al, 2017). This is alongside the deployment of 'push back' as a tactic, to distance themselves from the condition, but to also create a sense of normality in their lives (Dale et al, 2015, p. 10). This reflects the notion of personhood in which there is 'a moral and ethical category, tied to the concepts of autonomy, agency and self-determination' (Sofronas et al, 2018, p. 407). This is caused by their perceived loss, but also the uncertainty of their role in future (Gentili et al, 2019; Persson et al, 2019). Gender-based delivery of services has been suggested as a means to remedy some of the aspects mentioned, whilst acknowledging men are not a homogenous group (Robertson and Baker, 2017). Despite this approach being advocated, at present, it has yet to be fully developed or delivered (Lonnberg et al, 2020; Robertson and Baker, 2017).

2.7 - Strengths and limitations

The qualitative review is one of the first to identify, appraise and undertake a meta-aggregation in this area. This extended to the systematic review and process that was undertaken across the available databases. However, the study also has limitations by not including non-English studies caused by no access to translation services. Equally, several studies did not present a clear separation between male and female accounts, thus making it challenging to ensure they fully represented men and their narratives.

2.8 - Conclusion

Lymphoedema impacts widely across men within the studies retrieved. Studies with a higher representation, or had a clearer account of men, led to two synthesised themes, (1) 'forced normalcy' and (2) 'journey into the unknown', that identify the challenges men face in both accepting and managing their lymphoedema condition. Whilst still offering insight, the disruption faced by men was less apparent within the two remaining themes, due to the combination of men and women into one account, still offered insight. It equally took a different tone and focus, with the concept of having 'access', coupled with overall impact upon 'personhood'. Appropriate knowledge information and access to expertise negated some of the biopsychosocial complications of lymphoedema. However, this was connected to their 'personhood', and the value they derive for themselves and from the wider society. The surrounding literature resonated with the findings of the review and the way men engage within their health set against their perception of masculinity. This places a greater demand on services to consider intersectionality within the

healthcare economy and requires further empirical research to be undertaken within men and lymphoedema.

2.9 - Chapter Contribution

Chapter 2 has added to the existing literature by providing one of the first systematic meta-aggregation reviews of men's experiences with lymphoedema. It has used a qualitative methodological approach that aligns with the approach outlined in Chapter 1 and identified four themes within the twenty-two studies retrieved and subjected to appraisal. The themes included, 1) The new norm, 2) the journey into the unknown, 3) access, access, access, and 4) personhood. These findings indicate the disruption men experience in their lives and how they attempt to adapt to lymphoedema. The findings in Chapter 2 have been built upon within Chapter 3 by answering the first sub-question outlined in Chapter 1.

3.0 – Renegotiating hegemonic masculinity: a qualitative online survey of the experiences of men with lymphoedema.

3.1 - Chapter Rationale

The systematic review within Chapter 2 provided an outline of the literature that existed at the time of its completion. It indicated that no other systematic review had been undertaken at that time, with no study focusing solely on the experiences of men with non-cancer-related lymphoedema. As part of the review, it provided further support for the methodological approach outlined in Chapter 1, as no other study used narrative inquiry, or focused upon gender within the proposed theoretical concepts of hegemonic masculinity or HIMM framework. The four synthesised themes of 1) The new norm, focused upon the shift in the baseline men perceived of themselves and how they attempted to adapt to this change. 2) journey into the unknown, considered the limited preparation and support men received when managing lymphoedema. 3) access, access, access, focused upon the positive outcomes when men accessed knowledgeable healthcare professionals who were able to diagnose lymphoedema and offer support. 4) personhood, continued from theme 1 but considered how the lymphoedema affected their perceptions of themselves negatively as a man, such as social standing.

The findings in Chapter 2 provided insight into the experiences of men before this being explored within this Chapter, through the narrative inquiry and survey outlined in Chapter 1. The narrative survey answered the first sub-question in Chapter 1, *how do men perceive engagement within their self-management of their non-cancer-related lymphoedema?* Chapter 3 outlines how the validated lymphoedema quality of life tool (LymQoL) was used in the creation of the online

survey with data subject to thematic analysis that led to three themes being created,
1) psychological impact, 2) physical control and 3) support networks.

3.2 - Abstract

Background

Lymphoedema is a long-term condition resulting in the formation of oedema in any part of the body and is incurable. This paper focused on answering '*How do men perceive their engagement within their self-management of non-cancer related lymphoedema?*' due to the paucity of research in this area.

Methods

An online survey based upon an adapted version of the validated lymphoedema quality of life tool (LYMQoL), was applied using an inductive narrative inquiry approach with findings analysed through the application of thematic analysis. Theories related to hegemonic masculinity, such as traits and behaviours, and the health, illness, men, and masculinities [HIMM] framework, regarding life events across a man's life course, were used to frame the findings and discussion.

Findings

Three themes were identified using thematic analysis, with this further refined by considering associated traits and behaviours within hegemonic masculinity. The associated traits and behaviours were used by men in varying degrees, depth and nuance across all three themes. Theme 1 considered the strategies men used to manage the psychological impact of their self-care, such as physical concealment. Theme 2 considers the use of physical control as a means to manage their perceived vulnerability and in the creation of capital. Theme 3 focused on relationships and their place within a man's approach to self-care.

Conclusion

The findings provide insight into the complexity of self-care within lymphoedema and how this disrupts their masculinity. The findings reflect the wider literature around the use of available resources (masculine capital) to minimise further erosion of their masculinity and its renegotiations. This is in response to the vulnerability men perceive within their lives and the need to create control which is reflected in other studies.

3.3 - Background

Internationally and within the United Kingdom [UK], improving men's health has received great interest with calls for the creation of health improvement strategies (Women Equalities Committee [WEC], 2018; World Health Organisation [WHO], 2018). This is in response to addressing health disparities that exist regarding men's physical and mental health (Office National Statistics (ONS), 2022c), but also in recognition of the impact wider structural factors such as social class and ethnicity can have on one's well-being (William et al., 2009). This study explored the perceptions of men engaging in the self-care of lymphoedema through the theoretical concepts of hegemonic masculinity and a life course approach.

Lymphoedema is a long-term condition caused by the failure of the lymphatics resulting in fluid formation and is biological in nature (Rankin, 2016; International Lymphoedema Framework [ILF], 2006). The resulting failure leads to oedema developing in any part of the body, and is associated with physical complications, such as an increased risk of infections (Rankin, 2016). Physical complications represent one factor in this complex condition, which can be caused by genetics in early life, and/or the result of cancer treatment (ILF, 2006). The risk of developing lymphoedema increases with age 3.99 (<64yrs) to 28.6 (>85yrs) per 1,000 of a given population, due to deterioration of the lymphatics and other physical systems, such as vascular, and other long-term conditions (Moffatt et al., 2017; 2019c). Gender differences are noted with the risk of lymphoedema being 2.48 (men) and 5.37 (women) per 1,000 of a given population (Moffatt et al., 2017; 2019c), within UK lymphoedema service caseloads it is estimated that 73-84% are women compared to

15-22% being men (Cooper and Bagnall, 2016; Keeley et al, 2019; Moffatt et al, 2019c).

The prevalence and physical presence of lymphoedema is a small part of the overall impact upon men, with a need to create a nuanced and intersectional narrative around the conceptual thinking on masculinity within lymphoedema. Previous explorations of lymphoedema and its impact within the literature involved quality of life scores, or qualitative studies in which men are omitted or represent a minority amongst a larger sample (Cooper-Stanton et al., 2022; Cosgiff, 2010). A recent review found that up to 43% of studies within lymphoedema focused on breast cancer (from a total of 21 studies identified) (Cooper and Bagnall, 2016). The limited focus on men detracts from the impact the condition has upon them. Studies have indicated the burden and grief men experience, as a result of the physical, emotional, and social changes in their lives (Towers et al., 2008; Boulton, 2017; Evans et al., 2011; Oster et al., 2014). The limited exploration extends to the experiences of men with non-cancer-related causes and their engagement in self-management behaviour (Cooper-Stanton et al., 2022).

Non-cancer-related causes include secondary lymphoedema which represents the largest proportion of caseloads within lymphoedema service (Cooper & Bagnall, 2016; ILF, 2006). Keeley et al., (2019) suggest, secondary lymphoedema accounted for 82.5% of all lymphoedema causes, with non-cancer representing 66% of that figure. Despite, non-cancer being more prevalent. Current research has focused on cancer-related causes in the majority with no application of hegemonic masculinity or a life course approach (Cooper-Stanton et al., 2022). The health, illness, men and masculinity framework [HIMM], acknowledges masculinity as a social determinant

within a man's life course, such as hegemonic masculinity, and the impact life events, such as long-term conditions have upon their health as they age (Evans et al., 2011). Lymphoedema can be considered a life event that requires long-term self-management, and if not managed successfully can lead to further health inequalities, such as increased illness, mobility difficulties and increased levels of absenteeism (Cooper-Stanton et al., 2022).

3.4 - Theory

The study presented here drew on two theoretical lenses within the analysis of the data, presentation of the findings and discussion. This included hegemonic masculinity and its application within a man's life course via the HIMM framework (Lindon and Barry, 2021; Evans et al., 2011). Overlaying the two theories offered further insight into men and masculinity. We recognise that other theories may be applied in this area, such as the theory of self-care, and the common-sense regulation framework (Reigel et al., 2019; Leventhal et al., 2016). However, it was felt they do not specifically address masculinity and the gap in the current literature in lymphoedema (Cooper-Stanton et al., 2022).

Hegemonic masculinity is defined as embodying *'the currently most honored way of being a man'* by requiring *'all other men to position themselves in relation to it'* by fulfilling the expected *'pattern of practice (i.e., things done, not just a set of role expectations or an identity'*, such as projection of strength, independence, autonomy, self-reliance, and superiority via occupation (Connell and Messerschmidt, 2005; p. 832). Masculinity is considered both a social construct and a spectrum that leads men to demonstrate their masculinity in a variety of ways, such as hypermasculine or feminine traits (Courtenay, 2000; 2009). Debates exist around masculinity and its

expression, such as through traits and behaviours (Connell and Messerschmidt, 2005), in which men avoid seeking help as an embodiment of their masculinity (Courtenay, 2000; 2009), or use them as helpful behaviours to promote self-care within their health (Lindon and Barry, 2021; Courtenay, 2009). There is a recognition other masculinities exist, but there will be a dominant accepted version of masculinity present within Western societies (Connell and Messerschmidt, 2005). Masculinities overall, including hegemonic masculinity, are time and context-based and will change over a period in response to events at a macro level (society) (Connell, 1993), or the micro level (individual) due to health changes (Flurey, et al, 2018). The use of hegemonic masculinity in the study recognises its continued presence in society and how it led to the development of other concepts of masculinity, such as inclusive and hybrid (Boulton, 2017). We are unaware of published studies exploring men's experience of living with lymphoedema that have used hegemonic masculinity as an interpretative lens or theoretical framework.

The HIMM framework offers an extended perspective within our study, due to its recognition that masculinity is a social determinant within a man's life (Evans et al., 2011). The life course approach within HIMM considers how life events and the ageing process can affect a man's masculinity. For example, physical deterioration and the ability of men to produce and reproduce what is socially expected of them, such as engaging in sports or appearing healthy (Evans et al., 2011). The HIMM framework reflects the study's application of narrative inquiry, in which there are distinct parts or chapters within a man's life because of life events, such as birth (Evans et al., 2011). Lymphoedema as a life event within the HIMM framework, can occur at any point in a man's life course, with the requirement to self-manage the

condition for the rest of their life. Exploring masculinity within lymphoedema is to enter the perceived world of men, and their response to self-management. Therefore, this article addresses the following research question:

1. How do men perceive engaging in their self-management of their non-cancer-related lymphoedema?

3.5 - Methods:

3.5.1 - Study Design

An online survey study design based on the validated lymphoedema quality of life tool was used [LymQoL] (Keeley et al., 2010). The LymQoL (Keeley et al., 2010) was adapted by including space for free text at various points in the survey to establish the perceptions and meaning men had regarding their choices within the Likert scales. Surveys, dependent upon their design are considered '*similar to other qualitative inquiry methods*' when gathering opinions, thoughts, and feelings (Tran et al., 2017, p.72). The application of the semi-structured survey enabled the exploration of the stories, meanings and perceptions men have in the context of managing their lymphoedema (Casey & Schaefer, 2016; Caine et al., 2013). The paradigm adopted considers the interpretivism and constructivism presence within the narratives that exist within a man's social world and how these are interpreted (Caine et al., 2013; Parahoo, 2014).

Accounts men shared in the survey as part of the free text led to the application of thematic analysis, due to its focus upon 'content' and 'what' is present within researchers' inductive interpretations, and how it can intersect with a constructivist paradigm (Riessman, 2008). The thematic analysis supported the identification of patterns within the narratives and began raising questions about the

theoretical assumptions within the data (Riesman, 2008). Theoretical assumptions focused on the social construction of gender identities and their expression within society through hegemonic masculinity (Green, 2013; Connell and Messerschmidt, 2005). Compared to the proposed influences that occur across a man's life course within their interactions, gender identity and its expression and how this may later be because of life events as part of the HIMM framework (Evans et al., 2011).

3.5.2 - Access, Recruitment and Sampling

Participants were recruited using purposive and snowballing sampling within the UK (all four nations) and the Republic of Ireland. Purposive sampling focused on obtaining a representation of men diagnosed with non-cancer-related causes of lymphoedema. Debates exist within qualitative-based surveys around the focus on sample size, such as 30 people, and reaching saturation, or whether this should be determined by the researcher and the findings of the study (Terry and Braun, 2017; Tran et al., 2017). Pre-determined sample sizes are not commonly used in narrative inquiry; however, theoretical saturation was reached within the twenty-two men who participated, through the constant review of the data and analysis that indicated there were no new avenues of interpretation. Recruitment took place over twelve months from September 2021 until August 2022.

Promotion of the study was undertaken by online social media, such as X (previously known as Twitter), national and local organisations representing service users affected by lymphoedema, and the healthcare professionals who support them. Potential participants had the opportunity to contact the main researcher and watch a pre-recorded introductory video embedded within the host site for the survey (Microsoft Forms). The video introduced the researcher, including the aims and

details of the study, and the nature of the survey questions. Each participant had to watch the video, read the participant information, and complete the consent form before undertaking the survey. This also included reference to specific support organisations if needed. A postal option was offered to participants who did not have access to digital devices.

Each man met the inclusion and exclusion criteria outlined in Table 3.0. In addition, participants were asked to provide details regarding their age, educational attainment, ethnicity, occupation (current or past), geographical location, and duration of their diagnosis. This was to provide information about socioeconomic and intersectionality factors within the perception of their long-term condition as shown in Table 3.1. The study sample represented the main group of men affected by lymphoedema which are white men over the age of 45 years as indicated in an international study (Moffatt et al, 2019).

Table 3.0 – Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1) over 18 years of age	1) below 18 years of age
2) identify as a man	2 do not identify as a man
3) diagnosed with primary or secondary lymphoedema (non-cancer related)	3) not diagnosed with primary or secondary lymphoedema (non-cancer related)
4) living within the UK (all four nations), and Ireland.	4) living outside the UK (all four nations) and Ireland.

Table 3.1 – Participant Demographics

Total	22 Men
Lymphoedema Diagnosis	17 (primary lymphoedema), 5 (secondary lymphoedema)
Lymphoedema Diagnosis Duration	Range 2-62 years, Majority (14) 2-20 years
Ethnicity	21 (white), 1 (black), 19 (heterosexual)
Age	Range 33-77, 30-39 yrs. (20%), 40-49 yrs. (15%), 50-59 yrs. (40%), 60-69 yrs. (5%), 70-80yrs (20%).
Educational Qualifications	GCSE (6), A-Level or equivalent (4), Degree (10), Masters (2),
Employment Status	15 (employed), 2 (unemployed) and 5 (retired).

3.5.3 - Data Collection

Each participant completed an online survey within their chosen setting. Online surveys are regarded as offering flexibility and being ‘*resource-lite*’ when compared to other approaches, such as interviews, and remove several barriers, such as geographical locations (Terry and Braun, 2017, p. 15). Surveys have also gained prominence and increased usage within health research and social science, including a level of anonymity compared to post or email, which can be preferable by men who engage in research (Greenhalgh et al., 2020; Hu et al., 2020; Sexias, Smith and Mitton, 2018; Jansen, 2010). Survey results were downloaded into an Excel sheet format from Microsoft Forms and then subject to formatting as part of the analysis process (Table 3.2) shown within the data analysis section.

3.5.4 - Data Analysis

Thematic Analysis was chosen to reflect the unfolding narrative around men. It afforded flexibility and robustness within the analysis of open-text responses as part of the online survey (Riessman, 2008; Table 3.2). This led to each case being examined separately, to identify 'underlying assumptions' that were named and coded, with examples provided from the text to illustrate the patterns (Riessman, 2008; 57). Due to data being 'interpreted' but also 'developed' by the 'investigator' there is a need to consider the influence this may have on the findings (Riessman; 2008; 54). To take account of possible inferences by the researcher, led to the application of a reflexive approach proposed by Mauthner and Doucet (1998) and is shown in Table 3.2. The approach considers that the meanings within data are created rather than explicitly present or found (Mauthner and Doucet, 2003; 1998). To reflect but also acknowledge the potential influences that may be present led to a reflexive diary being kept. The reflective accounts in the diary were shared with co-authors with provisional themes shared with participants. (Parhoo, 2014). Information was transferred from the online survey into an Excel sheet and ordered according to demographics. Free text comments were subject to analysis and coding using the thematic analysis (Table 3.2) with three themes developed (Table 3.4).

Table 3.2 Analysis and Reflexive Approaches

Thematic Analysis	Reflexivity
1 - Single text examined at a time	1 – Reading for the plot and the researcher's response to the narrative.
2 - Order the account in chronological order.	2 – Reading for the active 'I' who is telling the story

3- Identity underlying assumptions in each account are named and coded,	3 – Reading for the respondent's relationship with family and close friends
4- Cases are selected to illustrate the patterns, but also the range and variation within the narratives.	4 – Reading for the broader social and cultural context of the respondent.

3.6 - Ethics

Ethical approval was approved by the University of Birmingham University Ethics Committee (ERN_20-1729). The study followed the ethical standards outlined in the Declaration of Helsinki (World Medical Association, 2022). Data was managed and stored per the Data Protection Act, such as the use of encryption (Data Protection, 2018). All participants provided written consent to participate in the study and were informed about the use and storage of personal data. Any information that may directly, or indirectly identify participants was removed with the use of pseudonyms as shown in Table 3.3. Participants were not financially incentivised to take part.

Table 3.3 – Participant Pseudonyms

Name	Age	Name	Age
Alfie	37	Jake	54
Andy	59	Joe	68
Arman	47	Leo	47
Arthur	70	Luke	34
Barry	77	Matt	53
Ben	71	Mike	54
Chris	50	Noel	75
Freddie	43	Oliver	45
George	56	Ryan	39
Harry	41	Ted	33
Henry	56	Will	55

3.7 - Results

Data gathered from participants and the subsequent analysis led to three themes that collectively encompass the perceptions of men (Table 3.4). Pseudonyms were used to maintain confidentiality and are shown in Table 3.3. The themes were contextualised against hegemonic masculinity through its expression by men in the form of traits and behaviours, but also within the HIMM framework discussed in the theory section. To answer the research question about *‘How do men perceive engaging in their self-management of their non-cancer related lymphoedema?’*

Table 3.4 – 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, which 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 identity as a man.

3.7.1 - Theme 1 – Psychological Impact of Self-Care and the Renegotiations of Hegemonic Masculinity

In this theme, the focus is on 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, such as friendships through shared activities, as shown within the account by Alfie:

“Since being diagnosed I have given up my regular physical activities (military fitness, 5-a-side football, surfing). I also have a lot of difficulty with other activities, running, cycling, swimming, hiking” (Alfie)

Difficulties in undertaking sport, or other recreational activities, not only can lead to physical and mental health declining, but also limits their ability to express themselves as a man through these activities. All men mentioned varying degrees of perceived vulnerability either in the present or in the past caused by lymphoedema, as seen within Harry and Jake's account:

“I hate the fact I am afraid to go swimming or wear shorts for self-consciousness reasons...this bugs me so much” (Harry)

“I constantly feel worthless, as I feel 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 expressions, which are collectively shown within the quote by Joe and Ben:

“I try not to let it get me down” (Joe)

“I learned to cope” (Ben)

Whilst some men indicate the potential stoicism used to support them to engage in self-management, it does not consider 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, to their perceptions presently, as shown in the account by Andy and Chris:

“lymphoedema has impacted greatly on me and but is now well managed”
(Andy)

“These are all good questions which can be scored differently depending on how close to my original diagnosis 10 years ago, compared to today” (Chris)

Andy and Chris indicate the changes that occur to men over time to a more positive position. Other men at the beginning of their journey reflect the sentiment shared by Luke:

“I find it mad that I am dealing with this at my age” (Luke)

The quotes collectively indicate changes in perceptions men have about themselves. However, the changes taken to accommodate the condition and self-management, involve trying to work around the limitations, and, or hiding it from others. Thus, the condition is never visible, with men choosing what is seen by others, as shown in the quotes from Harry and Alfie.

“I've had it so long that I've 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 to looser fitting clothes” (Alfie)

By concealing their lymphoedema men provide a curated version that is less vulnerable to themselves and others. However, this is not always possible due to the cause, severity or how it is managed as shown in the quote by Matt:

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

While other men choose not to hide their condition and instead reframe it within their lives. The framing was one based upon acceptance of the condition, set against their own and other perceptions, as to the role of lymphoedema within their

lives. This approach is different to concealment to hide vulnerabilities, to one in which strength is derived from their situation, as shown within Will, Ryan, and Arthur:

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

3.7.2 - Theme 2 – Physical Control and its influence within Hegemonic

Masculinity

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

engaged in some form of self-reliance, even adapting to the condition's changeable daily presentation, as shown within the quotes from Arman, Ben and Noel:

“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’ can indicate the internalisation of their masculinity, and the use of traits or behaviours that support their masculinity, such as self-reliance and independence. Pursuing control can indicate the level of uncertainty and even fear of not being in control of their health or condition. All men experienced some form of physical complications associated with lymphoedema. To some men, these complications enabled them to gain experience and knowledge which they used when required, as shown in the quotes from Luke, Harry, and Mike:

“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 way I can by elevating where possible.” (Arman)

The way men employed this knowledge and experience was also 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, as seen within the quotes by Chris and Ryan:

“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 upon 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, as shown in the quotes by George and Ryan:

“I do have days when I just want the lymphoedema to disappear. The stockings remind me every day 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 indicated in the findings. The tentative presence of stigma may indicate the potential complexity that is present when men engage in the physical control of their lymphoedema. Especially, when engaging in activities that may be considered risky, to establish what they perceive as a 'breaking point'. Equally, the risk may lead men to engage or avoid existing or potential support networks that can form another coping strategy.

3.7.3 - Theme 3 – Support Networks and Renegotiation of Hegemonic Masculinity

In this theme, the presence of support networks can be perceived as supporting men as another coping strategy, but this is dependent upon the man's perception of masculinity at that time. Several men reflected on the challenges that are presented in forming and maintaining relationships, due to limited understanding of the condition. In the majority, men avoid groups-based activities, due to concerns in the past or present, which further isolate them and their ability to socially connect with other men. This is shown in the quotes by Noel And Mike:

"The risk of infection prevents me swimming and walking" (Noel)

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

The majority of men disengaged with activities that gave them a form of social connectedness. A small number of men continued with activities that they enjoyed, despite the possible complications it may cause, as shown in the quote by George:

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

The engagement in support networks, such as sports, or relationships was a rarity amongst the men. In most accounts, men avoided them, and the potential perceived vulnerability, due to possible physical complications. Three men sought support from those closest to them, which in certain accounts extended to others, as shown in the quotes from Will, Ted and Luke:

“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 and has been great” (Luke)

Whilst men in the quotes sought support, which ultimately did not undermine their perceptions of themselves. Other men did not share the same perception as seen with Jake's experience:

"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 a challenge for men when they perceive themselves as becoming dependent. Several men did not have any close support networks or found it hard to form new ones, in terms of a partner. This was due to the significance of self-managing the condition, its appearance that added a further dynamic in those relationships, as shown within the quotes by Arman and George:

"Relationships can be hard with lymphoedema" (Arman)

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

Physical changes represent an alteration in the man's ability to be secure in their gender expression, but also how that expression leads to connection. By men avoiding connection to others is a coping strategy in response to perceived

vulnerability but can represent a form of self-stigma that leads to men self-isolating from groups that may offer support and gender identity. Collectively, the findings indicate the varied negotiations men undertake when self-managing their condition, and how men frame the involvement of social support in their lives. However, renegotiations around masculinity form part of a transition that men complete at their own pace, and is influenced by perceptions of vulnerability, and whether coping strategies strengthen their expression as a man. This feeds into the notion that masculinity is a spectrum and one that is not fixed across a man's life course, due to life events that affect their lives.

3.8 - Discussion

To the best of our knowledge, this is the first qualitative study to explore hegemonic masculinity and its influence on 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 work (2018) offers insight into these transitions men undertake in response to their lymphoedema and the subsequent consequence of engaging in self-care.

3.8.1 - 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 identity formed by their masculinity (Flurey et al., 2018). Men in the article illustrate various aspects of their illness narrative (Kleinmen, 1998), but also the

biographical disruption (Bury, 1982), caused by their hegemonic masculinity or masculine script (Flurey et al., 2018). Disruption specifically biographical focuses on the man's 'loss of confidence in the body, leads to loss of confidence in social interaction' due to lymphoedema with its presence in their lives having 'meaning' and 'significance' (Bury, 1991, p. 453). The actions men took were in response to minimise its impact on 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 help-seeking (Karl et al., 2022), compared to women who will seek help more readily (Lindon and Barry, 2021). However, stoicism is also present in women, but to a lesser degree compared to men (Pathak et al., 2017). Men's responses align with Flurey's (2018) work in which men wish to retain their masculinity, whilst engaging in re-negotiations of their hegemonic masculinity over a period. These negotiations resonate with the work by Spector-Mersel (2006, p. 79) that can signify a 'disrupted hegemonic gender scripts' caused by a loss of 'harmony' with social expectations of male performance. The transition between retaining and re-negotiating may involve men inhabiting both points within the adaptations men undertake within their masculine identity as shown in the study by Hohne (2022).

Men engaging in coping strategies aligned to hegemonic masculinity, such as self-reliance and withdrawal, act as an expression of their masculinity (Flurey et al., 2018). It also provides them with a 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 the expectations of their gender (Eguchi, 2009). Gender or masculine scripts are seen as socially derived and provide men and women with ways of thinking and acting (Gast and Peak (2011). Men not engaging in expected behaviours, mark them out as different (Michael, 2016), and this can lead to the experience of stigma, either by men themselves or perceived by others (Stangl et al., 2019; Goffman, 1963). Stigma has been noted in studies that have focused on 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, p. 1424) in which men actively engage in 'managing self-perceptions' and by 'evading emotions', as coping strategies. The disruption itself focused on the 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 lymphoedema has upon them and the burden it represents (Demain et al., 2015). Rome (2021, p. 52) 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 attempts to restore or negotiate the changes within pre-held perceptions of masculinity align with the systematic review findings about establishing a 'new

norm' in response to the presence of lymphoedema and the changing masculinity (Cooper-Stanton et al., 2022, p. 22). The changes to hegemonic masculinity also indicate that masculinity is not fixed but one that can change in response to situation over a period (Rome, 2021; Connell and Messerschmidt, 2005)

3.8.2 - Physical Control and its influence within Hegemonic Masculinity

In response to psychological aspects of their condition, men focus on the ability to physically control the lymphoedema to frame it as a 'heroic struggle' in response to their perceived vulnerability (Gough, 2013, p. 1). Men undertake a journey to regain a sense of control over their body and disease and its relationship to their 'masculine identity' (Flurey et al., 2018, p. 118), but also represent 'strategies to protect and adapt their identities' (Wilde et al., 2020, p. 316), by becoming experts in their condition. In the study by O'Rourke (2022), men are reported to have a higher use of adaptive coping (active stress coping) compared to women. Equally, this is seen in the study by Zanchetta (2017), in which men become actively interested in gaining knowledge about their bodies to support them within their masculine expression. Further still, the acquiring of knowledge can imbue the notion of accruing more masculine capital, to use in mastering and managing to compensate for non-masculine behaviour (Arnell, 2014; de Visser et al., 2009). Thus, embodying a sense of independence, by becoming even more self-reliant to conceal any sense of vulnerability (Courtenay, 2009) in response to the perceived losses in their hegemonic masculinity (Wilde et al., 2018). Pursuing independence and expertise in the management of lymphoedema can be beneficial when the emphasis is on 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 not seeking help compared to women, but also the invisibility of men's health and their needs (Courtenay, 2009; Liddon & Barry, 2021). Equally, in the study by Zanchetta et al, (2017, p. 1087) it stated some men 'believed that society expects men to be less sensitive to their health issues and needs than women'. Men are adapting their masculinity, or its script in response to the physical changes and performative expectations through re-negotiation (Flurey et al., 2018), by acquiring new resources to manage the disruption across the life course 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).

3.8.3 - 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 a diminished and altered masculinity (Evans et al., 2011; Willis and Vickery, 2022). Whilst social support is seen as a protective factor (Frank, 1998) most men reporting in the study by Arnell (2014) stated their spouse or partner (80%) was their main social support, with this figure lower for women (59%) due to a wider support network. As indicated in other studies spouses can encourage health-enhancing behaviours (Willis and Vickery, 2022), but also discourage health-harming activities (Arnell, 2014), compared to men without social support networks. Equally, 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). Whereas women are noted as seeking social support more readily than men (O'Rourke et al., 2022), but this

requires men to 'reframe' its presence (Gough, 201, p. 2), 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 (2017, p. 1082) around 'stigma' and 'shame', leading men to become 'marginalised' (Flurey et al., 2018, p. 115). 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, p. 314) called this 'dual identity' between the man's perceived masculinity and their dependence upon others. Merdsoy (2020, p. 1427) linked this to the vulnerability of men leading to 'emotional self-management' within relationships to avoid further deterioration of their masculinity. Arnell (2014) suggests men use their masculine capital to negotiate these changes, by assessing their ability to contribute to the relationship, such as money and occupational status, as a means of exchange. This can allow men to progress through periods of 'adjustment, assimilation and acceptance' (Flurey et al, 2018, p. 118) by using masculine capital as compensation for non-masculine behaviours, such as reliance on others (Arnell, 2014; de Visser et al., 2009), but must be re-framed as capital to mitigate perceived stigma (Gough, 2013).

Our findings show men experience vulnerability caused by the disruption in their hegemonic masculinity. Men use associated traits and behaviours (hegemonic masculinity) as coping strategies to reduce further erosion of their masculinity. Using these coping strategies as resources, or masculine capital, supports men to

renegotiate their masculinity, but may perpetuate their marginalisation and invisibility, due to lymphoedema its presence in society being concealed.

3.9 - Strengths and Limitations

The current study adds to the literature about men diagnosed with non-cancer-related lymphoedema. In addition, the study was based on building qualitative elements into a validated quality-of-life tool [LymQoL] which 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. Those who participated also provided a life course view of the condition, due to the variety of ages that participated in the study.

The limitations of the study related to the number of men who participated which was twenty-two in total. It is 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 a similar number or higher 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, but also cultural context and differences within other countries. The level of detail men provided within the free text may have an impact on the results in terms of a deeper understanding. Due to most men being White and only one Black participant, the ability of the study to be applied beyond this group is limited. 19 participants identified as heterosexual with three identifying as being gay.

Nevertheless, 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.

3.10 - Conclusion

This article has focused on men and their perception of self-management when diagnosed with non-cancer-related lymphoedema. Men in the article experienced disruption in their lives and within their perception of masculinity, due to lymphoedema representing a life event. In response, men used associated hegemonic masculinity behaviours to reduce their perceived level of vulnerability and increase their perception of control. This initial response upholds their original concept of masculinity, before 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 insight from this article creates opportunities to understand a man's response to self-managing lymphoedema in their life.

3.11 - Chapter Contribution

Chapter 3 has added to the existing literature outlined in Chapter 2 by answering the first sub-question outlined in Chapter 1, *how do men perceive engagement within their self-management of their non-cancer-related lymphoedema?* The narrative inquiry approach and survey led to the creation of three themes based on the thematic analysis of data gathered from twenty-two men. The themes included 1) psychological impact, 2) physical control and 3) support networks. The three themes indicated the changes in the perceptions men had about themselves and their masculinity. Men responded by using masculine traits to renegotiate perceived

changes within their lives. The findings of Chapter 3 have expanded the findings and understanding of men's perceptions established in Chapter 2. Further explorations of the perceptions of men continued into Chapter 4 by answering the next sub-question outlined in Chapter 1.

4.0 - Renegotiation of hegemonic masculinity following a diagnosis of non-cancer related lymphoedema: a qualitative solicited diary approach

4.1 - Chapter Rationale

The narrative survey within Chapter 3 focused on answering the first sub-question outlined in Chapter 1. *How do men perceive engagement within their self-management of their non-cancer-related lymphoedema?* The question was answered through the three themes created through the application of narrative thematic analysis. The themes included the 1) psychological impact of engaging in self-management that challenged their perceptions of hegemonic masculinity when they engaged in self-management. 2) physical control was used by men aligned to their traits and behaviours within hegemonic masculinity in response to the vulnerability they perceived in their lives and masculinity. 3) support networks offered some men another strategy when engaging in self-management and the effect this had upon them. What was noted in each of the themes was the negotiations surrounding their hegemonic masculinity. This built upon the findings in Chapter 2 and the four findings that identified similar aspects in terms of shifts within the way men perceived themselves and the journey men undertake to establish their new norm.

This chapter builds upon findings from Chapters 2 and 3 by answering the next sub-question outlined in Chapter 1, *how do men perceive their non-cancer-related lymphoedema within their daily lives?* Narrative inquiry as outlined in Chapter 1 was used in this chapter with data gathered through the completion of solicited diaries. The diaries offered men a period of reflection and the ability to share experiences they perceived as having meaning. Analysis of the data gathered used thematic analysis used in Chapter 2 and structural analysis as outlined in Chapter 1.

The two analytical approaches led to the creation of one main theme vulnerability and two sub-themes, a constant reminder, and solace in routines within this chapter.

4.2 - Abstract

Introduction

Lymphoedema is a chronic condition that can have a profound impact on men, their daily lives and their interactions with others. The impact is due to both the physical changes caused by the formation of oedema in any part of the body, and how that physical change is perceived by men in their daily lives. An important dimension of these changes is men's engagement with the norms of hegemonic masculinity. This study focuses on answering *'How do men perceive their non-cancer related lymphoedema within their daily lives?'*

Method

Solicited diaries were undertaken using a qualitative inductive narrative inquiry approach with 12 participants. The diaries were completed over two weeks, either daily, alternate days or weekly summaries of their experiences. The findings were interpreted using structural analysis followed by thematic analysis. Theories related to hegemonic masculinity, such as traits and behaviours, and the health, illness, men, and masculinities [HIMM] framework, regarding life events across a man's life course, were used to frame the findings and discussion.

Findings

One main theme and two sub-themes were identified using structural and thematic analysis. Further refinement of themes was undertaken by considering associated traits and behaviours within hegemonic masculinity to provide further nuances and depth across the main theme and sub-themes. The main theme was vulnerability connected to the health disruption experienced by men in their daily lives and within their masculinity. The two sub-themes were the presence of lymphoedema

being a reminder of the change men experienced in their lives, and how men formed routines to mitigate their perceived vulnerability. Mitigation involved mobilising their available resources, by using associated hegemonic behaviours and traits to support and inform their activities, such as self-care.

Conclusion

The findings of the study reveal a rich tapestry of how men renegotiate their hegemonic masculinity, by using or creating masculine capital to mitigate their perceived vulnerability. Renegotiation is shaped by their sense of vulnerability associated with lymphoedema, and the resulting disruption this causes in their expected social constructs (related to masculinity) within their daily lives.

4.3 - Introduction

Men and their health have been subject to national interest within the United Kingdom (UK) and globally due to identified health disparities (Alexandrou, 2023; GAOMH, 2020, 2021; Women and Equalities Committee [WEC], 2019; WHO, 2018). Health disparities have focused on increased mortality and poor health outcomes, such as physical, and mental health and social isolation (Rio-Gonzalez et al, 2021). For example, men's life expectancy on average is 4 years lower than women's, with global studies indicating reduced levels of social connectedness (friendships) compared to women's (ONS, 2022; GAOMH, 2020; McKenzie et al, 2018). Injuries and non-communicable diseases are the leading cause of death among men nationally and globally, such as cardiovascular disease and cancer (ONS, 2022; WHO, 2018; Robertson, 2017). Disease and injury can lead to the development of lymphoedema as a long-term incurable condition, but may also complicate lymphoedema management, such as compression therapy, due to the development of peripheral arterial disease (International Lymphoedema Framework [ILF], 2006).

In response to the disparity that exists within men's health in the UK, has led to calls for specific policies, and even a men's minister to address the issue present (Edwards & Fletcher, 2023; GAOMH, 2020; WEC, 2019; WHO 2018; Evans, 2011). Policies around men's health tend to recognise the need for 'targeted strategies' and 'focused research' regarding men and their health, due to the influence of structural factors such as gender, social class, and ethnicity upon a man's well-being (UK Parliament, 2019; p.1; Williams et al, 2009). This has led to a new inquiry in the UK, to examine factors surrounding men's health, how to improve health equity amongst men, and to review existing projects to reduce social isolation (UK Parliament, 2023).

This article explores the perceptions of men on engaging in their daily activities when diagnosed with lymphoedema, through the theoretical concepts of hegemonic masculinity and a life course approach.

4.4- Background

The risk of developing lymphoedema increases with age (Moffatt et al, 2017; 2019c), leading to a failure of the lymphatics to complete their main functions involving fluid movement and immunity, leading to oedema formation and an increased risk of infections (Rankin, 2016; ILF, 2006). The causes of lymphoedema include primary lymphoedema related to intrinsic factors, such as genetic abnormalities, or secondary lymphoedema, due to extrinsic factors, such as trauma via surgery (Cooper and Bagnall, 2016; Rankin, 2016; ILF, 2006). In addition to the development of lymphoedema, there is also an increased risk of developing other long-term conditions, such as diabetes, heart failure and neurological conditions as being the three most common co-morbidities alongside lymphoedema (Keeley et al, 2019). Men affected by lymphoedema within a given population is 2.48 per 1,000, compared to women at 5.37 per 1,000, with UK lymphoedema services caseloads indicating men represent 15-22% compared to 77-84% for women (Moffatt et al, 2017; 2019c; Cooper and Bagnall, 2016).

Physical complications, such as the formation of oedema, or infections, do not consider the other complications that are less tangible, such as the psychological and social impact on men and others. Lymphoedema can be perceived as a burden, both financially due to increased levels of work absence, and resources linked to managing the complications, such as infections, but also upon the man's quality of life (Cooper-Stanton et al, 2022; Hajat et al, 2018). Equally, there has been limited

consideration of the experiences of men related to non-cancer-related causes, such as within primary or secondary lymphoedema. This is despite up to 82.5% of lymphoedema caseloads being secondary lymphoedema with those with non-cancer conditions representing 66% of the figure (Keeley et al, 2019). Many lymphoedema studies have focused upon causes that affect mostly women, such as breast cancer, and have not explicitly considered variations by gender or age, nor used theories of masculinity to understand the data, leading to a non-disaggregated view of men, but also their experiences (Cooper-Stanton et al, 2022; Cooper and Bagnall, 2016; Cosgiff 2010). Lymphoedema can be seen as a life event within the health, illness, men and masculinity framework [HIMM], due to it being a long-term condition that can affect a man's perception of their masculinity, such as hegemonic, leading to the use of behaviours in response (Evans, 2011). Lymphoedema requires self-management that is delivered and monitored by the man throughout the day, which permeates their daily lives and may increase health inequalities if not managed appropriately, such as increased illness, mobility difficulties and increased levels of absenteeism (Cooper-Stanton et al, 2022).

4.5 - Theory

Gender and its expression in society are considered socially constructed in terms of what is feminine and masculine, but also the associated behaviours that encompass each gender (Courtenay, 2009; Connell and Messerschmidt, 2005; 1993). Masculinity has been associated with men, but women may also display masculine behaviours and men feminine behaviours (Courtenay, 2009; 2000). Hegemonic masculinity refers to a performative social construct that is dominant in the social world of men, but which many men may not meet (Connell and

Messerschmidt, 2005). It is important to note that there are multiple masculinities in existence, with each one constructed within specific times and contexts (Rome, 2021; Connell and Messerschmidt, 2005). Hegemonic masculinity has been described as embodying 'the currently most honoured way of being a man' by requiring 'all other men to position themselves in relation to it' by fulfilling the expected 'pattern of practice (i.e., things done, not just a set of role expectations or an identity', such as self-reliance, self-confidence with physical strength (Rome, 2021; Connell and Messerschmidt, 2005, p. 832). Men who do not fulfil the expectations of hegemonic masculinity can be perceived as being marginalised or subordinate to a proposed honoured way of being a man (Connell and Messerschmidt, 2005).

Despite, hegemony masculinity being present in society few men can meet all expectations within hegemonic masculinity (Connell and Messerschmidt, 2005). Other theories and literature indicate that masculinity is a spectrum ranging from what may be perceived as hypermasculine, masculine to feminine (Courtenay, 2009; 2000). Debates within the area of masculinity and hegemony, not only focus upon the way men behave, but whether that behaviour is helpful or not (Liddon and Barry, 2021; Courtenay, 2009; 2000). Hegemonic masculinity in the study recognises its continued presence in Western society and how men express this within traits and behaviours (Liddon and Barry, 2021; Boulton, 2017).

Overlaying the HIMM framework with theories of hegemonic masculinity extends the perspective of the study, by considering how a man's relationship to his masculinity changes across his life course in response to life events, such as lymphedema (Evans, 2011). Lymphoedema is a long-term condition that occurs at

any point in a man's life, from birth to death, and can be considered a life event within the framework that can occur at any point (Evans et al, 2011; ILF, 2006). Life events provide insight into how men react at the time that lymphoedema develops, and how this reaction is influenced by the masculinity men had formed based upon its 'specific historical time, culture and locale' (Evans, 2011, p. 8). Equally, life events lead men to 'define' and 'redefine' their masculinity, but it is unclear how this process occurs in the framework (Evans, 2011, p. 10). Alongside life events, the ageing process can affect a man's perception of masculinity, through their ability or inability to perform the patterns that are considered 'natural' for men, such as physical activities either in work or recreationally (Rome, 2021, p. 47). The HIMM framework provides a life course narrative for men in the study, and how this may be affected by the presence of lymphoedema in their lives, following the construction of their perceived masculinity (Evans et al, 2011; Connell and Messerschmidt, 2005). At the time of the study, no known published studies were exploring the experience of men with lymphoedema using either theories of hegemonic masculinity, or the HIMM framework as a theoretical lens. Therefore, these theoretical concepts were used to address the following research question:

1. How do men perceive their non-cancer-related lymphoedema within their daily lives?

4.6 - Method

4.6.1 - Study Design

A qualitative narrative inquiry was undertaken by using solicited diaries as part of the 'narrative methods toolbox,' with a focus on active participation, due to the participants recording and reflecting upon events within their lives (Milligan, Bingley,

Gatrell, 2005, p. 1882). The removal of the researcher within this process was considered as reducing or removing, what was classed as 'gendered performance,' and how 'men's performances of gender shape qualitative data' to allow the narrative to be formed (Broom, Hand, and Tovey, 2009, p. 52). Using solicited diaries was complemented by an inductive approach to analysis (Meth, 2017) within the narrative inquiry. This supported the exploration of the temporal and spatial context that exists for men diagnosed with lymphoedema, but also their perceptions through an interpretive perspective of those experiences in their daily lives (Caine et al., 2013; Clandinin, 2012; Green, 2013; Parahoo, 2014).

The depth and scope were determined by the men in the study. The approach allowed men to share and reflect upon their chosen experiences (Milligan, Bingley, Gatrell, 2005), as part of a 'cathartic' process (Meth, 2017, p. 99). A man's self-determination in the events that are shared provides insight into their world and the meaning that exists within it. However, the ability to explore why certain events have been shared and their meaning in further depth is a limitation (Pino and Adu, 2022). Despite, the potential limitation, the diaries were subject to interpretative inquiry by identifying patterns that exist within them through employing structural analysis (Labov, 1972) followed by thematic analysis (Riessman, 2008).

The patterns provided insight into the individual man's world and the meanings that exist. The relevance of these patterns indicated how men perceived their masculinity, set against societal expectations, such as through enacting traits and characteristics within hegemonic masculinity (Connell and Messerschmidt, 2005). Examining these patterns allowed the identification of the variations and alignment to

hegemonic masculinity within the study, but also the positive or negative impact this had upon each man (Connell and Messerschmidt, 2005; Courtenay, 2009; 2000).

4.6.2 - Access, Recruitment and Sampling

Participants were purposively recruited following their involvement in a previous study within the UK (all four nations) and Ireland that focused on men diagnosed with non-cancer-related lymphoedema. Debates within qualitative research regarding sample size exist, but the use of pre-determined sample size within narrative inquiry is not common (Braun and Terry, 2017; Tran et al; 2017). Equally, it has been suggested that the notion of data saturation within narrative inquiry is not appropriate and should be determined by the researcher and the data they gather (Caine et al, 2013). In review of the sample considerations, a cross-sectional sample of up to twelve men was considered sufficient, due to the ongoing review of emergent findings as part of the analysis, to ensure all avenues of interpretation were being explored. Twelve participants were recruited for this study with each man completing a consent form after reading the participant information leaflet. The diary was either emailed or posted with guidance on how to complete the diary and an agreed submission date.

Inclusion criteria and exclusion criteria as outlined in Table 4.0. In addition, participants were asked to provide details regarding their age, educational attainment, ethnicity, occupation (current or past), geographical location, and duration of their diagnosis. The demographic details were collected to allow for socioeconomic and intersectionality factors to be considered within the analysis and write-up of findings (Table 4.1). Participants were aged from 34-77 with the majority

of participants being aged between 50-59 years, further details are located in Table 4.1.

Table 4.0 Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1) over 18 years of age	1) below 18 years of age
2) identify as a man	2 do not identify as a man
3) diagnosed with primary or secondary lymphoedema (non-cancer related)	3) not diagnosed with primary or secondary lymphoedema (non-cancer related)
4) living within the UK (all four nations), and Ireland.	4) living outside the UK (all four nations) and Ireland.

Table 4.1 – Participant Demographics

Participant Characteristics	Number of Participants
Age	30-39 (3), 40-49 (1), 50-59 (6), 70-80 (2)
Ethnicity	White – British (10), White – Irish (1), White – Scottish (1)
Highest Qualification	GCSE (1), Apprenticeship (1), A-Level (1), Degree (7), Masters (2)
Diagnosis Type	Primary Lymphoedema (10), Secondary Lymphoedema (2)
Diagnosis Duration (years)	0-9 (5), 10-19 (4), 20-42 (3)

4.6.3 - Data Collection

Each participant engaged in the completion of their diary at their home setting between October 2021 to May 2022. Solicited diaries offered participants the ability to record selected events that occurred in their daily lives. The recording of events

provided extended insight beyond one point in time, to one that encompassed multiple points within two weeks. Each participant completed a solicited structured diary with the process supported by the '*Steps to Using Solicited Diaries*' by Meth (2017, p. 105; Appendix F) to provide a clear approach to support and encourage participation (Kenton, 2010; Meth, 2017). This led to the use of titles, such as when (date of event), what (situation/event details), how (feelings related to the event), whom (did they speak to anyone about the event), and others (to add further details if needed) (Appendix C). The frequency and exact time for completion remained flexible. Once started, participants were asked to complete their diary within two weeks, providing either daily, alternate days or weekly summaries. Debates exist around the way diaries are constructed and completed, but what is agreed upon is the need for a flexible approach to encourage a level of depth and breadth that is determined by each participant and the narrative they wished to share (Kenton, 2010; Meth, 2017; Milligan, Bingley, Gatrell, 2005).

4.6.4 - Data Analysis

Analysis was completed in two stages, 1) structural analysis followed by 2) thematic analysis (Table 4.2; Table 4.3). Structural analysis supported the sense-making of the text, by deconstructing and identifying potential meaning within the diaries through the identification of key points within the text, such as abstract, and resolution (Hunter, 2010; Labov, 1972). These key points were then subject to thematic analysis to 'uncover and categorize thematically' the meanings within the perceptions shared by men with lymphoedema (Riessman, 2008, p. 53). The two analytical approaches allowed exploration of the man's story set against social, cultural, and historical perceptions, such as masculinity with lymphoedema (Hunter,

2010). To support the analysis and potential influences the researcher applied Mauthner and Doucet's (1998) approach to reflexivity. This approach acknowledges the 'interpretation of data is reflexive' in which 'meanings are made rather than found' (Mauthner and Doucet, 2003, p. 414; 2008). To accommodate these influences, or what Mauthner and Doucet (2003, p. 425) suggest is the 'degree of reflexivity', led to a reflexive diary being kept. These reflections were shared with co-authors with provisional themes shared with participants for their initial response and feedback (Parahoo, 2014; Reissmann, 2008). Information provided in the solicited diaries was transferred and managed within Microsoft Excel with one main theme and two sub-themes ultimately being developed (Table 4.5)

Table 4.2 - Analysis and Reflexive Approaches

Structural Analysis	Thematic Analysis	Reflexivity
Abstract – What was this about?	1 - Single text examined at a time	1 – Reading for the plot and the researcher's response to the narrative.
Orientation – Who? What? When? Where?	2 - Order the account in chronological order.	2 – Reading for the active ‘I’ who is telling the story
Complicating Action -Then what happened?	3 - Identity underlying assumptions in each account is named and coded,	3 – Reading for the respondent's relationship with family and close friends
Evaluation – How did it make you feel?	4 - Cases are selected to illustrate the patterns, but also the range and variation within the narratives.	4 – Reading for the broader social and cultural context of the respondent.
Resolution – So what?		
Coda – Return to present – end of story		

Reference: Labov (1972)	Reference: Riessman (2008)	Reference: Mauthner and Doucet (1998)

Table 4.3 - Example Diary Analysis

Labov (1972) – Structural analysis identified within the diary content	Reissmann (20084) - Thematic Analysis identified themes following structural analysis
I went to buy clothes in the January sale, most of the trousers were narrow leg and the ones that were wide leg (AB). When I took them home and tried them, they were too tight to wear, and I had to return to the shop for a refund (CA) I felt embarrassed when I said they did not fit, and they offered me a larger waist and I said it was not the waist (EV) I told them about my ‘swollen legs’ and lymphoedema but they looked at me like it was an excuse for being overweight. (RE) I spoke to no one about it (C)	<u>Naming</u> 1) Awareness 2) Reminder <u>Coding</u> 1. Vulnerability – Awareness 2. Vulnerability – Reminder <u>Theme</u> • Main Theme – Vulnerability <i>“limited understanding or interest”</i> • Sub-Theme – A Constant Reminder- <i>“affects you day to day”</i>. Example Case – Trying to get clothes that fit is a nightmare and the ones that I do wear are not fashionable or desirable to wear.
Key: Abstract (AB), Orientation (OR), Complicating Action (CA), Evaluation (EV) Resolution (RE), Coda (C)	

4.7 - Ethics

Ethical approval was obtained from the University of Birmingham University Ethics Committee (ERN_20-1729). All participants consented to the study with all

data coded for anonymity purposes with the removal of identifiable features and the use of pseudonyms as shown in Table 4.4. Data was managed in line with the Data Protection Act that sets the EU General Data Protection Regulation regarding data storage, such as password-encrypted computer (Data Protection, 2018). Participants were not financially incentivised to take part.

Table 4.4 - Participant Pseudonyms

Name	Age	Name	Age
Luke	34	Mike	54
Alfie	37	Will	55
Ryan	39	George	56
Harry	41	Henry	56
Chris	50	Arthur	70
Jake	54	Ben	71

4.8 - Findings

Data gathered from the completion of the solicited diaries led to the identification of one main and two sub-themes (Table 4.5). These were contextualised against hegemonic masculinity (traits/behaviours) and the HIMM framework to answer the question *How do men perceive their non-cancer-related lymphoedema in their daily lives?*

Table 4.5 – Theme and Sub Themes

Main Theme	Subthemes
Vulnerability- “<i>limited understanding or interest</i>” – men are marginalised and isolated due to the limited awareness of	A constant reminder– “<i>affects you day to day</i>” – men perceive lymphoedema as a constant reminder of the changes both physically and relationally, adding to a sense of vulnerability.

lymphoedema and its effects specifically upon men.	Solace in Routine– “<i>Early morning routine as always</i>” – men sought control through strategies that enabled them to perform their expected activities and to become experts.

4.8.1 - Main Theme – Vulnerability - “*limited understanding or interest*”

All men reported a sense of vulnerability in their daily lives, that affected them as a man due to the presence of lymphoedema. Alfie and Henry’s accounts illustrate the sense of vulnerability, due to limited awareness of lymphoedema amongst the public and healthcare professionals. Alfie shares his encounter with a consultant and how his experience served to sum up his past experiences:

“This was the third vascular consultant I have seen since developing lymphoedema. I have found they have a very limited understanding or interest in the condition. This consultant looked at both my legs and said they looked fine, just continue wearing my compression stocking. Altogether the consultation was about 3 minutes in duration”. (Alfie)

Whilst encounters with healthcare professionals are one example, some men noted their lymphoedema drew the attention of those in the public. However, this attention did not always lead to positive outcomes, and even led men to feel even more isolated as shown in Henry’s account:

“Went Christmas shopping but due to the lymphoedema I can’t walk in a straight line, and I heard a couple behind me saying that I must be in the

Christmas spirit already thinking I was drunk. I felt like screaming at them and educating them that it was a health problem causing my walking. I couldn't wait to get back home" (Henry)

Henry's story connects to the limited awareness and how that extended for some men into their working environments, and their inability to engage in recreational activities, such as exercise. Concealing this from people was one way in which men mitigated their sense of vulnerability, as seen within the account by Alfie:

"Today we had our monthly well-being meeting at work. We were asked what areas of well-being are important to us. One of the team members is trying to encourage more physical activity like cycling and running in the wider team. I am still uncomfortable sharing any more detail about my condition, in part because I feel people are unfamiliar and do not understand it, therefore cannot relate to it" (Alfie)

Perceived vulnerability connects to the effect lymphoedema has on men's lives. Men using strategies, such as concealment, can be seen as a resource man used by men. However, this can perpetuate the limited awareness of lymphoedema, and the potentially disabling effects it has on their lives, leading to possible stigma being present. Henry recounts the time he was stopped by the police and the negative outcome this had upon him:

“I was walking to my vehicle without my walking stick, but due to my lymphoedema, I cannot walk straight. I look as though I am walking drunk. I got in and started to drive when I was pulled over by a police vehicle, I was asked if I had been drinking as they believed I was intoxicated. I told them I don’t drink, and they then asked if I had taken drugs. I told them no and they didn’t believe me at first, I asked why they stopped me. They said I presented as being intoxicated or under the influence of drugs and being in control of a vehicle is an offence. I was totally embarrassed as I had to explain to them that I was suffering from lymphoedema and had to show them my swollen leg for them to believe me. They then told me I would need to use my walking stick; I didn’t even get an apology from them” (Henry)

Limited awareness is one aspect that can exacerbate the situation for men and the negative effects this has upon them, such as marginalisation and even stigma. For some men non-disclosure of their lymphoedema was their preferred option to avoid their vulnerability. However, when public awareness is raised about lymphoedema, this led to internal conflict, such as the account by Alfie related to a newspaper article:

“I read an online article published in the Guardian newspaper about Lymphoedema. I had conflicting emotions. On the one hand, I was delighted that the condition was getting attention in the media. I thought about sharing the article with some friends that were aware but don’t really understand. I decided against it because I didn’t want to be identified as a sufferer. While it

was inspiring to read of other lymphoedema patients living with the condition, overall reading the article upset me a lot.” (Alfie)

Despite, Alfie, and Henry’s account summarising the majority of the men’s experience of lymphoedema. Not all men choose to mitigate the vulnerability they perceive by hiding, others are challenged by raising awareness, as shown in the account by Luke:

“I was contacted by a support group who had seen posts I made about my lymphoedema. They want me to contribute to their website and magazine. It is fantastic, as there needs to be more positivity about lymphoedema” (Luke)

The reaction by men in response to perceived vulnerability varied from most men hiding their lymphoedema to possible defiance. An oedematous limb acts as a constant reminder of the changes within their social practices, which may have led to a perceived marginalisation of their masculinity which will be discussed in the next sub-theme.

4.8.2 - Sub-Theme 1: A constant reminder – “affects you day to day”

All men expressed a sense of vulnerability that became entangled within the continual physical presence and effects of the lymphoedema within their daily activities. Lymphoedema served as a reminder of changes in their lives with all men commenting on different forms of disruption. Jake and Ryan’s quotes reflect what it is like to wake up with lymphoedema each day:

“Waking up for work again, my leg is feeling fat, small things like this make you realise how this condition affects you day to day.” (Jake)

“Every morning I wake up with something different, It irritates me. It’s like a little surprise every morning. It’s been such a fight trying to find out what is happening in my body and learning how to manage” (Ryan)

Whilst the morning acts as the first reminder, this continues throughout the day, due to the effect lymphoedema has upon a man’s ability to use their body to complete their work or expected activities:

“I stopped to buy a coffee after the school run. Sometimes it itches or doesn’t feel right in the leg hosiery. Usually, I don’t like to and can’t properly readjust the compression hosiery in a public space. I have to find a public restroom in a café or shop” (Mike)

By men continuing to engage in activities, men are attempting to maintain a sense of who they are as a man. However, even when engaging in activities they are reminded that the condition could progress, leading to both concerns for the present and future, as seen within the quote by Harry:

“I’ve had a long walk today. After climbing rocks along the coast, the skin on my lower left leg looks incredibly dry even after a shower. A common theme

with this condition is frustration and remembering what it was like to not have to worry about these issues. Dry skin can crack causing lesions that could get infected, leading to cellulitis not long after, which sets me back every time”

(Harry)

Men in the study experience emotions that go counter to what they considered they should be able to perform as a man. Certain situations signified the contextual nature of the changes in their masculinity and its expression. Mike reflected on a situation with his son how he was no longer able to fulfil an aspect of being a father, due to lymphoedema:

“In a play area with my son, I overheard him discussing my leg with a child he was playing with at the time. They were talking about running to the far side of the field and back in a race. My son just piped up and said, ‘My dad can’t race, he’s got a rubbish leg’. I was embarrassed and annoyed with myself that I’m not more physically fit, but also annoyed at myself at getting annoyed” (Mike)

Mike’s account is one example of the perceived physical restrictions. All men reflected upon the restriction and its presence in their lives. Key events in their lives, such as birthdays, provided a fixed reference point each year of how much had changed, in the case of Alfie and his birthday:

“Today is my 38th birthday – almost 4 years since I started seeing swelling in my right leg, and 3 years since I was diagnosed with lymphoedema. The

occasion of my birthday has caused me to reflect on how difficult the last few years have been. I worry about my lymphoedema getting progressively worse, and the knock-on effects that will have on my health.” (Alfie)

Alfie’s birthday served as a reminder of what had changed in his life. Other men reflected on the way lymphoedema had affected their relationships as provided another reminder of how their lives have changed. Jake’s quote indicates how his lymphoedema has led to greater dependency on his wife:

“I ordered paint online for collection from my local DIY store. I wasn’t really thinking as I thought I would go collect it that afternoon. I suddenly realised “how are you going to carry two 5 litre tins of paint”. I had two choices, either ask for help at the store or wait until my wife was free to help. I opted for the latter. I felt completely useless and dependent on other people to do simple tasks.” (Jake)

Not all men perceived the changes in their lives negatively within their current relationship. Luke illustrated how his partner enabled them to ‘fight’ lymphoedema, and how this fed into behaviours that challenged possible negative perceptions of having lymphoedema:

“I got my boyfriend to take a picture of me dressed up before our date night. I wanted to post it to show I had accepted my condition. Even though it’s visible

and I will continue to fight it with support. My boyfriend knows the most about how this condition affects me.” (Luke)

Lymphoedema was a daily reminder of the changes that had occurred in the man's life and how this affected their ability to engage in daily activities. Whilst changes in relationships may lead one man to perceive it negatively, another man may see it as a reference point for growth. Certain aspects of growth, or a man's wish to gain control of their life, fed into the routines they created, which will be explored in the next sub-theme.

4.8.3 - Sub-Theme 2- Routine – “*Early morning routine as always*”

Routines and strategies created by men were used by all of them to manage the impact lymphoedema had upon them. Routines allowed men to engage in efforts to control their lymphoedema and limit the possible complications due to its presence in their lives. All the men in this study sought refuge in their daily self-management routines. Ben's quote indicates the daily routine for all men, but also the anticipation of resolvable problems:

“Early morning routine as always. Aware of leg and check swelling and appearance. As always, some difficulty in putting my sock despite being soft tops. Enjoyed the bike ride” (Ben)

Anticipation of the changing nature of lymphoedema enabled men to partially accept it within their lives. This was perceived as transactional, with compression

therapy enabling them to continue in their accepted activities, as seen in Luke's account:

"Having to adjust my compression stocking throughout the day. I feel frustrated but I can at least be active throughout the day. I do not usually speak to anybody; it is a common part of life with this condition." (Luke)

Each man created their routine in their daily life, but this varied amongst the men, due to their context. All men sought to be independent and self-reliant when managing the physical routine of their care, such as compression hosiery. These served as resources that they used to improve the management of their lymphoedema and become experts. However, reaching a point of control and acceptance in their daily lives was not immediate, as shown in the account by Ben:

"Once I overcame the shock that I had the condition for life. My overriding concern has become to manage it well and avoid cellulitis. My fears have always been that as I age (I'm now 70) the condition would get harder to manage. I like to regard myself as an expert patient and my duty to myself but also to the NHS to manage my condition as best I can" (Ben)

Routines in this sub-theme offer the strategies men use to manage and accommodate the impact lymphoedema has upon them. Routines also served as reference points indicating how men adapted over time, but how these were influenced by their context, such as relationships and their background. By using

their existing resources, such behaviours and relationships enabled men to control and/or adapt to certain aspects within the lymphoedema story.

4.9 - Discussion

The study and its findings offer an exploration but also an examination of the perceived effect lymphoedema has upon men's daily lives. At the time of this qualitative study, no other research had explored the impact lymphoedema had upon the daily lives of men, nor applied the theory of hegemonic masculinity or HIMM framework (Evans et al, 2011; Connell and Messerschmidt, 2005). The solicited diaries have led to one overarching theme and two sub-themes being identified from the individual accounts. The themes will be discussed against the wider literature and the proposed theoretical concepts outlined in the theory section of the article.

4.9.1 - Vulnerability - "*limited understanding or interest*"

Vulnerability perceived by men in their daily lives is not explicitly linked to the concept of 'life events' in the HIMM framework (Evans et al, 2011, p. 10). However, the outcome of vulnerability in the HIMM framework focuses on the increased risk to mental health, avoiding perceived weakness and expressing emotion in response to life events, which are present in the findings of this article (Evans et al, 2011). Analysis and findings indicate that perceived vulnerability experienced by men is due to not only the physical aspects but also the limited awareness of lymphoedema and specifically the effect it has upon men engaging in 'social practices' that demonstrate their masculinity, such as sport or work (Connell and Messerschmidt, 2005, p. 851). Limited awareness of lymphoedema amongst the public and healthcare professionals is noted as a leading reason for the delays in diagnosis, access to services, and support for over 20 years (Schulze et al, 2018; UK Parliament, 2013; Moffatt et al,

2003). Hence, leading men to perceive their condition as one that is 'highly visible' but remains 'largely invisible or unknown' in the wider public (Hamilton and Thomas, 2014; 4). Whilst lymphoedema could be considered as a life event within the HIMM framework (Evans et al, 2011), what that may encompass is vague. Due to its vagueness, it fails to consider the impact lymphoedema may have upon men as an example of disruption.

Whilst, hegemonic masculinity, acknowledges that men may become marginalised, when they do not meet 'idealized' concepts of masculinity, due to 'difficulties in responding to illness or injury' (Connell and Messerschmidt, 2005, p. 834, 838). It fails to fully consider the disruption and its effect on men. The work by Bury (1982, p. 167) may offer insight into a life event and its effect upon hegemonic masculinity was perceived as a 'biographical disruption', caused by someone having a chronic condition and perceived limitations. Equally, disruption can be considered as a reason for the varying responses by men in the findings. The response may align with the study by Flurey et al (2018), in which men transition back and forth between three hegemonic masculinities typologies, by retaining, negotiating, or rejecting. In certain instances, men in the article may be upholding the proposed 'hegemonic ideals of masculinity', by concealing their condition from others (Flurey et al, 2018, p. 118). Concealing weaknesses by men with lymphoedema has been seen in other studies to avoid changes to their 'social standing' (Cooper-Stanton et al, 2022; Maree and Beckmann, 2016; Perera et al, 2006, p. 6). However, not all men wish to hide, providing the possibility that some men, may have negotiated changes in their masculinity (Flurey et al, 2018).

However, the upholding of hegemonic masculinity ideals may also be concealing fear of discrimination and stigma which has been noted in previous work (Cooper-Stanton et al, 2022). As noted in one man's account when interacting with shop assistants and police, can indicate the constructed layer within society, regarding expectations of men and health, that may lead to discrimination as a result (Karl et al, 2022; Liddon and Barry, 2021). When men in the article interacted with these societal structures, led to what could be perceived as discrimination based upon misunderstanding by others, and is reflective of work within disability discrimination (Hackett et al, 2020). The resulting interactions can perpetuate the perception of stigma in which lymphoedema is an 'attribute that is deeply discrediting' that can perpetuate 'drivers' of stigma, due to limited awareness and understanding of men with lymphoedema (Stangl et al, 2019, p. 2; Schulze et al, 2018; Goffman, 1963). Whilst stigma is not explicit within the findings it is suggestive that the vulnerability perceived by men, is due to the disruption in their masculinity, and the resulting perceived marginalisation, that may feed into constant reminders.

4.9.2 - A constant reminder – “affects you day to day”

Lymphoedema by its long-term biological nature acts as a reminder of the physical changes men experience (ILF, 2006). Whilst HIMM framework and hegemonic masculinity acknowledge physical changes as affecting a man's masculinity, either due to life events or the impact this has upon their social embodiment (Evans et al, 2011; Connel and Messerschmidt, 2005). Men in the study illustrate the impact lymphoedema has within their lives, either by limiting their ability to perform expected roles physically and socially within hegemonic masculinity, such as fatherhood or sport. Frid et al (2006) study acknowledges that the discomfort

within lymphoedema goes beyond the physical appearance. The notion of extending beyond the physical is noted in the study by Demain et al (2015, p. 8) within their term 'treatment burden' that encompasses the biographical, relational, and biological disruptions. Disruption is a reminder of the changes that have occurred in the lives of men, with its significance aligning to a man's own 'meaning-making process' and whether they perceive themselves as being reduced to a condition instead of a man (Holman and Borgstorm, 2015, p. 6). In the study by Cooper-Stanton (2022, p. 25) focusing on men, the swollen limb was not only a 'reminder' but also a 'symbol' of the changes within their lives. Bury (1982) considered this within the notion of a merging disablement, which can be perceived as deficit-focused. The perceived deficit reported by men can be seen as challenging their 'constructed baseline' of masculinity (Viehoff et al, 2016, p. 415).

Men in the study experienced varying degrees of what the literature refers to as a 'crisis' in their daily lives, due to 'uncertainty' caused by a chronic condition that may lead to a '...reassessment and taking stock of their lives...' (Evans et al, 2011; 12; Bury 1982, p. 172). By taking stock, men may respond to upholding their previous version of hegemonic masculinity and continue to pursue activities they once did or negotiate those changes by adapting (Flurey, et al 2018). How men ultimately engage in these changes, is not clear in the work by Flurey et al (2018), there are instead indications of behavioural changes that occur over a period. Whether this reflects the proposed time and context-based view of hegemonic masculinity that changes occur over some time may offer one explanation (Connel and Messerschmidt, 2005). However, avoidance of situations by men, also reduces the

ability for them to demonstrate their masculinity in a social setting, leading to 'relational disruptions' in existing relationships (Demain et al, 2015, p. 8).

A small number of men in the article commented on their experiences of accepting support either positively or negatively. Why men, may or may not accept support, is not addressed explicitly within the existing theories of masculinity, beyond it being acknowledged women seek help more readily than men (Courtenay, 2009). Both genders can engage in what Bury (1982, p. 463) states as 'active denial' of their condition and impact. Flurey et al (2018) suggest men may have negotiated aspects of their hegemonic masculinity to view support as a less significant consequence of the overall disruption. Any change by men, maybe dependent upon how men perceive spousal or partner support as either maintaining their masculinity or diminishing it (Arnell, 2014), and whether they can 'confide in others' (Bury, 1982, p. 462). Alternatively, men may have to engage in the rebuilding of their relationships (Cooper-Stanton et al, 2022), leading to a 'dual identity' between a man's masculinity and accepting of support positively (Wilde et al (2020, p. 314). Men in the study indicate that the treatment of lymphoedema is a burden, that requires them to consider their masculinity when responding to the physical and relational changes, which is not explicitly stated in the HMM framework or hegemonic masculinity. Including additional perspectives adds to the way men in the study respond to lymphoedema, such as routine formation as outlined below.

4.9.3 - Routine – “*Early morning routine as always*”

Routines in the findings appear to be in response to the disruption in their lives in which men are employing associated hegemonic masculinity traits and behaviours from the literature in response, such as seeking self-reliance and independence

(Courtenay, 2009; Connel and Messerschmidt, 2005). Why men form routines appears to be based on establishing control over their health from the existing literature on lymphoedema (Cooper-Stanton et al, 2022). The HIMM framework and hegemonic masculinity, consider the need for control as being incumbent in hegemonic masculinity (Evans et al, 2011; Connel and Messerschmidt, 2005) with some suggesting men 'compensate; if they are not able to fulfil hegemonic or traditional masculine expectations (Courtenay, 2009, p. 21). How men compensate and what is considered as being socially acceptable within that process of compensation is not clear. The work by Arnell (2014, p. 17) on men and the concept of 'masculine capital', offers an ability to view this differently, in which 'any behaviour by men can be endowed with masculine capital'. If any behaviour can be imbued and used, means men can use existing traits and behaviours associated with hegemonic masculinity, as masculine capital in response to the disruption in their lives, thus avoiding the perception of engaging in feminine traits (Arnell, 2014; Courtenay, 2009).

Masculine capital, though not mentioned within the work of Bury (1982), can be considered as a resource that is mobilised in response to chronic illness as a disruption in a man's life. This offers flexibility when viewing a man's use of hegemonic masculinity traits and behaviours, such as maintaining self-reliance in terms of forming routines as a masculine capital. However, the use of capital is dependent upon the man and how they use that capital, to either support themselves to engage in social situations or to avoid them. Arnell (2014, p. 17) suggests this is dependent upon the perception of the behaviour, such as seeking support as being 'reframed' as being 'brave', such as spousal or partner involvement in routines. As

indicated in the findings, there is a dichotomy between a man remaining independent and accepting support and within the literature in which men seeking support is lower than women (O'Rourke et al, 2022; McKenzie et al, 2018; Courtney, 2000; 2009; Holman and Borgstorm, 2015). Whilst the work of Flurey (2018) extends hegemonic masculinity and the possible transitions they may undertake, it does not mention the use of masculine capital, but there are possibilities that it is used, and can be supportive for men when managing their chronic illness.

Our findings show how men are influenced by lymphoedema in their daily lives, by perceptions of vulnerability linked to its disruptive effect. Disruption extends beyond the physical to encompass the relational aspect and their masculinity. The findings illustrate the way men undertake routines, supported by their masculine capital to negotiate changes in their masculinity.

4.10 - Strengths and Limitations

This study has explored the experience of men in their daily lives following their diagnosis of non-cancer-related lymphoedema. The findings of the study and discussion add to the literature surrounding men's experience of lymphoedema, by using theoretical frameworks that have not been applied within this area.

Representation of men with lymphoedema being majority White and aged over 45 years, correlates with national and international studies within developed westernised countries (Keeley et al., 2019; Moffatt et al., 2019c). Future research could explore the experiences of other groups, such as Black, South, or East Asian populations and those who identify as Lesbian, Gay, Bisexual Transgender, or Queer+ (LGBTQ+). Those who participated also provided a life course view of the condition,

due to the variety of ages that participated in the study and can offer a level of transferability of these findings to other similar groups of men with lymphoedema.

The study recruited a similar number of participants as other studies within the subject area of lymphoedema (Cooper-Stanton et al, 2022), it is noted that men's involvement in research is lower compared to women (Pathak et al, 2017; Markanday et al, 2013). Despite being similar, it is whether the findings in the study, are present in a larger sample of men that includes a greater diversity as mentioned above. The transferability of findings outside the UK (all four nations) and the Republic of Ireland needs to be considered against the variety of healthcare provision and access, but also cultural context and differences within other countries. Due to most men being White in the sample, with 10 identifying as heterosexual and two as gay, the ability for the findings to be applied beyond this background is unclear. Nevertheless, the study indicates the impact lymphoedema has upon their daily lives relationally, physically, and psychologically, and how this is mitigated through coping strategies to manage their lymphoedema.

4.11 - Conclusion

This article has focused on the daily lives of men and their perceptions of lymphoedema within it. Answering this question has shed light on the vulnerability men experience, due to the disruption that is caused by lymphoedema. Leading to changes in the way that men engage within their social world and the practices that enable them to demonstrate their masculinity. The accounts by men indicate the negative challenges this had upon them, such as fulfilling roles at work or in relationships. Not all men's perceptions were the same, leading to changes not only within their lives and the management of their condition but also within their

perception of masculinity. It is noted this period of change, is not linear with each man engaging within it differently, through embodying masculine traits or challenging these by accepting support from partners or friends. The current theoretical concepts offer insight into the possible effects lymphoedema has upon a man's masculinity but there is a need to consider other theoretical works. By considering all aspects we can begin to understand the journey men undertake.

4.12 - Chapter Contribution

Chapter 4 has added to the existing literature and findings outlined in Chapters 2-3 by answering the second sub-question outlined in Chapter 1. *How do men perceive their non-cancer-related lymphoedema within their daily lives?* The narrative inquiry approach and solicited diaries led to the creation of one main theme, 1) vulnerability, and two sub-themes 2) constant reminder and 3) solace in routines. Based upon the structural and thematic analysis of the data gathered from twelve men. The themes of vulnerability permeated the two sub-themes, due to the limited awareness and understanding of the negative effect lymphoedema had upon men and their masculinity. Having a swollen limb acted as a constant reminder of their vulnerability, in which they sought physical control over lymphoedema. The findings of Chapter 4 continue to expand the findings established in Chapters 2 and 3. Further explorations of men's perceptions continued into Chapter 5 with the final two sub-questions outlined in Chapter 1 being answered.

5.0 – Renegotiating support for managing long-term health conditions in the context of hegemonic masculinity: A linguistic analysis of men’s narratives of living with non-cancer related lymphoedema in the United Kingdom

5.1 - Chapter Rationale

In Chapter 4, the analysis of the solicited diaries through thematic and structural analysis created one main theme and two sub-themes. The main theme 1) vulnerability focused upon the limited awareness across the public and among healthcare professionals regarding lymphoedema as a condition, its effect upon a person, but also it being presence within men. This led men to perceive themselves as being marginalised which affected their demonstration of their masculinity. Vulnerability fed into the sub-theme constant reminder, due to the physical aspect of having a swollen limb that permeated their lives in the completion of activities that affected their masculinity. While men in the next sub-theme sought solace in routines that controlled their lymphoedema. The perceived vulnerability led them to use associated hegemonic masculinity traits and behaviours as a form of masculine capital. A central aspect that crossed all themes was the disruption men perceived within their masculinity and its renegotiation.

This Chapter builds upon Chapters 2-4 through further exploration of men's perceptions by answering the remaining two sub-questions outlined in Chapter 1. *What are men’s perceptions of support within their non-cancer-related lymphoedema? And What are men’s perceptions of masculinity within their non-cancer-related lymphoedema?* Narrative inquiry outlined in Chapter 1 was used within this Chapter, through the completion of online semi-structured interviews with an agreed interview schedule. Subsequent analysis involved narrative linguistic

analysis across the transcripts of twelve men that led to three parts being created, 1) disruption, 2) journey and 3) masculinity which are discussed in this Chapter.

5.2 - Abstract

Introduction

Literature indicates the potential impact lymphoedema has upon men due to having an incurable but physically visible condition, due to lymphatic failure. Due to the long-term and physical nature of lymphoedema. Its impact can be perceived as affecting the support men receive but also their perception of masculinity. *The study focused on exploring two questions, men's perceptions of support and their masculinity with lymphoedema.*

Method

This was a qualitative study within narrative inquiry that involved twelve participants. Data was gathered from the completion of online semi-structured interviews that lasted between 45-90 minutes via Zoom. An interpretive approach was used. Data was subject to linguistic narrative analysis through the theoretical lenses of hegemonic masculinity and the health, illness, men and masculinities framework [HIMM].

Findings

Interviews and data analysis led to the identification of three parts of the stories men tell themselves. Part 1 – disruption, focuses upon the start of their story following their diagnosis coupled with limited support offered to men. Part 2 – journey focuses upon the different journeys men undertake, to manage changes within their masculinity, through behaviours or available resources. Part 3 – masculinity, considers how men perceive their masculinity currently compared to the past, and how this may be viewed in the future. The three parts reveal the temporal nature of

their stories and the differences that are present within them, due to their varying backgrounds.

Discussion

Our findings reflect the held view that hegemonic masculinity and its expression are still present in society. However, what is not considered is the disruption to a man's masculinity, due to having a physical long-term condition. The findings within the wider literature, indicate men may uphold their masculinity, whilst others will begin to adapt their masculinity and how it is performed. Appreciating that lymphoedema is not only a disruption within a man's health, but also their masculinity may lead to services, policies and strategies that take a more nuanced approach.

5.3 - Introduction

Men within the United Kingdom (UK) and globally experience health inequalities that span physical and mental health. Men continue to have shorter life expectancies compared to women, whilst the incidence of mental health in women with a long-term condition is higher than in men, men are less likely to seek help which may explain this disparity (ONS, 2022; GAOMH, 2020; McKenzie et al, 2018; Naylor, 2012; WHO 2018). Historically the health inequalities experienced by men have led to past attempts by past governments and third-sector organisations to address these disparities (Robertson and Baker, 2017). It has been suggested that these disparities reflect the structural nature of society, such as gender, class, and ethnicity, from which men derive their constructed identity and expected norms (Bosson et al, 2021; Valved et al, 2021).

When this constructed identity is challenged by the inability to perform or portray associated behaviours, such as physical strength, it can lead men to experience negative emotions as noted within the theory of 'precarious manhood' (Bosson et al, 2021, p. 235). The theory centres around manhood being achieved through repeated actions, that support a man's social status that is 'hard to earn' but 'easy to lose', leading men to compensate when this is challenged (Bosson et al, 2021, p. 235; Vandella and Bosson, 2013; Vandella et al, 2008). Compensatory approaches can involve riskier behaviour and may help to explain why men are at higher risk of non-communicable diseases, such as heart disease, and increased risk of social isolation compared to women when masculinity is disrupted (ONS, 2022; GAOMH, 2020; McKenzie et al, 2018). There is a renewed interest and focus on men's health, due to societal and political perceptions there is a 'crisis of masculinity',

with other authors calling for a shift away from negative connotations in the use of the word 'crisis' (Katarzyna, 2021, p. 1; Tosh, 2005).

In the UK, the Women's Equalities Committee [WEC] (2019) called for an inquiry into men's health. These calls follow actions taken by other countries, such as Brazil and Australia who have developed country-wide strategies for men's health (GAOMH, 2020). Following the WEC (2019) letter the UK government have launched an inquiry focusing on men's health to improve health equity and to review the benefit of projects to reduce social isolation (UK Parliament, 2023). The inquiry and its focus acknowledged criticisms that services at that time marginalised men's health by not embedding gender-considerate approaches (Liddon and Barry, 2022; Robertson and Baker, 2017). Gender consideration includes 'targeted strategies' and the need for 'focused research' in men's health (UK Parliament, 2019, p1). In considering the national and global interest in men, this article explores how men interpret support and their perception of masculinity with lymphoedema, by using the theoretical concepts of hegemonic masculinity, alongside the health, illness, men and masculinities framework [HIMM] (Evans et al, 2011; Connell & Messerschmidt, 2005).

5.4 - Background

In the UK, the prevalence of lymphoedema in the general population ranges from 3:99 per 1000 rising to 28:76 per 1000 aged over 84 years (Moffatt et al, 2017; 2019c). When this figure is understood with gender in mind, a man's risk of developing lymphoedema in the UK is between 0.47-2.48 per 1,000 (Moffatt et al, 2017; 2019c), with their representation being 15-22% within caseloads held by UK lymphoedema services (Cooper and Bagnall, 2016). Men and women with lymphoedema, are affected by an incurable long-term term condition, which is

present within the umbrella term chronic oedema (Rankin, 2016). Lymphoedema has multiple causes, which include intrinsic primary lymphoedema, linked to lymphatic malformation, such as genetic, or extrinsic secondary lymphoedema caused by external damage, such as surgery (Cooper and Bagnall, 2016; International Lymphoedema Framework, [ILF], 2006). It is estimated secondary lymphoedema accounts for 82.5% of caseloads, with non-cancer-related lymphoedema accounting for 66% of this figure (Keeley et al., 2019). Lymphatic failure as part of lymphoedema leads to oedema formation in any part of the body, leading to an increased risk of infections and reduced mobility (Rankin, 2016; ILF, 2006).

The figures above indicate that men represent a minority of those affected by lymphoedema but fail to indicate the impact this has upon men, their lives or masculinity. The impact on men is a gap in the literature identified within a systematic review by Cooper-Stanton et al, (2022), which focused on the gathering and interpretation of qualitative studies. The systematic review identified lymphoedema affected a man's identity of what they perceived as normal, but also the changing dynamics of their relationships with others, such as increased dependence on partners (Cooper-Stanton et al, 2022). Despite these findings, the studies in the review did not consider, masculinity theory, or solely focused on men with non-cancer-related causes of lymphoedema (Cooper-Stanton et al, 2022; Cooper and Bagnall, 2016; Cosgiff 2010). Limited consideration of the voice of men and their masculinity within the existing literature, can continue to perpetuate biases within the care men receive and that they are only affected by cancer-related lymphoedema (Liddon and Barry, 2021; Tidhar et al, 2018; Williams et al, 2004; Cosgiff et al, 2010). This study adds to the existing evidence base, due to its focus on men diagnosed

with non-cancer related lymphoedema within the UK (all four nations), but also the consideration of masculinity theory within a life course framework, by giving men a distinctive voice (Evans et al, 2011; Connell & Messerschmidt, 2005).

5.5 - Theory

The theoretical lenses used within the article acknowledge the current and changing perceptions of what constitutes being a man within society (Bosson et al, 2021; Evans et al, 2011; Connell & Messerschmidt, 2005; Tosh, 2005). Hegemonic masculinity provides a theoretical lens to explore masculinity, through possible associated traits that influence behaviours, which may change over a man's life due to life events identified within the Health, Illness, Men and Masculinities [HIMM] framework (Evans et al, 2011; Connell and Messerschmidt, 2005; 1993). Overlaying the two theories provides explicit insight into masculinity and its applications to men with lymphoedema across their lifespan (Cooper-Stanton et al, 2022; Evans et al, 2011; Connell and Messerschmidt, 2005).

Hegemonic masculinity requires men to embody and align to the dominant expectations (Connell and Messerschmidt, 2005), and has been described as 'the degree to which a person possesses attributes that constitute manhood' (Valved et al, 2021, p. 267). Attributes can be associated with the performative nature, or the ability to produce and reproduce what is expected by fulfilling a 'pattern of practice' (Boulton, 2017; Connell and Messerschmidt, 2005, p. 832). For example, behaviours that support invulnerability, independence, and self-reliance (Rome, 2021; Connell and Messerschmidt, 2005, p. 832). When men are unable to perform their masculinity can be perceived as a threat to their 'social status' (Valved et al, 2021; 266) leading to them being perceived as being sub-ordinate or marginalised to what

is considered the dominant masculinity (hegemonic) (Valved et al, 2021; Courtenay, 2009; 2000). However, the concept of masculinity is noted as being time and context-bound and will change over time including expectations (Connell and Messerschmidt, 2005). Additionally, masculinity has been considered a spectrum in which men may express masculine or feminine behaviours, with an acknowledgement that other versions of masculinity exist, due to the non-homogeneous nature of men, such as caring masculinities (Liddon and Barry, 2021; Valved et al, 2021; Courtenay, 2009; 2000). The application of hegemonic masculinity recognises its continued presence in Western society in which traditional expressions may persist (Bosson et al, 2021; Liddon and Barry, 2021; Valved et al, 2021; Boulton, 2017).

As masculinity changes over time, requires the application and overlaying of a framework that provides a platform to explore this across a man's life course (Evans et al, 2011; Connell and Messerschmidt, 2005). The HIMM framework in combination with hegemonic masculinity provides an ability to extend the insight of this study, by recognising masculinity as a social determinant of health that 'intersects other determinants' such as age (Evans et al, 2011). Recognising masculinity in this way acknowledges the 'complexity of social relations and practices attached to biological sex' but also its influence on men's health (Evans et al, 2011, p. 7). Life events, such as ill health or a diagnosis of a long-term condition, can affect a man's ability to perform masculinity, but how men perceive and respond to this inability is unclear in the HIMM framework (Evans et al, 2011). Beyond a proposal that men 'define' and 'redefine' their masculinity in response to life events (Evans, 2011, p.10). Using the HIMM framework provides an opportunity to explore how men define and redefine their masculinity following an event within their life course. At the time of the study,

no other research had used or explored lymphoedema and the experiences with men through the theoretical lenses of hegemonic masculinity, or the HIMM framework. Therefore, these theoretical concepts were used to inform and address the following research questions:

1. What are men's perceptions of support within their non-cancer-related lymphoedema?
2. What are men's perceptions of masculinity within their non-cancer-related lymphoedema?

5.6 - Method

5.6.1 - Study Design

Online semi-structured interviews were used to answer the two proposed research questions as part of the narrative inquiry approach taken in this article (Caine et al., 2013). Narrative inquiry allowed men to share their stories of lymphoedema, its context and interpretation within their lives set against their masculinity, and for these stories to be taken forward as a collective narrative construction (Caine et al., 2013; Parahoo, 2014). Narrative inquiry acknowledges that 'the researcher does not find narratives but instead participates in their creation', signifying that a researcher is interacting within a man's social world (Green, 2013; Riessman, 2008, p. 21). Creation in narrative inquiry signifies the intersubjective process that occurs in the sharing of personal stories, and how a man is allowing the researcher access to the 'real thing' to establish the meanings held within them (Riessman, 2008; 22). By entering the social world of men, it allowed the researcher to understand the disruption lymphoedema had upon their socially constructed

identity and gender (Boulton, 2017; Bury, 1982; Connell, 1993; Courtenay, 2000; Earthy et al, 2016).

5.6.2 - Access, Recruitment and Sampling

Twelve men were recruited within the UK (all four nations) and the Republic of Ireland over twelve months from September 2021 until August 2022. Purposive sampling was undertaken to obtain a cross-sectional representation of men diagnosed with non-cancer-related causes of lymphoedema. Narrative inquiry sample size is determined by the purpose and scope of the study with suggestions that up to ten participants and above are acceptable (Clandinin, 2012). Twelve participants were recruited which is reflective of previous research on men with lymphoedema (Cooper-Stanton et al, 2022). Data saturation within narrative inquiry is a contentious issue, with suggestions that 'narrative research and the role for saturation is harder to discern' with it being more relevant in other qualitative methods, such as grounded theory (Parahoo, 2014; Saunders, 2018, p. 1899). To this end, theoretical saturation within this study was reached when there was an agreement between authors that there was 'completeness' of the man's 'biographical account' which occurred within the 12 participants (Saunders, 2018, p1899).

Promotion of the study took place via national organisations representing service users affected by lymphoedema, healthcare professionals who supported them and online social media, such as X (previously known as Twitter). Potential participants had the opportunity to contact the main researcher if they had any questions. Each man received and declared they had read the participant information as part of the signed consent form before the interview. Participants were offered an alternative option if the online interview via Zoom was not possible, such as a

recorded telephone call. Inclusion and exclusion criteria details are outlined in Table 5.0. In addition, participants provided details regarding their age, educational attainment, ethnicity, occupation (current or past), geographical location, and duration of their diagnosis. This was to provide information about socioeconomic and intersectionality factors within the perception of their long-term condition (Table 5.1). Participants were aged from 34-77 with most participants being aged between 50-59 yrs. (Table 5.1).

Table 5.0 – Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1) over 18 years of age	1) below 18 years of age
2) identify as a man	2 do not identify as a man
3) diagnosed with primary or secondary lymphoedema (non-cancer related)	3) not diagnosed with primary or secondary lymphoedema (non-cancer related)
4) living within the UK (all four nations), and Ireland.	4) living outside the UK (all four nations) and Ireland.

Table 5.1 – Participant Demographics

Participant Characteristics	Number of Participants
Age	30-39 (3), 40-49 (1), 50-59 (6), 70-80 (2)
Ethnicity	White – British (10), White – Irish (1), White – Scottish (1)
Highest Qualification	GCSE (1), Apprenticeship (1), A-Level (1), Degree (7), Masters (2)
Diagnosis Type	Primary Lymphoedema (10), Secondary Lymphoedema (2)
Diagnosis Duration (years)	0-9 (5), 10-19 (4), 20-42 (3)

5.6.3 - Data Collection

Twelve participants completed the online semi-structured interviews that lasted between 45-90 minutes. Development of the interview schedule and questions, led to the review of previous research on men with lymphoedema, followed by the involvement of stakeholders, such as men affected by lymphoedema (Cooper-Stanton et al, 2022; Cosgiff, 2010; Taylor, 2005). Online interviews and their value within qualitative research have gained prominence following the recent pandemic but also overcome prohibitive geographical distances (Greenhalgh et al, 2020; Hu et al, 2020; Krouwel et al, 2019; Sullivan, 2012). The interviews were all digitally recorded and stored per the agreed data management plan that formed part of the ethics application and aligned to the UK-based General Data Protection Regulation (2016) and the Data Protection Act (2018) (UK Government, 2018). An initial analysis of the first five interviews was undertaken to establish the initial themes to inform subsequent interviews to expand points related to the research questions (Vasileiou et al, 2018). All interviews were transcribed verbatim and then subject to formatting as part of the linguistic narrative analysis (Table 5.2).

5.6.4 - Data Analysis

To support the process of 'meaning-making' from the information gathered led to an approach that considered the discourse elements found within narratives (Reissman, 2008). Language not only builds but maintains identities that are conveyed within the social world (Gee, 2007). Linguistic narrative analysis focuses on how stories can be broken down into units that convey meaning (Gee, 1991). Meaning is deduced through what is 'actually said' with 'pitch signals' indicating a focus point by the speaker to the listener (Reissman, 2008; 93). The 'pitch signals'

indicate idea units, supported by lines from the text, which are grouped into stanzas that represent a 'single topic' which then form into strophes which then form into the parts, or 'chapters' of the man's story (Tomassini et al, 2019, p. 4; Reissman, 2008, p. 93; Table 5.2 and 5.3).

To support the analysis, all interviews were transcribed by the researcher to enable immersion in the data and the development of sensitivity to the issues of importance with data transferred manually into an Excel sheet (Holloway and Wheeler, 2010). Reflexivity incorporated the approach offered by Mauthner and Doucet (1998; 2003) (Table 5.2) supported through the use of a reflexive diary, focusing upon the decisions and inferences within the analysis. These inferences were subject to discussions with co-authors every 1 to 2 months, which assisted with the analysis and triangulation of findings (Table 5.2), with initial findings shared with participants (Parhoo, 2014). Initial findings led to the identification of three overarching parts within the narratives shared by men following linguistic narrative analysis (Table 5.5). The three parts reflect the social world of men, and the disruption lymphoedema has had upon their socially constructed gender and its expression (Boulton, 2020; Bury, 1982; Connell, 1993; Courtenay, 2000; Earthy et al, 2016).

Table 5.2 - Analysis and Reflexive Approaches

Linguistic Narrative Analysis	Reflexivity
Idea unit – pitch indicating different focus within the text	1 – Reading for the plot and the researcher's response to the narrative.
Lines – include extracts from the transcript to support the idea unit.	2 – Reading for the active 'I' who is telling the story
Stanza – Group of up to four lines about a single topic.	3 – Reading for the respondent's relationship with family and close friends
Strophes – the stanzas then form into related pairs.	4 – Reading for the broader social and cultural context of the respondent.
Parts – the strophes form the parts that represent the story as a whole.	

Table 5.3 – Analysis Example Gee (1991) Linguistic Narrative Analysis

Source	Transcript Examples	Idea Unit with Lines	Stanza	Strophe	Part
Researcher	could you tell me a little bit about yourself and then also your experience of living with lymphedema?				
Luke	Well, um, yeah, so I'm 34 now and I work as an HGV driver. Regards to lymphedema it almost just popped up out of nowhere about two years ago, well just over two years ago now. My leg started swelling in 2020.	01 – (Line) It almost just popped out of nowhere. 02 – (Line) Well just over two years ago	1	Out of nowhere	1 – Disruption - <i>'It came from nowhere'</i>
Luke	I was at work, one day, and I just happened to notice my left calf was quite tense quite big just you know it's your own body something's not right.	01 – (Line) My left calf was quite tense and quite big. 02 – (Line) You it's your own body know something's not right.	2	It's not right	1 – Disruption - <i>'It came from nowhere'</i>

5.7 - Ethics

Ethical approval was obtained from the University of Birmingham University Ethics Committee (ERN_20-1729). All participants consented to the study with all data coded for anonymity purposes with the removal of identifiable features and the use of pseudonyms as shown in Table 5.4. Data was managed in line with the Data Protection Act that sets the EU General Data Protection Regulation regarding data storage, such as password encrypted computer (UK Government, 2018).

Participants were not financially incentivised to take part.

Table 5.4 - Participant Pseudonyms

Name	Age	Name	Age
Luke	34	Mike	54
Alfie	37	Will	55
Ryan	39	George	56
Harry	41	Henry	56
Chris	50	Arthur	70
Jake	54	Ben	71

5.8 - Findings

Data gathered from the completion of the semi-structured interviews led to the identification of three distinct narrative parts (Table 5.5). The parts were contextualised against hegemonic masculinity (traits/behaviours) and the HIMM framework to answer two proposed research questions, *what are men's perceptions of support within their non-cancer-related lymphoedema?* And *what are men's perceptions of masculinity within their non-cancer-related lymphoedema?*

Table 5.5 – Narratives Parts

Parts	Details
Disruption- “<i>It came from nowhere</i>”	Men retrace the beginning of their story in which neither themselves nor services were prepared or ready to support them.
Journey- “<i>Trying to live normally</i>”	Men try to live a normal life, by adapting to their lymphoedema by acquiring knowledge through experience, or available information sources.
Masculinity- “<i>I’ve lived with it all my life</i>”	Men and their masculinity were tied to the actions they undertook, to minimise its effect upon them and their perceived marginalisation

5.8.1 - Part 1 – Disruption – “*It came from nowhere*”

Men recounted the beginning of their experiences when the signs and symptoms of lymphoedema first manifested and are seen as the focal point of when their lives changed. The change itself can be seen as a disruption that triggered a series of events, with all men reporting similar experiences leading up to an eventual diagnosis. None of the men in the study had heard of lymphoedema or expected it to happen in their lives, which is exemplified by the words shared by Chris and Harry:

“It came from nowhere without warning and I had a severe bout of cellulitis, which hospitalised me for two weeks” (Chris)

“I can only remember when I got it in one leg, but I can’t remember how I got it in the second one. The first leg was a spider bite.” (Harry)

However, for some men, the development of lymphoedema was not obvious to them but was noticed by others close to them. Ryan and Will share their accounts

of other people noticing changes before they were aware of its presence or significance. This can signify the gradual nature of the condition, which men may have accommodated, by giving other reasons for changes, due to being unaware of lymphoedema.

“When I was 17, my mum's friend who was a nurse... noticed it” (Ryan)

“I first saw symptoms of lymphedema when I was 34 due to it being noticed by a friend of mine at a party” (Will)

Significance to men was around the unknown nature of what was occurring to them and how this would affect their lives. Chris shared his story of experiencing complications that led to him being in hospital for weeks. This reflects the wider concept that men were not prepared for the potential changes and vulnerability this may cause in their lives, as reflected by Mike:

“I didn't really know what I was dealing with and how potentially dangerous it could be” (Mike)

When men began to access services to establish the cause of their swelling, was a long process with varying levels of support. Whilst all men accessed some form of medical support, such as the GP, the eventual diagnosis took the form of eliminating other causes, as shown in the account by Ben:

“It then followed at least six months of many tests at the hospital to identify what the issue was” (Ben)

Not all men perceived they could rely on healthcare professionals to reach a diagnosis. Whether this related to a sense of vulnerability, there appeared to be a need to gain control through acquiring knowledge before speaking to a healthcare professional. This was seen more in those men aged in their 30s, as shown in the quote from Luke:

“I’d already done my own googling... it was potentially a deep vein thrombosis. I was adamant I was going to go in there and get a referral to the vascular team” (Luke)

When a diagnosis was reached it had a profound impact and even crisis for men which was not always recognised by healthcare professionals. The limited level of compassion for men and their situation is reflected in the way information was communicated which was neither tailored, nor person-centred as illustrated by Harry’s account:

“When I was in hospital I was basically told, yeah you got lymphoedema and a cellulitis infection...you’ve got it for life. There’s absolutely no way of getting rid of it, more or less just learn to live with it. You’re probably going to have antibiotics periodically each year, for the rest of your life” (Harry)

The limited ability to adapt to a person's needs, or specifically to what a man with lymphoedema may need to support them, is reflective of a one-size-fits-all approach as shown by Henry:

"To be honest I haven't had any help from anybody...you get given a leaflet"

(Henry)

Even when information is provided, the needs of men may exceed the ability of those supporting men. This reflects the need for continuing professional development but also access to the wider multi-disciplinary team within the quote from Ryan:

"It is a continuous journey trying to get the answers. Personally, I think that they could do more. If they had the right training...like diet, exercise" (Ryan)

Men experience disruption in their lives from the first signs and symptoms to when they receive a diagnosis. Their experiences vary, but what is a common account is a limited preparation and awareness of the significance this may have upon men. Both by men themselves and those in positions to support them. How men accommodate the changes to their health within their lives is discussed in the next theme.

5.8.2 - Part 2 – Journey – "Trying to live normally"

Men are trying to accommodate the changes in their health and to try to live what they perceive as a normal life. However, the journey men take in response to the changes in their lives is not linear, but one that requires them to challenge their

own held beliefs. Even if that challenge leads them to cause harm to themselves to avoid being considered different to other men, as shown in the quote by Ryan:

“Trying to live normally as a chef. I’d get wrecked [inebriated via alcohol]...I wasn’t thinking about my ankles...it actually gave me the mental capacity to not think about my legs” (Ryan)

Trying to maintain and perform earlier activities, or even occupations, was a first response by men. All men reported similar challenges as seen in the quote by Ben:

“It took time to make things work with all that I cannot do at the moment, due to the lymphoedema. At the start it was difficult, you put one little bit on top of another then all of a sudden you’ve got a massive problem. It has taken 11 years to get here” (Ben)

Equally, the response by men to continue with activities is intricately linked to who they are as a man. However, this also required them to accommodate the changes lymphoedema had upon their ability to fully engage in earlier activities, such as walking by Ben:

‘I still have my regular daily walk for about an hour, but no longer than that since 2017. In previous years, I’d enjoy driving out into the countryside and taking a packed lunch, rucksack, bottle of water and having a jolly good

tramp. I no longer do lengthy country walks, say two to four hours, due to it causing my leg to become painful and very warm' (Ben)

Despite some men accommodating the changes, there was a sense of loss at what they had been able to undertake before having lymphoedema. Other men considered the impact, as leading to them being in a weaker position, and altered how they perceived themselves, and what they wished to avoid from others, which is reflected in Mike's quote:

'I don't want to be seen as having a deficiency or a weakness. You want to rumble through it and come out the other side, and hope everybody's with you.' (Mike)

Coming out the other side showed the support men needed when dealing with lymphoedema. Other men acknowledged feeling overwhelmed and how those closest to them provided them with psychological support in the absence of formal services, as shown in the quote by Luke:

"I can get absolutely overworked about everything...really thankful that I had my partner..., to keep me level-headed. I really didn't know what I would have done without him." (Luke)

"I'm very fortunate I've got a very supportive wife, family and three sons."
(Will)

Whilst some men sought support from those closest to them. Others sought support through their self-reliance, due to acquiring knowledge from managing other long-term conditions that affected them. Thus, reinforcing a sense of independence, but also reinforcing who they are as a man, as seen within Ben's quote:

"I have a heart problem, I've survived, and it is typical that men will..." (Ben)

For several men having access to reliable information from experts enabled them to take control of their lives, and to develop their own skill set, as seen in the account shared by Mike:

"The lymphoedema specialist was the first person to give me an A to Z of it and tailored it for me." (Mike)

Men undertake journeys that vary from when they started and how they reacted to events within that period. Their behaviours and responses aligned with their perception of what is a normal life as a man, either to seek support from others or to rely on themselves. In both perceptions, men needed to acquire knowledge and experience to engage in the management of lymphoedema. The acquisition led some men to pursue behaviours that caused them harm, before adapting them to accommodate what they can undertake physically since having lymphoedema. Adapting led some men to perceive it as a loss from their original concept of being a man and what is a normal life. How their masculinity was affected by lymphoedema will be explored in the next part.

5.8.3 - Part 3 - Masculinity – “I’ve lived with it all my life”

Previous parts indicate how men accommodate changes in their lives that affect their ability to engage in certain activities. Whilst these are important considerations, how men perceive their masculinity is another aspect that was affected and changed by lymphoedema. What was apparent is not all men had reflected upon their masculinity until it was posed as a question, which proved challenging for some men, as within the quote by Arthur:

“My masculine image is one I can’t quite articulate because I’ve lived with it all my life.” (Arthur)

Even when men expressed their masculinity it was rooted in the physical changes that had occurred to them, and their expected roles. Their behaviours were in response to their perceptions of masculinity, but also the potential perceptions of others close to them, and others that intersect their lives. Leading men to take action in response, as seen within the accounts by Chris and Harry:

“My masculinity at first was affected when I had to put these stockings on every day. It was incredibly embarrassing that I was putting a stocking on in front of my wife.” (Chris)

“In terms of masculinity some men are like, why is that dude wearing long pants, he must be fucking baking. People don’t have that look on their faces, but I could imagine them saying it so it’s probably 90% in my head. I don’t

even like going to the gym now. I used to love my legs days. I don't even wear shorts at home. When I walk by a mirror I just freak out” (Harry)

Some men acknowledged the impact this had upon them. Others felt that the condition had either no effect or was harder for women compared to men, due to the aesthetic effects. Several men reflected upon their perceptions of themselves in the past to the time they engaged with the study. The quote by Alfie indicates his perceived changes in himself compared to others over ten years:

“I don't think it really affects me in that kind of cosmetic aspect to it. I think it's probably a harder condition for women to deal with than men to be able to disguise the issue. I'm able to wear long pants everywhere, and nobody says there's anything wrong with my leg. I think, if I got a 10 years earlier, it probably would have mentally affected me a lot more” (Alfie 37 yrs.)

Alfie's quote can indicate how men may change their perception of their masculinity over time. Equally, by comparing to others, such as women, men are using certain traits, such as stoicism to support themselves or to minimise the perceived impact of the condition within their masculinity. However, for some men, there is a need to hide perceived differences from other men and to continue to fulfil what is expected of them as a man. Men relying upon themselves caused increased levels of isolation and anxiety, as seen in the quote from Chris:

“On holidays when we would go swimming I would be covering up my leg with a towel. I would also wear baggy trousers rather than shorts. Certain activities were limited because I was scared of breaking the skin and getting an infection” (Chris)

Despite men’s concerns surrounding their condition, the majority of men did not share the presence of their condition beyond partners and close friends. The quote by Chris indicates the reasons why men may not choose to share lymphoedema with others:

“My wife bless her, she said, you know it's just a case of getting used to the new normal. That saying and those words have stuck with me ever since. The pre-lymphoedema version of me that was confident, social, healthy, and a fun guy. Took an absolute battering for the first two or three years,” (Chris)

Whilst men engaged with informal support, formal places were absent for men specifically to discuss their experiences, which perpetuates a marginalisation of them within lymphoedema care. Even when formal spaces are provided they are either not suitable or do not provide interaction with other men. This can amplify how their masculinity has been affected as seen in the quote by Henry:

“I was invited to a coffee morning support group, and it was basically all women talking about breast cancer. They seem to think it's a woman's only problem. It is more ignorance to the fact that men get lymphedema,” (Henry)

The absence of support groups for men, can perpetuate the invisibility of their needs, but also reinforce the need for them to rely upon themselves as men. Despite men acknowledging the impact lymphoedema has had on their lives and masculinity. Throughout the findings, masculinity, and its influences upon men, are a continual thread within the social fabric of society, despite its intangible nature.

5.9 - Discussion

The findings of this study, at the time it was undertaken, were one of the first to explore the perceptions of support and the effect lymphoedema has upon a man's masculinity. The interviews led to three parts being identified, that represent the temporal elements of the collective story of men within the article. From the beginning of their story to the present and how men perceive their future with lymphoedema. In the discussion, the findings will be explored within the theoretical concepts outlined in the theory section of this article and the wider literature available.

5.9.1 - Disruption – “*It came from nowhere*”

The present study found that men experience a disruption in their lives as a result of lymphoedema that was either gradually noticed by others or following complications. Whilst the physical manifestation of lymphoedema is to be expected (ILF, 2006). The significance of lymphoedema and whether this can represent a ‘life event’ mentioned within the HIMM framework is not clear (Evans et al 2011, p. 10). Despite, the possible link to lymphoedema, there is no definition as to what a life event entails and is left to individual interpretation, with only a tentative inference that ill health may be an event. Lymphoedema as an event, can lead men to undertake a ‘journey into the unknown’, in which they search for answers as to the origin and management of lymphoedema (Cooper-Stanton et al, 2022, p. 22). The unknown

origin and gaps in men's knowledge are seen within the study by McGarvey (2014) in which men had limited time to be prepared or adapt to a long-term condition they had not expected. Reactions by men can reflect the way lymphoedema has led to a disruption in the man's body as an 'object', but also in their 'social practices' within their demonstration of masculinity (Connell and Messerschmidt, 2005, p. 851).

Disruption is not mentioned specifically within hegemonic masculinity (Connell and Messerschmidt), but a life event (Evans et al., 2011) can be considered as a focal point in terms of 'biographical disruption' offered by Bury (1982, p. 167) that encompasses the disrupted masculinity in terms of identity due to a chronic illness. By men seeking answers, they are reacting to the disruptions and resulting vulnerability. Equally, seeking answers by men could be considered as asking for help, which is lower amongst men, and can be classed as 'feminine' (Courtenay, 2000, p. 1389). However, this is not seen within the data as men sought answers to gain an understanding of the origin of lymphoedema. This is reflected in the study by Bogan et al (2007, p. 219) in which men manage their perceived vulnerability through seeking answers which can function as a 'turning point'. To reach answers is not a linear process, with many men relying on 'serendipitous' encounters, due to limited access to services and the resulting delay in receiving a diagnosis, or support (Cooper-Stanton et al, 2022, p. 24). Delays, in obtaining a diagnosis have been noted as leading to negative reactions within the studies by Perera et al, (2007) and Watts and Davies, (2016) in which men reported increased anxiety and complications, due to delays in obtaining a diagnosis.

Multiple tests are common to eliminate other causes (Cooper-Stanton et al, 2022). Men reported needing to become their advocates to challenge those in positions of authority to gain access to support. Whilst this can be seen as the

beginning of a change within the man's 'gender hierarchy' that may lead to them becoming 'subordinate' within hegemonic masculinity (Connell and Messerschmidt, 2005, p. 834, 847), and even towards a self-perceived 'crisis' (Evans et al, 2011; 13). Whilst, this may explain overarching aspects, the work by Flurey (2018) with men and rheumatoid arthritis, may offer further insight about hegemonic masculinity. Flurey (2018) proposed three typologies, in which men may uphold, negotiate, or reject their hegemonic masculinity. Reflective of their work and in this article, initially men responded by attempting to retain their hegemonic masculinity, by using masculine traits and behaviours, such as assertiveness. Men upholding their hegemonic masculinity enables them to continue to express their gender, despite it being disrupted and altered from its original baseline (Flurey et al, 2018; Courtenay, 2009)

The use of these behaviours is in response to bodily changes but is also reflective of the limited awareness of lymphoedema, training and education that exists within medical and healthcare education (Schulze et al, 2018; Moffatt et al, 2003). Limited understanding of lymphoedema, undermines the significance lymphoedema has upon men, leading to a perceived disinterest or lack of compassion when healthcare professionals interact and communicate with men (Schulze et al, 2018). Limited recognition of the needs of men can signify a change in the gender hierarchy mentioned previously, but also a societal bias known as gamma bias that may perpetuate stigma (Seagar and Barry, 2020; Stangle et al, 2019). Gamma bias reinforces pre-held notions surrounding gender, such as men (Liddon and Barry, 2021), in which certain behaviours are expected and not questioned, such as expecting men to be self-reliant (Connell and Messerschmidt, 2005).

These expectations do not consider the loss men experience with changes in their health or perceived social status. Studies indicate the loss men experience due to lymphoedema (Cooper-Stanton et al, 2022), but is also shown within wider studies within long-term conditions (Flurey et al, 2018; Dale, 2015; Hamilton and Thomas, 2014). Loss can reflect a man's inability to produce what is expected within their hegemonic masculinity but is not specifically stated within the proposed hegemonic theory (Connell and Messerschmidt, 2005). Loss is noted in the HIMM framework (Evans et al, 2011; 1) and may help to expand what is meant by a life event, but it does not fully encompass the disruption men in the article reveal, or their perception of *'It came from nowhere'*.

5.9.2 - Journey – “trying to live normally”

Previously, the focus was upon the initial disruption men experienced, within this part is to consider how men accommodated lymphoedema. It is considered that a life event can lead to the 'define' and 'redefine' of individual masculinity (Evans et al, 2011; 10), but how this is achieved is not clear. The work by Flurey (2018, p. 122) may view this event as one in which men are 'trying to renegotiate masculinity'. The concept of change is present within hegemonic masculinity and is influenced by factors, such as 'time' and may also be 'intentional' (Connell and Messerschmidt, 2005, p. 846, 853). However, how men engage in change is unclear in the theory. Evans et al (2011;13) use the word 'transitions' but do not expand further, beyond a focus on 'career' or 'work-life' towards 'retirement'. Flurey et al (2018, p. 122) proposed typologies can offer possible explanations regarding the transitions men undertake by 'trying to renegotiate masculinity', which may align with suggestions of a 'New Norm' for men (Cooper-Stanton et al, 2022, p. 22).

Accommodating these changes, or a 'new version,' is to initially engage in past activities, before adapting or omitting them from their lives (Cooper-Stanton et al, 2022; 22). It has been suggested that men engaging in past activities use them as a means of establishing the boundaries and patterns that are present within their long-term condition, such as increased swelling of the limb due to certain periods of activity (Nixon et al, 2019; Deng and Murphy, 2016). The men in the study use these to gain knowledge through experience due to the absence of support from others with specialist knowledge. The ability to control or manage the condition can represent another way men can embody masculinity, as a 'social practice' to themselves and others, through mastery (Boulton, 2017; Connell and Messerschmidt, 2005). Whether this refers to what Courtenay (2000, p. 1388) suggests are 'behaviours and beliefs that people adopt simultaneously define and enact representations of gender', which help men to demonstrate masculinity is a possibility. Despite the potential wish for men to become experts in their condition, not all men approached this in the same way, revealing the differences that are present in masculinity (Connell and Messerschmidt, 2005).

The availability of support networks was seen as crucial by some men to support them with the changes in their masculinity. This reflects studies that have considered the positive outcomes partners can have upon men including greater social connectedness, such as friends and groups (Arnell, 2014; McKenzie et al, 2018). However, this has to be considered against men's perceptions about whether this is acceptable and does not undermine their masculinity. Arnell (2014) suggests it may involve men and those closest to them reframing support as strengthening their position as a man. Other men sought support from themselves, through repurposing existing knowledge used to manage existing conditions, which has been suggested

as an example of masculine capital (Arnell, 2014). Reframing and masculine capital, are not concepts used within the proposed theoretical concepts, but they provide insight into how men in the study perceive support.

5.9.3 - Masculinity – “I’ve lived with it all my life”

This part considers more closely how the condition affected men and their perception of masculinity. As mentioned previously life events can lead to change within a man’s perceived masculinity (Evans et al, 2011). Whilst change is noted in the theoretical concept of hegemonic masculinity and the HIMM framework, what is absent are details surrounding how men’s masculinities change, or adapt (Evans, 2011; Connell and Messerschmidt, 2005). Men did indicate the varying ways in which hegemonic masculinity is embedded within society and their perceptions, but also behaviours (Connell and Messerschmidt, 2005). Some men initially were not able to articulate their perception of masculinity with lymphoedema. All men eventually referred to the physical expectations of hegemonic masculinity, such as physical strength and being robust (Evans et al., 2011; Connell and Messerschmidt, 2005). The difference in what they expected from themselves as men, was emphasised when they referred to past sports activities or the embarrassment of their appearance. Despite, physical deterioration being expected within a man’s life course (Evans et al, 2011), the inability to fully engage in past activities, or the effect lymphoedema had upon their appearance, illustrates a potential shift in their gender hierarchy and status (Courtenay, 2009). Equally, concerns about their appearance are in opposition to what is expected of masculinity, or a ‘real’ man, and whether these are more feminine concerns (Courtenay, 2009, p. 16). Studies indicate the importance of appearance for men, that are used within their projection of

masculinity, with physical changes indicating vulnerabilities that have affected their interactions within their social world (Nixon et al, 2018; McGarvey, 2014).

Whilst these were the concerns of some men, regarding physical ability and appearance, other men denied that lymphoedema had any impact upon them. This may reflect a man's use of 'stoicism' (Evans et al, 2011, p. 12) to deny 'discomfort' and the ensuing association with feminine 'characteristics' (Courtenay, 2009, p. 16). Alternatively, men may be undertaking aspects of 'negotiating' their hegemonic masculinity thus leading to varying responses by men (Flurey, 2018, p. 122). Men in the study reported it took them years to reach a point of accommodating changes in their lives with lymphoedema, which is seen in studies in this area (Cooper-Stanton et al, 2022). This is reflective of the concept that hegemonic masculinity may alter over time (Connell and Messerschmidt, 2005). Some men hide their condition which may lead to them becoming 'marginalised' (Connell and Messerschmidt, 2005, p. 844). Whilst, other men shared their experiences and challenged, or even rejected the expectation of hegemonic masculinity with the support of partners (Flurey et al, 2018).

The differences in approaches taken by men may reflect the notion of social connectedness, in which partners are relied upon in 'private' for emotional support, whilst other men and friends serve a more 'instrumental' support in terms of practical help (McKenzie et al, 2018, p. 1248, 1255). However, what was evident in the study was the limited access to other men with lymphoedema and specific support groups, which exacerbated the marginalisation men perceived in being diagnosed with lymphoedema. Access to 'peer support' is seen as a fundamental matter that needs to be addressed, to support men whose masculinity has been affected by lymphoedema (Cooper-Stanton et al, 2022; 23). McKenzie (2018) notes that when

men interact with each other it can have positive benefits. However, this does depend on the dynamic of the group so that men are automatically welcomed, due to a lack of 'in-group' bias that can be present within men-only groups (Ríos-González et al, 2021, p. 2018; Rudman, 2004).

Undertaking this study led to an increased understanding of how men respond to lymphoedema through the support available and the effect on their masculinity. From the disruption caused at the beginning, and how men accommodate these changes, both within their lives and masculinity. Whilst certain notions of hegemonic may be challenged, such as help-seeking at the beginning. What is present is how hegemonic masculinity is present and its influence upon men. Acknowledging its presence is to begin a discourse around men and developing an equitable and holistic service provision but needs to extend to policy development following the UK's men's health inquiry.

5.10 - Strengths and Limitations

The current study has attempted to answer specific questions related to how men perceive support around their condition, but also the notion of masculinity with lymphoedema. Exploring these specific areas adds further insight into men diagnosed with non-cancer-related lymphoedema, due to the paucity of literature and lack of application of hegemonic masculinity theory. Exploration within this specific area has been enhanced using narrative inquiry and the use of linguistic narrative analysis (Gee, 1991), which is absent from the existing literature in this area. Examining the data through different theoretical lenses, and the use of the chosen methodological approach increases the credibility, dependability and even transferability of these findings to other similar groups. The ethnicity (White) and age being over 50 years is consistent with other research both national and international

within developed westernised countries as being representative of men with lymphoedema.

The possible limitations of the study can relate to the sample and the number of participants being twelve in total. Despite these possible concerns, the number of men in the article reflects similar studies in this area, in terms of diversity and participant numbers (Cooper-Stanton et al, 2022). Whether the findings are seen within a larger and more diverse sample of men will have to be the subject of future research. The transferability of the findings outside the UK (all four nations) and the Republic of Ireland needs to be considered against a country's healthcare provision and access, but also the cultural context and differences within other countries. Due to most men being White, with 10 identifying as heterosexual and 2 as being gay, the ability of the study to be applied beyond this group is limited. Nevertheless, the study indicates the perceptions of support and the impact lymphoedema has on their masculinity.

5.11 - Conclusion

This study focused on men diagnosed with non-cancer-related lymphoedema and their perception of support and masculinity. The study found that men experience a protracted period in obtaining a diagnosis of lymphoedema, with limited support offered to them, due to a lack of understanding and appreciation of the significance the condition had upon them. In response men use their resources supported by hegemonic characteristics, such as independence, to locate information, and to become their own advocates. Partners form the main support network for men and represent their main source of support both psychologically and socially. The absence of other men to function as role models led men to initially focus on their deficits rather than strengths. Negotiations within men's masculinity

take years, due to reestablishing their identity within a new social world, that is reflective of their perceived losses, and what remains within their control. By considering the experiences and negotiations men undertake to develop services that are gender considerate, thus providing men with services that are equitable to their needs and context.

5.12 - Chapter Contribution

Chapter 5 has added to the existing literature and findings outlined in Chapters 2-4 by answering the remaining two sub-questions outlined in Chapter 1. *What are men's perceptions of support within their non-cancer-related lymphoedema?* And *What are men's perceptions of masculinity within their non-cancer-related lymphoedema?* The application of narrative inquiry outlined in Chapter 1, led to the gathering of data through the completion of twelve online semi-structured interviews. Analysis of the transcripts used narrative linguistic analysis within the creation of three parts, 1) disruption, 2) journey and 3) masculinity. The findings aligned with Chapters 2-4, in which men's masculinity aligned with the concept of hegemonic masculinity and was disrupted due to lymphoedema. That led men to use masculine traits and behaviours to support themselves as a form of masculine capital in response to lymphoedema and within the negotiations of their masculinity. Chapter 5 is the final study out of three undertaken across this thesis. It represents the final part in the exploration of men's perceptions of non-cancer-related lymphoedema. Chapter 6 brings together Chapters 2-5 within a general discussion of both the findings and their implications.

6.0 - Chapter 6 - General Discussion

6.1 - Chapter Rationale

This Chapter brings together the findings across Chapters 2-5. Chapter 5 was the final study that was used to answer the overarching research question outlined in Chapter 1. The two sub-questions within Chapter 5 and outlined in Chapter 1 were answered within the three parts created through narrative linguistic analysis. The first two parts answered the first question, *what are men's perceptions of support within their non-cancer-related lymphoedema?* Disruption was a concept that was present across Chapters 2-5 in varying degrees. In Chapter 5, findings focused on 1) disruption when men first noticed the swelling in their limbs and the subsequent period in which they attempted to obtain a diagnosis. Limited knowledge, support, and understanding offered by those in positions of power, such as healthcare professionals was perceived negatively by men that fed into their disrupted masculinity. The second part indicated 2) the journey men undertook to accommodate lymphoedema being present in their lives, in terms of their reactions but also the development of strategies over several years. Strategies involved men using traits and behaviours that may or may not be associated with hegemonic masculinity as a form of masculine capital to give them control and confidence when managing lymphoedema. The final part 3) masculinity provided further insight into how men aligned to the proposed hegemonic masculinity theory, but also provided nuances in the perceptions men held.

The findings of the final Chapter align with Chapters 2-4 which noted the disrupted masculinity men perceive due to lymphoedema. Coupled with men responding by using masculinity traits and behaviours as a form of masculine capital within the renegotiations of their masculinity. Renegotiations may or may not align

with hegemonic masculinity due to the presence of multiple masculinities that exist within society and amongst men. This Chapter revisits key aspects of the thesis including the proposed questions and how they were answered within Chapters 3-5. It also outlines and discusses the implications within 1) policy, 2) practice, 3) theory, and 4) research and considers the strengths but also weaknesses within the thesis.

6.2 - Thesis Questions

The thesis was a qualitative exploratory study that used narrative inquiry to answer the overarching question, what are the perceptions of men diagnosed with non-cancer related lymphoedema? The question was answered through the four sub-questions: 1) how do men perceive engagement within their self-management of non-cancer-related lymphoedema? (Chapter 3), 2) how do men perceive their non-cancer related lymphoedema in their daily lives (Chapter 4), 3) what are men's perceptions of support within their non-cancer related lymphoedema and 4) what are men's perceptions of masculinity within their non-cancer related lymphoedema (Chapter 5).

Before undertaking the exploratory studies outlined in Chapters 3-5, a scoping review was undertaken. The scoping review established the coverage and focus of the existing evidence at that time regarding the experiences of men with lymphoedema and was a precursor to the systematic meta-aggregation review approach offered by JBI (Lockwood et al, 2020). The systematic review (Chapter 2) and the findings within it, suggested men experience changes within their lives, such as physical and relational, following the development of lymphoedema. It was noted men accommodated changes in their health through varied approaches, such as strategies, and forming a new baseline in what they perceived as normal. There was no consideration of masculinity explicitly within the included studies.

The review noted the paucity of literature that had focused upon men specifically and solely with non-cancer-related lymphoedema and masculinity. In the absence of specific studies on men, this supported the exploration of the thesis questions stated above, with the findings from the review to inform Chapters (3-5). Equally, the absence of the use of narrative inquiry within the qualitative approaches

indicated within the review supported this method as an alternative approach in the exploration of men's experiences. A summary of the findings collectively across the thesis is shown in the next section.

6.3 - Summary of Findings

As outlined above a systematic review was undertaken that identified no other reviews had focused upon the experiences of men with lymphoedema and specifically non-cancer related lymphoedema at the time of this thesis (Chapter 2). The majority of the studies 19 out of 22 within the systematic review (Chapter 2) were performed outside of the United Kingdom (UK), such as Australia, the USA, and Europe (Frid et al, 2006; Nixon et al, 2018; Stollendorf et al, 2016). Despite the insights these studies provided, only one out of twenty-two studies focused solely on men and their experiences with cancer-related causes of lymphoedema (Michael et al, 2019). Men were the smallest number of participants in sixteen out of twenty-two studies included in the review (Chapter 2), with a combined sample size of 30% (N=182) across the studies compared to women of 70% (N=425). Equally, the male and female narratives in several studies were merged into a singular account of their experiences, limiting the nuances that can be present within individual accounts by men (Cooper-Stanton et al, 2022).

When reviewing the application of theory within these studies (Chapter 2) none of the studies applied or considered masculinity or gender theory. The main theoretical concepts applied to the experiences of men were biopsychosocial (Tidhar et al, 2018), social construction (Meiklejohn et al, 2019), hope-based theory (Hamilton et al, 2016), and adaptation theory (Maree et al, 2019). The absence of alternative theoretical concepts, such as hegemonic masculinity or multiple masculinities, limits the exploration as to how men engage in their health, especially

within lymphoedema and within the wider political landscape of men's health (UK Parliament, 2023; Robertson and Baker, 2017). Additionally, none of the 22 studies, applied narrative inquiry as a methodological approach, with the majority applying a qualitative approach (Watts et al, 2016), phenomenology (Williams et al, 2004), or mixed methods (Stolldorf et al, 2016). The absence of alternative forms of methodological exploration of men with lymphoedema supported the need for research completed as part of this thesis. (Chapters 3-5). Four key findings were identified in the review that illustrated how men may respond to lymphoedema, 1) The new norm, 2) the journey into the unknown, 3) access, access, access, and 4) personhood. Forming a new norm was undertaken through the journey men undertook due to the presence of lymphoedema in their lives. The journey included trying to gain access to services that addressed their physical needs but did not address their psychological or relational needs. Overall, the systematic review provided insight into the literature that supported and informed the proposed research questions.

6.4 - Men's Experiences of Lymphoedema

Therefore, to answer the gaps in the literature, led to a three-stage sequential qualitative approach in the form of an online survey, solicited diary, and semi-structured interviews (Chapters 3 to 5). The exploration of these areas brought about a greater understanding of the perceptions of men with non-cancer-related lymphoedema. The findings from Chapters 3 to 5 demonstrated that all participants were affected by the development of lymphoedema as a life event within the HIMM framework (Evans et al, 2011), which challenged their pre-held masculine identity as a self-identified disruption event (Bury, 1982). Men in the findings demonstrated and used behaviours associated with hegemonic masculinity (Connell and

Messerschmidt, 2005) to varying degrees either initially or at different points in their life as a response to what is termed as disrupted masculinity. The use of these traits can be partially seen in the work of Flurey et al (2018) in which men engage in certain practices when managing the impact of a long-term condition. Disrupted masculinity encompassed the physical, psychological, and relational effects of lymphoedema. This fed into men perceiving themselves as being vulnerable including the perceived stigma men associated with having lymphoedema.

The notion of disrupted masculinity resonated with the proposed concept of 'gender scripts' and even the presence of 'disrupted hegemonic scripts' (Spector-Mersel, 2006, p. 79). The use of behaviours and traits by men in the thesis was equally influenced by their concept of masculinity due to an acknowledgement that multiple masculinities exist that go 'across persons' but also 'within persons' (Spector-Mersel, 2006, p. 68). Hegemonic masculinity coexists with other masculinities that are influenced by social class, and race as examples, with each one potentially having a different level of status (Yang, 2020; Spector-Mersel, 2006). While 'within persons' includes masculine styles that are accepted or perceived as being subordinate to hegemonic masculinity (Evans et al, 2011; Spector-Mersel, 2006, p. 68). Subordinate masculinities as noted in Evans et al (2011) and Yang (2020) were present in the thesis at varying points such as George who was 56 years expressing the impact his lymphoedema had upon him as a gay man in Chapter 3 page 119. For example, black and gay men, are cited as experiencing poorer health outcomes compared to other men, such as heterosexual and white men (Evans et al, 2011). Whilst this may be present as a subordinate masculinity, it also signifies the different masculinities that are present within it (Connell and Messerschmidt, 2005). For example, Luke as a gay man speaks about publicly

talking about his condition and how his relationship supports him in Chapter 4 pages 148 and 151. This may explain why there are differences in the way traits and behaviours are presented.

As mentioned in the findings, some men continued with activities, such as sports, while others withdrew. Others explicitly shared their condition with others, such as one gay man who initially kept his condition hidden and then chose to share it through social media, thus challenging traditional interpretations of hegemonic masculinity. Variability in men's responses to lymphoedema indicates there is a diverse range of nuances related to interpreting masculinity that may or may not encompass hegemonic masculinity (Yang, 2020; Connell and Messerschmidt, 2005), but dependent on how men form their masculinity over time (Evans et al, 2011). Time as a factor reflects the concept that masculinity is not a fixed point in time nor a single concept but one influenced by events that occur across a man's life course (Evans et al, 2011; Connell and Messerschmidt, 2005). It was recognised men recruited as part of research undertaken for this thesis appeared to use masculine capital, such as masculine behaviours, and/or support networks in response to the effects of lymphoedema when shaping their masculinity. Arnell's (2014) study supports the findings of the thesis in terms of masculine capital and the involvement of spouses or partners in their health. While the study by Flurey (2018) does not explicitly mention masculine capital, parallels can be drawn from their proposed three typologies especially the renegotiation of masculinity in men diagnosed with rheumatoid arthritis. Throughout the findings of this thesis, lymphoedema affected men's perceptions of disrupted masculinity, vulnerability, and the renegotiations within their masculinities. The findings of Chapters 3-5 are discussed below.

In Chapter 3 the question focused on *how men perceive engaging in self-management of their non-cancer-related lymphoedema?* (Chapter 3). The three themes created from the survey data and analysis indicated how lymphoedema affected men across their psychological, physical and support networks within their self-management.

Psychologically men experienced vulnerability due to a loss of their perceived masculine identity (Charmaz, 1983; Demain et al., 2015). A loss of masculine identity within the theoretical concepts of hegemonic masculinity and the HIMM framework was not stated, and neither was the term disrupted masculinity (Cooper-Stanton et al., 2022; Evans et al., 2011; Connell and Messerschmidt, 2005). However, changes in masculinity related to health, such as long-term conditions, coupled with social determinants, such as sexuality or ethnicity, can lead to a perceived inferiority of men to other men who do not have these restrictions (Yang, 2020; Evans et al., 2011). Loss in masculinity due to physical ill health, such as prostate cancer was noted in the HIMM framework by Evans et al (2011), which has similarities to the study by Michael et al (2016) in which men experience a loss of masculinity and control in their lives. Men in the thesis perceive similar concepts of loss that made them feel “*worthless*” at different points in their lives, which led some to withdraw from activities that gave them social connectedness, such as visiting the gym. Men in the thesis responded to disrupted masculinity by men using associated traits and behaviours of hegemonic masculinity to different degrees that altered over time, such as stoicism or withdrawal. Some men stated they “*learned to cope*” whilst others indicated that they had changed, as their answers would have been different if it had been closer to their *diagnosis*. Flurey et al (2018) study considers these changes as indicating a change in the perceptions men have about their masculinity

in which they move between given points of retaining or renegotiating their masculinity.

Men equally sought physical control over their lymphoedema when they performed self-management. Despite men noting that lymphoedema and its presentation changed each day. Some men tested their boundaries of endurance that align with the perceived 'idealized or hegemonic version of masculinity' (Evans et al, 2011, p. 12). Whilst others sought to minimise possible complications, which is similar to the findings in the study by Flurey et al (2018) but may be a response to changes in their 'gender scripts' and the production of masculinity (Spector-Mersel, 2006, p. 79; Connell and Messerschmidt, 2005). While men used traits and behaviours, such as self-reliance within their self-management, they also used it within the back-and-forth negotiations within their hegemonic masculinity and other masculinities and as a possible form of masculine capital (Flurey et al., 2018; Arnell, 2014). Studies have indicated that the use of self-reliance can have both positive and negative effects on men (Baker, 2018; Zanchetta et al, 2017). Either leading to poorer mental health outcomes (Baker, 2018; Zachary et al, 2017) or improved outcomes by learning from other men. In their literature analysis, Zanchetta et al (2017) highlighted the challenges Canadian men face when dealing with ill health, both physically and psychologically, about their concept of masculinity. This often results in men either resisting responsibility for self-care or engaging in it with limited knowledge, due to a lack of support networks. Consequently, some men perceive a worsening of their condition as an internal motivation to seek understanding and actively reduce its burden by acquiring knowledge and accessing support services. Self-reliance can be perceived as a component of masculine capital, as discussed by Arnell (2014),

supporting men in affirming their perceived masculinity through their behaviours and the acquisition of knowledge and skills.

Masculine capital as a concept is not mentioned or applied in the proposed theories of hegemonic masculinity or the HIMM framework but may be present nonetheless in the broad range of diverse masculinities that exist. The use and accruing of masculine capital in the thesis were based on the man's perception of their masculinity to hegemonic masculinity, but also upon the type, availability, and acceptance of support networks (Yang, 2020; Arnell, 2014). Wilde's (2020, p. 313) study explored masculinity within myalgia encephalomyelitis (ME) which led to the suggestion that men embody a 'dual identity', first as a man and second as a man coping with a chronic illness. Wilde's (2020, p. 313) findings noted the variation in men's 'adjustments, assimilation and acceptance', which has been noted in the data presented in this thesis too, in which men are at different points of adaptation despite being similar age and diagnosis, such as in their 30s. A key difference in thesis between two men in their 30s was the time from diagnosis to participation in the study, by which one man was continually addressing challenges associated with his condition while the other indicated he had adapted to his lymphoedema. The study by Flurey et al (2018) may explain the changing perception and negotiations of masculinity, but equally, the difference may be due to the presence of multiple masculinities (Yang, 2020). Understanding the concept of multiple masculinities sheds light on the various ways men navigate their health conditions. For instance, Evans et al. (2011) propose that different masculinities, including subordinate masculinity, can influence how men respond to their condition and ultimately affect their health outcomes. This concept acknowledges earlier work by Connell and Messerschmidt (2005) that focused upon hegemonic masculinity but also the diverse

masculinities that are present in society. This suggests that men in the thesis may approach their health challenges from diverse perspectives shaped by societal expectations and personal experiences, underscoring the complexity of masculinity's role in health behaviours and outcomes.

Furthermore, some men used support networks within their self-management in two ways, either emotionally such as when they felt overwhelmed or instrumentally, such as physically through applying compression hosiery from spouses and partners. Varied responses by men, indicated the different points of renegotiation they may be experiencing within their masculinity (Flurey et al, 2018), and whether support networks were perceived as enabling them to produce or erode their perceived masculinity, such as within the study by Wilde et al (2020) and Arnell, (2014) Equally shame or stigma implicitly surrounded the acceptance of support to varying degrees within the findings. Wilde et al (2020) noted in their study the potential stigma related to a long-term condition, such as ME, that may exist both internally and externally which can create a barrier to receiving support. Two men in their 50s in the thesis shared very different perceptions of support, with one accepting the support of their wife and children, while another man disliked that he relied “*heavily*” on his wife. Differences between the men included not only having children or not but also whether they were employed. Thus, indicating possible differences in perceptions of marginalisation by one man compared to the other (Evans et al, 2011) and how they negotiated that change in their lives (Flurey et al, 2018). Further consideration of the way that men engage with lymphoedema in their daily lives is outlined in Chapter 4.

Chapter 4 focused on *how men perceive their non-cancer-related lymphoedema in their daily lives?* One main theme and two subthemes were

created. Vulnerability was the main theme, with the two subthemes encompassing that men perceived lymphoedema as a constant reminder of the changes in their lives, with men seeking solace in self-management routines.

Vulnerability focused upon the effect of limited public awareness of lymphoedema that extended to healthcare professionals and the impact this had upon men. Limited awareness among the public and healthcare professionals was considered an area of concern that has spanned over 20 years (Schulze et al, 2018; UK Parliament, 2013; Moffatt et al, 2003). All men sought support from healthcare professionals, such as consultants, which can be perceived as being contrary to limited help-seeking by men (Robertson and Baker, 2017). It was considered that limited awareness created a perception of marginalisation and vulnerability amongst men that impacted upon their masculinity and its demonstration which was varied across the men in the thesis (Evans et al, 2011; Connell and Messerschmidt, 2005). One man in his 50s in the thesis experienced the impact of limited awareness when he was stopped by police to explain why he was walking like he was “*drunk*” due to having a larger lower limb which caused him distress. As mentioned in the study by Hackett et al (2020) disability discrimination can lead to increased levels of depression and psychological distress. Another man in his 30s concealed his condition by avoiding group activities due to his perception that those around him could not “*relate*” to him. Wilde (2020, p 315) noted concealment as one way men can continue to appear ‘emotionally and physically strong’. Despite the concerns of limited awareness, the same men also shared their conflict when public attention was drawn to the condition, such as in a newspaper article. While another man shared their condition publicly to provide a positive perception of themselves with lymphoedema as a gay man. This approach can be seen as challenging hegemonic

masculinity which is perceived as being heteronormative compared to gay masculinities being considered subordinate to them when considering hierarchical concepts within multiple masculinities (Yang, 2020; Evans et al, 2011).

The thesis considers disrupted masculinities as potentially explaining the various responses and adaptations undertaken by men in their lives, particularly in response to long-term health conditions, as discussed by Flurey et al (2018). This concept, however, is not explicitly addressed within hegemonic masculinity or the HIMM framework (Evans et al, 2011; Connell and Messerschmidt, 2005). Despite disrupted masculinity as a concept not being explicitly mentioned, the theories do consider multiple masculinities and how they may interact with men and their varied responses (Evans et al, 2011; Connell and Messerschmidt, 2005). As mentioned previously, concepts of disrupted gender scripts including hegemonic can lead to varied responses by men (Spector-Mersel, 2006). Additionally, consideration of the work of Bury (1982) within biographical disruption, and the three hegemonic typologies offered by Flurey et al (2018) provided means to examine the findings further. The three typologies of retaining, renegotiating, and rejection were used to explain why men in the thesis may conceal their lymphoedema (retain masculinity) or share their condition (renegotiating masculinity). Equally men in the thesis and within the study by Flurey et al (2018) move back and forth between the typology points over a period thus indicating the bi-directional approach men undertake.

Over this period men referred to lymphoedema as being a constant reminder of a change that took place in their lives, which was considered a form of disrupted masculinity. Equally, the change itself indicated that men and their masculinities had altered as an effect of having a long-term condition which resonated with the study by Flurey et al (2018). Changes in their health challenged their perception of

masculinity that may have aligned with hegemonic ideals of health and strength (Connell and Messerschmidt, 2005). The challenges within their masculinity were perceived as loss that required time to navigate and adapt as seen in the studies by Wilde et al (2020) and Dale (2015). Lymphoedema was perceived as drawing attention to a deficit in their masculinity (Viehoff et al, 2016) or loss (Evan et al, 2011), such as one man in the thesis who was in his 50s not being able to engage in activities with his son due to physical restriction thus impacting his role as a father. Not all men perceived it in this way, with one man in his 30s publicly stating he was to “*fight*” the condition with support from his boyfriend. The thesis findings suggest lymphoedema is a potential life event within the HIMM framework (Evans et al., 2011), that is affected by the man’s perception of masculinity. Due to a limited definition of a life event, the work of Bury (1982) within long-term conditions was used to define a life event as a biographical disruption, thus suggesting that lymphoedema can be represented as one, due to it being a chronic illness.

Whilst self-care routines had the potential to be perceived as being a reminder of changes in their lives. Zanchetta et al (2017) literature review illustrated the way men may positively or negatively perceive self-care and even avoid it. Men in the thesis viewed self-care routines as supporting them in response to the vulnerability and disruption with some men perceiving lymphoedema management as a potential burden. In the systematic review of long-term conditions by Demain et al (2015, p. 8) ‘treatment burden’ was noted as being present that may or may not lead to adaptive or non-adherence to management approaches. Burden as a concept, in the thesis, was perceived by men in varying terms from the effort to put on compression stockings or the need to adjust compression stockings during the day. Routines equally provide men with the ability to produce or express their masculinity (Connell

and Messerschmidt, 2005) by trying to control the condition and use associated traits, such as self-reliance to 'compensate' for changes they perceived in their masculinity (Courtenay, 2009, p. 21). Across the age groups, men were also concerned with the progression and complications of the condition, such as infections that can impact their lives further. Equally, these concerns and the use of compensatory approaches can be perceived as men renegotiating their masculinity Flurey et al., (2018) by using masculine capital, such as traits and behaviours as outlined in Chapter 3 to facilitate movement. Whilst masculinity was considered within the findings of Chapters 3-4, it was specifically addressed within Chapter 5 and the perception of support.

Chapter 5 focused on answering two questions, *what are men's perceptions of support within their non-cancer-related lymphoedema?* And *what are men's perceptions of masculinity within their non-cancer-related lymphoedema?* Three parts were created that illustrated the stories men tell. The first two parts, disruption and journey aligned with the question posed about support, with the final part focusing specifically on men's perceptions of masculinity.

Disruption formed the beginning of the story men told about their experiences and perceptions of lymphoedema. Lymphoedema represented a potential life event within the HIMM framework (Evans et al., 2011) that affected their masculinity negatively due to its impact upon the 'social practices' that men use to express their masculinity (Connell and Messerschmidt, 2005, p. 851). The type of social practice employed in response to a disruption in their lives was also dependent upon the masculinity they perceived and may explain the variable responses by men beyond hegemonic masculinity (Yang 2020; Evans et al, 2011). Disruption as a concept was not explicitly mentioned within the HIMM framework or hegemonic masculinity

(Evans et al., 2011; Connell and Messerschmidt, 2005). In its absence, men perceived that the manifestation of lymphoedema was a focal point of change in their lives, thus aligning to the concept of 'biographical disruption' (Bury, 1982, p. 167) with this extended to encompass masculinity with the creation of the term disrupted masculinity. As mentioned in Chapter 4, men sought support from healthcare professionals to establish why their limb was swelling. Men who sought answers from healthcare professionals can be considered a form of help-seeking behaviour which is contrary to hegemonic or traditional masculinity (Courtenay, 2009; 2000). Zanchetta et al.'s (2017) study emphasises the importance of considering men's engagement with their health within the context of their cultural reference points and historical influences. Understanding the cultural, temporal, and contextual factors in men's lives can help elucidate differences in help-seeking behaviours among men (Evans et al., 2011; Connell and Messerschmidt, 2005). The findings in the thesis may also reflect Wildes et al (2020) proposed dual identities that resonate with the study by Flurey et al (2018) regarding changes in men's masculinities. Similarly, men may either embrace or reject regional or national ideals of hegemonic masculinity, a phenomenon described as 'adopting' or 'distancing' themselves (Connell and Messerschmidt, 2005, p. 841). This can influence their willingness to seek help. Some men may align with a locally adapted version of masculinity, prevalent within their family or community, which actively supports help-seeking behaviours (Yang, 2020; Connell and Messerschmidt, 2005, p. 841). In Arnell's (2014) study, local influences including spouses and partners played a role in improving help-seeking behaviours by challenging their pre-held beliefs of masculinity. Similarly, Zanchetta et al (2017) found that local cultural contexts can either support or discourage forms of help-seeking.

Help-seeking by men in the thesis led to multiple assessments, investigations and tests being undertaken by different healthcare professionals to establish the cause of their oedema. Not all men received a diagnosis immediately leading to years of uncertainty, distress, and increased complications, such as infections. Knowledge and education about lymphoedema within the causes and management are the leading reasons for delays in people obtaining a diagnosis (Schulze et al, 2018; Moffatt et al, 2003) with men in the study offered limited support when adapting to a change in their health. Men responded by using their skills, knowledge, and to some degree masculine behaviours to independently support themselves (Courtenay, 2009; Connell and Messerschmidt, 2005). Men in their 30s within the thesis engaged in actively researching their situation and swelling before a consultation to become their advocate, compared to men in their 50s and above who did limited or no research. Zanchetta et al, (2017) review indicates the way men perceive help-seeking can be either supporting them or their masculinity or eroding it as noted in the study by Wilde et al (2020). The differences within the approaches taken by men, aligned with the concept of hegemonic masculinity that it will change over a period (Connell and Messerschmidt, 2005), but it may also reflect its renegotiation as an outcome of lymphoedema (Flurey et al, 2018), or the presence of different masculinities (Evans et al, 2018).

When men obtained a diagnosis of lymphoedema their journey continued by embodying the 'social practices' of masculinity mentioned previously (Connell and Messerschmidt, 2005). What followed for some men was the need to continue with what they had undertaken before lymphoedema by 'retaining hegemonic ideals', despite it causing them physical and psychological harm (Flurey et al., p. 118). Flurey (2018) associated this approach with the preservation of masculinity among

men, while Wilde et al (2020, p. 313) perceived it as a protective measure, integral to their 'adjustment, assimilation and acceptance' within their masculine identity (Wilde et al, 2020, p. 313). One man in his 40s, as recounted in the thesis, persisted in his occupation despite its detrimental effects on his lymphoedema. This led to resorting to substances as a means of coping with the psychological and physical toll it imposed. Men in the thesis used the period of engagement in past activities to develop new knowledge and experiences (Cooper-Stanton et al., 2022), which may initially align with the social practices within hegemonic masculinity and associated behaviours that included independence and self-reliance (Courtenay, 2009; Connell and Messerschmidt, 2005). While not all men continued to cope with activities alone, some sought support from spouses, family members or partners. This variation in coping strategies, with some men prioritising support from close relationships. suggests a spectrum in alignment with hegemonic masculinity and reflects diverse presentations of masculinities and the importance men may place on alternative coping methods (Evans et al, 2011). It was acknowledged in the study by Arnell (2014) that partners and spouses are the main sources of support for men up to 80% compared to women at 49%. Men engaging with partners or spouses were found to play a role in the renegotiation of their masculinity as discussed by Flurey et al. (2018), and in the accumulation of masculine capital, as noted by Arnell (2014). Renegotiations provided men with an opportunity to rethink, reconsider, or even diversify their understanding of masculinity in their lives.

When men were asked directly about their perception of masculinity with lymphoedema proved to be challenging initially for them to explain. Eventually, men articulated their perceptions through their chosen words and the behaviours they described, such as self-reliance and stoicism throughout the interview that aligned

with certain aspects of hegemonic masculinity (Courtenay, 2009; Connell and Messerschmidt, 2005). Furthermore, the thesis delves into the varied and nuanced engagement of men in stoicism, showcasing a diverse range of masculinities and their evolving expressions. This exploration sheds light on the dynamic nature of masculinity, highlighting shifts and adaptations over time. Moreover, the study reveals how men's reliance on support networks ebbs and flows in response to changes in physical appearance, underscoring the vital role of social connections in their lives. Similarly, some men perceive a compromise in their projected masculinity due to negative associations with physical aesthetics or the pressure to meet idealised physical standards. Nixon et al (2018) study involving men with head and neck cancer with lymphoedema, the aesthetic outcomes following treatment affected them negatively psychologically and physically. Aesthetic considerations have often been perceived as being more a feminine consideration (Courtenay, 2000; 2009) that may challenge their pre-held masculine 'identity' (Connell and Messerschmidt, 2005, p. 851), but equally this may indicate a wish by men to uphold a certain image of masculinity (Flurey et al, 2018). In response, some men used strategies that drew attention away from their perceived weakness, such as clothing that was loose as the swollen limb challenged their ability to produce and embody social practices of masculinity, such as the body being an 'object' of strength (Connell and Messerschmidt, 2005, p. 851).

In their study, Wilde et al (2020) observed that men often felt compelled to conceal their health issues initially, driven by a desire to uphold an image of physical strength. However, a notable finding from the thesis was that a minority of men chose to openly acknowledge the impact of their condition on their physical well-being. For instance, individuals in their 30s and 50s were among those who bravely

shared their experiences of how the condition had affected them physically. By acknowledging what might be perceived as vulnerabilities, these men deviate from traditional ideals of hegemonic masculinity (Evans et al., 2011). This suggests a renegotiation or adaptation of their masculine identities (Flurey et al., 2018), potentially indicating a shift towards more inclusive and nuanced expressions of masculinity in response to personal experiences and societal expectations. Shifts or changes within men's masculinities indicate s similar to the back-and-forth movement with the three typologies within the study by Flurey et al (2018) from a point of retaining to renegotiating masculinity. Furthermore, masculine capital in the form of support networks was used by some men in the back-and-forth changes within their masculinity but was varied due to the type of relationship. McKenzie et al (2018, p. 1248) study elucidated the diverse ways men express themselves in society, to gravitate to emotional support in 'private', such as spouses or partners to preserve their masculine image. Conversely, other men sought more 'instrumental' forms of support, such as participating in support groups (McKenzie et al, 2018, p. 1255). This underscores the complex interplay between the man's masculinity and perceived societal expectations. Additionally, when this complexity is overlooked can result in negative consequences, as illustrated by one man in the thesis who was the sole participant in a support group. The situation led to a perception he was marginalised and isolated from other men. By failing to account for gender the diverse expression of masculinity and the importance of social connections amongst men (Connell and Messerschmidt, 2005), support groups or similar settings may inadvertently reinforce perceptions of exclusion and disconnection.

Overall, the findings from the individual studies within this thesis underscore the impact a disrupted masculinity has upon men's perceptions of themselves

indicating the disruption men experience in their lives as a result of lymphoedema. The disruption caused by lymphoedema extended beyond the physical aspects, influencing their perceptions of masculinity. This phenomenon has been identified as disrupted masculinity within this thesis. Men used masculine capital to navigate perceptions of vulnerability stemming from this disruption. Moreover, they engaged in a process of renegotiation, assessing the alignment of their masculinity with hegemonic ideals, either wholly or partially. While hegemonic masculinity theory and the HIMM framework offered insight into the way men's responses to life change, additional theories were applied to contextualise the findings. This included exploration of hegemonic typologies as well as recognising the presence of other masculinities. In the upcoming section, the findings of the thesis will be further examined, with a focus on their implications.

6.5 - Implications

6.5.1 - Implications for Policy

Following this thesis there are several policy implications. First, by bringing a renewed focus upon this area, is to build on the work of previous and existing projects that have been attempting to address men's mental health, and the sharing of men's experiences of their health by public figures to reduce associated stigma (Department of Health, 2003; Scottish Government, 2002; Robertson, 2017). The findings indicate that gender consideration and or gender transformative approaches that consider how men and women may engage differently with their health or challenging pre-held beliefs of gender that are considered unhelpful (Galdas et al, 2023), would acknowledge the influence of gender and masculinity upon men's behaviour and engagement within their health and lymphoedema. This consideration aligns with the World Health Strategy (2018) within the European region with a focus

on gender approaches that improve men's health overall. Both the WHO (2018) and the HIMM framework (Evans et al, 2011) recognise the influence masculinity has on men's health outcomes whilst considering the cultural, political, and socioeconomic factors. Men in the thesis experience the impact of limited gender consideration, such as approaches that are gender-neutral or more female-focused, and fail to acknowledge the impact the condition has upon their masculinity, and how their masculinity influences their engagement in services let alone their health outcomes when managing the condition. Additional policymakers would need to consider that multiple masculinities exist in society due to men not being one homogeneous group when acknowledging the presence of disrupted masculinities in the development of future healthcare policies for those who identify as male (Galdas et al, 2023; Yang, 2020; Evans et al, 2011). By including the concept of masculinity within future policies is to also recognise its presence and influence, as a social determinant that intersects other determinants present within a man's life course in the UK and Westernised societies (Evans et al., 2011).

Second, men's health and their needs require a greater focus nationally and for that conversation to be led by men themselves. Some men appear to be renegotiating their masculinity and challenging their concept of being a man. Whilst some men may not wish to engage, due to their perceptions of masculinity and vulnerability in having a condition that has limited public awareness. Both points are relevant to the national conversation regarding men (UK Parliament, 2023). Men are a varying points in their life course but also within their perceptions of masculinity, its renegotiation, and its influences in their lives (Yang, 2020; Evans et al, 2011). This has relevance to the Men's Health Inquiry that is currently being undertaken to nationally address challenges, such as health equity, factors affecting men

accessing services and why men remain at greater risk of certain health conditions (UK Parliament, 2023). Bringing masculinity and lymphoedema as a subject that is discussed nationally, is to raise its awareness and relevance within the UK and its influence on the decisions men make regarding their health and accessing services more generally.

Third, policy development will need to consider how services can become gender considerate initially or even gender transformative towards men engaging in lymphoedema or adjunct services (Galdas et al, 2023). As the findings within the thesis suggest, men's masculinity and the associated behaviours that may or may not align with hegemonic masculinity, are used by them to navigate their social world when faced with lymphoedema. Currently, masculinity and behaviours are not recognised or used to inform targeted approaches with men and lymphoedema. By using existing frameworks such as the HIMM framework (Evans et al, 2011), to aid targeted approaches (Galdas et al, 2023). Taking a more nuanced approach by examining men and masculinity together allows gender as a factor in how men decide whether to engage in services. Despite gender and masculinity being an identified influence, it has to be considered against other intersectional aspects, such as sexuality, race, and class as examples (Evans et al, 2011; Yang, 2020). Bringing masculinity within the political landscape is to begin the process of turning policies into ones that produce deliverable outcomes that address the varying needs of men within society. This is to avoid the perpetual cycle of policies and forums that have existed previously, and which delivered variable outcomes, such as national service frameworks and men's health forums (Robertson and Williamson, 2005; Robertson, 2017).

Fourth, as mentioned and illustrated within this thesis, is the notion that men are not a homogenous group and vary in the way they express themselves and engage with their health (Connell and Messerschmidt, 2005; Courtenay, 2000). As the findings noted, younger men (30s) engaged in more proactive approaches to their health, such as searching for information, compared to men in their 50s and above. Age provides a potential illustration of the variations that exist across men as a group that equally intersect other aspects mentioned within the HIMM framework (Evans et al, 2011). Considering these additional aspects within the HIMM framework acknowledges the social determinants that are present within masculinity, but also the variable ways this may affect men and their expression (Yang, 2020; Evans et al, 2011; Connell and Messerschmidt, 2005). Multiple masculinities acknowledge that men are not a homogenous group, this needs to be reflected in the creation of policies.

All four aspects need to feed into current and future policies that consider long-term conditions. In addition, policies need to reflect and build upon the work of the World Health Organisation (WHO) men's health strategy (WHO, 2018), and how this approach can be turned into strategies for the UK, similar to those within Australia and Brazil (GAOMH, 2020).

6.5.2 - Implications for Practice

About practice, there are several implications. First, the provision of lymphoedema services or those that offer alternative access, such as tissue viability, will need to consider how they will embed and evaluate the effectiveness of gender-considerate or gender-transformative targeted approaches (Galdas et al, 2023). Targeted gender approaches represent one way that services can begin to address differences between how men and women engage in their health and services. A

systematic review and meta-analysis explored the effectiveness of gender-neutral versus gender-targeted approaches within dietary intake and physical activity (Sharkey et al., 2020). The systematic review indicated that approaches that were gender-targeted may prove more beneficial compared to gender-neutral. However, the noted benefits did not reach a statistical significance between gender-neutral, and gender-targeted, due to limited studies within gender-targeted approaches and those that specifically considered men (Sharkey et al., 2020). Despite the review's focus not being on lymphoedema, it offers a possible perspective as to the approaches and outcomes that may be achieved through gender consideration and targeted approaches. At the current time, gender and other intersecting aspects within lymphoedema research are limited and have yet to reach any level of maturity (Chapter 2). This continues into the provision of services, and the limited level of support offered to men and how this can be rectified (Cooper-Stanton et al, 2022; Cosgiff, 2010; Roberston, 2017).

Second, there is a need to consider how men can become engaged in the development of support within lymphoedema services, such as through co-production or co-design (Galdas et al, 2023; Madden et al, 2023; Reed et al, 2021). Co-producing is to avoid theoretical assumptions, and inadvertently feminising the support offered to men, by allowing men to determine what is appropriate, such as offering information that allows men to master their condition (Flurey et al, 2018; Seagar and Barry, 2020). In the East of England in 2014 a commissioned programme was set up to embed and evaluate co-production with people diagnosed with a long-term condition, such as neurological and mental health (Harfleet and Greig, 2016). The reported outcomes indicated improved experiences of service, quality of life, self-management, choice, and control (Harfleet and Greig, 2016).

Since the report Galdas et al (2023) has proposed a 5C framework for designing men's health programs involving co-production. This framework could provide a comparative approach to addressing the health of men with lymphoedema.

There is a need to address both parts outlined above to bring about active change in the dialogue around long-term conditions, their connection to lymphoedema and how men are included. Therefore, there is a need for an overall approach to address the unmet needs of men diagnosed with lymphoedema. While ensuring men are involved as stakeholders in the effective development of sustainable and achievable outcomes within clinical practice.

6.5.3 - Implications for Theory

First, the dual application of hegemonic masculinity and the HIMM framework had not been undertaken before this thesis. Neither had the application of the HIMM framework within long-term conditions. Applying the two theoretical lenses within the subject area of lymphoedema is to address an omission in the current research on men with lymphoedema. Currently, men and their representation in the existing research on lymphoedema is smaller compared to the larger research focusing on women (Cooper-Stanton et al, 2022). This presented a unique opportunity that led to the exploration of men's perceptions and the extent to which the two theories could be applied. Exploring their application led to other theoretical frameworks and studies being used in this thesis, such as biographical disruption and masculine capital.

Second, to enhance the use of the HIMM framework, there is a need to define what is meant by a 'life event' (Evans et al, 2011, p. 10) so that it is applied appropriately within future studies. Whether the current ambiguity is to allow a more individualised perception is something for wider debate. In the findings of the thesis, I

have referred to and used the work of Bury (1982) within chronic illness, as defining a life event as a disruption. Additionally, it acknowledges those with a long-term condition may undertake 'narrative reconstructions' (Bury, 1982, p. 455). The concept of reconstruction aligns with the work of Flurey et al (2018) and the three proposed masculinity typologies (retaining, renegotiating, and rejecting), in which men may move back and forth, as part of their negotiations. Equally, the typologies acknowledge how men in the thesis are forced to change or reframe their masculinity, which can lead to diversity in its expression, such as accepting support rather than avoiding it. Despite the typologies referring to hegemonic masculinities, other diverse expressions of masculinities can lead to changes too. By considering that lymphoedema can be encompassed within the Bury (1982) as a biographical disruption that defines a life event within the HIMM framework, would recognise its continued relevance in chronic illness and within lymphoedema (Engman, 2019).

Third, a future definition of a life event that uses the work of Bury (1982) would be welcomed. I noted a central aspect that was present across all the findings, was the concept of disrupted masculinity. The term disrupted masculinity is about the vulnerability and stigma men experience in response to the disruption caused by lymphoedema as a life event. Disrupted masculinity as a term is not used within hegemonic masculinity, HIMM framework or within the concept of biographical disruption (Evans et al., 2011; Connell and Messerschmidt, 2005; Bury, 1982). Including this as a distinct term within existing theories would support the influence masculinity has upon men, as outlined in the life course approach offered in the HIMM framework (Evans et al, 2011). Equally, the term can be applied across the multiple masculinities that intersect with hegemonic masculinity (Yang, 2020; Evans

et al, 2011). However, the impact masculinity disruption has upon a man will be unique, based on their masculinity and long-term condition.

Fourth, the existing theories did not consider or use the term masculine capital and how this may encompass traits and behaviours when referring to resources men may employ in response to health changes (Evans et al., 2011; Connell and Messerschmidt, 2005; Bury, 1982). What I established within the findings of this thesis was how men used aspects of hegemonic masculinity-associated traits and behaviours in response to their disrupted masculinity. The use of men in the thesis aligned with certain aspects of the study undertaken by Arnell (2014) within masculine capital. Masculine capital is seen as credit or insurance that men use to compensate for when they are not able to meet certain masculinity ideals as seen in the study by De Visser (2009). Additionally masculine capital and what it encompassed varied between men, such as using certain traits and behaviours to varying degrees, but also with the way it was used within the renegotiations of their hegemonic masculinity (Flurey et al, 2018). By including associated hegemonic masculinity behaviours and traits as potential masculine capital, acknowledge its presence but also the variability in the way men use it in their lives.

Fifth, despite hegemonic masculinity and the HIMM framework noting there are multiple masculinities which can change over a period, such as a life event, they do not explicitly address how men adapt their masculinity or the possible outcomes (Evans et al., 2011; Connell and Messerschmidt, 2005). In response to this potential limitation led to the work by Flurey et al (2018) being applied. In the findings of the thesis, I noted that men appeared to be moving between, or remaining in two of the proposed typologies suggested by Flurey et al (2018) which included retaining and renegotiation. None of the men appeared to reject their hegemonic masculinity. This

is not to say men would reject hegemonic masculinity, but rather it was not present in the data. What was also present in the findings was men used the masculine capital mentioned previously within the back-and-forth process within the two typologies when adapting their hegemonic masculinity. The work by Flurey et al (2018) does not mention or use the term masculine capital when describing the typologies and the way men move between them. In this thesis what has been added is the use of typologies to fill the gap that is present within the applied theories to explain the adaptations men undertake within their masculinity and the use of masculine capital.

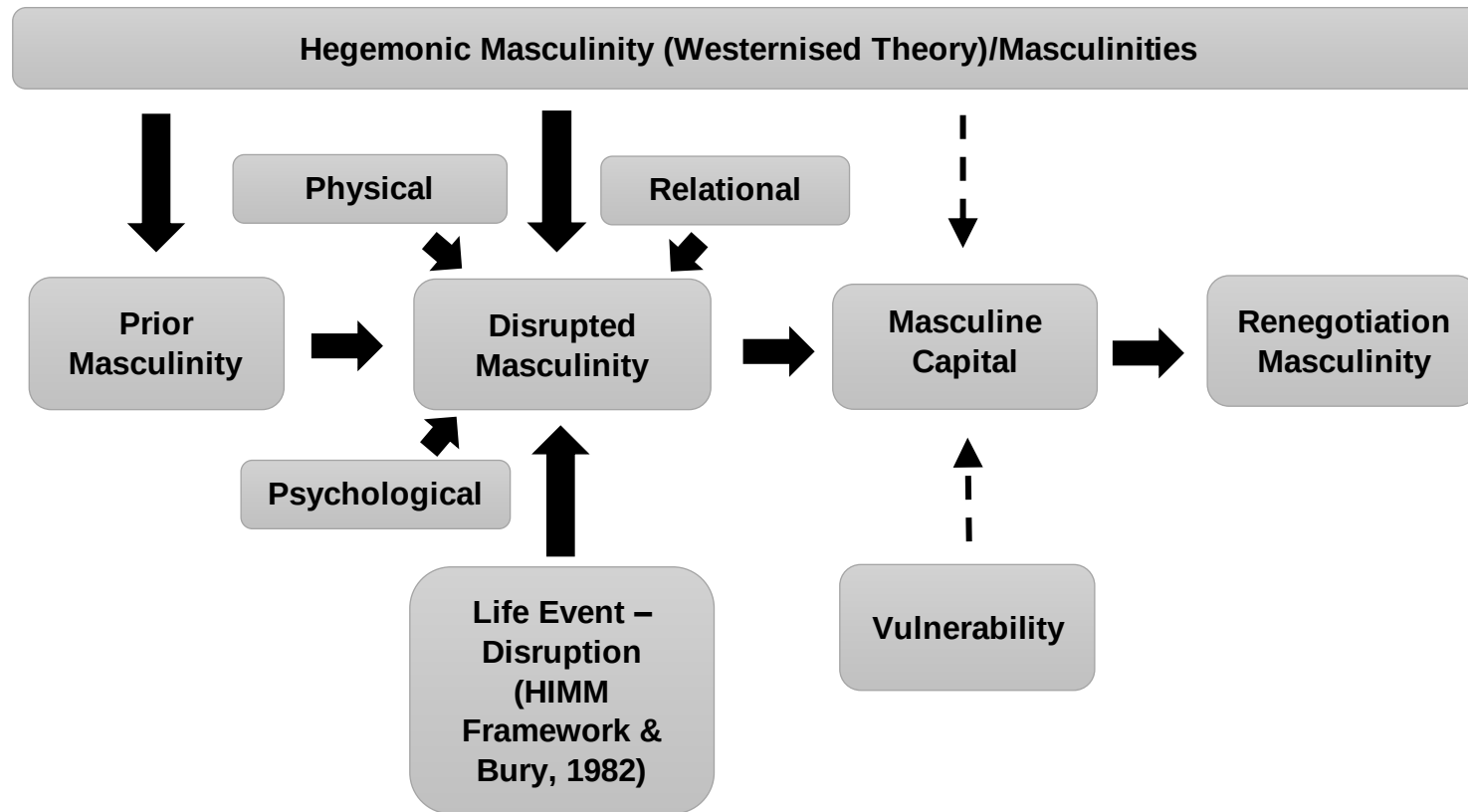
Sixth, methodologically, the thesis has been enhanced through the application of narrative inquiry in men with lymphoedema that had yet to be undertaken based on the available literature that formed the systematic review (Chapter 2). Narrative inquiry provided an alternative research approach within the exploration of the stories men told and shared across all three stages within this thesis (Reissmann, 2008; Chapters 3-5). The use of narrative inquiry throughout the study provided an approach that was trustworthy and rigorous, but also appropriate when considering masculinity as a social construct and its presence within the stories men told (Gavida and Adu, 2022; Reissmann, 2008; Polkinghorne, 1995). Applying narrative inquiry within the thesis led to a variety but complimentary use of narrative analysis approaches within each stage, such as thematic, structural, and linguistic narrative analysis (Reissmann, 2008; Gee, 1991; Labov, 1972). Each narrative analysis was appropriate to the type of study undertaken in the thesis with each approach adding further depth to the findings (Reissman, 2008). As the perceptions of men were explored, led to a focus that was not only upon the 'what' within thematic analysis (Chapter 3), but also the 'form' within structural analysis (Chapter 4), and 'how' narratives are spoken within linguistic narrative analysis (Chapter 5; Reissmann,

2008; p. 53, 77, 95). Different approaches within the gathering of data and analysis provided a means of demonstrating 'method triangulation' and increasing the credibility and dependability of the findings (Carter et al, 2014, p. 545).

Figure 6.0 titled Disrupted Masculinity illustrates the theoretical aspects outlined above that are related to the findings of this thesis. In Figure 6.0 hegemonic masculinity influences a man's socially constructed gender identity and the way it is expressed privately and publicly, such as being in control or engaging in sporting activities that demonstrate physical strength. Equally other masculinities could be used in its place to represent varying responses to lymphoedema, avoiding a homogeneous perception of masculinity. Men's prior concept of masculinity becomes disrupted due to lymphoedema as a life event, which reduces or prevents them from performing and expressing themselves according to societal expectations of men (hegemonic masculinity). Disrupted masculinity is affected by the ability of men to perform physically, psychologically, and relationally. Physically due to having a swollen limb that reduces their ability to perform sports. Psychologically feeling overwhelmed or a perceived loss of control. Relationally the need to rely on partners to support them emotionally or physically instead of being self-reliant. Disrupted masculinity led men to perceive themselves as being vulnerable and regard lymphoedema as having a stigma due to limited awareness of the condition. To mitigate the perceived disruption and vulnerability, men used masculine capital, such as self-reliance, in the management of lymphoedema by creating a sense of control. The use of masculine capital primarily men, served dual purposes: reinforcing their masculinity or gradually adapting to accommodate lymphoedema within their lives. This nuanced exploration reveals how individuals navigate gender norms and health challenges.

In crafting this thesis, a diverse range of approaches has been employed across theory, methodology, and methods. This multifaceted approach has resulted in a thesis that not only offers novel insights but also extends the application of existing theories. By integrating various perspectives, the study contributes to a deeper understanding of the complex interplay between gender, health, and identity.

Figure 6.0 – Disrupted Masculinity



6.5.4 - Implications for Research

The findings of this thesis indicate the experiences and perceptions of men with lymphoedema which are representative of them in terms of ethnicity and age (Cooper-Stanton et al, 2022; Moffatt et al, 2017). Future research could be undertaken to go beyond the studies that were undertaken within this thesis.

First, future research would need to consider whether the thesis findings are representative of men from diverse backgrounds, such as ethnicity or sexual orientation within an expanded application of intersectionality. Equally, there is a need to explore whether the findings are present within non-westernised countries, such as the Middle East, South and East Asia as examples. It is also worth exploring whether a larger sample size of men within the UK and Ireland would support the findings or indicate differences and nuances that may be present. Consideration of intersectionality and different perspectives of masculinity within non-Westernised countries applies to the other implications of research that will be outlined.

Second, there is a need to explore specifically how men define and perceive masculine capital, and whether masculine behaviours and traits are considered as being part of it, due to its use by men within the findings of the thesis (Arnell, 2014). Exploring the concept of masculine capital is to determine whether men recognise it within their lives.

Third, the formation of masculinities resulting from masculinity disruption presents an avenue for further exploration and research. This entails investigating the presence and recognition of the three typologies proposed by Flurey et al. (2018): retaining, renegotiation, and rejection of hegemonic masculinity. It is important to

examine whether nuances are necessary within these definitions and their applicability to other masculinities as discussed in the study by Flurey et al. (2018).

Fourth, as noted in the findings there is a gap in the provision of person-centred support for men within targeted approaches for men with lymphoedema. Future research would need to establish what type of support men need within their lives and the effectiveness of targeted interventions that support them (Galdas et al, 2023; Harfleet and Greig, 2016). As indicated in the findings of this thesis, men may benefit from peer support groups with other men, and targeted approaches that use masculine traits and behaviours within tailored education programmes.

Future research in the areas above reflects national conversations that are present within the UK following the commencement of the men's health inquiry (UK Parliament, 2019; 2023). By considering future research recognises the need to engage with men further, as part of co-production (Madden et al, 2020), or participatory action research (Frances and Lucas, 2023). To move the dialogue from a one-size-fits-all perception of men to one that acknowledges the presence of masculinity and its nuances within men as a group (Liddon and Barry, 2022; UK Parliament, 2023).

6.6 – Strengths and Limitations

Strengths and limitations have been mentioned throughout chapters 3-5 and within this general discussion chapter. This section intends to bring these together.

A strength within this thesis is the application of the two theoretical frameworks, hegemonic masculinity and the HIMM framework (Evans et al, 2011; Connell and Messerschmidt, 2005) that had not been applied within lymphoedema. Equally the HIMM framework had yet to be applied in long-term conditions and is

another strength within this thesis in the application of new theoretical approaches. Combining the two theories was a novel approach that had yet to occur at the time of this thesis. Limitations were noted in the two theories that were applied and were discussed across Chapters 3-5 and within the implications to theory section of this chapter. However, these limitations led to other complementary theories and studies being applied, such as masculine capital that extended their relevance. Exploring hegemonic masculinity and the HIIMM framework within this thesis has expanded our understanding of men which can be used to inform future research studies.

In addition, the material generated to recruit men could have been enhanced through greater involvement of men in its creation (Ryan et al, 2019). Involving men may have increased their participation, due to the acknowledged challenges in recruiting and engaging men within research, especially if it is considered sensitive to men (Markanday et al., 2013; Slauson-Blevins and Johnson, 2016). Despite the possible limitations the study was supported and promoted by several national and local charities, such as the British Lymphology Society, Lymphoedema Support Network and Lymphoedema Services. Enhancing future recruitment of men can be done through co-production but also through the adoption of the five-phased approach within the study by Ryan et al (2019).

The sample size following recruitment was considered as a potential limitation within this thesis. At the time of the thesis, twenty-two men were in the survey with twelve men taking part in the diary and interviews. Despite the potential limitation in terms of the number of men. The men who participated in the studies were a cross-sectional representation of men affected by lymphoedema within the UK and Ireland, in terms of age and ethnicity (Moffatt et al, 2017). Equally theoretical saturation was

achieved within each of the studies (Tran et al., 2017). Saturation within narrative inquiry has been debated, and if applied it should be determined by the researcher when 'completeness' has been achieved (Saunders et al., 2018, p. 1899).

Completeness was supported through methodological triangulation (Carter et al, 2014) as mentioned in the implications to theory section and within the reflexive approach outlined in Chapter 1 and used throughout Chapters 3-5.

A further limitation mentioned within the chapters of this thesis was the diversity of the cross-sectional representation that was recruited. Despite it being representative of the main ethnicity as mentioned earlier and age. It is acknowledged that the findings may not apply to different ethnic minority groups, such as Black, South, or East Asian as an example, or to groups that identify as Lesbian, Gay, Bisexual or Transgender (LGBT+). Despite the potential limitation, there is a certain level of diversity that was present at different stages of the thesis with one black man and three gay men participating. Equally, the findings can be transferred to other men with lymphoedema, and possibly other long-term conditions, that are similar to men who participated in the studies.

Whilst the thesis has limitations, its strength is that it has answered the questions posed within it regarding men's perceptions of their experiences with non-cancer-related lymphoedema. Any limitations are a result of testing theories and methodologies that have yet to be applied, and which can lead to further questions, but also refinement of approaches. Thus, the research undertaken in the thesis can be used in future research to build on the findings and the approaches taken.

6.7 - Conclusion

The findings of this thesis have established the complexity and multifaceted aspects that are present within the experiences of men with lymphoedema. By focusing on masculinity, the study has provided a window into the disruption men perceived within their masculinity. Men's disrupted masculinity led to the perception of vulnerability in which men used traits and behaviours aligned to hegemonic masculinity. Exploring and understanding the meanings behind the actions taken by men is to begin an informed process of engagement, but also co-production of services and resources. Engagement with men is a relevant topic within this thesis, due to the national drivers, and the current men's health inquiry in the UK. Whilst this thesis has provided insight into the area of men with lymphoedema, future research can develop this further. This could include exploring the notion of disrupted masculinity further and if it is present in other Westernised and non-Westernised countries as examples. Exploring the findings further in different settings and populations can expand our understanding of men and their perceptions. Further exploration can offer a means of raising awareness of the stories and voices of men that may otherwise remain hidden. Thus, the thesis adds to the growing body of work and its application to men and those supporting them.

7.0 - References

- Abrams, J. (2016) 'Debunking the Myth of Universal Male Privilege', *Journal of Law Reform*, 49 (303), pp. 303-334. Available at:
<https://repository.law.umich.edu/mjlr/vol49/iss2/1>.
- Alexandrou, B. (2023) *Men's Health: understanding Men's Perspective on health and Health Services*. Healthwatch Barnet. Available at:
<https://www.healthwatchbarnet.co.uk/report/2023-06-06/mens-health-report>.
- Anderson, C., Kirkpatrick, S. (2016) 'Narrative interviewing', *International Journal of Clinical Pharmacy*, 38 (3), pp. 631–634. Doi: 10.1007/s11096-015-0222-0
- Andrews, M. (2007) '*Exploring Cross-Cultural Boundaries*', in Clandinin, J (ed) *Handbook of Narrative Inquiry: Mapping a Methodology*, Thousand Oaks, CA: SAGE Publications, pp. 489–511.
- Anderson, E., McCormack, M. (2018) 'Inclusive Masculinity Theory: overview, reflection, and refinement', *Journal of Gender Studies*, 27 (5), pp. 547-561.
DOI: 10.1080/09589236.2016.1245605.
- Arber, A. (2006) 'Reflexivity: A challenge for the researcher as a practitioner?', *Journal of Research in Nursing*, 11 (2), pp.147–157. Doi:
[org/10.1177/17449871060056](https://doi.org/10.1177/17449871060056).
- Arnell, M. (2014) *The Role of Masculinity, Masculine Capital, and Spousal Social Control on Men's Health Behaviours*. Thesis. Utah State University. Available at:
<https://digitalcommons.usu.edu/etd/3293> (Accessed: 1 July 2023).
- Baker, P. (2018) 'Men's health: time for a new approach', *Physical Therapy Reviews*, 23 (2), pp. 144-150. Doi: 10.1080/10833196.2018.1452562.

- Bettany-Saltikov J (2016) *How to do a systematic literature review in nursing: a step-by-step guide*. 2nd ed. London: Open University Press.
- Beuthin, E. (2014) "Breathing in the Mud: Tensions in Narrative Interviewing.", *International Journal of Qualitative Methods*, 13 (1), pp. 122–134. Doi: org/10.1177/160940691401300103.
- Bogan, L., Powell, J., Dugeon, B. (2007) 'Experiences of living with non-cancer-related lymphedema: implications for clinical practice', *Qualitative Health Research*, 17 (2), pp. 213–224. Doi:10.1177/1049732306297660.
- Bolton, G., Delderfield, R. (2018) *Reflective practice: Writing and professional development*. London: SAGE Publications.
- Booth, A., Carroll, C., Iltott, I. (2013) 'Desperately Seeking Dissonance: Identifying the Disconfirming Case in Qualitative Evidence Synthesis', *Qualitative Health Research*, 23 (1), pp.126-141. Doi: org/10.1177/10497323124662.
- Borbassi, S., Hawes, C., Addicoat, R., Emden, C. (2004) 'Getting it together: Men's and their carers' experience of lymphoedema', *Cancer Nurses Society of Australia* 5 (2), pp.25–33.
- Bosson, J., Jurek, P., Vandello, J, Kosakowska-Berezecka, N, Olech, M., Besta, T., Bender, M., Hoorens, V., Becker, M., Timur Sevincer, A., Best, D., Safdar, S., Włodarczyk, A., Zawisza, M., Żadkowska, M., Abuhamdeh, S., Badu Agyemang, C., Akbaş, G., Albayrak-Aydemir, N. (2021) 'Psychometric Properties and Correlates of Precarious Manhood Beliefs in 62 Nations', *Journal of Cross-Cultural Psychology*, 52 (3), pp. 231–258. Doi: org/10.1177/0022022121997997.
- Bourke, B. (2014) 'Positionality: Reflecting on the Research Process', *The Qualitative Report*, 19 (33), pp. 1-9. Doi: org/10.46743/2160-3715/2014.1026.

- Boulton, M. (2017) *An introduction to gender studies, unshackling human talent and optimising military capability for the coming Era of Equality: 2020 to 2050*. Australia: Australian Army Research Centre.
- Braun, V., Clarke, V., Terry, G. (2014) 'Thematic Analysis', in Rohler, P., Lyons, A. (ed). *Qualitative Research in Clinical and Health Psychology*. London: Palgrave Macmillan. pp. 95-113.
- Bridges, T., Pascoe, C. (2014) 'Hybrid Masculinities: New Directions in the Sociology of Men and Masculinities', *Sociology Compass*, 8 (3), 246-258. Doi: 10.1111/soc4.12134.
- Broom, A., Hand, K., Tovey, P. (2009) 'The role of gender environment and individual biography in shaping qualitative interview data', *International Journal of Social Research Methodology*, 12 (1), pp. 51-65. doi.org/10.1080/13645570701606028.
- Bruner, J. (1990) *Acts of meaning*. Cambridge: Harvard University Press
- Bruner, J. (1985) *Actual minds, possible worlds*. Cambridge: Harvard University Press
- Bury, M. (1991) 'The sociology of chronic illness: a review of research and prospects', *Sociology of Health & Illness*, 13, pp. 451-468. <https://doi.org/10.1111/j.1467-9566.1991.tb00522.x>.
- Bury, M. (1982) 'Chronic Illness as biographical disruption', *Sociology of Health and Illness*, 4 (2), pp.167-182. doi:10.1111/1467-9566.ep11339939
- Caine, V., Estefan, D., Clandinin, J. (2013) 'A Return to Methodological Commitment: Reflections on Narrative Inquiry', *Scandinavian Journal of Education Research*, 57 (6), pp. 574-586. Doi: 10.1080/00313831.2013.798833.

- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., Neville, A. (2014) 'The use of triangulation in qualitative research', *Oncology Nurse Forum*, 41 (5), pp. 545-7. Doi: 10.1188/14.ONF.545-547.
- Caruso, A., Roberts, S. (2017) 'Exploring constructions of masculinity on men's body-positivity blog', *Journal of Sociology*, pp. 1-20. DOI: 10.1177/1440783317740981.
- Casey, A., Schaefer, L. (2016) 'A narrative inquiry into the experience of negotiating the dominant stories of physical education: living, telling, re-telling and re-living', *Sport, Education and Society*, 21 (1), pp. 114–130.
<https://doi.org/10.1080/13573322.2015.1108300>.
- Charmaz, K. (1983) 'Loss of self: A fundamental form of suffering in the chronically ill', *Sociology of Health and Illness*, 5 (2). pp. 168-195. <https://doi.org/10.1111/1467-9566.ep10491512>.
- Chew-Graham, A., May, R., Perry, S. (2002) 'Qualitative research and the problem of judgement: Lessons from interviewing fellow professionals', *Family Practice*, 19 (3), pp. 285–289. Doi: [org/10.1093/fampra/19.3.285](https://doi.org/10.1093/fampra/19.3.285).
- Chhabra, G. (2020) 'Insider, outsider or an in-between? Epistemological reflections of a legally blind researcher on conducting cross-national disability research', *Scandinavian Journal of Disability Research*, 22 (1), pp. 307–317. Doi: 10.16993/sjdr.696.
- Clandinin D. (2012) *Handbook of Narrative Inquiry: Mapping a Methodology*. London: Eiley Blackwell.
- Clandinin, D. (2007). *Handbook of Narrative Inquiry: Mapping a Methodology*. London: Sage Publications.

- Clandinin, D. J. (2006) 'Narrative Inquiry: A Methodology for Studying Lived Experience', *Research Studies in Music Education*, 27 (1), pp. 44-54. Doi: [org/10.1177/1321103X060270010301](https://doi.org/10.1177/1321103X060270010301).
- Clandinin, D., Connelly, F. (2004) *Narrative Inquiry: Experience and Story in Qualitative Research*. San Francisco: John Wiley.
- Coghlan, D. (2019) *Doing Action Research In Your Own Organization*, 5th Ed, London: Sage
- Coles, R., Watkins, F., Swami, V. (2012) 'History and the challenge of gender history', *Men and Masculinities*, 15 (1), pp. 103–113. Doi: [org/10.1080/13642529708596318](https://doi.org/10.1080/13642529708596318).
- Connell, R. W. (1993) 'The big picture: Masculinities in recent world history',
- Connell, R.W., Messerschmidt, J.W. (2005) 'Hegemonic masculinity rethinking the concept', *Gender and Society*, 19 (6), pp. 829–859. [https://doi:10.1177/0891243205278639](https://doi.org/10.1177/0891243205278639).
- Cooper, G., Bagnall, A. (2016) 'Prevalence of lymphoedema in the UK: Focus on the southwest and West Midlands', *British Journal of Community Nursing Supplement*, 21 (4), pp. 6–14. Doi:[org/10.12968/bjcn.2016.21.Sup4.S6](https://doi.org/10.12968/bjcn.2016.21.Sup4.S6)
- Cooper-Stanton, G., Gale, N., Sidhu, M., Allen, K. (2022) 'A qualitative systematic review and meta-aggregation of the experiences of men diagnosed with chronic lymphoedema', *Journal of Research in Nursing*. Doi:[10.1177/17449871221088791](https://doi.org/10.1177/17449871221088791).
- Corfield, P. (1997) 'History and the challenge of gender history', *Rethinking History*, 1 (3), pp. 241-258, Doi: [10.1080/13642529708596318](https://doi.org/10.1080/13642529708596318).
- Cosgiff, N. (2010) 'Cancer-related lymphoedema in males: a literature review', *Journal of Lymphoedema*, 5 (2), pp. 49–61.

Courtenay, W. H. (2000) 'Constructions of masculinity and their influence on men's well-being: A theory of gender and health', *Social Science and Medicine*, 50 (10), pp. 1385–1401. Doi.org/10.1016/S0277-9536(99)00390-1 [https://doi.org/10.1016/S0277-9536\(99\)00390-1](https://doi.org/10.1016/S0277-9536(99)00390-1).

Courtenay, W. (2009) 'Theorising masculinity and men's health', in Broom, A., Tovey, P. (ed.) *Men's Health: Body, identity and social context*. London: Willey-Blackwell, pp. 9-32.

Crow, E. (2020) *Illuminating the experience of growing up and living with primary lymphedema: A life history study*. Thesis: Oklahoma State University. Available at: https://shareok.org/bitstream/handle/11244/325496/Crow_okstate_0664D_16703.pdf?sequence=1 (Accessed: 7 August 2023).

Dale, C., Angus, E., Seto Nielsen, L., Kramer-Kile, M., Pritlove, C., Lapum, J., Clark, A. (2015). "I'm no superman": Understanding diabetic men, masculinity, and cardiac rehabilitation', *Qualitative Health Research*, 25 (12), pp. 1648–1661. Doi.org/10.1177/104973231456663.

Data Protection (UK Government) Act 2018 (asp12). Available at: <https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted> (Accessed 2 July 2023).

De-Fina, A. (2015) Narrative and Identities. In Fina, A., Georgeakopoulos, A. *The Handbook of Narrative Analysis*. London: Willey Blackwell. pp. 351-368.

Demain, S., Gonçalves, A., Areia, C., Oliveira, R., Marcos, ., Marques, A., Parmar, R., Hunt, K. (2015) 'Living with, managing and minimising treatment burden in long term conditions: a systematic review of qualitative research', *PLoS One*, 10 (5). doi: <http://10.1371/journal.pone.0125457>.

- Demetriou, D. Z. (2001) 'Connell's concept of hegemonic masculinity: A critique', *Theory and Society*, 30 (3), pp. 337-61. Doi: [org/10.1023/A:1017596718715](https://doi.org/10.1023/A:1017596718715).
- Deng, J., Murphy, B. (2016) 'Lymphedema self-care in patients with head and neck cancer: a qualitative study', *Supportive Care in Cancer*, 24 (12), pp. 4961–4970. Doi:[org/10.1007/s00520-016-3356-2](https://doi.org/10.1007/s00520-016-3356-2).
- De Visser, O., Smith, J., McDonnell, J. (2009). 'That's not masculine: Masculine capital and health-related behavior', *Journal of Health Psychology*, 14 (7), pp.1047-1057. Doi:[10.1177/1359105309342299](https://doi.org/10.1177/1359105309342299).
- DOH (2007) *Creating a Gender Equality Scheme: A Practical Guide for the NHS*. London: DOH.
- Doucet, A., Mauthner, N. (2008) 'What can be known and how? Narrated subjects and the Listening Guide', *Qualitative Research*, 8 (3), pp. 399-409. doi: [10.1177/1468794106093636](https://doi.org/10.1177/1468794106093636).
- Earthy, S., Cuncev, A., Cronin, A. (2016) 'Narrative Analysis', In Gilbert, N. (eds.) *Researching Social Life*, 4th Ed, London: Sage. pp. 461-484.
- Edward, D., Fletcher, N. (2023) 'We need a minister for men', *The Times*, London, 27 June
- Eguchi, S. (2009) 'Negotiating Hegemonic Masculinity: The Rhetorical Strategy of "Straight-Acting" among Gay Men', *Journal of Intercultural Communication Research*, 38 (3), pp. 193-209. doi:[10.1080/17475759.2009.508892](https://doi.org/10.1080/17475759.2009.508892).
- England, K. (1994) 'Getting personal: Reflexivity, positionality, and feminist research', *The Professional Geographer*, 46 (1), pp. 80–89. Doi: [org/10.1111/j.0033-0124.1994.00080.x](https://doi.org/10.1111/j.0033-0124.1994.00080.x).

- Engman, A. (2019) 'Embodiment and the foundation of biographical disruption', *Social Science and Medicine*, 225, pp. 120-127. Doi: 10.1016/j.socscimed.2019.02.019.
- Evans, J., Frank, B., Olife, J., Gregory, D. (2011) 'Health, Illness, men, and Masculinities (HIMM): a theoretical framework for understanding man and their health', *Journal of Men's Health*, 8 (1), pp. 7-15. Doi.org/10.1016/j.jomh.2010.09.227.
- Flurey, C., White, A., Rodham, K., et al. (2018) 'Everyone assumes a man to be quite strong': Men, masculinity and rheumatoid arthritis: A case-study approach. *Sociology of Health & Illness*, 40 (1): 115–129. doi:10.1111/1467-9566.12628.
- Frances, T., Lucas, S. (2023) 'Participatory research with women in the perinatal period: Considerations for reflexive, community-oriented and power-sensitive research practices', *Qualitative Social Work*, 0 (0), Doi: org/10.1177/14733250231214203.
- Frank, A. W. (1998) 'Just listening: Narrative and deep illness. Families, Systems, & Health', 16 (3), pp. 197–212. <https://doi.org/10.1037/h0089849>.
- Freeman, M. (1998) 'Experience, narrative and the relation between them', *Narrative Inquiry*, 8 (2), pp. 455–66. Doi: 10.1075/ni.8.2.16fre
- Frid, M., Strang, P., Johansson, J. (2006) 'Lower Limb Lymphedema: Experiences and Perceptions of Cancer Patients in the Late Palliative Stage', *Journal of Palliative Care*, 1, pp. 5–11. Doi; org/10.1177/0825859706022001.
- Frost, N., Nolas, S. M., Brooks-Gordon, B., Esin, C., Holt, A., Mehdizadeh, L., Shinebourne, P. (2010) 'Pluralism in qualitative research: the impact of different researchers and qualitative approaches on the analysis of qualitative data', *Qualitative Research*, 10 (4), pp. 441-460. Doi.org/10.1177/1468794110366802.

Galdas, P., Seidler, Z., Oliffe, J. (2023) 'Designing Men's Health Programs: The 5C Framework', *American Journal of Men's Health*. 17 (4), pp. 1-9. Doi: doi:10.1177/15579883231186463.

Galdas, P., Fell, J., Bower, P. (2015) 'The effectiveness of self-management support interventions for men with long-term conditions: a systematic review and meta-analysis', *BMJ Open*, 15 (5) Doi:10.1136/bmjopen-2014-006620.

Gast, J., Peak, T. (2011) "'It used to be that if it weren't broken and bleeding profusely, I would never go to the doctor": Men, masculinity, and health', *American Journal of Men's Health*, 5 (4), pp. 318-331. doi:10.1177/1557988310377926.

Gavidia, P., Adu, J. (2022) 'Critical Narrative Inquiry: An Examination of a Methodological Approach', *International Journal of Qualitative Methods*, 21. Doi.org/10.1177/16094069221081594.

Gawley, T. (2018) 'Using Solicited Written Qualitative Diaries to Develop Conceptual Understandings of Sleep: Methodological Reviews and Insights From the Accounts of University Lives', *International Journal of Qualitative Methods*, 17 (1), pp. 1-12. Doi: 10.1177/1609406918794255.

Gee, J. (2007) *An Introduction to Discourse Analysis: Theory and method*, 2nd Edn, Oxon: Routledge

Gee, J. P. (1991) 'A linguistic approach to narrative', *Journal of Narrative and Life History*, 1 (1), pp. 15–39. Doi:10.1075/JNLH.1.1.03ALI

Gentili, C., McClean, S., Hackshaw-McGeagh, L. (2019) 'Body image issues and attitudes towards exercise amongst men undergoing androgen deprivation therapy (ADT) following diagnosis of prostate cancer', *Psycho-oncology*, 28 (8), pp. 1647–1653. Doi; org/10.1002/pon.5134.

Giorgi, A. (2012) 'The descriptive phenomenological psychological method', *Journal of Phenomenological Psychology*, 43 (1), pp. 3–12. Doi: [org/10.1163/156916212X632934](https://doi.org/10.1163/156916212X632934).

Global Action on Men's Health (2021) *Delivering Men's Health*. GAOMH. Available at: <https://gamh.org/wp-content/uploads/2021/09/Delivering-Mens-Health-report.pdf>.

Global Action on Men's Health (2020) From the margins to the mainstream: next steps. GAOMH. Available at: <https://gamh.org/from-the-margins-to-the-mainstream-next-steps-2/>.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, Inc.

Gordon K, Varney R, Keeley V, Riches K, Jeffery S, Van Zanten M, Mortimer P, Ostergaard P, Mansour S. (2020) Update and audit of the St George's classification algorithm of primary lymphatic anomalies: a clinical and molecular approach to diagnosis. *Journal Medical Genetics*, 57 (10), pp. 653-659. Doi: [10.1136/jmedgenet-2019-106084](https://doi.org/10.1136/jmedgenet-2019-106084).

Gough, B. (2013) The psychology of men's health: maximizing masculine capital, *Health Psychology*, 32 (1), pp. 1-4. doi: [10.1037/a0030424](https://doi.org/10.1037/a0030424). PMID: 23316848.

Green, B. (2013) 'Narrative inquiry and nursing research', *Qualitative Research Journal*, 13 (1), pp. 62-71. Doi:[10.1108/14439881311314586](https://doi.org/10.1108/14439881311314586).

Greenhalgh, T., Wherton, J., Shaw, S., Morrison, C. (2020) 'Video consultations for covid-19', *British Medical Journal*. Doi:[https://www.bmj-com.ezproxye.bham.ac.uk/content/368/bmj.m998](https://www.bmj.com.ezproxye.bham.ac.uk/content/368/bmj.m998).

- Hackett, R., Steptoe, A., Lang, R., Jackson, S. (2020) 'Disability discrimination and well-being in the United Kingdom: a prospective cohort study', *BMJ Open*. 12;10(3): e035714. doi: 10.1136/bmjopen-2019-035714. PMID: 32169928.
- Hajat, C., Stein, E. (2018) 'The global burden of multiple chronic conditions: A narrative review', *Preventive Medicine Reports*, 12, pp. 284-293. doi: 10.1016/j.pmedr.2018.10.008.
- Hall, S. (1990) 'Cultural identity and diaspora', in Rutherford, J (ed) *Identity: community, culture, difference*. London: Lawrence & Wishart, pp. 2-27).
- Hamilton, R., Thomas, R. (2016) 'Renegotiating hope while living with lymphoedema after cancer: a qualitative study', *European Journal of Cancer Care* 25 (50), pp. 822-831. Doi:10.1111/ecc.12382.
- Hare-Mustin, R.T. & Merecek, J. (1988) 'The meaning of difference: Gender theory, postmodernism, and psychology', *American Psychologists*, 43 (6), 455–463. <https://doi.org/10.1037/0003-066X.43.6.455>.
- Harfleet, N., Greig, R. (2016) *Co-producing support for people with long-term health conditions: Evaluation of an NHS East of England co-production programme*. Bath: National Development Team for Inclusion.
- Haydon, G., Browne, G., Riet, P. (2018) 'Narrative inquiry as a research methodology exploring person-centred care in nursing', *Collegian*, 25 (1), pp. 125-129. Doi: [org/10.1016/j.colegn.2017.03.001](https://doi.org/10.1016/j.colegn.2017.03.001).
- Hearn, J., Hall, M. (2005) *Looking at Men and Masculinities through Information and Communication Technologies, and Vice Versa*. In: U. Kempf & B. Wrede (ed.), *Gender-Effekte: Wie Frauen die Technik von morgen gestalten*. Bielefeld, Germany: Bielefeld University, pp. 60–71.

- Hearn, J., Nordberg, M., Andersson, K., Balkmar, D., Gottzén, L., Klinth, R., Pringle, K., & Sandberg, L. (2012) 'Hegemonic Masculinity and Beyond: 40 Years of Research in Sweden', *Men and Masculinities*, 15 (1), pp. 31–55. Doi: [org/10.1177/1097184X11432113](https://doi.org/10.1177/1097184X11432113).
- Heaton, J. (2022) 'Pseudonyms Are Used Throughout: A Footnote, Unpacked', *Qualitative Inquiry*, 28 (1), pp. 123-132. Doi: [10.1177/10778004211048379](https://doi.org/10.1177/10778004211048379).
- Helmreich, S. (2017) 'The Genders of Waves', *WSQ: Women's Studies Quarterly*, 45 (1–2), pp. 29–51. Doi: [10.1353/wsq.2017.0015](https://doi.org/10.1353/wsq.2017.0015).
- Hohne, H. (2022) *The Temporality of Illness Experience: How People with Chronic Illness Narrate their Past and Future*. MSc Thesis. University of Twente. Available at: <http://essay.utwente.nl/89411/> (Accessed 2 July 2023).
- Holloway, I and Wheeler, S. (2010) *Qualitative Research in Nursing and Healthcare*, 2nd Edn. London: Wiley-Blackwell.
- Holman, D., Borgstrom E. (2016) 'Applying social theory to understand health-related behaviours', *Med Humanit*, 42 (2), pp.143-5. Doi: [10.1136/medhum-2015-010688](https://doi.org/10.1136/medhum-2015-010688).
- Horsfall, M., Eikelenboom, M., Draisma, S., Smit, H.(2021) 'The Effect of Rapport on Data Quality in Face-to-Face Interviews: Beneficial or Detrimental?', *International Journal Environmental Research Public Health*, 18 (20), pp. 10858. Doi: [10.3390/ijerph182010858](https://doi.org/10.3390/ijerph182010858).
- Hu, N., Pan S., Sun, J. (2020) 'Mental health treatment online during the COVID-19 outbreak', *European Archives Psychiatry Clinical Neuroscience*, 270, pp. 783-784. <https://doi.org/10.1007/s00406-020-01129-8>.
- Huberman, M., Miles, B. (2002) *The qualitative researcher's companion*. London: SAGE Publications.

Hunter, S. (2010) 'Analysing and representing narrative data: The long and winding road', *Current Narratives*, 1 (2), pp. 44-54.

International Lymphoedema Framework. (2012) *Surgical Intervention: A position document on surgery for lymphoedema*. London: ILF. Available at: www.lympho.org/uploads/files/files/Surgery-final.pdf.

International Lymphoedema Framework (2006) *Best practice for the management of lymphoedema*. Available at: www.lympho.org/uploads/files/files/Best_practice.pdf (Accessed 29 September 2023).

Jansen, H. (2010) 'The logic of Qualitative Survey Research and its Position in the Field of Social Research Methods', *Qualitative Social Research*, 11 (2) doi: <https://doi.org/10.17169/fqs-11.2.1450>.

Jarvinen, M., Mik-Meyer, N. (2020) *Qualitative Analysis: Eight Approaches for the Social Sciences*. London: Sage.

Jeans, C., Ward, E., Cartmill, B. (2019) 'Patient perceptions of living with head and neck lymphoedema and the impacts to swallowing, voice and speech function', *European Journal of Cancer Care*, 28 (1), pp. 1–9. Doi: [org/10.1111/ecc.12894](https://doi.org/10.1111/ecc.12894).

Jønsson, A.R., Reventlow, S., Guassora, A.D. (2020) 'How Older Men With Multimorbidity Relate to Successful Aging', *Journals of Gerontology Series B: Psychological Sciences & Social Sciences*, 75 (5), pp. 1104–1112. Doi: [org/10.1093/geronb/gbz019](https://doi.org/10.1093/geronb/gbz019).

Kahn, R., Cannell, C. (1957) *The Dynamics of Interviewing: Theory, Technique, and Cases*. New York: Wiley & Sons.

Karl, J.A., Verhaeghen, P., Aikman, S.N. (2022) 'Misunderstood Stoicism: The negative Association Between Stoic Ideology and well-Being', *Journal of Happiness Studies*, 23, pp. 3531–3547. doi:<https://doi.org/10.1007/s10902-022-00563-w>.

Kassan, A., Nutter, S., Green, A., Arthur, N., Russell-Mayhew, S., Sesma-Vasquez, M. (2020) 'Capturing the Shadow and Light of Researcher Positionality: A Picture-Prompted Poly-Ethnography', *International Journal of Qualitative Methods*, 19. Doi: [org/10.1177/1609406920977325](https://doi.org/10.1177/1609406920977325).

Katarzyna, W. (2021) 'Men and masculinities in times of crisis: between care and protection, International', *Journal for Masculinity Studies*, 16 (1), pp. 1-5, Doi:[10.1080/18902138.2021.1885860](https://doi.org/10.1080/18902138.2021.1885860).

Keeley, V., Franks, P., Quéré, I., Mercier, G., Michelini, S., Cestari, M., Borman, P., Hughes, K., Clark, K., Lisle, J., Benson, M., Noerregaard, S., Karlsmark, T., Murray, S., Moffatt, C. (2019) 'LIMPRINT in Specialist Lymphedema Services in United Kingdom, France, Italy, and Turkey', *Lymphatic Research and Biology*, 17 (2), pp. 141-146. Doi: [org/10.1089/lrb.2019.0021](https://doi.org/10.1089/lrb.2019.0021).

Keeley V, Crooks S, Locke J, Veigas D, Riches K, Hilliam, R. (2010) 'A quality-of-life measure for limb lymphoedema (LYMQOL)', *Journal of Lymphoedema*, 5 (1), pp. 26–37. Doi: <https://doi.org/10.1080/09638288.2021.1890842>.

Kenten, C. (2010) 'Qualitative Social Narrating Oneself: Reflections on the use of solicited diaries with diary interviews', *Forum: Qualitative Social Research*, 11 (2), Article 16. Available at: <http://nbn-resolving.de/urn:nbn:de:0114-fqs1002160> (Accessed: 25 August 2023).

Kleinman, A. (1998) *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.

Kodriati, N., Pursell, L., Hayati, E. (2018) 'A scoping review of men, masculinities, and smoking behavior: The importance of settings', *Global Health Action*, 11 (3). Doi: 10.1080/16549716.2019.1589763

Krouwel, M., Jolly, K., Greenfield, S. (2019) Comparing Skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome – an exploratory comparative analysis. *BMC Med Res Methodol*, 19 (219). Doi: org/10.1186/s12874-019-0867-9.

Lazard, L., McAvoy, J. (2017) 'Doing reflexivity in psychological research – What's the point? What's the practice?', *Qualitative Research in Psychology*, 17, pp. 159–177. Doi: org/10.1080/14780887.2017.1400144.

Labov, W. (1972) *Language in the Inner City: Studies in the Black English Vernacular*. Pennsylvania: University of Pennsylvania Press, pp. 358-359.

Labov, W., Waletzky, J. (1967) Narrative Analysis: Oral Versions of Personal Experience. In: Helm, J., Ed., *Essays on the Verbal and the Visual Arts*, University of Washington Press, Seattle and London, pp. 3-38.

Law, C. (2019) 'Men on the margins? Reflections on recruiting and engaging men in reproduction research', *Methodological Innovations*, 12 (1). Doi: org/10.1177/2059799119829425.

Leventhal, H., Phillips, A., Burns, E. (2016)' Modelling management of chronic illness in everyday life: A common-sense approach', *Psychological Topics*, 25 (1), pp. 1-18. doi: <https://dr.lib.iastate.edu/handle/20.500.12876/57976>.

Liddon, L., Barry, J. (2021) *Perspectives in Male Psychology: An Introduction*. Chichester: Willey Blackwell.

Lima, A. (2023) 'Understanding narrative inquiry through life story interviews with former prisoners', *Irish Educational Studies*, 42 (4), pp. 775-786. Doi: 10.1080/03323315.2023.225767.

Lockwood, C., Porritt, K., Rittenmeyer. (2020) 'Chapter 2: Systematic reviews of qualitative evidence', in Aromataris, E., Munn, Z. (eds.) *JBIManual for Evidence Synthesis*. Adelaide: JBI, pp. 2.1-2.8.

Locock, L., Ziebland, S., Dumelow, C. (2009) 'Biographical disruption, abruption and repair in the context of motor neurone disease', *Sociology of Health & Illness*, 31 (7), pp.043–1058. Doi:<https://doi.org/10.1111/j.1467-9566.2009.01176.x>.

Lönnberg, L., Damberg, M., Revenäs, Å. (2020) "'It's up to me": the experience of patients at high risk of cardiovascular disease of lifestyle change', *Scandinavian Journal of Primary Health Care*, 38 (3), pp. 340–351. Doi: [org/10.1080/02813432.2020.1794414](https://doi.org/10.1080/02813432.2020.1794414).

Madden, M., Morris, S., Ogden, M., Lewis, D., Stewart, D., McCambridge, J. (2020) 'Producing co-production: Reflections on the development of a complex intervention', *Health Expect*, 23 (3), pp. 659–669. Doi:[org/10.1111/hex.13046](https://doi.org/10.1111/hex.13046)

Maree, J., Beckmann, D. (2016) 'Just live with it': having to live with breast cancer-related lymphedema', *Health SA Gesondheid*, 21, pp. 77–85. Doi: [oi.org/10.4102/hsag.v21i0.937](https://doi.org/10.4102/hsag.v21i0.937).

Markanday, S., Brennan, S, L., Gould, H., Pasco, J. (2013) 'Sex-differences in reasons for non-participation at recruitment: Geelong Osteoporosis Study', *BMC Research Notes*, 6 (104). doi: <https://doi.org/10.1186/1756-0500-6-104>.

Mauthner, N., Doucet, A. (1998) Reflections on a Voice Centred Relational Method of Data Analysis: Analysing Maternal and Domestic Voices, in Ribbens, J., Edwards, R.

(eds.) *Feminist Dilemmas in Qualitative Research: Private Lives and Public Texts*.

London: Sage, pp. 119-144.

Mauthner, N., Doucet, A. (2003). 'Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis', *Sociology*, 37 (3), pp. 413–431.

Doi.org/10.1177/00380385030373002.

McGarvey, A., Osmotherly, P., Hoffman, G. (2014) 'Lymphoedema following treatment for head and neck cancer: impact on patients, and beliefs of health professionals', *European Journal of Cancer Care*, 23 (3), pp. 317–327.

Doi.org/10.1111/ecc.12134.

McKenzie, S, Collings, S., Jenkin, G., River, J. (2018) 'Masculinity, Social Connectedness, and Mental Health: Men's Diverse Patterns of Practice', *American Journal Men's Health*, 12 (5), pp. 1247-1261. Doi: 10.1177/1557988318772732.

Meiklejohn, J., Heesch, K., Janda, M. (2013) 'How people construct their experience of living with secondary lymphoedema in the context of their everyday lives in Australia', *Supportive Care in Cancer*, 21 (2), pp. 459–466. Doi: org/10.1007/s00520-012-1534-4.

Mercier, G., Pastor, J., Moffatt, C. (2019) 'LIMPRINT: Health-related quality of life in adult patients with chronic edema', *Lymphatic Research and Biology*, 17 (2), pp. 163–167. doi: <https://doi.org/10.1089/lrb.2018.0084>.

Merdsoy, L., Lambert, S., Sherman, J. (2020) 'Perceptions, needs and preferences of chronic disease self-management support among men experiencing homelessness in Montreal', *Health Expectations*, 23 (6), pp. 1420–1430. doi:<https://doi.org/10.1111/hex.13106>.

- Merriam, S., Johnson-Bailey, J., Lee, M., Lee, Y., Ntseane, G., Muhamed, M. (2001) 'Power and positionality: Negotiating insider/outsider status within and across cultures', *International Journal of Lifelong Education*, 20 (5), pp. 405-416. Doi: [org/10.1080/02601370120490](https://doi.org/10.1080/02601370120490).
- Messner, M. (1998) 'The limits of "the male sex role": An analysis of the men's liberation and men's right movements' discourse', *Gender and Society*, 12 (3), pp. 255-276. Doi: [org/10.1177/0891243298012003002](https://doi.org/10.1177/0891243298012003002).
- Meth, P. (2017) 'Coughing Everything Out': The Solicited Diary Method', in Braun, V., Clarke, V., Gray, D. (ed) *Collecting Qualitative Data*. Cambridge: Cambridge University Press, pp. 94-116.
- Michael, C. (2016) 'The experiences of prostate cancer survivors: Changes to physical function and its impact on quality of life', *International Journal of Therapy and Rehabilitation*, 23 (7), pp.323-30. Doi: <https://doi.org/10.12968/ijtr.2016.23.7.323>.
- Milligan, C., Bingley, A., Gatrell, A. (2005) 'Digging deep: Using diary techniques to explore the place of health and well-being amongst older people', *Social Science and Medicine*, 61 (9), pp. 1882-1892. Doi: doi.org/10.1016/j.socscimed.2005.04.002.
- Miloš, J. (2021) 'Bourdieu's Theory and the Social Constructivism of Berger and Luckmann', *Philosophy and Society*, 32 (4), pp. 518–537. Doi: [org/10.2298/FID2104518J](https://doi.org/10.2298/FID2104518J).
- Moffatt C., Keeley, V., Qué'ré, I. (2019a) 'The Concept of Chronic Edema—A Neglected Public Health Issue and an International Response: The LIMPRINT Study', *Lymphatic research and biology*, 17 (1). Doi: <https://doi.org/10.1089/lrb.2018.0085>.

- Moffatt, C, Gaskin, R., Sykorova, M. (2019b) 'Prevalence and risk factors for chronic edema in u.k. community nursing services', *Lymphatic Research and Biology*, 17 (2), pp. 147–154. Doi: [org/10.1089/lrb.2018.0086](https://doi.org/10.1089/lrb.2018.0086).
- Moffatt, C., Keeley, V., Hughes, A., Clark, K., Lisle, J., Benson, M., Gaskin, R., Sykorova, M., Dring, E., Murray, S., Mercier, G., Quéré, I., Franks, P. (2019c) 'The UK Experience—Subjective Control of Swelling in Patients Attending Specialist Lymphedema Services', *Lymphatic Research and Biology*, 17 (2), pp. 211-220. Doi: [org/10.1089/lrb.2019.0020](https://doi.org/10.1089/lrb.2019.0020)
- Moffatt, C., Keeley, V., Franks, P., Rich, A., Pinnington, L. (2017) 'Chronic oedema: a prevalent health care problem for UK health services', *International Wound Journal*, 14 (5), pp. 772-781. doi: <https://doi.org/10.1111/iwj.12694>.
- Moffatt, C., Franks, P., Doherty, D., Williams, A., Badger, C., Jeffs, E., Bosanquet, N., Mortimer, P. (2003) 'Lymphoedema: an underestimated health problem', *QJM*, 96 (10), pp. 731-738. doi:10.1093/qjmed/hcg126.
- Mortimer, P., Rockson, S. (2014) 'New developments in clinical aspects of lymphatic disease', *Journal Clinical Investigation*, 124 (3), pp. 915–921. Doi.org/10.1172/JCI71608.
- Moules, N., Venturato, L., Laing, C., Field, J. (2017) 'Is it really “yesterday’s war”? What Gadamer has to say about what gets counted', *Journal of Applied Hermeneutics*, Doi: [org/10.11575/jah.v0i0.53302](https://doi.org/10.11575/jah.v0i0.53302).
- Moynihhan, C., Bancroft, E, K., Mitra, A. (2017) 'Ambiguity in a masculine world: Being a BRCA1/2 mutation carrier and a man with prostate cancer', *Psycho-oncology*, 26 (11), pp. 1987–1993. Doi: [org/10.1002/pon.4530](https://doi.org/10.1002/pon.4530).

- Nasheeda, A., Abdullah, B., Krauss., Ahmed, B. (2019) 'Transforming Transcripts Into Stories: A Multimethod Approach to Narrative Analysis', *International Journal of Qualitative Methods*, 18. Doi.org/10.1177/1609406919856797.
- Naylor, C., Parsonage, McDaid, D., Knapp, M., Fossey, M., Galea, A. (2012) Long-term conditions and mental health: The cost of co-morbidities. London: Kingsfund. Available at: <https://www.kingsfund.org.uk/publications/long-term-conditions-and-mental-health> (Accessed: 29 September 2023).
- Neary, S. (2014) 'Professional identity: What I call myself defines who I am', *Career Matters*, 2 (3), pp. 14–15.
- NIHR (2021) 'Multiple long-term conditions (multimorbidity): making sense of the evidence', *Public Health*. Doi: 10.3310/collection_45881
- Nixon, J., Pigott, A., Cartmill, B. (2018) 'A mixed methods examination of distress and person-centred experience of head and neck lymphoedema', *Oral Oncology*, 83 (5), pp. 18–24. Doi: org/10.1016/j.oraloncology.2018.05.025.
- O'Neill, R. (2015) 'Whither Critical Masculinity Studies? Notes on Inclusive Masculinity Theory, Postfeminism, and Sexual Politics', *Men and Masculinities*, 18 (1), pp. 100–120. Doi: org/10.1177/1097184X14553056.
- O'Rourke, T., Vogel, C., John, D., Pryss, R., Schobel, J., Haug, F., Haug, J., Pieh, C., Nater, U., Feneberg, A., Reichert, M., Probst, T. (2022) 'The Impact of Coping Styles and Gender on Situational Coping: An Ecological Momentary Assessment Study With the mHealth Application TrackYourStress', *Journal Frontiers Psychology*, 13. doi: frontiersin.org/articles/10.3389/fpsyg.2022.913125
- ONS (2022a) Mortality in England and Wales: past and projected trends in average lifespan. ONS. Available at:

<https://www.ons.gov.uk/releases/mortalityinenglandandwalesanoverviewofpastandprojectedtrendsinlineevity>.

ONS. (2022b) *Suicides in England and Wales: 2021 registrations*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesintheunitedkingdom/2021registrations>. (Accessed 2 July 2023).

ONS (2022c) *UK health indicators: 2019 to 2020*. ONS. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/ukhealthindicators/2019to2020>. (Accessed 1 December 2023).

ONS (2021) *Leading causes of death, UK: 2011 to 2018*. ONS. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/articles/leadingcausesofdeathuk/2001to2018>. (Accessed 1 December 2023).

Oster, C., McGuiness, C., Duncan, A., Turnbull, D. (2014) 'Psychology of Men & Masculinity Masculinity and Men's Participation in Colorectal Cancer Screening', *Psychology of Men & Masculinity*, 16 (3), pp. 254-263.
doi:<http://dx.doi.org/10.1037/a0038154>.

Parahoo, K. (2014) *Nursing Research: Principles, Process and Issues*, 3rd ed. Basingstoke: Palgrave.

Pathak, B., Wieten, S., Wheldon, C. (2017) 'Stoic beliefs and health: development and preliminary validation of the Pathak-Wieten Stoicism Ideology Scale', *BMJ Open*, 7:e015137. doi:10.1136/bmjopen-2016-015137.

- Perera, M., Whitehead, M., Molyneux, D. (2007) 'Neglected patients with a neglected disease? A qualitative study of lymphatic filariasis', *PLoS Neglected Tropical Diseases*, 1 (2). Doi: doi.org/10.1371/journal.pntd.0000128.
- Persson, S., Grogan, S., Dhingra, K. (2019) "I don't mind being ugly but I don't wanna have skin cancer": A qualitative study of attitudes to UV exposure and a facial morphing intervention in men 35 years and older', *Psychology & Health*, 34 (12), pp. 1486–1503. Doi: org/10.1080/08870446.2019.1622014.
- Pino Gavidia, L. A., Adu, J. (2022). 'Critical Narrative Inquiry: An Examination of a Methodological Approach', *International Journal of Qualitative Methods*, 21. Doi: https://doi.org/10.1177/16094069221081594.
- Polkinghorne, D. (1995) 'Narrative configuration in qualitative analysis', *International Journal of Qualitative Studies in Education*, 8 (1), pp. 5-23, Doi: 10.1080/0951839950080103.
- Rankin, J. (2016) 'The national lymphoedema partnership', *British Journal of Community Nursing Supplement*, 4, pp. 40–S41. doi.org/10.12968/bjcn.2016.21.Sup4.S40.
- Reed, H., Couturiaux, D., Davis, M. (2021) Co-production as an Emerging Methodology for Developing School-Based Health Interventions with Students Aged 11–16: Systematic Review of Intervention Types, Theories and Processes and Thematic Synthesis of Stakeholders' Experiences. *Prevention Science*, 22, pp.475–491. https://doi.org/10.1007/s11121-020-01182-8.
- Reigel, B., Jaarsma, C., Lee, C., Strömberg, A. (2019) 'Integrating Symptoms into the Middle-Range Theory of Self-Care of Chronic Illness', *Advances in Nursing Science*, 42 (3), pp. 206-215. doi: https://DOI: 10.1097/ANS.0000000000000237.

- Rich, L., Chojenta, C., Loxton, D. (2013) 'Quality, Rigour and Usefulness of Free-Text Comments Collected by a Large Population-Based Longitudinal Study – ALSWH', *PLoS ONE*, 8 (7), e68832. Doi:10.1371/journal.pone.0068832.
- Riessman, C. (2008) *Narrative Methods for the Human Science*. London: Sage.
- Rios-Gonzalez, A., Molina-Rueda, F., Palacios-Ceña, D. (2018) 'Living with lymphoedema—the perspective of cancer patients: a qualitative study', *Supportive Care in Cancer*, 26 (6), pp. 2005–2013. Doi: org/10.1007/s00520-018-4048-x.
- Ríos-González, O., Ramis-Salas, M., Peña-Axt, J., Racionero-Plaza, S. (2021) 'Alternative Friendships to Improve Men's Health Status: The Impact of the New Alternative Masculinities' Approach', *Int J Environ Res Public Health*, 18 (4), 2188. Doi: 10.3390/ijerph18042188.
- Robertson, S., Baker, P. (2017) 'Men and health promotion in the United Kingdom: 20 years further forward?', *Health Education Journal*, 76 (1), pp. 102-113. Doi: doi.org/10.1177/0017896916645558.
- Rodriguez, M. (2016) Chapter 7 – “The Stories We Tell Each Other” Using Technology for Resistance and Resilience Through Online Narrative Communities, Tettegah, S., Garcia, Y. (eds), *Emotions, Technology, and Health*, London: Academic Press, pp. 125-147.
- Rogers, A. (2007) 'The Unsayable, Lacanian Psychoanalysis, and the Art of Narrative Interviewing', in Clandinin, J (ed) *Handbook of Narrative Research*. Thousand Oaks, CA: SAGE Publications, pp. 99–119.
- Rome, J. (2021) 'Bloggng Wounded Manhood: Negotiating Hegemonic Masculinity and the Crisis of the Male (In) Fertile Body', *Women's Studies in Communication*, 44 (1), pp. 44-64. doi org/10.1080/07491409.2020.1752342.

- Rudman, L. A., Goodwin, S. A. (2004) 'Gender differences in automatic in-group bias: why do women like women more than men like men?', *Journal of Personality and Social Psychology*, 87 (4), pp. 494-509. doi:10.1037/0022-3514.87.4.494.
- Rushton, C. (2023) 'Positionality', *Nursing Philosophy*, 24 (4), e12415. Doi: org/10.1111/nup.12415.
- Ryan, J., Lopian, L., Le, B. (2019) 'It's not raining men: a mixed-methods study investigating methods of improving male recruitment to health behaviour research', *BMC Public Health*, 19 (814). Doi: org/10.1186/s12889-019-7087-4.
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., Jinks, C. (2018) 'Saturation in qualitative research: exploring its conceptualization and operationalization', *Quality and Quantity*, 52 (4), pp. 1893-1907. Doi: 10.1007/s11135-017-0574-8.
- Savin-Baden, M., Major, C. (2013) *Qualitative research: The essential guide to theory and practice*. London: Routledge.
- Schulze, H., Nacke, M., Gutenbrunner, C. (2018) 'Worldwide assessment of healthcare personnel dealing with lymphoedema', *Health Economics Review*, 8 (10). Doi: doi.org/10.1186/s13561-018-0194-6.
- Seager, M., Barry J. (2020) 'Delta bias in how we celebrate gender-typical traits and behaviours', *Psychreg Journal of Psychology*, 4 (3), 168-171.
- Seager, M., Sullivan, L., & Barry, J. (2014) 'Gender-Related Schemas and Suicidality: Validation of the Male and Female Traditional Gender Scripts Questionnaires', *New Male Studies*, 3 (3), pp. 34-54.
- Sexia, B., Smith, N., Mitton. C. (2017) 'The Qualitative Descriptive Approach in International Comparative Studies: Using Online Qualitative Surveys', *International*

Journal Health Policy Management, 7 (9), pp. 778-781. doi:[https://10.15171/ijhpm.2017.142](https://doi.org/10.15171/ijhpm.2017.142).

Shakespeare, L. (2012) Lymphoedema in a remote and rural area: An investigation into the prevalence of lymphoedema and its effect on daily living and quality of life in a remote and rural area in the far north of Scotland. PhD. Thesis. University of Edinburgh, UK. Available at: Lymphoedema in a remote and rural area — University of the Highlands and Islands (uhi.ac.uk) (Accessed 5 November 2023).

Sharkey, T., Whatnall, M., Hutchesson, J., Haslam, L., Bezzina, A., Collins, E., Ashton, M. (2020) 'Effectiveness of gender-targeted versus gender-neutral interventions aimed at improving dietary intake, physical activity and/or overweight/obesity in young adults (aged 17-35 years): a systematic review and meta-analysis', *Nutritional Journal*, 19 (78), pp. 1-20. Doi: [10.1186/s12937-020-00594-0](https://doi.org/10.1186/s12937-020-00594-0).

Shkedi, A. (2004) 'Narrative survey: A Methodology for studying multiple populations', *Narrative Inquiry*, 14 (1), pp. 87-111. Doi: [org/10.1075/ni.14.1.05shk](https://doi.org/10.1075/ni.14.1.05shk)

Slauson-Blevins K, Johnson KM. (2016) 'Doing Gender, Doing Surveys? Women's Gatekeeping and Men's Non-Participation in Multi-Actor Reproductive Surveys', *Sociological Inquiry*, 86, pp. 427-449. doi: <https://doi.org/10.1111/soin.12122>.

Sofronas, M., Wright, D, K., Carnevale, F, A. (2018) 'Personhood: An evolutionary concept analysis for nursing ethics, theory, practice, and research', *Nursing Forum*, 53 (4), pp. 406–415. Doi: [org/10.1111/nuf.12267](https://doi.org/10.1111/nuf.12267).

Spector-Mersel, G. (2006) 'Never-aging Stories: Western Hegemonic Masculinity Scripts', *Journal of Gender Studies*, 15 (1), pp. 67-82. doi: [http/10.1080/09589230500486934](https://doi.org/10.1080/09589230500486934).

- Stamarski, C., Son Hing, L. (2015) 'Gender inequalities in the workplace: the effects of organizational structures, processes, practices, and decision-makers' sexism', *Frontiers in Psychology*, 6 (1400), pp. 1-20. Doi: [org/10.3389/fpsyg.2015.01400](https://doi.org/10.3389/fpsyg.2015.01400).
- Stangl, A., Earnshaw, V., Logie, C., Brakel, W., Simbayi, L., Barre, I., Dovidio, J. (2019) 'The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related Stigmas', *BMC Medicine*, 17 (31). doi: <https://doi.org/10.1186/s12916-019-1271-3>.
- Stolldorf, D. P., Dietrich, M. S., Ridner, S. H., Perera, M., Whitehead, M., Molyneux, D., Gunatilleke, G. (2007) 'A Comparison of the Quality of Life in Patients With Primary and Secondary Lower Limb Lymphedema: A Mixed-Methods Study', *Western Journal of Nursing Research*, 38 (10), pp. 1313–1334. Available at: <https://doi.org/10.1371/journal.pntd.0000128>.
- Sullivan, J. (2012) 'Skype: An appropriate Method of Data Collection for Qualitative Interviews?', *The Hilltop Review*, 6 (1), pp. 54-60.
- Swann, J. (1992) *Boys, Girls, and Language*. Oxford: Blackwell.
- Taylor, C. (2005) 'Collecting Data', in Holloway, I. (ed.) *Qualitative Research in Health Care*. Maidenhead: Open University Press, pp. 37-53.
- Taylor-Smith, A., Dumas, A. (2019) 'Class-based masculinity, cardiovascular health and rehabilitation', *Sociology of Health & Illness*, 41 (2), pp. 303–324. Doi: [org/10.1111/1467-9566.12827](https://doi.org/10.1111/1467-9566.12827).
- Terry, G., Braun, V. (2017) Short but Often Sweet: The Surprising Potential of Qualitative Survey Methods. In Braun, V., Clarke, V., Gray, D. (eds.) *Collecting Qualitative Data*. Cambridge: Cambridge University Press, pp.15-44.

- Thomas, R., Hamilton, R. (2014) 'Illustrating the (in)visible: Understanding the impact of loss in adults living with secondary lymphoedema after cancer', *International Journal of Qualitative Studies on Health and Well-being*. 9 (24354), pp. 1-9. Doi: [org/10.3402/qhw.v9.24354](https://doi.org/10.3402/qhw.v9.24354).
- Tidhar, D. (2018) 'The meaning of success in lymphoedema management', *Journal of Lymphoedema*, 13 (1), pp. 37–42.
- Tomassini, L., Font, X., Thomas, R. (2019) 'The case for linguistic narrative analysis, illustrated studying small firms in tourism', *Tourism Geographies*. ISSN 1461-6688. Doi:[org/10.1080/14616688.2019.1619824](https://doi.org/10.1080/14616688.2019.1619824).
- Tosh, J. (2005) 'Masculinities in an industrializing society: Britain, 1800–1914', *Journal of British Studies*, 44 (2), pp.330–342. Doi:[10.1086/427129](https://doi.org/10.1086/427129).
- Towers, A., Carnevale, F., Baker, M. (2008) 'The psychosocial effects of cancer-related lymphedema', *Journal of Palliative Care*, 24 (3), pp. 134–43.
- Tran, V, T., Porcher, R., Tran, V, C., Ravaud, P. (2017) 'Predicting data saturation in qualitative surveys with mathematical models from ecological research', *Journal of Clinical Epidemiology*, 82, pp. 71-78. Doi: <https://doi.org/10.1016/j.jclinepi.2016.10.001>.
- UK Parliament (2013) Health Committee: Written evidence from the Lymphoedema Support Network (LTC 10). United Kingdom: Health Committee. Available at: <https://publications.parliament.uk/pa/cm201415/cmselect/cmhealth/401/401vw09.htm>. (Accessed; 4 November 2023).
- UK Parliament (2023) MPs to examine men's mental and physical health in new inquiry. United Kingdom: Health and Social Care Committee. Available at: <https://committees.parliament.uk/committee/81/health-and-social-care->

committee/news/196589/mps-to-examine-mens-mental-and-physical-health-in-new-inquiry/#:~:text=The%20Health%20and%20Social%20Care,how%20this%20might%20be%20addressed.

Valved, T., Kosakowska-Berezecka, N., Besta, T., & Martiny, S. E. (2021) 'Gender belief systems through the lens of culture—Differences in precarious manhood beliefs and reactions to masculinity threat in Poland and Norway', *Psychology of Men & Masculinities*, 22 (2), pp. 265–276. Doi.org/10.1037/men0000331.

Vandello, J. A., Bosson, J. K. (2013) 'Hard won and easily lost: A review and synthesis of theory and research on precarious manhood', *Psychology of Men & Masculinity*, 14 (2), pp. 101–113. Doi.org/10.1037/a0029826.

Vandello, J. A., Bosson, J. K., Cohen, D., Burnaford, R. M., Weaver, J. R. (2008) 'Precarious manhood', *Journal of Personality and Social Psychology*, 95 (6), pp. 1325–1339. Doi.org/10.1037/a001245.

Vasileiou, K., Barnett, J., Thorpe, S. (2018) 'Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period', *BMC Medical Research Methodology*, 18 (148). Doi: org/10.1186/s12874-018-0594-7.

Viehoff, M., Trompetter, H., Bohlmeijer, E. (2016) 'Acceptance and mindfulness-based interventions for the treatment of chronic pain: a metanalytic review', *Cognitive Behaviour Therapy*, 45 (1), pp. 5–31. Doi: doi.org/10.1080/16506073.2015.1098724.

Watts, T, Davies, R. (2016) 'A qualitative national focus group study of the experience of living with lymphoedema and accessing local multi-professional

lymphoedema clinics', *Journal of Advanced Nursing*, 72 (12), pp. 3147–59. Doi: [org/10.1111/jan.13071](https://doi.org/10.1111/jan.13071).

World Health Organisation (2018) Strategy on the health and well-being of men in the WHO European Region. Available at:

http://www.euro.who.int/__data/assets/pdf_file/0003/378165/68wd12e_MensHealthStrategy_180480.pdf?ua=1. (Accessed 28 July 2023).

Wilde, L., Quincey, K., Williamson, I. (2020) "The Real Me Shining Through M.E.": Visualizing Masculinity and Identity Threat in Men With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Using Photovoice and IPA', *Psychology of Men & Masculinities*, 21 (2), pp. 309–320. doi: <https://doi.org/10.1037/men0000220>.

Williams, A. (2004) 'A phenomenological study of the lived experiences of people with lymphoedema', *International Journal of Palliative Nursing*, 10 (6), pp. 279–86. Doi: doi.org/10.12968/ijpn.2004.10.6.13270.

Williams, R., Robertson, S., Hewison, A. (2009) 'Men's health, inequalities and policy: contradictions, masculinities and public health in England', *Critical Public Health*, 19 (3), pp. 475–488. Doi: <https://doi.org/10.1080/09581590802668457>.

Willis, P., Vickery, A. (2022) 'Loneliness, coping practices and masculinities in later life: Findings from a study of older men living alone in England', *Health and Social Care in the Community*, 30 (5), e2874–e2883. doi: <https://doi.org/10.1111/hsc.13732>.

Wilson, C., Janes, G., Williams, J. (2022) 'Identity, positionality, and reflexivity: relevance and application to research paramedics', *British Paramedic Journal*, 7 (2), pp. 43–49. Doi: [10.29045/14784726.2022.09.7.2.43](https://doi.org/10.29045/14784726.2022.09.7.2.43).

Winchester, N. (2021) Women's health outcomes: Is there a gender gap. House of Lords Library. Available at: <https://lordslibrary.parliament.uk/womens-health-outcomes-is-there-a-gender-gap/>.

Women and Equalities Committee. (2018) Letter from the chair. Available at: <https://www.parliament.uk/documents/commons-committees/women-and-equalities/Correspondence/191030-Letter-to-Nadine-Dorries-MP-regarding-MMH%20inquiry.pdf>. (Accessed 7 July 2023).

World Medical Association. (2022) Declaration of Helsinki - Ethical principles for medical research involving human subjects. Available at: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects>. (Accessed 23 May 2023).

Yang, Y. (2020) 'What's Hegemonic about Hegemonic Masculinity? Legitimation and Beyond', *Sociological Theory*, 38 (4), pp. 318-333. Doi: <https://doi.org/10.1177/0735275120960792>

Zanchetta, M, S, Maheu, C., Kolisnyk, O. (2017) 'Canadian Men's Self-Management of Chronic Diseases: A Literature Analysis of Strategies for Dealing With Risks and Promoting Wellness', *American Journal of Men's Health*, 11 (4), pp. 1077–1095. Doi: <https://doi.org/10.1177/1557988315577674>.

Zinn, J. (2004) 'Health, risk, and uncertainty in the life course: A typology of biographical certainty constructions', *Social Theory & Health*, 2 (3), pp. 199–222. Doi: <https://doi.org/10.1057/palgrave.sth.8700033>.

Zinn, J. (2005) 'The biographical approach: A better way to understand behaviour in health and illness', *Health, Risk & Society*, 7 (1), pp. 1–9. doi: <https://doi.org/10.1080/13698570500042348>.

8.0 - Appendices

8.1.1 – Appendix A (LymQoI)

(Q1) How much does your swollen leg affect the following activities? If any of the items are not applicable to you, please tick N/A in the relevant answer box(es)

	Not at all	A Little	Quit as bit	A Lot	N/A
a) your walking					
b) your ability to bend, e.g. to tie shoelaces or cut toenails					
c) your ability to stand. D) your ability to get up from a chair.					
e) your occupation					
f) your ability to do housework					

Please could you give a brief reason for some or all your scores?

(Q2) Does the swelling affect your leisure activities/ social life? If any of the items are not applicable to you, please tick N/A in the relevant answer box(es)

	Not at all	A Little	Quit as bit	A Lot	N/A

Please could you give a brief reason for your score?

Question – If any of the items are not applicable to you, please tick N/A in the relevant answer box(es)	Not at all	A Little	Quit as bit	A Lot	N/A

(Q3) How much do you feel the swelling affects your appearance?

(Q4) How much difficulty do you have finding clothes to fit?					
(Q5) How much difficulty do you have finding clothes you would like to wear?					
(Q6) Do you have difficulty finding shoes to fit?					
(Q7) Do you have difficulty finding socks/ tights/ stockings to fit?					
(Q8) Does the swelling affect how you feel about yourself?					
(Q9) Does it affect your relationships with other people?					
Please could you give a brief reason for some or all your scores?					
Question – If any of the items are not applicable to you, please tick N/A in the relevant answer box(es)	Not at all	A Little	Quite a bit	A Lot	N/A
(Q10) Does your lymphoedema cause you pain?					
(Q11) Do you have any numbness in your swollen leg(s)?					
(Q12) Do you have any feelings of “pins & needles”					

or tingling in your swollen leg(s)											
(Q13) Does (do) your swollen leg(s) feel weak?											
(Q14) Does (do) your swollen leg(s) feel heavy?											
Please could you give a brief reason for some or all your scores?											
Question – If any of the items are not applicable to you, please tick N/A in the relevant answer box(es). In the past week....	Not at all	A Little	Quite a bit	A Lot	N/A						
(Q15) Have you had trouble sleeping?											
(Q16) Have you had difficulty concentrating on things, e.g. reading?											
(Q17) Have you felt tense?											
(Q18) Have you felt worried?											
(Q19) Have you felt irritable?											
(Q20) Have you felt depressed?											
Please could you give a brief reason for some or all your scores?											
(Q21) Overall, how would you rate your quality of life at present? Please tick your score on the following scale:											
Poor	1	2	3	4	5	6	7	8	9	10	Excellent

Please could you give a brief reason for your score?
(Q22) Please add anything that you would like to share that has not been covered in the questionnaire?

8.1.2 - Appendix B - Solicited Diary Instructions and Format

Dear diary-writer,

Thank you for agreeing to write this diary for my research. This is an unusual method of research, but it is used because interviews only tell you about what a person is thinking in any one day. Writing a diary allows you to tell your personal stories over a longer period. In the papers that have been written at universities not much is known about men's perceptions of living with lymphoedema – and therefore I want to learn more about this. You can write whatever you want in the diary, but what I am specifically interested in learning about is your day-to-day feelings and thoughts surrounding lymphoedema within your daily life. This could be affecting you personally now within your life.

I am interested to know **WHAT** are those experiences and/or feelings, are and **HOW** you managed or responded to them. This diary is a chance for you to write your personal stories about living with lymphoedema – there is no right or wrong answer, anything you write will be useful and help me and others to understand your day-to-day perceptions. I will keep your name secret, for example, if your name is Mr Smith, I will call you Participant 1 when I am writing up my research reports.

Please can you try and fill in the following details about each description (if possible):

- 1) WHEN was it? (date/time)
- 2) WHAT happened to make you think about your lymphoedema? (describe the event)
- 3) HOW did you feel and respond to the experience? (were you worried and chose to leave)
- 4) WHO did you talk to about the experience and how much did you tell them? (partner, family, nurse)

Even though I want you to include something about the four points above, please write in full sentences if possible, and if there is anything else you want to say or

elaborate upon that is fine too. Please keep a diary for two weeks and then return your diary as arranged. I do understand that writing a diary takes up time. I do not expect you to write in it every day. Some days you might write a lot and other days you might just write a few words or nothing at all, and that is fine.

Thank you, Garry Cooper

Garry Cooper Diary (this is just an example for you):

On the 1st of January 2020, I was walking in my local park in Clearwater, it was a hot day and I wore my shorts. Despite having swollen legs, it was so hot, and I used to wear them a lot. As I was walking around the park a little boy shouted, "Look at his legs, Mum". I realised he was pointing at me, and those legs were my legs. I suddenly felt conscious, embarrassed, and wanted to escape, as everyone was looking at me. I thought I had come to terms with my big legs, but this made me look at them differently, and how they needed to be covered, but also hidden. I spoke to my partner, who was great, and let me talk about it. I do not usually talk to them about it as I tend to just get on with things.

Diary Entry
<u>WHEN</u> was it? (date/time)
<u>WHAT</u> happened to make you think about your lymphoedema? (describe the event)
<u>HOW</u> did you feel and respond to the experience? (worried and led you to leave
<u>WHOM</u> did you talk to about the experience and how much did you tell them? (partner, family, nurse)
<i>Other</i> – Please add anything else you would like to share?
Name:

8.1.3 - Appendix C – Interview Schedule and Protocol

Interview:

- Introduce Self
- Review the consent form
- Explain the research and thank the participant for agreeing to participate ...
reiterate confidentiality.
- Obtain a verbal biography of the participants including demographics: Age, Gender, Ethnicity, Socioeconomic Data, Lymphoedema diagnosis, and current medical history related to co-morbidities.

Questions:

- 1) Open with the generative question: 'Could you tell me a little about yourself and your experience of living with lymphoedema?'
- 2) Did you have any conversations about your preferences when it came to treatment? For example, compression hosiery or the choice of colours? How did they take this into account for your care?
- 3) Describe your experience of accessing services, such as lymphoedema services, and how you feel at each stage of the journey? Level of support?
- 4) How would you describe what it's like to be a man and your masculinity to a friend/close other?
- 5) Any further points you wish to contribute?

Prompts (Use prompts as needed):

- If they discuss people and settings – Could you describe the person and/or the setting that you were in?
- Describe how you felt at the time?
- How do you feel about it now?

Thank you for participating and inform the participant that it will be 8 weeks before themes and interpretations will be sent to them for checking.

Interview Protocol

If the online platform fails the below protocol should be followed.

1) Restart the online platform

If this fails

2) Mobile telephone call with a dictaphone to record the conversation.

3) Face-to-face interview with a dictaphone if a telephone is not possible or suitable

8.1.4 - Appendix D – Ethical approval/participant information/consent form

Dear Dr Gale

Re: "Male Mask & Monologue: Voices from the silent minority within lymphoedema"
Application for Ethical Review ERN_20-1729

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at <https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx>) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (<https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx>) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Participant Information Leaflet



Study title: Male Mask & Monologue: Voices from the silent minority within lymphoedema.

Invitation paragraph

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with anyone of your choosing, such as family, friends or healthcare professionals. It is important to take time to decide whether you wish to be a participant in the study. Thank you for taking the time to read this information. If you do not wish to take part in the study, please simply dispose of this pack.

What is the purpose of the study?

The purpose of this study is to explore how male patients' describe their experience of living with lymphoedema.

What is the aim of the study?

The aim of the study is to understand male lymphoedema patient' perceptions of lymphoedema and the perceived impact this has upon their lives. Research has already been undertaken to detail the experiences of female patients', with some combining these with male patients', however, there is limited research that is focused on the male experiences of lymphoedema and accessing healthcare. No research has been undertaken within the UK that focuses solely on this area.

Why have I been chosen?

You have been chosen as you may meet the following criteria:

- Male
- Over the age of 18 years old

- Diagnosed Secondary Lymphoedema (non-cancer related) by a healthcare professional
- Living in the United Kingdom

Do I have to take part?

The research is entirely voluntary, and it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time up until the point of data analysis and without giving a reason.

What will happen if I decide to take part?

If you decide to take part in the study, you will be asked to complete the 'qualitative survey', which will ask you several open-ended questions about your experiences of living with lymphoedema. If you would like to participate further, you can choose to be involved in the next two stages of the study. This will involve writing in a diary, which will be structured in terms of questions, which can be written either daily, weekly or a mixture. The period for the diary is 4 weeks (28 days), which will be given to the researcher, your answers can help the researcher and others to understand, what it is like to experience lymphoedema. This will then lead to an interview to explore this further. There would be two meetings, one will involve discussing the study, gaining consent and explaining how to keep the diary. This will be completed online if possible, via Skype or Zoom as examples. The first meeting would last 20-30 minutes, with the follow-up interview taking approximately 45-60 minutes in length. This may alter depending upon the content being discussed, and whether further exploration will be beneficial. The interview will discuss the research and will ask you to think about your experiences of living with lymphoedema. The experiences you share can indicate your journey past, and present and how this has impacted your future choices. The interviews will be audio recorded to allow the researcher to review the information obtained and to complete analysis and transcribing. If you do agree to participate you will be given a copy of the information sheet and signed consent form.

What are the potential benefits and risks of taking part?

Although there are no direct benefits for you if you take part, by taking part you will help the researcher to find out about the experiences of men diagnosed with lymphoedema in both accessing and receiving healthcare to manage their condition which may improve care delivery and the training of healthcare professionals in the future.

There are no risks to you in taking part outside of those you would experience in everyday life. However, by taking part, you may remember things that you may find upsetting. If this occurs, the researcher will ask you if you want to continue to participate in the interview. Any decision you make will be respected. If any distress/upset is caused as part of the process you will be provided with a list of support agencies.

Will my taking part in the study be kept confidential?

Yes. All the information about your part in the study will be kept confidential. The data will be held securely following the General Data Protection Regulation and Act (2018), the University of Birmingham (UOB) policy on Data Protection (2020) and the Code of Practice for Research (2018). This will involve the use of a lockable cabinet for any paper-based data with electronic data held on devices such as a computer will have password protection/encryption only known to the researcher. Although the information you give will be kept confidential, if you provide any information that is considered harmful the researcher is bound within her professional duty to raise concerns with other relevant agencies.

The researcher will aim to keep anonymity and confidentiality throughout, however, although you will not be identifiable in any publication by name direct quotations may be used to discuss themes which you may be able to recognize as taken from your interview. All transcriptions and audio will be anonymised, or destroyed upon completion of the study, and its purpose within the research (UOB, 2020; 2018). Data relating to publications will be retained for 10 years following each publication before deletion.

What will happen at the end of the research study?

All the information that has been gathered will be analysed and submitted as part of the PhD thesis. This will also include the publication and presentation, either in part or full, within appropriate journals, or presented at a conference. A summary of the findings will be sent to each participant unless they specifically state they do not wish to receive this information.

What if I have a problem or concern?

If you have a concern about any aspect of this study, you should speak with me as the researcher and I will do my best to answer your questions. The supervisors supporting me in this study and who can also be contacted if you have any concerns are Nicola Gale, Kerry Allen and Manbinder Sidhu who are contactable via the University of Birmingham on 0121 414 3344.

Nicola Gale Email - [REDACTED].

Kerry Allen Email - [REDACTED]

Manbinder Sidhu - [REDACTED].

Who has reviewed the study?

The University Birmingham Research Ethics Panel reviewed the study and granted permission for it to be conducted.

Contact for further information:

If any clarification is required or further information is sought please do not hesitate to contact the researcher on his work e-mail at: [REDACTED].

Researcher Name: Garry Cooper

Telephone number: (0121) 414 8780

Supervisors names: Nicola Gale, Kerry Allen and Manbinder Sidhu Contact number: (0121) 414 3344.

Participant Consent Form



UNIVERSITY OF
BIRMINGHAM

Title of Project: Male Mask & Monologue: Voices from the silent minority within lymphoedema.

Name of Researcher: Garry Cooper- Stanton

Eligibility Criteria:

Age	Over 18 years of age
Gender	Identify as a man
Diagnosis	Secondary Lymphoedema (Non-Cancer Related)
Geography	Living in the UK

Please tick the boxes

1. I confirm that I have read and understand the participant information sheet ☐
for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to ☐
withdraw at any time up until the point of data analysis, without giving any
reason.
3. I understand that my data will be stored securely and confidentially ☐
and that I will not be identifiable in any report or publication.
4. I understand that the researcher may wish to publish this study ☐
and any results found, for which I give my permission.

5. I agree for my interview to be audio recorded and for the data to be used for the purposes of this study. ☐

6. I agree to take part in the above study. ☐

Name:	Signature:	Date:
Researcher:	Signature:	Date:

8.1.5 - Appendix E – Data Management Plan

Title - Male Mask & Monologue: Voices from the silent minority within lymphoedema

Creator: Garry Cooper-Stanton

Affiliation: University of Birmingham

Funder: N/A

Template: UoB short template

ORCID iD: 0000-0002-8758-8665

Grant number: N/A

Proposed Start Date: September 2019

Proposed End Date: June 2025

Project abstract

The aim of the study is to understand male lymphoedema patients' perceptions of lymphoedema and the perceived impact this has upon their lives. This answer is supported by the two further research questions that include the positive and negative impacts the condition has on their lives. Alongside the level and type of support offered in the management of their condition by healthcare staff. This will form the basis of a narrative inquiry study design within the interpretive methodology. Recruitment of participants will focus on the United Kingdom and Ireland via two charities that represent patients' groups and commissioned services. This will include the Lymphoedema Support Network (LSN) and Lymph What Oedema (LWO) support group. It is intended that 100 participants will be recruited for stage 1 (qualitative survey), stage 2 (solicited diary) 10-15 participants and stage 3 (interviews) the same 10-15 participants in stage 2. This may increase to achieve any form theme, by those who meet the inclusion criteria. All participants will be sent an information leaflet and consent form, plus details regarding the interview process. This will be undertaken via online communication platform, for example, Skype to engage with individuals across the West Midlands, and will be recorded, but will also follow the patient information and agreed interview schedule. The subsequent

information that has been gathered will be inputted into NVivo, to support the narrative analysis through a pluralistic application of and application of Williams's (1998) 'thematic analysis', Labov's (1972) 'Structural Analysis - Transcription' and finally Gee (1991) 'Structural Analysis – Poetic' model. Data will be stored and remain confidential in accordance with the General Data Protection Regulation and Act (2018), which has informed the University of Birmingham's Data protection policy (2020, 2018). The results of the analysis will be shared with participants who have consented for this to occur and will be used in future publications, but also conferences.

Data description

What types of data will be used or created?

Information gathered as part of the study and used in the creation of further data will be appropriate and minimal. The type of information that will be gathered, includes consent forms, demographics, and information via online communication platforms, for example, Skype interviews. Refer to the research proposal Appendix 1-5. The creation of new data through analysis will be within the use of an Excel document and NVivo 12 software. Data regarding the following demographics will be obtained verbally in stage 1 in the completion of the information before the qualitative survey (Appendix 8), in stages 2 to 3, they will be obtained in the first meeting (Appendix, 5), and will include the following:

- Age
- Gender
- Ethnicity
- Socioeconomic Data
- Lymphoedema Diagnosis
- Past and Current Medical History

The information gathered above will be used in the generation of descriptive statistics within Excel. The use of this data format supports cross connections, with the

existing evidence base regarding long-term conditions, age and co-morbidities as examples. This will feed into the results and discussion parts of the thesis. Information gathered from the interviews will be analysed using a narrative analysis framework but compiled within the NVivo software. This will lead to the creation of codes that relate to the participants. This will be used in the following format:

- Narrative Analysis - Words and sentences
- Meaning generator via Williams (1998), Labov (1972) and Gee's (1991) analysis models
- Coding (open, axial and focused)
- Non-verbal Body Language (field notes)

Data generation will begin in June 2021 and will continue until December 2022. This will involve interviewing 10-15 participants, with subsequent recording, transcribing and analysing. The data generated will be shared with participants if they agree or wish for this to occur. The collective data and any identifiable data will be anonymised for article publication and presentation at conferences. The details of the data use will be contained within the patient information leaflet and consent form.

How will the data be structured and documented?

The information mentioned above will be gathered from the participants in the form of completed consent forms, demographic data and interview data. The demographic data will be structured as stated above and completed within an Excel sheet initially. A unique ID will be generated by the participant in terms of a nickname that only they and the researcher will know. This will allow the anonymisation of the data to meet both legal and ethical frameworks, which include the GDPR (2018) and the Equality Act (2010). However, the only exception will be the consent forms that require name and signature but will be secured in line with the guidance and policies of the University of Birmingham (UOB) regarding Data Protection (2020) and the code of practice for research (2018).

The information gathered will be structured so that it can be fed into the two proposed software programs mentioned above. This will include personal data regarding demographics that will be stored in an Excel document for the generation of descriptive statistics to be undertaken. The information gathered from the interviews undertaken online will be fed into the NVivo programme for narrative analysis purposes. The information gathered within the online platforms will be downloaded as an audio, or MP4 file, for example, Microsoft Skype, to be stored accordingly. Files will be stored in the following format DDMMYYRID (Date, Month, Year, Patient ID/nickname). This is further supported by the University of Birmingham naming conventions guidance.

Data storage and archiving

How will your data be stored and backed up?

The storage of data will involve multiple levels by the provision by the University of Birmingham and the guidance. The backing up, and storage of data, will occur at each point that the data is changed. Digital data that contains identifiable details, will be stored on the OneDrive facility provided on behalf of the University of Birmingham. This will provide security measures from Microsoft and access will be password protected. Once Data has been anonymised and is classed as working data will be stored in a research data store (RDS). The separation of identifiable and working data ensures greater security and that only certain persons have access to the information. Any data downloaded from the software systems mentioned (NVivo) will be stored in the RDS system. The storage of data within the online platforms, for example, Skype will be maintained by Microsoft security measures. Any MP4 video or MP3 audio files will be downloaded for review, and stored within the OneDrive facility. Any paper-based data that may be gathered, or required for the study, for example, consent forms, will be stored in a lockable cabinet within the researcher's home location. The key to the cabinet will only be accessible by the researcher. Data generated from the Excel document and NVivo software that is not identifiable will be downloaded and stored, within the UOB Bear Archive provision. This will lead to the deletion of data in the OneDrive and RDS system to meet the retention

guidance for the University of Birmingham. Data underlying publications should be retained for 10 years from the date of any publication. Unless access to data is requested, which will reset the retention clock, and if no access is requested will lead to the data being deleted.

Is any of the data of (ethically or commercially) sensitive nature? If so, how do you ensure the data are protected accordingly?

The data that is being gathered would fall under the legal frameworks of the GDPR (2018) and the Equality Act (2010). The maintaining of confidentiality for those participating in the study will be in the formats mentioned above, including anonymising the data, through the application of unique identification and naming conventions. This is alongside the use of RDS and OneDrive provisions that contain password protection, but also security measures. Before any gathering of information, participants will have received guidance verbally and written (Appendix 1-5) on the aims of the study, consent and what constitutes disclosure of information. This will focus on safeguarding concerns regarding themselves, or others, which will lead to onward referral to appropriate organisations and services.

The results of the study will be anonymised, with participants aware that these will be used in future conferences and publications. Due to the potentially sensitive nature of the study, relating to the recall of experiences may prove difficult for some participants. Signposting to services that participants may wish to access will be included within the leaflet, with the option to discuss this at the end of each interview (Appendix 1-5). The PI is a clinical nurse specialist in the area and can offer further signposting as required. This will be in addition to participants being aware that they may withdraw at any point before the analysis stage of the data that has been gathered. They do not need to give any reason for the withdrawal and that their data will be removed. As mentioned above regarding the structure and storing of Data has been discussed with as much data anonymised.

Where will your data be archived in the long term?

After the study, manually completed paperwork or data captured online, for example, Skype interviews will be deleted manually, or will automatically be deleted after 90 days. This will be reviewed by the PI to ensure this has occurred, and that the data remains secure. Data generated from the Excel document, or NVivo software that is not identifiable, will be downloaded and stored, within the UOB Bear Archive provision. This will lead to the deletion of data in the OneDrive and RDS system to meet the retention guidance for the University of Birmingham. Data underlying publications should be retained for 10 years from the date of any publication. Unless access to data is requested, which will reset the retention clock, and if no access is requested will lead to the data being deleted.

Data Sharing**Which data will you share, and under which conditions? How will you make the data available to others?**

There is no intention to share the data beyond the PI, and agreed programmes, transcribing software, or services, which have been included within the research proposal. Data will be anonymised as per above. Data will be stored within the data services mentioned above, with information disclosure occurring for safeguarding and public interest. The transfer of data outside the UOB provision, or those agreed upon within the proposal, would require an amendment to the original ethics proposal. This would lead to contact with the UOB IT department, and supervisors regarding the matter. Long-term sharing will be managed by the UOB's policies and guidance.

8.1.6 - Appendix F – Steps to Using Solicited Diaries

Steps	Explanation
1 <i>Identify the target participants for the project</i>	This will involve identifying the sample for the study, which will be 'men with lymphoedema,' and which form the inclusion/exclusion criteria.
2 <i>Identify how many participants for your project</i>	This requires considering the sample required for the study, which at the current time is a minimum of between 10-15 male participants.
3 <i>Determine the mode of collection and prepare all materials needed</i>	This refers to the way in which participants will engage in the diary process. Participants will be given the option of a pre-prepared diary in word document format that can be completed digitally and emailed, or a paper-based option that can be posted.
4 <i>Identify the appropriate writing period</i>	This will involve agreeing what is an appropriate timeframe for the diary to be kept, and in the generation of rich data. The time period is seen as variable from 7 days up to 18 months. In this study participants will be complete the diary over a 2-week time period.
5 <i>Draft and re-draft any necessary instructions</i>	The ability to give clear instructions for participants is crucial in the completion of the study. This will involve creating instructions, and for them to be reviewed by a lymphoedema specialist and a patient representation group.
6 <i>Pilot the diary</i>	To ensure that the diary is appropriate for the intended outcome of the study, piloting of the tool is recommended. This will support the rigour of the study, by receiving feedback from the participant and reviewing of the diary

		entries. A volunteer from the patient representation group will be requested for the pilot.
7	<i>Decide how the diary writing task will commence</i>	This will focus on the information given to participants and the gaining of consent. An initial meeting will take place, online, by telephone, or face-to-face, to explain and complete the consent process.
8	<i>Agree on time and date for collection but also when to contact the researcher</i>	The agreement of the time period will ensure that all participants are aware, but also understand the time investment required for the research. In this study, the time period will be four weeks, with the participant able to contact the researcher at any point during this period of time to ask further questions. At the end of the time period, the participant will send the diary to the researcher via the agreed channel. For example, stamp addressed envelope or email.
9	<i>Collect the diary data</i>	The approach taken in the collection of diary data can add a further ethical check to the process, due to the time and emotional connection that is attached to the diary. It has been determined in this study that participants will be given the option to have contact prior to sending their diary. This can be done online, or face-to-face, depending on what is convenient and reasonable for both parties.
10	<i>Set up expectations around any ongoing contact</i>	The information given pre and post-completion ensures that there is an understanding of any future contact. Each participant will be given the opportunity to be considered for the next stage. As the study will involve follow-up interviews to explore the diary entries and will involve the completion of semi-structured interviews.