

**RECONFIGURING LIFE:
A Grounded Theory Study on
Living with Lower Limb Lymphoedema**

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2023

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A thesis submitted to

Auckland University of Technology

in partial fulfilment of the requirements for the degree of

Doctor of Health Science

Abstract

This thesis presents the theory of Reconfiguring Life which explains how adults live with moderate to severe lower limb lymphoedema. Lymphoedema is a long-term, progressively deteriorating condition; with associated symptoms such as limb swelling, heaviness, changes in personal appearance, reduced mobility and complications that are disruptive, debilitating, and, on occasions, life threatening. Lymphoedema may affect one or two limbs and adjacent areas but can occur anywhere in the body. Left untreated the condition leads to significant physical and psychosocial incapacity. Lymphoedema is a health issue in lower- and higher-income countries, through differing causal factors. Lymphoedema is an under researched area.

Most lymphoedema in higher-income countries, such as Aotearoa New Zealand, is acquired through treatment for cancer. As cancer rates increase, so too does the risk of lymphoedema. The literature is dominated by breast cancer related lymphoedema which affects the upper limb (arms). This research set out to give voice to those living with the more burdening lower limb lymphoedema.

The research question was “How do people live with moderate to severe lower limb lymphoedema?” A constructivist grounded theory study informed by Charmaz was undertaken. Twelve participants who lived with primary or secondary lower leg lymphoedema were interviewed. Data collection and analysis followed a constructivist approach. The resulting theory provides an in-depth view into how people live following the onset of moderate to severe lower limb lymphoedema.

This thesis proposes that there are three phases in adapting to living with lymphoedema which leads to transformative change. Transformation is initiated in phase one through physical changes termed ‘being led by the body.’ During this time, moderate to severe lower limb lymphoedema often dominates life experience with a loss of previous normality. There is a subsequent fracturing of the previous identity, which precipitates phase two termed ‘being led by feelings.’ A turning point is reached, and transformative change is triggered. Phase three, termed ‘leading with the mind,’ reconfigures the new normal through ‘what I learn,’ ‘what I do’, and through ‘how I come to be.’ Through this process, lymphoedema assumes an appropriate place as a condition to be managed. The main motivator for the process is managing disruption which refers to responding to the demands of an unstable condition which alters and disrupts ordinary life.

My study identified that lymphoedema therapists are critical to the process of supporting transformative change for those adapting to living with lower limb lymphoedema. Those who receive self-care support are positioned to learn how to manage disruptions, mitigate the disruptions of lymphoedema, and place the condition within the context of their lives. Without sufficient support for self-care, achieving self-management is highly problematic.

The implications for clinical practice relate to providing an explanatory framework for lymphoedema therapists to convey the transformative reconfiguring through which people move. The framework may be useful for advocating for policy change and to those working alongside lymphoedema therapists such as oncologists, surgeons, nurses, and general practitioners. The framework may be useful for supporting people living with lymphoedema to understand their own journey; and for friends, family, and support people to gain an insight into this under researched, under recognised, and misunderstood condition.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

22 March 2023

Signature

Date

Acknowledgements

I dedicate this thesis to all those living with lymphoedema who have struggled to re-find their place in the world, particularly the participants of this study; and I acknowledge the passing of one participant who died before this thesis was published. I thank my parents who instilled in me a love of both the English language and education; and my wider family who have supported me along this journey, particularly my partner Claire, who in the sentiment of Charmaz, combines the essence of what it means to face loss with courage.

A warm thanks to my supervisors, Associate Professor Deborah Payne and Dr David Healee, who have guided me through every step including bleak and breakthrough moments. With perhaps one exception, when I became a public health nurse and was coached by Dr Mary Dang, I have not received such consistent mentoring in my professional life. Thank you to those who have transcribed, edited, advised, created graphics, read drafts, and taken over the cooking, cleaning, and gardening—Claire Virtue, Rebecca Ott, Dr Jan Wilson, Dr Shoba Nayar^{1*}, Dr Barb McKenzie-Green, the AUT Grounded Theory Group, Dr Jen Rankin*, Dr Grace Wong, Associate Professor Heather Came-Friar, and Sue Knox*.

I would also like to thank the Lymphoedema Therapists group, the Lymphoedema Support Network, and the Australasian Lymphology Association who cooperated in recruitment of participants. A special thank you to the lymphoedema therapists Michele Urlich, Mary Wakefield, and Di Graham who have been sounding boards and provided information.

¹ * Denotes services for which payments were received. Graphics Dr Jen Rankin, transcribing and editing Dr Shoba Nayar, and formatting Sue Knox.

Ethics Approval

Ethics approval was sought and received from Auckland University of Technology Ethics Committee AUTEK 17/350, with minor changes (Appendix A).

Chapter 1 Introduction

Rationale and Significance of the Study

The purpose of the research was to provide insight for health professionals, consumers, policy makers, researchers, and educators on the social context and clinical implications for people living with moderate to severe lower limb lymphoedema, in Aotearoa New Zealand, to guide care, including advice on prevention and self-management. Lymphoedema is a regional swelling in the body, often to one or more limbs, caused by insufficient transport of lymph from the periphery back to the heart. In Aotearoa New Zealand, most lymphoedema is iatrogenic (caused by medical intervention) related to treatment for cancer. Cancer is a leading cause of death and disability in Aotearoa New Zealand. New cancer registrations continue to rise, and survival rates are improving, leading to more people living longer with the effects of cancer treatment. In addition, the population is aging and susceptibility to cancer increasing commensurately (Te Aho o te Te Aho o Te Kahu, 2021). Treatment techniques are improving; however, surgery, radiation, and chemotherapy remain the mainstay of treatment and leave a physical legacy.

Lymphoedema is poorly understood by health professionals and the public (Rockson & Rivera, 2008; Thomas & Hamilton, 2014), under recognised (Cooper, 2010; Keast et al., 2015), and a neglected area of research (Ridner et al., 2018; Rockson & Rivera, 2008; Viehoff et al., 2013), with research quality described as poor (Paskett et al., 2012). Although lymphoedema is prevalent, doctors remain disinterested (Maclellan et al., 2015) and people living with lymphoedema feel neglected (Barlow et al., 2014; Crow, 2020; S. H. Ridner, C. M. Bonner, et al., 2012; Waters, 2009).

Whilst lymphedema affects millions of people in high- and low-income countries, the incidence and prevalence are poorly understood (Greene, 2015; Rockson & Rivera, 2008). It is not known how many New Zealanders live with lymphoedema. Rockson and colleagues (2019) estimated that one in seven people who are treated for cancer will get lymphoedema. Aotearoa New Zealand had over 25,000 incidences of cancer (excluding non-melanoma skin cancers) in 2020 (Te Aho o Te Kahu, 2021); thus, thousands of people each year are being exposed to the risk of lymphoedema.

Using health professional report and follow up diagnostic assessment, Moffatt et al. (2016) found a crude prevalence of chronic oedema of 3.93 per 1000 people in a locality in

the United Kingdom. Differing cancer rates and surgical and radiation protocols make extrapolation of lymphoedema prevalence and incidence rates problematic (Asim et al., 2012; Stuiver et al., 2015). The variance in prevalence can, in part, be attributed to the lack of a replicable, validated, and internationally agreed definition of lymphoedema, inadequate research, and differing follow up timeframes (Leung et al., 2015; Paskett et al., 2012; Rockson & Rivera, 2008; Zhang et al., 2022).

Irrespective of the cause of lymphoedema, self-care is believed to be critical to a successful outcome and lessens the negative impact of lymphoedema on quality of life (International Society of Lymphology, 2020). Self-care is defined as active care initiated by the person living with lymphoedema to carry out tasks unassisted (Ridner et al., 2011). Self-care involves living successfully with one or more long-term condition requiring management of symptoms; concordance with treatment; changes in way of life; and managing psychological, social, and physical consequences of the condition (Wilkinson & Whitehead, 2009). Self-care includes efforts to minimise swelling and other symptoms and prevent further deterioration through care of the skin and avoidance of injury (International Society of Lymphology, 2020).

Self-care is a successful strategy to maintain wellness (Deng et al., 2015; Martin et al., 2021); nevertheless, there are varying rates of attendance at follow up and not everyone follows the recommended self-care recommendations (Brown et al., 2014). In a 5 year follow up study by Ochalek and colleagues (2015), subsequent to treatment for breast cancer, 40 women who attended follow up and had worn compression sleeves had, on average, a 13% initial reduction in arm volume which was maintained 5 years later. In comparison, 20 women who had not attended follow up nor worn compression but responded to a request for reassessment, were found to have, on average, a 14% increase in arm volume, after the initial reduction of 11%, 5 years previously. Therefore, the difference in arm volume between the women in this study who did and did not follow self-care recommendations was more than 25%.

To live well with lymphoedema extensive life changes are needed that can cover every aspect of ordinary life. Research is emerging on the role of self-care and symptom management (Deng et al., 2015; Fu & Kang, 2013; Jeffs et al., 2016; Karlsson et al., 2015; Maree & Beckmann, 2016; S. H. Ridner, C. M. Bonner, et al., 2012; S. H. Ridner, M. R. Fu, et al., 2012; Tidhar et al., 2014; Vaillant-Newman, 2002; Van Hecke et al., 2017); however, a review of the literature at the commencement of the study found scant information on how people

live everyday life with lower limb lymphoedema beyond the symptoms and self-care demands. There is a dearth of literature on the ways people make meaning of their life situation, social context, and relationships, after developing lymphoedema (Meiklejohn et al., 2013).

As far as can be determined, this study is the first qualitative research on lower limb lymphoedema in Aotearoa New Zealand and thus forms a foundational understanding for future qualitative research and clinical practice. One qualitative study from the late 1990s using an interpretative approach on breast cancer related lymphoedema was found (Clark, 1999). I undertook a search of the literature on Scopus, CINHAL, Cochrane Library (via OVID), EBSCO (including MEDLINE), Health and Psychosocial Instruments, AccessPhysiotherapy, and Google Scholar. A filter of New Zealand as a geographic term was used when available. Three clinical practice articles were located (Needham & Martin, 2009; Thomson & Walker, 2011; Walker & Thomson, 2012), three case studies (Liu, 2020; Shaw & Leggat, 2006; Tan et al., 2015), and one report (Hayes et al., 2016); the remainder were quantitative articles. Less than 20 documents comprise the total sum of research on lymphoedema found with human participants from Aotearoa New Zealand in the past 25 years. Of these, eight focus on breast cancer related lymphoedema exclusively and none focus solely on lower limb lymphoedema.

Services for lymphoedema are poor, possibly due to a low profile and lack of medical advocates. The incidence in Aotearoa New Zealand is unknown but the condition is described as “comparatively common” and a public health issue (Stout et al., 2013), and prevalence is believed to be rising (Maclellan et al., 2015). In the past 10 years there has been a surge in literature on quality of life and self-care; yet, despite this, the area remains under studied. There is scope for research from Aotearoa New Zealand looking at this issue which is of personal and public health significance.

How the Research Came About

Like most health professionals I was almost unaware of lymphoedema during my 20-year nursing career until I developed upper limb lymphoedema following surgery for cancer. I learned to manage my arm and, whilst it was distressing in the first 4 years, I developed strong self-management skills. To this day my arm remains only mildly swollen.

As lymphoedema treatment was so expensive, I decided to train as a lymphoedema therapist attending clinically only to myself. At that time, I was halfway through my Master’s

degree and chose to focus on lymphoedema during my studies. I became active in the lymphoedema consumer group. I was in demand as a guest speaker at the YWCA post breast cancer recovery Encore exercise programme, the Cancer Society, and multiple other support groups. I took on a service role looking after the website and supporting conferences for the national lymphoedema therapists' group, and was the Australasian Lymphology Association representative for Aotearoa New Zealand for 3 years. I attended lymphology conferences and undertook professional development in the field. However, I have never worked clinically as a lymphoedema therapist.

Some years after treatment for cancer, I had laser therapy for varicose veins and developed bilateral lower limb oedema which gave me insight into the additional complexity of leg oedema. Five years after that, my sister developed bilateral lower limb lymphoedema following surgery on her hip and groin, which was not related to cancer. My sister's experience of lower limb lymphoedema was so emotionally distressing that we were concerned for her future.

I have been acutely aware of my insider perspective during the course of the research. I recall writing an assignment as part of the taught component of the Doctor of Health Science, where I listed about a dozen symptoms and my supervisor suggested I cut them back. The point for me was to list **all** the symptoms so that the misery or burdening of lymphoedema was made transparent. Such feedback has been useful to trigger reflection on my own agenda. During early analysis I was excited by the codes and categories that developed. I related personally to the categories that became losing previous normality and burdening. I recall putting all the codes on a pinboard and crying for the sense of validation. Here was the unspoken misery of living with lymphedema, corroborated by strangers. Although I had read the literature, doing my own research was incredibly powerful. I knew symptom burden was expressed in the literature. I recall reading Hare (2000) some years ago on breast cancer related lymphoedema and feeling utterly validated by this grounded theory method and methodology study. Here I was, 20 years later, with the same experience of my data. The difference was that now all the symptoms of lymphoedema related to the region of the body have been systematically documented by researchers in the intervening years. Issues of researcher positionality and the emic and etic are discussed in the Chapter 3 – Methodology.

Research Project

My research question is “*How do people live with moderate to severe lower limb lymphoedema?*” Because I bring an insider’s perspective to my research, I chose Charmaz’ (2014a) constructivist grounded theory for the methodology. My goal was to co-construct my research with the research participants using my theoretical sensitivity and my reflexivity, which has been honed over many years working as a nurse and nursing lecturer. The aim of the research was to undertake an exploratory study of how people in Aotearoa New Zealand experienced lymphoedema, with the aim of developing a mid-range theory.

Choosing a Methodology

I undertook a Doctor of Health Science programme, a professional doctoral programme designed to meet the needs of health professionals pursuing clinically focused research study (Larmer et al., 2019). This practice focused doctoral study is suited to students with a strong practice background, such as mine with decades of community nursing experience. I chose to enroll in a professional doctorate as my focus was on clinically relevant findings. I also considered that the taught doctoral programme would provide additional support to a novice researcher such as myself. The taught doctorate provided a cohort of likeminded peers and mentors for encouragement and support (Rees et al., 2019).

As is usual with taught doctorates I undertook 18 months of study, submitting assignments that were credited towards the degree including preparation to submit a research proposal and ethics application (Rees et al., 2019). The programme included three core courses covering philosophical approaches to research, locating the research issue within the health care context, ethics application, research proposal, and open critique (Larmer et al., 2019), with on campus components and assignments. A mentor supported me from the outset to help attune the direction of my study. The three courses were Practice and Philosophies, Health Systems Analysis, and Research Practice and Methodologies.

The focus of the first courses was to identify a topic, refine a research question, and explore a suitable research approach. This confirmed my decision to remain with the topic, and clearly identified less literature overall on lower limb lymphoedema internationally and the almost total absence of literature in Aotearoa New Zealand investigating how people live with lymphoedema. From here a choice was made to explore the lived experience of moderate to severe lower limb lymphoedema. I was drawn to constructivist grounded theory

methodology because my insider perspective could be accommodated and added value through research in which the input of the researcher is transparent (Charmaz, 2014a).

The second course on health systems included an analysis of lymphoedema in relation to socio-political-legal aspects with an emphasis on the ways research in this area could effect systems change. The final course resulted in a research proposal including research design and methodology, defense of my argument, and a review of my proposal prior to acceptance into the next stage of the doctoral programme.

Use of Language and Formatting

Researchers and clinicians are drawn to differing terminology for the person living with lymphoedema. Those with a biomedical stance may refer to patients, while private practitioners may refer to clients, and the cancer literature sometimes refers to survivors. The lived experience perspective may use the term consumer or the person living with the condition. None of these terms seem perfect for every eventuality. For example, 'patient' may denote a passive recipient of care, while 'client' implies some form of monetary transaction, and 'consumer' may imply receiving a marketed product. My preference is mostly for the long-winded term, person living with lymphoedema. I have not abbreviated this to PLWLO as in some research articles, because in my lens there is a diminishment in the abbreviation; the sense of being in relationship is lost.

This issue of complexity in terminology plays out in the clinical field where practitioners and agencies develop a culture related to the preferred word. When a counter word is used one is marked as being an outsider. I have a sense that clinicians notice the words visitors, such as me (a nursing educator), use. The terminology one uses becomes a display of one's world view. For people such as me, this becomes a dilemma when writing up research. For this reason, the terminology in my study for the person living with lymphoedema varies depending on the context. This inconsistency is intentional so as to convey the perspective behind the terms.

At the suggestion of Dr Jen Rankin who assisted with the graphics, colours are used in the findings' chapters to support the reader to keep track of the three categories—being led by the body, being led by feelings, and leading with the mind. The colours themselves relate to issues represented within the categories. Being led by the body is reddened maroon in reference to the inflammatory experience and related heat in the body associated with lymphoedema. The category of being led by feelings uses khaki colour, to identify the

muddiness of distress experienced at that time. The category of leading with the mind uses a fresh spring green which signals healing and renewal in the reconfiguring a new normal. The colours are used in the headings, graphics, and for the font in the tables of the respective categories to support the reader to locate the relevant phase of the findings.

Structure of the Thesis

This thesis is presented in 10 chapters.

Chapter 1 - Introduction

This chapter has introduced the significance of the topic of lymphoedema, provided rationale for the research, my own perspective, the Aotearoa New Zealand context, insight into how the research came about, and situated the thesis within the context of a clinical doctoral course of study.

Chapter 2 – Literature Review

Chapter 2 locates the place of a literature review within the Charmaz version of grounded theory methodology and explores key elements of extant lymphoedema literature.

Chapter 3 – Methodology

Chapter 3 reviews the theoretical perspective of Charmaz' constructivist grounded theory and outlines my emic perspective and the position I hold as a researcher on this topic, given that I live with the condition.

Chapter 4 – Research Methods

Chapter 4 details the application of the methodology, including ethical considerations, sources of data, and data sampling, interviewing, data analysis, coding, memo notes, and the use of constant comparison. The process of reasoning, theory development, and theoretical sensitivity are addressed. In addition, issues related to quality including trustworthiness, recognising assumptions and matters related to Māori and Pacific involvement are explicated.

Chapter 5 – Findings

There are five findings' chapters. Chapter 5 introduces and provides an overview of the theory of Reconfiguring Life, along with participants and their backgrounds.

Chapter 6 – Findings

Chapter 6 explores the first category of the theory of Reconfiguring Life which is being led by the body with the subcategory of losing previous normality. This chapter details the ways that lymphoedematous swelling initiates a succession of symptoms and experiences that result in disruption to everyday life and alters the course of life. It describes the loss of previous normality through symptoms engendered, wardrobe dilemmas to manage the new body shape, changes to mobility, impact on self-esteem, and shows how one's life course is disrupted through a negative impact on livelihood and social connection.

Chapter 7 – Findings

In Chapter 7, the second subcategory of being led by the body which relates to the experience of burdening is explored. I describe how the term burdening expresses the demands of self-care, including managing disruptions related to fluctuating swelling and the mental demands, termed cognitive labour. It describes the experience of fearing for the future with issues of managing the additional costs of lymphoedema and concerns about coping as an older adult.

Chapter 8 – Findings

Chapter 8 outlines the second category of Reconfiguring Life which is being led by feelings. In this chapter I show how lymphoedema evokes either feeling forced into action through the arduousness or in response to feeling out of control. I argue that those who are forced into action either sought help or relied on themselves. Those whose turning point came through feeling out of control pursue a solution through resourcefulness which results in receiving help. A turning point is also reached through; feeling hopeful that control is possible; sharing the burden; and feeling spurred on to self-care, which led on to active coping.

Chapter 9 – Findings

Chapter 9 concludes the findings by exploring the third and final category of leading with the mind. I describe how leading with the mind can result in transformative change through taking charge and regaining a sense of control of the swelling. This chapter also highlights the significant role that lymphoedema therapists play in supporting self-care. The impetus for change is initially led by the lymphoedema therapist who activates progress towards self-care through providing a safe haven, guidance, and treatment, experienced as getting ongoing help. I argue that the therapeutic relationship supports those living with lymphoedema to become amenable to the changes needed to self-manage lymphoedema. I

explain how the platform for self-care is initiated through the actions of lymphoedema therapists who tailor the care, support learning through trial and error, and provide treatment, resulting in feeling spurred on by symptom improvement.

This chapter explains how leading with the mind supports the reconfiguring of a new normal through what people learn, how they come to be, and what they do. I describe a process of becoming amenable to self-care through acquiescing and accepting that lymphoedema cannot be cured but can be managed. Colloquially, this process is referred to as getting to “it is what it is.” I argue that this stage can be characterised as mentally transformative through using the mind to adjust to self-management, regaining a sense of control, and rebuilding a new normal.

Chapter 10 – Discussion

Chapter 10 provides a brief overview of the theory of Reconfiguring Life, reinforces the quality elements, and identifies the significance of the research. Extant literature is then compared and contrasted to my findings. I provide a reflection of my learning; and the implications of the research for clinical practice, policy, research, and education are examined. I provide a critique of the methodology, recommendations, and identify some limitations of the research before my concluding comments.

Summary

Having provided the rationale, significance, background of the study, justified the choice of topic and methodology, explained the formatting choices and flow of the thesis, I now turn to the review of the literature.

Chapter 2 Literature Review

Introduction

This chapter outlines key issues relevant to living with lower limb lymphoedema. First, an explanation of the grounded theory approach to reviewing the literature and the state of lymphoedema literature generally are considered. Second, I overview the lymphatic system and the ways lymphoedema is defined and categorised, the pathophysiology, epidemiology, risk factors, prevention, diagnosis, and treatment of the condition. Then, symptoms, self-care, and quality of life issues are reviewed, within a context of deficiencies in health care availability. Third, issues related to lymphoedema management in Aotearoa New Zealand and the health care system are addressed. Finally, I provide a summary and identify gaps in the literature that this thesis may serve to address.

Literature Review within Grounded Theory Methodology

The starting point for grounded theory in relation to a literature review has traditionally been to maintain researcher neutrality, thereby not exposing the researcher to ideas that may influence theory development. Grounded theory is based initially on inductive reasoning and data comparison. However, avoiding an early literature review is unrealistic and may omit opportunities, inspiring ideas, and lead to reworking old problems. It is likely that even novice researchers undertake studies in a field with which they have familiarity (Charmaz, 2014a; Thornberg & Charmaz, 2014). Two literature reviews were undertaken. An early broad scoping literature review identifying key issues and themes in the literature, and a later review updating literature and comparing this study's findings with extant literature. The benefit of correlating findings with academic literature after the grounded theory has been developed is that literature can be used for data comparison (Charmaz, 2014a).

Current State of Literature

There are multiple issues with the current state of literature and clinical practice protocols for lymphoedema. Viehoff and colleagues (2013) stated that lymphoedema "is not a regularly registered disease" (p. 1). Due to Viehoff's leadership, by 2020 lymphoedema was classified as a disease within the World Health Organization International Classification of Diseases (International Society of Lymphology, 2020). Such a recent addition to formal recognition may explain why the definitions and parameters of the condition are not

standardised. For example, in a review of lymphoedema-specific research the authors noted that 51 different types of questionnaire were identified and it appeared that researchers compiled their own survey questions (Viehoff et al., 2013).

Overall, lymphoedema is poorly researched with poor quality research (Leung et al., 2015; Paskett et al., 2012; Ridner et al., 2018; Viehoff et al., 2013). More qualitative and quantitative research is needed in the area. There are few randomised control trials or Cochrane level 1 or level 2 evidence on many aspects of lymphoedema, and older studies were deemed less rigorous (Paskett et al., 2012). There is conflicting evidence from literature reviews that span differing causal categories of lymphoedema (Paskett et al., 2012). Research and evidence-based clinical practice are complicated by a lack of standard definition of lymphoedema and clinical measurement criteria (Chima et al., 2022; Moffatt et al., 2019). Best practice guidelines are frequently based on 'international consensus' and rely on expert opinion written by the most eminent international clinical researchers (International Society of Lymphology, 2020).

Breast cancer related lymphoedema has been investigated more extensively than other lymphoedemas, although lower limb lymphoedema is more burdensome (Ridner et al., 2018). While breast cancer related lymphoedema remains dominant in the literature, in the last 10 years there has been a wider focus on other body regions including lower limb lymphoedema. However, filariasis lymphoedema, which is the most common internationally and dominant in low-income countries, remains comparatively less studied and less well understood (Medeiros et al., 2022), as is non-cancer lymphoedema (Shallwani et al., 2020).

Lymphatic System

Lymphoedema is caused by an inadequacy of the lymphatic system to transport lymph fluid from the peripheries back to the heart. The lymphatic system includes lymph vessels and organs including tonsils, the thymus, spleen, and lymph nodes. The functions of the lymphatic system include immune response, filtering cellular debris, fluid homeostasis via lymph transfer, absorption and transport of lipids from the gut, immunity, and inflammatory response. The lymphatic system is also thought to play a role in obesity (Mortimer & Rockson, 2014). Understanding the mechanism of both the normal and altered lymph flow is important to both lymphoedema therapists and those with the condition so as to have sufficient understanding to manage an inherently unstable swelling.

Lymph fluid is derived from blood. While the blood system is circulatory, flowing out from and back to the heart, the lymph system is one way from the peripheries back to the heart (Goswami et al., 2020). Blood is circulated through arteries which become smaller until the blood vessel cell wall is thin and permeable at the capillaries. Clear fluid, which becomes lymph, leaks through the permeable blood capillary cell wall to support interstitial tissue. The size of red blood cells precludes diffusion out. The fluid that leaked out is then reabsorbed largely via lymphatic vessels (Goswami et al., 2020).

Lymph fluid, which contains debris from the interstitium, is drawn to open ended lymph collectors, from where it travels in lymph vessels that grow increasingly larger and joins back with the venous system at the heart. On route to the heart, fluid enters lymph nodes which filter out debris and microorganisms while concentrating the lymph. Lymph nodes are a vital component of the immune system, as a repository for white blood cells that fight infection. Cancer cells may also be caught up in the filtering at lymph nodes, hence the removal of lymph nodes in cancer surgery to check for spread of cancer cells.

Whereas the blood system is comparatively fast, likened to a highway, the lymphatic system could be compared to a series of side roads ambling back to the heart (Goswami et al., 2020). The speed of lymph flow and its proximity to the surface become important when looking at treatment options for lymphoedema. The lymphatic system does not contain a pump, such as the heart, and fluid moves through the vessels against gravity due to an aggregation of forces. Lymph vessels contain smooth muscles along the cell wall which contract systematically, similar to peristalsis, and include a one-way valve system to prevent back flow. In addition, lymph moves in response to changing pressures including capillary pressure, musculo-skeletal movement, the pulse of the adjoining blood vessels, breathing, peristalsis in the intestines, and external physical compression (MacLellan, 2015; Martin-Almedina et al., 2021).

Despite enormous advances in the understanding of the lymphatic system, questions about the pathophysiology of the condition remain. The lymphatic system has been a neglected area of research continuing over decades due to the technical obstacles of studying the lymphatics and a lack of interest. Increased recent attention has been stimulated by advances in molecular biology, technological advances, and a deeper understanding of the complex physiological role of the lymphatic system in the prominent contemporary diseases of cancer, cardiovascular disease, infections, obesity, and immune system diseases (Martin-Almedina et al., 2021; Mortimer & Rockson, 2014).

Lymphoedema Defined and Categorised

Lymphoedema is classified three ways—by cause, severity, and the affected part of the body. Lymphoedema is caused by damage to the lymphatic system through surgery to remove lymph nodes, trauma, or a poorly developed lymphatic system due to congenital issues which lead to a reduction in lymph fluid capacity (Martin-Almedina et al., 2021).

Conventionally, lymphoedema has been defined as a long-term, progressive regional oedema, generally affecting one or more limbs; although the trunk, back, chest or genitals, and head and neck may also be affected. Extracellular fluid builds up in the area distal to the damaged lymph nodes or obliterated vessels. Oedema results when lymph transport demands exceed the capacity of lymphatic nodes or vessels. Some definitions of lymphoedema include that it is an incurable condition (Paskett et al., 2012), whilst in a small group of women (N=15) who developed lymphoedema following treatment for endometrial cancer, 50% were symptom free within a year or so (Mitra et al., 2015). Ridner and colleagues (Ridner et al., 2012, 2018) definition recognises that “multiple symptoms” are inherent and proffered a redefining of lymphoedema that included the pathophysiology as above and incorporated the burden of living with lymphoedema and the demands of self-care or self-management.

Lymphoedema is categorised by cause as primary or secondary lymphoedema. Primary and secondary lymphoedema differ in aetiology and presentation. Primary lymphoedema is caused by genetic mutations to the lymphatic system and may manifest at any time during the life span (Martin-Almedina et al., 2021). To date, 31 genes or areas of genes are implicated in the condition with another 18 implicated in primary lymphoedema (Brouillard et al., 2021). In primary lymphoedema the lymphatic structures may be underdeveloped, known as hypoplasia, or overdeveloped but with inadequate structures (valves/vessels), known as hyperplasia. The physiology of primary lymphoedema has been understudied; however, advances are progressing in gene testing for primary lymphoedema and genetic syndromes such as in Down and Turner syndrome, in which lymphoedema is one of the symptoms (Martin-Almedina et al., 2021).

Onset of primary lymphoedema is more common at growth time points of infancy, adolescence, and mid-life (Rockson & Rivera, 2008). Primary lymphoedema may affect one part or the whole of the body, although the lower limbs are most often affected (Hespe et al., 2015). Primary lymphoedema is a rare condition, expected to affect less than five people per 10,000 births per genotype (Brouillard et al., 2021).

Secondary lymphoedema may arise as a result of assault to the lymphatic system. Worldwide, the greatest cause of lymphoedema is filariasis; an infection caused by round worms transmitted in endemic countries and associated with elephantiasis (Smith et al., 2014) which, as the name suggests, is an extreme form of lower limb lymphoedema (Stout et al., 2012; Watu, 2020) found in over 50 countries. Filarial lymphoedema is a neglected tropical disease affecting about 200 million people worldwide (Cromwell et al., 2020). In Western countries, the most common cause of secondary (or acquired) lymphoedema is surgical removal of lymph nodes for cancer staging, radiotherapy to lymph nodes (Greene et al., 2015), and metastatic tumours (Bowman et al., 2020). Factors leading to lymph stasis include recurring skin infections, inflammation, varicose veins, and obesity and can result in lymphoedema (Lopez et al., 2022; Shallwani et al., 2020), which may also arise as a complication of metallic joint implants, some medications, or inflammatory conditions such as rheumatoid arthritis (Todd et al., 2017).

In secondary lymphoedema, the limb distal to damage is directly affected (Hespe et al., 2015). As the lymphatic system is interconnected in the lower limbs, lymphoedema to one leg can lead to lymphoedema in the contralateral limb. Women are disproportionately represented in both primary and secondary lymphoedema (Tashiro et al., 2016), and nearly twice as likely to experience any form of chronic oedema (Moffatt et al., 2016). Lower limb lymphoedema is considered non-life threatening; however, it can result in immobility, distress, and pain; and infectious complications can cause septicaemia (Ridner et al., 2018).

Lymphoedema is also categorised by severity and staged from subclinical to severe. At Stage 0, swelling may not be visible, although subjective symptoms may be detectable and may register on some high-fidelity technologies. This condition may or may not develop further and can be present for months or even years as the interstitium may hold the fluid before swelling is visually obvious and other signs may not be recognised. Early lymphoedema is reversible (Allen & Cheng, 2016). Post-surgical numbness, altered sensation and discomfort from other causes, can mask mild early lymphoedema symptoms.

Stage I signifies early and mild lymphoedema, visible to the eye, with high protein fluid and some changes at cellular level. It may include pitting oedema and swelling that reduces on elevation. Stage II indicates more moderate swelling, and the limb often does not reduce on elevation. In Stage IIb, the swelling becomes more solid, pitting is often not present; increased fibrosis and fatty deposits begin. Stage III signals a stasis in lymph function; the limb solidifies so pitting is absent. Severe lymphoedema is characterised by

thickened, fibrotic, brawny, oedematous areas causing pain and disability, with overhanging folds and wart-like growths (Allen & Cheng, 2016). Stage III is sometimes referred to as elephantiasis (International Society of Lymphology, 2020). That language could be deemed unhelpful from a patient perspective. Garza and colleagues (2017), referred to these three numbered stages as four stages which are essentially the same. Such variations can be confusing, particularly for clinicians accessing the same patient record and researchers. There are other variations in the staging systems—some use fluid percentage increases, some use the terms mild, moderate, and severe. More recently, with the advent of Indocyanine green lymphography capable of assessing dermal backflow, the MD Anderson Staging System has been developed (Suami et al., 2022). Other modifications to standard staging are based on clinical issues such as repeated infections and prominent skin issues (International Society of Lymphology, 2020). More recently, the International Classification of Functioning Disability and Health, which is based on a concept of impairments, has been used (Ridner et al., 2018; Viehoff et al., 2015).

The International Society of Lymphology (2020) made note that the staging system is limited to physical attributes of lymphoedema. As new technology becomes available and further research is undertaken in the area, other factors which are known to be significant in lymphoedema progression could be considered. For example, the impact of lymphoedema on functioning and wellbeing, level of inflammation, and potentially the use of lymph node or vessel biopsy to determine changes in immunohistochemical levels could be included in staging in the future.

There are differences and similarities in the experience and prevalence of primary, filariasis, cancer, and non-cancer related lymphoedema. Lymphoedema caused by cancer is classified as a single condition, despite varying locations and issues (Bowman et al., 2020). More recently, research has been published distinguishing between shared and specific symptoms for upper limb, lower limb, and midline lymphoedema (head and neck, breast/chest wall, back and genital areas) with clusters of symptoms common across all types of lymphoedema and some specific to each body location (Ridner et al., 2021; Viehoff et al., 2015). For example, of the 15 groups of symptoms for lower limb lymphoedema, eight or more are also characteristic of breast cancer related lymphoedema (Ridner et al., 2018). The authors identified generalised symptoms as “swelling, appearance concerns, heaviness, tightness, fatigue, less physical activity, achiness, pain, and difficulty sleeping” (2018, p. 545).

Some studies are specific to the type of lymphoedema, while other studies use data from differing forms of lymphoedema. Breast cancer related lymphoedema research is more prolific and advanced (Bowman et al., 2020; Ridner et al., 2018) and has provided a platform for research into other forms of lymphoedema. This literature review draws on data from the range of extant literature, particularly lower limb and other literature.

Epidemiology

Improvements in cancer treatments have led to increased cancer survival (Paskett et al., 2012), so lymphoedema remains an important issue. Lymphoedema incidence and prevalence is categorised by causal factors and incidence and prevalence data varied wildly, even within the same causal category (Asim et al., 2012). The variances can, in part, be attributed to the lack of replicable, validated, and internationally accepted definition of the threshold of what constitutes lymphoedema (Leung et al., 2015; Paskett et al.; Rockson & Rivera, 2008), compounded by inconsistent diagnostic parameters such as circumferential measurements versus bio-impedance. New cases of secondary lymphoedema continue to emerge over time and many studies are of short duration making comparisons difficult. Longitudinal cohort studies are problematic, while retrospective studies may rely on self-report or the patients' various therapists. Incidence is affected as lymphoedema is under recognised, under diagnosed, and misdiagnosed (Moffatt et al., 2019; Rockson & Rivera, 2008). Rockson and Rivera (2008) concluded that "[t]he challenge to correctly surmise the incidence and prevalence of lymphedema is complex and the relevant medical literature is scanty" (p. 147).

Lymphoedema is a complex area of study due to the lack of an international standard definition across researchers and clinicians, uncertainty about prevalence rates, diagnostic variability, and poor understanding of the lymphatic system. Assessment of lymphoedema depends upon some form of measurement. Parts of the body that are hard to measure such as head and neck, breast, chest, back, and genitals have posed difficulties for researchers and epidemiological data are poor (Fu, 2014). Post cancer treatment lymphoedema prevalence is further complicated by changes to surgical procedures and radiotherapy protocols (Asim et al., 2012; Stuiver et al., 2015). In addition, there is a lack of study in the whole area. Diagnosing lymphoedema is complex due to a myriad of differing diagnostic processes used with disparate thresholds of what constitutes a diagnosis of lymphoedema. Without strong incidence data it is difficult to assess health care costs.

Risk Factors and Prevention in Lower Limb Lymphoedema

Lymphoedema may occur spontaneously (primary) or be triggered (secondary). Not everyone at risk for developing lymphoedema develops the condition. In secondary lymphoedema the cancer itself, cancer treatment, and patient risk factors have been identified. Risk factors for developing lymphoedema associated with the cancer include the site, characteristics of the cancer, and extent of metastases (Tada et al., 2009).

Adjustments to cancer treatment protocols can reduce cancer related lymphoedema prevalence and severity. Lymph node preserving surgery such as sentinel node biopsy reduces the risk of lymphoedema (Mathevet et al., 2021). Risk is increased by postoperative chemotherapy (particularly taxanes), radiotherapy, and complications (Bowman et al., 2020; Pigott et al., 2020; Shinaoka et al., 2022). Lymphoedema risk is also reduced through less invasive surgery, and a reduction in external beam radiation for patients at lower risk of developing secondary cancer (Yost et al., 2014). The risk of lymphoedema can be reduced with gynaecological cancers through the use of radiation inserts known as vaginal brachytherapy, and surgery that minimised development of postoperative lymphocysts, which are cysts full of lymph fluid (Achouri et al., 2012; Allam et al., 2020; Stout & Armer, 2022). However, Wedin and colleagues (2022), in a prospective longitudinal study of 235 women treated for endometrial cancer, reported that 4.3% of women had lymphocysts which did not appear to cause clinical issues.

Risk factors not directly associated with cancer that increase the risk of developing lymphoedema were infections (Huang et al., 2017; Lawenda et al., 2009), and post-surgical trauma (Greene, 2015) to the 'at risk region.' Patients with an increased risk of developing lymphoedema may be offered surgical prophylactic lymphatic-venous shunts immediately after lymph node surgery (Garza et al., 2017).

Individual factors that increase lymphoedema risk are raised body mass index (Rebegea, et al. 2020; International Society of Lymphology, 2020; Yost et al., 2014); multi-morbidity such as kidney disease or failure, congestive heart failure, hypertension, and diabetes or hyperglycaemia (Yost et al., 2014); increasing age (Rebegea, et al. 2020) and burdening the limb .

Lymphoedema may be prevented through reducing individual modifiable risk factors such as managing weight, preventing trauma or infection in the at risk region of the body, graduated exercise programmes, and not burdening the limb (Huang et al., 2017; Vignes et al., 2022). Stout and Armer (2022) added that the risk of lymphoedema is increased

for those with lower physical activity prior to surgery or in the presence of peripheral vascular disease. Lymphoedema identified and treated early leads to better quality of life, improved treatment outcomes, and cost saving both to the individual and the health care system (International Society of Lymphology, 2020).

Research is emerging to support more intensive preoperative screening and treatment to reduce the incidence of secondary lymphoedema (Hayes et al., 2017). Preoperative evaluations along with postoperative monitoring systems based on risk, health education, and intervention on risk factors, increasing exercise, supportive self-care strategies, early detection with appropriate referral and treatment, reduces lymphoedema severity or incidence (Stout & Armer, 2022).

Onset of secondary lymphoedema is most common in the first 3 years after damage to the lymphatic system and a lifetime risk remains (Rockson & Rivera, 2008; Ručigaj & Žunter, 2015). The development of lymphoedema is feared and often insidious (Ručigaj & Žunter), and people living at risk of lymphoedema have poor access to services and receive conflicting advice (Cooper, 2010; Keast et al., 2015).

Lymphoedema clinicians may advise patients with lymphoedema or those at risk of lymphoedema to avoid a long list of potentially hazardous situations, as documented in the breast cancer literature (Asdourian et al., 2016). More contentious risk factors include aircraft flights, blood pressure monitoring, venepuncture, or injections in the 'at risk' or affected limb. In recent years, literature has emerged countering these concerns as triggers of lymphoedema (Cheng et al., 2014; International Society of Lymphology, 2020). Some researchers (Ručigaj & Žunter, 2015) and others closely associated with treating lymphoedema, continue to advise against exposure to any trauma including needle stick and blood pressure cuff harm (Jakes & Twelves, 2015; Lymphoedema Framework, 2006; McLaughlin et al., 2013), creating a disconnect between researchers and clinicians. There is evidence to avoid heat including everyday activities such as spa pools and heat packs on the affected area (Brown, 2018). Preventing the development of lymphoedema is an active discourse in both the literature and clinical practice, and further research on factors that increase or reduce risk are required (International Society of Lymphology, 2020).

Diagnosis

Lymphoedema is diagnosed through history, including treatment for cancer and family history, combined with clinical assessment of anatomy, functioning, symptoms, asymmetry, and cancer spread (Armer et al., 2013; International Society of Lymphology,

2020). Diagnosis may involve the use of imaging, exclusion of differential diagnoses, and objective measurement (Armer et al.). Numerous objective measures to assess limb variance are used, and due to the multifaceted nature of lymphoedema there may not be one ideal way to measure excess fluid. Low fidelity measures include subjective assessment and assessing limb volume against a non-affected limb where possible. Measurement may be done through water displacement or by measuring the circumference of limbs at graduated intervals, known as circumferential measurement (Fu, 2014; Paskett et al., 2012; Ridner et al., 2018). High fidelity measures include magnetic resonance imaging (MRI), computed tomography (CT), bio-electrical impedance spectroscopy of skin (measuring impedance and resistance of extracellular fluid), infra-red perometry (optoelectronic measurement using light), lymphoscintigram (injected radioactive tracer provides images of lymphatic system and rate of lymph flow), and Indocyanine green (ICG) dye lymphography (radiation free imaging of superficial lymphatic flow rate and back flow) (International Society of Lymphology, 2020). Bio-impedance, perometry, tissue dielectric constant ratios (moisture metre comparison), and the more recent ICG lymphography are evolving as useful assessment technologies (Paskett et al., 2012; Tuğral et al., 2017; Yoon et al., 2021).

Measurements of excess fluid frequently rely on an unaffected limb for comparison which makes interpretation of the extent of swelling problematic in bilateral limb lymphoedema. Mechanical measurement of swelling is problematic in midline areas such as shoulder and genitals. In addition, while perometry is a useful and valid tool, the foot cannot be measured and cost may be a barrier (International Society of Lymphology, 2020). The lack of a standard diagnostic tool for lymphoedema creates issues for researchers when comparing lymphoedema data and for clinicians' assessment. It seems that until the issue of alignment in measuring and staging are resolved, comparing research results will remain problematic, with significant consequences in an arena which is under researched.

Lymphoedema is an obscure condition shaded in ambiguity (Moffatt et al., 2019; Rockson & Rivera, 2008). Comparison across research and clinical areas is hampered by differences in definition of what constitutes lymphoedema and varying measurement processes. Research quality has been described as poor with contradictory findings. Until recently, the research was dominated by the bio-medical model. Lower limb lymphoedema and primary lymphoedema are neglected areas (D. P. Stollendorf et al., 2016). Refreshingly, Ridner, Fu, and colleagues concluded that symptom report by patients provided a suitable and cost-effective screening assessment tool for detecting early lymphoedema and assessing severity (Fu, 2014; Hu et al., 2020; Ridner et al., 2018).

Under Recognition and Treatment Delay

Lack of awareness by both health professionals and people living with lymphoedema leads to a delay in diagnosis, diminishment of the condition (Cooper, 2010; Shaw & Thomas, 2011), misdiagnosis, conflicting advice from health professionals, inept treatment (Greene et al., 2015), lack of services (Barlow et al., 2014; Cooper, 2010), and some never receive treatment (Rockson & Rivera, 2008). Possible explanations for medical indifference include lack of profile in the curriculum, lack of treatment options, poor appreciation of the pathophysiology of lymphoedema, and absence of medical speciality (MacLellan et al., 2015). Lymphoedema is a condition which one can 'live with, rather than die from' and may thus be relegated to a lower status health concern.

People who live with lymphoedema experience health professionals as uninformed, under valuing the impact on quality of life and financial burden (Cooper, 2010; Waters, 2009). More than 75% of cancer patients treated for endometrial cancer at the Mayo clinic reported that the surgeon had not provided information on the risk of lymphoedema (Yost et al., 2014), confirmed in principle by Cooper (2010). In breast cancer survivors, those who were informed of the risk, considered that the significant impact on daily life was never explained (Fu & Rosedale, 2009). Women were disappointed by the lack of information and support from health professionals (Barlow et al., 2014; Maree & Beckmann, 2016). Many were diagnosed with lymphoedema following a life threatening diagnosis of cancer and bore the experience of two existential crises (Thomas & Hamilton, 2014).

Barlow and colleagues (2014) concluded that women who had experienced breast cancer needed to become their own expert. Fu and Rosedale (2009) considered that the literature for women on managing lymphoedema came from a compliance model, whereas women assessed consequences and made decisions about how to cope with a long-term condition within the context of insufficient professional support. Locating and receiving specialist lymphoedema services was problematic, costly, and further exacerbated by recommendations of unaffordable services to maintain self-care (Maree & Beckmann, 2016). Women felt left alone to cope with new, enduring, and demanding challenges without the support of a lymphoedema therapist (Fu, 2014; Maree & Beckmann, 2016).

When lymphoedema is left untreated, the condition progresses more rapidly resulting in fibrosis of soft tissues underlying the skin; brawny changes to the skin; altered sensations such as pain, paraesthesia; an increased risk of cellulitis; and reduced mobility and quality of life (Lawenda et al., 2009; Ridner et al., 2018). Delayed diagnosis increases

health care service costs and reduces quality of life (Cooper, 2010; Yildiz et al., 2022). With early intervention, self-management, and compression garments, the condition may remain in the mild to moderate spectrum and respond well to treatment (Lawenda et al., 2009; Paskett et al., 2012).

Treatment

Successful treatment relies on the patient to adopt self-care (International Society of Lymphology, 2020). Treatment can be either conservative or surgical. The goals of treatment are to minimise swelling, maintain limb function, improve quality of life and wellbeing, and reduce complications such as lymph leaking through the skin (lymphorrhoea), cellulitis (also called erysipelas), and reduce symptom burden (Grada & Phillips, 2017; Paskett et al., 2012). Quality of life is directly correlated with the number and degree of symptoms in lower limb lymphoedema, so treatment success may be measured by subjective experience of reduced symptoms or objective measures (Bowman et al., 2020; Ridner et al., 2018).

Treatment for Stages 0-I involves skin care, manual lymphatic drainage (a specific light touch massage) if it is effective, whole body exercise, and compression garments which are individually measured and prescribed (International Society of Lymphology, 2020). Treatment for Stages II and beyond involves complex decongestive therapy.

Complex Decongestive Therapy

After diagnosis the recommended care is a course of an intensive combination of treatments known as complex decongestive therapy, followed by maintenance therapy, which scaffolds increasingly to self-care. Complex decongestive therapy is a concentrated course of conservative therapy including bandaging 3-6 times a week, manual lymphatic drainage, skin care and specified exercises intended to reduce excess fluid volume (Bakar & Tuğral, 2017). The course may be as long as 8 weeks for severe lymphoedema (Costello et al., 2021) or a couple of days of bandaging for a mild oedema. The percentage of excess fluid volume reduction during the intensive phase, varies widely across studies. Bakar and Tuğral (2017) reported an average reduction of 63% for lower limb lymphoedema with complex decongestive therapy. Costello and colleagues (2021) reported a range between 3-30% reduction in a cohort in which 60% of participants had a body mass index above 30. Where lymphoedema is complicated by obesity, or vice versa, reductions in fluid volume are less (Johnson & Damarell, 2020). There is evidence from clinical practice that reduction is sustained; however, there have been insufficient quality trials to determine how long the benefit lasts (Brandão et al., 2020). Costello and colleagues (2021) noted a mean increase of

2.43% after the end of the intensive phase while participants were in the self-maintenance phase, however the overall reduction of over 12% remained at 24 weeks.

A specific multi-layer short stretch bandage is used, applying a higher pressure at the feet, gradually reducing pressure up to the thigh; or alternatively below knee if the swelling does not go higher. The bandaging is applied tightly and designed to squeeze out fluid which is still moveable. The excess fluid joins the lymphatic system beyond the damaged area and is excreted as urine. Alternatively, short stretch Velcro wraps may be used with similar effect (Borman et al., 2021). Complex decongestive therapy is a significant investment in staff time, materials, and patient commitment. Bandaging and limb constriction can be poorly tolerated; although patients were inspired to continue with the unpleasant experience of intense compression by the resulting reduction in limb size, improved mobility, and personal appearance (Costello et al., 2021). I am reminded of a patient who is reported to have said to their lymphoedema therapist, “the bandages are tight, but I will endure.”

Following the bandaging period, patients are fitted with compression garments which may be made to measure or purchased off the shelf. There are many varieties such as flat knit, round knit, Velcro wraps, knee high, thigh high, and panty type. They come in a range of colours and styles, although mostly functional. Transitioning into well-fitting compression is essential to retain the gains made during the intensive bandaging period (Costello et al., 2021). Continued wearing of compression garments is the single most important factor to manage swelling and complications such as infections, trophic skin changes, and loss of function and mobility (International Society of Lymphology, 2020). Information, advice, and support for adherence and self-care is critical. Many factors need to be taken into account, such as client preference, tolerance of the fabric, tolerance of constriction, ambient heat, affordability, and opportunities for other forms of compression such as medical taping or compression pumps (International Society of Lymphology, 2020). It takes time to adjust to compression garments so support, choice, and a therapeutic relationship with the health professional guide may scaffold the client into willingness/agreeability.

During the course of the treatment, patients receive manual lymphatic drainage which is designed to move lymph beyond the areas of blockage and encourage fluid drainage. Manual lymphatic drainage has been a standard of care for treatment of lymphoedema across the various body locations; however, evidence of effectiveness has not yet been demonstrated. According to a Cochrane Database review, evidence for manual

lymphatic drainage as a treatment for breast cancer related lymphoedema was inconclusive (Stuiver et al., 2015), and more recently again, with breast cancer patients, found to be no better than placebo even though the manual lymphatic drainage was guided by fluoroscopy (De Vrieze, 2020; De Vrieze et al., 2022). While manual lymphatic drainage has been recommended in best practice guidelines in the past (Armer et al., 2013; Lymphoedema Framework, 2006), it appears that support is waning.

Manual lymphatic drainage is a type of soft slow massage which is considered soothing and relaxing for clients (Woods, 2003). There is debate in the literature about the efficacy of lymphatic drainage (Thompson et al., 2021). Two Belgium studies used fluoroscopy guided imaging to highlight lymphatic blockages and pathways in order to measure the efficacy of manual lymphatic drainage. These studies showed that manual lymphatic drainage with fluoroscopy guided imaging did not statistically improve results and did not improve outcomes over the placebo group (De Vrieze, 2020; De Vrieze et al., 2022). However, research from the ALERT team at Macquarie University has found that a firm slow technique is effective at moving fluid through dermal backflow areas. This may explain why there is a variance in research on the efficacy of manual lymphatic drainage.

As this form of treatment undergoes analysis for effectiveness, it is possible that an opportunity for clients feeling safe and well-treated (Costello et al., 2021) while under the personal attention of a lymphoedema therapist may change. It is likely that therapists use the time during manual lymphatic drainage massage to build clients' knowledge and the therapeutic relationship.

The other two components of complex decongestive therapy are skin care and whole-body exercise, including deep breathing. Careful skin and nail care involves daily use of skin moisturiser, skin check including between the toes for potential infections, safe nail clipping, and prevention of injury (including sunburn) to reduce the risk of cellulitis (Vignes et al., 2021). Whole body exercise is recommended during the intense phase (Costello et al., 2021), with even mild exercise supporting lymphatic flow. There is no evidence that physical strengthening, fitness and conditioning leads to increased pain or a reduced quality of life. Further research is needed as the effect of exercise on symptoms, skin condition, and quality of life has not yet been determined (Johnson & Damarell, 2020). There is evidence that water based exercise is not detrimental, improves limb volume and quality (Maccarone et al., 2023), although the ideal type and level of exercise is unknown (Johnson & Damarell, 2020). Given the pathophysiology of lymph moving in response to musculoskeletal activity,

increased breathing, and the benefits of weight management, it is prudent to advise exercise appropriate for age and lifestyle. An ideal exercise routine is likely to be one that fits around lifestyle, is low cost or free, close to home, and undertaken without supervision from health professionals (Johnson & Damarell, 2020). The complexity of determining safe and effective exercise is that lymphoedema is a heterogenous condition, with non-standardised measures, therefore multi study comparison is difficult (Maccarone et al., 2023)

Pneumatic Pumps and Low-Level Laser

In Aotearoa New Zealand, some treatments are less available, such as low-level laser and intermittent pneumatic compression pumps. Low-level laser therapy provided by specialists was found to be effective (Paskett et al., 2012). External compression pumps were found to be effective in some studies (Armer et al., 2013) and in another study no more successful than usual care (Shao et al., 2014). Further research may be useful as some people may find pneumatic pumps more acceptable than usual care, and pneumatic pumps may provide treatment options when there is reduced mobility, lack of transport or trained staff, or in residential care contexts.

Surgery

There appear to be few surgical treatment options available locally. Advancements in microsurgery are improving the results of surgical intervention. Surgeries such as debulking through liposuction and lympho-venous anastomosis (connection) have gained ground along with vascularized lymph node transfer (Watanabe et al., 2019). The first surgery in a district health board was performed in Aotearoa New Zealand in 2016; however, lymphoedema therapists as a collective were not aware of any publicly funded lymphoedema surgery currently (personal communication, Lymphoedema Therapists' Google Group, 3 November 2022), although a lymph node transfer trial for upper limb lymphoedema was undertaken in this country with self-reported efficacy (Travis et al., 2015). Problems with lymphoedema developing at the donor site have been reported in surgery designed for Stages II-III (Schaverien & Coroneos, 2019; Watanabe et al., 2019). Surgery is able to reduce the vicious cycle of cellulitis and lessens limb volume (Schaverien & Coroneos, 2019). One potential drawback is that patients need to wear compression garments 24 hours a day for the rest of their lives (Allen & Cheng, 2016), although a reduction in a very large limb may and improved quality of life compensate and patients in need of surgery, often wore compression 24 hours a day prior to surgery .

Quality of Life

Quality of life embraces clusters of factors that impact varying spheres of life, such as the effect of symptoms caused by swelling which cascades to other issues including personal appearance and self-esteem, function, mobility, and managing life roles (Bowman et al., 2020). Sometimes this is referred to as health related quality of life, which centres the individual's perspective. Quality of life and symptom assessment are essentially patient focussed issues. Quality of life in this study focuses on health and wellbeing directly impacted by lymphoedema.

The literature appears to be dominated by survey based, quantitative literature with a physiotherapy focus. More recently literature focussing on the client perspective is emerging, although many treatment studies are assessed solely from a clinical outcomes position without recognising patients' preferences (Finnane et al., 2015; Karlsson et al., 2015; Yildiz et al., 2022), which seems counterintuitive with long-term conditions requiring self-care and client investment in time, energy, and resources. Despite the lack of robust literature and varying methodologies, there are many commonalities about the impact on quality of life across the methodologies (Chima et al., 2022).

Lower limb lymphoedema impacts quality of life across multiple spheres when compared with patients without lymphoedema. Unpleasant physical symptoms are experienced daily with restrictions on everyday life; the burden of self-care; disruption to coping, social, psychological, and emotional wellbeing; and a sense of being abandoned by health care services. Symptoms are subjective and, thus, can be more difficult to assess. To address this issue, a group of researchers developed the validated "Lymphedema Symptom Intensity and Distress Survey-Lower Limb" questionnaire (Ridner et al., 2018, p. 538). Through testing the questionnaire, 31 symptoms applicable to lower limb lymphoedema have been identified. Some of these symptoms are generic to lymphoedema and some specific to the lower extremity. The symptoms scores are sufficiently sensitive as to be diagnostic of lymphoedema, with or without other measuring.

Symptoms including fluid fluctuations are more intrusive in lower limb lymphoedema. The most consistently recorded physical symptoms in the literature were swelling, heaviness, pain, loss of range of movement, stiffness, limb fatigue, altered sensation, warmth or redness, skin changes, reduced mobility, and difficulties sleeping (Bowman et al., 2020; Chima et al., 2022; S. Ridner et al., 2012; S. H. Ridner, C. M. Bonner, et al., 2012; Ridner et al., 2018; D. P. Stollendorf et al., 2016; Yost et al., 2014). One participant with

breast cancer related lymphoedema explained it thus, “Until you get lymphedema, you cannot really know what it is. And, you are the only one who is bearing this plethora of perpetual discomfort every day” (Fu & Rosedale, 2009, p. 853). Symptoms of massive swelling vary less on a day to day basis. These symptoms include skin changes with skin folds, dry, flaky, brawny, fibrotic, hyperkeratotic (thickening of the) skin, giant verrucous nodules, non-pitting oedema, limb alopecia (hair loss), recurrent cellulitis, and lymphorrhoea (Hotta et al., 2015; Lawenda et al., 2009; Nowicki & Siviour, 2013; Renshaw, 2007). Lower limb lymphoedema is more severe and more likely to result in hospitalisation and complications than other forms of lymphoedema (Roberson et al., 2021).

The mental and social quality of life issues are complex with harm to personal appearance/self-image, emotional distress, loss of occupational and work opportunities, and loss of social activities and networks (Chima et al., 2022; Yost et al., 2014). Further issues include distress about being revealed; feeling discriminated against; and unsure about being received in public, even at clinic appointments (Costello et al., 2021).

Women are more likely to seek cosmetic solutions (Feins & Bairdain, 2015), possibly because of the differing social pressures to retain the idealised body. Women express distress at not being able to find clothes that fit with changing limb sizes, feeling lopsided, and loathing being limited for clothing choice and jewellery that does not fit (Costello et al., 2021; Crow, 2020). The impact is all encompassing across every sphere of life from self-image, personal presentation, to learning the activities that can be done safely, cannot be done, and what must be done to maintain wellness (Finnane et al., 2015).

Men’s self-esteem was impacted too with the onset of a condition associated with women, breast cancer, and body image, which Crow (2020) termed a feminisation of the condition, further isolating men. Cooper-Stanton and colleagues (2022), in a systematic review of literature, focussed on men’s experience of lymphoedema and found that issues of personal appearance were just as present for men but with fewer outlets for discussion. The authors recommended a tailored approach to men’s care and meeting other men with the condition. Crow (citing Harding, 2012) mentioned that men had made “derogatory comments” (p. 237) about their bodies. A changed body appearance and subsequent impact on self-esteem, along with managing a long-term condition, also led to emotional distress.

Emotional distress such as anger, anxiety, and depression accompanied the physical and social demands that lymphoedema wrought (Brown, 2018; Finnane et al., 2015; Ridner et al., 2018). Work capacity around the home and in paid employment was limited by

restrictions in mobility, concerns about increasing the risk of infections (Cooper-Stanton et al., 2022; Finnane et al., 2015; Keast et al., 2015; Tuğral & Bakar, 2017), along with feeling marginalised (Cooper-Stanton et al., 2022; Crow, 2020; Fu et al., 2013) as a result of having lymphoedema .

Everyday pleasures were hampered by advice such as avoid spa pools, saunas, deep massage, pedicures, waxing, and reduce standing (Jakes & Twelves, 2015; Lawenda et al., 2009). In addition, people mourned the loss of the person who existed before lymphoedema; the loss of freedom, efficiency, and energy; and considered that they were debilitated, aged before their time with concerns for future coping (Cooper-Stanton et al., 2022; Finnane et al., 2015; D. P. Stolldorf et al., 2016; Yost et al., 2014).

Exercise improved body image and sense of wellbeing (Paskett et al., 2012), and gentle land based exercise while wearing compression and water based exercise were considered safe (Maccarone et al., 2023). Quality of life impact was greatest on women who had both obesity or morbid obesity and lymphoedema (Costello et al., 2021; Yost et al., 2014). People living with lymphoedema faced a life of altered being, intrusive symptoms, and a demanding self-care regime. Given the nature of the condition with an association with cancer, it is interesting that in a systematic review of 18 studies on quality of life with lower limb lymphoedema, not one study included a spiritual component in the questionnaire (Chima et al., 2022). There is a developing body of literature on the patient experience of lymphoedema.

Self-Care

The burden of managing symptoms, the intrusiveness of symptoms, and self-care demands are a theme in the literature (Bowman et al., 2020; Yost et al., 2014). The realisation that lymphoedema was probably lifelong, progressively deteriorating requiring daily ongoing effort and symptom management that was physically, socially, and emotionally demanding was unexpected and intimidating (Bowman et al., 2020; Ridner et al., 2018). Some people expressed guilt about not doing enough self-care, which added to the burden (Crow, 2020; Lindquist et al., 2015) and many do not continue (Ochalek et al., 2015). Some people spend up to 2 hours a day on self-care activities (Lindquist et al., 2015), which have previously been described in this chapter as including whole body exercise, wearing compression garments, using a compression pump, avoiding even minor injury to the affected limb/s, protection from infections, skin hygiene and moisturising, time consuming self-massage, weight management, self-monitoring, and responding to concerns (S. H.

Ridner, M. R. Fu, et al., 2012). Common barriers to self-care include fatigue, pain, compromised mobility, skin changes, cellulitis, and disruption to psychological and social wellbeing including depression (Yost et al., 2014). Fatigue may relate to active cancer treatment, recovery from cancer or be associated with lymphoedema (Lindquist et al., 2015).

Taking a lifetime active role in their own treatment is a necessity for the person living with lymphoedema as there are currently no curative treatments (International Society of Lymphology, 2020; S. H. Ridner, M. R. Fu, et al., 2012), and even those successfully treated by surgery need to continue compression and self-care (Allen & Cheng, 2016). A systematic review by Ridner, Fu and colleagues (2012) found that recommended practice and self-care activities reflected prevention and treatment protocols at that time. Ten years later, treatment protocols are being refined as new evidence comes to hand (International Society of Lymphology, 2013, 2020; Lymphoedema Framework, 2006). Precautions have been lessened, as explained in this chapter, and the value of practices such as manual lymphatic drainage and self-massage are disputed (De Vrieze et al., 2022). The authors of a study on changing lifestyle to support the management of gastric reflux, posited that lack of clear protocols or changing guidelines may impact clients willingness to participate (Guadagnoli et al., 2022). The issues of carrying out burdensome self-care is further exacerbated by high health care costs and reduced capacity to work in paid employment (Bowman et al., 2020).

Health Care Costs

Direct health care costs associated with lymphoedema include hospitalisation, usually for cellulitis, supply of subsidised compression garments, and staff costs to monitor and support management. Other costs include long-term home care and clinic (district) nursing services to dress lymphoedema related lesions. It is difficult to ascertain the financial burden on the health care system of under treatment. A United States based study found that over 90% of hospitalisations were attributable to lower limb lymphoedema; but as the research used crude data rather than rates per 100,000 people, extrapolation of costs to Aotearoa New Zealand was problematic (Roberson et al., 2021). A compression supplier in Aotearoa New Zealand noted that many people with lymphoedema continue working, purchase their own compression garments, and do not incur significant costs to publicly funded health services (R. Kinnear, personal communication, 9, November, 2018).

A study reviewing health care costs of working-age women with breast cancer related lymphoedema, found that over 2 years direct health care costs were greater by about \$US15,000–23,000, than the control group. The increased costs were associated with

cellulitis, lymphatic inflammation, mental health care, and imaging (Shih et al., 2009). In a large study of over 56,000 who had undergone axillary lymph node dissection (Basta et al., 2016), the women living with complicated lymphoedema were five times more likely to have been admitted to hospital for any reason than women without lymphoedema. The health care costs for those with lymphoedema were 1.8 times greater over 2 years. As lymphoedema is a long-term progressively deteriorating condition, worsened by episodes of cellulitis (Teerachaisakul et al., 2013), it is likely that the discrepancy in health care costs would continue to diverge.

A study in Germany, where lymphoedema treatment in modern times was pioneered (Ko et al., 1998), found that costs for patients with lymphoedema in the community largely related to cellulitis and leg ulcers (Gutknecht et al., 2017). The study found that 77% of costs related directly to the condition of which 11% was borne by the patient, with the remaining 23% of costs related to indirect costs which included lost opportunities such as paid work. Due to differing health care, payment, and insurance systems it is difficult to correlate cost across jurisdictions. There is, however, evidence of lymphoedema associated costs which further support the feasibility of risk reduction, preventative measures, and early intervention (Gutknecht et al., 2017).

Gaps in the Literature

The lymphoedema literature is building strength from a meagre base. Much of the early literature had a biomedical and quantitative approach as does the medical and surgical literature today. It would appear from this overview of the literature that despite one recent article (Cooper-Stanton et al., 2022) there is little information about men and lymphoedema and the impact on quality of life for men specifically. Literature remains scant in the areas of primary lymphoedema, non-cancer lymphoedema, obesity related lymphoedema, head and neck and truncal oedema including genital oedema, lymphoedema in non-Western countries, lived experience particularly on non-breast cancer related lymphoedema, and quality of life with gross swelling.

Breast cancer related (upper limb) lymphoedema has received relatively more attention in the quality of life and self-management literature (Fu, 2014; Fu & Rosedale, 2009; Maree & Beckmann, 2016; Rhoten et al., 2015; S. H. Ridner, C. M. Bonner, et al., 2012). Despite this, overall the whole field remains under researched (Thomas et al., 2015). The literature remains sparse particularly in the areas of symptoms of lower limb and non-breast cancer

related lymphoedema from the lived experience, impact on quality of life, and issues related to self-care.

Fu and Rosedale's (2009) study corroborated the loss of the "pre-lymphoedema being" (p. 849) of lost freedom, competence, and energy. A participant from their study reported, "Lymphedema has slowed me down. I can no longer be a get-up-and-go person because things with lymphedema cannot be done in a speedy way, like putting on the sunscreen, doing self-massage, exercising, putting on the [compression] sleeve and glove" (Fu & Rosedale, 2009, p. 855). Literature on how people recover or do not recover from the diagnosis is almost entirely absent and forms only part of the findings of two qualitative studies (Karlsson et al., 2015; Lindquist et al., 2015). There is scope for looking at how people manage following a diagnosis of lower limb lymphoedema.

Summary

In the words of Rockson and Rivera (2008), lymphoedema is an "elusive" (p. 147) condition, and embarking on studying lymphoedema felt like entering a terrain of uncertainty. The question arises as to whether lymphoedema has been an 'orphan' without medical advocates. There was a lack of services for lymphoedema (Cooper, 2010), and the condition was poorly understood by health professionals and the public (Stout et al., 2013). The lymphatic system has been under researched, and the quality of evidence described as poor. There was an absence of clear internationally agreed definition and assessment methods, making correlations problematic. The incidence and prevalence are poorly understood; and the health care cost, burden, and quality of life are hidden.

Much of the literature reviewed has a biomedical focus, with a growing body of evidence about the lived experience of lymphoedema and self-management. Living with lymphoedema involves regular follow-up appointments, arduous self-care including daily exercises, wearing and washing compression garments, skin care (Costello et al., 2021; Fu, 2014), and moisturising whilst avoiding getting cream on the expensive compression garment. The routines are time consuming, detract from restorative activities, and some people have repeated episodes of cellulitis to manage. The symptoms are intrusive and lifelong (Fu et al., 2014; Ridner et al., 2018). Self-esteem is affected on an everyday plane. There are issues of finding clothes to fit an asymmetrical body, needing to choose clothes to cover up, and being limited in style (Rhoten et al., 2015). Health care costs are increased (Basta et al., 2016; Fu, 2014); and for many the ability to earn is reduced by a lifetime of impairment. The under researched challenges to everyday life and life course for people in

Aotearoa New Zealand led to my research question, what does it mean to understand how people live with moderate to severe lower limb lymphoedema?

Chapter 3 Research Methodology

Introduction

The research question is “How do people live with moderate to severe lower limb lymphoedema?” Phenomenology was considered and relinquished. The final aim of the research was to understand the process of living with lymphoedema in order to provide insight for those living with lymphoedema and those providing services and support, such as lymphoedema therapists and other health professionals. Grounded theory was chosen because it provided the potential to explicate a process that could be packaged to deliver succinct insight into the social context, meaning making, and evolving experience of clients living with lymphoedema. Other factors when considering the research methodology were my insider perspective and social justice orientation. Living with upper limb lymphoedema, I wanted to maximise the value of theoretical sensitivity while recognising that the findings needed to reflect participant data. Charmaz’ (2014a) version of grounded theory was chosen as a methodology that enabled co-construction of the research with participants and accommodated social justice perspectives. The pragmatic underpinning of grounded theory had the potential to achieve clinically relevant findings that could be readily absorbed by busy clinicians and understood by those who were not health professionals.

The following two chapters set out the methodology—including positioning the research and a description of constructivist grounded theory—and methods used in the study. Chapter 3 begins with a short historical overview of grounded theory. I explain the epistemological underpinnings of constructivist grounded theory including pragmatism, symbolic interactionism, constructivism, and sensitising concepts.

Grounded Theory: Historical Overview

Understanding the historical and philosophical frameworks of the Charmaz version of grounded theory were important first steps to undertaking the research. Grounded theory was first posited by Anselm Strauss and Barney Glaser in their ground-breaking work “*The Discovery of Grounded Theory*” (Glaser & Strauss, 1967). The original conception of grounded theory resulted from the combination of Strauss and Glaser’s intellectual and philosophical traditions (Glaser, 1992). The research methods were developed through methodical review of their own research processes, priorities, and decisions. The two academics met at the University of California, where Strauss gained a position in the School of Nursing in 1960

(Birks & Mills, 2015). Strauss had studied sociology at the University of Chicago, influenced by Herbert Mead and symbolic interactionism. The University of Chicago also had a reputation for pragmatism influenced by the work of John Dewey (Birks & Mills, 2015; Strauss, 2008).

Glaser studied at Columbia University in the late 1950s in an academic environment influenced by Merton and Lazarsfeld. Robert Merton advocated for sociological research based on verifying hypotheses generating middle range theory. Paul Lazarsfeld developed new ways to collect and analyse data, leading to substantive findings and methodological refinements through the use of secondary quantitative data (Barton, 2001) which “inadvertently lead to discoveries of new social patterns and new hypotheses” (Glaser & Strauss, 1967, p. 186) thereby developing new sociological theory. Qualitative ethnographic and field work research were experiencing an upsurge in the 1960s and 1970s; yet, there was a dearth of analytic strategies and methodological texts for undertaking qualitative research (Charmaz, 2014a). Glaser brought a quantitative orientation to the development of grounded theory and contributed a methodical positivist approach, empiricism, coding, and the quest for mid-level theory development (Glaser & Strauss, 1967).

Amsteus (2014) concluded that a major flaw in the early grounded theory writings was that methodological and philosophical underpinnings of the new research processes were not sufficiently articulated. The underpinnings of Strauss’ grounded theory, namely symbolic interactionism and pragmatism, were eventually conveyed in the publication by Corbin and Strauss (2008) and further elaborated by Charmaz (2008c, 2014a). Glaser considered that Strauss remodelled grounded theory through preconceived forcing of the data resulting in research that strayed from grounded theory principles, and that the joint work of the two founders of grounded theory differed significantly from the outset (Glaser, 1992). Eventually, Strauss and Glaser went on to develop grounded theory in different ways with Strauss conveying the method and methodology including interactionism and pragmatism (Corbin & Strauss, 2008), which was first published in 1990.

Theoretical Perspective

Symbolic Interactionism

Essentially, symbolic interactionism is a sociological perspective that interprets the ways people choose to act with a focus on interaction and process. Symbolic interactionism postulates that interaction between individuals establishes symbolic worlds. These symbolic

worlds exist in peoples' perception of themselves, others, and the way others view them. Interactions and the memory of past interactions shape peoples' worldviews, behaviour, and the meaning they make which, in turn, shapes society. Thus, society is created through repeated interaction and perceptions of interactions (Strauss, 2008). Symbolic interactionism guides the researcher into understanding the meaning people make of phenomena, through understanding the nature of participants' reactions and interactions.

Blumer's (1969) symbolic interactionism forefronts the agency of the individual, and the power of social interaction to shape peoples' actions. Interactions—past and present—form society and portray meaning, within the socio-cultural context. Interaction is thus a symbolic process revealed through language (Charmaz, 2014a), spoken and unspoken. People inhabit both a physical and symbolic world. Communication and behaviour depend upon beliefs of a shared understanding and shared meaning making (Charmaz, 2014a). Meaning is made through analysing language and communication (Charmaz, 2016). Understanding comes through naming and labelling which is usually value laden. Thus, renaming creates a reframing of perception and, potentially, identity (Charmaz, 2014a). “Symbolic interactionism views interpretation and action as reciprocal processes each affecting the other” (Charmaz, 2014a, p. 262).

Symbolic interactionism is not an explanatory theory identifying variables or consequences, rather it is a lens or perspective (Charmaz, 2014a). There are three recognised foundational concepts of symbolic interactionism: firstly, action is based on the meanings people make; secondly, meaning comes from human interactions; and thirdly, people interpret the social interactions and meaning with self-agency (Blumer, 1969). Using the lens of symbolic interactionism the researcher seeks to understand the meaning of participants' experiences, timeframes, change points, reasons for changes, and the resulting change in experience or meaning (Charmaz, 2014a).

Interaction and responsive reconsiderations change the way people act, resulting in feedback and feedforward leading to open ended, dynamic social processes. Symbolic interaction holds that change is inherent within the system, including the image people hold as reflected by others. This concept, known as Cooley's 'looking-glass self,' explains the impact of other's perception on self (Charmaz & Rosenfeld, 2006). Simply put, this could mean that I see me in the way that you reflect me. People hold internal dialogue about the perceptions of others which may be internalised and accepted or rejected as unfair or incorrect (Charmaz, 2014a). People act in response to their interpretation of the

circumstances and the meaning they make. Participants in my study spoke about the impact that the stares of strangers had on their self-esteem, especially in the early days after the swelling developed, when they were still coming to terms with their new shape and gait. The experience of being stared at, being ‘othered,’ or treated differently by society because of how they looked, affected how they felt about themselves. In turn, participants said that they became careful about how they looked at others with visible impairments. Participants also spoke about becoming motivated by what they felt.

Symbolic interactionism assumes that society existed prior to the individual. Peoples’ individual and collective interactions re-create society, consciously and unconsciously. Everyone contributes to the building of society, no matter how minute the contribution. Thus, society is recognised as fluid, shifting, and evolving. In turn, we are all shaped by society and accept or resist such shaping in varying ways, again reflecting human agency (Charmaz, 2014a).

Symbolic interactionism is suited to qualitative research, such as how people live with lymphoedema, when the social setting and circumstances are included in the investigation. The diagnosis of lymphoedema and the experience of uncontrolled bodily swelling is unsettling on many levels of identity and marks a change in people’s self-perception and experience in the world. Some people develop lymphoedema following a diagnosis of cancer and lymphoedema may thus be associated with an existential crisis; while for others, lymphoedema comes out of the blue and may disrupt an otherwise normal world. These experiences provide a highly interactive and change rich research setting.

Constructivist grounded theory holds that people respond to the sequence and markers of time, actions, and processes which are intertwined (Charmaz, 2014a). In my study, participants experienced lymphoedema differently across time, learning to adjust and manage as time went on. There was a continual focus of asking “what is happening here?” in order to understand how participants managed their lives and the part that lymphoedema played in their life. This approach is in line with symbolic interactionism which is underpinned by pragmatism as the philosophy that supports traditional grounded theory.

Grounded Theory and Pragmatism Epistemology

Strauss brought pragmatism to grounded theory (Corbin & Strauss, 2008) and a focus on human processes as opposed to social structures. Pragmatism contributes to philosophy and qualitative research methodology through the inclusion of scientific processes of

analysis and interpretation to the experience of being human. Pragmatism arose in the United States in the 1870s founded on the work of Charles Sanders Peirce and William James, who influenced both John Dewey and George Herbert Mead (Emirbayer & Maynard, 2011).

Pragmatism maintains an open ended perspective and is aligned with symbolic interactionism through an emphasis on language and action in response to situations (Charmaz, 2014a). In a pragmatic worldview, reality is shifting with numerous explanations and interpretations. Pragmatism is useful for research such as understanding how people make meaning following a diagnosis of lymphoedema. Recognising that the meaning of interactions cannot be known prior to an action, and significance and meaning are understood after the social interaction or experience (Denzin, 2012), requires of me, as a researcher, to avoid assumptions of what I already know about the topic.

Mead's (1932) concept of emergence, from the early 1930s, recognised the contribution of personal history to ongoing interactions and meaning, and fosters researchers to review the impact of change on situations (Charmaz, 2014a). Developing lymphoedema and adjusting to a new way of being is a dynamic situation befitting to analysis through personal narrative. It is through experience that beliefs and actions unfold, and meaning is made through the interplay of those beliefs and actions. Dewey, a key thinker in pragmatism, presented the model of reflection on actions to adopt beliefs and reflection on beliefs to adopt actions (Morgan, 2014).

Pragmatism underpins this research with the assumption that practice experience is a prerequisite of knowledge development and that practice is inextricably connected to theory development (Doane & Varcoe, 2005). Morgan (2014) clarified the meaning of pragmatism for social science research as a means of valuing and recognising the ways people solve complex problems. Pragmatism in research reorients the approach from conceptual to action or experience (Morgan, 2014). Thus, pragmatism supports the purpose of the research through guiding theory that is translatable into practice. For this reason, pragmatism fits well with practice-based disciplines such as nursing. My research was designed to develop original research useful to practice.

Epistemology of Social Constructionism

According to Charmaz (2008c; Bryant & Charmaz, 2011b) there is an epistemological fit between grounded theory, symbolic interactionism, and social constructivism. Symbolic

interactionism assumes reality is understood to be created by people, through personal and shared interactions (Charmaz, 2008a). “(S)ociety, reality, and self” (Charmaz, 2014a, p. 9) are understood and created through action by self and in relationship with others (Charmaz, 2008a). The researcher, too, is part of the dynamic interactive process. Hence, it was essential for me, the researcher, to be self-reflective about my influence on the research process and, in turn, how the research process influences me.

Social constructionism was a move away from structuralism in which structures were viewed as stable with an inherent equilibrium existing beyond the people who inhabit the structures. There is a synergy between social constructionism and symbolic interactionism as both value language as a symbol for making meaning (Leeds-Hurwitz et al., 2006). The authors continued that whilst symbolic interactionism has a focus on the individual and seeks to understand social roles, social constructionism seeks to understand the characteristics and structures related to the social world. The quality of the research is evaluated by the level of trustworthiness and authentic representation of the phenomena under study.

Constructionism offers a paradigm about knowledge. It is a subjective epistemology in which people are inseparable from what they know. Certainty is rejected and subjective realities are valued. Social constructionism is based on the premise that reality is collectively constructed and evolving through interaction (Birks & Mills, 2015; Charmaz, 2014a) and knowledge constructed by society. Society persists both as an objective and subjective reality. Individuals and communities share understanding which produces a taken-for-granted reality. Reality is defined and redefined by society leading to an understanding of subjective human experience. Social constructionism focusses on the existence of everyday life and subjective experiences and humanity in contrast with scientific knowledge. In Charmaz’ version of constructivism, the aim of the research is to uncover and understand realities. The experience of the phenomena begins to be understood through analysing the multiplicity of meanings.

Constructivist Grounded Theory

Constructivist grounded theory is distinguished from constructionist grounded theory as Charmaz sought to differentiate the new social constructivist model from constructionism which recognised research spheres as social constructions, but which did not include the actual researcher’s subjectivity, interpretation, or participation in the research process (Charmaz, 2008a, 2014a). Constructivist grounded theory methodology

accommodates perceptions of power, rights, quality of life (Casper, 1997), and social justice which is aligned with a respectful research process that investigates the ways people live after the diagnosis of a long-term condition.

Constructivist grounded theory provided a strong platform of methods for people like me as a novice researcher. In constructivist grounded theory, multiple perspectives and voices are recognised, and knowledge is co-created by both the participants and the researcher. Both parties are moulded by their subjectively constructed meaning related to their situation and context. To retain clarity, the researcher reflects on their own processes and data to discern influences and the impact of their own values and assumptions on the research. The voice of the researcher is inherent in the findings; and participants' understanding and knowledge is safeguarded through the process of grounding findings in the data (Lincoln et al., 2011). To retain clarity, I reflected on my own processes and data to discern influences. As a researcher who lives with the condition under investigation, the perspectives that I bring need to be transparent (Chapter 3, Emic and etic perspectives).

My study used grounded theory, specifically, social constructivist grounded theory method and methodology based on Charmaz (2008a, 2014a, 2016). Constructivist grounded theory supports both a methodology and a method for research (Charmaz, 2014a). Using Charmaz' (2014a) constructivist grounded theory approach provided scope for inductive, deductive, and abductive analytical research processes. Abductive reasoning, developed by the philosopher Peirce, involves drawing logical interpretations through applying the most straightforward and most probable interpretation (Charmaz, 2014a). Social constructivism is based on the now non-radical notion that all the perceived world is socially constructed (Hacking, 1999), including the contribution of the researcher (Charmaz, 2014a).

Individual constructivism, as the name implies, relates to an internalised psychological perspective in which reality is constructed by the individual who develops knowledge based on their individual past experiences and interactions, through reasoning and symbolically converting past interactions into a personal perspective. An example of this is Piaget's developmental theory (Watkins, 2000). Whereas in social constructivism, reality is constructed through the interaction of communities of people, such as those living with lymphoedema. Knowledge and meaning are established through repeated interactions, historical interactions, and shared beliefs. The meaning people make of situations changes over time in response to societal interaction (Watkins, 2000).

Charmaz' Version of Grounded Theory

The original grounded theory research process has evolved into several differing approaches and variations that preserve key components. Epistemological and ontological perspectives have varied. Key thinkers in grounded theory have responded to differing epistemological influences and contexts (Bowers & Schatzman, 2016; Charmaz, 2014a, 2016; Clarke, 2003; Corbin & Strauss, 2008). Grounded theory variations all share a set of core elements that define the research as grounded theory. Charmaz (2016) considered that grounded theory “represents a constellation of methods” (p. 95). Bryant and Charmaz (2011b) contended that these variations need to be viewed as offering insights additional to, rather than detracting from, original grounded theory. The authors further stated that because grounded theory was originally based on a positivist paradigm that there is a need “to some extent [to] dismantle the method from its initial formulations” (Bryant & Charmaz, 2011a, p. 51). In summary, grounded theory is a systematic qualitative research methodology and method for the purpose of constructing “theoretical explanations of social processes” (Charmaz, 2014a, p. 7).

Bryant and Charmaz (2011a) contended that the strength of original grounded theory (Glaser & Strauss, 1967) is in the method, and Charmaz and colleague challenged the validity of a positivist epistemological approach. Positivism assumes the existence of a single knowable reality in which sociologists of the day would observe the same interactions and processes within a situation and draw similar conclusions. Grounded theory could, therefore, be ‘discovered’ (Bryant & Charmaz, 2011a). Constructivist grounded theory rejects the positivist paradigm of shared observable, objective reality, recognising an understanding of more than one reality (Bryant & Charmaz, 2011b). The authors asserted that both participants and researchers are active constructors of their world, and the subjectivity of the researcher infiltrates the research process and findings as the researcher employs a dialogue with the data (Bryant & Charmaz, 2011a; Charmaz, 2016).

Sensitising Concepts and Inductive Reasoning

The term sensitising concepts was postulated by Blumer and derived from the epistemology of symbolic interactionism (Van den Hoonaard, 2008). Blumer’s (1969) landmark publication identified the need for social theory beyond empirical concept classification. Blumer explored the need for research into sociologically relevant concepts that aligned with observations of natural world thinking and every-day practices. These sensitising concepts have fewer specific characteristics and suggest the path for research enquiry, compared to the fixed nature of definitive concepts. A “sensitizing concept lacks

such specification of attributes or benchmarks and consequently does not enable the user to move directly to the instance and its relevant content. Instead, it gives... a general sense of reference and guidance in approaching empirical instances” (Blumer, 1954, p. 7).

Sensitising concepts offer a starting place through which the researcher uses background and theoretical understanding to cautiously track and categorise concepts that arise during the research (Charmaz & Belgrave, 2014). The goal is to hold the potential concepts gently while seeking affirming data from participants, thus allowing the sensitising concepts to frame open ended questions to confirm or refute the emerging ideas. The researcher holds the possibility of either outcome while using reflexivity and theoretical sensitivity to discern whether their assumptions are forcing the data rather than grounding the data in the participants’ experience and voice (Charmaz, 2014a). These concepts are harnessed through the researcher’s theoretical sensitivity and ability to discern concepts applicable to the developing theory (Birk & Mills, 2015). The use and exploration of sensitising concepts is pervasive throughout grounded theory studies (Bowen, 2006).

In this way, sensitising concepts provide a perspective or guidance to the researcher for an avenue to pursue—opening possibilities to build analysis (Blumer, 1954). Sensitising concepts fit with symbolic interactionism and constructivism through supporting a subjective, relativist approach with fluid realities, interpreting social interactions requiring reflexivity and inductive reasoning (Charmaz, 2014a). Whereas theoretical sensitivity belongs to the attributes and personal qualities of the researcher, theoretical sensitivity supports the ability to interpret nuances of meaning in the data. Theoretical sensitivity may be developed through literature, research, and exposure to the phenomenon in varied contexts including clinical experience and judgement (Corbin & Strauss, 2008).

Inductive reasoning is used to draw theoretical concepts from sensitising notions and is a distinctive characteristic of grounded theory (Charmaz, 2014a). Inductive reasoning in research involves collecting evidence within a specified scope, identifying patterns and drawing a hypothesis as explanation for the observation through interacting with the data, while deductive analysis entails using established frameworks (Patton, 2003).

Grounded theory uses inductive reasoning and abductive logic. Evidence is collected within a specified scope, patterns identified, and a hypothesis is generated to explain the observation. Thus, inductive logic starts with the specific and draws more general conclusions. The observed experiences are abstracted towards a generalisable understanding. Inductive reasoning has the capacity to increase human knowledge as new

theories can be created. However, errors can occur as there is the possibility that something that could disprove the conclusion may not be perceived in the observation timeframe (Bryant & Charmaz, 2011a). Grounded theory provides strategies to analyse data, and early analysis accelerates the investigation and keeps enthusiasm and momentum going (Charmaz, 2014a).

Glaser and Strauss (1967) introduced inductive reasoning, sensitising concepts, and symbolic interactionism. The emphasis at the time of writing (1960s) was on explicating qualitative research methods (Milliken & Schreiber, 2012). Constructivist grounded theory uses a more overt epistemological base through emphasising researcher subjectivity, sensitising concepts, inductive reasoning, reflexivity, and social context (Bryant & Charmaz, 2011a). Consequently, constructivist grounded theorists consider the context of data collection, quality issues, relationships between parties, subjectivity, and the researcher's social location (Charmaz, 2014a), and repositions grounded theory away from a positivist stance. Social constructivism moves beyond the psychological and individual realm into social worlds. This repositioning is more closely aligned with current interpretive thinking of shifting realities and working with ambiguity (Bryant & Charmaz, 2011a).

Constructivism has grown from constructionism as espoused by Strauss (Charmaz, 2008b), in which realities are understood through analysing what processes people used to construct their social reality and the products of that social reality; specifically, the 'what' and 'how' of social reality. Constructivist grounded theory values symbolic interactionism, as an optional path, left to the individual researcher to assess the usefulness and appeal (Charmaz, 2014a). In the current study, symbolic interactionism will provide the basis to understand social processes and pragmatism will guide the research towards a practice-based theory.

Emic and Etic Perspectives

Emic and etic perspectives provide differing lenses through which data may be interpreted. The emic perspective provides an insider's view of the world under study, while etic knowledge is derived from scientific and second-hand sources. The terms are originally derived from linguistics and over time have come into social science research arenas (Harris, 1976; Headland et al., 1990). The emic perspective has the potential of providing insight into the internal thinking and belief systems of the people in the study group because the researcher brings their own experience of that world. Research with an emic perspective seeks to understand the norms from the perspective of the group under study (Tripp-Reimer,

1984). Harris (1976) considered that the etic perspective observed and interpreted behaviours, and in all events there was a need to separate conscious or unconscious thoughts and assumptions termed “autocognitions” (p. 331).

It is unhelpful to view emic and etic positions as being in opposition (Beals et al., 2020). The researcher may be positioned somewhere on a metaphysical continuum depending on their role and the social context of the research (Hoare et al., 2013). Constructivist research could, therefore, be construed as inherently emic, whether or not the researcher belongs to the group under study. Pike (1967) considered research with an emic perspective as derived from an investigator who understands the mechanism (the processes and activities involved) and “total system” (p. 38) of the phenomenon under study.

Researchers may view themselves as insiders and members of a community which, in turn, holds a nuanced position that does not accept the researcher as an insider (Olive, 2014). Researchers are often inherently privileged and positioned within academia which is aligned to an etic perspective and, as such, directs the narrative (Beals et al., 2020). Beals and colleagues (2020) argued that the position of the insider who is marginalised within academia can occupy a space at the margins moving between cultural worlds without compromising their identity in either sphere.

Researcher Position

It has been an interesting journey for me. I sit in the place as described by Olive (2014) somewhat an insider but not fully so. While I trained as a lymphoedema therapist I have not practiced as one and do not hold the privileged knowledge of those therapists. I have walked alongside them, attended and presented at lymphoedema conferences, and spent hours discussing lymphoedema as a clinical issue. I bring a nursing health professional insider perspective and hold a nursing frame of reference.

I have mild lymphoedema of the arm which, while it is well controlled, was an enormous effort in the beginning. I also have mild venous origin swelling of both legs. I wear compression stockings daily and understand the epic effort of self-management. However, I have not battled stigma as my arms and legs look almost normal when not in compression garments. I have also used the developing theory in conversation with people living with newly diagnosed lymphoedema and watched the impact on them of meeting someone who understood. I have seen the resonance for them of the understandings I have derived from this research.

What stood out for me were the moments of emotional connection to the data. I recall several occasions where I found a participant quote that explained just how burdensome the journey to self-management was, and I wept. At one stage I took about 300 codes printed and cut up into small pieces of paper and pinned them on a board under labels of my developing categories and subcategories. When it was complete, I was very emotional as though I had unlocked some subliminally known knowledge which truly was inside me waiting to be 'discovered.' There have been many such incidences during this research quest.

I am a naturally reflective person because I can recall stories of my own reflections many years before being introduced to Schon's theory of professional reflection first published in 1984 and republished more recently (Schön, 2017). I undertook a presuppositions process prior to starting interviews, which is detailed later (Chapter 4 Methods. Preparation to interview). To maintain reflective practice, I kept a journal and memos of my thinking and developing analysis and sought to reveal my unconscious thoughts and assumptions. I found many thoughts would emerge whilst I swam every day.

Summary

This chapter discussed my understanding of the epistemological, theoretical, and methodological underpinnings driving this research. The rationale and implications for the use of social constructivist grounded theory with symbolic interactionism, pragmatic foundations, and complex interplay of similarities and synergies amongst the theoretical underpinnings have been explicated. The dynamic nature of meaning, interaction, reflexivity, and co-construction has been explained. In the following chapter, I explain how the research methods further propelled and shaped my research.

Chapter 4 Research Methods

Introduction

The previous chapter explained grounded theory methodology and this chapter describes the methods and procedures used in my study. There are core elements that define grounded theory methods. These methods are concurrent data collection and analysis, data driven coding and categorising, constantly comparing data and incidents, inductive reasoning to construct abstracted categories, memo writing to support analysis, sampling based on the need of the developing theory, researcher theoretical sensitivity, avoiding preconceptions derived from literature and progressive abstraction to theory (Birks & Mills, 2015; Bryant & Charmaz, 2011a; Charmaz, 2014a).

The first part of the chapter outlines grounded theory methods, followed by an explanation of how grounded theory methods and procedures were used in this study. This chapter is presented in chronological order in sections related to the ethics approval process and considerations; sampling and recruitment; gathering data; data analysis; evaluating research – credibility, originality, resonance, and usefulness. Although these methods are itemised separately, the measures are non-sequential, entailing a weaving of the methods simultaneously with the goal of developing mid-range theory (Charmaz, 2008b). Charmaz (2014a), stated that “(m)ethods *are* merely tools” (p. 26) [original emphasis]. When used diligently and with reflexivity, methods can engender, extract, and fathom data. Charmaz added that each grounded theory study is unique, and methods offer guidance rather than strict protocols with processes to be followed.

Ethical Considerations

Ethics approval was obtained from the university ethics committee for research processes, including guidance on participant information sheets and all advertising (Auckland University of Technology Ethics Committee 17/350, Appendix A). The study began with tight inclusion and exclusion criteria which were later modified. Initially, inclusion criteria included adults aged 20 years or over, living in the Auckland region, who had undergone lymph node surgery or with confirmed moderate or severe lower limb lymphoedema, diagnosed at least 3 years prior by a lymphoedema therapist or a specialist. Based on looking for gaps in the literature, a decision was made to focus on lower limb lymphoedema. Despite reviewing the epidemiological literature on lymphoedema, no data

on the percentage of cases of upper limb compared to lower limb lymphoedema has been found. Breast cancer related upper limb lymphoedema research appeared to predominate. As non-limb lymphoedema appeared rarer there was concern that recruitment could be problematic. Exclusion criteria initially required participants to be taking two or less prescribed medications with no other conditions that could cause swelling such as heart or kidney disease or secondary cancer.

Ethics was approved with minor changes. I initiated four further applications for amendment to ethics committee. Three amendments were to facilitate recruitment, which was slow and included seeking to recruit outside the Auckland region and removing the exclusion criteria which limited participants who were prescribed two or more medications and relaxing the earlier requirement that participants were 3 years post diagnosis, thus allowing participants more recently diagnosed. On reflection, the exclusion criteria related to taking more than two doctor prescribed medication was not useful. The goal of the study was to explore how people lived with lymphoedema from different causes. The request to recruit participants diagnosed less than 3 years related to theoretical sampling. Another amendment was sought to recruit via social media.

The fourth ethics amendment related to a situation that arose during interview. An unexpected party (the participant's husband) sat in on the interview and spoke. Their data added richness and ethical advice was sought. The ethics advisor recommended requesting retrospective consent from the third party which was obtained within a week and approved by ethics committee.

Recruitment was mainly via flyers given to lymphoedema therapists for placement in a clinic, information emailed to lymphoedema therapists, and advertisements in the Lymphoedema Support Network communication to members. Potential participants made contact directly with me by email or phone. I then ensured that the inclusion and exclusion criteria were met, explained the study and the purpose of the research. I emailed or posted the Participant Information Sheet (Appendix B) and Consent Form (Appendix C). When the potential participant had received the information, I rechecked that the participant met the criteria and wanted to go ahead. Interviews took place at the participant's choice of venue, such as home, lymphoedema clinic, work or in a private room at AUT University. Eleven of the 12 participants were interviewed face to face. Four participants were from out of town and one of these participants elected to be interviewed over the phone rather than by face to face or video call. At the interviews I reviewed the information sheet and consent which was signed in person. Permission to audio record and transcribe interviews was obtained.

Recalling and reflecting on past events can bring unwelcome responses (Kalu & Bwalya, 2017). I prearranged access to AUT Health and Counselling services which was passed on to participants and was included in the Participant Information Sheet (Appendix B). I provided assurance that participants could contact me if the interview caused any unwanted thoughts or feelings. No participant followed up either with the professional offer of help or with me. I arranged to follow up with one participant, who had been diagnosed for less than 2 years and did not have an identified lymphoedema therapist for support. As agreed at interview, I checked back in with the participant who confirmed she was affected by the interview but did not consider she needed further follow up. My goal was to recognise the power imbalance inherent for all participants and to create as safe a place as possible.

Literature Review and Theoretical Sensitivity

From a pragmatic perspective, researchers undertaking study or applying for grants need to demonstrate an understanding of their field of study. It is unrealistic that researchers would avoid reading the literature (Thornberg, 2012). As is to be expected, I brought pre-existing knowledge of both the literature and the field of study through living with lymphoedema, being a lymphoedema educator in the past, and undertaking previous study. These pre-existing understandings are known as theoretical sensitivity (Charmaz, 1995b). Theoretical sensitivity refers to the researcher's propensity and proficiency at interpreting and sifting data germane to the nascent theory (Birks & Mills, 2015).

Like others, my theoretical sensitivity was developed through professional and personal life experience, which was augmented by techniques and tools of analysis, and continued to build as the study progressed (Birks & Mills, 2015). Drawing on Blumer, Charmaz (1995b) discussed theoretical sensitivity as supporting the researcher to seek out and analyse preconceptions which can then sensitise the researcher and heighten awareness of processes and issues in the data. In this way, the novice researcher, such as me, uses this theoretical sensitivity to provide insight into participants' motivations and actions. There were times during interview and analysis when I considered that my theoretical sensitivity supported further questioning and exploring. I also noticed that some ideas were not further substantiated and that other ideas that did not initially hold traction with me grew to become important. I had a negative reaction to one participant who seemed dismissive of the impact of lymphoedema with his repeated use of the term "it is what it is." Yet, this idea grew through corroboration. As discussed earlier, the advantage of the emic perspective

needed to be balanced by my own reflexive process and grounding the developing theory in the data.

Charmaz (2014a) advised that researchers can critically review and compare the literature relevant to the area of study, then leave the knowledge dormant until after the categories have been developed (Charmaz, 2014a; Charmaz & Thornberg, 2021). As is suggested I undertook a second literature review after theory development in order to deliberate on extant theories and literature that could support or contradict my findings. Thornberg (2012) contended that there is value in researchers reviewing the literature to achieve greater insights through using pre-existing wisdom and decrease the risk of insignificant findings or the false belief that their theory is new. In my case, I identified literature that supported my findings and two theories that corroborate my findings. My findings add depth and breadth to these models which have the potential to enhance clinical practice. As I had chosen grounded theory, I did not actively keep up with the lymphoedema literature during the research process until the theory development stage. The first step was to source and collect data.

Sources of Data and Sampling

In grounded theory, primary data may comprise participants' setting, interview material, observation at the time of interview, descriptions, field notes and documents (Charmaz, 1995b). Data were constructed through observing, interacting with, and insights from data. These forms of data were used in this study excluding documents. As a researcher I needed to sense what was happening, attune watchfulness and listening, with the backup of note taking and audio recording. In this way the research fitted with grounded theory in which actions and experiences are studied, and concepts induced using the researcher's knowledge, senses, and experience (Charmaz, 1995b). Feedback received after interviews indicated that participants appreciated the opportunity to reflect on actions, experiences, and the subjective meaning they made through thoughts and feelings of their situation, and also offered the researcher rich data to support analytic insights as recognised in the literature (Charmaz & Belgrave, 2014).

Data Sources

Interviewing was determined as the preferred method of gathering relevant data for this study and is the most practical way to collect data in grounded theory. Participants with personal experience of the phenomena under study can provide comprehensive, empirical, rich data (Charmaz, 2014a). Data were provided by participants who met the study criteria.

One participant spoke after recording had stopped and I asked the participant if they would consider writing the related thoughts, which they sent me in an email a day later. I added the email contents at the end of the transcript. Another participant emailed their lymphoedema therapist to enquire as to whether they fitted the participant inclusion criteria of moderate to severe lymphoedema. The participant sent me the therapist's email and gave consent for the information to be included in her data. In addition, field notes recording thoughts, feelings, and experiences were written at the time of interview.

Participants and Sampling

Initially the plan was to recruit participants aged over 20 years who had been formally diagnosed with moderate to severe lower limb lymphoedema from any cause, at least 3 years prior to joining the study. The rationale for interviewing at least 3 years after diagnosis was that the development of lymphoedema often follows treatment for cancer, general surgery, or trauma although it may arise unexpectedly because of a poorly developed or physiologically inadequate lymphatic system. In any situation, constructing a life after developing lymphoedema takes time. Adapting to long-term conditions can be complex (Charmaz, 1995a). Thus, people more experienced at adapting to lymphoedema were initially recruited.

The goal had been to interview participants from a diverse range of demographic features (see Participant Characteristics, Appendix D). However, the first five participants were New Zealand European (NZE) women, of whom four were aged in their 60s. Participant selection and interview timing were influenced by participant availability and the plan to space interviews sufficiently to provide time for analysis. After the first five interviews, an email was sent to about 70 lymphoedema therapists across the country seeking participants from a range of backgrounds. Two men were then interviewed on the same day in a provincial city and 2 months later another man from rural and remote Auckland. All men were NZE aged from mid-60s to mid-70s. In total eight participants were aged in their 60s, one in their 70s, and one each in their 30s, 40s, and 50s. Eleven participants were NZE, despite the request to lymphoedema therapists for a diverse range of ethnicities. Eight participants had lymphoedema secondary to cancer, three had a diagnosis of primary lymphoedema, and one with no known cause was told his lymphoedema was probably primary in origin.

Facilitating Sampling

An individualised 'locality agreement' between the researcher and the research department of the district health boards (Appendices E, F, and G) was required in order to be able to recruit participants through publicly funded lymphoedema clinic services. Three locality agreements were obtained. Two district health boards operating under the same umbrella group, asked for amendments to the Participant Information Sheet that had previously been approved by the university ethics committee. The research centre for the district health service, known previously as district health boards, requested the addition of face-to-face recruitment and for the inclusion of a statement for Māori participants advising the Māori research support process. These amendments were approved (Appendix H). I rang and spoke with the cultural advisor at length and later received a thank you email for the productive conversation stating that in her experience no researcher had ever followed up so thoroughly. On average it took about 40 sets of communication including face to face meetings, online forms, emails, and phone calls to achieve one locality agreement. The range was 10-60 communications as I wanted to ensure that participants were not all recruited from private practice in order to get a range of experiences. Three participants used only the public system, six used both public and private, and three had only used the private system. All three of the participants who had never received any public support had primary lymphoedema, two of whom lived in Auckland.

Preparation to Interview

A senior colleague steeped in grounded theory interviewed me on issues related to lymphoedema, assumptions, and the research process. Termed a presuppositions, pre-assumptions or pre-understandings interview, it refers to an interview with the researcher prior to data collection for the purpose of exposing the presuppositions or assumptions and to promote reflexivity (Crowther et al., 2017). The interview was recorded, and I reviewed and reflected on the issues and preconceptions. Advice was given at that time that proved invaluable from a theoretical and practical perspective. I conducted a pilot interview with a contemporary volunteer who fitted the participation criteria but was not a participant in this study.

Gathering Data and Interviews

Interviews took place between April 2018 and August 2019. Local lymphoedema therapists were requested to identify potential participants and offer an information sheet or provide the researcher's contact details. Flyers were placed in district health board lymphoedema clinics. Local therapists are either employed through publicly funded district

health boards or work in private practice. There were three DHBs in the Auckland region providing lymphoedema services to hundreds or potentially thousands of people living with lymphoedema. Advertisements were also placed in the local lymphoedema support group newsletter.

Despite attending the local lymphoedema therapists' quarterly meetings for at least 3 years, and meeting with lymphoedema therapists and managers from two district health boards, recruitment was slow. There was a gap of 5 months between ethics approval and the first interview. In the end, participants were recruited over a 16-month period. Four participants came from beyond the domiciled province. The final participant was recruited through social media and responded within an hour of the advertisement being placed online. Half of the participants were referred by lymphoedema therapists and the remainder approached the researcher after seeing an advertisement in the local support group newsletter or online; apart from one participant who was referred via another participant.

A semi structured interview schedule was formulated after reading several articles on the subject and responding to feedback from academic supervisors. A script for the introduction, including confirming consent and covering issues in the Participant Information Sheet was prewritten and tested on the volunteer (Appendix I). The volunteer was well known to me and able to give frank feedback. As a novice researcher the rehearsal interview was useful as it identified technical issues related to recording the interview and tested the conversation flow. In grounded theory, the interviewee determines the data direction more so than in other methods (Charmaz & Belgrave, 2014). A semi structured interview supports the researcher to identify issues or concepts raised by a participant and ask deepening questions.

A single interview with each participant was arranged, using an interview guide (Appendix I). Initially five people were identified and interviewed. The first question asked was "Can you please tell me about living with lymphoedema?" I then used prompts if needed to deepen and clarify. The first couple of interviews were less structured than later interviews. I also collected demographic data—participant characteristics such as dates of diagnosis, details of treatment, complications, types of compression garments worn if applicable, and whether public or private treatment had been received.

As the interviews proceeded and data analysis progressed, initial codes and patterns developed. Gradually connections were made between initial codes which subsequently merged. Data gathering continued and line by coding continued for the first 10 interviews.

Participants words were sometimes used as a label, known as *in vivo* codes. Concepts were checked with people living with lymphoedema and lymphoedema therapists from the early stages through to theory development. See Appendix J for an example of early analysis (December 2018). The final interview was on 10 August 2019.

As the interviews and concurrent data analysis progressed, questions arose and informants were sought who could potentially fill data gaps to clarify dimensions, properties, and categories as recommended (Charmaz, 2014a). It became apparent that managing lymphoedema was time consuming. Questions arose such as whether there was a difference between managing the demands of lymphoedema for people who were employed compared to those not employed; how do younger people manage; is there a difference between how men and women manage with lymphoedema? Thus, I theoretically sampled to see whether men and younger people managed lymphoedema differently. At each point participants were sought to answer these queries.

There was an energy generated by the process of pursuing and successfully enriching the data. The question arose as to whether Māori or Pacific people managed differently or received different care. However, it was difficult to recruit participants and, in the end, only one Māori participant, a woman, was interviewed. All remaining participants were of NZE ethnicity. Other notable characteristics were that seven participants were employed, including one working part time, and five participants were not in paid employment.

The first 10 participants had been diagnosed for at least 3 years. Further unanswered questions arose from the data relating to how people face and adapt in the early stages following diagnosis. An amendment to ethics was justified and two participants who had been diagnosed for less than 2 years were recruited. Data analysis proceeded until new data were not being generated for the identified categories. Data were not saturated for issues relating to characteristics for which further participants could not be recruited such as Māori or having been diagnosed as a teenager.

Interviews were transcribed verbatim by a professional transcriptionist. I listened to the recordings multiple times to gain an understanding of the nuances as recommended in constructivist grounded theory research (Bowers et al., 2009). Transcripts were imported into NVivo software to organise data and support labelling and coding.

Data Analysis

Organising the Data

From the outset, it was clear that organising and managing data for security and processing would be significant. I had 12 interviews, hard copy Consent Forms, field notes, coding, analysis, memos, journaling, transcripts, interview audio files, diagrams, and thesis draft chapters. Consent forms were kept in a locked cabinet. I had established password protected folders and I used a logical and consistent approach to electronic folder naming and hierarchy. I nested sub-folders within folders and named files systematically. I created backup data systems on a portable hard drive and used a Microsoft cloud data storage system. I set up a spreadsheet of the participants with basic demographic information. I added columns when issues such as whether employment or the duration of living with lymphoedema appeared significant. Participants were asked at interview to suggest a pseudonym and other names such as therapists or places were anonymised. The data and the full names of participants were kept separately. The interviews were transcribed literally, including pause fillers such as the word um and minimal responses such as mmm. These fillers, minimal responses, and repeated phrases were removed from participant quotes. Punctuation was added in line with participants' emphases. Ellipses (...) were used to indicate when words were edited in quotes. Square brackets [] were used when words were edited to retain anonymity or to improve comprehensibility. I reviewed the audio and transcript several times to check congruency. I established a template for the transcript allowing space for both coding on the right-hand side and researcher reflection on the left. (see Appendix K).

Reasoning

Grounded theory methods with systematic guidelines for collecting and analysing qualitative data to construct theories from the aggregated data were followed. The goal was to collect data to establish what was happening and to join the world of the participant. I followed the protocol that the researcher analyses, accounts for, and explores what is going on in order to make sense of the process (Charmaz, 2014a). The steps in grounded theory are structured and differentiates grounded theory research from other qualitative methods and methodologies. Systematically following the steps, leads to a grounded theory research process that is flexible and creative (Charmaz, 1995b, 2014a). Data were collected and analysed concurrently, methodically, and repeatedly.

Constructivist data analysis has been depicted as an emergent method that uses inductive reasoning, which is less definitive and open ended (Charmaz, 2008b). Inductive reasoning has been discussed earlier and is the beginning point for analysis. Inductive analysis begins with incomplete evidence which draws the researcher's attention. Some details that captured my attention early, fell away.

There were moments of small loss when a code that initially seemed fascinating was dropped when there was little resonance at the following interviews, and it was a little disappointing as they faded out. An early notion was from a woman who, like me, kept all her old compression garments, having invested significant amounts of money. Old compression garments are only really useful for tying up plants in the garden; but, for some, they are hard to throw away. What if there was a nuclear war in the Northern Hemisphere and they become unavailable? The first participant termed this her "lymphoedema museum." By this she meant she could never quite throw away her used stockings and paraphernalia. I loved the label, but it fell away as it was not reinforced. Similarly, codes that initially appeared on the margins gained strength through corroboration by later participants and went on to become part of the growing grounded theory. An example was noting the vivid remembering of dates and details. This continued to be supported by other participants and grew to be a signpost of the significance of the events surrounding lymphoedema development in participants' lives. Analysing data iteratively and concurrently during data collection resulted in rich data, as gaps could be identified and pursued during subsequent data gathering (Charmaz & Thornberg, 2021).

Each incident was separated, and pieces of data were analysed inductively. Reflexivity and analyses, including memoing, were used to explore and identify possible reasons or a theory behind a startling finding. A startling finding was the extraordinary connection and gratefulness participants felt for their therapists. The code that represented that was *finding solace* (see Appendix L). Categories and ideas were tested at the following interview when new data were collected to test the theory.

Constructivist grounded theory in particular draws on Peirce's abductive logic. Abductive reasoning was the basis of grounded theory as developed by Glaser and Strauss (1967). Abductive reasoning assesses and explains the most likely theory or conclusion (Bryant & Charmaz, 2011a). For example, having identified the gratitude with which lymphoedema therapists were held, the conclusion drawn related to the role therapists play

as a beacon in a storm, helping the discombobulated newly diagnosed participant begin to navigate a way back to a renewed normalcy.

Coding, Memo Notes and Constant Comparison

From the outset, data were labelled using line by line descriptors referred to as codes. Coding, comparing sections of data, comparing incidents began from the first interview and continued iteratively until all interviews were coded. Coding is a tool to condense and synthesise data, support data classification, description, labelling, organisation, and retrieval (Charmaz, 2014a). Eminent grounded theorists Strauss, Glaser, Corbin, Clarke, and Charmaz used varying words for initial and focussed coding. Birks and Mills (2015) proposed a streamlined wording using the terms initial, intermediate, and advanced coding.

Initial coding uses raw data and participant quotes from line-by-line coding. Intermediate codes capture the next abstraction of coding. Advanced codes identify ideas and processes related to theoretical labels and interconnections between categories. Codes can be clustered or constellated in a chart or a diagram to promote creativity and analysis (Charmaz, 2014a). Coding entails a minimum of two phases including initial (or open) coding and focussed (selective) coding (Charmaz, 2008b). This research uses the terms initial and focussed coding.

At the outset all my codes were in vivo quotes or comparatively long descriptive phrases, seeking to “construct meanings and actions from as close to the inside of the experience as possible” (Charmaz & Belgrave, 2014, p. 349). At the first supervision after starting coding, I was guided to use short phrases that included a gerund. From the outset almost all my codes, dimensions, properties, and categories contained a gerund to retain the focus on action (Charmaz, 2014a). Gerunds are verbs that operate as nouns, such as knowing, seeking, and finding, which reveal processes (Charmaz, 2008b) and are particularly favoured by Charmaz as a method to maintain the focus on action (Birks & Mills, 2015).

In the early stages of coding the researcher is encouraged to be cautious and continues to enquire and ask questions of the data and identify gaps. As a novice researcher, in the early days I developed multiple codes and did not cluster codes together or use the same initial code unless the incidents were very similar. I used different codes for incidents that could appear similar but held difference. For example, initially I categorised the fit of clothing differently from the fit of shoes. The benefit of developing so many initial codes was

that as abstraction began, I could see clusters of comparative incidents which were initially not visible.

The question asked during coding was “what is happening here?” Grounded theory, with its focus on process, provided an opportunity to view the social world of those living with lower limb lymphoedema. Social worlds can be understood through individuals as representatives of those social worlds, and through examples that span across individuals, offering a view into the social world such as living with a long-term condition (Charmaz, 2014a). The goal is to gain an insight into social processes within the area of study and to create a theoretical understanding to describe the processes uncovered (Charmaz & Belgrave, 2014).

Line by line analysis supports the researcher from becoming too immersed in the participants’ worldview, allowing some distance for analytical review (Charmaz, 1995b) and I found this to be true. Much of what started out as a theoretical process quite quickly turned into the way coding and analysis worked. Line by line analysis breaks the flow of the narrative whilst ensuring that initial codes are derived directly from the data and keeps coding sources trackable. This is an essential step to ensure that the findings are grounded in the participant data. Line by line analysis, along with member checking, is a strategy that can be employed to counter bias or perception of bias. I found that line by line coding and clustering codes supported the development of categories and, from there, processes became more apparent (Charmaz, 1995b).

Coding proceeded line by line or phrase by phrase. After the second interview a separate Microsoft Word document was opened, and codes were inserted into columns under a participant’s pseudonym. This facilitated comparing initial codes, finding similarities and clustering similar codes. The document rapidly became very long. I used this technique with the Word document set to landscape for the first five interviews.

Line by line initial codes become amalgamated as focussed codes (Charmaz, 1995b). My initial codes were wide ranging retaining potential for diverging. My goal was to keep focussed (intermediate) codes active and brief, allowing potential categories to develop (Charmaz, 2014a). Comparisons between the codes and categories were noted on memos, seeking to clarify the alignment and relationships between codes, identify gaps or perceived gaps in the data, and unexplained phenomena.

When I was part way through gathering data I found that codes could coalesce indicating a category (Charmaz, 2014a). Data were then re-compared, categories re-defined and refined. The refining process resulted in ongoing abstraction:

[W]e can see writ large that theory does not just 'emerge' from data; rather, data itself is constructed from many events observed or read about or heard about, constructed in a highly selective series of actions, and interpreted all along the course of the research project. For the research interpretations, actors' own words and interpretations are necessary, respected, but recast in new analytic terms. (Clarke, 1997, p. 64)

The first five interviews continued to raise new codes and concepts. Concepts arising from questions with focussed codes and categories were added to the interview schedule and gently raised in conversation at following interviews. I was careful to explain to participants that it was just as interesting to me if the concepts did or did not reverberate. This proviso was added as I did not want to influence participants' responses. Towards the 12th interview, although coding continued, new codes were rare and related to the gaps I had identified or wanted to corroborate.

I developed long lists of codes and grouped them on a Word document. Gradually umbrella terms or focussed codes were developed. Focussed codes changed and again merged. On occasions the connections were obvious; at other times connections which did not seem visible would suddenly become apparent. The process was a combination of arduous repetitive coding, sifting through long lines of codes and moments of exhilarating insight. Focussed codes remained flexible and I tracked the iterations on a growing Word document with revisions. The four columns of codes for the first four interviews reached 13 pages. At times, the amount of data appeared overwhelming as the number of codes continued to balloon. I used colour to code developing clusters, which I found very effective. At one point there were well over 600 codes, after which it became cumbersome, and codes were entered into NVivo software. I found NVivo problematic. I could easily make 'parent' codes but combining existing 'child' codes under a 'parent' code was more difficult.

As the clusters of codes grew, the codes became focussed. Focussed codes clustered into what are termed in grounded theory dimensions, properties, subcategories, and categories. A category is a concept that represents the phenomena. Subcategories provide clarity and specificity to a category. Properties further delineate and add meaning to a (sub)category. A dimension enhances understanding of the range and variance of a property (Birks & Mills, 2015; Charmaz, 2014a; Corbin & Strauss, 2008).

During analysis coding initially accelerated then condensed, and through iterative analysis, categories became evident. As explained by Charmaz (2014a) part way through analysing data, a code would become evident to me indicating a subcategory or category. Wording remained fluid. Prior to beginning analysis, the research activity I was most concerned about was: how would I know how to cluster codes? How would I know what constituted a valid comparison? However, the task, while painstaking and time consuming, seemed to develop its own momentum. I took categories to supervision where we would diagram the developing ideas and connections. At first, I thought the diagramming was too early and risked forcing connections between categories. However, connections that were not validated by ongoing analysis dropped away. The process of clustering codes into categories and raising categories up was significantly more intuitive than I expected.

There were aha moments of insight when I considered I had made a breakthrough. I rang my close peer volunteer who lives with lymphoedema or a close colleague, a lymphoedema therapist, and discussed my findings. On one occasion my peer living with lymphoedema said, “You have hit every nail square on the head, but what about family and support?” That context was missing from the iteration I shared. The codes of family and support were in the data but did not fit well with the narrative approach and had thus dropped off. Receiving feedback mid analysis supported theory development.

Despite condensing some focussed codes into subcategories, the data were quite overwhelming, and it became difficult to view all the categories, subcategories, and focussed codes. At supervision, I was guided to print off the focused codes which were cut into single items and pinned on to a board. This was helpful as each code could be visualised and moved. I realised some codes fitted more than one focussed code or subcategory. Some codes fell away through lack of corroboration.

I recall staring at the board and trying to work out why I was still unhappy with the first category, which had gone through at least five iterations by that stage and was ‘losing me.’ I knew it was wrong, but I could not work out why was it wrong. I had all the subcategories and focussed codes around the category ‘losing me’ when I realised that ‘losing me’ was passive. The words changed to ‘feeling lost’ of which ‘losing me’ (losing my identity) was a subcategory. In that moment, my confidence in coding and categorising grew. I realised that contemplating, focussing my thinking, and asking myself questions could result in progressing my thinking. Eventually ‘feeling lost’ became ‘losing previous normality.’

The process continued, and I became more confident about the patterns and meaning. The codes provided opportunity to refine concepts, analyse, compare, and raise further questions. The focus of the coding and analysis is on action and processes rather than identifying themes (Charmaz, 2010). My process followed Charmaz' process whereby codes that appear more relevant are assembled and large amounts of data are sifted through the focussed codes, enabling codes to become refined, generalised, and more conceptual (Charmaz, 1995b). Codes move from descriptions of events or processes to clear categories through analysis and synthesis (Charmaz, 2014a).

Codes were further refined. Charmaz (2014a) favoured an '*emergent*' analytical process (p. 148) [emphasis in original]. Sub categories and categories merged and developed through deepening understanding and diligently comparing incidents and situations (Charmaz, 1995b). Charmaz promoted the use of diagrams, tables, or word maps to facilitate analysis and help keep track of the shifting understanding of the data (Charmaz, 2014a). As the process progresses, the researcher begins to get an understanding of the depth and breadth of the experiences. The abstracted categories are thus more theoretical, yet directly derived from the data. Coding and analysis are used to inform the next set of data, again reiterating the constant comparative analysis (Charmaz, 2014b). This process proved to be more straight forward analytically than I was anticipating; however, as I said, keeping track of the codes was cumbersome.

Memos were used from the outset to capture and expand my thinking and remained a constant until the final theory was constructed. Memos were filed in alphabetical order as by the time categories developed, I had become accustomed to accessing memos in a list. In future research, I would commend the suggestion of Birks and Mills (2015) and cluster memos under categories. Memos were used in a variety of ways; to define terms and track the development of ideas within codes and clusters; to reflect on ideas raised through reading; and to support abstraction and analysis. Memos were not a one off. I added dates and insights regularly. I also used memos to track ideas and thinking, resulting in further questions for clarification from subsequent participants.

Despite my diligence with keeping memos, the writing from memos was barely used in the thesis as the memos were stark, pragmatic and explanatory. The one exception was the extensive memo on emic and etic perspectives. This memo began with the presuppositions interview and was supplemented throughout the research journey.

Whilst I journaled the process of developing a grounded theory, journaling did not constitute a full audit trail. I also used an evolving series of Word document tables to keep track of the developing analysis. The table of categories, properties and dimensions began in black font. I changed the font colour with each shift of category, property or dimension, by adding words and striking through the change. I noted the date of font colour changes. Once the Word table had become cluttered, I started a new table. I continued to use tables to record the shifts in thinking, using memos for specific topics and journaling to capture more amorphous processes and reflections.

Getting to Mid-Range Theory

Throughout the course of analysis, as questions arose memos were developed and questions posited at the next interview. While it may have been possible to return to earlier participants, that was not in my ethics agreement, so I asked further questions of alternative data sources, namely my subsequent participants. I used colleagues and a close peer with lymphoedema only for verification and discussion of the developing theory. This is corroborated by Charmaz. The researcher may return to earlier interviews and see whether the category was hidden within the data, or seek further data to corroborate the developing category (1995b). Seeking targeted data sources to corroborate, dismiss a category or concept, or saturate the evolving categories is known as theoretical sampling (Charmaz, 2014a). Analysis was facilitated by the impetus of coding, memos, and inductive thinking. The analysis and comparisons remained flexible even as the categories developed—staying open ended. Inductive abstraction is extrapolated from the observations and the detail, leading me to deepen my understanding of patterns, testing of assumptions, and development of theory, as suggested by Charmaz (2014a).

A couple of additional strategies were used to strengthen data analysis, integrate the concepts, support theory development, maintain the momentum and provide a reflective frame during data analysis. My supervisor suggested I write a storyline (Birks et al., 2009) which, despite my initial lack of confidence, served to provide a coherent narrative and strengthened my self confidence that analysis was progressing. Birks and colleagues (Birks & Mills, 2015; Birks et al., 2009) define storyline as a strategy to support the coalescence, development, configuration, and presentation of research findings. Condensing the data into a 3,000-word narrative provided the opportunity to distance and reflect on the findings. I consulted my close peer volunteer who lives with bilateral lower limb lymphoedema and after reading the storyline, she considered the findings highly corroborative of her experience. She cried and said it was good to know others felt the same way.

As suggested by other authors I also undertook several other measures (Corbin & Strauss, 2008; Hasselbusch & Penman, 2008). As mentioned, I printed off hundreds of codes and pinned them individually on a 2-metre board. The codes were then moved around over a period of weeks. Eventually, all the focussed codes and categories were written into a Word document table which again continued to shift as new insights developed. I presented my research process annually at the AUT doctoral presentations to peers during data gathering and analysis. I met regularly with the AUT Grounded Theory Group and presented my preliminary findings for critique and feedback. I was challenged about wording for categories during the development process that proved to be re-grounding and provided an external frame through which to reflect.

Development of Theory

As categories became more refined, theoretical abstraction developed through analysis of the coding, the categories, and the relationships between the categories. Notions arose and I constructed a conception of the experience of the participants and data as noted by Charmaz (2014a). I remained in an analytical state with the data, examining and re-examining, gaining insights and ideas (Charmaz, 2014a), which often appeared during my daily swim, making it hard to write down. Analysis was constant throughout the process until it became clear that the data set related to categories and areas of interest were saturated and the overarching category had been identified. The overarching category (managing disruption) took a long time for me to identify, although it was present within iterations of dimensions, properties, subcategories, and a category (see Appendix N).

The subcategories—being led by the body, being led by feelings, and leading with the mind—came about when I was reviewing a diagram of the developing theory and explaining my theory to my partner who is a psychotherapist. I was aware of the work of Assagioli, a psychotherapist, and the subcategories seemed to just fit. I took the developing theory to supervision and David, my supervisor, noted the issue of time across the whole theory. These three ‘corners,’ namely the core category, subcategories, and the issue of time were the last significant components of the theory development. As per Charmaz, the goal had been to identify an overarching category which embraced the subcategories. The core category became inherent with the grounded theory and is considered an “abstract theoretical understanding of the studied experience” (Charmaz, 2014a, p. 4).

In summary, the key to strongly constructed grounded theory is to methodically complete all the steps to identify a theory. This process begins with what is already known

about the phenomena and uses inductive reasoning as promulgated by Glaser and Strauss (1967), with constant comparison, and an open ended style that is flexible, noticing evolving threads, seeking reasonable explanations for what arises from the data, and the researcher's analysis (Charmaz, 2008a). In Charmaz' (2014a) version of the method, theory development may not be the main aim, in which case the steps above are completed until the point of theoretical sampling. As a method, grounded theory is an iterative process of reviewing the data through coding, memo notes, and continually studying the data in an inductive way to construct a theory grounded in the data. Whilst doing grounded theory research was new to me, I was surprised how following the steps of the method resulted in a coherent theory as described by Charmaz and colleagues.

Quality

Grounded theory offers researchers useful methods for managing and analysing large volumes of qualitative data, which has seen the method become popular across disciplines and countries. However, despite the methodical approach and success of grounded theory, suitable quality measures must be undertaken to avoid bias and support transparency and validity. These measures are discussed below.

The use of grounded theory presented the opportunity for participants to lead the narrative. Their rich descriptions combined with theoretical sensitivity resulted in a detailed account of the process. In addition, the study findings have been member checked by those living with lymphoedema, lymphoedema therapists, and other therapists in the grounded theory group. The findings reverberated strongly with these groups who also proffered feedback about the usefulness and clinical relevance. The quality of the theory and resonance with other health professionals is testament to the process followed.

There is debate in the literature about the way quality is measured in qualitative research and ultimately judgement is involved. Research is intrinsically complex, and processes vary along a continuum of transparent to oblique. Qualitative research has inherent preconceptions, the issue is to recognise one's own bias and provide clarity in identifying the reasons behind topic choice, previous experience, and assumptions (Marshall & Rossman, 2011). I have set out to be transparent at all levels in the execution of this research. My study process valued transparency and reflexivity which was evaluated through participant and peer verification and was explicitly sought throughout in supervision. I undertook a pre-assumptions interview which I analysed and explored in supervision.

Trustworthiness

To some extent, readers, particularly lay readers, such as health professionals or educators who want to use research, need to make a judgement about the research and trust the research, even though the trust may not be justified. The result is that people such as health professionals seeking evidence may vacillate between a deferential approach to knowledge and disregarding research findings (Hammersley, 2007). Within this context, researchers of social science need to consider the validity and the applicability of findings in different contexts (Hammersley, 2007).

Quality, including trustworthiness, is imperative in all research. Because I live with the condition under study, I am even more exposed to critique that assumptions and personal reality will feature in the analysis rather than the participant voice. The complexity is heightened as social constructivism recognises that phenomena reflect people's understanding of experiences and subjective realities are relevant and valued. As mentioned, I subjected my findings to myriad groups including lymphoedema therapists, people living with lymphoedema and grounded theory academics for scrutiny. The findings consistently reverberated at all steps on the research journey for all those groups.

Qualitative research, using a constructivist paradigm, adds to the diversity of what is understood about the phenomena by being undertaken in a natural environment where the researcher seeks to represent the participants' world, while remaining connected to the world of the participants. As mentioned earlier both participants and researcher co-construct the knowledge. The social context is imbued within the subjectivity of the individual (Charmaz, 2008b). In order for the research to be useful to health professionals this study must explicate the processes used to differentiate between the participant voice and researcher's partiality. Strategies are required to persuade readers of the trustworthiness of the findings. The findings from this study are grounded in participant data, inclusive of the subcategory level. As abstraction occurs the influence of the researcher comes more into play. The categories of being led by the body, being led by feelings and leading with the mind came while I was preparing to present to the AUT University Grounded Theory group.

Transparency supports trustworthiness including research positionality (Charmaz & Thornberg, 2021). Previously mentioned strategies of openness regarding topic choice combined with (judicious) use of academic literature also support credibility (Marshall &

Rossman, 2011). As suggested by Charmaz (2014a), academic literature provided strength to categories and theory construction (Charmaz & Thornberg, 2021).

An open-ended approach in social constructivism provides a forum for participants to contribute to the research direction in addition to the data contribution. This was facilitated by including observations, interviews, and recordings. As recommended by Golafshani (2003), dis-identified data were further exposed to supervisors and capable peers to strengthen trustworthiness. Charmaz and Thornberg (2021) proposed that quality could be assessed in grounded theory through a range of appraisals including scrutiny of rigour in coding and research procedure, conceptual connection and concentration, implications of theoretical findings, theoretical sensitivity, and researcher reflexivity, which Corbin and Strauss had also highlighted (1990). These issues have been previously addressed in this chapter.

For the researcher to provide authentic research, the topic chosen should be relevant and may arise from societal or personal experiences. Topics in which the researcher has personal investment, experience that is aligned with and resonates for participants, may facilitate trust and result in richer data (Berger, 2015). I have outlined my theoretical sensitivity arising from both living with and studying lymphoedema. I have a vested interest in furthering understanding of the ways people live with lymphoedema.

Cho and Lee (2014) recommended the use of the standard qualitative research practice of triangulation, whereby changing the controllable factors such as data sources, viewpoints, or localities, and checking for applicability across a range of varying situations supports trustworthiness. This study used theoretical sampling—recruited from a large city, provincial cities, and rural areas; and accessed participants who had developed lymphoedema from a range of causes at varying ages. Codes and ideas were tested on the following participant as explained earlier. Therefore, this study fulfilled recommendations (Creswell & Miller, 2000) in which triangulation can be achieved by using multiple data sources, rich data in analysing codes and categories, peer review and scrutiny. This is corroborated by Charmaz and Thornberg (2021).

Bowen (2006) discussed the value of member checking, and transparency in processes including discussing issues that do not fit or seems to contradict, known as negative case analysis. In this study, using constant comparison, incidents were compared to incidents. One participant did not have a working relationship with a lymphoedema therapist. The way this participant managed their lymphoedema was in stark contrast to

other participants which may serve to add strength to the data that a relationship with a lymphoedema therapist provided a strong basis for developing lymphoedema self-care.

Data analysis needs to be thick in order to satisfactorily explore the phenomena, while clear record keeping leaves an audit trail (Bowen, 2006; Charmaz & Thornberg, 2021). This study produced rich data providing detail of the ways people live with lymphoedema and the record keeping has been transparently described.

Charmaz and Thornberg (2021) contended that quality processes are nuanced depending on the variation of grounded theory utilised. They offered a checklist detailing quality processes. Robust Charmaz grounded theory research should include a number of points including, but not limited to, methodological consistency and demonstrating understanding of the methodology; the ability to answer the research question; the value of undertaking a literature review; being prepared to live with ambiguity in the research process; sharpening questions more specifically as analysis progresses; remaining open to possibilities and keeping results provisional until data analysis is completed. The quality measures noted in this section are derived from a number of authors of varying constellations of grounded theory, although the statements do not appear to contradict Charmaz (2014a; Birks & Mills, 2015; Charmaz & Thornberg, 2021). Originally, this study was written up including identifying the subcategories, properties, and dimensions all the way through. However, the use of these terms appeared to me to distract from the narrative and the essence of the study. For this reason, the subcategories, properties and dimensions, contexts and strategies are presented in Appendix N, with the use of tables throughout the findings' chapters.

Audit Trail

An audit trail was maintained through memos, diagrams, journaling, supervision minutes and Word document tables. These strategies were used to support the merging of codes during abstraction (Charmaz & Thornberg, 2019). For example – my initial codes ‘not knowing /not realising,’ ‘being a newcomer,’ ‘venturing into the unknown,’ ‘not being told at time of surgery,’ and ‘info subsumed by cancer’ were clustered under ‘being in the dark.’ The early codes of ‘finding inadequate help [the condition is ignored],’ ‘health professionals turning a deaf ear,’ ‘getting contrary (unhelpful) advice,’ ‘being let down,’ ‘leaving it to me,’ ‘losing my way [hypothesis],’ became ‘being in a support desert.’ During this process I sought to note my own thinking compared to data from participants. NVivo software was used as a

repository for quotes related to the developing categories, properties, dimensions, contexts and strategies.

A section from Birks & Mills (2015) on memoing and quality has been useful to articulate the way memos, diagrams, minutes and journaling were used both to track the process and the outcome of my study. Memos and diagrams tracked shifts in thinking, provided a forum for explicating rationale and linked significant advice from supervision minutes. I sought to capture and explore my musings. Going back to what I had written previously also helped me realise how far I had come. Some memos were not much more than a definition or description of a code, while I returned multiple times to other memos to explore my thinking.

Ethics and Quality

Formal ethical processes were followed. The researcher, supervisors, and AUT University have control over the study. I sought to support and protect the participants through stringently following the process as outlined and approved by the AUT Ethics Committee, including informed consent, anonymity, avoiding coercion, data security, confidentiality, and recognising participants' rights to withdraw data prior to data analysis. I recognise power dynamics and was keen to ensure that participants felt valued and had their mana upheld (sense of value, worth and respect in the eyes of themselves and others) before, during, and after the research process. Upholding mana involved acting with full respect for participants' autonomy and mental, social, and physical needs including anticipating and responding to participants' swelling related needs during interview.

Risks for participants were formally assessed through the ethics approval process and were deemed low. Pastoral support was offered to participants in the unlikely event of any repercussions or distress arising from the interview process. I was not aware of any participant needing formal support. However, I did telephone one participant following interview as agreed because they made a comment that alerted me. They explained at the end of the interview that I had asked questions which had not occurred to them before but that they could see where I was coming from. The tone was pensive, and I thought I may have raised issues that were new and possibly unwelcome.

I met monthly with two experienced AUT academic supervisors for the duration of the research to discuss processes and findings; diagrams were drawn and reviewed, writing was submitted, and I responded to comments. Other quality measures are identified below. I

am committed to providing feedback to those who have supported the research. Dissemination will happen via the networks with consumers and health professionals involved in lymphoedema services, through conferences, newsletters, webinars, and publication.

Issues Related to Māori and Pacific Involvement

There is an expectation that research undertaken in Aotearoa New Zealand will include opportunity for Māori participation and provide findings relevant to Māori. *Te Ara Tika Guidelines* (Hudson et al., 2010) provide a framework for research in Aotearoa New Zealand. As an active researcher in this country, I am expected to have prior understanding of how to approach research including Māori participation as part of quality processes.

Te Ara Tika Guidelines (Hudson et al., 2010) provide a framework for all researchers to prepare themselves culturally prior to starting research with Māori participants. For example, working through the guidelines required me to position myself in relation to socio-cultural Indigenous issues. As a researcher I am committed to ensuring research processes value te Tiriti o Waitangi obligations and responsibilities and enhance health equity for Māori and other groups that are underserved by mainstream health services. Te Tiriti o Waitangi was a promissory treaty signed between the English Crown representing the colonisers and Māori chiefs in 1840 and remains the foundation document of the colonial state of Aotearoa New Zealand. As a nurse I am guided by the regulatory Nursing Council of New Zealand guidelines on cultural safety and committed to a process of self-reflection.

Recruitment of Māori participants was difficult despite multiple conversations with Māori services at a local hospital board, requests via lymphoedema therapists, using a key Māori researcher and clinician in primary health care. Only one Māori participant was recruited, and ethnic specific data were not saturated.

Imbuing the principles and practice of cultural safety prepares the nurse researcher for interactions capable of connecting with diverse beliefs and meanings. Holding an analysis of institutional power, social justice, and the ongoing impact of colonisation on indigenous peoples prepares the researcher for interactions with people from minority populations. Similarly, I undertook a reflection in relation to Pacific health research guidelines (2014), but I was unsuccessful in recruiting Pacific participants. Unfortunately, my experience is echoed in other researchers' stories and speaks to the monocultural nature of the health systems and institutions within which I am located.

Recognising Assumptions

Corbin and Strauss (2008) commended the use of techniques such as journaling to bring taken for granted assumptions and presuppositions, values, and beliefs to the fore. Journaling and memos provide reflexivity. Strategies that support reflexive practice support the researcher to challenge predetermined notions and taken for granted assumptions (Charmaz, 2008b). As explained, I undertook a presuppositions interview. I used memos and reflective conversations. In this way, as a researcher, I may be more resourced to recognise the impact of such values and beliefs on theory development. Assumptions and preconceived knowledge can also be a place to begin rather than a fixed position (Charmaz & Thornberg, 2021). This has been true for me as through journaling I have seen my ideas and assumptions change throughout the research process.

Summary

Grounded theory is a well-established qualitative research method and methodology. The originators of grounded theory, Strauss and Glaser, devised a systematic process to provide rigour to the research process from the inception of the research process through data analysis and theory development. The goal was to generate original theory rather than test pre-existing theory. The original grounded theory methodology has positivist elements in that the researcher is perceived to be able to distance themselves from the data. Since the foundation of grounded theory, multiple variations have arisen. The variants are connected through adherence to basic grounded theory methods.

The Charmaz variant, termed constructivist grounded theory, has become popular because the epistemology appeals to researchers recognising the significance of subjectivity in every step of the research process and the inevitability that the researcher's interpretation will impact the research. The impact of subjectivity on data is offset by detailed attention to research methods including line by line analysis, constantly comparing data and incidents, using memos to track the progression and support the development of data analysis. Codes are clustered, subjugated into subcategories, and further abstracted into categories, as the basic process of the phenomena is delineated, and the theory grounded in the data is made transparent.

The researcher uses reflexivity and feedback from participants and informed parties to discern between their own assumptions and retain the developing theory grounded in the data. Just as the participant is unable to see all the research processes and assesses the grounded theory on its merit and fit with their reality, so too those who scrutinise the

research method must in some ways look at the evidence provided by the researcher and assess the quality of the research based on transparency, the perception of authenticity, and the apparent serviceability of the resulting theory. Having described the research methodology and method, I now present the findings resulting from my research.

Chapter 5 Findings

Reconfiguring Life: The process of living with moderate to severe lower limb lymphoedema

The following five chapters present the findings of the grounded theory study which describes how participants live with moderate to severe lower limb lymphoedema. An overview of the core category—Reconfiguring Life—is followed by an introduction to the participants with a detailed explanation of the first category: being led by the body. The following chapters provide in-depth explanation of the second and third categories which are being led by feelings and leading with the mind. Headings are used to support keeping track of the phases of the theory and are presented in a hierarchy of four levels. Each heading level uses a distinct format to reflect the heading hierarchy.

Reconfiguring Life is the core category in the process of how participants live with moderate to severe lower limb lymphoedema. Reconfiguring Life is defined as the transformational process initiated by the onset of lower limb swelling resulting in loss of previous normality and eventuating in a transformation to a new and adapted normal.

Overview of the Theory of Reconfiguring Life

The onset of significant swelling with or without a diagnosis leads to a sense of being out of control. Abnormal changes in body shape disturb the inner sense of equilibrium to which participants had become accustomed and previously took for granted. Bodily changes had a cascading effect leading to distress. The way through distress was by using the mind to understand, analyse the changes, relinquish any idealised thinking about previous normality, and acquiesce to the forces of lymphoedema through transformative change and acceptance. The physical changes and emotional response were exemplified by Helena:

When I realised my ankles were all swollen, I remember ... I couldn't even talk to [my husband]. I was just so distressed I remember sitting on the floor ... and just crying and crying and crying. I felt so isolated, so broken and, I didn't even know how to express all the things. It was all just that fear. I was just so, so frightened because things were happening that I had absolutely no control of. How do I get help? What do I do, where do I go? I didn't know. (Helena)

Uncontrolled swelling led to new symptoms that were disturbing and life changing. Changes in leg volume and shape caused varying intrusive symptoms such as ache, tightness, and excessive warmth. Where once activities, such as walking, were taken for granted, swelling reduced mobility, was burdensome, and caused discomfort. Clothes and shoes no longer fitted, and some participants had to change a whole wardrobe to both accommodate and cover up the swelling.

As reflected by Helena, swelling left participants feeling out of control. Some participants' life course was altered through the need to change employment, move house, change vehicles to accommodate the effects of their swollen limb; plans for international travel were disrupted in the long term and domestic life was impacted through loss of mobility and changes in life roles. Futures were disrupted through the loss of financial security and concerns about coping as an older adult. The cumulative effect of such life impacting change led to a loss of previous normality.

There were gender and class differences. Men working in physical jobs either retired or changed jobs. Women working in administrative and professional roles with flexibility were more able to adapt. One woman interviewed was unable to negotiate suitable working conditions and left work without regaining employment 4 years later. All participants talked about the need to change clothing and shoes. The struggle was greater for women to look smart and retain their sense of femininity. Both men and women spoke about their loss of athleticism and recreational options, as well as home maintenance.

In the midst of these changes were the demands of self-care, which involved juggling time and energy. Women participants were unpleasantly challenged by the need to shift focus onto themselves rather than from attending to the needs of others. The swelling demanded a consciousness about the minutiae of life which dominated time and thinking, and reoriented attention to their own needs.

The onset of swelling and the associated changes were often rapid leaving participants feeling lost, disorientated, and with nowhere to turn for help. Participants were in the dark about their condition with insufficient knowledge and options for treatment as many doctors seemed offhand and unable to provide guidance or help.

Almost all participants spoke of feeling out of control leading to a downward spiral through feeling forced into action or feeling out of control and losing hope. Most participants became driven by feeling out of control to pursue treatment, information, or help and

became connected to a lymphoedema therapist which was a turning point that generated hope, through feeling validated and understood. A small number of participants resisted advice about caring for their lymphoedema, making an active decision to “rebel” in the belief that it was possible for life to go on as though normal. Their turning point came when the limb deteriorated requiring frequent attention, or the heavy limb became too burdensome.

Getting ongoing help from a lymphoedema therapist was pivotal to healing. As a result of the therapeutic partnership, participants built critical knowledge and skills, came to understand the requirements of self-care, and the risks and factors influencing exacerbations and improvements. Effective treatment led to hope that swelling could be controlled; participants became active agents in their own care, spurred on by a reduction in symptoms. They became accustomed to the changes in lifestyle and began reflecting and analysing factors influencing swelling and symptoms. Therapists built self-belief through a warm, non-judgemental approach, supporting autonomy, tuning information to suit the individual, and priming participants to the realisation that lymphoedema could be controlled but not cured.

Transformative rebuilding of a new normal was mediated by the lymphoedema therapist inspiring hope, providing information and support, and facilitating symptom improvement. Transformative change occurred through acquiring knowledge and skills, a mental re-set of acquiescing and accepting that lymphoedema could be treated but not cured and becoming an active agent in self-management.

As participants became more accomplished at self-management, they embedded a routine for self-care, normalised the changes to clothing, and pragmatically managed activity limits, resulting in lymphoedema taking its appropriate position as a part of life rather than consuming their life. Regaining control signalled the move to rebuilding the new normal. Some participants chose to follow only the most important elements of self-care, while many resisted some changes and retained parts of their previous life. Participants also flexed the demands of care while remaining vigilant to the needs of their affected leg/s. Having re-established new norms, participants found new meaning through giving back, inspiring others on similar journeys, and through feeling grateful for a wide range of factors such as regaining a quality of life and meeting someone who helped.

A number of threads including transformation, time, and involvement of the body, feelings, and mind run through *Reconfiguring Life with lymphoedema* and forefront at

different points along the reconfiguring journey. First, transformation began at the onset of symptoms, cascading to a loss of previous normality. Substantial changes to how the body looked, felt, and functioned left participants feeling lost. The initial feeling out of control was often accompanied by a period of intense feelings of distress. Feeling out of control drove most participants to seek a turning point leading to a process of transformative reconfiguring of a new normal, led by the mind.

Second, time evolved across the journey with three junctures. In the period following the onset of symptoms, time was consumed by the demands of the body—the symptoms, restrictions, and the need to modify shoes and clothing. Lymphoedema at this time loomed large, separating participants from the person they once were. While the time immediately after diagnosis was dominated by the body, the second juncture of time, finding a turning point, was led by feelings of being forced into action or through feeling out of control. The turning point generally occurred at a moment in time, through a realisation, or meeting someone who was living with lymphoedema or a lymphoedema therapist. Whilst these meetings appeared to be serendipitous, it was as though the pursuit for solutions continued until a solution was discovered. In this way, being worn down and thereby feeling forced into action or being driven by feeling out of control were motivators, only relenting when help, in some form, was discovered. The third time juncture in the process of reconfiguring a new normal, involved participants reclaiming time through a sense of control over lymphoedema, as a new normal was established. The process of transformative change and acceptance that lymphoedema “is what it is” was led by the mind. Participants became amenable to change through building knowledge and skills, adopting self-care, with the realisation that lymphoedema was a lifelong condition requiring active self-management. This process was initially activated by the lymphoedema therapist, enabling those living with lymphoedema to take charge and reclaim their lives. The overall process is depicted in Figure 1 on the following page.

Figure 1

Theory of Reconfiguring Life with Lower Limb Lymphoedema

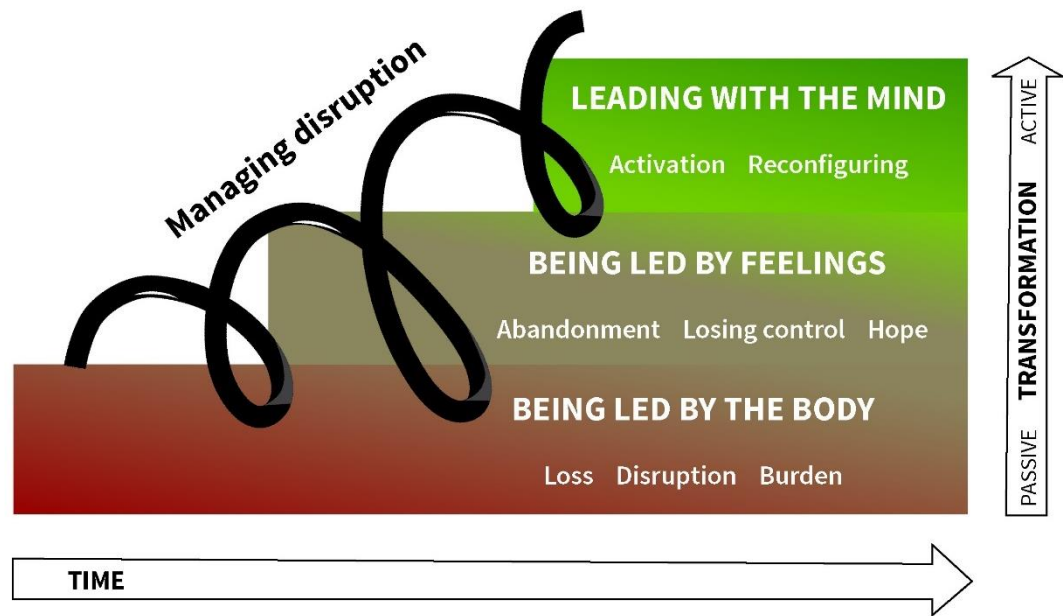


Figure 1 represents the theory of Reconfiguring Life, showing the overarching process of managing disruption (represented by a coil of fluctuations), with categories, time across the process, and passive to active transformation. The colours in Figure 1 relate to shades applied to differentiate the categories within the findings' chapters. The colours fade and merge into the next category to show that the process is not segmented but merging from one category to another, both forwards and backwards. The process of transformation begins as a passive experience and moves to become transformative as the person begins leading with the mind and taking control.

Participants and Their Backgrounds

Eight women and four men were recruited. Seven participants came from main urban centres, three from secondary centres, and two lived rurally. All participants from secondary centres and those living rurally were receiving regular publicly funded care. Three of the seven participants living in the main urban area had never received public care, although one had an appointment the following week, 2 years after their diagnosis.

Four of the 12 participants had primary lymphoedema. One was diagnosed as a teenager, one in their late 20s, and two in their 50s; the remaining were diagnosed aged in

their 60s. Eight participants had secondary lymphoedema following treatment for cancer. Ten participants had a lymphoedema therapist, although some with stable lymphoedema had not seen their private therapist for a year due to the cost. One participant had recently moved to a secondary city from a large urban area without a publicly funded lymphoedema service and was just establishing a relationship with a privately funded therapist who had not advised the participant that there was a publicly funded service in the city.

Ten participants used compression every day, with four wearing compression garments or bandages day and night. One participant applied medical taping regularly in lieu of compression garments. One participant, who was diagnosed as a teenager, only wore compression garments on long haul flights. One participant (Phoebe) was interviewed with her husband (Grant) present who unexpectedly contributed to the conversation. See Appendix D for further details of participant characteristics. Having provided a summary of the theory of Reconfiguring Life, and an introduction to participants, I now present the first of the following four chapters detailing the findings of the research.

Chapter 6 Being Led by the Body Part 1

Introduction

“... during the period following injury, the broken body occupies the entire field of experience.” (Ville, 2005, p. 332)

Reconfiguring Life begins with the first category of being led by the body. Physical changes, starting with swelling, dominated the early days of living with lymphoedema. Feelings and thoughts were present at the time, but the focus of attention and demand was led by changes to the body. This section outlines how participants' experience of lymphoedema began by being led by the body which was constituted by two main experiences: losing previous normality and feeling burdened. Tui illustrated the way the body dominated the early experience of living with lower limb lymphoedema:

You know I usually love working in the garden, but I haven't been able to do much at all. And just lifting my leg it is exhausting. There's the heaviness of it... It feels like I'm carrying a sack of spuds around. I'm restricted in what I can do as compared to what I used to do... Particularly with the pantyhose now, because you've got your knickers on and then you've got your pantyhose on and then you've got to go through the exhaustive process, process of putting them on and taking them off [when you go to the toilet] and changing them overnight and putting the other one on... And the washing [garments nightly]... That's a pain in the arse. ... The amount of effort it takes to lift this leg is a lot more... I've got to be really careful in case I get, any scratches or anything. So, I've got an elephant leg in one and I've got one skinny [leg] on the other side. I've always been really physical, and I can't get up there and climb the trees. ... [I can kneel] only just, with a lot of effort. It's very uncomfortable... I did what [my therapist] said you know around the shoes, around the socks, getting different socks. Around the knickers, getting the boy short things and couldn't find any of those in big sizes so I bought the boys' knickers. (Tui)

Figure 2 on the following page is a graphic representation of being led by the body. It shows three key elements of being led by the body representing a fracturing of previous normality.

Figure 2

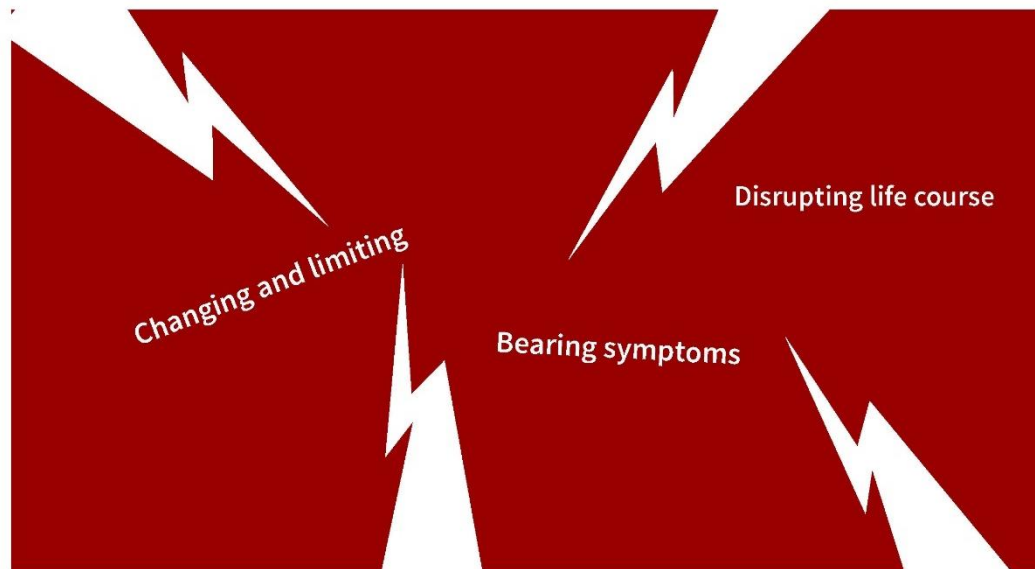
Being Led by the Body

Figure 2 shows three key elements of being led by the body representing a fracturing of previous normality.

Losing Previous Normality

Losing previous normality, which is shortened to losing normality, involves feeling out of control due to swelling and other unpleasant symptoms. As a consequence of the changing body, clothes no longer fitted or were inappropriate, mobility was limited, and some participants felt othered, as inherently different to the norm. Life was disrupted.

Participants, most of whom had comparatively healthy lives either until cancer or the diagnosis of primary lymphoedema, found themselves in new territory. Losing normality involved a loss of place-markers that underpinned pre-lymphoedema identity and of the changed self; a loss of the self, that existed before lymphoedema wrought body changes, loss of control, loss of meaning, and loss of an envisioned future. Place-markers are landmarks or signposts in one's life that signal the familiar. Everything is changed. The impact of lymphoedema left participants in a bewildering experience of lost normality, flung into another physical and social landscape with no way back to their previous self. The self encompasses all those characteristics, attributes, beliefs, opinions, temperament and perceptions of soul, that a person accepts as their own (Charmaz, 1999), and in differentiation to others (Charmaz, 1995a). This loss of a previous normal is exemplified by Helena:

I'm obviously still very dictated by lymphoedema. ... I don't want to not be able to walk. I don't want to have feet that are so swollen, that can't [fit] shoes. Even footwear, gets dictated by it. Even clothing gets dictated by it [lymphoedema]. ... I'd just get that bulging, ... even up here (at my waist) it can get a bit bulgy. (Helena)

Losing previous normality is the first subcategory of being led by the body and involves two properties—disrupting everyday life and disrupting life-course. The first subcategory of being led by the body is represented below in Table 1.

Table 1

Reconfiguring Life: Being Led by the Body. First Subcategory – Losing Previous Normality

Subcategory	Property	Dimension	Strategy	Context
Losing previous normality	Disrupting everyday life	Bearing symptoms	Self-sacrificing versus rebelling	Being in a support desert
		Finding nothing fits		Being in the dark
		Feeling othered		Access to public vs private therapist
	Disrupting life course	Limiting mobility		Gender
		Disrupting livelihood		Social class
		Disrupting social connection		Retired vs working

Table 1 shows the first subcategory of being led by the body, losing previous normality, along with the properties and dimensions. It also shows the strategies and contexts for the category being led by the body.

Disrupting Everyday Life

All participants experienced wide ranging physical changes that disrupted everyday life. Once the human body has passed through puberty, naturally occurring changes in body shape and size are generally incremental with the opportunity to adjust to changes over time. Lower limb lymphoedema swelling reshapes the body, specifically the size and shape of the legs, which can change over weeks or months and, sometimes, in the course of a day. For adults who had become accustomed to the dimensions of their body over decades,

swelling disrupted everyday life, leaving those newly diagnosed in unknown territory, feeling anchorless and lost. This section explains the components associated with the property disrupting everyday life which are bearing symptoms that were new and intrusive, resulting in finding nothing fits, feeling othered, including feeling that part of the body is ugly, and limiting mobility which affected leisure and domestic life.

It was starting to impact my life. Quite a lot, I wasn't able to play table tennis, or play outdoor bowls anymore because I couldn't get down... And it was sore, it was aching... It got bad sometimes at night and it was quite hard to get comfortable... I had a lot of aching around the groin... Putting on normal clothing was hard. I had to choose baggy clothing. ...It didn't worry me that much so long as people didn't make a comment... I was angry though, I thought here I am trying to ignore what I've got and the last thing you want is somebody to say what's up with your leg? Someone who doesn't know me. (Andy)

Swelling is the keystone symptom from which all other symptoms cascade. Other symptoms are wide ranging including painful, heavy, tight, aching legs; and altered sensations. Less common symptoms were lymph leaking from a swollen limb and cracked skin that required regular bandaging. Symptoms signalled physical changes which initially took centre stage. Some experienced symptoms as ever present, although the severity fluctuated. Most participants commented about pain or discomfort as illustrated by Scotty:

Feels like I've got a strainer post² tied to my hip. ...I get very, very, tired. I hate it. Sometimes wish they'd cut it off. (Scotty)

Scotty described the ache as “a tightness that doesn't go away” and as “tension and heat.” Scotty acquired his lymphoedema in his 50s and reflected on the dramatic change in his physique since developing lymphoedema. “I actually used to be quite a fine physical specimen!” (Scotty). Some participants found that on occasions symptoms worsened and were then relieved by rest, as exemplified by Sarah: “Okay, up with the legs, so that sort of helped.” As a result of the swelling and other symptoms, such as heat and increased sensitivity, participants needed to change whole wardrobes of clothing.

Wardrobe dilemmas started with what to wear. Trying on and discarding clothes that did not fit on that particular day caused frustration and wasted precious time, especially for those in paid employment. Elizabeth was 6 years post diagnosis and said “Even now it's a

² A strainer post is large, heavy, and buried deep, with stays or supports for additional fence strength.

whole thing getting dressed in the morning because it just depends how I'm feeling, what I can bear to wear. And sometimes I have to kind of look, reasonably respectable."

Having significantly asymmetrical legs or two large legs which can vary within hours, creates challenges finding suitable clothes and shoes. People not affected by an unstable long-term condition make wardrobe choices based on issues such as the weather, the requirements of the day, personal style, and budget. Choice of clothing is significantly more complex for people living with lymphoedema.

Finding suitable clothes affected both men and women; however, women focussed more on explaining clothing dilemmas and challenges related to either the fabric type becoming unsuitable or the need for a larger size. Personal clothing style is an outward expression of identity and forced changes in clothing resulted in some participants, particularly women, feeling distressed. The onset of lymphoedema resulted in significant wardrobe changes. What suits one person with lymphoedema may be an anathema to another, so finding suitable clothes was idiosyncratic. For example, Lauriane said "Not being able to wear jeans was the other hardest thing that I had to give up because I lived in jeans and that just broke my heart." Whereas Phoebe found the opposite, "I had a wardrobe full of really nice trousers and things, and I found I couldn't wear them... So, jeans are really a great thing because they're mainly cotton, so they don't stick [to my compression stockings]."

There is grief associated with losing normality through losing loved clothing and favoured style. Shopping and dressing are everyday activities which can be used to reinforce personal style, bolster self-esteem, or cover up. The focus when purchasing clothing or shoes moved from style and social appropriateness to items that would fit and accommodate lymphoedema.

Shoes were particularly problematic. Many participants had one foot larger than the other and struggled to get a range of shoes for various occasions such as smart casual or formalwear. Participants gravitated to the same shoe types that would work. Tui was advised to wear closed in shoes that provided support but found them impractical for her working lifestyle. Tui needed to take shoes off and put them back on during the day—a cultural requirement before entering classrooms or marae (meeting house) run according to Māori protocol. Tui said: "I love jandals [thongs]... I got fitted for trainer shoes... I need easy slip-on [shoes] because I'm in and out of classrooms and marae. I'm supposed to wear them, but I live in jandals... because jandals- they'll fit." Tui gravitated towards jandals because "they'll fit," meaning that if her feet swelled during the day she could still wear her jandals.

Sharn had a corporate job that also involved field work. Like other participants, she was forced to choose between comfort and appropriateness. In the past Sharn would have changed her shoes for fieldwork. For practical reasons Sharn needed to compromise a corporate style in favour of practicality and face the awkwardness of casual and potentially muddy shoes in the group presentation. Sharn explained: “So, it definitely swells during the day so I can’t take shoes off or anything because I’d never get them back on again.” The struggle to look smart and find appropriate clothes that were also tolerable to wear was a daily challenge for some. The more formal the role or occasion the more draining the task of getting dressed and ready for the day.

Modifying shoes and clothing choices involved trial and error. Participants talked about trying to go up a size in shoes and suits. The strategy was unsuccessful with shoes as Sharn explained: “can’t wear like leather shoes. Boots. I’ve tried those size ups, I’ve tried wide feet... and it doesn’t work.” Andy commented: “Sometimes I’d go and hire a suit and make sure that it was one size larger but there were times when even the larger suit looked too tight.” Trial and error cost time, money, and takes cognitive labour.

Both men and women spoke about the difficulties of finding respectable clothes to accommodate swelling, with some women losing a sense of femininity. The problems deepened when specific clothing or style were needed for work or special events. Either the person would look less smart than preferred, or they were less comfortable. For example, Lauriane said “Guys clothes fit better than women’s clothes... I buy guys shorts, ... because they have a wider leg.” Clothing, such as underwear or trousers, can aggravate swelling if there are constriction points. This led to limiting lingerie choice and compounded the loss of femininity that exacerbated the un-sexiness of the compression stockings or wraps, particularly for women.

Even a pair of pyjamas, was dictated by it (lymphoedema). ... I bought them, and I thought no ... and cut them [the cuffs off] and of course I wreck it [the pyjamas]. Even my underwear, is dictated. So, forget getting nice frilly lacy whatever – it’s just getting whatever is going to just give me the freedom and not constrict. (Helena)

Participants modified clothing choices, compromising style and femininity for comfort and to reduce potential constriction. Sharn wanted to be able to ignore the issue of looks. She vacillated between not wanting to care and retracting when she said “Clothes are something that make you feel good about yourself and when you can’t wear what makes you feel good about yourself then you feel shit about yourself... That’s when I start getting down

about it. But it's fine." Sharn found shopping with her sisters, an activity she used to love, no longer held the pleasure previously experienced. There was a feeling of resignation in Sharn's tone when she said: "I'll go out shopping with my sisters and I come away with nothing because nothing fits. It's frustrating more than anything, but it is what it is."

"It is what it is" implied that the situation was unchangeable and must be accepted. As a young woman and mother of a young child, the implications for Sharn's future seemed disheartening. Conversing with Sharn was an experience of tabulating the losses, missing out on lost life opportunities, as changing physically changed Sharn's future.

Changes in body shape, compression garments, clothing, and gait resulted in standing out and, on occasions, feeling othered; no longer part of the normal set. Clothing responses ranged from concealing to revealing the swollen limb. For example, some participants said that feeling comfortable enough to speak openly about the leg/s related to their own level of acceptance, or level of trust with family and friends. Some participants were less daunted when their leg/s or compression garments were in view, but all participants commented on being stared at or questioned.

Some participants, such as Phoebe, had a pragmatic approach. Like other women participants, she preferred to conceal and avoid the comments. "[If people ask] I just say I have lymphoedema. I've had cancer, I have no lymph nodes. ... I tend to dress for it ... I cover it up." Concealing involved wearing clothes that were likely to be baggier and avoiding shorts, skirts, and dresses.

Concealing the limb was a balancing act between tolerating feeling exposed to the gaze of others versus wearing additional clothing, thus generating more heat and potentially causing an exacerbation in swelling. Responses were inclined to change over time, relating to regaining control and self-acceptance as illustrated by Elizabeth:

In some situations, I still feel self-conscious about the taping,... I used to say, I've got a sore leg, or my leg tends to swell up. ...I think it's partly acceptance, that it's not going to go away and also partly maybe... that it's more under control... that confidence goes back to why I can now say I've got lymphoedema. (Elizabeth)

Not all women felt the need to cover up. In response to being asked about whether she covered up her lymphoedema Tui said: "I don't care. I don't notice. I'm used to perceptions and being stared at; I've had that all my life. I joke about it. I laugh about it. ...I'm not a conformist. So, it's like, so what?"

Some questions and comments cut participants to the quick and the traumatic memory remained painful years later. For example, Sarah recalled the distress she felt as a young woman:

About 20 years ago... I could see her looking at my feet... I thought 'Why are you looking at my feet? None of your business.' She actually asked, 'What's wrong with your feet?'... I said 'Nothing.' I thought, 'I don't know you. You're rude, piss off'... I was like grr. I found myself on the defensive straight away, I thought 'I'm not engaging with you'... But generally, if I know that person and we've struck up some rapport... I don't have an issue.
(Sarah)

Participants carried their personal histories of being affronted and deeply wounded by the words and stares of others. Friends could be tactless too, as exemplified by Sal: “Do I go off to the loo and have a wee cry, or do I just walk away? You walk away but, in your mind, you have an answer. It was devastating... I felt like slapping him.” Such comments affected self-esteem and contributed to losing previous normality.

Two men described parts of their body as ugly, referring to the disfigurement that can occur. Scotty said “To be honest, it looks absolutely ugly, above the knee... it’s three times the size and it looks horrible. So, I basically, wear three-quarter trousers.” In the past Len considered his legs were ugly but had learned to ignore the look. “Now I don’t, I just ignore it.” Initially, Len leaked lymph fluid from the legs; however, once that responded to treatment, he became accustomed to lymphoedema and on the day of the interview was wearing shorts.

Many participants considered that their self-image and self-esteem had been affected. One woman was influenced by a self-help type book and made a conscious effort to love all parts of her body. Lauriane said “I read a Louise Hay book. She does affirmations about loving your body. So, to me there is no good leg and there is no bad leg, I have two perfectly good legs.”

Self-image and self-esteem were affected by the swollen limb, the unattractive compression garment, a need to modify clothing to accommodate the swelling, and loss of mobility. Modifying clothing reduced clothing choice, often requiring clothing to be more functional and less respectable. Losing identity as healthy further contributed to a sense of losing normality.

For example, Andy found the words of the surgeon confronting. “My surgeon said, ‘What you have is a disability.’ So that was quite hard when you hear the word disability you think oh, I’m not normal anymore.” Andy mentioned the word disability several times in the interview. For Andy, the new identity of disabled had disrupted his self-concept of being healthy and normal. Changes in the size and shape of legs was further exacerbated by a loss of function.

Changing physically resulted in restriction in mobility, with everyday tasks becoming more demanding. Limiting mobility had wide reaching consequences, impacting recreation, home maintenance, and altering domestic roles. Limiting mobility led to participants worrying about coping in older age with the need to pull up compression stockings and manage self-care.

The most commonly mentioned mobility issue was reduced agility and knee bend, affecting a wide range of activities including gardening, driving, and tramping. A participant recounted being pulled by one hiker from the front and pushed by another at the back, which bears its own indignity. “I couldn’t bend my leg to get up where they could do it quite easily” (Lauriane). Changing physically resulted in limiting options in recreation and home maintenance, such as gardening and building a deck. “I usually love working in the garden, but I haven’t been able to do much. Just lifting my leg, is exhausting ... I’m restricted in my movement. I can’t get on my knees, so there is a restriction” (Tui). Knee swelling also dictated seating, requiring an aisle seat complicating theatre and plane bookings, and impacted driving.

In summary, participants reported lymphoedema disrupting everyday life through symptoms such as swelling, tightness, and pain. The enlarged leg/s forced wardrobe changes, limiting choice of clothes, unsettling perceptions of femininity for women, and leaving participants struggling to look smart. As a result of the size of the limb and the unglamorous compression garments, participants felt othered and many chose initially to conceal the limb. Previous normality was further lost through limited mobility impacting activities such as tramping, sport, gardening, and house maintenance. These disruptions, led by body changes, were not confined to everyday life. Lymphoedema wrought disruption to the course of participants’ lives. Participants lost jobs, modified work habit and settings, one moved house and changed vehicle type, and all modified their approach to international travel.

Disrupting Life Course

Physical changes disrupted everyday life and altered participants' life course. The second property, disrupting life course, is defined as interference with livelihood, workplace, housing, vehicle ownership, and international travel directly attributable to lymphoedema and associated social disruption. Most of these disruptions negatively affected participants' financial outlook. The financial burden of lymphoedema was often in addition to the costs incurred with cancer. The direct costs of staying well with lymphoedema will be addressed in Chapter 7. Some participants felt that having faced cancer and survived, that lymphoedema had taken yet another part of their future by disrupting their life course.

Moderate to severe lower limb lymphoedema in this group of participants had a substantial impact on employability and livelihood. All the participants who worked, except one, spoke about the impact of lymphoedema on employment. Four people with physical jobs directly attributed their retirement to lymphoedema. Of these, three men stopped working in their late 50s to late 60s, and one woman stopped in her late 50s as despite applying for jobs for the previous 4 years she could not find employment with sufficient flexibility. In addition, six women modified factors related to work, such as sitting position and moving around more.

Two of the three men forced into retirement by lymphoedema were self-employed with less security in leave entitlement or options to change roles. Scotty had set up a handyman business just prior to developing lymphoedema that provided a good income but found he lacked agility to do the work and was unable to climb ladders safely. "For the first 6 years, basically we had a struggle because I couldn't work... I was earning over \$100,000 a year (before then) ... and we had lived very high. But you just change your lifestyle" (Scotty). Scotty went from earning a high income to living in a shed. Lymphoedema disrupted the course of Scotty and his partner's life. Similarly, Len, in his late 60s at the time, had to stop working as he was worried about causing the limb harm: "Had to be careful... I couldn't crawl under houses any longer. I had to give that away. I worried about getting an infection in it all the time, that was the biggest thing." Andy also experienced a change in work and eventually left a workplace where "it was very hot in the warehouse, sometimes 35, 40 degrees. And the thought of having to wear a stocking" (Andy). He found wearing compression stockings in the hot workplace untenable and "rebelled" against wearing compression. Andy attributed the development of his lymphoedema, which was primary in origin, to the stress and heat of the workshop. Andy then took on a new career as a caregiver, which he left before retirement age as it was too demanding. Scotty and Andy retired early as

a result of lymphoedema before the age of superannuation and lost thousands of dollars of potential employment-related earnings. There was a direct relationship between developing lymphoedema and changing jobs or giving up employment for three men. Lymphoedema forced an abrupt disruption to life course along with a change in identity which can be associated with occupation and financial independence.

Lymphoedema also directly impacted employment and livelihood for six women. Women with administrative or professional roles were more protected from changes in work as they were more able to modify their work environment to accommodate lymphoedema. Tui developed lymphoedema 30 years after her surgery for cancer. She attributed the development of lymphoedema to the stress of the job, which involved domestic flights a couple of times a week. Tui reported that lymphoedema had caused her to review her career and step down from her national role.

So, it [my leg] does get tired. And it does feel like I'm dragging it. I'm thinking about how hard I've worked all my life and then thinking okay I don't want to continue doing that. I want to enjoy (my life), and I want to be able to make decisions about what I want to do rather than what I have to do or should do... So, it has triggered me [into] ensuring I get some quality of life. I am concerned about the possibility of getting, scratches, or injury where it can cause cellulitis. (Tui)

Tui also had a leadership/administrative role and was able to continue in her workplace, although she re-evaluated her life, values, and priorities. Professional roles and flexible workplaces protected livelihood for five women who could structure their days. The benefits of this were illustrated by Elizabeth when she said: "I sit a lot at work. So sometimes I will put my feet up on another chair. If I'm moving, it's better."

Conversely, Lauriane reported that when she worked, she had less control in her retail related workplace. Lauriane had struggled to get her work setting adapted. She was in her early 60s and had been unable to secure employment despite being motivated. Lauriane stated, "When I was working, ... none of the jobs I've ever had have said 'You've got something wrong with your leg can we set you up ergonomically' no one's ever said that." Lauriane's income and way of life was substantially disrupted.

Being employed while living with lymphoedema required flexibility in the environment, workplace support, and a level of autonomy. The more middle class the role, the more likely participants were able to exert sufficient independence to maintain employment. A social context of living with lymphoedema was thus the impact of working-

class and physical jobs on early retirement. Changes in employment imposed by lymphoedema disrupted life course and financial security. Life course was further disrupted through disruptions in social connections through the need to modify housing, vehicle ownership, and international travel.

In addition to employment, disrupting life course impeded social connections. Social connections are built up through networks in multiple spheres of life and are subject to change in social activities. Social disruption occurred on many planes, through changes in job or workplace, through changed roles in the home, increased dependency such as for nightly bandaging, changes to intimate activities or toileting, and in leisure activities.

Disrupted social connections were also impacted through changes in housing and international travel. One participant needed to move house and change communities. Len reported that “the kids worry about it more than me... I was living on my own round the head [headlands].” Len moved from a remote rural community to another rural hamlet in a different district, disrupting his community connections.

Another way that lymphoedema affected life course was through changing travel plans. Participants differed in their approach, but all modified international flights in some way. Phoebe explained that she did not want lymphoedema to define who Phoebe and her husband were and what they did, rather they wanted to adapt and retain as much of their pre-lymphoedema lifestyle as possible. The couple modified long haul flights to include multiple stopovers thus accommodating the needs of lymphoedema by allowing time for Phoebe’s legs to drain between flights. The result was that travel could be achieved but they paid a price—both time and money. “We went (Auckland) Sydney ... Perth ... Singapore ... Dubai. ... It just costs a hell of a lot more. ... People we were going with got on the plane and went straight to Dubai. We couldn’t do that” (Phoebe and Grant).

Flying can exacerbate swelling, thus some participants abandoned thoughts of flying long distance again, assessing there was a risk of destabilising health or being away from home without the essentials to manage. Prior to her lymphoedema, Helena regularly travelled to her family’s home country in the Northern Hemisphere. Relatives implored her to visit and were stunned at her decision to decline. Helena felt torn and resolute.

We’ve got heaps of family in [my home country]. Our son’s going over in a few weeks to play test rugby. ... I said to my husband, how can he even ask me? He knows I’m not going to do that. I get a bit upset, when people try to talk me out of what I believe is the right thing for me... They’re not really

taking on the enormity. ... I still get a little bit upset when I'm feeling pressured. What if ... I reacted to the flight, and I did end up having problems? I just don't want that. (Helena)

The pull for Helena to return to her home country was strong. She understood that others could not gauge the magnitude of the request and her struggle to regain her health after the disruption caused by lymphoedema. Deciding against traveling internationally can affect family milestone events. Like others, Sal chose to look after her lymphoedema rather than risk flying:

We've had a couple of weddings in the Islands. I think nah. If I got a mosquito bite or something happened on that leg... Not wanting to be paranoid... Just more cautious. I don't want to be stuck over there if anything happens. (Sal)

The risks of an event that could lead to cellulitis while away from home stopped her from travelling overseas. These stories exemplified the impact lymphoedema had on participants' life course and disruption to life choices.

Summary

Aspects of everyday life such as pain and discomfort, limited mobility, the need to change wardrobe and thereby personal style, a loss of femininity, feeling othered by society, and being labelled as disabled, destabilised the sense of self with a loss of control and previous normality. Swelling limited mobility, further reducing self-capability in recreation and domestic life. Disruption to employment, housing, vehicle ownership, and international travel impacting livelihood and employment affected life course. Plans to set up business were abandoned, some participants retired early, while others took significant time off work. Participants experienced a changed self-concept, including body image, self-esteem, and role functioning. In addition to losing normality, participants felt burdened by the demands of self-care and concerns about coping as an older adult.

Chapter 7 Being Led by the Body Part 2

Burdening

This chapter explains the second subcategory in the process of being led by the body which is burdening. Burdening is defined as the impact of coping with an inherently unstable condition, undertaking a demanding self-care regime, needing to take more care, and managing while being able to do less at home, work, and play. The burden of lymphoedema self-care can seem overwhelming. Self-care demands are multifaceted, wide ranging, and tedious, as exemplified by Sal when she said, “I mean some mornings I wake up and I think oh it would be just nice to lie here, stay in bed or, not have to- It’s like a job.” For all participants, daily self-care was viewed as essential because the alternative was untenable. Having to do self-care brought an often-unwelcome dependency on professional carers and family, a focus on oneself, additional living costs, and concerns about coping as an older adult. Burdening is the second subcategory of being led by the body and involved two properties—self-care is demanding and fearing for the future. The second subcategory is represented below in Table 2.

Table 2

Reconfiguring Life: Being Led by the Body. Second Subcategory – Burdening

Subcategory	Property	Dimension
Burdening	Self-care is demanding	Managing disruption Cognitive labour
	Fearing for the future	Bearing the cost Coping as an older adult

Table 2 shows the second subcategory of being led by the body—burdening—along with the properties and dimensions.

Self-Care is Demanding

Lymphoedema self-care required participants to take more care. Managing lymphoedema required participants to take an active role in both what they did and what they were advised to avoid. The active role of self-care entailed moisturising the skin, undertaking a specific form of self-massage, movement that stimulated but does not overload the lymphatic system, and wearing compression. While all participants did not

undertake all these activities every day, all experienced intensive periods of self-care—usually in the early years after diagnosis and after any significant disruption causing a worsening of the condition.

People diagnosed with lymphoedema have traditionally been given a long list of activities to avoid that involve modifying everyday life such as avoiding heat, constriction, injury, or infection to the affected skin. The list of precautions has included, for example, avoiding hot baths, saunas, steam rooms, sun beds, using sunscreen, keeping feet and stockings dry (Lymphoedema Support Network Pamphlet, 2017). In addition, many lymphoedema therapists would recommend a discussion prior to embarking on tattoos, surgery, or acupuncture on the affected area. The cumulative impact of the self-care regime and avoiding factors that may trigger lymphoedema could be daunting.

The consequences of not undertaking self-care and avoiding exacerbations or triggering events was untenable because living with the swollen limb was worse.

What are you going to do if you don't want to be bothered with doing your self-care? You don't actually have an option... You do have an option. Everyone has an option. But my option is to just let it go, it's part of me, yeah. (Sal)

For Sal, as for the other participants, self-care was experienced as compulsory. Having to attend to self-care involved demanding regimes, particularly for participants with the most unstable lymphoedema, in which swelling over and above the usual swelling did not drain on rest or elevation.

The more unstable the swelling, the more lymphoedema demanded a response and the greater the commitment shown by participants to self-care. For example, Phoebe's husband bandaged her most nights and recorded circumferential measurements before and after bandaging, night and morning to track the swelling. "We keep a chart. And measure at the same point [on the leg]... five nights a week and keep a check that nothing gets out of hand" (Phoebe). Earlier in the interview the couple had explained the extensive steps taken to find out everything they could about managing lymphoedema and then enacted the advice. Grant said:

We've worked on it together ... I used to get horribly pissed off at having to do those bandages. I thought crikey dick I'm not up for this. It used to wear me out and, in the end, I said no, come on get over it boy, you're going to have to be doing it for the rest of your life. (Grant)

Compulsion takes away a sense of choice and freedom and creates a situation where participants needed to weigh up the burden that self-care demanded or face the consequences. The consequences of not doing the self-care when tired or worn down, was that the lymphoedema continued to deteriorate and the self-care demand would deepen. Grant said: “But if I’m tired and deadbeat and Phoebe’s deadbeat and say ‘oh bugger it’ and she’s still got those hard spots [fibrosed areas], and we haven’t bandaged, then that thing [measurements on the chart] comes up there quite a bit.” The drive of having to attend to issues recurred in various ways in the data.

According to the literature and practice protocols, the most essential self-care is wearing compression. Compression garments form the mainstay of treatment for lymphoedema. Compression garments are elasticised and come in a variety of styles. There are thigh high individual stockings, a two-leg panty type; substantial wraps which are a thick semi-rigid material with Velcro closures; or multi-layer bandaging. Medical taping is a form of compression. One participant used a sequential intermittent pneumatic pump every day³ in addition to compression wraps.

Wearing and caring for compression garments was burdening. Garments were generally washed out every night. Garments are difficult to put on, particularly after showering or swimming. Stockings interfere with spontaneity, particularly for participants who would like to take their shoes off and walk along the beach or swim, a common pastime in Aotearoa New Zealand. Kip’s comment was typical: “It’s a pain in the arse to put it on every day... And if I could get rid of it [my stocking] I’d be the most happiest person in the world.”

Participants perceived compression garments as unsightly, unglamorous, demoralising, and conspicuous. Sal named her stockings ‘Gladys Emmanuel’ after a character in the Ronnie Barker television comedy series. The character wore a hairnet, industrial stockings, and was the antithesis of sexy, as Sal explained: “Well, it’s just like yeah Gladys Emmanuel.” Echoing the comments Helena said, “I was feeling so broken and less than, and unlovely anyway. And, for me, the stockings confirmed that because they were just, ugly, brown, thick stockings.”

³ A pneumatic pump is a device with one sided or bilateral leggings that applies sequential external pressure in a measured way to reduce swelling. Recommended use can be 45-60 minutes/day.

Because compression garments were difficult to put on and take off, some participants were dependent on family or caregivers. Phoebe could pull up her panty-style compression hosiery, but it was more comfortable and less likely to cause pinching when she had help. Ill-fitting compression hosiery is extremely uncomfortable and creased stockings can increase swelling. Phoebe said: “Grant will come and give me a hand... I can get it [compression] up... But ... he can get it just that little bit further.” There is a level of intimacy and dependency involved in needing help with toileting which is demanding on both parties. Len lives with his son and receives daily in-home help from a paid carer. Len explained that the carer “comes in every morning to put the toe gloves on because I can’t get down to put them on, they’re so blimmen awkward to get on.” When help was not available participants found themselves in predicaments. Managing lymphoedema is physically and socially demanding. The effort leaves less energy for other activities either due to reduced mobility or feeling worn out. Participants, whether employed or not, talked about the burden of arranging life around lymphoedema. This mental demand has been termed cognitive labour.

Cognitive labour is a term that has been used to understand domestic demands such as organising and decision making. Cognitive labour is defined as the effort involved in self-care related to planning, decision-making, reflecting, and responding to lymphoedema. It is often an unseen burden. Lauriane explained cognitive labour for an ordinary day out with friends.

You run this scenario through your head... I go ‘Where are we going? Are we going to the beach?’ ... but if ... we go out somewhere and then she goes ‘Oh do you want to stop at the beach?’ ... If I’ve got a brand-new garment on, I won’t go in the water, I won’t go on the sand. So yes, it does make a difference and it’s something that you kind of have to think through and prepare for. (Lauriane)

This level of micromanaging is burdening and can discourage sociability and spontaneity. Sal exemplified this when she said: “It’s quite draining remaining positive with such a physical thing. What you wear, how you feel, how far you can walk. Dressing. ... Day to day managing ... it’s a drag... It’s something that needs daily coping and planning.”

There is a tension between having to take extra time and care, balanced against an inclination to focus less on self and mundane issues. Elizabeth illustrated the issue when said, “I wouldn’t normally spend all this time thinking about what I’m going to wear. It really irritates me that I might change shoes because the first pair aren’t quite right... It’s a bit of a waste of time.” Elizabeth went on to say, “I don’t know whether self-obsessed is the right

word, but you have to be ... in some ways.” Elizabeth contended it was a struggle to spend time focussing on herself but considered “You know I think that’s true for a lot of women.” Gender issues were manifest across the spectrum including feeling uncomfortable focussing on self.

All participants experienced self-care as burdensome, while those not working recognised that self-care was more manageable. For example, Andy said: “Being retired has helped ... free to do what I want. I walk the dog... keeping up regular exercise... do some cycling... . Less stress in my life; all that’s helped. My lifestyle I think that would have helped.” Working in paid employment versus not was a social context supporting self-management including managing exacerbations of swelling.

Lymphoedema is exacerbated by multiple factors such as air travel, constriction, heat, some medications, injury, under and over exercise, and skin infections. Exacerbations were burdening, requiring additional self-care or professional help. Prevention was more effective; however, there were times when disruptions needed to be managed. Managing disruption is defined as acting to successfully reduce swelling or manage factors that could worsen swelling. Disruptions were ongoing, multifaceted factors that interrupted everyday life or life course. Awkwardly, disruptive triggers are more likely to emerge in association with other stressors such as time pressures, travel, and stressful events, making managing disruption more problematic.

All the participants reported managing heat. Heat may be externally or internally generated. There are multiple variables to manage, including ambient temperature, workplace, travel in hot countries, seasonal change, compression garments as an extra layer of clothing, modifying clothing and fabric, activities for the day, and opportunities to keep cool. Activities and temperatures vary, adding to the cognitive labour for participants. Almost all participants struggled with the heat: “Of course the heat is a nightmare” (Tui). In response, participants gravitated towards air conditioning and planning travel to avoid heat. Like others, Phoebe takes precautions: “The heat I find debilitating. ... We put in a heat pump [air conditioning].... We try and plan holidays, to go somewhere where it’s not so hot.”

Most participants managed heat stress through clothing choice, air conditioning, workplace settings, lower intensity exercise, managing travel in hot countries, avoiding optional heat sources, and using personal cooling methods. While managing heat was an inherent part of everyday life, participants were also conscious of the need to avoid or minimise breaks in the skin and skin infections.

Just as heat can exacerbate lymphoedema symptoms, so too can the skin infection cellulitis. People living with lymphoedema are at an increased risk of developing cellulitis. Cellulitis results in a double jeopardy as an infective episode can hasten the deterioration of lymphoedema and, at the same time, increase the risk of further episodes of cellulitis leading to a potential downward spiral of deterioration. Cellulitis is also potentially a medical emergency as it can lead to life threatening septicaemia. Participants were aware of the risk of cellulitis and consequent disruption to life and work.

Most participants had experienced cellulitis or folliculitis skin infections. Typically, the onset of cellulitis was rapid and disturbing. Cellulitis was something to dread; viewed as frightening and disruptive. Participants who had not experienced an episode of cellulitis spoke about wanting to avoid that “slippery slope” (Sharn) at all costs.

For some participants, cellulitis was a familiar burden. Participants reported having oral antibiotics on hand, especially when travelling. Phoebe talked of a “travelling pharmacy” as, like others, she carried an additional medicine kit when away from home. Participants reported various episodes of the disruption; being hospitalised with cellulitis, in one instance for 2 weeks; receiving intravenous antibiotics; wounds requiring repeated dressing changes; and being stuck in transit overseas with language barriers. For example, Sarah recounted her experience:

I got cellulitis. I was at work and then feeling quite tired. Then all this infection... these spots appearing and spreading... So, went to A & E [accident and medical clinic] and, they did the usual, like the drawing around. ... My last one [episode of cellulitis] was in 2014. That was probably my worst, and the bad thing was I was travelling back from Europe. ... I didn't feel right ... very shivery and flu-like... I always travel with antibiotics... So, I had those to manage it. [Then it got] worse and worse. On the plane, I'm like 'Oh shit. I've got cellulitis' ... and you're in a place like Japan... [Later] And she [my general practitioner, when I got back] just looked [sigh], my leg looked terrible because also, I'd been 11 hours in the air. And then, I remember her going, 'Oh, god!' Like her eyes... But the one [lesion] at the back [of my leg] was pretty gross because it was seeping.
(Sarah)

Sarah was clearly experienced at managing cellulitis. She said the general practitioner ‘did the usual,’ referring to having a line drawn around the reddened area to observe for change. Sarah was familiar with the routine, the symptoms of cellulitis, and the treatment. Managing cellulitis and managing the risk of cellulitis was burdening.

Disruption to normal life was a key feature in the early days following diagnosis, as participants learned to accommodate the swelling and ensuing changes. Disruptions are not confined to the early years after diagnosis; rather, continue throughout the course of living with lymphoedema. Managing disruption is an integrating process within how people live with a diagnosis of moderate to severe lower limb lymphoedema. Managing disruption is progressed throughout the findings chapters as the process of Reconfiguring Life is elucidated. Managing disruption speaks to actions that participants took in response to direct triggers of heat and cellulitis. Participants were also fearing for the future—concerned about bearing the costs of managing lymphoedema and coping as an older adult.

Fearing for the Future

Fearing for the future refers to concerns about the costs of lymphoedema and coping as an older adult. Fearing for the future is about the further narrowing of life choices, with a sense of loss of capacity before one's time. Lauriane, among others, expressed such thoughts when she said:

That's one of the things that I can see as being a possible problem in the future you know if I'm not flexible enough, to sit on the floor and put the garment on or haven't got the movement in my back. Or say I had arthritis.
(Lauriane)

One element of fearing for the future included managing the expenses of lymphoedema, including the direct costs of private lymphatic drainage massage and compression and also indirect costs. Indirect costs were wide ranging, such as changing wardrobe and taking more expensive flights or seating.

Some participants received a compression subsidy on two or more sets of garments a year. The subsidy is not applied equally or equitably across Aotearoa New Zealand, and some participants purchased additional stockings, as multiple pairs of stockings reduced the need to wash garments every night. Many participants attended a private lymphoedema therapist at a cost of about NZ\$100-150 an hour. Participants who attended private therapists wondered how people with less money managed, as privately funded stockings and lymphatic drainage massage cost hundreds of dollars. Like others, Phoebe noted the costs of lymphoedema:

I added it up and it was over NZ\$8000 a year in product and treatments... which is why I haven't been to [my lymphoedema therapist] now for a year... Then that impacts the rest of your life because... you can't spend it

on going, on a holiday or putting it towards a new car or oysters for dinner.
(Phoebe)

Not all participants could afford private treatment. For Sharn, with a young family and fewer resources, there were competing demands on finances. Even participants who could afford private treatment found the cost burdensome. Similarly, participants worried about how they would cope as an older adult managing the heavy demands particularly of pulling on and off compression and limited mobility.

Coming to the realisation that lymphoedema was a long-term condition involved thinking about the implications for aging. Some participants had considered the future deeply. The future was unknown and there was a sense of uncertainty.

Even now... I just stop and think about the rest of my life with lymphoedema. Yes, I've got faith, but I still think [about] when I'm in my 80s and putting these stockings on. I've even found myself wondering if I'm going to be able to do that. I wonder how that will work. What happens if I can't do that? Who would be able to help me? (Helena)

Participants talked about fearing how they would cope with the demands of self-care in the future. For participants aged in their 50s and 60s, thinking about older age raised issues about maintaining independence. Participants realised that as they grew older and frailer, pulling on and off stockings was likely to become more burdensome. Participants were distressed wondering about the future, which added to their sense of feeling burdened.

This section has described how the onset of lymphoedema was led by the body through two key processes—losing previous normality and burdening. Losing previous normality involved disruption to everyday life caused by bearing distressing symptoms, finding nothing fitted, deciding whether to reveal or conceal the limb which was associated with feeling othered by society, feeling part of oneself was ugly, and the limitations imposed on mobility. The result was disruption to everyday life. Participants experienced life course changes through disruption to livelihood; more so for participants whose work involved physical labour or frequent air travel. Participants moved house and changed vehicles in response to lymphoedema and modified or eliminated international travel, leading to disruption to social connectedness. The second major way in which being led by the body impacted participants' lives was through being burdened. Being burdened manifested as needing to take more care of the body, managing disruptions caused by exacerbations in lymphoedema and fearing for the future, such as bearing the associated costs and worrying

about coping as an older adult. The next section summarises some of the strategies and social contexts related to being led by the body for participants living with moderate to severe lower limb lymphoedema.

Strategies

As a result of the extensive physical changes, participants adapted to cope with the swelling and associated life changes. One strategy is termed self-sacrificing versus “rebellious.” Rebellious was a term used by two participants. In the process of losing previous normality, a need arose to choose between accommodating lymphoedema (self-sacrificing) or forfeiting lymphoedema in favour of retaining a sense of previous normalcy (rebellious against advice). Thus far in the chapter I have identified and described two of the three coping strategies which are led by the body and enacted when losing normality. The strategies are changing wardrobe and adapting to disrupted life course through changing jobs or moving house. Multiple strategies were used by participants, and many like some of the social contexts are woven through the study.

Self-Sacrificing Versus Rebellious

In self-sacrificing versus rebellious, participants made choices between the importance of preventing exacerbation of the lymphoedema through either accepting advice and self-sacrificing other wants and needs or rebellious against advice and risk exacerbating the swelling. While these positions appeared diametrically opposed, participants chose which strategy to use at different times depending on their satisfaction or dissatisfaction with their symptoms of swelling. Self-sacrificing is defined as foregoing valued elements of life by prioritising lymphoedema over normal preferences. Rebellious is defined as behaving against advice by prioritising other needs in pursuit of elements of previous normalcy.

The self-care regime was burdening, and participants were confronted with the need to make choices. Some physical activities, such as gardening or building a deck, could no longer be undertaken due to restricted mobility. Self-sacrificing refers to activities that can physically be undertaken but which could lead to deterioration such as air travel or walking barefoot on the beach, a practice not recommended for people living with lower limb lymphoedema due to the risk of cuts. Self-sacrificing often related to giving up recreational activities previously enjoyed and had two origins; lymphoedema therapists advised giving up or changing an activity, or participants made decisions for themselves. Prioritising lymphoedema over their recreational activity contributed to losing previous normality and emphasised the burdening effects of self-care.

Self-sacrificing included active and passive recreation. Reducing physical activity for those living with a long-term condition can lead to deconditioning and weight gain (Schmitz et al., 2009). Two of the cornerstones of care for people living with lymphoedema are exercise and weight management. Loss of recreation is a double jeopardy, namely missing out on what is desired and deconditioning. Many participants gave up sports, which were named as indoor netball, rugby, tennis, table tennis, outdoor bowls, fishing, cycling, and running. All participants who discussed giving up recreation noticed the loss but, on balance, decided to prioritise their lymphoedema. Most participants had been diagnosed several years earlier; yet, losing the loved activity appeared to remain vivid, As Lauriane illustrates: “There’s certain things I can’t do. When I was first diagnosed, I played indoor netball and then I was told I couldn’t play indoor netball anymore, so I bawled my eyes out over that.” The forfeiture involved loss of exercise, leisure, and social connection.

Taking more care led to self-sacrificing. The issues of the beach, sand, beach walks, swimming, and getting compression back on after swimming, were particularly vexed for participants. Some reported that using a pool was just easier. As Andy illustrates: “I probably choose to have a swim in the pool... The beach is tricky.” One participant had specific compression stockings she adapted and used for swimming and walking on the beach. Almost all participants mentioned the beach and swimming. Helena said she would not go barefoot on the beach:

I am very hesitant at the beach, ... There are things that I consciously choose not to do, because of the lymphoedema and ... potential risks. I don't want to test those risks ... I accept that, if that's the payoff for me to be well, I'm completely okay with that. (Helena)

Like others, Helena did a conscious risk/benefit appraisal and adamantly decided that self-sacrificing pleasures was preferable to unsettling lymphoedema control. Helena had found peace in self-sacrificing with staying well as the payoff.

While beach, swimming, sun, and garments predominated, other issues were also raised. Buying clothes no longer held the same pleasure. Other activities such as family events were affected. Participants decided against optional flying. Missing out by choosing self-sacrifice involved a wide range of recreational activities. When shared recreation was sacrificed, the loss affected significant others as well. There were financial and recreational implications for participants unable to continue domestic activities such as gardening or house maintenance, as discussed previously. (See the section on limiting mobility, Chapter

6). Self-sacrificing was a strategy used when lymphoedema was prioritised. The other strategy associated with self-sacrificing was rebelling, which was deployed when wants and needs were prioritised over the demands of lymphoedema.

The word *rebell*ing was used by two participants who explained their response in choosing not to follow best practice or conventional guidelines. One participant rebelled almost entirely against wearing compression, and one participant rebelled against compression for 4 years, the latter providing insight into rebelling. All except one study participant, which was the person not wearing compression, were recruited through a lymphoedema therapist, an existing informed lymphoedema support group, or a social media moderated Facebook page and were thus more likely to self-manage than a randomly identified group of participants. Yet, participants discussed episodes or behaviours that diverged from conventional practice, captured by the *in vivo* label – rebelling.

Sarah said on a few occasions that she knew what she needed to do but did not do so. She suggested that the reason for not wearing a compression garment was because it was easier not to. Sarah said: “I feel that I have been remiss with the stocking. I think I need to wear stockings more, particularly in wintertime. Because it’s easier I suppose. Today, I’ve got these big, baggy, pants on.” Sarah implied that she could have compression underneath baggy trousers with little impact. She followed up her comment about not wearing compression with a statement about what she was doing for her lymphoedema, by using a hand-held laser device⁴. Sarah was the only participant who developed lymphoedema as a young person/child and was told at the time that nothing could be done. She developed her behaviours and management approach to lymphoedema at a stage in life when she was more easily embarrassed. Sarah said, “You know, I was a bit embarrassed by it, but I just thought ‘Oh, there was nothing I can do.’ There was no treatment.” Sarah knows what needs to be done and manages her lymphoedema unconventionally. Sarah said: “Again, I was a little bit lazy. I wasn’t wearing them [compression garments] all the time. I’d only wear them if I was travelling on long haul, I knew I’d have to be a bit more careful about my legs.” Sarah said that although she had seen a lymphoedema therapist in private practice the treatment was not successful: “I quite like the effects cos it (lymphatic drainage massage) did make me feel good... She taped me up, but it didn’t seem to stick [laughs].” Sarah received lymphatic drainage massage and medical taping, which became loose and therefore ineffective. In

⁴ Handheld low-level laser device has been found to be effective in managing lymphoedema.

contrast, other participants were motivated to continue treatment by the beneficial effects experienced with treatment.

Participants sacrificed the things they preferred or avoided missing out by rebelling against usual care advice. Andy explained that he initially wore compression for 3 years after diagnosis. He then rebelled, stopped wearing compression for 4 years, and then later found a turning point and has been, in his words, “diligent” ever since:

It was earlier on in my whole journey that I must have been thinking differently then, taking it for granted that maybe if I just don't wear the stocking it will be okay. I didn't know enough. I should've sought advice. I should've asked [my therapist] 'What do I do? Is it okay if I don't wear the stocking?' And she would've said 'No'... So, it was in rebellion. And what caused me to feel like that? Probably getting sick of wearing the stockings basically. Impatient. (Andy)

It was burdensome wearing compression. Andy said: “I think it was arduous. It was having to put on a stocking every day. And I didn't have the skills in those early [times].” Andy linked rebelling with many factors including not knowing the consequences of his actions, not seeking advice from his therapist, the arduousness of wearing compression, and his lack of skill and familiarity with putting on a stocking.

Other participants, including Andy, Len, and Lauriane, said it took time to become accustomed to pulling on and wearing the stocking, which then became second nature. Andy's choice of the word rebelling implies active resistance to self-care. Andy explained that while he knew what he needed to do, he wanted to live as though unencumbered by lymphoedema. He recalled being affronted by the surgeon's comment that he had a disability and considered following his diagnosis he was “no longer normal.” Andy explained that he struggled to adapt his wardrobe, that the lack of choice in clothing and wanting to wear “tighter jeans” also contributed to the desire to go against advice.

Andy noticed the deterioration while not wearing the stocking, commenting “The leg got bigger; I was having to change my wardrobe more often.” He also worked in a hot warehouse up to 40 degrees Celsius and had to adapt his clothing to fit his increasingly swollen leg. Andy paid heavily for his 4 year period of rebelling and his limb “had solidified,” meaning that the skin and underlying tissue had become hard and leathery. Andy explained that his therapist said there was little that could be done for his leg which had taken on “a life of its own” and “nothing we do is going to make a difference.” At that point Andy began

to consider lymphoedema surgery which he underwent 5 months before the interview. Since the success of surgery, Andy has become very invested in maintaining his lymphoedema self-care regime and managing the swelling. Other participants explained that stockings were burdensome. For some, getting over the hump of becoming accustomed to wearing compression took time, during which participants were vulnerable to *rebellling*.

Doing just enough was a compromise position between rebelling and self-sacrificing. Some participants did the basics, which included wearing compression. Two participants who mentioned doing just enough were diagnosed in the previous 2 years. Data suggest that it takes months to years to establish a robust self-care practice. Tui does ankle exercises by rolling her feet in the shape of the alphabet but knows she should do more.

I know all the things that I should be doing but I do the compression and I just think, I'll wear that because if I don't wear it, it'll get bigger... Sometimes I elevate it. Mostly I don't. The only consistent thing is I wear the compression and I do the alphabet. (Tui)

Sharn said other activities were prioritised over the demands of self-care: "I just don't, it's just not top of my mind." Sharn described her attitude as rebelling against the health system due to the complete lack of publicly funded services available in her region. She was consternated that despite the enormity of the diagnosis, the lifelong prognosis, and extent of the implications, that she was left in the dark to find resources and care for herself.

I just still, to this day, do not understand why I have to do this [lymphoedema care] all by myself. It makes no sense to me. So maybe it's a bit of rebelling against the system but it's only affecting me, which is probably not a good thing to do. (Sharn)

This section has explained the strategy self-sacrificing versus rebelling. Participants preferred lymphoedema over their own wants and desires by self-sacrificing their needs or made decisions based on risk assessment to rebel against advice periodically. Participants' social contexts influenced strategies and responses to living with lymphoedema.

Social Contexts

The contexts of participants' lives in the early years after diagnosis of lymphoedema affected their experience of lymphoedema. A social context refers to "[s]tructural conditions that shape the nature of situations, circumstances, or problems to which individuals respond by means of action/ interaction/ emotions" (Corbin & Strauss, 2008, p. 87).

Several social contexts were found to impact the ways participants lived with lymphoedema. Two contexts, namely being in a support desert and being in the dark about my condition, are discussed below and are critical to understanding other elements of the findings. The other social contexts affect multiple areas and are woven through the study. The other social contexts of being led by the body are publicly available versus privately funded treatment, gender, the impact of social class such as labouring versus administrative employment, and the impact of being retired versus being employed on carrying out self-care.

Being in a Support Desert

Some participants experienced the lack of help following diagnosis or the journey to get diagnosed as being in a support desert. Being in a support desert refers to the lack of lymphoedema services, difficulty getting help and support to manage lymphoedema, and difficulties receiving a diagnosis, particularly for people with primary lymphoedema. Some health professionals provided little guidance about how to get help and some provided poor quality advice. The only advice a doctor gave Elizabeth was that “I should eat porridge because that would help the flow of the lymph system.” Participants who had undergone lymph node removal following a diagnosis of cancer generally, but not always, had a more straightforward path to diagnosis. Participants who developed primary lymphoedema underwent tests and scans, and some had fluctuating symptoms for many years before being diagnosed.

Most participants considered that health professionals often paid little heed to lymphoedema with the exception of those directly involved with lymphoedema. A subset of participants felt very alone, abandoned, and at sea, contributing to the experience of being led by the body. Some were emotionally distressed and “freaked out” about being in a support desert and felt left alone to cope. Being in a support desert was a place of profound desperation and signalled feeling out of control, where usual coping strategies failed and there was nowhere to turn for help. For a subset of participants, diagnosis of lymphoedema was an unbalancing and confusing experience. In some participants, the level of distress attributed to the onset of lymphoedema was extreme and unsustainable in the long term. Helena described being in a support desert in the opening words of her interview before I asked the first question:

I found it quite a bit of a desert, in terms of support... I was just so distressed I was so freaked out. I didn't react very well, and I just cried... I've got to say

that the oncologists surely know about it, but I certainly didn't get that impartation of knowledge or help. (Helena)

Helena used strong words to convey her distress. She frequently used the words “freaking out” to explain how she felt in the early days after diagnosis. Coming to terms with understanding what lymphoedema would mean for the future was perplexing and distressing and contributed to her losing her previous normality.

Sal, who had experienced many years of health issues, like others, experienced the early days of being in a support desert. Sal said: “When you were starting off down the lymphoedema track- it's the unknown, how it's going to track. Will it get better? ... Will it go away? Will it get worse?” Sal explained the uncertainty of not knowing what lymphoedema meant for the future, while Elizabeth called it “distressing, getting diagnosed with this,” commenting that “there wasn't any, referral to like a support group or service.” Both men and women experienced being in a support desert. Women explained their emotional response while men explained the situation.

Not all women participants recalled emotional distress at the time of diagnosis, which for Lauriane was 22 years prior. Lauriane sounded pragmatic, she said “having that calm lifestyle, relaxed. Go with the flow. Don't let anything upset you too much. You're either that type of person, or you aren't. I'm lucky that I am. I think that contributes a lot towards my positive outlook.” Lauriane made conscious decisions to use her mind to manage emotions and negative thinking. She decided that becoming distressed would work against self-care of lymphoedema. Her early days of lymphoedema were emotional but she did not isolate lymphoedema as the cause of that distress. She attributed the onset of her secondary lymphoedema 2 years postoperatively to the stress of her mother's death.

Not all participants found doctors dismissive, and the level of support participants received at the time of diagnosis varied. Andy and Scotty, from the same provincial city, did not experience being in a support desert. They received accurate advice and prompt appropriate referral. Andy reported a straightforward diagnostic journey. In stark distinction to other participants, he also reported immediate referral and commencement of treatment. Andy's lymphoedema started as a slow increase in leg swelling, then rapidly became alarming. His doctor referred him to a specialist, he had MRI imaging, and was referred to a lymphoedema therapist. Andy reported: “She knew straight away and diagnosed primary lymphoedema... . We started a course of compression bandaging, and then stockings.”

Being in the Dark

The second social context of being led by the body is being in the dark, which refers to being uninformed about the nature of the condition or management. Some participants who developed lymphoedema secondary to cancer considered they were left in the dark regarding the risks following lymph node surgery. A diagnosis of cancer is often an existential crisis (Sekse et al., 2010), and it was difficult for participants to absorb information about lymphoedema at the time of diagnosis.

Because it's like anything when you hear the word cancer, everything else goes out the window. So, all those conversations we could have had (about the risks of lymphoedema), I wouldn't know. It possibly was brought up.
(Kip)

Kip realised that the impact and risks of cancer related surgery, including that his leg could be amputated, dominated his thinking at the time. Kip, like others was unsure whether the risks of lymphoedema were mentioned or glossed over as Len said, mentioned “in the fine print.”

For the four participants with primary lymphoedema, being in the dark and being in a support desert generally lasted longer than for participants with secondary lymphoedema, as the journey to diagnosis was longer. Their path to diagnosis had common features. There was a history of unexplained swelling, meeting doctors who seemed to disregard the issue, being investigated for deep vein thrombosis, undergoing scans, seeing a vascular surgeon, receiving a diagnosis, and being provided little information or guidance. Six years prior, Elizabeth had an injury.

I was absolutely cast... And my right foot just blew up. When I look back, over many years, I had times when my ankles had really swollen. I hadn't coped with flying. And I had had cellulitis, of my legs one time, but I didn't really link it. One foot was huge, and I was going to an orthopaedic surgeon for my back and other professionals, and I kept asking 'what about my foot?' And the orthopaedic just said 'Well, I don't know anything about that.' It took about 3 months until my back was coming right, and I was mobile. ... It was a locum who suggested that I get a scan for deep vein thrombosis, an x-ray first. Which didn't particularly show anything. Then I was referred to a vascular surgeon at the hospital, it was a venous scan. And he told me that I had lymphoedema. (Elizabeth)

Although the diagnosis was several years earlier, Elizabeth, like the other participants, recalls the events, her experience, and the conversations clearly. This aspect

stood out in the research of vividly remembering details, verbatim conversations, and responses, particularly in relation to distressing situations. Elizabeth summed up the issue of dismissive doctors and being in the dark when she said: “I think my endless frustration, all the way through has been how little the medical profession or doctors anyway, know about lymphoedema. I mean I guess they must know about it. They haven’t asked me.”

Sarah’s journey to diagnosis of primary lymphoedema and post diagnosis experience has continued to be characterised by being in a support desert. She was 13 years of age when she developed swelling and 15 years at diagnosis. Sarah said “Well, I wasn't diagnosed. I mean, a year after I discovered it, I suppose. I was never diagnosed with anything.... There was no treatment.”

Sarah, like Elizabeth, recalled that there was little advice or help offered at that time. Sarah offers insight into her mindset as a teenager. The family tried some complementary medicine and home remedies including elevating the limb and wrapping the swollen limb in cabbage leaves. Sarah was not referred for treatment and there was a lack of treatment options in Aotearoa New Zealand at that time. Sarah acknowledged that the support desert, being in the dark and lack of treatment options 30 years ago, impacted her attitude and approach to lymphoedema.

I need to not think, ‘don’t do anything about it. I can’t do anything about it.’ And look, that might be a mindset that hung around since I was a teenager because there was nothing. There was nothing. Even with my [current] GP, I mean, I’ve had her for about 10 years.... I don't think she’s ever said the word lymphoedema. It’s always me saying ‘Oh lymphoedema.’ And she never said, ‘Oh well, maybe you should look at some treatment with the lymphoedema or do this.’ (Sarah)

Sarah seemed to have an internal dialogue back and forth countering the message that nothing could be done to treat her lymphoedema. She catches herself dismissing treatment options as unviable and then moves on to talk about the lack of support she has received from her doctor. Sarah summed up the issue of being in a support desert for 30 years as “I’ve never found any doctor to have any knowledge.”

Since Sarah’s diagnosis, treatment services have increased in Aotearoa New Zealand from a handful (H. Clarke, personal communication, 2006) to the current situation with over 100 therapists (including in the public health system). Disturbingly, Sharn’s recent experience is eerily similar to Sarah’s. Diagnosed with primary lymphoedema in 2017, Sharn

too, underwent a circuitous route. She was referred for multiple scans and investigated for a deep vein thrombosis, the details of which are clearly remembered. Sharn said: “Finally, they sent me to a vascular specialist. I waited a long time and they said, ‘It’s lymphoedema, see you later’ and that was that... In between... I Googled, and I pretty much knew I had lymphoedema.” Sharn showed a pragmatic approach to the diagnosis of primary lymphoedema but was in the dark and in a support desert. She considered the diagnosis of lymphoedema “disappointing,” but was most frustrated by the lack of treatment options. Apart from lymphoedema therapists, Sharn has found health professionals of all disciplines to be dismissive and unable to provide information or advice regarding any support systems. The impact of being in the dark with no referral and no help has left its mark on Sharn, just as it did for Sarah. Sharn said:

I wasn't upset, disappointed maybe... just a bit unlucky... . When I left the vascular surgeon I asked outright ... 'What can I do?' And then they just said, 'There's nothing you can do.' And that was it, that was end of the conversation. ... There was no advice... or any sort of acknowledgement that this needs to be dealt with. And then I was really mad for ages that I have this chronic lifelong progressive illness and there's no help from anyone for it. I used to go on and on about the doctors and my family are 'How is this even a thing?' that I have this illness forever and there's no one to help me except myself. It just seems ridiculous. But it is what it is now. I'm getting used to it now but it's still frustrating. (Sharn)

Like others Sharn was in a support desert and in the dark about how to get help. Sharn's access to lymphoedema treatment was complicated by moving cities. She was diagnosed in a city without a publicly funded lymphoedema service. Sharn did not have a consistent general practitioner either before or after she moved cities. The significant difference between 1989 with Sarah's diagnosis and 2017 when Sharn was diagnosed has been the internet. Participants impacted by the context of being in a support desert and being in the dark were aggrieved, distressed, and felt abandoned by the health care service. In addition, participants living with lower limb lymphoedema felt side-lined by the dominance of cancer, and most specifically breast cancer.

Participants who developed primary lymphoedema generally underwent more circuitous investigations. Being left to learn about the condition themselves, locate services, and often pay privately for treatment, contributed to the experience of being led by the body; feeling that life was dominated by physical symptoms. Being in a support desert and being in the dark, held uncertainty, isolation, and, on occasion, emotions so devastating that years later recalling the experience evoked abandonment and brought them back into that

space of losing previous normality and feeling burdened. Participants who could afford to pay for private lymphoedema treatment considered they received more personalised care; however, those treated solely in the public system considered they received good care.

Summary of Being Led by the Body

Chapters 6 and 7 have explained the first category of the theory of Reconfiguring Life: how people live with a diagnosis of moderate to severe lower limb lymphoedema while being led by the body. Being led by the body represents the way physical changes dominated the lives of participants in the early days after diagnosis. At the onset, participants experienced a change in normality and a sense of losing the life that existed before lymphoedema. The disruption to their previous life was dominated by the physical symptoms of lymphoedema, the experience of having to change clothing to accommodate lymphoedema, limiting mobility, and feeling treated like an outsider due to the observable physical changes, with some experiencing part of the body as ugly. Lymphoedema was physically and mentally demanding, requiring people to think ahead and plan. These changes, together, were experienced as a physical disruption and affected self-esteem and self-concept.

Developing lymphoedema also altered participants' life course. Livelihoods were disrupted through bodily changes affecting those most who worked in physical jobs, while other participants were forced to change work habits. To a lesser degree, lymphoedema disrupted housing and forced one participant to buy a different type of vehicle. Participants also talked about modifying international travel arrangements either by giving up long haul flights or modifying arrangements.

Another way that participants experienced being led by the body was through feeling burdened by the demands of self-care and being required to take more care of the limb, through managing triggers such as heat and cellulitis. Fears about the future burdened participants, worrying about the costs of managing lymphoedema and how to cope as an older adult with the physical demands of the garments and self-care.

Participants used a number of strategies in living with lymphoedema including self-sacrificing wants and desires through prioritising the needs of lymphoedema to retain control of the swelling. An alternative strategy was to prioritise the demands of everyday life by rebelling and hope that lymphoedema would not be too severely impacted.

The disruption to life brought about by lymphoedema unsettled the sense of self. The changes to the body and feeling out of control often stirred up feelings of distress. Participants experienced being in the dark regarding the nature and treatment of lymphoedema and what to expect. Participants typically found health professionals, particularly doctors, lacked understanding of lymphoedema, and many had a haphazard path to diagnosis and treatment. The confronting personal changes to the body and way of life left participants losing a sense of previous normality.

Participants living with lower limb lymphoedema on occasions felt side-lined by the dominance of breast cancer related lymphoedema, and those with primary lymphoedema felt side-lined by cancer related lymphoedema. Losing normality and being burdened by lymphoedema proceeds to the next category of being led by feelings.

Chapter 8 Being Led by Feelings

Introduction

“Should suffering become etched on the self, it shapes not only stories but views and feelings as well.” (Charmaz, 1999, p. 372)

This chapter presents the second category of the theory of Reconfiguring Life: being led by feelings. Feelings are a subjective experience (Orange, 1995). Feelings are experienced either through the mind or through the senses; and, although the words are often used interchangeably, feelings are not the same as emotions. A feeling may be an emotion, but it can also be a sensation—that is, literally feeling through sensing. While feelings are subjective, emotions are a social projection of how we feel (Shouse, 2005). A feeling may be anything that a person senses or experiences. All participants had feelings about their lymphoedema but not all expressed emotions. In this study feelings are differentiated from emotions.

Being led by feelings speaks to the participants’ response to the physical disruption of lower limb lymphoedema. Feelings shifted in response to physical changes that felt overwhelming. Such physical challenges could be posed by everyday events which, in turn, provoked an emotional response, although not everyone expressed the feelings as emotions. Sal summed it up for many when she said:

The frustration might be right at the time of trying to get a garment on or pulling it over your ankle and finding it’s inside out and having to – start again. That sort of, can tip you. (Sal)

Helena talked of her feelings in response to lymphoedema and how the depth of these feelings resulted in her being led by feelings:

But I feel sad that people have to suffer, and for me it was a real. It was just so physically so uncomfortable. Like my legs didn’t fit, it was just changed, and it was just mixed with that fear and the confusion and what am I meant to do and how am I meant to do this? (Helena)

Through the course of the interview, Helena explained that she was driven to find a solution. The physical changes brought on by lymphoedema led some participants through a tumultuous emotional journey that started with the physical changes, as exemplified by being led by the body, and quickly cascaded into being led by feelings. (The three categories being led by the body, being led by feelings, and leading with the mind are an integrated

experience).

A turning point was reached through two different processes. On one hand, a few participants were forced into action. A couple of participants went through a period of going on as normal and tolerating symptoms, only reaching a turning point when they felt their limb was deteriorating. Being forced into action to a turning point is essentially a passive stance resulting in deterioration leading to feeling forced to change. On the other hand, most participants responded to the experience of feeling out of control due to limb swelling and actively pursued solutions, relentlessly, until they achieved change. The process of being led by feelings is symbolised in Figure 3.

Figure 3

Being Led by Feelings

Being led by feelings



Figure 3 represents the experience of being led by feelings, wherein the experience fluctuates and become managed as time progresses.

Being Led by Feelings to a Turning Point

This section outlines the connection between being led by feelings and the two subcategories: feeling forced into action to a turning point and feeling out of control leading to a turning point. A turning point was almost always identified as a moment in time, such as

tiring of the deteriorating limb or experiencing the relief following treatment by a lymphoedema therapist. The turning point was activated by negative or positive factors. For example, negative factors were tiring of the arduousness of a weighty limb and concern about deterioration, forcing participants into action. Positive factors were pursuing solutions; resourcefulness; receiving help; feeling hopeful; sharing the burden with someone else, usually a lymphoedema therapist; and feeling spurred on by symptom improvement. For many, restrictions and the stress of daily life resulted in distress through living with a condition that challenged them physically, socially, emotionally, and mentally. For some, the journey of being led by feelings was short as they were referred for help immediately. For other participants the journey was longer.

Meeting someone who understood was noted by many participants as the context for a turning point. This is exemplified by Sarah when she said:

That was a bit of a turning point I think, for me with my lymphoedema. ... I said something about having lymphoedema ... and this woman says, 'I've got lymphoedema.' And that's the first time I've heard anyone say, 'I've got lymphoedema.' I got a little bit emotional. I remember turning, and collecting myself... So, she was like most people with lymphoedema, she had secondary lymphoedema as a result of breast cancer. (Sarah)

For Sarah, being the one person she knew with lymphoedema, was a lonely experience. In Sarah's case, meeting someone else living with lymphoedema helped her feel less alone, even though the lymphoedema was from a different cause affecting a different part of the body.

Feeling Forced into Action to a Turning Point

Some participants initially chose to live as though unaffected by lymphoedema. However, as the lymphoedema continued to deteriorate, participants experienced distress and were worn down, reaching a point of feeling forced into action. For one participant, the turning point involved reflecting on and analysing the circumstances that led to repeated bouts of cellulitis and a desire to break the vicious cycle. For another participant, feeling forced into action by tiring of the arduousness of the deteriorating limb led to becoming an expert in self-management. A third participant was on the brink of a turning point at interview having had an epiphany about the need to care for the deteriorating limb.

Lymphoedema was demanding, especially for physical workers such as Andy. Andy, like others, said he "rebelled," implying an act of resistance; of wanting to feel normal and

unencumbered by his lymphoedema. In the first few years after diagnosis Andy wore compression. “I did it [wore compression] for 2, 3 years, I was very diligent” (Andy). However, Andy tired of putting the compression stocking on every day and resorted to living as though he did not have lymphoedema.

But then I got a bit naughty. When I stopped seeing [my lymphoedema therapist] I thought, if I just ignore what I've got and just try to lead my life as normal, I'll see what happens. And I went through 4 to 5 years ... of not wearing a stocking at all. I just treated my leg like I didn't have anything wrong with it. Which was probably wrong but that's how I was feeling at the time. (Andy)

Andy's understanding of the implications of ignoring advice was only recognised in hindsight. Later Andy said, “I didn't know enough about lymphoedema. I just thought this is the way I'm handling it. I just got on with life and didn't let it hold me back.” But he found that the limb had deteriorated to the point where it could no longer be ignored.

I wish I'd been diligent and worn a stocking all the way through... But I did notice the leg looked different. That's why I went back to [named therapist] because it had moved from the pitting stage to more hard. (Andy)

Andy described that the skin thickened and hardened. Noticing changes in the skin and size of his leg, led participants, such as Andy, to reassess. Understanding that lymphoedema was a progressively deteriorating condition seemed to be critical knowledge. Participants such as Sarah, who, in Andy's terms, rebelled or took a less active approach because they had been told there was nothing that could be done, found that their lymphoedematous leg continued to deteriorate until they were worn down and forced into action. Both Andy and Sarah reached a turning point through noticing their legs deteriorating, reflected on their situation and changed behaviours.

Feeling forced into action to a turning point is the first subcategory of being led by feelings and involves two properties, getting help and relying on self. The first subcategory of being led by feelings is represented below in Table 3.

Table 3

Reconfiguring Life: Being Led by Feelings. First Subcategory- Feeling Forced into Action to a Turning Point

Subcategory	Property	Dimension	Strategy	Context
Feeling forced into action to a turning point	Getting help	Meeting non-judgment	Avoiding	Meeting someone who understood
		Feeling spurred on by success	Doing the minimum	Support from friends and family
	Relying on self	Becoming discouraged		Feeling side-lined
		Getting on okay		The demands of life roles: Retired/ working/ mothering
		Knowing I could do more		Availability of treatment services

Table 3 shows the first subcategory of being led by feelings, which is feeling forced into action to a turning point, along with the properties and dimensions, and the strategies and contexts of the category being led by feelings.

Getting Help

Getting help refers to locating and receiving effective lymphoedema treatment and management. The process of getting help for lymphoedema was characterised initially by dead ends and trial and error until real help was found. Andy was forced into action through a deteriorating limb. Meeting a therapist who was non-judgemental when he was feeling at a low point with his lymphoedema was critical to becoming linked back into care at this turning point.

What brought me back from my rebellion was non-judgement. ... It was like a confession. Sorry [name of therapist] I've been remiss; I haven't been wearing my stocking, what do you think I should do? She saw me straight away and she put me in compression bandaging again for 2 weeks, to try and get the swelling down... Because [my therapist] was... the openness, non-judgmental. She said it's my choice. And everything I did was my choice. She didn't tell me to do anything. Nothing was, 'this is what you have to do.' It was all nicely handled. My choice entirely to go off the stocking. (Andy)

On return to treatment after 4 years of rebelling against wearing a compression stocking daily, Andy's swelling did not reduce in response to standard treatment. Meeting a non-judgemental, practical, problem-solving approach from the lymphoedema therapist on his return to treatment was part of the healing and moving from feeling rebellious to listening to advice. Andy then took action to manage his lymphoedema to prevent further deterioration and the subsequent impact on his everyday life.

Getting help involved receiving information and strategies for participants, such as Andy, to take control themselves. Feeling spurred on by symptom improvement refers to the motivating effect of a reduction in swelling that galvanised participants to continue treatment with a therapist and in their own self-care. Feeling spurred on through symptom reduction was apparent with all participants at a range of times. In contrast, a deteriorating limb caused distress and motivated participants to return to treatment. Andy knew from earlier treatment experience that swelling could be controlled. In the intervening period without treatment, Andy's leg had "solidified." Feeling forced into action left him with few choices and resulted in Andy investing tens of thousands of dollars for private surgery in Australia, several months prior to interview, which had been successful. Andy was spurred on by the eventual reduction in symptoms.

But I feel it's all coming down now. And I'll be really interested ... to find out how much smaller it has got. ... It had come down from 67[%] to 29% [larger than the other leg] and now I think it's come down even more. And my [therapist's] really keen to find out too how much it's come down. And I'm prepared to do anything to help that process. I don't want to be disappointed. (Andy)

Feeling spurred on through symptom improvement or deterioration was a recurring theme across the reconfiguring journey. Feeling forced into action to a turning point resulted in getting help or, alternatively, relying on self.

Relying on Self

Sarah found a turning point through feeling forced into action. She was discouraged by a vicious cycle of repeated episodes of cellulitis and ensuing deterioration. Through problem solving and reflection she had successfully avoided infections for the 4 years prior to the interview. Sarah saw the pattern between her wet feet, recurring cellulitis, and deterioration, and learned to deal with wet feet rapidly, thereby stopping future infections. Sarah did not have a regular lymphoedema therapist. She was averse to wearing compression. She had also found that medical taping applied fell off and did not give relief—

possibly, because like Andy, the lymphoedema was long standing (Chapter 7, Rebellng). Thus, while Sarah was not following recommended practice to manage her lymphoedema, she developed her own self-care practices. Some years prior to the interview Sarah had her worst bout of cellulitis, describing the impact of cellulitis on her life in vivid terms:

I get to Frankfurt, and then it just gets worse and worse. Then I get on the plane, and I'm like 'Oh shit. I've got cellulitis... I was going to Tokyo for three nights... And then, the flight attendant said, 'Can you walk'?... I was by myself, so he got a wheelchair and I said, 'Can I see the airport doctor?' ... And they just said 'We can't give you antibiotics here. You have to go to hospital.' But I decided against the hospital because it's something I've seen before, plus I had oral antibiotics. So, if it was going to deteriorate within 24 hours, I would have taken myself off to a hospital. But I was okay... I just slept for about 24 hours and then the antibiotics took hold, and I was getting better... My leg looked terrible; I'd had this massive blister ... at the back of my leg and it 'ugh,' and then I'm going on this plane, and I've got all this blister ... - it was just horrible. It just looked disgusting. It looked disgusting... I was probably also freaking out a bit, I know I have to manage this by putting a surgical stocking on. And I don't know if I can put a surgical stocking on. So how is this going to affect my leg? If I don't put a stocking on, is it going to be... So, I made the decision to put the stocking on. It was just this leg that needed... proper medical attention... [On arrival] I made an appointment straight with my local doctor. And she just looked at, [sigh] you know, my leg looked terrible... I remember her going, 'Oh, god!' like her eyes... it was still massive because of the infection. And... she was like 'Woah'! like this at me... I had IV treatment at the surgery. So, that was a bad one. I had to go in for 5 days to get the IV treatment, plus be on the oral. (Sarah)

The last bout of cellulitis coincided with the year that Sarah had received 2 weeks of intensive lymphoedema treatment in Adelaide, been exposed to information at an Australasian lymphoedema conference held in Auckland, and, subsequently, acquired a handheld laser to treat hardened areas of skin. The confluence of these factors may have been useful to Sarah in solving the issue of repeated bouts of cellulitis.

In the space of about 3 years... I had quite a few infections... [I thought] 'Okay, this is something I've really got to manage. This condition means something else.'... I haven't been perfect and there's room for improvement... It's been a bit of a learning process... It was really not knowing exactly what I was dealing with and how to take care of things... My worst infection [was] 4 years ago... Again, my feet got wet... Since then, I haven't had one [bout of cellulitis], which is great. But on those last couple [of episodes of cellulitis] that [had] been quite bad. (Sarah)

Sarah's episodes of cellulitis disrupted her life, caused her concern, and forced her into action as she understood that she was in a cycle of deterioration. Through reflecting on

the why of her recurring infections. Sarah saw the pattern between her recurring cellulitis and deterioration. Sarah learned she needed to deal with wet feet rapidly to avoid infections. Despite seeking treatment in various lymphoedema treatment centres, the usual management strategies did not work, therefore Sarah needed to rely on herself.

It is not known exactly why Sarah relied on herself rather than seeking further treatment, but she gave insight into possible reasons. There appear to be a number of contributing factors as to why Sarah had not seen a lymphoedema therapist regularly. Sarah was not spurred on by symptom relief. When Sarah was diagnosed there was no treatment apart from “ugly brown surgical stockings” (Sarah) which were an anathema to her as a teenager. Sarah explained she had an internal voice telling her there was no point trying because there was nothing that could be done; a message she had received 30 years earlier when she was diagnosed. The subsequent treatment she received as an adult had not convinced her that lymphoedema treatment could be successful. Sarah, therefore, relied on herself and her own problem solving abilities to slow the deterioration.

Another possible reason Sarah did not pursue lymphoedema treatment, as did all other participants, was that in her youth lymphoedema was not a significant concern on a day-to-day basis as Sarah was getting on okay. Sarah looked back towards her younger days and said:

It never haunted me. I was always quite active, I was in the gym, dancing. I did a lot of dancing. It didn't really affect me in terms of day-to-day life. You just got on with it... I was a little bit self-conscious like oh that's that foot, and it's going to be harder to get into that boot ... that was probably the only hindrance. Nothing else really. Didn't give me any problems. I didn't get any infections... I mean, looking back it's a real immune system thing as well. ... [Later] I think my immune system's quite good. (Sarah)

Sarah repeatedly acknowledged she could do more, going so far as to label herself “lazy.” She mentioned her weight multiple times; for example, “I need to lose quite a bit of weight... easier said than done.” Sarah wondered aloud why she avoided self-care. She recognised that there was more she could do and, similar to Andy, Sarah stated:

Because it's easier I suppose [not to]. I feel that I have been remiss with the stocking. I think I need to wear stockings more. And particularly, you know, particularly in wintertime... What I should have [on now are] stockings... I don't. Why aren't I wearing those? (Sarah)

Avoiding tackling lymphoedema and doing the minimum were two strategies used by Sarah who had found a halfway ground between doing nothing and conventional

treatment through using her understanding of lymphoedema. She relied on herself; a decision underpinned by complex reasons to this unconventional approach. Such reasons included not feeling burdened day-to-day by lymphoedema when she was young, a mindset affected by being advised by doctors that there was no treatment apart from surgical stockings, avoiding traditional self-care approaches, receiving little benefit from treatment in her hometown, and trusting that maintaining good immunity and general health would support lymphoedema management. Both Andy and Sarah resisted changing and continued on until they reached a point where the deterioration was intolerable and they were forced into action, finding a turning point, through either getting help or relying on themselves which resulted in them taking a more active role in managing their lymphoedema. The alternative pathway was being proactive in pursuing solutions.

Feeling Out of Control Leading to a Turning Point

Feeling out of control as a result of changing appearance limited mobility and the effect on everyday life, drove a response which resulted in a pursuit for solutions and help. Most participants were in the dark and depended on their own resources to locate help. Like others, the turning point for Helena was meeting an experienced lymphoedema therapist. Helena's first treatment was with a private lymphoedema therapist who spoke her mother tongue and was attuned to her emotional and information needs in a one-on-one situation. Helena's despondency at being in a support desert when she first developed lymphoedema remained powerful 5 years later.

It wasn't even just the physical it was also the mental, the emotional, from something that I felt was just absolute doom and gloom, it was just so horrible for me and, it was just so hard for me to accept it and I really felt I was so alone, I didn't know who to turn to, who to talk to... Oh my gosh just magnificent. [The therapist] just changed [everything]. (Helena)

Participants driven by feeling out of control came to a turning point through pursuing solutions and feeling hopeful. The social contexts influencing aspects of being driven by feeling out of control to a turning point were the role of support from friends and family, feeling side-lined by the dominance of cancer/breast cancer, and availability of treatment services. Feeling out of control leading to a turning point is shown in Table 4.

Table 4

Reconfiguring Life: Being Led by Feelings. Second Subcategory - Feeling Out of Control Leading to a Turning Point

Subcategory	Property	Dimension
Feeling out of control leading to a turning point	Pursuing solutions	Resourcefulness Receiving help
	Feeling hopeful	Sharing the burden Feeling spurred on by symptom improvement

Table 4 shows the second subcategory of being led by feelings, which is feeling out of control leading to a turning point, along with the properties and dimensions.

Pursuing Solutions

Pursuing solutions is defined as devoting time and energy to the quest for help and answers about what to do in response to the swelling. Len found a turning point after feeling out of control. He had surgery for cancer followed by radiation therapy. Len said: “The swelling started in my legs about 6 months, [then] 3 months later it was starting to get worse, and it was swelling up and splitting open and leaking.” While Len’s words do not convey deep feelings, his actions show how hard he pursued a solution. Len’s legs leaked lymph before he was diagnosed. When asked about the treatment and for how long he replied:

Had a bandaging... For a year... I'd go in every 4 days for a day, and they'd massage and bandage. Then I'd go back 3 days later – had lymphorrhoea [leaking lymph]. It went on for ages. Until we got on the garments. And then they decided they'd try these and see how they went, and these have been successful. (Len)

Len, in his late 60s at the time, drove an hour each way to the hospital for his treatment every few days, while living in bandages. Without the treatment, Len considered that his mental health would have been affected, commenting “I don’t know where I’d be right now, probably round the twist.” Helena, too, spoke of reaching a turning point through pursuing solutions and her resourcefulness through locating the name of a therapist. The treatment was successful and, looking back, finding a lymphoedema therapist who provided help was her turning point.

And the only way I got those answers, was by me, taking it upon myself to go to places like that talk at the Cancer Society... But the absolute blessing, was that I got that [business] card. And that's what changed it for me... And that card was [therapist's]. (Helena)

Participants who were driven to a turning point through feeling out of control pursuing solutions showed resourcefulness.

Resourcefulness refers to determination and innovation to overcome difficulties brought about by lymphoedema. For example, Phoebe and her spouse reached out to an international expert. The couple appeared to have developed extraordinary self-care systems from their own astute and determined investigation.

We've been lucky, once we got ourselves, or [Grant] really, got us organised, he managed to contact Neil Pillar [lymphoedema researcher] in Adelaide and [when] we've come across something that we thought, should we or shouldn't [we]. Grant emails him and he [Neil] usually comes back and says no that's not a good idea or nobody knows, give it a try and see what happens. (Phoebe)

Grant showed a high level of resourcefulness and determination locating an international lymphoedema expert renowned for his accessibility and responsiveness. As with other participants, Elizabeth revealed encountering information about lymphoedema services due to pursuing solutions, resourcefulness, luck, coincidence, and networks.

If I hadn't known you [the researcher] because you said to me to make contact with [therapist]. And that was just [at] the park. I mean that's coincidence... Just a lot of it seems like the luck of being somebody who knows how to search the internet and put things together and contacts that happen to have the right resources. (Elizabeth)

Reaching a turning point required most participants to be resourceful and navigate. For example, Lauriane's first turning point came about through pursuing solutions to get a diagnosis. Her swelling began 2 years after treatment for cancer; yet it was a further 4 years of pursuing solutions before she was diagnosed. Lauriane said, "It took 4 years of going to doctors and specialists, having tests and x-rays and god knows what until one doctor looked at me and said, 'you have lymphoedema, there's nothing I can do for you.'" Lauriane then turned to her own resourcefulness. She went on the internet and found a lymphoedema therapist 5 hours' drive away. During the 2 week treatment phase, Lauriane resided at the lymphoedema therapist's home with her husband and was referred to a physiotherapist back in her home city.

When that surgeon told me I had lymphoedema, I just didn't go away, I got on Google and that was relatively new then. I found a lymphoedema therapist in Wellington myself, organised all that myself and then ... she put me in touch with the physio here in [my hometown] who works for the hospital, who'd never done anything with lymphoedema. ... Now she's the lymphoedema specialist at the hospital and physio and I have gone through this hand in hand. And I was her first patient. (Lauriane)

Lauriane spent 4 years looking for an answer, only to be told on diagnosis that there was nothing that could be done. Lauriane's words do not necessarily convey her depth of feelings, however, like Len, her behaviour does. She took an extreme form of action in leaving home for 2 weeks to learn how to manage her condition. Lauriane needed to be proactive and resourceful to find a turning point.

Pursuing solutions and resourcefulness resulted in receiving help. Receiving help is defined as locating and receiving acceptable lymphoedema treatment and management which resulted in finding hope through feeling that control of the swelling, and thereby control of other symptoms, was possible. On some occasions, receiving help resulted in prompt improvement. For example, Len said:

As soon as I got the stockings on and realised once we got the leaking under control and then I knew what was wrong, I was happy with that... Just determination to keep doing what I want to do... Oh I can do far more than when I was being taped up and leaking and all that... The fact is, I know what's wrong, I know how to keep it under control. And I've got help from ACC. ...I think in the back of your mind all the time if you trip up, you're not going to recover like before. ...Yeah, I am far more cautious. (Len)

ACC is the Accident Compensation Corporation, the government agency that manages accident compensation and related insurance in Aotearoa New Zealand. Len had a window into living life with uncontrolled lymphoedema and lymphorrhoea. During the early days after diagnosis his life was constrained by daily nurse visits to manage lymphorrhoea and change bandages. Lymphorrhoea prevented him from doing activities he loved, such as going out in his boat. That level of disruption created a drive in him to maintain control and not go back to those days before diagnosis and treatment. Participants who underwent emotional turmoil, such as "freaking out" while being in a support desert, articulated being driven by desperation and despondency until they received help. Receiving help led to feeling hopeful.

Feeling Hopeful

Feeling hopeful is characterised by a new-found confidence that treatment to control the swelling was possible. Participants previously in the dark about what to do met a turning point, found support, and felt less fearful. Finding a trusted lymphoedema therapist was often key to the turning point. Hope often arrived with the first treatment by a lymphoedema therapist, as explained by Helena: “I was given hope, the gift of hope that there are things that can be done and in fact they were.” Participants experienced finding a turning point when they began to understand their condition, treatment options, regained some control, and felt there was hope for the future.

Sharing the burden is characterised by feeling that another person understands the struggles and distress which in some way leads to being able to move on. Sharing the burden is influenced by feeling hopeful and feeling spurred on by symptom improvement.

I remember feeling so excited and ringing my mother and saying ‘Mama, Mama there’s this lady and she says she can help me’... And it’s just me understanding, that I wasn’t crazy, that I wasn’t imagining these things. That it [lymphoedema] was a very real thing, ... a consequence of the [cancer] treatment... Going to those appointments it was not only a physical therapy it was also for me mental... Because I left inspired.
(Helena)

In sharing the burden, participants felt inspired to act and moved out from a dark place of unknowing and into a place where a plan of action was possible. Helena exemplifies the process that participants went through in the early days of receiving help and feeling spurred on by symptom improvement when she stated: “And, when I get the measurements done and just so exciting that this is a centimetre less.” The circumference of Helena’s limb was measured and monitored along a number of points. The therapist shared the results with Helena who, like others, kept track of the measurements. Symptom improvement helped sustain participants through the demands of self-care.

A couple of participants from the same provincial city had a different experience of finding a turning point and indicated that getting a referral, becoming linked in with a lymphoedema therapy service, and receiving help were straightforward. These two participants did not experience being in the dark or being in a support desert. Their turning point was through a well-functioning health care system.

And they put me onto [my therapist] straight away, through the health board [public system] and we were fairly concentrated for a starter, ... once a month, just a gentle lymph massage ... for about an hour each time. ... and it never got any worse. I went straight into a stocking and still am. (Scotty)

Finding hope and receiving help generally signalled the beginning of a relationship with a lymphoedema service that involved regular monitoring, guidance, and learning self-care. Treatment included being measured and fitted for compression, with some publicly funded health services providing a subsidy and facilitating well-fitting compression.

Friends and family seemed an important social context at critical times for some participants, such as at finding a turning point. The perception of the need for support from friends and family and what constituted support varied. For some participants, being accompanied on the lymphoedema journey was viewed as support. Sharn recounted that she had “an epiphany or a revelation that I need to start managing it [lymphoedema].” Her siblings had arranged amongst themselves to raise the issue at a family dinner, and the intervention resulted in a plan for Sharn to connect with a lymphoedema therapist.

I have a really supportive family and my leg was getting really bad and they just pretty much, gave me a slight intervention... My sister looked at my leg and [said] ‘you really need to manage that,’ ... and they offered to fund some of it. (Sharn)

Sharn was ready to find a turning point and deal with her lymphoedema. The support was in the way the family gently communicated with an offer to help fund her treatment if money was a barrier. Sharn had “started talking” to the lymphoedema therapist “2 weeks” prior to the interview. The outcome was still in progress, but Sharn found the family nudging towards change helpful.

In contrast, for others, the involvement of friends and family in care was objectionable and they actively excluded their family. Sarah developed lymphoedema as a teenager and felt that her family continued to surveil her such as during an episode of cellulitis that was a turning point for Sarah in managing her lymphoedema. She took steps to evade comments or interventions from her family. She recounted a situation of being picked up from the airport by her father after a long-haul flight during which she had developed cellulitis.

When I got back, I remember my dad picking me up. And he goes he’ll take me to a supermarket [which he did]... I felt okay... the fever and all that stuff had gone. It was just ... that I had to get proper medical attention. And

I remember thinking, 'Oh, just go... just go... just go... I have to get to the doctor.' I have to get to the doctor. ... I didn't want to tell... my parents because I didn't want a lecture. (Sarah)

Participants sought the involvement of family in different ways. Kip decided that as the diagnosis and treatment for cancer had been so difficult, he wanted to keep his wife out of lymphoedema issues. He awoke from surgery not knowing whether he faced an amputation or not.

Bad enough having to go through this without her having to try. She wanted to. I think my personality, you're not doing it quite right, I'll do it better. It was rough enough going through this whole, bloody problem, it's pretty traumatic for her more than me. I just had to go through it. She had to think about everything. I didn't. I just, either I'm going to live or die, and they chopped me open. Didn't realise how quick, close I think I did come. If it had been a secondary, I don't think I'd be standing here talking to you. (Kip)

Participants chose to involve friends and family based on the context of what they had already faced. The other form of assistance for those living with lymphoedema was groups and seminars. However, some participants felt excluded even from the groups set up to support those living with lymphoedema.

Feeling Side-Lined

Feeling side-lined, even within the lymphoedema world, was a social context for some participants. Feeling side-lined related to feeling excluded from the limited resources that were available to support lymphoedema which advantaged those with cancer related lymphoedema particularly related to breast cancer over primary or secondary lower limb lymphoedema. For Sharn, feeling side-lined was more personal on one occasion. There were no lymphoedema services in the city where she lived, and she was shut out from attending a course set up by a cancer related organisation that was exclusively for people with breast cancer related lymphoedema.

They had a breast cancer lymphoedema course... It was only for breast cancer people so I [asked] 'I've got this can I come? I'll pay, I know it's free [for others], but I'd love to get some advice and need some help.' They were like 'it's funded through [a cancer agency] it's for breast cancer people.' So there's all this stuff out there for secondary lymphoedema and then there's just nothing - you're just left in the dark if you don't have cancer. ... Unless it's associated with the [cancer agency], you're stuffed and it's ridiculous it makes me so mad. (Sharn)

Similarly, Sarah commented that while there was a support group for those with lymphoedema, meetings were held at the Cancer Society, and she considered it held less

relevance for her. Sara said: “I remember getting newsletters and stuff... I joined, but I didn’t engage... I always felt, oh this is more of a cancer thing... I just didn’t feel that I would have connected so much with that.” Even those with cancer related lymphoedema such as Helena felt side-lined:

It was just so many, just breast and I’m not belittling that at all... And it was all [support group members] like the breast. ... being a gynaecological cancer ... I really, really, felt very alone and very lonely and ... very isolating... I didn’t have other people that I could talk to. [Until I went to] ... the Healthy Steps [movement class at the Cancer Society] that I met a couple of people who had leg lymphoedema and it just helped me so much. (Helena)

Summary

Finding a turning point through deterioration or feeling out of control was realised through many paths. Paths to finding a turning point through feeling forced into action included tiring of the arduousness of a deteriorating limb or through recurring cellulitis. In one case, the limb had solidified. Participants then moved on to receiving help or relying on themselves. Alternatively, most participants pursued solutions to reach a turning point through feeling out of control. These participants turned the corner towards effective self-care through their own resourcefulness and receiving help leading to feeling hopeful, sharing the burden of lymphoedema and feeling spurred on by symptom improvement. Generally, a turning point was attained by meeting others living with lymphoedema who guided and advised, or meeting a lymphoedema therapist who gave effective advice and treatment and from whom hope was derived. Once participants had reached a turning point, all went on to use their mental field to forge a path to self-management.

Chapter 9 Leading with the Mind

Introduction

This chapter presents the third category of the theory of Reconfiguring Life: leading with the mind. Leading with the mind is defined as responding to the physical and psychosocial challenges of living with lymphoedema through using the mental field. The first two phases—being led by the body and being led by feelings—were reactive to the effects of lymphoedema. Having reached a turning point, participants' distress reduced. Leading with the mind indicates a shift into taking control as participants began reconfiguring a new identity.

This section outlines the connection between leading with the mind and the subcategories of being activated by the therapist and reconfiguring a new normal. Table 5 represents the third category, leading with the mind.

Table 5

Reconfiguring Life: Leading with the Mind. The First Subcategory – Being Activated by the Therapist

Subcategory	Property	Dimension	Strategy	Context
Being activated by the therapist	Being in a safe haven	Valuing the relationship	Becoming accustomed	Therapist guidance
		Getting ongoing help	Noticing & responding	The demands of life roles: Retired/working/mothering
		Becoming amenable	Reflecting and analysing	Public vs private care & costs
Tailoring care		Using trial and error	Self-sacrificing and rebelling	Support from friends and family
		Getting symptom improvement	Slackening off	
			Managing risks	
			Becoming accomplished	
			Becoming discerning	
		Being vigilant		

Table 5 shows the first subcategory of leading with the mind which is being activated by the therapist including the properties, dimensions, strategies, and contexts.

Being Activated by the Therapist

The first subcategory of leading with the mind, being activated by the therapist, relates to the way participants were coached by lymphoedema therapists in readiness for self-management. Participants found lymphoedema therapists trustworthy. They felt supported, informed, accepted, and understood. Lymphoedema therapists seemed to have a way of gently confronting with information that galvanised participants to act. For all participants, except one, treatment by a lymphoedema therapist was pivotal to regaining control. For example, Sharn was more recently diagnosed than the other participants and recalled the advice from her lymphoedema therapist as “a wakeup call” (Sharn).

I've read a lot about cellulitis and that's something that I want to avoid. When I went to see [the therapist], she told me, I didn't realise, I know there are stages in lymphoedema, but I didn't realise that if you go up a stage, then you can't come back a stage that it's a permanent step. So, before I saw [the therapist] I was, well I'll just manage it at some point and I'll get it back down... but you can't, it doesn't work like that. So that was a real wakeup call. I don't want to get to stage 3 and 4 and then not be coming back from that, when I'm only 40. So that was my big okay I've got to get on to this because... I'm at about stage 2 and my leg's really hard and it's really not moving very well and I don't want to keep going that way. (Sharn)

Sharn had become informed through reading, lymphoedema groups on Facebook, blogs, and watching videos on the internet; yet her “epiphany” of needing to do more for her lymphoedema came from her family and being activated by the therapist. The therapist’s guidance and information, combined with Sharn’s deteriorating limb, placed Sharn in a position of having to act. The therapist provided a critical piece of information that became a motivator for Sharn to take more control. Being activated by the therapist has two properties—being in a safe haven and tailoring care.

Being in a Safe Haven

Being at lymphoedema therapy offered participants a safe haven where they experienced a degree of relief from their symptoms and the demands of their lymphoedema; an opportunity to be understood and to imagine a future where the condition could be managed. Being in a safe haven involved participants valuing the relationship with the therapist, getting ongoing help, and becoming amenable to taking on the task of self-care.

Participants who felt alone with their disturbing symptoms of swelling and unsupported by health professionals found the experience of finally receiving help a physical and psychosocial relief from the distress of losing normality and the burdening effects of lymphoedema. For example, while Sal did not “freak out” in the early days of her lymphoedema, she did find elements of lymphoedema “scary,” and that issues “can tip you.” Sal explained the concept of being in a safe haven.

When I come to [my therapist], I can talk about it. But if I'm talking to [my husband], I always feel like I'm whining or it is what it is, and my husband might say to me 'well at least you've got your [other] leg.' ... I mean, these are the people I'm relying on. I just want my carers to be like an umbrella. For me. (Sal)

Sal also said it was “draining remaining positive.” At lymphoedema treatment her needs were prioritised, and she could let down her guard. Being in a safe haven supported participants to talk freely about their lymphoedema without having to monitor their language or censor their feelings. Lymphoedema therapists were relied upon, trusted, and valued. Accordingly, participants valued their therapist.

Valuing the relationship is defined as the client experiencing the skills, healing effects, and benefits of the lymphoedema therapist. As lymphoedema is a long-term condition, participants and therapists often establish an enduring relationship. Participants' comments about therapists were exceptionally warm. They commented on the attributes of therapists such as empathy, communication skills, helpfulness, expertise, and making a special personalised effort. Therapists were valued for the relief the treatment provided, their tenacity, and ability to problem-solve. The therapists' attributes and skills supported the forging of trust and encouraged participants to heed the therapist's advice; thus being activated by their therapist. Tui's comments are typical:

She's just a gem. She's amazing. So, that someone cares and having someone not just look at you as a hunk of meat or something. [She] gets stuff out of me [encourages me to talk]. I think she really cares, and she really understands... she's empathetic, very knowledgeable, she goes the extra mile, she sees who you are. And she wants to help. She will advocate for you in ways that you probably wouldn't yourself. She can be a conduit... She is non-judgemental. She's awesome. [My therapist has] been amazing actually, she's a really amazing advocate. And she just so cares, aye. (Tui)

Participants valued the holistic approach of being seen as a person and not just a problem leg. The combination of practical advice, expertise, being seen fully, and the

therapist's empathy, supported the therapeutic relationship. The non-judgemental approach of the therapist as indicated by Andy (Chapter 8, Feeling forced into action) supported him finding a turning point (Getting help). Participants often met therapists at a time of being in a support desert. The ultimate value of being activated by the therapist was receiving effective treatment and getting ongoing help which is critical as it provides some relief through reducing physical symptoms. In addition, receiving ongoing help provides a launchpad to being activated by the therapist, as symptom reduction shows that control is possible.

Following diagnosis, the time taken for participants to locate a lymphoedema therapist ranged from immediate referral to 4 years. All participants had received lymphoedema treatment at some stage since diagnosis. Getting ongoing help through access to treatment by a lymphoedema therapist consistently led to improvements in lymphoedema symptoms, through building knowledge and skills and increasing the capacity to self-care. Getting ongoing help from a lymphoedema therapist galvanised the trust and supported participants to become amenable to self-care.

Valuing the relationship and receiving help are the foundation for becoming amenable. Becoming amenable is characterised by becoming receptive to information and willing to act. Part of becoming receptive to information included participants checking out the lymphoedema therapist's advice against their own reality. Generally, becoming amenable was led by the therapist and resulted from the confluence of trust, being in a safe haven, retaining autonomy, and symptom reduction. Symptom reduction and fear of deterioration secured participants' connection both to the therapist and to the treatment regime. In this way, therapists' activated participants into active self-care.

I got the information from [my therapist] first and the information I got from the computer just expanded my knowledge. ... She's an expert ... She was there to help but I had to allow. I felt that freedom. I didn't feel I was being told what to do... I still had the freedom to say yes or no. It was my choice... I'm very fortunate to have [my therapist]. She's the most lovely, knowledgeable person. I want to be satisfied that the leg comes down to an acceptable size. And I'm prepared to do anything to help that process.
(Andy)

A major motivation to becoming amenable is avoiding deterioration. For some participants that process took time, while for others the realisation was rapid. When Kip was asked why he chose to wear compression from day one, he recalled being told by a surgeon

at a follow up appointment “If you want this to not be a big fat friggin’ leg you need to wear your stocking. That was basically the words.” Kip confirmed that he had seen grossly swollen lymphoedema, when he replied, “She had lymphoedema in one leg so basically her leg was like this [huge]. And I always thought, don’t want to be like that.” When Kip was asked whether there were any other factors in becoming amenable to treatment he replied, “I think my personality... [thinking] ‘I’ll do it better.’” For Kip, seeing uncontrolled lymphoedema, being an athlete, taking control, and being a perfectionist all supported him becoming amenable. Therapists provided information while preserving autonomy and tailoring care to meet individual needs.

Tailoring Care

Lymphoedema manifests idiosyncratically. There is not a ‘one size fits all’ treatment plan. Tailoring care is characterised by participants receiving advice and guidance from therapists specific to their individual needs. Lymphoedema therapists informed and advised generally, as well as specifically, thereby building participants’ trust and capacity for self-care. Tailoring care is comprised of using trial and error and getting symptom improvement.

Trial and error were useful to identify the most successful strategies. Like other participants, Helena and her therapist worked as a team, with the therapist going the extra mile and answering questions outside appointment times, engaging in solving practical everyday issues. Helena asked her therapist for advice about buying underwear: “In the very beginning, even to the point of my underwear, how much trial and error there was and me checking in with [my therapist] ‘Are these ones okay’”? Therapists supported participants to understand principles of self-care management; in this case, the risk that clothing could cause constriction.

Phoebe’s swelling was unstable and difficult to reduce using simple strategies such as elevation. When asked about the strategies that helped build her knowledge in the early days she replied: “Trial and error. There’s not a lot out there. Having [my therapist] was brilliant as a therapist. She taught Grant to bandage.” Phoebe went on to say that paying hundreds of dollars for a treatment session, weekly or more often, was not sustainable financially. Phoebe explained “You’ve got to deal with it a lot more than once a week... You have to do it for yourself... She guided us a lot... really caring... listening to us... She came on board to help.”

Phoebe's husband bandaged her nightly. This level of self-care was proportionate with the intensity of Phoebe's symptoms, such as intrusive pain and heaviness. Phoebe, her husband, and the therapist worked in partnership through trial and error to identify home based strategies to control the swelling and maintain Phoebe's quality of life. The success of strategies was measured by symptom reduction.

Getting symptom improvement is interrelated with feeling spurred on by a reduction in symptoms. Symptom improvement included reduction in swelling experienced both subjectively and objectively. Helena's affected leg was measured at each appointment and the therapist shared the changes in measurements, offered advice and information about her lymphoedema. Helena speaks for others when she said: "And when I get the measurements done it's just so exciting, this is a centimetre less. I mean, how exciting that was for me."

Participants who were initially overwhelmed by the symptoms and the lack of support understood control was possible as their symptoms improved. Most participants mentioned changes in symptoms through improvement or deterioration. Once activated by the therapist, participants began the next step—reconfiguring a new normal.

Reconfiguring a New Normal

Reconfiguring a new normal is the final phase of transformative change that remoulds the self into a new normal. Losing previous normality physically is the beginning of the transformational phase. As the swelling came under control through successful treatment, participants became motivated to take charge and the process of transformative change moved into a new phase.

Helena was representative of the way participants came to the realisation of the need for comprehensive change in their everyday life. Helena articulates the switch from an emotional distress response to engaging her mind that led to adaptation when she stated:

And when I had to get into the next class [higher compression garment] I was again a mental wreck. Then I just think well... I've got something that can help me and this to me is my medicine. I'm so grateful I don't have to take drugs... I just don't care now. I used to feel like such a dick. I used to get so upset. [Initially I thought] it's all probably a vanity thing. But then it wasn't. It was actually adjusting to a whole new norm. And adjusting to the fact that this isn't something that's just going to go away. And adjusting to the fact that it's something that I absolutely have to adapt to. (Helena)

Through regaining control of the swelling, distress levels dropped. The first phase of reconfiguring a new normal is termed changing through what I learn. Figure 4 represents the subcategory of reconfiguring a new normal.

Figure 4

Reconfiguring a New Normal

Leading by the mind

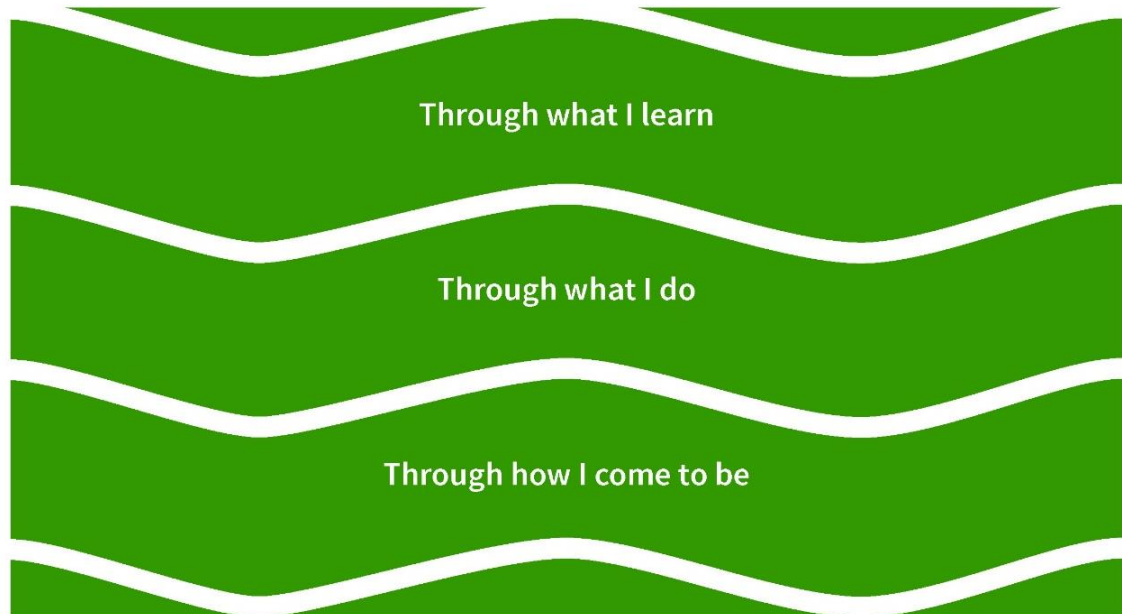


Figure 4 represents the third category of leading with the mind and three properties of the subcategory reconfiguring a new normal.

Reconfiguring a New Normal Through What I Learn

Reconfiguring a new normal through learning relates to developing a platform of understanding about the condition that enables participants to begin the process of taking control to manage their lymphoedema. Participants valued the learning and were informed through many sources including importantly from the therapist, as exemplified by Helena:

“Every appointment I went to I learned the things that I can do, to help myself.”

Reconfiguring a new normal through what I learn is developed through gleaning information, understanding the lymphatic system, and reflecting and analysing. These processes continued to be important as participants fashioned themselves into a new normal and beyond.

Table 6

Reconfiguring Life: Leading With the Mind. The Second Subcategory – Reconfiguring a New Normal

Subcategory	Property	Dimension
Reconfiguring a new normal	Through what I learn	Gleaning information Understanding the lymphatic system & risks Reflecting and analysing
	Through how I come to be	Acquiescing and accepting. Getting to “it is what it is” Being pragmatic
	Through what I do	Adopting self-care Embedding a routine Regaining control Rebuilding a new normal

Table 6 shows the second subcategory of leading with the mind which is reconfiguring a new normal including the properties, and dimensions.

Gleaning information is defined as building knowledge using multiple information sources. Gleaning, as a metaphor, came during an interview when I said to Helena “I’m getting this image, as we talk, of someone who has to collect information from everywhere, and put it [relevant information] together in a bouquet,” to which Helena replied “Absolutely.”

Sal kept a “folder of information” as “I want to know what I can do about it [lymphoedema]. Good or bad but then you put it [the folder] aside... and it just becomes the daily thing.” In this way, Sal explained, initially the information was amassed, valued, and held securely. Over time, as participants became more familiar with lymphoedema, the knowledge was embodied into everyday practice. Gleaning information continued with participants who were many years post diagnosis, continuing to be on the lookout for relevant and useful information. Kip also discussed gleaning information, when he said: “I just pick things up... Bit of a magpie. It’s talking to lymphoedema therapists and others. Don’t really Google, maybe Googled it at the start... I most probably picked up this, that and every other thing.” A main source of information was from lymphoedema therapists, part of the way therapists tailored the support individually.

Sharn, the youngest participant and most recently diagnosed, talked about building knowledge using social media.

When I think cellulitis, I think bad cellulitis, because on the Facebook pages you hear a lot about it and it sounds like once you start, it's like a slippery slope downhill to getting it quite often and it would just be so disruptive to my life, even to be in hospital or to not be able to move very well. ... if I start getting recurrent bouts of cellulitis then I'm going to be in big trouble, so I really want to avoid that slippery slope downhill. (Sharn)

Participants used lymphoedema therapists to acquire knowledge and filter conflicting advice. For example, Elizabeth recalled with a smile that she was advised by the vascular surgeon to eat porridge, however that information was not corroborated. Elizabeth, among others, mentioned going out of their way to glean information, "It's definitely helped to ... go to things like that conference [and] learn from [therapist A and therapist B] and the Vodder [lymphoedema] therapist [in Prague]... and the internet. It's just having the means and time to look." She was gleaning information from various sources including a one-day consumer conference organised by the Australasian Lymphology Association (ALA). Other organisations mentioned that provided information included the Cancer Society and Healthy Steps lymphoedema exercise and information programme. Books and articles were also used. Elizabeth said, "In Australia I got a book which talked about diet and various things." Key information that was gleaned was an understanding of the lymphatic system.

Two participants were referred to lymphoedema services immediately after diagnosis and had a straightforward journey to acquiring knowledge, directly from the lymphoedema therapist. As Scotty said: "Pretty much straight through... they put me onto [my therapist] straight away." However, for most participants there was a delay between symptoms developing and starting treatment during which they were in the dark about their condition and in a support desert.

Understanding the lymphatic system seemed to be a key strategy supporting self-care for all participants. In my experience, the lymphatic system tends to be poorly understood by the general public and many health professionals have little understanding of the role of the lymphatic system in fluid regulation. An unexpected finding was the extent of understanding by participants of the lymphatic system. Sarah said that when she got cellulitis or had skin issues that her general practitioner did not seem to seem to draw an obvious conclusion as illustrated by: "It's always just me saying things like 'Oh yes, because of my lymphoedema.'" Elizabeth looked back to when she was first building critical

knowledge and explained she developed an understanding of the lymphatic system from a baseline of unfamiliarity.

I hadn't thought about my lymphatic system. ... That [ALA] conference ... was just so important because I got a better understanding of how the lymphatic system worked... I've been much more conscious; ... more [careful]... It's taken me a long time to feel my lymph nodes when they're up or down. (Elizabeth)

Interestingly, participants recalled what and where they had learned about the lymphatic system, and associated knowledge. Some participants came to understand the lymphatic system to a sophisticated level, for example:

I think it affects how often I pee. If I'm blowing up, I suddenly realise my legs are getting swollen, I haven't been to the toilet for ages and that just makes my whole system feel sluggish. And if I've been doing the massage.... I have to pee a gazillion times and then it settles down. So, in subtle ways, it affects... your system in lots of different ways. (Elizabeth)

Participants learned to read their body. Many participants commented on the link between urination and lymphatic flow. They applied physiological rationale that prior to lymphoedema was barely notable. Once participants had built foundational knowledge about lymphoedema and the lymphatic system, they could further their understanding of their bodies through reflection and analysis.

Once a foundational knowledge base had been built, reflecting and analysing appeared the most effective skill to manage risks and disruption in lymphoedema. Reflecting and analysing is defined as using knowledge, information, and reasoning to monitor, identify significance, solve problems, assess response, and manage risks. Managing disruption involved changing perception of the risk factors. Issues that may have been perceived as minor prior to diagnosis may become significant and consequential. A small cut or crack in one's skin could pave entry to microbes, lead to cellulitis and a deterioration of the condition. When symptoms worsened, participants looked back on what they had recently done, eaten, or their stress levels to understand the fluctuations. For some, the swelling worsened the day after a triggering event:

It's [the symptom is] quite random but it usually tells me that I've done something wrong. Maybe I've sat too long ... and it's been hot. The combination of heat, (and) inactivity is enough to give me a tooth ache in my leg. Yet the couple of times when I've had really bad pain it has generally

been because I've been doing something, or we've been out, and the garment has either slipped and cut in behind my knee in my groin and created ... like a nerve pain. (Phoebe)

Triggers such as heat, sitting too long, overdoing things, or a creased garment required discernment and response. Participants actively reflected in order to understand the relationship between actions and the increase in symptoms. For some, the heaviness ebbed and flowed and was ameliorated by exercise as exemplified by Lauriane when she said: “additional swelling, usually around the knee, when I've overdone things.” However, not all lymphoedema responded to elevation and rest. It appeared that both the consumers and therapists became discerning about generalisations and the individuality of the lymphoedema, considering personality and willingness to modify behaviour.

Making mistakes and reflecting on the outcome was another way of learning. The first time Sal got cellulitis and septicaemia during the night with pain, fever, and chills, she waited till the next day to go you the doctor. Later, as she illustrated: “The second time I got it (cellulitis) I just phoned 111 and went by ambulance to hospital.”

Information about lymphoedema generally did not come all at once or in a tidy customised package; rather, it was gleaned from multiple sources. Understanding the lymphatic system, the characteristics of lymphoedema, and managing disruption was essential as a first step towards self-care leading to self-management. One striking point was how well-informed participants were about lymphoedema, its causes, and management strategies. Lymphoedema therapists were a trusted source of information and advice which contributed to participants reconfiguring a new normal through how they come to be.

Reconfiguring a New Normal Through How I Come To Be

Reconfiguring a new normal through how I come to be denoted a change in perspective which positioned participants as active agents. When lymphoedema first entered participants' lives it took on a dominant role through burdening symptoms which most participants could not ignore. Through the process of Reconfiguring Life, participants learned to manage lymphoedema and their lives and lymphoedema became a part of, rather than the centre of, their lives. Reconfiguring a new normal through how I come to be, explains how participants used their minds to accept, adapt, and move forward. Reconfiguring a new normal through how I come to be was activated by two processes. The first process was through acquiescing and accepting, the second through resisting change and retaining part of their previous normality. Participants resisted the dominance of

lymphoedema and retained parts of their pre-lymphoedema self while still managing lymphoedema.

Acquiescing and Accepting - Getting to “It is what it is”

“[H]e learned about surrender through facing defeat” (Charmaz, 1995a, p. 673).

Acquiescing and accepting is defined as realising that as moderate to severe lower limb lymphoedema was not curable, the only option is capitulating and acquiescing. Acquiescing may be a psychosocial dimension while accepting is a mental dimension. The social contexts of acquiescing and accepting are accessibility of lymphoedema treatment and support from friends and family. The term acquiescing was derived from hearing acceptance tinged with resignation, which appeared to be summed up in the phrase used by several participants; lymphoedema “is what it is.” Getting to “it is what it is” involved coming to the realisation that lymphoedema was something participants were compelled to learn to live with—there was no option.

When Sharn was asked what she meant when she said her lymphoedema was “fine” and mentioned the phrase “it is what it is” she spoke adamantly and replied thus:

I just mean that there’s nothing I can do about it. I can feel stink about it, but it’s not going to change the issue, or I can let it get me down. So, I think by saying ‘it’s fine’ I’m not saying I feel fine about it [lymphoedema], I’m just saying like, it’s accepted. Like it will be what it will be. I have lymphoedema. I won’t be able to wear these clothes anymore; it makes me feel a bit rubbish. But I can’t change it so, that will be it. Like, ‘it is what it is’ to me means you can’t do anything about, it’s not okay, but you just have to roll with it, you’ve got to accept it because it’s not going back to what it was... Like I don’t think it means that you can’t do anything about it to manage it, but you can’t do anything about it to get rid of it. By saying ‘it is what it is’ I’m not saying I’m just going to let it do what it does and let it take its course. I mean, I’m not changing it, I can still do things to fix it but even if I fix it, I’m not going to be wearing those jeans ever again. Those shoes are gone. (Sharn)

Acquiescing differs from accepting. Accepting can be viewed as an active choice, whereas acquiescing holds the tenor of resignation or giving in to a greater force. Accepting lymphoedema is tempered by acquiescence because accepting the disruption of managing lymphoedema is not welcomed but understood to be necessary. I suggest that acquiescing sets up the mental process that expedites the understanding of the need to modify habits, change thinking, and embed the change into unconscious behaviour to accommodate self-

care and thus potentially ameliorate some of the frustration and psychosocial distress of living with lymphoedema.

Becoming resigned to one's situation takes time. Eight of the 12 participants acquired lymphoedema as a result of cancer treatment. Adjusting to living with lymphoedema required a different skill set to cancer. It is common in Western society to hear about beating or battling cancer, as cancer detected before metastasising can be beaten. Whereas with lymphoedema the general belief is that once lymphoedema has progressed to moderate to severe it is irreversible. There appears to be no battle because there is no win. Participants were left with little option apart from acquiescing to the demands of lymphoedema and potentially seeking to keep life manageable through symptom control.

Kip no longer concealed his leg and, like others, was resigned to lymphoedema when he said: "It's happened. I can't do much about it. You can't just go and hide away. I wander around in my shorts nowadays.... Basically, you've got this now till you die.... It's not going to go away." There was a tone of resignation in his words.

Acquiescing and accepting could be a pragmatic coping strategy of minimising distress. The experience of acquiescing and accepting is a combination of acquiescing, acceptance, and adjusting to a new norm. Tui summed the situation up: "It is what it is, and I get on with it... It's not going to go away. So why worry about something you can't change." Participants needed to navigate acquiescing and accepting which helped mould them into a state of being in which they could adopt self-care. Acquiescing is a form of being pragmatic which, along with becoming accustomed, operates alongside accepting.

Being pragmatic is using practical problem solving to resolve difficulties and disruptions. Participants were pragmatic about what was possible. Sal was prepared to forego a shower or wear her compression for 2 days consecutively while dependent on her husband for 6 months due to other health issues.

Some days I won't get a shower... If I can't be up before he goes to work. And do all the things and, logically I can't do the [compression] pump and shower myself... It's just the way it has to be. I can't manage any of the garments. [Later she said] If my leg garment has to stay on for 2 days, I don't care. It is what it is... and [if] I can't do my thing, then I have to just manage. (Sal)

Participants' responses to situations became to manage as well as possible, and let the rest go and continue to manage in the longer term. Participants spoke about not feeling like a

victim, such as when Lauriane said “Like not feeling sorry for yourself. And just getting on with life.”

For the participants, being pragmatic involved understanding the issues and the solutions. A pragmatic approach externalised the problem of lymphoedema, meaning the person living with the problem has the problem but is not the problem. Thus, lymphoedema was reframed from overwhelming to solvable as participants became accustomed to living with lymphoedema.

Becoming Accustomed

A number of strategies were used in being led by the mind including becoming accustomed. Becoming accustomed is defined as accommodating to living with lymphoedema which was an ongoing process. Becoming accustomed to living with lymphoedema involved incorporating new behaviours and adjusting to physical and mental changes. As participants were reconfiguring through what they learned about the condition, they became aware of adjustments needed in everyday life. When asked about adjusting to the pressure of compression garments Sal explained, like others, that adjustments were needed:

I've become used to it; I think... When I first got the, it felt strange. It's just something that I'm used to now. [My therapist] said when she did the measurements, that this one had like 2 litres [of extra fluid]. Sometimes you do feel like you're swinging the extra around. But no, I'm not thinking about it so much. (Sal)

Becoming accustomed involved understanding the condition, the ramifications for everyday life, and changing behaviour. Participants needed time to build critical knowledge and become accustomed to their new normal. Participants fell back on trial and error and making mistakes through necessity as they became accustomed to lymphoedema.

This section has explained how participants reconfigured a new normal through how they came to be which involved acquiescing and accepting that lymphoedema could be managed but not cured, being pragmatic, and becoming accustomed to the practicalities of managing lymphoedema. While these processes are not linear, participants were also reconfiguring a new normal through what they did.

Reconfiguring a New Normal Through What I Do

Reconfiguring through what I do relates to the practical steps participants took to embed a self-managing approach to lymphoedema. It involves four elements: adopting self-care, embedding a routine, regaining control, and rebuilding a new normal.

After being activated by the therapist, gaining knowledge about lymphoedema, and acquiescing and accepting, participants were ready to become invested in self-management. Self-care in this study is used to signify activities practiced or avoided as part of regaining control over lymphoedema; whereas self-management involves a comprehensive approach to attaining and maintaining wellbeing while living with a long-term condition. Participants acquired the prerequisite understanding and adaptations, enabling them to configure their own approach to self-management based on their circumstances and idiosyncrasies. The first step was adopting self-care. After the first step, progression towards self-management was not necessarily sequential. For practical reasons the steps (processes) in reconfiguring a new normal are presented in a linear way. The preceding steps set the foundations for self-management. Elizabeth, like others, explained her growing confidence and reconfiguring a new normal through what I do in this way:

I have to look after myself. It's about finding a balance. Because, I've had times when my lymph nodes have been up and I have to think maybe there's something else going on, but then I learn to get myself back on track. It's about having a level of confidence that I can manage it. I think that confidence actually goes back to why I can now say to people I've got lymphoedema if they comment on the taping. (Elizabeth)

The road to self-management seemed to have many prerequisites dependent upon self-care support. Participants understood their own physiology, which led to gaining sufficient confidence to manage potential disruptions both physically and socially. The first step towards self-management is adopting self-care.

Participants chose how much focus to place on self-care and how to fit self-care into their life. Confidence in self-care grew through regaining control of the swelling which, in turn, was influenced by developing knowledge, skills, motivation, and becoming amenable. Participants drew on information from the therapist in the early days after diagnosis but as time went on, participants became more able to make their own decisions based on experience and understanding the idiosyncrasies of their lymphoedema. As participants gained some control over the swelling, mobility improved, freeing them to take a more active role in self-care, as explained by Len: "Since I've had the massage regularly, I've got

more ability to get down... Before that I couldn't get down and do my stockings [take them off]." Tui received advice about a range of self-care activities but due to her busy life the most consistent treatment she chose was wearing compression.

[My therapist] has given me exercises and I do what I can, but I don't. The most consistent thing I do is wear the compression. And that's because [of the] full-on-ness of my life. I bought myself a Lymphaciser [mini trampoline] but I've got to set it up yet. Set up the pool so I can do walks, but I haven't been in it yet, those kinds of things. I know all the things that I should be doing but I do the compression and I just think I'll wear that because if I don't wear it, it'll get bigger. But it's stable. (Tui)

Participants had a sophisticated understanding of the lymphatic system and were committed to maintain a self-management regime suited to their circumstances. They were motivated by the fear of deterioration. A couple of participants diagnosed in the previous 2 years were familiar with other self-care practices, but life was too busy.

When Sharn was diagnosed 22 months prior to interview, she lived in the only region in Aotearoa New Zealand without a publicly funded lymphoedema service. Sharn had taken a wait and see approach about her next step with lymphoedema. She said her lymphoedema was not really a problem on a day-to-day basis and she was on the cusp of adopting self-care, being aware she needed to act soon.

Probably the one major roadblock to me being able to manage this properly is that I can't afford to see [private] therapists... I started talking to [my therapist] 2 weeks ago because I had an epiphany ... But I'm still not at that real problem stage. ...it's an annoyance... but it's not severely impacting my day-to-day functioning... So, before I saw [my therapist] I thought, I'll just manage it at some point, and I'll get it [lymphoedema] back down to what it was, but it doesn't work like that... So, I've got to get on to this. (Sharn)

Sharn had recently become activated by the therapist and was beginning to prioritise her self-care. Guidance from the therapist who was pacing the delivery of information was critical to Sharn understanding the need for a self-care practice. The therapist's guidance and information, combined with Sharn's deteriorating limb, was placing Sharn in a position of having to act.

Sarah had not established regular lymphoedema treatment in the preceding 3 decades; for example, she did not wear compression except on long haul flights. Possibly due to the delay between diagnosis and starting treatment, her symptoms had not improved. I suggest that without feeling spurred on by symptom relief after treatment, there

was less incentive for Sarah to adopt self-care as usually recommended and her lymphoedema continued to “get worse.” Sarah has missed out on building knowledge and skills from a local therapist or being monitored. Sarah’s self-care involved exercise, minimising the risk of cellulitis, and keeping her whole body healthy. Sarah and Sharn were the only participants who had not received regular lymphoedema treatment from a lymphoedema therapist.

Embedding a routine into normal life, involved creating a predictable set of activities in a regular pattern that supported living with lymphoedema. This process seemed to provide some consistency and orderliness to counter the disruption of lymphoedema and offset some of the burdening demands of lymphoedema as using a routine may require less cognitive labour. For example, Lauriane explained her daily routine:

I have a routine; in the morning, I moisturise only my left [unaffected] leg [as moisturiser affects compression stocking], put my garment on the right leg. And when I take it off at night, my right leg gets moisturised..., making sure my garment goes on before I do anything else in the day. ... I put it on inside out and the foot part [of the stocking] goes halfway down my foot... And then I slip my foot into that. Then I pull the stocking up over my leg, ... up to my knee and ... I put four strips of the waterproof glue from knee to thigh- front, back and each side. Then ... it sticks to the glue and stays on all day... At night... I take my garment off round 8.30. But I make sure ... my foot remains elevated until I go to bed.... I put it in the washing machine on a rinse and spin cycle with warm water... [For] drying ... I have a heated towel rail ... lay the garment over the towel. By the morning it's dry. (Lauriane)

Routines had been refined over many years, and often involved monitoring using the lymphoedema therapist’s or their own measurements. Daily routines, however, require rethinking when events such as travel occur. Lauriane later explained, “When you go away... I have a problem with ... [getting] my garment dry overnight.” Similarly, when away from home there may not be the “luxury of a washing machine” (Lauriane). During airline travel, routines are further interrupted by time zone and temperature changes at a time when the flight may exacerbate lymphoedema.

In contrast to those participants who had a detailed daily routine, three participants appeared to have a minimal self-care routine. Tui and Sharn, who were diagnosed more recently, wore compression every day and took more care with their limb. Sarah challenged herself about self-care, wondering whether she could do more to manage her weight, wear compression more regularly, and see a lymphoedema therapist. For most participants,

embedding a routine became part of the way of life and supported the goal of regaining control.

Regaining control of the swelling is at the heart of habilitating and is integral to rebuilding a new normal and managing disruption for almost all participants. Habilitating is defined as making fit or capable and differs in meaning from habilitate. Regaining control is the reward for successful self-management. Helena summed it up for many when she said: “Because, right as it is now, yes, I am so grateful that my lymphoedema is in control.”

Regaining control is the culmination of the multiple strategies and influences that bring participants a full circle from losing previous normality. Regaining control was also achieved through strategies such as noticing and responding, using trial and error, and becoming discerning about factors that strengthened control or reduced disruption.

Noticing and Responding

Three strategies—learning to notice, reflecting and analysing, and managing risk—were intrinsically interconnected from the perspective of self-care. In turn, participants learned from noticing. Noticing changes and responding is an important step in regaining control. For example, Sharn noticed skin changes that alerted her to the need to take more care.

I've noticed, my husband notices as well, my skin's getting a bit hard. I'm starting to get more aware now about how it looks as well as how it affects me, like cellulitis. I want to really try to avoid break[s in] my skin and just take better care of this part of my body. (Sharn)

Some participants had sophisticated processes around noticing and responding. For example, Helena, when asked how she knew what was going on with her body and when to react, replied:

With my legs, I think it's something that I do automatically now. I did this mindfulness course. And they talk about a body scan. I think, maybe, I just subconsciously, automatically do my leg scans. I just know when it just doesn't feel free and comfortable. I just have that awareness. (Helena)

From Helena's description, mentally scanning the body could appear straightforward. Yet, maintaining a body awareness during stressful times is demanding and potentially disruptive in the midst of life's busyness. On some level, Helena remained on guard and vigilant, despite whatever was happening around her. Helena appeared to have

embedded a way to be unconsciously conscious about her legs. That is, she has developed the skill which she activates unconsciously and is also able to consciously explain.

However, not all noticing resulted in a response. Action to reduce symptoms by some participants was influenced by social norms. Scotty explained that when he had focussed physical activities, including playing golf, he was prepared to ignore symptoms. Some participants were prepared to pay the price of additional swelling to maintain a sense of normality. When asked how he coped, Scotty replied: “After a couple of hours... You’ve hit the wall, but you’ve gone through it and away you go again.” When asked what drove him to push on, Scotty replied that he needed exercise, “It’s simple as that really... the rest of my body needs exercise.”

Scotty, like some other participants whose swelling reduced with rest, tolerated some additional swelling. Scotty exemplified this situation when he said: “The following morning, I’m fine... There is a bit of trade-off... If I’ve had to get up more than once during the night, for a wee ... I know ... I’m having a little bit of drainage... clearing stuff out.” Participants who pushed on were still noticing, monitoring, and managing risk, and had become discerning and accomplished.

Elizabeth articulated how she addressed details in everyday life to manage risk by being “Probably a bit I don’t know, vigilant, hyper vigilant.” Examples of being vigilant were Phoebe and her husband’s nightly measuring and bandaging, Lauriane logging and monitoring her leg measurements for decades, and Helena’s leg scanning. Like others, Helena responded throughout the day to symptoms of pressure and indicated how often she adjusted her stocking, carrying rubber gloves to be ready to adjust at any and all times:

Getting the stockings to fit right. I realise I need to go to the bathroom get out my gloves and adjust the stockings, they can't be adjusted on the spot. Sometimes they're uncomfortable behind the knee. So, I need to keep an eye on how my body is feeling during the day and respond. I don't need to do major adjustments anymore. When stockings aren't right or something is wrong, my legs just feel heavy, congested. I respond by pumping my legs or self-massage to ease it. I become aware of a physical change. (Helena)

From experience, Helena learned she needed to respond to discomfort without delay. Being vigilant is a skill that some participants embedded at an almost unconscious level. In this way, constrictions were noticed, and risks averted. Participants demonstrated being vigilant, managing risks, and being diligent no matter how apparently insignificant the issue.

Noticing, responding, reflecting and analysing, and understanding the lymphatic system seem to be prerequisites for being vigilant.

A key factor in regaining control and becoming accomplished was being motivated. Participants explained that they were motivated to ensure that managing lymphoedema was a priority, taking precedence over other aspects of life. The motivation was spurred on by the fear of deterioration and the memory of the early days after diagnosis when some participants were desperate. It seemed that for some participants desperation provided the drive to self-manage. Helena was “freaking out” when she first developed lymphoedema, was overwhelmed by the symptoms and confused by the changes in her body. Like others, Helena drew on the memory of those early days as illustrated when she said:

I don't want to compromise how I am now. I'm 60 years old. I just don't need to go over there [travel to my homeland]. That joy, that peace and that good stuff it comes from within here... But I just realise how lymphoedema, the whole thing really is at the forefront. Just sharing with you now, about the travel [and] my reason why I wouldn't do that, is because of this condition. I don't want to risk it being flared up, unbalanced, aggravated in any way whatsoever... And if the reason I'm not going over there, is because I really value my physical wellbeing, and I want to protect the state of my physical being. If that's for me, the pay off, I'm accepting that. (Helena)

Like others, Helena was willingly acquiescing and accepting, putting lymphoedema at the forefront and making life plans around protecting her wellbeing. She was sacrificing the joy she could get from travelling back to her homeland to see family and connect. Helena made the choice consciously to retain control despite being encouraged by others to travel and missing out on her son playing rugby in her homeland. The threat that travelling poses and the risk of unbalancing her lymphoedema were too great a price to pay. Participants reached this galvanised position because of fears about going back to life with uncontrolled lymphoedema. Lymphoedema propelled participants, like Helena, into a stance where their priorities were clear. Some participants were highly motivated, maintaining control and self-managing lymphoedema expertly. Once control was regained, participants were able to look beyond the demands of managing lymphoedema towards rebuilding a new normal. Participants fine-tuned their approach to self-management through using trial and error.

Using trial and error by finding out for oneself was a feature of testing and integrating learning and regaining control, particularly for participants who experienced being in the dark. This form of self-learning differs from therapist-led trial and error such as

explained in the section on Tailoring care (Chapter 9, Being activated by the therapist). Many participants used trial and error including participants who built a frame themselves to get the stocking on. Store purchased frames were available but Scotty, among others, found they did not work as he explained: “A little plastic dofus to put my foot into with a stocking on so I could pull the stocking on easier.” Other examples of using trial and error were Sarah’s mother who had heard that cabbage could reduce swelling. “I remember my mum wrapping my foot in cabbage. She’d boil up some leaves, and then she'd put a cloth over it and then I'd have to sleep with that. To reduce the swelling.” Most participants had used trial and error to support regaining control.

Summary and Steps to Regaining Control

At this point self-management was established. The development of self-management in lymphoedema involved a scaffolding and integration of a series of processes. Regaining control was a critical step in developing self-management. Preliminary steps to regaining control were experiencing lymphoedema as intrusive, getting help, feeling hopeful that control was possible, being spurred on by success or the fear of deterioration, and noticing and responding to fluctuations in swelling and changes. Participants used trial and error while in the dark about how to manage and became discerning, accomplished, and vigilant during the process of regaining control.

The overall trajectory of the development of self-management was non-linear with participants moving backward and forward in response to the ebb and flow of disruption, as shown in the coil in the model Reconfiguring Life (Figure 1). Some processes appeared to be dependent upon having achieved an earlier step. All participants found a turning point and responded to loss of control or deterioration. From there key steps to successful self-management were the realisation that some control was possible; being spurred on by success; building knowledge and skills; acquiescing and accepting that lymphoedema could be controlled but not cured; embedding a routine in readiness to rebuild a new normal.

These processes can be symbolised by a triple helix. The first string of the helix is building critical knowledge and skills to understand the lymphatic system and the condition, and modify behaviour in response, through reflecting and analysing, leading to becoming accomplished at self-care. The second string of the helix is being activated by the therapist and getting ongoing help. Getting help resulted in participants regaining control realising the symptoms were manageable and adopting self-care. The third string of the helix was coming to terms with the condition through acquiescing and accepting, embedding a routine and

rebuilding a new normal. In the phase of acquiescing and accepting participants made an active decision to change in order to accommodate lymphoedema or in Sarah's case, possibly a passive decision without changing and then living with the consequences.

Rebuilding a new normal

Rebuilding a new normal is the last process of reconfiguring a new normal through what I do. For participants living with moderate to severe lower limb lymphoedema the process of rebuilding a new normal begins with finding a turning point and then navigating the process as described in my study up to this point. Once participants were successfully managing the disruption caused by the unstable early days of lymphoedema, attention could focus on reclaiming their lives and selfhood. As Lauriane illustrated when she explained the place of lymphoedema in her life: "Yeah it's just become part of my life."

Rebuilding a new normal involves a number of elements: self-sacrificing and rebelling; having the confidence in self-management, thereby slackening off from the intensity of self-care regime; and finding new meaning. Finding new meaning manifested through a willingness to give back, positivity and gratitude, being inspired and inspiring others.

Self-Sacrificing and Rebelling

Self-sacrificing and rebelling were discussed as a coping strategy earlier (Chapter 6, Losing previous normality). Self-sacrificing supported rebuilding a new normal through prioritising lymphoedema in order to preserve the new normal having regained control. After regaining control some participants could rebel against advice with the assurance that they could restore balance. Some participants who were diagnosed many years earlier had learned how to minimise the disruption of lymphoedema and tolerated temporary swelling which they then remediated through individualised approaches. Rebelling supported autonomy in the face of acquiescing. Similarly, being able to ease back on the intensity of self-management demands after regaining control and stabilising lymphoedema for a few years gave participants the opportunity to slacken off.

Slackening Off

For some participants, managing lymphoedema remained upper most. Some participants could later allow themselves some leeway or slackening off from the demands of self-care once control had been regained through successful self-management. Elizabeth explained that after regaining control she slackened off; self-care was mundane, and burdening.

Doing the massage. Because I actually used to do it every day and I've got quite slack probably in the last year because it's got better. I used to do it every night ... all the massage, neck, arms, thing. And now I tend to be a bit more reactive about it. (Elizabeth)

Others, such as Helena, who was 6 years post diagnosis, appeared to remain diligent for several years until the limb/s stabilised. Sacrificing, rebelling, and slackening off related to maintaining homeostasis; whereas finding new meaning as a path to rebuilding a new normal came through regaining a sense of self-worth and altruism.

All participants showed goodwill in contributing to this study and by giving back, signalling a willingness to potentially improve the situation for others through research. Scotty even offered to be a "guinea pig" saying, "If they want to use me for experiments that's fine as well. And I mean that in all sincerity." Scotty's attitude with its cheerfulness and lack of hesitancy was typical. Several participants voiced interest in supporting research to find a cure. Participants were keen to pass on their learning to smooth the experience for others living with lymphoedema.

Participants recognised that the researcher could delve into private aspects of life and offered to open up. Kip said, "ask me anything, anything at all." Participants understood the dearth of research in Aotearoa New Zealand on lymphoedema. Helena said, "I just think anything like this [research topic] is so, so rare."

Positivity was mentioned in relation to giving back and inspiring others. Scotty mentioned that he gets pleasure from teaching workshop skills. "So, then I joined Men's Shed. Now teaching all these old fellas how to do things." The reasons given for wanting to contribute to research varied but all came from a place of beneficence. Participants also talked about inspiring others.

Inspiring others was mentioned specifically by all the men and linked to being positive and a role model in connection with both cancer survival and managing lymphoedema. Scotty was seen as a role model by his oncologist. Scotty said "My own oncologist, he's actually given a couple of people my name to talk to as well. I'm a pretty positive person!" Inspiring others generally implied carrying on with life with a minimum of fuss. Andy, who had adult onset primary lymphoedema, valued his family's response to the way he had managed his condition.

My family have said I'm inspirational in how I've dealt with my whole condition... 'You're so positive you're not preoccupied with what you've got. You don't moan and groan every day to people.' And I don't. I just get on with life. (Andy)

It appeared that the ability to inspire others was both a tool to rebuild a new normal and an indicator of having successfully done so. Len explained how he supported his mates going through the cancer journey, offered information, and encouraged them to be perspicuous in their needs. In this way, Len used his experience of facing unwellness to reassure and inspire others.

I've got a mate ... he's just been diagnosed with cancer... First time – 2 days ago – he was, making a big deal about laughing it off, trying to be brave about the whole thing. Last night he wasn't. We talked about it. And he thanked me as we were leaving the club... And I said, 'Well you've got to talk to us guys been through it.' So, talk about it and you share it with other people. (Len)

Participants inspired others in different ways. These examples show that the men have used their experience at overcoming a long-term condition to inspire others.

Being able to inspire others may be possible due to finding a secure place within themselves and, to some extent, feeling grateful. Feeling grateful was present on a number of levels. Those who had acquired lymphoedema through cancer treatment spoke of being grateful to be living with lymphoedema and “I dodged that bullet” (Kip) by not dying of cancer. For some participants, meeting another person living with lymphoedema was serendipitous and something for which to be grateful. There was a gratefulness to therapists who provided key support for coping. For some, holding faith and believing God had healing powers was uplifting and a major support. Holding hope was a theme for participants, as was the way therapists held hope. There was a sense of feeling blessed with what one has.

You look not very far and see someone worse off... Without being Pollyanna the leg's there, it's functional. Yes, it's heavy. Yes, it takes some care, but it's not been amputated. I can walk on it and there's worse other things. (Sal)

Yet gratefulness does not discount the challenges. Participants sought a balance in feeling grateful without wanting to diminish or disregard the impact of lymphoedema on wellbeing and capabilities. Lymphoedema does demand more of everyday life. Much of the gratefulness expressed was implied. For example, feeling grateful compared to others living

with a worse impairment, such as when Len said: “[He’s] got a [colostomy] bag.” Participants were also grateful for finding a therapist and receiving treatment (Chapter 9, Reconfiguring a new normal). Helena spoke of being grateful that her stockings were her medicine and participants were grateful to their therapists (Chapter 9, Valuing the relationship).

For most participants, feeling grateful was secular. Helena was the participant who spoke the most about being grateful, appreciating support from God and something she termed “sacred awe.” God was present in Helena’s life and responsible for helping her healing. She could not imagine her healing without the assistance of God.

God helps me. There are little miracles. No one can tell me I haven’t had new lymph nodes popping up. My body has been amazing for that number of lymph nodes removed. I believe God is at work in my body. I’m overcome with gratitude. (Helena)

Helena understood the lymphatic system and that the growth of secondary and collateral lymph pathways were possibilities. For Helena, healing from genital oedema⁵ and the regeneration of lymphatic vessels was attributable to God. “Sacred awe” is related to understanding that things happened for a reason. “They’re not coincidences but God-incidences. God is watching over me in everything, making the way for me, helping me, and guiding me. And then, that gratitude - sacred awe... And I don’t believe that any experience is wasted” (Helena).

Participants recognised that the adversity they faced made them more whole. Helena had looked into the pit of despair, the difficulties of genital oedema, of not coping, and had healed. Of all the participants, Helena spoke the most about distress and being in a support desert. Helena was also the participant who appeared to have moved the furthest from desperation in the early days to regaining control of her lymphoedema. She received intensive early treatment, lost weight, and her faith has been strengthened by the experience of cancer and lymphoedema. Helena said she did not intentionally lose the weight but that the weight loss contributed to her habilitating: “12 kilos. Something like that... But I’ve got to say that hasn’t happened through me doing any kind of dieting per se. It’s just happened I guess, organically.”

⁵ Prior to interview Helena forwarded an email from her lymphoedema therapist. Helena stated, “Here is the info.” During the interview Helena stated, “when I read that email and I actually read it to my son I said I just can’t believe this, listen to this, this is just a miracle.” Helena had forgotten how significant her genital oedema had been. The therapist emailed “your genital oedema i.e., symphysis pubis plus...”

Helena's faith, "little miracles," and the "God-incidences," such as finding a private therapist through being handed a business card, contributed to her rebuilding a new normal. Helena, like other participants, found new meaning in life. The traumatic and difficult experiences participants endured were not pointless but equipped participants to help others and face future adversity successfully. Helena said, "To be able to reach out and share it with another person and to be able to say, yeah I get that." In some instances, faith smoothed the way for habilitating and brought a calmness to distress.

Through reconfiguring a new normal, participants found a way through losing their previous normality to habilitating. Participants became knowledgeable about lymphoedema, reflecting and analysing to solve challenges, acquiescing to lymphoedema, adopting self-care, embedding a routine, and regaining control of the swelling and consequently other parts of their lives. As participants grew more confident about self-management, they were able to focus more on other issues in their lives. Once participants had regained control of the swollen limb, they could test the boundaries by choosing whether they sacrificed parts of their previous life or rebelled and managed the lymphoedema later. Participants who were able to reduce additional swelling could slacken off self-care. Evidence that participants had successfully reconfigured a new normal and were rebuilding a new normal was through reports of successful self-management, finding new meaning through giving back, inspiring others, and feeling grateful.

Summary

The theory of Reconfiguring Life is derived from the data and explains the ways moderate to severe lower limb lymphoedema disrupts life and how people reconfigure their lives, manage disruptions, regain control, and rebuild a new normal. The theory begins through explaining how the swelling leads to intrusive symptoms resulting in losing previous normality and is burdening in multiple aspects of life. Participants experienced being in a support desert and having their life course disrupted. Participants generally responded to the disruption either by sacrificing elements of their life in order to care for lymphoedema or ignored their lymphoedema in order to try to live life "normally." All participants were driven or worn down and forced into action to a turning point. Those who ignored self-care practice found that they were confronted by a deteriorating limb and were motivated to respond. Participants pursuing solutions but in the dark about their condition continued to strive for answers. Meeting a lymphoedema therapist and getting ongoing help resulted in a turning point, finding hope and a path to rebuilding a new normal.

After reaching a turning point, participants began the journey of rebuilding a new normal. Once participants had the knowledge and skills to regain control of the swelling, they adopted self-care. Participants rebuilt a new normal and positioned themselves to give back and inspire others and felt grateful for what they had.

The process of Reconfiguring Life is transformational from the outset. Reconfiguring Life is initially led by the body which is burdened by symptoms which dissolve previous normality and capacities. The loss of the once taken for granted body and associated loss of meaning brings feelings to the fore which then led participants to a turning point through feeling forced into action or a feeling out of control that drove a pursuit for solutions. The third phase of transformative change is led by the conscious mind, through accepting and acquiescing that lymphoedema “is what it is,” becoming amenable to adopting self-care and rebuilding a new normal through transformative learning.

So, how do people live with lymphoedema? In essence, swelling breaks the previously taken for granted experience of the body and one is catapulted into an altered normality. From there, distress experienced through either being worn down and forced into action and then getting help or relying on self, or alternatively distress at feeling out of control, drives the person to pursue solutions. Either way, there is a turning point to better manage lymphoedema. This can go two ways, either small changes are made to keep the lymphoedema just under control or transformative change happens through what people learn, through what they do, and through how they come to be. Transformative change results in acquiescing and accepting that lymphoedema “is what it is” and a new normal and new meaning are created.

Chapter 10 Discussion

Reconfiguring Life: Living with Lower Limb Lymphoedema

The previous five chapters set out the findings of this study. This chapter provides a synopsis of the study and identifies and explains the significance and contribution of four key areas of the findings. I explore the concurrence between what is already known and how this study adds to an understanding about factors that influence how people adjust to living with lymphoedema. First, my study is the only study found that identified a step by step process resulting in transformation, self-management, and adjusting to living with lymphoedema. Second, lymphoedema therapists are pivotal in providing self-care support to people living with lymphoedema. Third, successful self-care support can lead to self-care management whereby a person can place their condition within the context of their lived life, conditional upon being able to manage the fluctuations and disruptions instigated by the swelling. Without self-care support, self-care is extremely difficult to attain (Kopanoglu et al., 2019). Fourth, the process of living with lymphoedema is influenced by three elements: i) managing disruption, ii) time, and iii) a process of transformation. I then reflect on some elements of research learning followed by the implications for clinical practice and implications and recommendations for research and policy. Finally, I outline some limitations of the study, and conclude the thesis.

Overview of the Research

This research set out to understand the experience and response to living with moderate to severe lower limb lymphoedema. The theory of Reconfiguring Life resulted from interviews with participants who provided rich data analysed using grounded theory methods and methodology. Reconfiguring Life expresses the overarching experience of transformative change across the three phases of being led by the body, being led by feelings, and leading with the mind. Contexts vary within and between the three phases; however, the momentum is towards transformation of self through Reconfiguring Life to adapt to living with lower limb lymphoedema.

The overall finding was that participants initially experienced such a significant disruption to their lives that previous normality was destabilised. Destabilisation led to disruption, which was experienced initially as loss of previous normality outside of the person's control. Physical changes wrought a cascade of bodily symptoms resulting in

feeling forced into action to manage a deteriorating limb or a feeling out of control resulting in a pursuit for solutions. Thereby, a turning point was reached, hope regained, cognitive processes took over, and, ultimately, this led to transformative change towards Reconfiguring Life as a new normal. Disruptions continued throughout the course of living with lymphoedema; although disruptions became manageable. Managing disruptions is a key feature of living with lymphoedema.

Managing the disruptive effects of lymphoedema is the ongoing process throughout the journey of Reconfiguring Life and beyond. Managing disruption was physically, emotionally, and mentally demanding. Through understanding lymphoedema, building knowledge and skills, and reflecting and analysing, participants developed the capacity to manage ongoing disruptions, resulting in regaining control, rebuilding a new normal, and reclaiming a renewed self. These findings are similar to Charmaz' (1995a) who identified the complexity in managing severe chronic illness, the restrictions on life, the burden of managing in the face of "the lost unity between body and self" (p. 657), and a diminished sense of self and identity.

The findings of living with moderate to severe lymphoedema from the current research consolidate earlier studies (Cooper-Stanton et al., 2022; Meiklejohn et al., 2013; Ridner et al., 2018). This research also contributes new understanding in two main areas. First, my study provides an exposition illustrating the steps of transformative change from first receiving help to rebuilding a new normal and sense of self. Second, the ways that lymphoedema therapists build a therapeutic relationship is explicated from the perspective of the person experiencing lymphoedema. Despite the significance of these two areas, it seems that this study illustrates areas of lymphoedema research which appear to be absent in extant literature.

As people are living longer after treatment for cancer and cancer rates are rising, understanding the implications of lymphoedema and treatment pathways remains highly relevant. The findings also come at a time of restructuring the health service, with an underlying intent to reduce inequities within a population-based funding formula (Health and Disability System Review, 2020). Publicly funded lymphoedema service delivery is currently not funded equitably by population or region in Aotearoa New Zealand.

Significance and Contribution of the Research

Step by Step Process of Adjusting to Living with Lymphoedema

My study identified a multi-step process of adjusting to living with lower limb lymphoedema. These steps constitute a process map which is useful for navigating complex health related areas, such as self-management of long-term conditions, and can reveal otherwise unseen processes. Process mapping, as the name implies, identifies steps in a process. These steps are derived from the patients' perspectives, whereas it is significantly more common that data from clinicians are used (Antonacci et al., 2021). This is the first study to detail an explanation of the process of how participants can reconfigure their lives through lymphoedema self-management and is displayed in Figure 5 below.

Figure 5

The Steps from Finding a Turning Point to Regaining Control

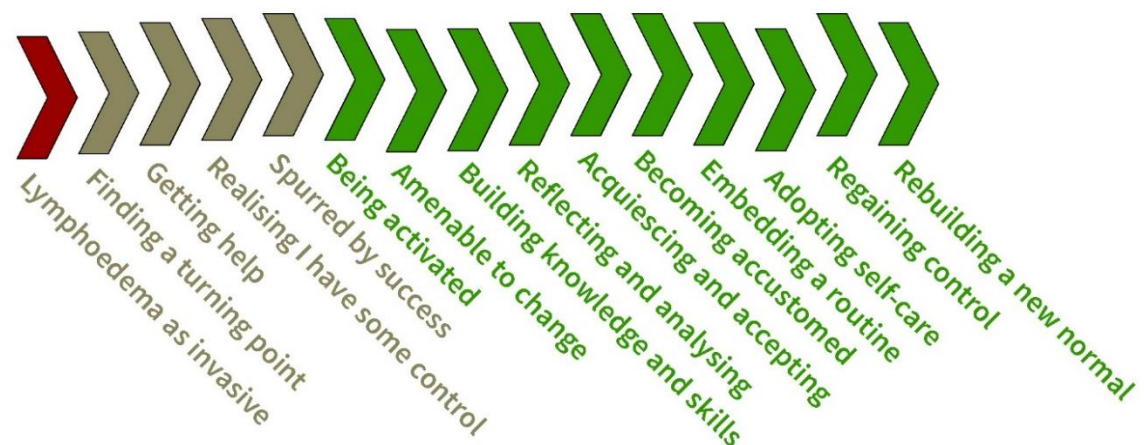


Figure 5 details the steps within the categories being led by feelings and leading with the mind that comprise a process of change in adjusting to self-managing lymphoedema.

The steps are detailed in the findings' Chapters 8-9 (particularly the section Regaining Control, Chapter 9). A key element with the multi-step process appears to be the role of feelings which led up to being activated by the lymphoedema therapist for some participants. Feelings arising in response to developing lymphoedema is well supported in the literature as part of the suite including psycho-social effects of lymphoedema (Bowman et al., 2020; Brown, 2018; Finnane et al., 2015; Fu et al., 2013; Morgan et al., 2005; D. P. Stollendorf et al., 2016; D. P. Stollendorf et al., 2016). My study found that feelings were a significant factor in propelling participants towards the journey of successful self-management. When the person living with lymphoedema turns for help from health

professionals there is often a gap in knowledge or a dismissal of the significance of lymphoedema, except with lymphoedema therapists. For some participants, the loss of self-efficacy combined with feeling abandoned by the medical profession resulted in distress and despondency. There was a pursuit for solutions, to understand the changes to the body, and how the person could help themselves. In addition, there was often a delay in receiving a diagnosis or getting help, meaning the time of distress was extended.

Unlike my model, most models of self-management generally lack specificity (Lorig & Holman, 2003). However, after reviewing over 100 qualitative articles, Schulman-Green and colleagues (2012) extrapolated three categories related to self-management for long-term conditions; namely, “focusing on illness needs; activating resources; and living with a chronic illness” (p. 136). Their findings, including the skills and tasks within the categories, corroborate the findings of my study. One key finding of my study was that the lymphoedema therapist was key to receiving help and learning to self-manage.

The Pivotal Role of Lymphoedema Therapists

Ten out of the 12 participants in my study reconfigured their lives through learning to manage the disruptions caused by fluctuations in swelling and complications; and one further participant had begun the journey. The path to self-care was guided by lymphoedema therapists who enabled their patients to adjust through a complex series of steps detailed above. There is tentative data from my study that even with the advent of the internet young people living with lymphoedema are unable to navigate this process on their own.

In my study, lymphoedema therapists were highly valued for their knowledge and support, particularly at a time of great need. Lymphoedema therapy is undertaken by lymphoedema therapists who are health professionals associated with another discipline such as physiotherapy, nursing, massage therapy, or occupational therapy. Lymphoedema therapists undertake additional formal training with approved trainers in order to be credentialled by the Australasian Lymphology Association and the New Zealand Lymphoedema Therapists group. The value of the lymphoedema therapist is heightened, as participants experienced being in a support desert with health professionals who were often disinterested, uninformed, gave conflicting information or poor advice, and showed little regard for psychosocial or medical needs. Surprisingly, some participants whose lymphoedema was related to treatment for cancer had difficulty getting a diagnosis,

information, and referral. These findings are reflected in earlier studies (Barlow et al., 2014; Thomas, 2021; Watts & Davies, 2016).

There are limited resources in the publicly funded health care system. Therefore, those who had money to go privately increased their chances of meeting a lymphoedema therapist who could guide them through the complex maze of lymphoedema self-care support. This creates inequity whereby those with the greatest privilege have their privilege reinforced, while those who miss out are further deprived. The question arises as to how much the health care system is able to respond to those living with lymphoedema and whether supporting those with lymphoedema is cost effective in terms of actual costs to the health care system and indirect costs associated with loss of employment reduced quality of life. Further investigation and evaluation into the cost effectiveness of providing local lymphoedema clinics offering lymphoedema self-care support is warranted (Watts & Davies, 2016).

Development of the Therapeutic Relationship

In my study, the development of the therapeutic relationship is a critical turning point in the lives of those who received sufficient self-care support. Scant literature about the therapeutic relationship related to health outcomes for people living with lymphoedema was found. However, the elements identified within my study relating to the development of a therapeutic relationship are corroborated by a wide range of literature related to long-term conditions.

Study participants living with lymphoedema, without prompting, stated that their therapist was the “best” (Chapter 9, Being activated by the therapist). Therapists were held in the highest esteem for supporting participants physically, socially, and emotionally. Meeting a lymphoedema therapist was often the beginning of receiving effective treatment, which inspired hope in almost all instances. During the second literature review a number of articles were found that explored and outlined what is known about the therapeutic relationship from the perspective of the consumer in relation to long-term conditions (Agarwal, 2018; Greenhalgh & Heath, 2010a; Klein et al., 2007; Wienke Totura et al., 2018), but which, until now, lacked corroborating evidence in relation to lymphoedema.

Understanding and quantifying elements of the therapeutic relationship between practitioners and consumers is complex. Descriptions of the qualities of therapeutic relationships are flawed due to the intangible and personal nature of such relationships (Greenhalgh & Heath, 2010a). Key attributes of therapists identified in my study were

warmth, empathy, supporting autonomy, going the extra mile, willingness to share information, individualised care, and being non-judgemental. These findings are supported by research into the client perspective of the therapeutic relationship for those with long-term conditions (Agarwal, 2018; Babatunde et al., 2017; Greenhalgh & Heath, 2010a; Street Jr et al., 2009; Wienke Totura et al., 2018). Together, these attributes constituted a relational approach. A relational approach goes beyond person-centred care through meeting the client on a human level; acknowledging the whole person, their social context, and autonomy; and through validating the lived experience (Franklin et al., 2023).

The studies located in the second literature review focussed on the development and impact of the therapeutic relationship in the context of long-term conditions and were not specific to lymphoedema. No data were found in the lymphoedema literature about the relational skills and attitude of the lymphoedema therapist as perceived by clients. One study (Karlsson et al., 2015) focussed on perceptions of lymphoedema treatment from the client perspective but did not look at perceptions of the lymphoedema therapist. Another study (Keir, 2020) explored perceptions from consumers and lymphoedema therapists surveyed across Australasia. Their findings contrast to my findings and will be explored later in this chapter.

Therapeutic Relationships Guiding Self-Care

Along with achieving symptom improvement, in my study developing a therapeutic relationship appeared to be a critical success factor in activating the development of self-care. Yet, as stated above, almost no literature was found in relation to the client perspective on the impact of the therapeutic relationship and lymphoedema self-care. The therapeutic relationship is generally understood to include practitioner led collaboration, building rapport, establishment of trust, and empathic approach built through communication, connection, listening, and responsiveness to social and emotional concerns (Pinto et al. 2012)—termed relational skills. It was as though the client, pursuing solutions, met the willing therapist who understood how to tailor care, attend to the whole person, improve symptoms, impart information, and promote the value and underpinnings of self-care.

A therapeutic relationship between practitioner and consumer involves engagement (working together) and connecting (understanding each other or the fit). The quality of the therapeutic relationship in long-term conditions affects client health outcomes (Babatunde et al., 2017; Street Jr et al., 2009), but the mechanism by which that operates is still being discovered. My study adds weight to understanding that mechanism.

From my study it appears that a strong therapeutic relationship resulted in participants becoming activated, having a better understanding of their condition and management, and an increased trust and stronger agreement on the approach and plan of care. These findings are corroborated by Street Jr and colleagues (2009) who found that the therapeutic relationship positively affected adherence with the treatment plan, improved self-management, and bettered quality of life and wellbeing. Similarly, Wienke Totura and colleagues (2018), in a comprehensive literature review related to psychiatric medication adherence utilising meta-analysis, found a positive relationship between therapeutic relationship and adherence.

All participants in my study named their therapists, with some naming two therapists—one in the public and one in the private system. Participants had often seen their lymphoedema therapist for many years and they had become well known to each other. This is supported by Wienke Totura et al. (2018) who concluded that there was evidence that continuity of care and treatment, patient empowerment, incentives to change, and feelings of warmth and attachment to a practitioner positively affected adherence to self-management strategies. Similarly, in another study, seeing the same practitioner with sufficient time for the consultation supported the development of therapeutic relationship over time (Greenhalgh & Heath, 2010b).

In my study, lymphoedema therapists tailored care for the individual, which was valued in the therapeutic relationship and, in turn, supported adopting self-care. My findings are affirmed by a range of authors including Klein and colleagues (2007). Their study with consumers who had experienced severe mental illness, found a relationship between medication adherence and meeting clients' self-perceived needs. Similarly, Greenhalgh and Heath (2010a), in a concept analysis of the therapeutic relationship, found consumer satisfaction with health care improved when the appointment dedicated time and focus to social and emotional factors, also corroborated by Klein and colleagues. Greenhalgh and Heath (2010b, citing Mol 2008), presented an argument that the therapeutic relationship develops through collaboration between parties when practitioners seek to individualise knowledge and treatments suited to the consumer's specific presentation rather than through offering patient choice in decision making, that is individualising care. My study found that participants valued being seen as a whole person and not just a "hunk of meat" (Tui). This holistic approach is person-centred; attuned specifically towards the client and is supported by Klein et al.'s findings that consumers sought recognition of the complexity of their lives and to be seen holistically; that is, within their social and emotional context.

My study found that lymphoedema therapists who went the “extra mile” were guided by the biomedical model while taking the opportunity to collaborate with the whole person, their social context, and empower consumers. These findings are supported by Agarwal (2018) in a study related to a single practitioner in complementary and alternative medicine. Consumers with ongoing pain, valued a practitioner described as going above and beyond expectations and “in tune” (Agarwal, 2018, p. 2406), who listened empathetically and related at a deeper level. A practitioner who guided and connected holistically, encouraged client self-reflection and learning which promoted self-management. The place of lymphoedema beyond the edge of medical mainstream and outside of medical purview in Aotearoa New Zealand, alongside the influence of massage therapy holism, may support this differentiation in lymphoedema therapists’ approach compared to other physical care.

Another element of the relational approach discussed by participants was supporting autonomy. In my study, preserving client autonomy resulted in one participant feeling sufficiently respected that they were able to return to treatment after not wearing compression for 4 or so years. Therapists walked a fine line between supporting autonomy, freedom of choice, and promoting best practice self-care. For example, when asked about the benefit of spa pools, one therapist is quoted by the client as responding, “it depends”, and then engaged in a conversation about the benefits of water, movement, pressure, and the risks of heat. These findings are supported by a survey of consumers with severe mental health issues that concluded taking client preferences into account and supporting autonomy predicted consumer outcomes (Stanhope et al., 2013), wherein client outcomes appeared to refer to medication adherence, appointment attendance, and satisfaction with the service. The study reinforced other findings such as the development of a therapeutic relationship mediated the process of adherence.

My study participants valued the way lymphoedema therapists accommodated autonomy, thereby promoting their clients to adopt a demanding self-management regime. Autonomy is long recognised as an important element in health care related to informed consent, decision making, taking charge of one’s life (Ringstad, 2016), and, to some extent, living with the consequences of those decisions. Within the context of living with a long-term condition, such as lymphoedema, and interacting with lymphoedema therapists, preserving autonomy involved having a sense that one is free to choose and is genuinely supported in that choice. According to study participants, therapists accepted that change took time. Therapists’ advice was evaluated against lived reality by participants and therapists gained

respect and buy-in when their predictions and advice came to pass. In my study, trust and engagement in self-management then grew commensurately.

In summary, my study found that participants valued and responded to a warm and empathic therapeutic relationship that was holistic, supported autonomy, individualised care, and provided advice that was tested in real life. These findings are supported by Greenhalgh and Heath (2010b) who contended that the therapeutic relationship is a complex interplay where there are no quick fixes, such as patient satisfaction survey feedback or “brief interventions” (p. 481). Rather, the development of the therapeutic relationship hinges on high quality human to human connection which remains focussed and engaged in the present without distraction.

One lymphoedema study was found that did not corroborate my findings. Using a mixed methods research method and methodology, Keir (2020) investigated the match between the expectations of people living with lymphoedema and the educational approaches of lymphoedema therapists with a goal to improve self-management. Therapists and clients in the study were surveyed using two different survey tools. Converse to my findings, Keir’s interpretation of the lymphoedema therapists’ practice did not appear to match possible expectations of consumers. Keir’s findings included that lymphoedema therapists were not perceived to embrace person-centred care. Rather, survey results of lymphoedema therapists’ responses indicated an authoritarian approach, and insufficient theoretical understanding of learning theory to motivate or activate clients for self-management. Whilst therapists in Keir’s study expressed support for client autonomy and highlighted their role in supporting clients to become adept in self-management, data indicated there were few therapeutic strategies to support client empowerment. Therapists freely supported lymphoedema self-management as the responsibility of the client but appeared less keen to recommend that clients act independently in problem solving or pursuing information.

Keir (2020) found that lymphoedema therapists used metaphors and specialised language that may not have built client knowledge and skills. Effectively, the findings showed a gulf between the aims and aspirations of consumers and the pattern of intervention, care, and strategies by the lymphoedema therapists. However, in Keir's study, those living with lymphoedema were not directly asked about their views of their lymphoedema therapists. The two groups of participants, lymphoedema therapists and consumers, were not matched or expected to be in a therapeutic relationship with each

other. Comparative perspectives related to self-management education were analysed using quantitative, qualitative, and comparative methods. Keir's study sheds light on future opportunities to strengthen lymphoedema self-management education.

In contrast, my study found lymphoedema therapists were almost adored for their individualised, person-centred care, their vast knowledge, support in problem solving, and preservation of autonomy. My findings revealed that lymphoedema therapists, despite a potential theoretical gap between how therapists articulated their practice and consumers' needs (Keir, 2020), were skilled at activating clients in readiness for self-management.

Personal Nature of the Relationship

People living with lymphoedema, meeting a therapist for the first time, have usually either undergone treatment for cancer or had a circuitous route to a diagnosis of primary lymphoedema. Lymphoedema is a condition in which most people conceal the affected part of the body. It is as though intimate skin to skin contact with parts of the body that may otherwise be untouched by anyone else appeared to create an element of intimacy and responsiveness to vulnerability which differs in other nursing and physiotherapy arenas. Massage therapists, who are also lymphoedema therapists, experience skin to skin contact in all elements of their role. The difference for those with lymphoedema receiving massage is that lymphatic drainage is an integral part of remaining healthy and may not feel optional.

During interviews with participants, stories were shared of the connection between therapist and client indicating that personal issues were shared both ways. Participants spoke about what was said during treatment but requested that I not share these happenings because they were too personal and identifiable. It seemed that these intimacies shared between therapist and client made the relationship more real and personal, potentially acting to create more balance in the vulnerability. The individualised care and relational character of the therapist galvanised trust, furthering receptiveness to the substantial amount of information and life adjustment required to begin the path to self-management.

Self-Care Support

Aotearoa New Zealand Inconsistent Service Provision

There are nearly 70 lymphoedema therapists in private practice around the country (Lymphoedema NZ, 2022). Many therapists are engaged only part time in lymphoedema. There are 20 local hospital and community service localities and 18 of those have at least

one lymphoedema clinic. Available and accessible support from a lymphoedema therapist is essential in order for those living with lymphoedema to be successfully guided to self-management (Watts & Davies, 2016).

One region, Wellington and Hutt Valley cities, with a population of nearly 900,000 (Te Whatu Ora. Health New Zealand, 2022) has no publicly funded lymphoedema assessment or treatment services, despite years of lobbying (D. Graham, Personal communication, 9 November, 2022). The other 18 district localities provide assessment and monitoring services. Some regions supply or subsidise compression garments. Very few localities seem to provide manual lymphatic drainage or initial bandaging. Information about services came from publicly funded lymphoedema therapists themselves and was confirmed by Te Whatu Ora by email via the response to an Official Information Act enquiry (personal communication, March 30, 2023). There appears to be no systematic coordination or policy on lymphoedema. It has not been possible to find out whether lymphoedema is on the schedule of services required to be provided by Te Whatu Ora, the publicly funded health service. On 16 January 2023 I received an unsolicited personal communication from the Wellington region about setting up a lymphoedema service as there are development plans. According to my study, as detailed above, the path to self-management was fully guided by lymphoedema therapists who enabled their patients to adjust through a complex series of steps. My study indicates that in order to maximise quality of life, access to lymphoedema self-management support is critical, yet not always available in Aotearoa New Zealand.

Significance of Self-Care Support

My findings of the need for self-care support for people living with lymphoedema by health professionals is affirmed by Kopanoglu and colleagues (2019). An appropriate, self-care programme provides information and support suited to the client's stage of learning and self-care journey, such as those setting out, those at the experimental phase of still learning how to self-care, and those who have developed expertise. Receiving information or guidance not tuned to the particular stage is ineffective. Kopanoglu and colleagues have devised a framework for behaviour change based on previous models of change (citing Prochaska & DiClemente, 1983; Ryan & Deci, 2000) and scenario-based learning processes. This framework has been co-designed with eight women, half of whom had primary and half secondary lymphoedema, and all, except one, with lower limb lymphoedema.

Kopanoglu and colleagues' (2019) conclusions strongly support my findings related to the role of the lymphoedema therapist and becoming activated to self-care. The authors

identified processes including the need to learn to self-monitor, develop competence, support autonomy and motivation, develop a realistic routine, and support for both psychological and social wellbeing, given the challenges to personal appearance, self-esteem, potential isolation, and changes in life roles.

So much in self-management with long-term conditions is left to chance (Greaney & Flaherty, 2020; S. H. Ridner, M. R. Fu, et al., 2012; Watts & Davies, 2016). The health care system supports the diagnosis but often provides minimum resources to support self-care. Therefore, those living with lymphoedema often need to rely on their own resources to navigate the system. This study provides rich data on how participants need support early in the self-management journey which then, in most cases, decreases. The current study has shown how the path to receiving a diagnosis and receiving self-care support was a haphazard journey, a finding supported by Cooper-Stanton et al. (2022) and Meiklejohn (2013).

Coincidences

My findings further add to extant literature in relation to what has been described as diagnosis through coincidence (Cooper-Stanton et al., 2022; Meiklejohn et al., 2013). According to my analysis, coincidences are not coincidental—they are actually a reflection of structural inadequacies of health care provision which are echoed in other countries. In the early days, before diagnosis, there was a pursuit for solutions. Reaching a turning point came through what was considered a coincidence (or God-incidence with divine intervention); yet I suggest it was not a coincidence. Coincidence, as previously described in the literature (Cooper-Stanton et al., 2022; Meiklejohn et al., 2013), actually reflects the lack of structured support for people with swelling to receive a diagnosis. There was a pattern that participants experienced ‘coincidences’ as part of the pursuit for solutions (Chapters 8 and 9) in the face of being in a support desert. It was as though there was no alternative to coincidence because there were so few formal processes for receiving help. The drive for a solution continued until either the confluence of factors, referred to by participants as “a coincidence,” arose, or the person got beyond hope and gave up.

Experienced therapists have told me that those who do not find coincidental help fall into depression, despair, and become overwhelmed by the experience of the burden, which can become life threatening. The alternative to finding help through a coincidence, for the minority, is direct referral from diagnosis to a lymphoedema therapist or being directed to a lymphoedema therapist for diagnosis. Direct referral bypasses the experience of being in a

support desert, being in the dark, and finding somebody to help. Direct referral would be the outcome where there is systematic self-care resourcing.

Miriam Meiklejohn (2011) and colleagues (Meiklejohn et al., 2013) investigated everyday lives of Australasians living with lymphoedema arising from any form of cancer using Charmaz grounded theory methods and methodology. They found that coincidence was the path to diagnosis. The participants in Meiklejohn and colleagues' (2013) study were living with cancer related lymphoedema, predominantly from breast cancer, with about 25% experiencing lower limb lymphoedema. Meiklejohn identified three phases—"altered normalcy," "accidental journey," and "ebb and flow of control," with the core category, "sense of self." "Altered normalcy" supports my study's findings of losing previous normality. "Accidental journey" related to the haphazard way in which people living with lymphoedema accessed help and services, such as by coincidence.

Cooper-Stanton (2022) undertook a systematic review synthesising data from 22 aggregated qualitative studies to identify experiences of men living with long-term lymphoedema. Their themes confirm my findings:

(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' – challenge in receiving a diagnosis, and support; and (4) 'Personhood' – the impact of the condition upon external constructs and relationships. (Cooper-Stanton, 2022 p. 1)

Receiving help haphazardly has been termed abandonment by medicine and is well documented in the literature (Barlow et al., 2014; Carter, 1997; Kalfa et al., 2019; Morgan et al., 2005). Lymphoedema therapists enter the lives of their patients at a time when lymphoedema may be experienced as overwhelming. The quality of the help then provided contributes to the appreciation of lymphoedema therapists.

Summary of Self-Care Support

As discussed above, in Aotearoa New Zealand self-care support is often not available, leaving those living with lymphoedema without access to publicly funded care. The significance of self-care support for long-term conditions in Ireland was investigated by Greaney and Flaherty (2020) who contended that self-care support is often neglected and constitutes a form of health services rationing. As in Ireland, the current model of health care delivery in Aotearoa New Zealand focusses on diagnosis and treatment. There is a need to reorient the health care policy and, therefore, the system towards a model that supports self-care.

My study provides an opportunity to reassess the self-care support systems for lymphoedema to improve fairness, add value to quality of life, and reduce the burden on the health care system. Aotearoa New Zealand health reforms are driven by an agenda of equity with a population based funding model (Health and Disability System Review, 2020), which provides additional funding to primary care providers for vulnerable populations, those with low socioeconomic status, and for people with long-term conditions (Gauld, 2020). The problem remains that lymphoedema is not treated or supported by general practitioners; therefore, there needs to be a model for self-care support which includes lymphoedema therapists and does not rely solely on general practitioners.

In summary, my research provides local, relevant findings which other researchers corroborate. There is evidence that providing robust self-care support for those with lymphoedema or at risk of developing lymphoedema would have benefits for individuals, families, and society. The time is ripe for creating a more equitable service provision for lymphoedema within Aotearoa New Zealand. Cancer rates are rising, the population is aging, and people are living longer. There has never been a more imperative time to develop lymphoedema self-care support for those adjusting to living with lymphoedema.

Learning to Live with Lymphoedema

This section outlines the contribution of my study in relation to the three elements of learning to live with lymphoedema. The three elements are: managing disruption, the influence of time on the evolution of self-management, and the transformative process of Reconfiguring Life related to body, feelings, and mind.

Managing Disruption

My study identified that living with lymphoedema involved an ongoing juggling of managing disruption. To recap, managing disruption is defined as taking action to manage factors that could worsen swelling or successfully reducing swelling. Disruptions cover every facet of life from the minutiae of everyday life to disrupting life course. Disruptions do not stop once self-management is established due to the possibility of injury and other triggers such as heat and cellulitis.

Other studies confirm my findings. For example, Person and colleagues (2007), who also drew on grounded theory methods and methodology, found that lymphoedema led to “disrupted social connectedness” (p. 279) for women from the Dominican Republic with endemic filarial lymphoedema. A participant reported “This leg commands all of my life!”

(Person et al., 2007, p. 282). Crow (2020) identified “biographical disruption” as a significant component of living with lymphoedema, which corroborates my findings of transformational processes and turning points.

Biographical disruption was coined by Bury (1982), a medical sociologist. Describing the impact of chronic illness, Bury stated “the structures of everyday life and the forms of knowledge which underpin them are disrupted” (p. 169). Bury contended that chronic illness disrupted the individual’s circumstance, as well as family and wider social relationships whereby normal social balance and reciprocity were disturbed through changes in health-related needs, independence, and previously experienced mutuality. Chronic illness also changed visions and hopes for the future. Bury’s key concepts were first, that chronic illness undermined the taken for granted everyday functioning of life, with attention suddenly drawn to the previously taken for granted physical being. Second, that the disruption then alters the sense of self and disrupts the biography of life course. Third that managing chronic illness required resources and support, which further support my findings.

In my study, disruption was linked with facets across many aspects of life such as changes in body shape, personal appearance, routines, and self-management. In contrast, Crow (2020) linked biographical disruption to critical experiences of a life-threatening episode of cellulitis and the diagnosis of another long-term condition alongside lymphoedema. Crow also discussed transformation, but their application is limited to transformation arising from changes to manage cellulitis and risks more effectively. In comparison, my study considers biographical disruption and repair as foundational to the experience of *Reconfiguring Life*, a changed identity wrought by the onset of lower limb lymphoedema.

Managing disruption and repair through transformation of self is the core process in my study when viewing the whole trajectory of managing lymphoedema. Initial swelling disrupts the normalcy of everyday life arising from new symptoms to changes in clothing, activities, mobility, perception of self through feeling othered, and disrupting life course. The disruption continues through managing triggers that exacerbate lymphoedema such as heat and the risk of cellulitis. Finances are disrupted through additional costs. Feelings are disrupted through feeling forced into action or feeling out of control. During the third phase of my study, leading with the mind, knowledge and skills are applied to manage the disruption caused by fluctuations in swelling and to maintain control.

The concept of disruption is not new but the explication of the process and depth, breadth, and nuance of managing disruption as a lived process was not found in previously published research on living with lymphoedema. A handful of articles on lymphoedema were found that made passing mention on disruptive elements of lymphoedema (Deng et al., 2013; Jones, 2013; Morgan et al., 2005; Renshaw, 2007; Tuğral & Bakar, 2017). Johnson and Damarell (2020) concurred with my findings that lower limb lymphoedema is “profoundly disruptive to physical and mental health, often progressing to a reduced quality of life (QoL) and loss of function” (p. 41). Similar to Thomas (2021), disruption is not elucidated beyond the opening remarks.

Whilst disruption is mentioned in the lymphoedema literature, there is little substantive theory that disruption is central to the world of living with lymphoedema. My findings indicate that disruption is central to living with lymphoedema, and the entire experience of living with lymphoedema can be marginalising. The person that existed before is changed in physique, sense of attractiveness, self-care demands, capabilities for everyday life, livelihood, adventure, and aspirations. The marginalisation is caused by the simultaneous disruption in the physical and social self, and the negation of the impact of the disruption. There is also habilitating—a path through disruption to rebuilding self and a new normal, through transformative change. My study has identified that transformation occurred across three clear phases—being led by the body, being led by feelings, and leading with the mind—which can be used to assess the individual’s movement towards self-management. Lymphoedema therapists in my study were already found to have a strong understanding of how to build knowledge, skills, and trust to support self-care.

Being Led by the Body, Being Led by Feelings, and Leading with the Mind

The experience of being led by the body, being led by feelings, and then leading with the mind speaks to the comprehensive whole of person experience that lymphoedema is and becomes to the person. Being led by the body is well described in the literature whereas the feelings and the mind portions are less so. An area of note about being led by the body, being led by feelings, and leading with the mind is that the phases are initiated in a time sequence.

The first event is that the body is involved. As a result of the changes in the body the feelings become involved. Disrupted feelings provide a driving force and energy directed towards finding a solution. Distress is dampened by receiving help and recognising that control of swelling is possible. This creates the platform for reaching a turning point and

finding hope. Once the corner is turned, leading with the mind begins the process of active transformative change. The three phases are derived from the data, but the wording is from a conceptual framework developed by Roberto Assagioli⁶ (1974). Transformational change was triggered by swelling in the body beyond the person's control. This change began at the onset of symptoms when swelling changed the taken for granted form and function of the body, resulting in being forced to act or pursuing solutions.

Not all long-term conditions result in physical changes which can be seen by others. The lower limbs combined, without swelling, constitute around 1/3 of the body mass for men and slightly more for women (Plagenhoef et al., 1983). Moderate to severe swelling to such a significant part of the body is noticeable. In lymphoedema, swelling can occur within a matter of weeks or months, changing personal appearance, affecting mobility, leading to struggles with body image, and the practical elements of not being able to find clothing or shoes that fit. For those experiencing these new symptoms, their whole lives began to reformulate around accommodating their body and feelings about themselves and their condition.

Changing appearance is used in both a physical and symbolic sense; as such a substantial change to the body results in a change in how one appears both to oneself and to others (Charmaz, 1995a). Long-term conditions that do not alter personal appearance are more able to be hidden from the purview of others (Charmaz, 1995a). These substantial physical changes to personal appearance, mobility, and functioning impacted everyday life and gave rise to concerns for the future. Being led by feelings was dispiriting, as swelling brought stress at multiple levels. The realisation that a body that had previously functioned inconspicuously then changed inexplicably, was a traumatic experience for many. The combination of these factors instituted distress which ranged from being "pissed off," "disappointed," to "freaking out," or being worn down, with consideration that it was possible to lose mental health described as going "round the twist." Those living in a support desert devoid of health professional help had no way of knowing whether the condition could be managed.

Leading with the mind began by building knowledge and skills to manage lymphoedema, reflecting and analysing on their individual circumstance, feeling spurred on

⁶ Assagioli, an Italian psychiatrist, founded a transpersonal psychology known as psychosynthesis. He guided trainees to engage in what he called a body, feelings, and mind disidentification exercise. The exercise included becoming aware of the four components of self; spirituality is inherently included in the model.

by a reduction in symptoms, leading to a renewed sense of autonomy and the possibility of regaining control of the swelling over time. Significant perceptions of time traverse the three phases in different ways.

Time

Time: Being Led by the Body

The experience of living with lymphoedema is intrinsically temporal. Participants responded to issues in the moment and reconstructed the telling of their past based on their memory of how that was experienced at the time. Participants explained that in the early days lymphoedema was time consuming and burdening. Putting on a garment inside out and having to start again “can tip you” (Sal). Living with lymphoedema consumed more of everyday life, taking time away from other activities, family, and friends. Sacrificing wants and needs for lymphoedema drew time away from pleasures and imposed restrictions on time and spontaneity from pleasures such as beach walks. Lymphoedema created a need to focus on self in a novel and unwelcome way, particularly for women.

Time was spent and considered “wasted” by some undertaking self-care such as applying medical tape or nightly bandaging to manage swelling. Self-care also took energy and participants spent time doing more for less, such as dressing. In this way, lymphoedema appeared as a thief of time and participants experienced a loss of meaning and their previous life capabilities.

Time: Being Led by Feelings

The turning point from either feeling forced into action or feeling out of control and pursuing solutions was often a moment in time. For some, the moment in time was a realisation or epiphany that change was needed; while for others, reaching a turning point was meeting someone with lymphoedema or a lymphoedema therapist.

Time Leading with the Mind

The experience of time evolved for participants as they moved through being led by the body in which lymphoedema consumed time, through being led by feelings, when a turning point was often found in a moment in time. Once participants had accepted and acquiesced to lymphoedema, and found ways to manage the swelling, lymphoedema took a more appropriate role in their lives and participants reclaimed time and their lives. Changes to the body, feelings, and mind, along with fluctuating swelling, led to disruption across

multiple spheres of life. The path to rebuilding self is achieved through transformative change.

Transformative Change

The theory of Reconfiguring Life details one way that change can occur in adults diagnosed with lymphoedema. This has not been described previously in the lymphoedema literature. However, Mezirow's (1978, 2006) theory of transformative learning concurs in principle with my findings. Mezirow's grounded theory study investigated women returning to community college after a break in education. Mezirow proposed 11 steps (later consolidated to 10) that signalled transformative learning leading to a new world view for the student. Transformative learning is viewed as an exclusive form of adult "metacognitive reasoning" (Mezirow, 2003, p. 58). Mezirow defined reasoning as the ability to logically deduce conclusions from evidence that endorses beliefs and leads to action. Transformative learning theory holds that beliefs can be changed as a result of a rational understanding of benefit.

My study explains how lymphoedema unsettles previous normality. Similarly, Mezirow (1978) posited that one form of adult development and learning results from predicaments or "life crises" (p. 101) that do not respond to usual problem-solving methods and life becomes unmanageable. In response, adults undergo a process of reflection, reconsideration, and change through challenging familiar assumptions and forging successive new directions and a new identity. Transformative learning through self-reflection is a generic process not tied to adult education (Mezirow, 1978). A comparison with Mezirow is presented below alongside my Reconfiguring Life in Table 7.

Table 7

Theory of Reconfiguring Life Compared to Mezirow's Theory of Transformative Learning

Theory of Reconfiguring Life with lower limb lymphoedema	Mezirow's transformative learning theory
Losing previous normality	"a disorienting dilemma;
Being led by feelings	self-examination with feelings of fear, anger, guilt or shame;
The realisation that the body was taken for granted	a critical assessment of assumptions;
Finding somebody who understands	recognition that one's discontent and the process of transformation are shared;
Using trial and error; valuing the relationship with the lymphoedema therapist	exploration of options for new roles, relationships and action;
Becoming amenable to change	planning a course of action;
Building knowledge and skills; reflecting and analysing	acquiring knowledge and skills for implementing one's plans;
Acquiescing and accepting; trial and error	provisional trying of new roles;
Adopting self-management	building competence and self-confidence in new roles and relationships;
Rebuilding a new normal	a reintegration into one's life on the basis of conditions dictated by one's new."

Table 7 shows the process of transformative change as expressed in my theory Reconfiguring Life compared with Mezirow's (2006, p. 94) theory of adult learning through transformative change.

Participants use of reflection to analyse what had happened and to carve a path forward is a key component of my theory Reconfiguring Life, as it is with transformative learning (Mezirow, 1998). In the theory of transformative learning, adults move through the phases of change at different rates and not everyone will progress through all the phases. In addition, there is a correlation between remembering the number of transitional phases experienced and the extent of change through transformative learning (Brock, 2010). In my theory of Reconfiguring Life, the change processes were able to be explicated because participants recalled the path to change in detail.

Transformative learning has been used extensively in research investigating change associated with long-term conditions (e.g., Barclay-Goddard et al., 2012; Dubouloz et al., 2007; Kessler et al., 2009; King et al., 2019). No literature was found relating to lymphoedema

and transformative change through transformative learning. My finding may, therefore, be useful as a platform for future research on the relationship between successful self-management and transformative change processes.

I suggest that the path to transformative change is facilitated by lymphoedema therapists. The theory of Reconfiguring Life details the steps clients go through after reaching a turning point to regaining control. Regaining control is the ultimate goal of self-management. Knowledge of these steps could prove useful to those living with lymphoedema and therapists as a road map, making conscious, and thus teachable and learnable, a path to self-management.

Reflections

Much of the literature on lymphoedema is led by researchers with a physiotherapy lens and based on quantitative studies. This study adds to the small but growing qualitative research literature on lower limb lymphoedema. The key issue of quality of life is largely well documented in the literature. Qualitative studies, such as this current study, bring the impact of the issues faced by consumers to life in a way that may be absent in quantitative studies. In depth attitudes and responses can be captured without taxing informants.

The interplay and detailed processes guiding lymphoedema therapists and their clients were made possible through grounded theory methods and methodology. The grounded theory process of sequential interviewing, data analysis, and theoretical sampling offered me scope to delve into results whilst still collecting data, and deepen specific areas, which is not possible through a survey. Such flexibility added depth to the inquiry. In this way, participants guided and co-constructed the passage of the research.

Grounded theory coding, clustering of codes, inductive and deductive reasoning predisposes the research to varying interpretations. During the early phases of coding and clustering, the exorbitant number of labels can become overwhelming and a novice researcher, such as myself, is forced to learn to trust intuition, insight, and reflection. Even as the codes became focussed and clustered into subcategories, it was difficult to know which way the research findings were heading. My supervisors advised me to trust the process. I wanted a manual that showed me how to get to the outcome. The process of analysis is well described in grounded theory literature (Charmaz, 2014a). It has been a revelation to re-read the methods and methodology processes with a deeper understanding of the evolving purpose. It was as though the words were there prior but did not capture the experience

until the experience had been undertaken. Once I was looking at the process in hindsight, the words were crystal clear, and I wondered how they could have appeared confusing.

Using Charmaz constructivist grounded theory gave scope to use my theoretical sensitivity developed from living with lymphoedema and supporting others through countless conversations. At the same time, I needed to ensure that the analysis was grounded in the data through reflecting, memoing, and frequent use of checking for resonance, dissonance, and missing elements with trusted informed therapists and those living with lower limb lymphoedema.

When setting out to do research the results cannot be predicted, although elements of the findings were not surprising to me. The sections of the study that were initially more significant to me were being led by the body and being led by feelings, despite these data being well described in the literature, with detail in my study adding to that literature. Initially I could see that transformational and transformative change happened, but I did not know how it happened. Deep into analysis, I realised that the processes described from finding a turning point onwards articulated how the change happened. Much of what is explored in academic literature explains the 'what' of phenomena, but it is noteworthy to contribute research into the 'how' of phenomena.

My experience of knowing lymphoedema therapists and familiarity with lymphoedema support groups, consumers, and the literature could be expected to have influenced my approach. This is also likely to have been a benefit as stated in the critique of the methodology. Over the nearly 6 years of this research, I believe there has been ample time to reflect and consult on processes and reasoning.

Lower limb lymphoedema research appears to have developed significantly during the process of the writing of this thesis. I have been grateful to the researchers in all fields of lymphoedema who have gone before and hope that this research similarly adds support to clinical practice, future research, and policy.

Implications

This section discusses the implications of my study for clinical practice, research, and policy. I then identify some recommendations and the limitations of my study.

Implications for Clinical Practice

My findings underline the importance of self-care support. Diagnosis was often delayed, even in participants with cancer related lymphoedema. The time between onset of symptoms, diagnosis, and receiving help was burdensome and sometimes led to emotional distress. The health care system has generally been poor at providing self-care support (Audulv et al., 2009). The usual biomedical model of care is not well suited to supporting long-term conditions and there is a focus on adherence without recognising the complexity (Franklin et al., 2023) or health care system resources required (Mays et al., 2013). The usual avenue for medical care in the community is the general practitioner. My research and the international experience are that often doctors do not discuss or diagnose lymphoedema or support self-care. In my study, on the whole, general practitioners were not helpful facilitating referral.

Learning to adjust to lower limb lymphoedema has a comprehensive impact on quality of life including physical symptoms, wellbeing, distress, employability, mobility, and autonomy. Lymphoedema can lead to disfigurement, immobilisation, severe infections, and reduced quality of life (Deonni P. Stollendorf et al., 2016). Early treatment prevents deterioration, improves quality of life and reduces the demands of self-care (Ridner et al., 2018). There are no consistent formal processes for people living with lymphoedema in Aotearoa New Zealand to receive help at diagnosis. People who do not get real help with swelling can be left without a path to healing. Reaching a turning point should not be left to chance. Participants left in a support desert and, therefore, in the dark about their condition, suffered longer before receiving treatment.

The current system of self-care support appears inadequate. Most participants had paid a private lymphoedema therapist, another participant had their first appointment in public care more than 18 months after developing swelling following cervical cancer years earlier, and three participants with primary lymphoedema had never received any publicly funded care. For some, the opportunity of publicly funded assessment and self-care support is not an option as the Wellington region only provides garment subsidy. Providing less than adequate self-care support leaves people relying on their own financial resources and navigating access in order to attend private lymphoedema therapists. Self-funding leads to inequity where those with financial resource can access care and those without miss out.

The path to transformative change in my theory is led by lymphoedema therapists. Their role and availability are critical to reconfiguring one's life after lymphoedema. The

theory of Reconfiguring Life details the steps clients go through after reaching a turning point to regaining control. Regaining control is the ultimate goal of self-management. These detailed steps could help those living with lymphoedema and therapists to navigate a hitherto undocumented process, making conscious, and thus teachable and learnable, a path to self-management. Understanding these steps may also shorten the experience of being in a support desert and the associated distress.

My findings indicate that providing early referral and lymphoedema management services that minimise swelling and progression of the condition might maximise function and avoid the unnecessary psychosocial burden. The path to receiving a diagnosis and getting self-care support can be a haphazard journey, dependent upon the publicly available services and personal resources to pay for help. Personal circumstances such as being employed or parenting young children can also affect time available for the demands of self-care. In addition, my research indicates that clients will make shifts in self-care when the benefits of self-care are more rewarding than avoiding self-care.

Successful self-management lies at the crux of improving quality of life and capability (S. H. Ridner, M. R. Fu, et al., 2012); yet, this is a multicomponent complex process (Franklin et al., 2023; Pearce et al., 2016) which is particularly burdening for those with lymphoedema—more so than many other conditions (S. H. Ridner, M. R. Fu, et al., 2012). Ample factors related to self-management with long-term conditions are left to chance with the onus falling on the individual (Greaney & Flaherty, 2020; S. H. Ridner, M. R. Fu, et al., 2012; Watts & Davies, 2016). My research provides accessible evidence to those advocating to establish or strengthen lymphoedema service provision.

Self-management is dependent upon at least three sectors; namely health care system availability and acceptability (Audulv et al., 2009; Mays et al., 2013; Watts & Davies, 2016), a person's individual resource or capacity (Audulv, 2013), and their sociological circumstance (Ong et al., 2014). A sociological conceptualisation of self-care in long-term conditions includes understanding the ways that social class, gender, and cultural factors combine with the individual's psychological capabilities, such as self-agency and self-efficacy. The framework of body, feelings, and mind may be useful for therapists to explain the trajectory in a recognisable and assimilable way for people living with lymphoedema. According to my research, knowing that others have been on the journey before supports the process of getting to "it is what it is."

Lymphoedema management involves physical assessment, monitoring for deterioration or improvement, provision of advice and treatment options. Clinicians are in a privileged role with access to information and the physical purview of clients. Health care services tend to be busy and functional places with health professionals flexing between the ordinary and the intimate. Health professionals need to be mindful of the effects of exposing a limb that may not ordinarily be exposed and may be perceived as ugly. Living with severely enlarged limbs or leaking lymph fluid can impact self-esteem, which may be exacerbated by casual comments. A non-judgemental approach supports the therapeutic relationship, thereby supporting the person's development of self-care.

There is a need to communicate better with people undergoing treatment that may result in lymphoedema. Information about the possibility of developing or preventing lymphoedema is not well absorbed during the treatment phase. The use of the word lymphoedema may be foreign and unhelpful. Information may be better absorbed if advice is given about responding to early symptoms such as swelling or heaviness, along with referral information. Consideration can be given to involving support people or significant others when advice and information about the risk of lymphoedema is shared. Ryan and colleagues (2003) found the provision of bookmarks with information about symptoms and referral were well received. There is a need for recognition that the timing and quality of information should correlate with a person's capacity and the stage of their journey to maximise benefit.

My findings indicate that health professionals lack understanding about the pathophysiology and referral options for lymphoedema. Health professionals, particularly those who work in the area of cancer or primary care, such as practice nurses, general practitioners, physiotherapists, midwives, psychologists, radiation therapists, and podiatrists, could support their patients by becoming familiar with basic physiology of the lymphatic system and pathophysiology of lymphoedema, the impact on quality of life, delay in diagnosis, treatment options, risks of cellulitis, and referral pathways. Clinicians need access to relevant and trustworthy information, particularly about prevention and early intervention. Aotearoa New Zealand has a website with information about referral to publicly funded and private lymphoedema services. For example, Te Whatu Ora funds a website (Health Navigator New Zealand, 2022) that includes a link to free online learning for clinicians. However, this may not be well publicised.

There is scope for researchers, lymphoedema therapists and accredited lymphoedema training providers to offer workshops and webinars (with reimbursement) to health professionals, potentially as part of a certified learning programme or partnership. The Australasian Lymphology Association and the New Zealand Lymphoedema Therapists group run conferences for health professionals involved in lymphoedema research and management. Stakeholders such as foundations supporting those with breast gynaecological, prostate cancer, and melanoma, along with the Cancer Society, may wish to partner in sessions for health professionals and consumers. Training and information could be offered in partnership with Primary Health Organisations (conglomerations of general practice), nursing organisation special interest colleges and sections, and associations of other health professionals, such as physiotherapists and podiatrists.

Students undertaking a health professional training are sometimes offered additional online learning modules to supplement their curricula. There could be scope for a learning module on lymphoedema that provides a credentialled certificate of learning suited to portfolios that demonstrate professional development.

Lymphoedema costs the client, the health care system, and society. Preventative measures, early treatment, and appropriate support may reduce physical and psychosocial costs. With changes in technology and learning online there is an opportunity to explore new ways to provide self-care support. For example, lymphoedema therapists may offer video calling support to areas in Aotearoa New Zealand where there is a lack of therapists, such as rural and remote.

Implications and Recommendations for Research

Research into the value and contribution of lymphoedema therapists to self-management is an area worthy of further study. An interesting next step would be to further delineate the ways lymphoedema therapists activate their client. There is a need for further understanding of best practice to support people living with lymphoedema towards self-care; as well as further research evaluating key processes in self-care and self-care support to identify efficacy, appropriate self-care support material, and explore new ways of using technology to provide self-care support.

There were data to indicate that personality as a context may play a significant role in learning to self-manage but this is outside of my scope as a nurse. Further research in this area may be warranted.

If I was starting again, I would remove the process of participants being referred by a third party—in my case, lymphoedema therapists. The benefit and reason I used this pathway for recruitment was to ensure that participants met the criteria of moderate to severe lower limb lymphoedema. Using referral from lymphoedema therapists is likely to have created a bias towards participants who were linked into care and could self-manage effectively. This is also a limitation of my study. Recruitment to reduce participant homogeneity may be problematic for those not able to recruit through a clinic. Obviously, people living with primary lymphoedema are underrepresented or absent in cancer related clinics and may be more difficult to recruit. Recruitment for me was slow; hence, in the future there is a need to consider having a wide base with as few exclusions as possible.

Further research is warranted on all aspects of living with lymphoedema. In particular, there is a lack of literature on men's experience of lymphoedema. This is in part because of the emphasis in the research on breast cancer related lymphoedema and because men experience lymphoedema proportionately less. This model has been developed with participants from a demographic group that generally represent older New Zealand Europeans. Research is needed that represents the experience of people from other ethnic groups.

Participant recruitment and interviewing processes are changing with new technologies such as video calling. Recruitment via social media was very fast and may be useful as one avenue of recruitment and may provide a younger sample; however, there is implicit bias in the users of social media as well. Accessing a moderated Facebook group run by recognised experts, such as the Australasian Lymphology Association, proved helpful and supportive.

In some countries, such as Aotearoa New Zealand, the lymphoedema community is small. Researchers in my position can be expected to meet up with participants at a later date. If the likelihood is that the researcher could meet participants again outside of the research context, such as in my situation, consideration must be given to the agreement established with participants at the time of interview. For me, this agreement included that I would not allude to anything related to the research, with the understanding that participants were free to ask me or comment, although I do have formal agreement to provide feedback to participants.

Implications for Policy

Lymphoedema appears to be an orphan condition that does not fit into universally funded services in Aotearoa New Zealand. Lymphoedema, as a condition, does not belong within the full scope of medical professionals and it is likely that there is no medical voice advocating for service provision at the decision-making table. That means that it is probable that there is no one at the executive decision-making arena representing lymphoedema in funding or service provision. There are very few stakeholders to advocate for lymphoedema services, with the exception of the Australasian Lymphology Association equity committee which includes Aotearoa New Zealand representation.

There is a need for equitable lymphoedema service provision using an integrated model of care to provide timely and appropriate prevention, assessment, and treatment by staff trained in lymphoedema management using a holistic model of care with consideration of the patients' social circumstances. Current advocacy occurs largely through nurses and physiotherapists, often with insufficient power to campaign for new funding for services. There has been a sense that because much of lymphoedema is iatrogenic in an area where the focus is on saving lives from cancer that doctors have avoided and ignored lymphoedema treatment, although progress has been made on modifying surgical techniques to prevent or reduce lymphoedema. There is an urgent need to identify medical specialists to work in the area. Two plastic surgeons from Middlemore Hospital were trained in Australia in liposuction for lymphoedema (Lymphoedema NZ, 2017) although no publicly funded surgery is currently taking place. The lack of adequate services appears to be a form of rationing whereby services are inadequately resourced to meet the need. The current health reforms appear to be an opportunity to develop lymphoedema services to support client self-care as Te Whatu Ora is undertaking a review of services nationally with a focus on population health and equity.

Study Limitations

One limitation was the number of participants and their ethnic homogeneity, with one exception. Recruitment was slow. Over 16-months, 12 participants were recruited. I returned to AUT's Ethics Committee on a number of occasions for three changes to improve recruitment. Despite the small sample size, data were saturated for all elements except the subcategory forced into action to a turning point. In addition, only one participant developed lymphoedema before adulthood. Studying a wider cross section of people living with lymphoedema may have brought a more diverse response to living with lymphoedema.

Ethics approved recruitment was initially through lymphoedema therapists and the Lymphoedema Support Network. This gave assurance that participants met the inclusion criteria of moderate to severe lower limb lymphoedema which was checked by the participants with their lymphoedema therapists where there was doubt. This process of recruitment favoured participants who were engaged with either a lymphoedema therapist or a support group. On reflection, it appears that lymphoedema therapists referred hand-picked participants who self-managed proficiently. The three exceptions were one snowball participant who had never engaged locally with a lymphoedema therapist for any duration, one newly diagnosed participant, and one participant who had been through a period of rebelling against their self-care regime. Had I used a broader base for recruitment, participants may have had a more heterogenous self-management profile.

Participants with lower limb lymphoedema from any cause were recruited and the spread of varying cancer types including primary and secondary lymphoedema was useful because the data showed the similarities across causes of lymphoedema. Theoretical sampling sought to understand the experience of men, Māori, and Pacific people. Thirty three percent of participants were men (n=4); however, only one Māori participant and no Pacific participants were recruited despite additional effort (see Appendix D Participant Characteristics). Extra effort was made to recruit Māori participants including conversations with and support from a Māori nurse and a Māori primary health provider clinical director. It is best practice with research undertaken in Aotearoa New Zealand that, at the least, Māori data should be embedded as this is the only place in the world where such a contribution can generally be made. Not meeting this standard was disappointing.

My study focussed on the overall experience of living with lymphoedema and there are a number of nuances not explored; for example, the impact of social roles such as mothering and being employed versus not working. Whilst my study recognises loss, such as losing normality, being burdened, and living with disruption, grief is not explicit. There is recognition of the sense that feeling lost is due to feeling the loss. Data related to grief were explicated and interpreted as loss. Feedback from experienced lymphoedema therapists and those living with lymphoedema have stated that this element is under represented in my research.

Conclusion

What stands this research apart internationally is the expansiveness of the theory generated. The theory of Reconfiguring Life adds to what is known about living with

lymphoedema and is the only known qualitative research on the topic undertaken in Aotearoa New Zealand in the past 20 years, and the only study of its type focussing on lower limb lymphoedema. This thesis represents a voice for those living with lower limb lymphoedema which, as an “unsexy” condition, is under recognised and underrated by health professionals. In the words of Helena, “And to think that even if you just have a positive impact on one person’s life, how awesome, is that?”

Reconfiguring Life provides an exemplar of how people experience living with moderate to severe lower limb lymphoedema. Given the right circumstances lymphoedema can be prevented, minimised, or managed, freeing people up for a more productive and less restricted life. Cancer rates are increasing, and the health care system is under increasing financial and staffing pressures. People are living longer with more long-term illness at a cost in quality of life to the individual, health care resourcing, and to society as a whole. Effective self-management serves consumer autonomy, ongoing wellness, and productivity, while preserving health care resources. However, self-care for those living with lower limb lymphoedema requires initial focused individualised input from a lymphoedema therapist which is unable to be provided via a primary care pathway which is often the fallback position for managing long-term conditions when hospital based clinics are oversubscribed.

Self-care, despite the term, is not care done alone. Adjusting to living with lymphoedema is a complex process. Some people arrive at the need for self-care more resourced financially and personally. Those less resourced to pay for themselves and without advocates, navigate a complex health care system and probably miss out, creating inequitable health outcomes for those already living in disadvantaged circumstances.

Lymphoedema service provision in Aotearoa New Zealand is inconsistent across the health board localities. Lymphoedema self-care support is only able to be provided by lymphoedema therapists. As Aotearoa New Zealand is undergoing health care reforms there is an opportunity to advocate and lobby for more equitable health services. The health care system is not orientated towards self-care support. There is a need to reassess service provision for people living with long-term conditions, particularly where self-care is burdensome. This thesis provides a platform at a time when the population is aging, facing more long-term conditions, with people living longer. Advocates and stakeholders of those living with moderate to severe lower limb lymphoedema and other oedemas can unite to improve lymphoedema self-care and self-management support with the potential to make meaningful differences in people’s lives.

References

- Achouri, A., Huchon, C., Bats, A.-S., Bensaïd, C., Nos, C., & Lécuru, F. (2012). Postoperative lymphocysts after lymphadenectomy for gynaecological malignancies: Preventive techniques and prospects. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 161(2), 125-129. <https://doi.org/10.1016/j.ejogrb.2011.12.021>
- Agarwal, V. (2018). Re-conceptualizing pain through patient-centred care in the complementary and alternative medicine therapeutic relationship. *Journal of Advanced Nursing*, 74(10), 2406-2415. <https://doi.org/0.1111/jan.13734>
- Allam, O., Park, K. E., Chandler, L., Mozaffari, M. A., Ahmad, M., Lu, X., & Alperovich, M. (2020). The impact of radiation on lymphedema: A review of the literature. *Gland Surgery*, 9(2), 596. <https://doi.org/10.21037/gS.2020.03.20>
- Allen, R. J., Jr., & Cheng, M. H. (2016). Lymphedema surgery: Patient selection and an overview of surgical techniques. *Journal of Surgical Oncology*, 113(8), 923-931. <https://doi.org/10.1002/jso.24170>
- Amsteus, M. N. (2014). The validity of divergent grounded theory method. *International Journal of Qualitative Methods*, 13(1), 71-87. <https://doi.org/10.1177/160940691401300133>
- Antonacci, G., Lennox, L., Barlow, J., Evans, L., & Reed, J. (2021). Process mapping in healthcare: A systematic review. *BMC Health Services Research*, 21(1), 1-15. <https://doi.org/10.1186/s12913-021-06254-1>
- Armer, J. M., Hulett, J. M., Bernas, M. J., Ostby, P., Stewart, B. R., & Cormier, J. N. (2013). Best-practice guidelines in assessment, risk reduction, management, and surveillance for post-breast cancer lymphedema. *Current Breast Cancer Reports*, 5(2), 134-144. <https://doi.org/10.1007/s12609-013-0105-0>
- Asdourian, M. S., Skolny, M. N., Brunelle, C., Seward, C. E., Salama, L., & Taghian, A. G. (2016). Precautions for breast cancer-related lymphoedema: Risk from air travel, ipsilateral arm blood pressure measurements, skin puncture, extreme temperatures, and cellulitis. *The Lancet Oncology*, 17(9), e392-e405. [https://doi.org/10.1016/S1470-2045\(16\)30204-2](https://doi.org/10.1016/S1470-2045(16)30204-2)
- Asim, M., Cham, A., Banerjee, S., Nancekivell, R., Dutu, G., McBride, C., Cavanagh, S., Lawrenson, R., & Campbell, I. (2012). Difficulties with defining lymphoedema after axillary dissection for breast cancer. *New Zealand Medical Journal*, 125(1351), 29-39. <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2012/vol-125-no-1351/article-asim>
- Assagioli, R. (1974). *The act of will* (Vol. 3866). Penguin Books Baltimore.
- Babatunde, F., MacDermid, J., & MacIntyre, N. (2017). Characteristics of therapeutic alliance in musculoskeletal physiotherapy and occupational therapy practice: A scoping review of the literature. *BMC Health Services Research*, 17(1), 1-23. <https://doi.org/10.1186/s12913-017-2311-3>

- Bakar, Y., & Tuğral, A. (2017). Lower extremity lymphedema management after gynecologic cancer surgery: A review of current management strategies. *Annals of Vascular Surgery*, 44, 442-450. <https://doi.org/10.1016/j.avsg.2017.03.197>
- Barclay-Goddard, R., King, J., Dubouloz, C.-J., Schwartz, C. E., & ScD Response Shift Think Tank Working Group. (2012). Building on transformative learning and response shift theory to investigate health-related quality of life changes over time in individuals with chronic health conditions and disability. *Archives of Physical Medicine and Rehabilitation*, 93(2), 214-220. <https://doi.org/10.1016/j.apmr.2011.09.010>
- Barlow, S., Dixey, R., Todd, J., Taylor, V., Carney, S., & Newell, R. (2014). 'Abandoned by medicine'? A qualitative study of women's experiences with lymphoedema secondary to cancer, and the implications for care. *Primary Health Care Research & Development*, 15(4), 452-463. <https://doi.org/10.1017/S1463423613000406>
- Barton, A. H. (2001). Paul Lazarsfeld as institutional inventor. *International Journal of Public Opinion Research*, 13(3), 245-269. <https://doi.org/10.1093/ijpor/13.3.245>
- Basta, M. N., Fox, J. P., Kanchwala, S. K., Wu, L. C., Serletti, J. M., Kovach, S. J., Fosnot, J., & Fischer, J. P. (2016). Complicated breast cancer-related lymphedema: Evaluating health care resource utilization and associated costs of management. *The American Journal of Surgery*, 211(1), 133-141. <https://doi.org/https://doi.org/10.1016/j.amjsurg.2015.06.015>
- Beals, F., Kidman, J., & Funaki, H. (2020). Insider and outsider research: Negotiating self at the edge of the emic/etic divide. *Qualitative Inquiry*, 26(6), 593-601. <https://doi.org/10.1177/1077800419843950>
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234. <https://doi.org/10.1177/1468794112468475>
- Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide*. SAGE.
- Birks, M., Mills, J., Francis, K., & Chapman, Y. (2009). A thousand words paint a picture: The use of storyline in grounded theory research. *Journal of Research in Nursing*, 14(5), 405-417. <https://doi.org/10.1177/1744987109104675>
- Blumer, H. (1954). What is wrong with social theory? *American Sociological Review*, 19(1), 3-10. <https://doi.org/10.2307/2088165>
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley.
- Borman, P., Koyuncu, E. G., Yaman, A., Calp, E., Koç, F., Sargut, R., & Karahan, S. (2021). The comparative efficacy of conventional short-stretch multilayer bandages and velcro adjustable compression wraps in active treatment phase of patients with lower limb lymphedema. *Lymphatic Research and Biology*, 19(3), 286-294. <https://doi.org/10.1089/lrb.2020.0088>
- Bowen, G. A. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods*, 5(3), 12-23. <https://doi.org/10.1177/160940690600500304>

- Bowers, B., Charmaz, K., & Corbin, J. (2009). Dialogue on "cleaning" transcripts. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory. The second generation* (pp. 54). Left Coast Press.
- Bowers, B., & Schatzman, L. (2016). Dimensional analysis. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory. The second generation* (pp. 86-126). Routledge.
- Bowman, C., Piedalve, K.-A., Baydoun, M., & Carlson, L. E. (2020). The quality of life and psychosocial implications of cancer-related lower-extremity lymphedema: A systematic review of the literature. *Journal of Clinical Medicine*, 9(10), 3200. <https://doi.org/10.3390/jcm9103200>
- Brandão, M. L., dos Santos Soares, H. P., do Amparo Andrade, M., de Campos Faria, A. L. S., & Pires, R. S. (2020). Efficacy of complex decongestive therapy for lymphedema of the lower limbs: A systematic review. *Jornal Vascular Brasileiro*, 19. <https://doi.org/10.1590/1677-5449.190074>
- Brock, S. E. (2010). Measuring the importance of precursor steps to transformative learning. *Adult Education Quarterly*, 60(2), 122-142. <https://doi.org/10.1177/0741713609333084>
- Brouillard, P., Witte, M. H., Erickson, R. P., Damstra, R. J., Becker, C., Quéré, I., & Vikkula, M. (2021). Primary lymphoedema. *Nature Reviews Disease Primers*, 7(1), 1-23. <https://doi.org/10.1038/s41572-021-00318-6>
- Brown, J. C., Cheville, A. L., Tchou, J. C., Harris, S. R., & Schmitz, K. H. (2014). Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Supportive Care in Cancer*, 22(1), 135-143. <https://doi.org/10.1007/s00520-013-1962-9>
- Brown, M. (2018). *The experiences, occupational performance impacts and needs of people who are at risk of, or have developed lymphoedema following groin or pelvic node dissection for metastatic melanoma: An interpretive descriptive study*. [Unpublished Master's thesis, University of Queensland]. <https://espace.library.uq.edu.au/view/UQ:a3a004f>
- Bryant, A., & Charmaz, K. (2011a). Grounded theory in historical perspective: An epistemological account. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 31-57). SAGE. <https://doi.org/10.4135/9781848607941>
- Bryant, A., & Charmaz, K. (Eds.). (2011b). *Introduction. Grounded theory research: Methods and practices*. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 1-28). SAGE. <https://doi.org/10.4135/9781848607941>
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167-182. <https://doi.org/10.1111/1467-9566.ep11339939>
- Carter, B. J. (1997). Women's experiences of lymphedema. *Oncology Nursing Forum*, 24(5), 875-882. <https://www.scopus.com/inward/record.uri?eid=2-s2.0-0031160774&partnerID=40&md5=40e5dad49675f7b8d886a60f0cbee82c>
- Casper, M. J. (1997). Feminist politics and fetal surgery: Adventures of a research cowgirl on the reproductive frontier. *Feminist Studies*, 23(2), 233-262.

- Charmaz, K. (1995a). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36(4), 657-680. <https://doi.org/10.1111/j.1533-8525.1995.tb00459.x>
- Charmaz, K. (1995b). Grounded theory. In J. A. Smith, R. Harré, & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 27-49). SAGE. <https://doi.org/10.4135/9781446221792>
- Charmaz, K. (1999). Keynote addresses from the Fourth Qualitative Health Research Conference. Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research*, 9(3), 362-382. <https://doi.org/10.1177/104973239900900306>
- Charmaz, K. (2008a). Constructionism and the grounded theory method. In J. A. Holstein & J. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397-412). Guilford Press. https://www.academia.edu/27800716/Constructionism_and_the_Grounded_Theory_Method
- Charmaz, K. (2008b). Grounded theory as an emergent method. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods*. (pp. 155-172). The Gilford Press. [https://www.google.co.nz/books/edition/Handbook_of_Emergent_Methods/vbyxBkKjFeYC?hl=en&gbpv=1&dq=charmaz+rCharmaz,+K,+2008b\).+Grounded+theory+as+an+emergent+method&pg=PA155&printsec=frontcover](https://www.google.co.nz/books/edition/Handbook_of_Emergent_Methods/vbyxBkKjFeYC?hl=en&gbpv=1&dq=charmaz+rCharmaz,+K,+2008b).+Grounded+theory+as+an+emergent+method&pg=PA155&printsec=frontcover)
- Charmaz, K. (2008c). The legacy of Anselm Strauss in constructivist grounded theory. In *Studies in symbolic interaction* (Vol. 32, pp. 127-141). Emerald Group Publishing. [https://doi.org/10.1016/S0163-2396\(08\)32010-9](https://doi.org/10.1016/S0163-2396(08)32010-9)
- Charmaz, K. (2010). Studying the experience of chronic illness through grounded theory. In G. Scambler & S. Scambler (Eds.), *New directions in the sociology of chronic and disabling conditions*. Palgrave Macmillan. https://doi.org/10.1057/9780230297432_2
- Charmaz, K. (2014a). *Constructing grounded theory* (2nd rev. ed.). SAGE. [https://www.google.co.nz/books/edition/Constructing_Grounded_Theory/v_GGAwAAQBAJ?hl=en&gbpv=1&dq=charmaz+2014+Constructing+grounded+theory+\(&pg=P1&printsec](https://www.google.co.nz/books/edition/Constructing_Grounded_Theory/v_GGAwAAQBAJ?hl=en&gbpv=1&dq=charmaz+2014+Constructing+grounded+theory+(&pg=P1&printsec)
- Charmaz, K. (2014b). Grounded theory in global perspective: Reviews by international researchers. *Qualitative Inquiry*, 20(9), 1074-1084. <https://doi.org/10.1177/1077800414545235>
- Charmaz, K. (2016). Shifting the grounds. Constructivist grounded theory methods. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory. The second generation* (pp. 94-137). Routledge. <http://ebookcentral.proquest.com/lib/aut/detail.action?docID=4578605>
- Charmaz, K., & Belgrave, L. (2014). Qualitative interviewing and grounded theory analysis. In J. Gubrium, J. Holstein, A. Mavasti, & K. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (2nd ed., pp. 347-366). SAGE. <https://doi.org/http://dx.doi.org.ezproxy.aut.ac.nz/10.4135/9781452218403>
- Charmaz, K., & Rosenfeld, D. (2006). Reflections of the body, images of self: Visibility and invisibility in chronic illness and disability. In D. Waskul & P. Vannini (Eds.), *Body/embodiment: Symbolic interaction and the sociology of the body* (pp. 35-49). Ashgate.

- Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative Research in Psychology, 18*(3), 305-327. <https://doi.org/10.1080/14780887.2020.1780357>
- Cheng, C.-T., Deitch, J. M., Haines, I. E., Porter, D. J., & Kilbreath, S. L. (2014). Do medical procedures in the arm increase the risk of lymphoedema after axillary surgery? A review. *ANZ Journal of Surgery, 84*(7-8), 510-514. <https://doi.org/10.1111/ans.12474>
- Chima, C., Murray, B., Moore, Z., Costello, M., & George, S. (2022). Health-related quality of life and assessment in patients with lower limb lymphoedema: A systematic review. *Journal of Wound Care, 31*(8), 690-699. <https://doi.org/10.12968/jowc.2022.31.8.690>
- Cho, J. Y., & Lee, E.-H. (2014, 2014). Reducing confusion about grounded theory and qualitative content analysis: Similarities and differences. *The Qualitative Report, 19*(32), 1-20. <http://www.nova.edu/ssss/QR/QR19/cho64.pdf>
- Clark, R. R. (1999). *My fat arm: Living with lymphoedema following treatment for breast cancer* [Unpublished Master's thesis, Victoria University of Wellington].
- Clarke, A. E. (1997). A social worlds research adventure: The case of reproductive science. In A. Strauss & J. M. Corbin (Eds.), *Grounded theory in practice* (pp. 63-94). SAGE.
- Clarke, A. E. (2003). Situational analyses: Grounded theory mapping after the postmodern turn. *Symbolic Interaction, 26*(4), 553-576. <https://doi.org/10.1525/si.2003.26.4.553>
- Cooper-Stanton, G. R., 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, 17449871221088791*. <https://doi.org/10.1177/17449871221088791>
- Cooper, G. (2010). Early diagnosis of lymphoedema helps to reduce its psychological and social impact. *Nursing Times, 106*(49-50), 15-17. <http://www.scopus.com/inward/record.url?eid=2-s2.0-79952273542&partnerID=40&md5=004760dd318aa5046d81a17ccf865aee>
- Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13*(1), 3-21.
- Corbin, J., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE. <https://doi.org/10.4135/9781452230153>
- Costello, M., Moore, Z., Avsar, P., Nugent, L., O'Connor, T., & Patton, D. (2021). Non-cancer-related lower limb lymphoedema in complex decongestive therapy: The patient experience. *Journal of Wound Care, 30*(3), 225-233. <https://doi.org/10.12968/jowc.2021.30.3.225>
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice, 39*(3), 124-130.
- Cromwell, E. A., Schmidt, C. A., Kwong, K. T., Pigott, D. M., Mupfasoni, D., Biswas, G., Shirude, S., Hill, E., Donkers, K. M., & Abdoli, A. (2020). The global distribution of lymphatic filariasis, 2000–18: A geospatial analysis. *The Lancet Global Health, 8*(9), e1186-e1194. [https://doi.org/10.1016/S2214-109X\(20\)30286-2](https://doi.org/10.1016/S2214-109X(20)30286-2)

- Crow, D. E. (2020). *Illuminating the experiences of growing up and living with primary lymphedema: A life history study* [Unpublished Doctoral thesis, Oklahoma State University].
- Crowther, S., Ironside, P., Spence, D., & Smythe, L. (2017). Crafting stories in hermeneutic phenomenology research: A methodological device. *Qualitative Health Research*, 27(6), 826-835. <https://doi.org/10.1177/1049732316656161>
- De Vrieze, T. (2020). *Effectiveness of fluoroscopy-guided manual lymph drainage for the treatment of breast cancer-related lymphedema*. [Unpublished Doctoral thesis, Universiteit Antwerpen]. <https://repository.uantwerpen.be/docstore/d:irua:2104the>
- De Vrieze, T., Gebruers, N., Nevelsteen, I., Fieuws, S., Thomis, S., De Groef, A., Tjalma, W. A., Belgrado, J.-P., Vandermeeren, L., & Monten, C. (2022). Manual lymphatic drainage with or without fluoroscopy guidance did not substantially improve the effect of decongestive lymphatic therapy in people with breast cancer-related lymphoedema (EforT-BCRL trial): A multicentre randomised trial. *Journal of Physiotherapy*, 68(2), 110-122. <https://doi.org/10.1016/j.jphys.2022.03.010>
- Deng, J., Murphy, B. A., Dietrich, M. S., Wells, N., Wallston, K. A., Sinard, R. J., Cmelak, A. J., Gilbert, J., & Ridner, S. H. (2013). Impact of secondary lymphedema after head and neck cancer treatment on symptoms, functional status, and quality of life. *Head and Neck*, 35(7), 1026-1035. <https://doi.org/10.1002/hed.23084>
- Deng, J., Radina, E., Fu, M. R., Armer, J. M., Cormier, J. N., Thiadens, S. R. J., Weiss, J., Tuppo, C. M., Dietrich, M. S., & Ridner, S. H. (2015). Self-care status, symptom burden, and reported infections in individuals with lower-extremity primary lymphedema. *Journal of Nursing Scholarship*, 47(2), 126-134. <https://doi.org/10.1111/jnu.12117>
- Denzin, N. (2012). Triangulation 2.0. *Journal of Mixed Methods Research*, 6(2), 80-88.
- Doane, G. H., & Varcoe, C. (2005). Toward compassionate action: Pragmatism and the inseparability of theory/practice. *Advances in Nursing Science*, 28(1), 81-90. <https://www.scopus.com/inward/record.uri?eid=2-s2.0-14844348778&partnerID=40&md5=e69837e7baca211fa0cb1c4e52ad8f51>
- Dubouloz, C.-J., Paterson, B., Chevrier, J., Ashe, B., King, J., & Moldoveanu, M. (2007). *A meta study method for analysis of primary sources on transformative learning in the context of health care: Preliminary results*. Seventh International Transformative Learning Conference, Albuquerque, New Mexico.
- Emirbayer, M., & Maynard, D. W. (2011). Pragmatism and ethnomethodology. *Qualitative Sociology*, 34(1), 221-261. <https://doi.org/10.1007/s11133-010-9183-8>
- Feins, N. R., & Bairdain, S. (2015). Staged skin and subcutaneous excision. In A. K. Greene, S. A. Slavin, & H. Brorson (Eds.), *Lymphedema. Presentation, diagnosis, and treatment* (pp. 301-312). Springer International Publishing. <https://doi.org/10.1007/978-3-319-14493-1>
- Finnane, A., Janda, M., & Hayes, S. (2015). Does treatment alleviate lymphedema symptoms? A cross-sectional study evaluating patient perspectives. *Lymphology*, 48(3), 110-120. <https://eprints.qut.edu.au/98345/>

- Franklin, M., Willis, K., Lewis, S., & Smith, L. (2023). Chronic condition self-management is a social practice. *Journal of Sociology*, 14407833211038059. <https://doi.org/10.1177/14407833211038059>
- Fu, M. R. (2014). Breast cancer-related lymphedema: Symptoms, diagnosis, risk reduction, and management. *World Journal of Clinical Oncology*, 5(3), 241-247. <https://doi.org/10.5306/wjco.v5.i3.241>
- Fu, M. R., Axelrod, D., Guth, A. A., Cartwright, F., Qiu, Z., Goldberg, J. D., Kim, J., Scagliola, J., Kleinman, R., & Haber, J. (2014). Proactive approach to lymphedema risk reduction: A prospective study. *Annals of Surgical Oncology*, 21(11), 3481-3489. <https://doi.org/10.1245/s10434-014-3761-z>
- Fu, M. R., & Kang, Y. (2013). Psychosocial impact of living with cancer-related lymphedema. *Seminars in Oncology Nursing*, 29(1), 50-60. <https://doi.org/10.1016/j.soncn.2012.11.007>
- Fu, M. R., Ridner, S. H., Hu, S. H., Stewart, B. R., Cormier, J. N., & Armer, J. M. (2013). Psychosocial impact of lymphedema: A systematic review of literature from 2004 to 2011. *Psycho-Oncology*, 22(7), 1466-1484. <https://doi.org/10.1002/pon.3201>
- Fu, M. R., & Rosedale, M. (2009). Breast cancer survivors' experiences of lymphedema-related symptoms. *Journal of Pain and Symptom Management*, 38(6), 849-859. <https://doi.org/10.1016/j.jpainsymman.2009.04.030>
- Gabe-Walters, M., & Thomas, M. (2021). Development of the Lymphoedema patient reported outcome measure (LYMPROM). *British Journal of Nursing*, 30(10), 592-598. <https://doi.org/10.12968/bjon.2021.30.10.592>
- Garza, R., Skoracki, R., Hock, K., & Povoski, S. P. (2017). A comprehensive overview on the surgical management of secondary lymphedema of the upper and lower extremities related to prior oncologic therapies. *BMC Cancer*, 17(1), 1-18. <https://doi.org/10.1186/s12885-017-3444-9>
- Gauld, R. (2020). The New Zealand health care system. *International Profiles of Health Care Systems*. New York, 149-158. https://www.commonwealthfund.org/sites/default/files/2020-12/International_Profiles_of_Health_Care_Systems_Dec2020.pdf#page=147
- Glaser, B. G. (1992). *Basics of grounded theory analysis. Emergence vs forcing*. Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Adline Publishing.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597-606. <https://doi.org/10.46743/2160-3715/2003.1870>
- Goswami, A. K., Khaja, M. S., Downing, T., Kokabi, N., Saad, W. E., & Majdalany, B. S. (2020). Lymphatic anatomy and physiology. *Seminars in Interventional Radiology*, 37(03), 227-236.
- Grada, A. A., & Phillips, T. J. (2017). Lymphedema: Diagnostic workup and management. *Journal of the American Academy of Dermatology*, 77(6), 995-1006. <https://doi.org/10.1016/j.jaad.2017.03.021>

- Greaney, A. M., & Flaherty, S. (2020). Self-care as care left undone? The ethics of the self-care agenda in contemporary healthcare policy. *Nursing Philosophy, 21*(1), e12291. <https://doi.org/10.1111/nup.12291>
- Greene, A. K. (2015). Epidemiology and morbidity of lymphedema. In A. K. Greene, S. A. Slavin, & H. Brorson (Eds.), *Lymphedema* (pp. 33-44). Springer. <https://doi.org/10.1007/978-3-319-14493-1>
- Greene, A. K., Slavin, S. A., & Brorson, H. (2015). The lymphedema center and multidisciplinary management. In A. K. Greene, S. A. Slavin, & H. Brorson (Eds.), *Lymphedema. Presentation, diagnosis, and treatment* (pp. 51-55). Springer. https://doi.org/10.1007/978-3-319-14493-1_6
- Greenhalgh, T., & Heath, I. (2010a). Measuring quality in the therapeutic relationship—Part 1: Objective approaches. *BMJ Quality & Safety, 19*(6), 475-478. <https://doi.org/10.1136/qshc.2010.043364>
- Greenhalgh, T., & Heath, I. (2010b). Measuring quality in the therapeutic relationship—Part 2: Subjective approaches. *BMJ Quality & Safety, 19*(6), 479-483. <https://doi.org/10.1136/qshc.2010.043372>
- Guadagnoli, L., Simons, M., McGarva, J., Taft, T. H., & van Tilburg, M. A. (2022). Improving patient adherence to lifestyle changes for the management of gastroesophageal reflux. *Patient Preference and Adherence, 16*, 897. <https://doi.org/10.2147/PPA.S356466>
- Gutknecht, M., Herberger, K., Klose, K., Purwins, S., Dietz, D., Blome, C., & Augustin, M. (2017). Cost-of-illness of patients with lymphoedema. *Journal of the European Academy of Dermatology and Venereology, 31*(11), 1930-1935. <https://doi.org/10.1111/jdv.14442>
- Hacking, I. (1999). *The social construction of what?* Harvard University Press.
- Hammersley, M. (2007). The issue of quality in qualitative research. *International Journal of Research & Method in Education, 30*(3), 287-305. <https://doi.org/10.1080/17437270701614782>
- Hare, M. (2000). The lived experience of breast cancer-related lymphoedema. *Nursing Standard (through 2013), 15*(7), 35.
- Harris, M. (1976). History and significance of the emic/etic distinction. *Annual Review of Anthropology, 5*(1), 329-350. <https://doi.org/10.1146/annurev.an.05.100176.001553>
- Hayes, S. C., Janda, M., Steele, M., Cornish, B., Ward, L., Box, R., Gordon, S., Matthews, M., Poppitt, S., & Plank, L. (2016). *Identifying diagnostic criteria for upper-and lower-limb lymphoedema*. QUT ePrints. <https://eprints.qut.edu.au/107210/>
- Hayes, S. C., Janda, M., Ward, L. C., Reul-Hirche, H., Steele, M. L., Carter, J., Quinn, M., Cornish, B., & Obermair, A. (2017). Lymphedema following gynecological cancer: Results from a prospective, longitudinal cohort study on prevalence, incidence and risk factors. *Gynecologic oncology, 146*(3), 623-629. <https://doi.org/10.1016/j.ygyno.2017.06.004>

- Headland, T. N., Pike, K. L., & Harris, M. E. (1990). *Emics and etics: The insider/outsider debate*. SAGE.
- Health and Disability System Review. (2020). *Health and Disability System Review – Final report – Pūrongo whakamutunga*. <https://www.health.govt.nz/publication/health-and-disability-system-review-final-report>
- Health Navigator New Zealand. (2022). *Lymphoedema*. Retrieved November 26, 2022, from <https://www.healthnavigator.org.nz/health-a-z/l/lymphoedema/#Clinicians>
- Hespe, G. E., Nitti, M. D., & Mehrara, B. J. (2015). Pathophysiology of lymphedema. In A. K. Greene, S. A. Slavin, & H. Brorson (Eds.), *Lymphedema. Presentation, diagnosis, and treatment* (pp. 9-18). Springer. https://doi.org/10.1007/978-3-319-14493-1_2
- Hoare, K. J., Buetow, S., Mills, J., & Francis, K. (2013). Using an emic and etic ethnographic technique in a grounded theory study of information use by practice nurses in New Zealand. *Journal of Research in Nursing, 18*(8), 720-731. <https://doi.org/10.1177/1744987111434190>
- Hotta, E., Asai, J., Okuzawa, Y., Hanada, K., Nomiyama, T., Takenaka, H., & Katoh, N. (2015). Verrucous lesions arising in lymphedema and diabetic neuropathy: Elephantiasis nostras verrucosa or verrucous skin lesions on the feet of patients with diabetic neuropathy? *The Journal of Dermatology, 34*(3), 235-287. <https://doi.org/10.1111/1346-8138.13063>
- Hu, Z.-y., Feng, X.-q., Fu, M. R., Yu, R., & Zhao, H.-l. (2020). Symptom patterns, physical function and quality of life among head and neck cancer patients prior to and after surgical treatment: A prospective study. *European Journal of Oncology Nursing, 46*, 101770. <https://doi.org/10.1016/j.ejon.2020.101770>
- Huang, J., Yu, N., Wang, X., & Long, X. (2017). Incidence of lower limb lymphedema after vulvar cancer: A systematic review and meta-analysis. *Medicine, 96*(46).
- Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2010). *Te Ara Tika. Guidelines for Māori research ethics: A framework for researchers and ethics committee members*. Health Research Council of New Zealand.
- International Society of Lymphology. (2013). The diagnosis and treatment of peripheral lymphedema: 2013 Consensus document of the International Society of Lymphology. *Lymphology, 46*(1), 1-11. <https://www.scopus.com/inward/record.uri?eid=2-s2.0-84880719062&partnerID=40&md5=096321aaa9ea98dc5765c76e5d94e72b>
- International Society of Lymphology. (2020). The diagnosis and treatment of peripheral lymphedema: 2020 consensus document of the International Society of Lymphology. *Lymphology, 53*(1), 16.
- Jakes, A. D., & Twelves, C. (2015). Breast cancer-related lymphoedema and venepuncture: A review and evidence-based recommendations. *Breast Cancer Research and Treatment, 154*(3), 455-461. <https://doi.org/10.1007/s10549-015-3639-1>

- Jeffs, E., Ream, E., Shewbridge, A., Cowan-Dickie, S., Crawshaw, D., Huit, M., & Wiseman, T. (2016). Exploring patient perception of success and benefit in self-management of breast cancer-related arm lymphoedema. *European Journal of Oncology Nursing*, 20, 173-183. <https://doi.org/10.1016/j.ejon.2015.08.001>
- Johnson, K. B., & Damarell, R. A. (2020). The impact of land-based exercise on quality of life and subjective symptoms in lower-limb lymphoedema: A systematic review. *Journal of Lymphoedema*, 15(1).
- Jones, J. (2013). Lymphoedema management in breast cancer-related lymphoedema. *British Journal of Community Nursing*, 18(Sup4), S6-S11. <https://doi.org/10.12968/bjcn.2013.18.Sup4.S6>
- Kalfa, S., Koelmeyer, L., Taksa, L., Winch, C., Viveros, H., Gollan, P. J., Mackie, H., & Boyages, J. (2019). Work experiences of Australian cancer survivors with lymphoedema: A qualitative study. *Health & Social Care in the Community*, 27(4), 848-855. <https://doi.org/10.1111/hsc.12698>
- Kalu, F. A., & Bwalya, J. C. (2017). What makes qualitative research good research? An exploratory analysis of critical elements. *International Journal of Social Science Research*, 5(2), 43-56. <https://doi.org/10.5296/ijssr.v5i2.10711>
- Karlsson, K., Biguet, G., Johansson, K., & Nilsson-Wikmar, L. (2015). Perceptions of lymphoedema treatment in patients with breast cancer - a patient perspective. *Scandinavian Journal of Caring Sciences*, 29(1), 110-117. <https://doi.org/10.1111/scs.12138>
- Keast, D. H., Despatis, M., Allen, J. O., & Brassard, A. (2015). Chronic oedema/lymphoedema: Under-recognised and under-treated. *International Wound Journal*, 12(3), 328-333. <https://doi.org/10.1111/iwj.12224>
- Keir, S. A. (2020). *Lymphoedema self-management education: Exploring perspectives from people with lymphoedema and lymphoedema therapists* [Unpublished Doctoral thesis, University of Newcastle]. NOVA. <https://nova.newcastle.edu.au/vital/access/manager/Repository/uon:37343>
- Kessler, D., Dubouloz, C.-J., Urbanowski, R., & Egan, M. (2009). Meaning perspective transformation following stroke: The process of change. *Disability and Rehabilitation*, 31(13), 1056-1065. <https://doi.org/10.1080/09638280802509512>
- King, J., Barclay, R., Ripat, J., Dubouloz, C.-J., & Schwartz, C. E. (2019). An investigation of occupational therapists' and physical therapists' perspectives on the process of change that occurs among clients during rehabilitation, including their use of response shift and transformative learning. *Physiotherapy Canada*, 71(4), 355-366. <https://doi.org/10.3138/ptc-2018-0047>
- Klein, E., Rosenberg, J., & Rosenberg, S. (2007). Whose treatment is it anyway? The role of consumer preferences in mental health care. *American Journal of Psychiatric Rehabilitation*, 10(1), 65-80. <https://doi.org/10.1080/15487760601166365>
- Ko, D. S., Lerner, R., Klose, G., & Cosimi, A. B. (1998). Effective treatment of lymphedema of the extremities. *Archives of Surgery*, 133(4), 452-458. <https://doi.org/10.1001/archsurg.133.4.452>

- Kopanoglu, T., Beverley, K., Eggbeer, D., & Walters, A. (2019). Uncovering self-management needs to better design for people living with lymphoedema. *Design for Health*, 3(2), 220-239. <https://doi.org/10.1080/24735132.2019.1686326>
- Larmer, P. J., Smythe, E., & Jones, M. (2019). Professional doctorates: Grasping a new way. *Health Education in Practice: Journal of Research for Professional Learning*, 2(2), 52-64. <https://doi.org/10.33966/hepj.2.2.13348>
- Lawenda, B. D., Mondry, T. E., & Johnstone, P. A. (2009). Lymphedema: A primer on the identification and management of a chronic condition in oncologic treatment. *CA: A Cancer Journal for Clinicians*, 59(1), 8-24. <https://doi.org/10.3322/caac.20001>
- Leeds-Hurwitz, W., Braithwaite, D., & Baxter, L. (2006). Social theories: Social constructionism and symbolic interactionism. In D. O. Braithwaite, E. A. Suter, & K. Floyd (Eds.), *Engaging theories in family communication: Multiple perspectives* (pp. 229-242). SAGE.
- Leung, E. Y. L., Tirlapur, S. A., & Meads, C. (2015). The management of secondary lower limb lymphoedema in cancer patients: A systematic review. *Palliative Medicine*, 29(2), 112-119. <https://doi.org/10.1177/0269216314545803>
- Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (4th ed., Vol. 4, pp. 97-128). SAGE.
- Lindquist, H., Enblom, A., & Bergmark, K. (2015). Self-care among female cancer survivors with secondary lymphedema: A qualitative study. *Rehabilitation Oncology*, 33(1), 51-57. <http://ezproxy.aut.ac.nz/login?url=http://search.proquest.com/docview/1674462855?accountid=8440>
- Liu, L. (2020). Integrative therapy in breast cancer rehabilitation. *Physical Therapy Reviews*, 25(4), 208-212. <https://doi.org/10.1080/10833196.2020.1784572>
- Lopez, A. D., Alcaraz, I., Luna, C., Aguirre, J. S., Cabanillas, Y. L., & Montoya, L. L. (2022). Lymphedema in Mexico: A clinical and epidemiological overview. *Cardiology and Angiology: An International Journal*, 21-31. <https://doi.org/10.9734/ca%2F2022%2Fv11i130186>
- Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01
- Lymphoedema Framework. (2006). *International consensus. Best practice for the management of lymphoedema*. <https://www.woundsinternational.com/download/resource/6020>
- Lymphoedema NZ. The website of New Zealand lymphoedema therapists. (2022). *Lymphoedema Therapists' Conferences (2017)*. Retrieved January 24, 2023, from <http://www.lymphoedemanz.org.nz/site/lymphoedema/conferences/Conference%20Programme%2018Aug%202017.pdf>

- Lymphoedema Therapists. (2022). *Lymphoedema therapists in New Zealand*. Lymphoedema therapists in New Zealand.
<http://www.lymphoedemanz.org.nz/Lymphoedema+Therapists.html#LTPP>
- Maccarone, M. C., Venturini, E., Menegatti, E., Gianesini, S., & Masiero, S. (2023). Water-based exercise for upper and lower limb lymphoedema treatment. *Journal of Vascular Surgery: Venous and Lymphatic Disorders*, *11*(1), 201-209.
<https://doi.org/10.1016/j.jvsv.2022.08.002>
- Maclellan, R. A. (2015). The lymphatic system. In A. K. Greene, S. A. Slavin, & H. Brorson (Eds.), *Lymphedema. Presentation, diagnosis, and treatment* (pp. 3-7). Springer.
https://doi.org/10.1007/978-3-319-14493-1_1
- Maclellan, R. A., Couto, R. A., Sullivan, J. E., Grant, F. D., Slavin, S. A., & Greene, A. K. (2015). Management of primary and secondary lymphedema: Analysis of 225 referrals to a center. *Annals of Plastic Surgery*, *75*(2), 197-200.
<https://doi.org/10.1097/sap.0000000000000022>
- Maree, J. E., & Beckmann, D. (2016). "Just live with it": Having to live with breast cancer related lymphedema. *Health SA Gesondheid*, *21*, 77-85.
<https://doi.org/10.1016/j.hsag.2015.08.003>
- Marshall, C., & Rossman, G. B. (2011). *Designing qualitative research* (5th ed.). SAGE.
- Martin-Almedina, S., Mortimer, P. S., & Ostergaard, P. (2021). Development and physiological functions of the lymphatic system: Insights from human genetic studies of primary lymphedema. *Physiological Reviews*, *101*(4), 1809-1871.
<https://doi.org/10.1152/physrev.00006.2020>
- Martin, J., Doyle, N., & McCarroll, M. (2021). Preliminary development of a leg lymphoedema self-care adherence questionnaire. *Journal of Lymphoedema*, *16*(1), 39-42.
- Mathevet, P., Lécuru, F., Uzan, C., Boutitie, F., Magaud, L., Guyon, F., Querleu, D., Fourchette, V., Baron, M., & Bats, A.-S. (2021). Sentinel lymph node biopsy and morbidity outcomes in early cervical cancer: Results of a multicentre randomised trial (SENTICOL-2). *European Journal of Cancer*, *148*, 307-315.
<https://doi.org/10.1016/j.ejca.2021.02.009>
- McLaughlin, S. A., Bagaria, S., Gibson, T., Arnold, M., Diehl, N., Crook, J., Parker, A., & Nguyen, J. (2013). Trends in risk reduction practices for the prevention of lymphedema in the first 12 months after breast cancer surgery. *Journal of the American College of Surgeons*, *216*(3), 380-389.
<https://doi.org/http://dx.doi.org/10.1016/j.jamcollsurg.2012.11.004>
- Mead, G. H. (1932). *The philosophy of the present*. La Salle, IL: Open Court Press.
- Medeiros, Z. M., Vieira, A. V., Xavier, A. T., Bezerra, G. S., Lopes, M. d. F. C., Bonfim, C. V., & Aguiar-Santos, A. M. (2022). Lymphatic filariasis: A systematic review on morbidity and its repercussions in countries in the Americas. *International Journal of Environmental Research and Public Health*, *19*(1), 316.
<https://doi.org/10.3390/ijerph19010316>

- Meiklejohn, J. A. (2011). *The role of physical activity in the lives of people with lymphoedema following cancer treatment: A social constructionist study* [Unpublished Master's thesis, Queensland University of Technology].
https://eprints.qut.edu.au/49853/1/Judith_Meiklejohn_Thesis.pdf
- Meiklejohn, J. A., Heesch, K. C., Janda, M., & Hayes, S. C. (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), 459-466.
<https://doi.org/10.1007/s00520-012-1534-4>
- Mezirow, J. (1978). Perspective transformation. *Adult Education*, 28(2), 100-110.
https://journals.sagepub.com/doi/pdf/10.1177/074171367802800202?casa_token=RFCeLWob5IAAAAA:Vb3XfFSUdUAHDriN8hLWqtz2LclBpk9P1gPfquYLxosnlmr4LigL_3SOknwbMcewC13FLJ4OISwL
- Mezirow, J. (1998). On critical reflection. *Adult Education Quarterly*, 48(3), 185-198.
https://journals.sagepub.com/doi/pdf/10.1177/074171369804800305?casa_token=ZlrVtsslyoAAAAA:vf4nmllgqfocCNwgS518rGic53DoeV9lAxiudLZoCWm5p3ZYf7DObuTADg7gP6iVsVLDpNm9nt88
- Mezirow, J. (2003). Transformative learning as discourse. *Journal of Transformative Education*, 1(1), 58-63. <https://doi.org/10.1177/1541344603252172>
- Mezirow, J. (2006). An overview on transformative learning. In J. Crowther & P. Sutherland (Eds.), *Lifelong learning* (pp. 24-38). Routledge.
- Milliken, P. J., & Schreiber, R. (2012). Examining the nexus between grounded theory and symbolic interactionism. *International Journal of Qualitative Methods*, 11(5), 684-696.
<https://doi.org/10.1177/160940691201100510>
- Mitra, D., Catalano, P. J., Cimbak, N., Damato, A. L., Muto, M. G., & Viswanathan, A. N. (2015). The risk of lymphedema after postoperative radiation therapy in endometrial cancer. *Journal of Gynecologic Oncology*, 27(1). <https://doi.org/10.3802/jgo.2016.27.e4>
- Moffatt, C., Keeley, V., & Quéré, I. (2019). The concept of chronic edema—a neglected public health issue and an international response: The LIMPRINT study. *Lymphatic Research and Biology*, 17(2), 121-126. <https://doi.org/10.1089/lrb.2018.0085>
- Moffatt, C. J., Keeley, V., Franks, P. J., Rich, A., & Pinnington, L. L. (2016). Chronic oedema: A prevalent health care problem for UK health services. *International Wound Journal*, 14(5), 772-781. <https://doi.org/10.1111/iwj.12694>
- Morgan, D. L. (2014). Pragmatism as a paradigm for social research. *Qualitative Inquiry*, 20(8), 1045-1053. <https://doi.org/10.1177/1077800413513733>
- Morgan, P. A., Franks, P. J., & Moffatt, C. J. (2005). Health-related quality of life with lymphoedema: A review of the literature. *International Wound Journal*, 2(1), 47-62.
<https://doi.org/10.1111/j.1742-4801.2005.00066.x>
- Mortimer, P. S., & Rockson, S. G. (2014, 03/03/). New developments in clinical aspects of lymphatic disease. *The Journal of Clinical Investigation*, 124(3), 915-921.
<https://doi.org/10.1172/JCI71608>

- Needham, M., & Martin, M. (2009). Therapeutic laser treatment for post mastectomy lymphoedema: A perspective for nurses. *Laser Therapy*, 18(2), 103-110. <https://doi.org/10.5978/islsm.18.103>
- Nowicki, J., & Siviour, A. (2013). Best practice skin care management in lymphoedema. *Wound Practice & Research: Journal of the Australian Wound Management Association*, 21(2), 61. https://search.informit.org/doi/pdf/10.3316/informit.394443924579712?casa_token=ZmjiknyUC9EAAAAA:QAadc53Uf22qMF6Qq53z-B350y-unac0dAW00QabHeZEduCX3BHac9JknhYn1MtJ7qY5I9y8ydSLtw
- Ochalek, K., Gradalski, T., & Szygula, Z. (2015). Five-year assessment of maintenance combined physical therapy in postmastectomy lymphedema. *Lymphatic Research and Biology*, 13(1), 54-58. <https://doi.org/10.1089/lrb.2014.0027>
- Olive, J. L. (2014). Reflecting on the tensions between emic and etic perspectives in life history research: Lessons learned. *Forum qualitative sozialforschung/Forum: Qualitative Social Research*, 15(2). <https://doi.org/10.17169/fqs-15.2.2072>
- Ong, B. N., Rogers, A., Kennedy, A., Bower, P., Sanders, T., Morden, A., Cheraghi-Sohi, S., Richardson, J., & Stevenson, F. (2014). Behaviour change and social blinkers? The role of sociology in trials of self-management behaviour in chronic conditions. *From Health Behaviours to Health Practices*, 69-81.
- Orange, D. M. (1995). *Emotional understanding: Studies in psychoanalytic epistemology*. Guilford Press.
- Paskett, E. D., Dean, J. A., Oliveri, J. M., & Harrop, J. P. (2012). Cancer-related lymphedema risk factors, diagnosis, treatment, and impact: A review. *Journal of Clinical Oncology*, 30(30), 3726-3733. <https://doi.org/10.1200/JCO.2012.41.8574>
- Patton, M. Q. (2003). Qualitative evaluation checklist. *Evaluation Checklists Project*, 21, 1-13.
- Pearce, G., Parke, H. L., Pinnock, H., Epiphaniou, E., Bourne, C. L., Sheikh, A., & Taylor, S. J. (2016). The PRISMS taxonomy of self-management support: Derivation of a novel taxonomy and initial testing of its utility. *Journal of Health Services Research and Policy*, 21(2), 73-82. <https://doi.org/10.1177/1355819615602725>
- Person, B., Bartholomew, L. K., Addiss, D., & van den Borne, B. (2007). Disrupted social connectedness among Dominican women with chronic filarial lymphedema. *Patient Education and Counseling*, 68(3), 279-286. <https://doi.org/10.1016/j.pec.2007.06.015>
- Pigott, A., Obermair, A., Janda, M., Vagenas, D., Ward, L. C., Reul-Hirche, H., & Hayes, S. C. (2020). Incidence and risk factors for lower limb lymphedema associated with endometrial cancer: Results from a prospective, longitudinal cohort study. *Gynecologic Oncology*, 158(2), 375-381. <https://doi.org/10.1016/j.ygyno.2020.04.702>
- Pike, K. L. (1967). Etic and emic standpoints for the description of behavior. In K. L. Pike (Ed.), *Language in relation to a unified theory of the structure of human behavior* (pp. 37-72). Mouton & Co. <https://doi.org/10.1037/14786-002>

- Plagenhoef, S., Evans, F. G., & Abdelnour, T. (1983). Anatomical data for analyzing human motion. *Research Quarterly for Exercise and Sport*, 54(2), 169-178. <https://doi.org/10.1080/02701367.1983.10605290>
- Rebegea, L. F., Stoleriu, G., Manolache, N., Serban, C., Craescu, M., Lupu, M. N., Voinescu, D., Firescu, D., & Ciobotaru, O. R. (2020). Associated risk factors of lower limb lymphedema after treatment of cervical and endometrial cancer. *Experimental and Therapeutic Medicine*, 20(6), 1-1. <https://doi.org/10.3892/etm.2020.9311>
- Rees, S., Ousey, K., Koo, K., Ahmad, N., & Bowling, F. L. (2019). Higher degrees in nursing: Traditional research PhD or professional doctorate? *British Journal of Nursing*, 28(14), 940-945. <https://doi.org/10.12968/bjon.2019.28.14.940>
- Renshaw, M. (2007). Lymphorrhoea: 'Leaky legs' are not just the nurse's problem. *British Journal of Community Nursing*, 12. <https://doi.org/10.12968/bjcn.2007.12.Sup2.23261>
- Rhoten, B., Radina, M., Adair, M., Sinclair, V., & Ridner, S. (2015). Hide and seek: Body image-related issues for breast cancer survivors with lymphedema. *Journal of Womens Health Issues Care* 4(2), 1-7. <https://doi.org/10.4172/2325-9795.1000180>
- Ridner, S., Deng, J., Fu, M., Radina, E., Thiadens, S., Weiss, J., Dietrich, M., Cormier, J., Tuppo, C., & Armer, J. (2012). Symptom burden and infection occurrence among individuals with extremity lymphedema. *Lymphology*, 45(3), 113-123.
- Ridner, S. H., Bonner, C. M., Deng, J., & Sinclair, V. G. (2012). Voices from the shadows: Living with lymphedema. *Cancer Nursing*, 35(1), E18-E26. <https://doi.org/10.1097/NCC.0b013e31821404c0>
- Ridner, S. H., Deng, J., Doersam, J. K., & Dietrich, M. S. (2021). Lymphedema symptom intensity and distress surveys—Truncal and head and neck, Version 2.0. *Lymphatic Research and Biology*, 19(3), 240-248. <https://doi.org/10.1089/lrb.2020.0071>
- Ridner, S. H., Dietrich, M. S., & Kidd, N. (2011). Breast cancer treatment-related lymphedema self-care: Education, practices, symptoms, and quality of life. *Supportive Care in Cancer*, 19(5), 631-637. <https://doi.org/10.1007/s00520-010-0870-5>
- Ridner, S. H., Doersam, J. K., Stoldal, D. P., & Dietrich, M. S. (2018). Development and validation of the lymphedema symptom intensity and distress survey-lower limb. *Lymphatic Research and Biology*, 16(6), 538-546. <https://doi.org/10.1089/lrb.2017.0069>
- Ridner, S. H., Fu, M. R., Wanchai, A., Stewart, B. R., Armer, J. M., & Cormier, J. N. (2012). Self-management of lymphedema: A systematic review of the literature from 2004 to 2011. *Nursing Research*, 61(4), 291-299. <https://doi.org/10.1097/NNR.0b013e31824f82b2>
- Ringstad, Ø. (2016). Being an autonomous person with chronic disease. *Croatian Medical Journal*, 57(6), 608. <https://doi.org/10.3325/cmj.2016.57.608>
- Roberson, M. L., Strassle, P. D., Fasehun, L.-K. O., Erim, D. O., Deune, E. G., & Ogunleye, A. A. (2021). Financial burden of lymphedema hospitalizations in the United States. *JAMA Oncology*, 7(4), 630-632. <https://doi.org/10.1001/jamaoncol.2020.7891>

- Rockson, S. G., Keeley, V., Kilbreath, S., Szuba, A., & Towers, A. (2019). Cancer-associated secondary lymphoedema. *Nature Reviews Disease Primers*, 5(1), 1-16.
<https://doi.org/10.1038/s41572-019-0072-5>
- Rockson, S. G., & Rivera, K. K. (2008). Estimating the population burden of lymphedema. *Annals of the New York Academy of Sciences*, 1131(1), 147-154.
<https://doi.org/10.1196/annals.1413.014>
- Ručigaj, T. P., & Žunter, V. T. (2015). Lymphedema after breast and gynecological cancer – A frequent, chronic, disabling condition in cancer survivors. *Acta Dermatovenerologica Croatica*, 23(2), 101-107. <http://adc.mef.hr/index.php/adc/article/view/1481>
- Ryan, M., Stainton, M. C., Jaconelli, C., Watts, S., MacKenzie, P., & Mansberg, T. (2003). The experience of lower limb lymphedema for women after treatment for gynecologic cancer. *Oncology Nursing Forum*, 30(3), 417-23. <https://doi.org/10.1188/03.ONF.417-423>
- Schaverien, M. V., & Coroneos, C. J. (2019). Surgical treatment of lymphedema. *Plastic and Reconstructive Surgery*, 144(3), 738-758.
<https://doi.org/10.1097/PRS.0000000000005993>
- Schön, D. A. (2017). *The reflective practitioner: How professionals think in action*. Routledge.
<https://doi.org/10.4324/9781315237473>
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., Redeker, N. S., Reynolds, N., & Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44(2), 136-144. <https://doi.org/10.1111/j.1547-5069.2012.01444.x>
- Sekse, R. J. T., Dunberger, G., Olesen, M. L., Østerbye, M., & Seibæk, L. (2019). Lived experiences and quality of life after gynaecological cancer—An integrative review. *Journal of Clinical Nursing*, 28(9-10), 1393-1421. <https://doi.org/10.1111/jocn.14721>
- Shallwani, S. M., Hodgson, P., & Towers, A. (2020). Examining obesity in lymphedema: A retrospective study of 178 new patients with suspected lymphedema at a Canadian hospital-based clinic. *Physiotherapy Canada*, 72(1), 18-25.
<https://doi.org/10.3138/ptc-2018-0076>
- Shao, Y., Qi, K., Zhou, Q. H., & Zhong, D. S. (2014). Intermittent pneumatic compression pump for breast cancer-related lymphedema: A systematic review and meta-analysis of randomized controlled trials. *Oncology Research and Treatment*, 37(4), 170-174.
<https://doi.org/10.1159/000360786>
- Shaw, M. T., & Leggat, P. A. (2006). A case of exposure to Bancroftian filariasis in a traveller to Thailand. *Travel Medicine and Infectious Disease*, 4(5), 290-293.
- Shaw, R., & Thomas, R. (2011). Role of GPs in breast cancer-related arm morbidity care. *Journal of Lymphoedema*, 6(2), 10-19.
<https://www.scopus.com/inward/record.uri?eid=2-s2.0-84884509372&partnerID=40&md5=c4090d17b3b3eab2ad5f6e0afbc3684e>

- Shih, Y.-C. T., Xu, Y., Cormier, J. N., Giordano, S., Ridner, S. H., Buchholz, T. A., Perkins, G. H., & Elting, L. S. (2009). Incidence, treatment costs, and complications of lymphedema after breast cancer among women of working age: A 2-year follow-up study. *Journal of Clinical Oncology*, 27(12), 2007-2014. <https://doi.org/10.1200/JCO.2008.18.3517>
- Shinaoka, A., Kamiyama, K., Yamada, K., & Kimata, Y. (2022). A new severity classification of lower limb secondary lymphedema based on lymphatic pathway defects in an indocyanine green fluorescent lymphography study. *Scientific Reports*, 12(1), 309. <https://doi.org/10.1038/s41598-021-03637-6>
- Shouse, E. (2005). Feeling, emotion, affect. *Media/Culture Journal*, 8(6). <https://doi.org/10.5204/mcj.2443>
- Smith, E. L., Mkwanda, S. Z., Martindale, S., Kelly-Hope, L. A., & Stanton, M. C. (2014). Lymphatic filariasis morbidity mapping: A comprehensive examination of lymphoedema burden in Chikwawa district, Malawi. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 108(12), 751-758.
- Stanhope, V., Barranger, S. L., Salzer, M. S., & Marcus, S. C. (2013). Examining the relationship between choice, therapeutic alliance and outcomes in mental health services. *Journal of Personalized Medicine*, 3(3), 191-202. <https://doi.org/10.3390/jpm3030191>
- Stolldorf, D. P., Dietrich, M. S., & Ridner, S. H. (2016). A comparison of the quality of life in patients with primary and secondary lower limb lymphedema. *Western Journal of Nursing Research*, 38(10), 1313-1334. <https://doi.org/10.1177/0193945916647961>
- Stolldorf, D. P., Dietrich, M. S., & Ridner, S. H. (2016). Symptom frequency, intensity, and distress in patients with lower limb lymphedema. *Lymphatic Research and Biology*, 14(2), 78-87. <https://doi.org/10.1089/lrb.2015.0027>
- Stout, N. L., & Armer, J. M. (2022). Lymphedema prospective surveillance and risk reduction. In M. Schaverien & J. Dayan (Eds.), *Multimodal management of upper and lower extremity lymphedema* (pp. 23-27). Springer. https://doi.org/10.1007/978-3-030-93039-4_4
- Stout, N. L., Brantus, P., & Moffatt, C. (2012). Lymphoedema management: An international intersect between developed and developing countries. Similarities, differences and challenges. *Global Public Health*, 7(2), 107-123. <https://doi.org/10.1080/17441692.2010.549140>
- Stout, N. L., Weiss, R., Feldman, J. L., Stewart, B. R., Armer, J. M., Cormier, J. N., & Shih, Y.-C. (2013). A systematic review of care delivery models and economic analyses in lymphedema: Health policy impact (2004-2011). *Lymphology*, 46(1), 27-41.
- Strauss, A. L. (2008). *Continual permutations of action*. AldineTransaction.
- Street Jr, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74(3), 295-301. <https://doi.org/10.1016/j.pec.2008.11.015>

- Stuiver, M. M., ten Tusscher, M. R., Agasi-Idenburg, C. S., Lucas, C., Aaronson, N. K., & Bossuyt, P. M. (2015). Conservative interventions for preventing clinically detectable upper-limb lymphoedema in patients who are at risk of developing lymphoedema after breast cancer therapy. *The Cochrane Database of Systematic Reviews*, 2, CD009765. <https://doi.org/10.1002/14651858.CD009765.pub2>
- Suami, H., Thompson, B., Mackie, H., Blackwell, R., Heydon-White, A., Blake, F. T., Boyages, J., & Koelmeyer, L. (2022). A new indocyanine green fluorescence lymphography protocol for diagnostic assessment of lower limb lymphoedema. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 75(11), 3946-3955. <https://doi.org/10.1016/j.bjps.2022.08.017>
- Tada, H., Teramukai, S., Fukushima, M., & Sasaki, H. (2009). Risk factors for lower limb lymphedema after lymph node dissection in patients with ovarian and uterine carcinoma. *BMC Cancer*, 9(1), 1-6. <https://doi.org/10.1186/1471-2407-9-47>
- Tan, J., Gandhi, J., Sinha, S., & Rafique, M. (2015). Massive localised lymphoedema: A new benign entity in the morbidly obese patient. *New Zealand Medical Journal*, 128(1424), 70-74. <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2015/vol-128-no-1424-30-october-2015/6714>
- Tashiro, K., Shibata, T., Mito, D., Ishiura, R., Kato, M., Yamashita, S., Narushima, M., Iida, T., & Koshima, I. (2016). Indocyanine green lymphographic signs of lymphatic collateral formation in lower extremity lymphedema after cancer resection. *Annals of Plastic Surgery*, 77(2), 213-216. <https://doi.org/10.1097/SAP.0000000000000599>
- Te Aho o Te Kahu. (2021). *He Pūrongo Mate Pukupuku o Aotearoa 2020, the state of cancer in New Zealand 2020*. [https://teaho.govt.nz/static/reports/state-of-cancer-in-new-zealand-2020%20\(revised%20March%202021\).pdf](https://teaho.govt.nz/static/reports/state-of-cancer-in-new-zealand-2020%20(revised%20March%202021).pdf)
- Te Whatu Ora. Health New Zealand. (2022, 1 July 2022). *About Capital, Coast and Hutt Valley District*. Retrieved November 11, 2022, from <https://www.ccdhb.org.nz/about-us/about-capital-coast-and-hutt-valley-district/>
- Teerachaisakul, M., Ekataksin, W., Durongwatana, S., & Taneepanichskul, S. (2013). Risk factors for cellulitis in patients with lymphedema: A case-controlled study. *Lymphology*, 46(3), 150-156.
- Thomas, M. (2021). Breast cancer-related upper limb lymphoedema: An overview. *British Journal of Community Nursing*, 26(Sup4), S30-S35. <https://doi.org/10.12968/bjcn.2021.26.Sup4.S30>
- Thomas, R., Hack, T. F., Quinlan, E., Tatemichi, S., Towers, A., Kwan, W., Miedema, B., Tilley, A., Hamoline, R., & Morrison, T. (2015). Loss, adaptation and new directions: The impact of arm morbidity on leisure activities following breast cancer. *Canadian Oncology Nursing Journal/Revue Canadienne de Soins Infirmiers en Oncologie*, 25(1), 49-53. <https://doi.org/10.5737/236880762514953>
- Thomas, R., & Hamilton, R. (2014). Illustrating the (in)visible: Understanding the impact of loss in adults living with secondary lymphedema after cancer. *International Journal of Qualitative Studies on Health and Well-being*, 9, Article 24354. <https://doi.org/10.3402/qhw.v9.24354>

- Thompson, B., Gaitatzis, K., Janse de Jonge, X., Blackwell, R., & Koelmeyer, L. A. (2021). Manual lymphatic drainage treatment for lymphedema: A systematic review of the literature. *Journal of Cancer Survivorship*, 15, 244-258.
<https://doi.org/10.1007/s11764-020-00928-1>
- Thomson, M., & Walker, J. (2011). Collaborative lymphoedema management: Developing a clinical protocol. *International Journal of Palliative Nursing*, 17(5), 231-238.
<https://doi.org/doi:10.12968/ijpn.2011.17.5.231>
- Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research*, 56(3), 243-259. <https://doi.org/10.1080/00313831.2011.581686>
- Thornberg, R., & Charmaz, K. (2014). Grounded theory and theoretical coding. In F. Uwe (Ed.), *The SAGE handbook of qualitative data analysis* (Vol. 5, pp. 153-169). SAGE.
<https://doi.org/10.4135/9781446282243.n11>
- Tidhar, D., Hodgson, P., Shay, C., & Towers, A. (2014). A lymphedema self-management programme: Report on 30 cases. *Physiotherapy Canada*, 66(4), 404-412.
<https://doi.org/10.3138/ptc.2013-46>
- Todd, M., Key, M., Rice, M., & Salmon, M. (2017). Audit of skin changes present in referrals to a specialist lymphoedema service. *British Journal of Community Nursing*, 22(Sup5), S42-S47. <https://doi.org/10.12968/bjcn.2017.22.Sup5.S42>
- Travis, E. C., Shugg, S., & McEwan, W. M. (2015). Lymph node grafting in the treatment of upper limb lymphoedema: A clinical trial. *ANZ Journal of Surgery*, 85(9), 631-635.
<https://doi.org/10.1111/ans.13171>
- Tripp-Reimer, T. (1984). Reconceptualizing the construct of health: Integrating emic and etic perspectives. *Research in Nursing and Health*, 7(2), 101-109.
<https://doi.org/10.1002/nur.4770070206>
- Tuğral, A., & Bakar, Y. (2017). Does lower extremity lymphedema affect quality of life, functionality, and kinesiophobia? *European Journal of Lymphology and Related Problems*, 29(76), 49.
- Tuğral, A., Viren, T., & Bakar, Y. (2017). Tissue dielectric constant and circumference measurement in the follow-up of treatment-related changes in lower-limb lymphedema. *International Angiology: A Journal of the International Union of Angiology*, 37(1), 26-31. <https://doi.org/10.23736/s0392-9590.17.03843-3>
- Vaillant-Newman, A. M. (2002). Limits of self management of lymphedema. *European Journal of Lymphology and Related Problems*, 10(37-38), 15-17.
<https://www.scopus.com/inward/record.uri?eid=2-s2.0-2342607018&partnerID=40&md5=c3b27b079793df204cb90152d84bcd2f>
- Van den Hoonaard, W. C. (2008). On ethics regimes and the problem of maintaining the face of qualitative research: A commentary on Lara CZ Guerriero's and Sueli Dallari's paper. *Ciência & Saúde Coletiva*, 13, 312-314.

- Van Hecke, A., Heinen, M., Fernández-Ortega, P., Graue, M., Hendriks, J. M. L., Høy, B., Köpke, S., Lithner, M., & Van Gaal, B. G. I. (2017). Systematic literature review on effectiveness of self-management support interventions in patients with chronic conditions and low socio-economic status. *Journal of Advanced Nursing*, 73(4), 775-793. <https://doi.org/10.1111/jan.13159>
- Viehoff, P., Hidding, J., Heerkens, Y., Van Ravensberg, C., & Neumann, H. (2013). Coding of meaningful concepts in lymphedema-specific questionnaires with the ICF. *Disability and Rehabilitation*, 35(25), 2105-2112. <https://doi.org/10.3109/09638288.2013.771710>
- Viehoff, P. B., Heerkens, Y. F., Van Ravensberg, C. D., Hidding, J., Damstra, R. J., Ten Napel, H., & Neumann, H. A. M. (2015). Development of consensus International Classification of Functioning, Disability and Health (ICF) Core Sets for lymphedema. *Lymphology*, 48(1), 38-50. <https://www.scopus.com/inward/record.uri?eid=2-s2.0-84938588428&partnerID=40&md5=f430c800d2871e614d740ae90194565e>
- Vignes, S., Albuissou, J., Champion, L., Constans, J., Tauveron, V., Malloizel, J., Quéré, I., Simon, L., Arrault, M., & Trévidic, P. (2021). Primary lymphedema French National Diagnosis and Care Protocol (PNDS; Protocole National de Diagnostic et de Soins). *Orphanet Journal of Rare Diseases*, 16(1), 1-12. <https://doi.org/10.1186/s13023-020-01652-w>
- Vignes, S., Poizeau, F., & Dupuy, A. (2022). Cellulitis risk factors for patients with primary or secondary lymphedema. *Journal of Vascular Surgery: Venous and Lymphatic Disorders*, 10(1), 179-185. e171.
- Ville, I. (2005). Biographical work and returning to employment following a spinal cord injury. *Sociology of Health and Illness*, 27(3), 324-350. <https://doi.org/10.1111/j.1467-9566.2005.00445.x>
- Walker, J., & Thomson, M. (2012). Managing lymphoedema in palliative care patients. *Nursing New Zealand (Wellington, N.Z.: 1995)*, 18(1), 18-19. <https://www.scopus.com/inward/record.uri?eid=2-s2.0-84860231253&partnerID=40&md5=e6ddcb576a4378357a8252ac9119c6ae>
- Watanabe, Y., Koshiyama, M., Seki, K., Nakagawa, M., Ikuta, E., Oowaki, M., & Sakamoto, S.-i. (2019). Development and themes of diagnostic and treatment procedures for secondary leg lymphedema in patients with gynecologic cancers. *Healthcare*, 7(3), 101. <https://doi.org/10.3390/healthcare7030101>
- Waters, B. (2009). *Unknown stories: Biographies of adults with primary lymphoedema* [Unpublished Doctoral thesis, University of Southampton]. <http://eprints.soton.ac.uk/336241/>
- Watkins, M. (2000). Ways of learning about leisure meanings. *Leisure Sciences*, 22(2), 93-107. <https://doi.org/10.1080/014904000272876>
- Watts, T. E., & Davies, R. E. (2016). A qualitative national focus group study of the experience of living with lymphoedema and accessing local multiprofessional lymphoedema clinics. *Journal of Advanced Nursing*, 72(12), 3147-3159. <https://doi.org/10.1111/jan.13071>

- Watu, E. (2020). The effect of lymphoedema exercises and foot elevation on the quality of life of patients with elephantiasis. *Journal of Tropical Medicine*, 2020. <https://doi.org/10.1155/2020/6309630>
- Wedin, M., Ståhlberg, K., Marcickiewicz, J., Ahlner, E., Åkesson, Å., Lindahl, G., Wodlin, N., Kjølhede, P., & LASEC Study Group. (2022). Impact of lymphadenectomy and lymphoedema on health-related quality of life 1 year after surgery for endometrial cancer. A prospective longitudinal multicentre study. *BJOG: An International Journal of Obstetrics and Gynaecology*, 129(3), 450-460. <https://doi.org/https://doi.org/10.1111/1471-0528.16870>
- Wienke Totura, C. M., Fields, S. A., & Karver, M. S. (2018). The role of the therapeutic relationship in psychopharmacological treatment outcomes: A meta-analytic review. *Psychiatric Services*, 69(1), 41-47. <https://doi.org/10.1176/appi.ps.201700114>
- Wilkinson, A., & Whitehead, L. (2009). Evolution of the concept of self-care and implications for nurses: A literature review. *International Journal of Nursing Studies*, 46(8), 1143-1147.
- Woods, M. (2003). The experience of manual lymph drainage as an aspect of treatment for lymphoedema. *International Journal of Palliative Nursing*, 9(8), 336-342.
- Yildiz, E. D., Bakar, Y., & Keser, I. (2022). What do lymphedema patients expect from a treatment and what do they achieve? A descriptive study. *Journal of Vascular Nursing*, 40(1), 59-65. <https://doi.org/10.1016/j.jvn.2022.01.002>
- Yoon, J. A., Shin, M. J., & Kim, J. H. (2021). Indocyanine green lymphography and lymphoscintigraphy severity stage showed strong correlation in lower limb lymphedema. *Lymphatic Research and Biology*, 19(1), 80-85. <https://doi.org/10.1089/lrb.2020.0043>
- Yost, K. J., Cheville, A. L., Al-Hilli, M. M., Mariani, A., Barrette, B. A., McGree, M. E., Weaver, A. L., & Dowdy, S. C. (2014). Lymphedema after surgery for endometrial cancer: Prevalence, risk factors, and quality of life. *Obstetrics and Gynecology*, 124(2 Part 1), 307. <https://doi.org/10.1097/AOG.0000000000000372>
- Zhang, X., McLaughlin, E. M., Krok-Schoen, J. L., Naughton, M., Bernardo, B. M., Cheville, A., Allison, M., Stefanick, M., Bea, J. W., & Paskett, E. D. (2022). Association of lower extremity lymphedema with physical functioning and activities of daily living among older survivors of colorectal, endometrial, and ovarian cancer. *JAMA Network Open*, 5(3), e221671-e221671. <https://doi.org/10.1001/jamanetworkopen.2022.1671>

Appendices

Appendix A Ethics Approval



AUTEC Secretariat

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 E: ethics@aut.ac.nz
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8 November 2017

Debbie Payne
 Faculty of Health and Environmental Sciences

Dear Debbie

Ethics Application: 17/350 Living with moderate to severe lower limb lymphoedema

Thank you for submitting your application for ethical review. I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application in stages at their meeting on 6 November 2017, subject to the following conditions:

1. Note that this approval is in stages, and is only for the interviews and focus groups with consumers. Should interviews with health professionals be undertaken an amendment application for these should be submitted, along with a customized Information Sheet and Consent Form;
2. Amend the recruitment poster so that all relevant inclusion and exclusion criteria; (the committee notes inconsistency in the terms mild/moderate/severe throughout the application);
3. As this is health data the appropriate storage period is 10 years;
4. Amendment of the Information Sheet as follows:
 - a. Please clarify a bit more about the difference between the interviews and focus group. For example, please explain clearly that persons have a choice about attending an interview or focus group, and breakdown each component into location, costs of time, differences concerning withdrawal of data and opportunity to review and confirm transcripts;
 - b. Review for clarity of expression, and consistent use of the first person when talking about the researcher;
 - c. Review the inclusion/exclusion criteria – particularly in relation to the statements “if your cancer has returned” – is the condition under investigation always related to cancer? Also “treating people like you”;
 - d. Please consider if AUT counselling is the appropriate referral for upset participants. For example, it is not available for persons who cannot attend face-to-face in Auckland, and is only in connection to upset occurring as a result of participation, rather than the consequences of living with a health condition. Please remove this offer, or supplement it with alternative support pathways;
 - e. Please reflect on the statement provided in the Consent Form regarding discussions about meeting the researcher in the future; perhaps some context around this would aid clarity.

Please provide me with a response to the points raised in these conditions, indicating either how you have satisfied these points or proposing an alternative approach. AUTEC also requires copies of any altered documents, such as Information Sheets, surveys etc. You are not required to resubmit the application form again. Any changes to responses in the form required by the committee in their conditions may be included in a supporting memorandum.

Please note that the Committee is always willing to discuss with applicants the points that have been made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood.

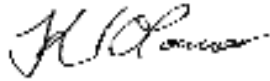
Once your response is received and confirmed as satisfying the Committee’s points, you will be notified of the full approval of your ethics application. Full approval is not effective until all the conditions have been met. Data collection

may not commence until full approval has been confirmed. If these conditions are not met within six months, your application may be closed and a new application will be required if you wish to continue with this research.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

I look forward to hearing from you,

Yours sincerely



Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: Claire Doole; David Healee

Appendix B Participant Information Sheet



Appendix B Participant Information Sheet

Living with moderate to severe lower limb (leg) lymphoedema.

Date Information Sheet Produced:

23/11/2017

Project Title

Living with moderate to severe lower limb lymphoedema.

An Invitation

My name is Claire Doole. I am doing research on how people manage their lymphoedema. This study is looking for people to interview aged over 20 years who have had lymph node surgery, or investigation to confirm moderate or severe lower limb (leg) lymphoedema that was diagnosed at least 3 years ago by a lymphoedema therapist or a specialist. Participation in an individual interview is voluntary (your choice) and you can withdraw if you change your mind.

You are unable to participate if you are on any more than two different prescribed drugs or have other conditions like heart or kidney problems or secondary cancer.

The research is part of my study for a degree at AUT University. I am a member of the Lymphoedema Support Network, however all information is kept confidential and I would not raise any issues with you if we met at a meeting. Whether you choose to participate or not will neither advantage nor disadvantage you in any way.

At a later date I may want to talk with health professionals who care for people living with lymphoedema.

What is the purpose of this research?

The purpose of the research is to better understand the issues for people living with lymphoedema so that health professionals can provide better care. The research will be written up as a thesis and submitted into a library. As a result of completing the thesis I would get a degree of Doctor of Health Science. The information may also be used in some articles published in academic journals or presented at health conferences. You would not be identifiable.

How was I identified and why am I being invited to participate in this research?

You have received this information sheet either because your lymphoedema therapist has thought that you might be interested in taking part in the study or you have responded to

the various advertisements I have placed in clinics or in the Lymphoedema Support Network newsletter.

How do I agree to participate in this research?

Your participation is your choice. Whether or not you participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

At the interview you will be asked to sign a Consent form.

If you are interested in taking part in this study, please contact me either by phone or email.

My contact details are at the end of this sheet.

What will happen in this research?

If you become part of this study, interview with individuals will last about an hour either face to face or on the telephone: whatever is most suitable for you. You can choose the time and place for the interview. I will post you a written copy (transcript) of the interview so you can check it and make changes if needed. You can choose to give feedback on the themes. I am a nurse and I trained in lymphoedema in 2004 and have worked as a lymphoedema educator. I will ask you to talk about how you manage your lymphoedema. The research is expected to identify themes about how people live with lymphoedema. It would be useful if I could check those themes with some participants. I will ask all participants if I can contact you again in the next year to check my findings. Responding to my request is voluntary (your choice). I will only follow up with my request once.

What are the discomforts and risks?

The research involves talking to me about your lymphoedema. Some people may find talking about their lymphoedema unsettling as having lymphoedema is generally seen as unpleasant. However, some people may also get some relief from talking about managing their lymphoedema.

How will these discomforts and risks be alleviated?

AUT Health Counselling and Wellbeing can offer three free sessions of confidential counselling support for participants in an AUT research project who live in Auckland. These sessions are only available for issues that have arisen directly because of participating in the research and are not for other general counselling needs. To access these services, you will need to:

Phone 09) 921 9992. Clinics are available at AUT City Campus North Shore campus and South Campus.

Let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing>.

What are the benefits?

The benefits to you relate to contributing to understanding lymphoedema which may help therapists treating this condition in the future. There are no real benefits to you apart from the opportunity to sit with me and talk about your lymphoedema. As a result of the research I would gain experience in understanding lymphoedema and submitting the thesis is expected to lead to a qualification of Doctor of Health Science.

How will my privacy be protected?

All information about you will use a pseudonym, and in any articles or presentations no specific information will be used that could identify you.

What are the costs of participating in this research?

I expect to be able to come to your home or somewhere near you or to have the conversation on the telephone (I would pay any charges). However, there is the cost of your time and as a contribution to your travel costs a voucher is offered. Those interviewed individually will get a \$40 petrol voucher or other voucher for their time and costs.

What opportunity do I have to consider this invitation?

You have two weeks to get back to me about the research. If I haven't heard from you, I will contact you only once to ask if you are considering the option or not. You may decide not to be interviewed and I won't be offended.

Will I receive feedback on the results of this research?

You can get a summary of the research findings. I can email or post this to you after I have sent in the thesis.

Where can I go if I have cultural concerns or questions?

Tēnā koutou, if you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.

If you have any questions or cultural concerns about the study you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868920 ext 3204.

What do I do if I have concerns about this research?

Any concerns about the nature of this project should be notified in the first instance to the Project Supervisor, Associate Professor Deborah Payne, her email is *dpayne@aut.ac.nz* Her phone number is 09 9219999 ext 7112.

Concerns about the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz* 921 9999 ext 6038.

Who do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference.

You are also able to contact the research team as follows:

Researcher Contact Details:

Claire Doole, my email is *cdoole@aut.ac.nz* and my phone number is 09 921 9999 ext 7135.

Project Supervisor Contact Details:

Associate Professor Deborah Payne, her email is *dpayne@aut.ac.nz* Her phone number is 09 9219999 ext 7112.

Dr David Healee, his email is *david.healee@aut.ac.nz* His phone number is 09 921 9999 ext 7642

Approved by the Auckland University of Technology Ethics Committee on 22/11/2017,
AUTEC Reference number 17/350.

Mail code is D-88. The courier address is 46 Wakefield Street, Auckland 1010.

Appendix C Consent Form - Interview

23 November 2017

Project title: Living with moderate to severe lower limb lymphoedema.

Project Supervisor: Associate Professor Deb Payne

Researcher: Claire Doole

- I have read and understood the information provided about this research project in the Information Sheet dated 23 November 2017.
- I have had an opportunity to ask questions and to have them answered.
- I understand the interview will be audio-taped and transcribed and notes will be taken during the interviews.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I have discussed what I would like to have happen if I meet the researcher in the future.
- I wish to receive a summary of the research findings (please tick one): Yes No
- I agree to be contacted again in the next year to check the findings (please tick one): Yes No

Participant's signature:.....

Participant's name:.....

Participant's contact details if you want a summary of the research

.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 22/11/2017 AUTEK

Reference number 17/350.

Note: The Participant should retain a copy of this form.

Appendix D Participants' Characteristics

Characteristics of participants at baseline This is being reformatted by Dr Jen Rankin of Words and Pictures

	No.		No.		No.		No.		No.		No.	
Women	8											
Men	4											
Ethnicity	NZE or European	11										
	Māori	1										
Age	30-39	1	40-49	1	50-59	1	60-65	6	66-75	2		
Cause of lymphoedema	Cancer (5 different types)	8	Primary	4								
Uni or bilateral	Unilateral	7	Bilateral	5								
Onset trigger	Onset within a year of surgery	5	Long haul flights	2	Stress	2	Heat	1	Injury	1	Unknown	1
Garments	Off the shelf	6	Custom made	4	Combination off shelf and custom made	1	Medical taping only	1	Long haul flights only	1		
Years since diagnosis	22 months to 5 years	4	6-10 years	5	11-20 years	1	21-31 years	2				
Cellulitis	Yes including 3 with septicaemia	5	Nil cellulitis (all <7 yrs)	4	Unspecified	2						
Delay in receiving care	Inadequate care	7	Not specified	4	Straight to care	1						
Payment	Have paid for private LO therapist	10	Receiving both public and paying	4	Public only	3						
Medications	Nil medications or topical inhaler	10	One medication	1	Multiple meds	1						
Other conditions	Nil	9	Respiratory	2	Multimorbidity	1						
Garment funding	DHB subsidy	8	Not funded (2 out of 3 are primary LO)	3	ACC	1						
Employment	Full time	6	Not working	3	Part-time	1	Retired	2				
Recruited via	Lymphoedema therapist	6	LO Support Network	4	Snowball	1	Facebook	1				

Appendix E Locality Agreement ADHB

Auckland DHB

Research Office
 Level 14, Support Bldg
 Auckland City Hospital
 B 92024, Grafton, Auckland
 Phone: 64 9 307 4949 Extn. 23854
 Fax: 64 9 307 8913
 Email: mwoodnorth@adhb.govt.nz Website:
<http://www.adhb.health.nz/healthprofessionals/research/>

27th February 2018

Institutional Approval

Claire Doole
 School of Clinical Sciences
 North Shore
 Campus AUT

Dear Claire,

Re: Research project A+7927 (AUT 17/350) How do people live with a diagnosis of lymphoedema?

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project. The term of this approval is one calendar year from the date of this letter. If you wish to extend the approval after that date, contact the Research Office.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions, please do not hesitate to contact the Research Office.

Yours sincerely



On behalf of the ADHB Research Review Committee Dr Mary-Anne Woodnorth Manager,
 Research Office ADHB

c.c. Sue Callender, Beth Rogers /continued next page

POST-APPROVAL REPORTING

Your Ethical and Institutional approval is dependent on the Research Office (RO) having up-to-date information and documentation for your research and being kept informed of any changes to your study. It is **your responsibility** to ensure you have kept Ethics and the RO up to date and have the appropriate approvals. This applies even if ADHB is not the main site for the study.

Please note, when missing or updated document reminders are sent, if the RO receives no response from you after **2 reminders** it will be assumed that your research has been completed and we will notify the relevant Department CD, the RRC and Ethics Committee that your **Locality Assessment Approval has been withdrawn**. This will not be reinstated until all issues have been resolved.

All documents / communications must be referenced with the **ADHB project number**.

TOPIC	REQUIREMENT	ACTION
ETHICS		
HDEC Annual Progress Report	Use HDEC PAF form, complete and submit <u>BEFORE</u> anniversary date of original HDEC approval	<ul style="list-style-type: none"> ○ send copy of HDEC approved annual progress report letter to RO when received
Major amendments, design, CI, safety, temporary stops etc. (see HDEC SOP section 11 for definitions)	Write letter detailing changes, mark up changes in relevant documents. Use HDEC PAF form, complete and submit and obtain HDEC approval	<ul style="list-style-type: none"> ○ copy letter, changes to RO ○ send fully signed ADHB amendment form to RO ○ send copy of HDEC approval letter to RO when received
Financial amendments, including changes in study visits, tests, funding etc.	Liaise with research accountant and adjust budget accordingly. If financial amendment is related to a major amendment also follow requirements for a major amendment.	<ul style="list-style-type: none"> ○ Send revised budget using template to RO ○ send fully signed ADHB amendment form to RO
Minor amendments	Amendments that are minor in nature are reported to HDEC as part of the annual progress report. Only report minor amendments to the RO if proposed amendment will a) impact ADHB resources, e.g. staffing, facilities or consumables, b) potentially impact access to ADHB services for patients NOT in the study, c) require review of revised legal documents, d) involve ADHB service areas that have not previously authorised the research.	<ul style="list-style-type: none"> ○ If required send fully signed ADHB amendment form to RO

Serious study related adverse event reporting	If an ADHB patient enrolled in a research study is seriously harmed as a result of their participation in the study the SAE must be reported to the RO	<ul style="list-style-type: none"> ○ send the detailed, written SAE report to RO
High risk studies	Studies deemed by RRC to be of high risk must notify ADHB patient enrolments and SAEs to RRC	<ul style="list-style-type: none"> ○ notify RO when new ADHB patients are enrolled in the study ○ immediately notify RO of any SAEs for ADHB patients ○ send the detailed, written SAE report to RO when available
Notification of conclusion of study	Complete HDEC PAF form and submit	<ul style="list-style-type: none"> ○ Send HDEC approved notification of conclusion of study letter to RO ○ Inform RO if all finance elements also complete
Final Report	Complete HDEC PAF form, upload final report and submit	<ul style="list-style-type: none"> ○ Send final report and HDEC approved final report letter to RO ○ Inform RO when all finance elements also complete

LEGAL		
Contracts, Indemnities, Agreements, insurance certificates, amendments both financial and nonfinancial of above	All legal documents must be reviewed and approved before signing. Revise budget where relevant	<ul style="list-style-type: none"> ○ Send all legal documents to RO ○ Send revised budget using template to RO where relevant
FINANCIAL		
Budget maintenance	It is recommended that you review and update budgets at least quarterly	<ul style="list-style-type: none"> ○ Liaise with accountant and forward update to RO

All documents must be referenced with the ADHB project number and can be sent via email to:

ResearchOffice@adhb.govt.nz. All paper copies can be faxed to: 09 307 8913 or by post to: Research Office, Level 14, Support Building, Auckland City Hospital, Private Bag 92024, Auckland, New Zealand.

For further information go to <http://www.adhb.health.nz/health-professionals/research/>

Appendix F Locality Agreement WDHB

From: Research & Knowledge Centre
To: [Claire Doole](#)
Cc: [Gloria Paterson](#)
Subject: RM13938 Locality Authorisation
Date: 23 March 2018 4:50:08 PM

Dear Claire

The Research & Knowledge Centre has now received the relevant approvals for the following study:

Title: Lymphoedema - life after diagnosis

Registration #: RM13938

This study now has Waitemata DHB Locality Authorisation. All amendments to your study must be submitted to the Research & Knowledge Centre for review.

Note that all research, audit and related activity must meet ethical standards in relation to the safe storage, retention and destruction of research data.

At the conclusion of this study a copy of any outputs, reports or publications should be forwarded to research@waitematadhb.govt.nz Good luck with your study.

Regards

Research & Knowledge Centre

Level 1, Kahui Manaaki (Building 5)

North Shore Hospital

Campus Waitemata DHB

research@waitematadhb.govt.nz

ph. (09) 486 8920 ext 43740

Cc Gloria Paterson

Appendix G Locality Agreement CMDHB

From: Indunil Senarath (CMDHB)
To: [Claire Doole](#)
Cc: [Peggy Williams \(CMDHB\)](#)
Subject: Study application # 635 Finalised at Research Office
Date: 6 April 2018 4:07:22 PM

Dear Claire & Peggy

Please be informed that your study titled "Living with moderate to severe lower limb lymphoedema" has been finalised at the research office.

Generally, the CMH internal facilitator, Peggy should receive an automated email link of the approval. Unfortunately, the system does not send emails to any address that is not within the CMH network.

However, there have been some on- going network issues this week. So, Peggy you may or may not have received the automated link. Under the circumstances, I would like to confirm via email that the research team can begin this study.

All the Best

Indu

Indunil Senarath

Research Coordinator

Ko Awatea Research and Evaluation Office

DDI: +64 276 55089 | T: +64 9 276 0044 | Ext: 55089

This e-mail message and any accompanying attachments may contain information that is confidential and subject to legal privilege. If you are not the intended recipient, do not read, use, disseminate, distribute or copy this message or attachments. If you have received this message in error, please notify the sender immediately and delete this message.

Visit www.kiwihealthjobs.com, New Zealand's largest employment site for jobs in the public health sector. 100% owned and supported nationally by the District Health Boards (DHBs) and the New Zealand Blood Service (NZBS).

If you are looking for medical jobs in New Zealand, your career in health starts with us.

Appendix H Approval Māori Involvement WDHB and ADHB



He Kamaka Waiora

Waitematā and Auckland DHB

Level 2, 15 Shea Terrace,

Auckland 0740,

New Zealand

Private Bag: 93-503

27/02/2018

Claire Doole
Nursing lecturer
School of Clinical Sciences
North Shore Campus
Akoranga Drive
Northcote

Re: How do people live with a diagnosis of lymphoedema?

Thank you for providing the following documents the:

- RRC application
- Study protocol
- PIS/CF
- HDEC application

This is a regional study that explores how people live with a diagnosis of lymphoedema. There will be between 12-20 participants recruited from within the Auckland DHB region. It is estimated that the number of Māori participating in the study may be approximately 2-4.

Māori responsiveness:

The researchers explain that Lymphoedema is a complex area of study that is currently under-researched. While the study is too small to support sub-analysis by ethnicity, new information may be produced that sheds light on how the disease impacts on quality of life and patients experiences of the care pathway. The use of grounded theory will support further investigation of findings that appear to be significant in terms of Māori patient experiences.

The research includes the gifting of koha to participants to thank them for their participation.

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee
the study has been approved.

Heoi ano

[Kim Southey](#)

Kaupapa Māori Analyst

Waitematā and Auckland DHB

Level 2, 15 Shea Terrace, Auckland 0740,
New Zealand

Private Bag: 93-503 p:

+64 9 486 8920

email kim.southey@waitematadhb.govt.nz

Appendix I Interview Guide

Research question: How do people live with moderate to severe lower limb lymphoedema?

KOHA, recorder x 2
 Read participant info sheet
 Sign consent

Check inclusion exclusion

- people aged over 20 years.
- who have had lymph node surgery, or investigation to confirm moderate or severe leg lymphoedema?
- diagnosed at least three years ago by a lymphoedema therapist or a specialist. (Then revised)
- Exclusion: No more than two different prescribed drugs. (Revised)
- Exclusion: if have other conditions like heart or kidney problems or your cancer has recurred. (Revised).

No need to answer any question, can withdraw up to time of analysis when data is amalgamated.

Don't use your name, do you have a name you'd like to be known by for the research.

Greeting

What said in the room stays in the room.

Demographics and background

Age range and

Have you had surgery what sort and when?

Do you recall when you were diagnosed? Who?

Are one or both legs affected?

Are you on any medications, if so may I know what please?

Do you have any other medical conditions- just because sometimes other conditions make a difference to the swelling?

Which ethnic group do you belong to?
 Mark the space or spaces that apply to you.

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

other (such as DUTCH, JAPANESE, TOKELAUAN). Please state:

Initial open ended questions

- 1) Can you please tell me about living with lymphoedema?
- 2) When did you first notice the swelling?
- 3) Tell me about what happened or how you found out you had lymphoedema.
- 4) What was that like? What did you think, feel or experience then? Did anyone else influence you at that time? Could you tell me about how you think he / she / they influenced you?
- 5) Do you remember what was going on in your life then?
- 6) Can you tell me about your thoughts or feelings when you first learned you had lymphoedema.
- 7) Clarify any unknowns such as: You've talked about so & so how were they involved? Was anyone else involved?

Intermediate questions – Participants' concerns and experiences.

- 1) How would you describe the person you were before getting lymphoedema?
- 2) Could you tell me about the early days of developing lymphoedema such as what you thought or felt?
- 3) Have your thoughts and feelings about lymphoedema changed since diagnosis?
- 4) What do you think has influenced you or the way you approach lymphoedema as time has gone on?
- 5) Can you tell me about a typical day – consider varying times. And a typical day when the swelling is better/ worse?
- 6) How do you think you've changed and how would you describe the person you are now? If so, what do you think led to this change?
- 7) Do you think lymphoedema has changed your view of life?

Goal- reveal the narrative discussion.

Start with general, then basic social process what is happening here (Charmaz & Belgrave 2014).

Ending questions

- 1) Could you tell me what you think are the most important things you learned through having lymphoedema?
- 2) Have there been any changes in you as a person since lymphoedema? Tell me about what you discovered or developed through lymphoedema. What do you most value about how things are now? What do others most value about you?
- 3) After reflecting on your experiences with lymphoedema is there something else you'd like to add?

Is there anything you'd like to ask me?

Appreciation

Thank you, offer koha, explain what will happen to their story and information, reassure about security of data and confidentiality.

Appendix J Example of Coding Early Analysis

16 March 2019				
ADJUSTING Accommodating Adjusting to new norm is a process Being adaptable Staying on track Being pragmatic Changing my thinking Adapting constantly (even years later) Changing with fluctuations	Getting to diagnosis Early days TIPPING THE BALANCE Doing normal things upset lymphoedema Doing little things improves lymphoedema Fluctuating Episodic grief	DISENFRANCHISED BY MEDICINE Health professional disinterest / communication/ navigating system/ poorly understood Treatment/ treatment response / 4 year delay (ineffective) BEING LET DOWN Getting contrary advice about lymphoedema	BEING UNDERSTOOD Meeting others/ someone who knows/ other consumer OR therapist. Sound advice GP understands IT IS WHAT IT IS Minimising symptoms Sucking it up Having to Not plumbing the depths	Support Detailing swelling / swelling had 'life of its own' / adiposing. Symptoms/ intrusive/ improving Taking on impositions Trial and error Travelling/ new environment
INTERRUPTING LIFE Affecting my sleep Changing my work/ retirement/ how I do things Faffing (stockings sea sand) Changing what I wear Clothing/ asymmetry Clothing / loosing choice (repeat) Building critical knowledge/ r/ship with being more vigilant Knowing the risks BEING VIGILANT Attending (attention) to details/ diligent/ conscientious/ being specific/ Avoiding Balancing / getting the fit right/ Being attuned Being systematic (pt & therapist) Taking control / doing what I can for myself Thinking ahead/ Planning Tracking my numbers	Exercising proactively Family support, BEING ON THE OUTER Feeling labelled Feeling on the outer / Being different Isolation lack support/ feeling alone with the enormity Being different Embarrassed/ Being asked/ Standing out/ Getting comments (when it looks better) BEING AFFRONTED Meeting rudeness Doubting myself / self-esteem Feeling lost Losing control/ travelling FINDING ME Focussing on healing/ directing my own healing Self focussing Claiming time for self FREAKING OUT/ Distress/ alarm Being cross/ pissed off Being disappointed / dismayed	Lifelong / treating symptoms/ incurable Injuring REBOOTING Judging myself Wasting time <i>Needing to press reset</i> LOSING ME Losing agility Losing identity as healthy Slows me down/ getting in the way of life Esteem/ clothing/ asymmetry Clothing / loosing choice Consuming mental space Sacrificing spontaneity Losing freedom LIMITING Limiting restricting Changing the normal It's stopping me Changing how I am Reduced emotional tolerance Lymphoedema another blow Reminders Concealing/ pretending/ wanting to feel normal/ fitting in TACKLING IT	BODY BOUND Not getting comfortable /not being comfortable BODY DISTRESS Pain/ ache/ aching round groin/ night/ hard to get comfortable Leaking lymph BEING IN THE DARK Not knowing Not realising / hindsight Not being told at time of surgery Pressing on Serendipity Spreading the word/ Helping others Wondering how others less resourced cope (is this a sub set of being grateful?) Feeling relieved and grateful Feeling grateful/ something good has come of it Feeling grateful to therapists Holding hope Spurring me on GETTING REAL HELP Lymphoedema therapists/ being referred/ getting help Recovering lost abilities	Trying new things/ Trial and error Turning point VIVID REMEMBERING Life threatening sepsis Triggers/ exacerbation/ Delays & timings Early days Wait and see (surgery options) Weight PUTTING IT TOGETHER Working it out for myself /Intuition /Putting it together Relying on self/ putting it together Researching/ applying to self Understanding implications & complications/ understanding pathophys / putting it together Relying on self/ putting it together Finding out for myself

<p>Noticing Juggling prioritising Heightening my carefulness Monitoring by therapist & self / foresight Having treatment regime Getting the fit right Getting the payoff Doing what I need to do to stay well. CONFORMING Conforming/ Thinking about consequences Sacrificing</p>	<p>Being pissed off/ angry / rage Emotional distress /dreading Internet/ freaking out Intrusiveness/ anger Hearing worst case scenarios TAKING CARE Being cautious Avoiding Rejecting risk Assessing risks Compression Carrying a box of bits Shoe horn Gloves in the car Using glue REBELLING Rebelling against advice</p>	<p>Being willing receptive and changing Gaining control/ what I do counts Gaining understanding / Learning Making choices Taking advice Taking charge WEIGHING UP Weighing up the faff & the pleasure Rationalising Prioritising LO Changing the normal Missing out led to rebellion Not being able to swim contributed to rebellion Paying the price Weighing benefits Deteriorating)/ Helix/ Infections</p>	<p>Noticing big improvement Therapists cautioning & informing Therapists making a difference Getting advice Following advice (r/ship with conscientiousness) Being realistic Understanding Being informed (understanding context). Incentivised by surgery, trying harder MISSING OUT Weighing up the faff & the pleasure Compromising Juggling Losing out Using pool over beach</p>	<p>Learning to trust myself or trusting myself / relying Internet/ finding out Gleaning information Managing my own care/ navigating self Gender Body comfort Managing when I'm older HOLDING BACK politeness with own reaction Family not commenting until it looks better BEING STUCK Being without what I need Stuck In public toilets Airplanes Beach Using humour Damp feet SIGNIFICANT EPISODES TURNING POINTS Cellulitis storying/ Recounting symptoms Surgery Protecting the precious stocking</p>
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Appendix K Transcript Template

Reflections	Transcript	Coding

Appendix L Example of Coding Context for “Finding Solace”

24/07/2019		
Categories & Subcategories	Properties: AND Dimensions:	
<p>LOSING ME</p>	<p>Bearing symptoms</p> <ul style="list-style-type: none"> - Affecting my sleep - Not getting comfortable - Leaking lymph - Lacking knee bend - Aching <p>Holding me back</p> <ul style="list-style-type: none"> - Slowing me down - Stopping me 	<p>Becoming dependent</p> <p>Changing my life plan</p> <ul style="list-style-type: none"> - Life changing - Disrupting my work/retirement/ how I do things/ <p>Demanding of me</p> <ul style="list-style-type: none"> - Consuming time - Consuming mental space - Timetabling the demands - Resenting the demands <p>Missing out on what I love - Sacrificing</p> <ul style="list-style-type: none"> - Limiting activities - Missing out on beaches, weddings travel - Juggling swimming and stockings - Faffing (stockings, sea & sand) - Losing choice (choosing pools cos it's easier) - Losing freedom - Sacrificing spontaneity <p>Missing out on what I love - Rebellng</p> <ul style="list-style-type: none"> - Ignoring symptoms - Trying (wanting) to be normal - Not wanting to be held back - Missing out led to rebelling - Not being able to swim contributed to rebelling - Taking control <p>Prioritising the here and now</p> <ul style="list-style-type: none"> - Feeling impatient - Feeling defiant <p>Understanding only in hindsight</p> <ul style="list-style-type: none"> - Not realising (damage) <p>Reassuring myself (it's OK to not wear it)</p>
	<p>Interrupting my life</p> <p>Responding to a new body</p> <p>Being body bound body</p> <p>Changing the normal</p> <p>Accommodating a larger leg</p> <p>Disrupting my life – Changing identity</p> <p>Losing control – losing hope</p> <p>Note: Rebelling is a subset of missing out on what I love. One side is sacrifice – the other side is rebelling</p> <p>Is rebelling a form of taking control?</p>	<p>Modifying clothing</p> <ul style="list-style-type: none"> - Customising my wardrobe - Modifying clothing/ asymmetry - Things not fitting - Losing choice - Choosing comfort - Choosing loose fitting - Compromising for appearances - Appreciating normalcy (Finding style shoes, Being relieved fitting my clothes) - Struggling to look smart <p>Changing identity</p> <p>Changing my physique</p> <ul style="list-style-type: none"> - Muscling up (to carry the weight) <p>Affecting my self esteem</p> <ul style="list-style-type: none"> - Embarrassed in togs. - Feeling part of me is ugly <p>Losing control</p> <ul style="list-style-type: none"> - Making decisions about travelling - PLUS WAY MORE... <p>Losing identity as healthy</p> <ul style="list-style-type: none"> - Losing agility (nimble)/ mobility/strength (falls) - Losing joy <p>Doubting myself (do they fit)</p> <p>Feeling lost</p>

<p>Freaking out Losing control</p>	<p>Feeling desperate – Being annoyed/angry/rage</p> <ul style="list-style-type: none"> - Emotional distress /dreading - Being disappointed Being distressed - Being cross /pissed off - Being alarmed - Being dismayed 	<p>Being triggered</p> <ul style="list-style-type: none"> - Internet/ freaking out - Hearing worst case scenarios Intrusiveness/ anger
<p>CONTEXT Being in a support desert This is LOSING ME because this part is about not being able to use my usual coping mechanisms.</p>	<p>Being in the dark</p> <ul style="list-style-type: none"> - Not knowing /Not twigging /Not realising - Being a newcomer (not understanding implications) - Venturing into the unknown - Not being told at time of surgery - Info subsumed by cancer 	<p>Finding inadequate help [My condition is ignored]</p> <ul style="list-style-type: none"> - Health professionals turning a deaf ear - Getting contrary (unhelpful) advice about lymphoedema - Being let down - Leaving it to me [GP asking me for guidance] - Losing my way (hypothesis)
<p>CONTEXT Being different Being on the outer Standing out Being othered</p>	<p>Concealing / Pretending [Taking control so as not to be 'othered']</p> <ul style="list-style-type: none"> - Maintaining my image - Avoiding being confronted - Wanting to feel normal - Fitting in <p>Choosing to reveal</p> <ul style="list-style-type: none"> - As an act of defiance (check data) - When I'm strong enough 	<p>Being singled out (when I can't conceal or are not fussed or feeling defiant, - ie just try and take me on.</p> <ul style="list-style-type: none"> - Being affronted - Meeting rudeness - Feeling shy and embarrassed - Feeling labelled - Being cut to the quick - Retorting (deciding whether to make) Making a scene - Responding 'matter-of-factly'
<p>TURNING POINT</p>	<p>Being understood (category) Meeting others (with lymphoedema or therapist)</p>	<p>Getting to diagnosis Specialists understand</p>
<p>Getting real help Finding hope</p>	<p>Finding a lymphoedema therapist</p> <ul style="list-style-type: none"> - Getting sound advice - Being monitored/ measured - Therapists cautioning & informing - Feeling relief from the symptoms - Realising I have some control 	<p>Recovering lost abilities (surgery)</p> <ul style="list-style-type: none"> - Treatment working <p>Travelling for treatment Being supported & guided (by other health prof who understand) Finding hope</p>
<p>Bottoming out</p>	<p>Deteriorating Tiring of arduousness</p>	<p>Realising the cause of recurring cellulitis Reflecting on the 'why' Realising the impact of aging</p>
<p>GETTING THROUGH</p>	<p>Understanding my condition (early phase)</p> <ul style="list-style-type: none"> - Gleaning information - Finding the internet useful and scary - Understanding implications & complications 	<p>SKILLS – Tackling it Developing self-management (early phase)</p> <ul style="list-style-type: none"> - Learning to notice - Managing risks

<p>Building critical knowledge Putting it together</p>	<ul style="list-style-type: none"> - Understanding risks - Finding out for myself - Analysing and reflecting - Realising small things matter - Taking a long-term view - Being realistic (won't cure) 	<ul style="list-style-type: none"> - Making independent decisions - Planning ahead - Becoming accomplished (at what)
<p>Tackling it (Building critical skills)</p>	<p>Understanding my condition (later phase)</p> <ul style="list-style-type: none"> - Understanding physiological rationale - Realising the idiosyncrasies of me <p>Accepting regulation (process)</p> <ul style="list-style-type: none"> - Being primed by therapist - Being willing and receptive - Realising the consequences of neglect - Being spurred on by symptoms (caution related to Andy & his surgery). - Gaining some control/ what I do counts (mentalising the improvement) - Understanding my best interests - Becoming invested - Tackling it together - Taking on impositions 	<ul style="list-style-type: none"> - Becoming vigilant (enacting little things matter) Clothing / losing choice / r/ship <p>Managing my own care/ navigating self (later)</p> <ul style="list-style-type: none"> - Applying the physiological rationale - Being my own final decisionmaker [Learning to trust my judgement Relying on self] - Making choices - Managing symptoms - Moderating activity (depending on how managing)
<p>Building relationship with therapist</p>	<p>Trusting the therapist (process)</p> <ul style="list-style-type: none"> - Getting symptom relief - Becoming informed - Gaining some control - Fostering of hope - Enlightening (one visit) - Being affirmed (extra fluid) - Becoming motivated 	<p>Therapist preserving autonomy</p> <p>Believing in my therapist</p> <ul style="list-style-type: none"> - Being in the hands of an expert - Knowing my therapist is the best. <p>Relying on my therapist (an element of desperation)</p> <ul style="list-style-type: none"> - Preserving the relationship - Maximising what's available - Tip toeing in the politics of public and private care.
<p>Engaging with my care Turning the corner</p>	<p>Scaffolding into managing myself</p> <ul style="list-style-type: none"> - Partnering (both therapist & client) - Having a real relationship - Finding solace in therapist - Anticipating (good results) - Following advice - Developing intimacy/ Crossing boundaries 	<p>Therapist passionate (about LO) meets desperate client (assumption)</p>

Appendix M Analysis Continues. 24 August 2022

Core category: <i>Disrupting, Managing disruption, Regaining control</i>						
<i>Category 2</i>	<i>Subcategory 3</i>	<i>Property level 4 heading</i>	<i>Dimension social physical & emotional (5)</i>	<i>Strategy 3</i>	<i>Context</i>	<i>Time</i>
Being led by the body Outcome of all changes: Loss Grief,	Fracturing identity Losing (previous) normality. Affecting self-concept, including body image, self-esteem, and role functioning. (Loss)	1) Disrupting everyday life	1. Bearing symptoms (Pain, heaviness, tightness, and swelling, pressure, tension, heat)	← ←	1. Being in the dark (about my condition)	Sudden onset. LO the theft of time
			2. Finding nothing fits (Losing choice, limiting shoes, struggling to look smart, femininity)	1-Changing wardrobe ← ←	4. Gender	Self-focus, lymphoedema looms large
			3. Feeling othered Revealing/ Concealing. Standing out Being othered, including by self. Feelings, responses, Self-acceptance leads to being able to respond Includes Feeling part of me is ugly	3-Self -sacrificing versus rebelling (being forced to choose, Sophie's choice) Doing enough	2. Being in a support desert –abandoned by medicine	Frustration & time. Waste of time. (taping) Consuming time (as are all/most of these strategies & dimensions)
			4. check if this is 3. Limiting mobility (Limiting activity, recreational & domestic)		3. Feeling side-lined (breast dominates or cancer dominates for those with primary LO) Reinforces support desert	
		Disrupting life course life chances	i) Disrupting livelihood, (finances, employment), ii) housing, iii) vehicle ownership iv) international travel,	2.-Changing jobs accommodation,	5. Class	Time consuming, slows my progress
	Burdening (Loss)	Taking more care is this having to?	1-Self-care is demanding - Consuming cognitive labour Having to - Focussing on self, no heading -self-care dependency		6. Retired vs working	Retired Demands of self-care Takes time & energy
			2-Wearing compression -arduous			
			1-Managing heat This is really managing risk	4-Paying the price (rebellion)		Demands of self-care Takes time & energy Steals time
			2-Managing cellulitis			

Core category: <i>Disrupting, Managing disruption, Regaining control</i>						
<i>Category 2</i>	<i>Subcategory 3</i>	<i>Property level 4 heading</i>	<i>Dimension social physical & emotional (5)</i>	<i>Strategy 3</i>	<i>Context</i>	<i>Time</i>
				3-Planning & strategising		Loss spontaneity
						Slows me down. time. Juggling time
		Fearing for the future	1- Bearing the cost			Doing more for less Cognitive labour
			2 – Coping as an older adult	Domestic life focus, narrowed world.		Being embroiled in domestic world

Appendix N Subcategories, Properties, Dimensions, Context, and Strategies

The first category is being led by the body, reflecting the dominance of physical changes initiated by the onset of swelling. There are two subcategories of being led by the body: losing previous normality and burdening. The first subcategory losing previous normality has two properties which are disrupting everyday life and disrupting life course. Disrupting everyday life has four dimensions: 1) bearing symptoms, 2) finding nothing fits, 3) feeling othered, and 4) limiting mobility. The consequence of such rapid loss of normality within a few months impacted self-esteem and self-concept. The second property of losing previous normality is disrupting life course. Disrupting life course has two dimensions: 1) disrupting livelihood, and 2) disrupting social connection.

The second subcategory of being led by the body is burdening with two properties which are self-care is demanding and fearing for the future. Self-care is demanding has two dimensions: 1) managing disruption, and 2) cognitive labour. The second property of burdening is fearing the future has two dimensions: 1) bearing the cost, and 2) coping as an older adult.

There is one strategy associated with being led by the body: self-sacrificing versus rebelling. In self-sacrificing participants gave up wants and desires to protect their lymphoedema, whereas in rebelling participants chose to risk lymphoedema exacerbation by continuing living as they had prior to lymphoedema. There are six social contexts associated with being led by the body: 1) being in a support desert, 2) being in the dark about my condition, 3) access to public funded versus private funding, 4) gender, 5) social class, and 6) retired versus working.

The second category of Reconfiguring Life is being led by feelings, which explains that the dramatic physical changes brought on by swelling lead to participants to experience a response associated with feelings. There are two subcategories of being led by feelings: forced into action to a turning point and feeling out of control leading to a turning point. The first subcategory of forced into action to a turning point has two properties: getting help and relying on self. Getting help has two dimensions: 1) meeting non-judgement, and 2) feeling spurred on by a reduction in symptoms. The second property of forced into action to a turning point; relying on self, has three dimensions: 1) becoming discouraged, 2) getting on okay, and 3) knowing I could do more.

There second subcategory of being led by feelings is feeling out of control leading to a turning point with two properties which are pursuing solutions and feeling hopeful. Pursuing solutions has two dimensions: 1) resourcefulness, and 2) receiving help. Feeling hopeful has two dimensions: 1) sharing the burden, and 2) feeling spurred on by symptom improvement.

There are two strategies associated with being led by feelings: 1) avoiding, and 2) doing the minimum. There are five social contexts associated with being led by feelings: 1) meeting someone who understood; 2) support from friends and family; 3) feeling side-lined by the dominance of cancer, most particularly breast cancer related lymphoedema; 4) the demands of life roles: retired/ working/ mothering; and 5) the availability of treatment services.

The third category of Reconfiguring Life is leading with the mind, which explains the ways participants reconfigured their new identity. There are two subcategories of leading with the mind: 1) being activated by the therapist, and 2) reconfiguring a new normal. The first subcategory, being activated by the therapist has two properties: 1) being in a safe haven, and 2) tailoring care. Being in a safe haven has three dimensions: 1) valuing the relationship, 2) getting ongoing help, and 3) becoming amenable. The second property of being activated by the therapist is tailoring care, which has two dimensions: 1) using trial and error, and 2) getting symptom improvement.

There second subcategory of leading with the mind is reconfiguring a new normal with three properties: 1) through what I learn, 2) through how I come to be, and 3) through what I do. Through what I learn has three dimensions: 1) gleaning information, 2) understanding the lymphatic system, and 3) reflecting and analysing. The second property of reconfiguring a new normal is through how I come to be which has two dimensions: 1) acquiescing and accepting, and 2) being pragmatic. The third property of reconfiguring a new normal is through what I do which has four dimensions: 1) adopting self-care, 2) embedding a routine, 3) regaining control, and 4) rebuilding a new normal.

There are nine strategies associated with being led by the body: 1) becoming accustomed, 2) noticing and responding, 3) reflecting and analysing, 4) self-sacrificing and rebelling, 5) slackening off, 6) managing risks, 7) becoming accomplished, 8) becoming discerning, and 9) being vigilant. There are four social contexts in leading with the mind: 1) availability of lymphoedema therapist; 2) the demands of life role (being a mother, working

versus retiring); 3) access to resources such as publicly funded services or private lymphoedema therapist; and 4) support from friends and family.

Time as a social construct is also experienced differently across the whole journey from being led by the body, through being led by feelings and leading with the mind. For example, during being led by the body lymphoedema looms large, consumes time, slowed participants down, whereby there was an experience of doing more to achieve less. During being led by feelings the turning point was often a moment in time of meeting someone. While during leading with the mind newfound control over the lymphoedema gave participants a sense of regaining life and thereby time.