Osteopathic manual therapy as an adjunct treatment for self-management of breast cancer related lymphoedema: The lived experience of lymphoedema and osteopathic treatment

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Preface

This study explores women’s lived experience of breast cancer related lymphoedema and osteopathic manual therapy (OMT) as a form of treatment. Women who were part of a study investigating OMT to manage lymphoedema were interviewed or participated in a focus group. Their responses regarding their experience were analysed in order to gain further knowledge of these phenomena.

This thesis is presented in four chapters. Chapter one introduces the study. Chapter two is a literature review to orientate the reader to relevant literature on the topic of lymphoedema and OMT. Chapter three describes the phenomenological methodology used and the application of this approach to the research methods.

Chapter four is presented as a manuscript. It contains the results and discussion in manuscript style to suit publication as stipulated by the International Journal of Osteopathic Medicine. Appendices follow chapter four, with documentation of ethical approval, information and consent forms and examples of process in the analysis of the data.

1 There are several different forms of lymphoedema, for the purposes of this thesis; breast cancer related lymphoedema will be referred to as lymphoedema.
Abstract


Background: Despite numerous studies evaluating interventions to manage breast cancer related lymphoedema (BCRL), patients’ experiences of these interventions have received limited attention. This qualitative phenomenological study explores the lived experience of individuals who participated in a partner study investigating osteopathic manual therapy (OMT) as an adjunct treatment to manage BCRL.

Objective: To investigate the lived experience of women with lymphoedema whilst under osteopathic care.

Method: Seven participants were recruited following the completion of the OMT intervention study. Data were gathered via semi-structured interviews and a focus group and analysed using an interpretative phenomenological analysis.

Results: Qualitative analysis produced three major themes: (1) the continual search for a sense of control, (2) uncertainty of lymphoedema progression, and (3) novel treatments and miraculous cures. Much of the experience of BCRL is characterized by feelings of a lack of control, particularly in relation to support received from the health system and the uncertainty of lymphoedema progression. Osteopathic care highlighted the potential benefits from expanding the treatment and self-management focus beyond the affected limb, and the participants’ desire for an intervention to support self-care in the long term. There were high expectations for osteopathy as a new treatment for lymphoedema and narratives of curative treatment for lymphoedema were common in the group.

Conclusion: Results suggest that women with lymphoedema are continually searching for a sense of control. A sense of control for some may be enhanced by self-management that is wider than the affected arm. Infrequent self-care may also be related to a sense of control. Osteopathic treatment for lymphoedema was approached with high expectations. Self-management may be supported through symptomatic relief from treatment.

Keywords: Lymphoedema; Breast cancer; Osteopathy; Qualitative research; Patient experience
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Abbreviations

BCRL  Breast cancer related lymphedema
OMT  Osteopathic manual therapy
MLD  Manual lymphatic drainage
CDT  Complete decongestive therapy
IPA  Interpretative phenomenological analysis
CHAPTER ONE

Introduction
CHAPTER ONE: Introduction

Breast cancer is the most common cancer affecting women in the world (WHO, 2014). In New Zealand (NZ) it is estimated that 2,500 women are diagnosed each year (Breastscreen Aotearoa, 2009). This thesis focuses on lymphoedema, which is a relatively unknown side effect of breast cancer treatment affecting a large proportion of breast cancer survivors. As the population of long-term survivors of breast cancer is on the rise, more women will likely be affected by lymphoedema (Darby et al., 2011).

Despite the high profile of breast cancer in NZ and internationally, lymphoedema still suffers from a lack of recognition (Australasian Lymphology Association, n.d.; Meiklejohn, Heesch, Janda, & Hayes, 2013). The chronic and progressive nature of lymphoedema makes it one of the most problematic and unanticipated side effects of treatment (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Norman et al., 2009). The prevalence of this condition varies immensely, with estimates ranging from 8 - 56% of breast cancer survivors affected (Ahmed et al., 2008). In NZ, prevalence has been reported between at 23.3% and 31% (Asim et al., 2012; Clark, Wasilewska, & Carter, 1997). Recent international estimates of incidence report that up to 21% of breast cancer survivors will go on to develop lymphoedema (Huang et al., 2013).

The efficacy of treatment for lymphoedema is variable (Huang et al., 2013; Moseley, Carati, & Piller, 2007; Preston, Seers, & Mortimer, 2008). Intensive decongestive techniques can significantly decrease swelling, however, long term care for lymphoedema lies primarily with the patient (Szuba, Achalu, & Rockson, 2002). Daily self-care helps to prevent infection and further progression of swelling. Other self-care strategies such as exercise and wearing a compression garment also contribute to maintaining health and function of the limb (Lawenda, Mondry, & Johnstone, 2009).

Although lymphoedema is best characterised by swelling in the upper limb, it has a profound impact on psychosocial as well as physical well-being (Ahmed et al., 2008). Within the literature there is a growing acknowledgement of the psychosocial and emotional burden of lymphoedema and the impact this has on the ability to manage illness complications (McWayne & Heiney, 2005).
Despite numerous studies evaluating interventions to manage lymphoedema, patients’ experiences of these interventions have received little attention (Sierla, Sze Mun Lee, Black, & Kilbreath, 2013). In addition, within osteopathy the experience of treatment from the patient’s perspective is also limited. Finally, there is also no qualitative research into the experience of lymphoedema in NZ. It is hoped that this study will contribute to the understanding of the experience of lymphoedema from the unique perspective of the lived experience of osteopathic treatment.

The present study drew participants from a partnered project investigating osteopathic manual therapy (OMT) as an adjunct treatment to manage lymphoedema (Eydt, 2014). Eydt’s study is designed as a case series, based on preliminary studies which suggest OMT may provide a unique and effective treatment approach to lymphoedema (Bradshaw & Snider, 2006; DeLaughter & Gamber, 2005). Neither of these original studies addressed the patients’ perspective. As mentioned earlier, patient-centered research is limited in osteopathy and wider manual therapy fields (Thomson, Petty, Ramage, & Moore, 2011). Thus, this study was designed to contribute to these areas of research through considering the experience of lymphoedema and osteopathic treatment.

**Personal Background**

I am a thirty year old osteopathic masters student, with a previous degree in physical education and an interest in health.

I have always had a fascination with personal accounts of experiences, and how people make sense of their lives. In the last four years of studying to be an osteopath I recognise this interest has also emerged from a clinical angle through enjoying reading case studies and individual accounts of their experience of illness and injury.

My initial introduction to breast cancer related lymphoedema was through a research proposal of the Eydt (2014) study in 2011. I, like many others, had never heard of lymphoedema following breast cancer treatment and was surprised at how many women could potentially be affected. After some initial reading and discussion of the topic, the idea of a qualitative study linked to the quantitative Eydt intervention study arose. Now the research proposal that was initially an assignment has developed into a fully-fledged study of its own.
CHAPTER TWO

Literature Review
CHAPTER TWO: Literature Review

This chapter covers a review of the literature outlining current research on breast cancer related lymphoedema. Three main areas are covered starting with an overview of breast cancer related lymphoedema, including the characteristics and management. This is followed by qualitative literature on the experience of women with lymphoedema and the experience of treatment. Lastly, osteopathy for lymphoedema is considered with a brief outline of patient-centered research in the experience of OMT and manual therapy. The review identifies the place for qualitative inquiry into the experience of lymphoedema and OMT, and how inquiry into this topic can inform osteopathic clinical practice.

Literature Search and Strategy

Literature included in the review was identified through database searches using EBSCO, Science Direct, Health Source, PubMed and Google Scholar using keywords: lymphoedema, breast cancer related lymphoedema, treatment, treatment experience, psychosocial effects, manual therapy, osteopathy, and patient experience. Potential articles for inclusion were also identified through searching reference lists of relevant articles. Where possible, an emphasis on current literature was used.

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2 There are several types of lymphoedema both of primary and secondary causes. In this document “lymphoedema” in refers to secondary lymphoedema caused by treatment for breast cancer (surgery and radiotherapy) unless stated otherwise.

3 Patient-centered research is research based on patient experiences, giving insight on how biological, personal and social factors impact on a patient’s illness or health experiences (Thomson, Petty, Ramage & Moore, 2011).
Breast Cancer Related Lymphoedema

Lymphoedema is one of the most common complications of breast cancer treatment but despite this it is often unanticipated (Norman et al., 2009; Thomas-MacLean, Miedema, & Tatemichi, 2005). At its most basic, lymphoedema is a manifestation of lymphatic system insufficiency. Altered lymph transport causes swelling of the hand, forearm, upper arm, axillary region and even the trunk and breast on the side treated for breast cancer (Sierla et al., 2013). The swelling caused by lymphoedema can be unsightly, cause pain in the limb, limit movement and be prone to infection. There is currently no known cure for lymphoedema, and therefore management and in particular self-care of the limb is required on a daily basis to prevent further swelling and infection (Lawenda et al., 2009).

Breast Cancer and the Onset of Lymphoedema

Breast cancer related lymphoedema is a type of secondary lymphoedema. Primary lymphoedema arises from congenital causes, while secondary lymphoedema follows disruption of the lymphatic vessels due to axillary nodal sampling, irradiation, surgery and repeated infection (International Society of Lymphology, 2013). Cancer treatment is the most common cause of secondary lymphoedema in the industrialised world (International Society of Lymphology, 2013).

The onset of lymphoedema following breast cancer is immensely variable, ranging from weeks to years after diagnosis (Ahmed, Schmitz, Prizment, & Folsom, 2011; Bell et al., 2013). There is no international consensus on the diagnosis of lymphoedema, which may partly contribute to the variability in onset. A recent systematic review estimates a 21% incidence of lymphoedema following breast cancer, however incidence and prevalence rates also vary (DiSipio, Rye, Newman, & Hayes, 2013) This will be discussed further in a later section.

Technological advances in both diagnosis and treatment of breast cancer have lead to early detection and better survival outcomes. Therefore, the population of long-term survivors is on the rise (Darby et al., 2011). For breast cancer survivors, risk factors for developing lymphoedema include: obesity, having 10 or more lymph nodes excised (axillary lymph node dissection), sentinel lymph node dissection, radiation particularly of the axillar region, hypertension and low physical activity (Ahmed et al., 2011; Meeske et al., 2009).
Diagnosis methods include measuring the circumference of the limb, volume measurement, bioimpedance spectroscopy and self-report (International Society of Lymphology, 2013). Use of a combination of subjective and objective tools appears to offer more reliable results in diagnosis of lymphoedema (DiSipio et al., 2013). Once diagnosed, lymphoedema is generally categorised on a three-stage scale from Stage 0 (subclinical or latent condition, where swelling is not yet evident) to overt lymphoedema at stage III (International Society of Lymphology, 2013).

**Lymphoedema in Australasia**

Breast cancer is the most prevalent cancer affecting women in New Zealand (NZ), with approximately 2,500 women diagnosed each year (Breastscreen Aotearoa, 2009). Despite the high profile of breast cancer in NZ and internationally, lymphoedema still suffers from a lack of recognition both in the general public and wider health professions (Australasian Lymphology Association, n.d.).

There is, nevertheless, a growing awareness of lymphoedema reflected in the media. In Australia, it is interesting to note that March 2012 was designated “Lymphoedema Awareness Month” by the Australasian Lymphoedema Association (ALA), with media stories focusing on treatment, comment from health professionals, research and personal stories about different types of lymphoedema (Australasian Lymphology Association, n.d.) Doctors from New Zealand have also been on record in a newspaper article calling for more funding from district health boards in New Zealand to provide funding to support management of lymphoedema (Rankin, 2003). This emphasizes a growing awareness of this condition beyond academic and health specific spheres and indicates the need for further research on lymphoedema.

A review of literature into breast cancer related lymphoedema in NZ has revealed two studies with a primary focus on lymphoedema. Results of the studies recommend improved education on lymphoedema during and after breast cancer treatment (Clark et al., 1997) and report 23.3% prevalence of lymphoedema in women who had axillary node dissection during treatment for breast cancer (Asim et al., 2012). A search for NZ-specific qualitative literature and/or lived experience of lymphoedema has revealed no published research at the time of writing. Certainly the prevalence of lymphoedema and the lack of research suggest that is an important area for further study.
Effects of Lymphoedema

This section discusses the physiology of lymphoedema, the most common symptoms and effects associated with breast cancer related lymphoedema, followed by the effect of lymphoedema on quality of life. Health related quality of life (HRQoL) is utilised in the literature to encompass the wider effects of lymphoedema beyond physical symptoms, and objective measures and how lymphoedema affects an individual’s quality of life or well-being.

Physical Effects

Although the most visible manifestation of breast cancer-related lymphoedema is swelling, survivors with lymphoedema often experience multiple symptoms. On a physiological level, these symptoms of swelling are caused by an accumulation of excess water, filtered and diffused plasma proteins, extravascular blood cells and other cell products. The decreased capacity of the lymphatic transport system results in deposition of extracellular matrix substances and often, adipose tissue (International Society of Lymphology, 2013).

Symptoms may include tenderness, soreness, aching, heaviness, tightness, firmness, numbness, fatigue and stiffness in the affected limb (Norman et al., 2009). Associated issues such as nerve injuries, venous obstruction and ligament strain have also been reported (Bosompra, Ashikaga, O’Brien, Nelson, & Skelly, 2002). Wider symptoms also include reduced function due to altered limb shape, as well as changes in skin appearance and increased risk of skin infection (Bulley, 2007). The change in function of the arm may require women to alter activities of daily living, employment, sleep, exercise and often clothing.

Psychological and Social Effects

Beyond the physical symptoms, lymphoedema can have significant negative effects on psychological, social and emotional aspects of wellbeing. Reported psychological effects include frustration, distress, depression, anxiety, guilt regarding the cause of lymphoedema and fear of cancer returning (McWayne & Heiney, 2005). Social effects comprised changes in role function, lack of social support, negative body image, and reduced self-esteem (Bulley, 2007; McWayne & Heiney, 2005).
In a recent review of 11 quantitative and 12 qualitative studies on the psychosocial impact of lymphoedema, Fu, Ridner, Hu & Stewart, (2013) identified statistically significant poorer social well-being in individuals with lymphoedema. The qualitative studies reviewed consistently described negative psychological impact with negative self-identity, emotional disturbance and psychological distress, and negative social impact (marginalisation, financial burden, perceived diminished sexuality, social isolation, perceived social abandonment, public insensitivity, and non-supportive work environment). While this review considered both breast cancer related lymphoedema and other types of secondary and primary lymphoedema, only three included individuals with non-breast cancer related lymphoedema.

**Lymphoedema and Quality of Life**

Unsurprisingly, health related quality of life (HRQoL) in those with lymphoedema is reported as lower than breast cancer survivors without lymphoedema (Ahmed et al., 2008; Morgan, Franks, & Moffatt, 2005; Sagen, Karesen, Sandvik, & Risberg, 2009). Survivors report a lack of understanding by health professionals about lymphoedema and poor information provided to patients as key factors affecting their well-being (Morgan et al., 2005).

HRQoL as identified above, has been utilised as a relatively reliable and reproducible measure of the wider effects of lymphoedema and has contributed significantly to the picture of the effects of lymphoedema on well-being. Where the HRQoL measures are limited, is that they can only measure predetermined categories, and may fail to encompass the wider experience of lymphoedema. Qualitative research on lymphoedema provides the opportunity to consider what is not known about lymphoedema, and thus contribute to the knowledge base of lymphoedema as a multi-faceted condition.

More research has begun to focus on the psychological and social complications associated with lymphoedema, as this has been previously identified as a neglected area of research (Preston et al., 2008). Nonetheless, the psychosocial complications continue to be overlooked in favour of objective measures such as arm volume, particularly in research on treatment efficacy (Ridner, Bonner, Deng, & Sinclair, 2012).

Part of this issue is that lymphoedema is primarily conceptualised as a condition associated with excess swelling. Ridner et al (2012) suggests that lymphoedema needs to be re-conceptualised as a multi-dimensional condition that encompasses both the psychological and social aspects of lymphoedema as equally important as the biological. Taking this stance,
researchers would be challenged to consider lymphoedema as more than a swollen limb. These discrepancies in the literature will be discussed further in the following section.

**Defining Lymphoedema**

An important aspect of the context of literature on lymphoedema is the lack of consensus in defining, diagnosing and measuring lymphoedema. The following section summarises this variability and briefly the effect on incidence and prevalence rates of lymphoedema. The use of subjective data to measure the presence and status of lymphoedema is discussed in addition to physiological measures as they encompass the wider domains of health that are affected by lymphoedema.

**Rates of Lymphoedema Among Breast Cancer Survivors**

The reported prevalence and incidence rates of lymphoedema are very variable in the literature. Prevalence amongst breast cancer survivors has been estimated between 8% - 56% (Ahmed et al., 2008). Incidence rates are also variable. A recent systematic review using 30 prospective cohort studies estimates a 21% incidence of women diagnosed with breast cancer will go on to develop lymphoedema (DiSipio et al., 2013).

This variability in defining lymphoedema status is due to a lack of a standardised diagnosis, differences in criteria used for studies, timing of lymphoedema measurement in relation to breast cancer diagnosis and variability in treatment types and timing (Asim et al., 2012). The extent of arm swelling such as measured circumference of the arm, or volume, has been the main outcome focused on in the literature (Didem, Ufuk, Serdar, & Zumre, 2005; Huang et al., 2013; Torres Lacomba et al., 2010). When measuring both circumference and volume there are several different methods and criteria used. For instance volume may be compared to the unaffected arm or compared to the pre-surgery or post surgery circumference where available. The immense variability in methods of defining highlights that both health professionals and patients have to contend with a relatively indeterminate and changeable field.

Self-reporting methods are increasingly being used to detect the onset of lymphoedema and monitor it from a subjective perspective. These methods suggest a greater prevalence of lymphoedema and more variability in symptoms than reported by measurement of limb size alone. Sagen et al. (2009) described a prevalence of lymphoedema of 50% in breast cancer survivors who reported symptoms suggestive of lymphoedema with or without a clinical
diagnosis. Self-reports of lymphoedema offer a new way of defining lymphoedema and appear to contribute further detail to the change in lymphoedema over time. Over a four year duration, the presence or absence of lymphoedema symptoms fluctuated more than was previously thought (Bell et al., 2013). Self-reported measures add an additional dimension by identifying those actually disturbed by the condition, which clinically can be considered more relevant than those based on volume or circumference alone. Self-reported lymphoedema is potentially a reliable and inexpensive way to assist in identifying onset and monitoring the condition (Bell et al., 2013; Bulley et al., 2013; Radina, Armer, Culbertson, & Dusold, 2004; Sagen et al., 2009).

**The Role of Subjective Data in Defining Lymphoedema**

Research suggests that psychosocial complications, distress from symptoms and decreased quality of life may not be directly related to the extent of swelling in the arm (Bulley et al., 2013; McWayne & Heiney, 2005; Sierla et al., 2013). For instance a significant number of women in the Sierla et al. (2013) study reported swelling at a level that ‘only you would notice’ (characterised as mild swelling) but reported that symptom distress caused by the swelling to be moderate to severe. Bulley et al. (2013) compared arm swelling to quality of life (QOL) and found no correlation between the amount of swelling and the negative affect of lymphoedema on QOL.

The results above question the validity of research that measures change in volume or swelling circumference alone. Changes in swelling by volume or circumference are the most common outcome measures of research considering treatment efficacy. All three of these studies suggest an important role for subjective and patient-centered data on the experience of lymphoedema, and that subjective data may provide a better reflection of the diversity of physical, functional, social and psychological symptoms experienced by women with lymphoedema. These findings make a subjective method of data collection such as qualitative research, well-suited to inquire further into the experience of treatment for lymphoedema.

**Management of Lymphoedema**

This section discusses conservative management of lymphoedema including the two main forms of physical therapy treatment – complete decongestive therapy CDT and manual lymphatic drainage MLD. Standard lymphoedema care in NZ is briefly touched on, followed by OMT for lymphoedema. While there is a wide range of treatments used for lymphoedema, they are
beyond the scope of this document. Self-care tasks such as skin care and compression garments are outlined to highlight the reliance on motivation of the individual in management of lymphoedema. Finally, the literature on self-care of lymphoedema is discussed, particularly in relation to the lack of conclusive evidence contributing to current management of lymphoedema.

**Treatment of Lymphoedema**

The most common management options for lymphoedema are combinations of physical therapy, self-care, and wearing a compression sleeve (Lawenda et al., 2009). Without intervention, lymphoedema can lead to progressive swelling, fibrosis of the soft tissues, pain, discomfort and infection, and associated psychosocial effects (Lawenda et al., 2009). Treatment aims to decongest the reduced lymphatic pathways in order to decrease the size of the limb, encouraging the development of collateral drainage routes and stimulating the function of the remaining routes (Casley-Smith, Boris, Weindorf, & Lasinski, 1998). Common physical therapy includes complete decongestive therapy (CDT), manual lymphatic drainage (MLD), and bandaging. Less common treatments include laser therapy, pneumatic compression (Wilburn, Wilburn, & Rockson, 2006), kinesio taping also known as medical taping (Tsai, Hung, Yang, Huang, & Tsauo, 2009), pharmacotherapy, and in severe or rare cases surgical resection, lymph node transplant and liposuction (International Society of Lymphology, 2013; Podgórska, Drożdż, Bieniek, & Szuba, 2011).

**Physical Therapy for Lymphoedema**

The current ‘gold-standard’ and approach for onset and acute episodes of swelling is complete decongestive therapy (CDT) or complex physical therapy (McCallin, Johnston, & Bassett, 2005). CDT is a two-phase, intensive multi-intervention treatment incorporating manual lymphatic drainage (MLD), compression bandaging and fitted garments, special exercises and skin care. The CDT approach requires daily, one-on-one skilled therapy with a specialized provider over the course of four to six weeks. Upon optimal decongestion of the limb, phase two begins with self-care by the patient to maintain the reduction in swelling. Compression garments are applied daily to prevent re-accumulation of fluid in the limb, alongside self-administered MLD, bandaging, exercise and skin care (McCallin et al., 2005). Maintaining the reductions of CDT relies primarily upon self-care to reduce the impact of lymphoedema on well-being, decrease
the number of acute episodes of swelling and avoid progression of lymphoedema and reduce health care costs.

Demonstrable efficacy of CDT has been reported, with initial reductions of the measured excess limb volume that approximate 50% (Szuba et al., 2002). Despite this, CDT poses significant barriers to the adherence to treatment as it is time consuming and costly due to the amount of practitioner input required (Lawenda et al., 2009).

MLD is an intervention commonly used by many women with lymphoedema, separately from other aspects of CDT (Huang et al., 2013). It consists of rhythmic lymphatic massage, which produces a mild pressure gradient to help remove edema from the limb (Mason, 1993). Gentle skin massage is thought to cause superficial lymphatic contraction, thereby increasing lymph drainage (Huang et al., 2013). MLD is also thought to be potentially useful to stimulate the remaining lymphatic mechanisms to remove the excess fluid (Mason, 1993). Despite the widespread use of MLD, studies of its efficacy have been inconclusive (Huang et al., 2013; Preston et al., 2008).

**Standard Care for Lymphoedema in NZ**

A brief survey of practice in NZ reveals that MLD with bandaging is the primary practitioner applied intervention (E. Eydt. personal communication, July 12, 2012). At present, pneumatic pumps are not recommended in NZ and there is limited access to laser treatment (Lymphoedema Support Network, n.d.). The most common management option in NZ is the regular use of compression garments as part of self-care of the limb (E. Eydt. personal communication, July 12, 2012).

**Osteopathy and Lymphoedema**

Osteopathy is a manual therapy that may provide a unique and effective perspective to the management of lymphoedema (Bradshaw & Snider, 2006; DeLaughter & Gamber, 2005; Ota, 2006). Osteopathy has a long history of considering the lymphatic system as a fundamental component in health and disease, with ‘lymphatic pump’ techniques first reported in 1926 (Ward, 2003). The techniques were used to treat infection and edema through improving the filtering and removal of fluid, inflammation and metabolic waste from the interstitial space (Chikly, 2005). Additionally, osteopathic texts frequently discuss treating lymphoedema and
particular attention is given to the lymphatic system in fundamental principles and clinical practice guidelines (DiGiovanna, Schiowitz, & Dowling, 2005; Kuchera, 1994; Wallace, McPartland, Jones, Kuchera, & Buser, 2003; Ward, 2003).

There is, however, little empirical research into treatment of lymphoedema through OMT. Bradshaw and Snider (2006) published a promising case study on upper extremity lymphoedema, which provided the impetus for the intervention study partnered to this project. An earlier case study also explored the positive effects of OMT on lower extremity lymphoedema (DeLaughter & Gamber, 2005). Both case studies frame osteopathy as a viable treatment option for sufferers of lymphoedema. Preliminary evidence suggests that the amount of time and consequently associated costs required may be reduced with OMT.

**Self-care of Lymphoedema**

Regardless of the type of volume reduction treatment, daily self-care is recommended in the literature and clinical guidelines as the mainstay of successful management of lymphoedema. Self-care is believed to be critical to reduce exacerbations of swelling, prevent infections and manage other lymphoedema-associated symptoms. Self-care may also have a positive effect on other symptoms of lymphoedema outside of the swelling, such as fatigue, psychological distress, and changes in body image (Ridner, Bonner, et al., 2012).

Self-care tasks generally consist of skin care, limb elevation, self or partner massage, specific and general exercise and wearing a compression garment (International Society of Lymphology, 2013; Lawenda et al., 2009). As the tissue environment created by lymphoedema is ideal for infection, skin care is very important (Rockson, 2010). This may include daily inspection of the limb (nails and skin) to confirm that it is free of any cuts, scratches, areas of irritation or signs of infection. Prompt treatment is required following any signs of damage.

Compression garments are strongly recommended for long term care required to maintain lymphoedema reduction after CDT (International Society of Lymphology, 2013). The garment is a sleeve and/or hand piece of custom-made low stretch elastic fabric generally worn throughout the day. The sleeve promotes lymph movement and reduces edema formation by increasing the pressure gradient within the arm (McCallin et al., 2005). The garments have a high level of use, gradually lose elasticity and replacement is recommended every three to six months (Rockson, 2010). The frequent replacement of the compression garment adds to the financial burden of lymphoedema (Thomas-MacLean et al., 2005; Towers, Carnevale, & Baker,
The reported costs of lymphoedema related care can be extensive. An American study estimated from claims costs, lymphoedema care over two years was nearly twice that of breast cancer survivors without lymphoedema (US$14,877 to US$23,167) (Shih et al., 2009).

**Literature to Support Self-care**

The burden of self-care is considerable and ongoing, however despite widespread recommendations, there is little definitive evidence for the effectiveness of self-care activities for lymphoedema (Ridner, Fu, et al., 2012). In a 2012 review of 16 quantitative studies considering self-care efficacy, only two interventions were ‘likely to be effective’ – full body exercise and Phase 2 CDT. Inclusion of Phase 2 CDT however, was based entirely on expert opinion in the absence of definitive research in this area. Many of the most common strategies used were rated as ‘effectiveness not established’ such as compression garments, infection management, self-monitoring of volume, skin care, simple MLD, and weight reduction (Ridner, Fu, et al., 2012). The lack of conclusive evidence of this review highlights opportunities for further research in the area of self-care.

**Efficacy of Treatment for Lymphoedema**

The management of lymphoedema has an absence of definitive answers despite numerous studies on modes of treatment (Huang et al., 2013; International Society of Lymphology, 2013; Preston et al., 2008). As yet, no treatment method for peripheral lymphoedema has undergone a rigorous meta-analysis, leaving clinicians, researchers and patients alike to interpret available research on diagnosis and management of lymphoedema. A Cochrane review by Preston et al. (2008), found most forms of compression garments were effective in reducing the volume of the upper extremity, however MLD had no effect. In contrast, a separate review of physical therapy modalities found MLD to be one of the most effective interventions (Moseley et al., 2007). Clearly, the debate over the most effective manual therapy treatment is extensive and on-going.
Studies of treatment efficacy have also failed to acknowledge the role of symptomatic relief from treatment (Devoogdt, Van Kampen, Geraerts, Coremans, & Christiaens, 2010; Torres Lacomba et al., 2010). As discussed above, subjective data, which encompasses psychological and social effects of lymphoedema, may be more clinically relevant measure of lymphoedema status than objective measures of arm size (Bulley et al., 2013; McWayne & Heiney, 2005; Sierla et al., 2013). Clearly, lymphoedema is a multifaceted condition, with many possible options and combinations of management. A beneficial and successful treatment requires acknowledgement of subjective experience as well objective changes, reinforcing the direction of this study in considering patient experience of lymphoedema and OMT.

Qualitative Inquiry into Lymphoedema

The following section reviews nine qualitative studies that provide an overview of the qualitative literature on the experience of lymphoedema after breast cancer. The results of the studies are categorized into four broad areas. Two of these studies (Meiklejohn et al., 2013; Towers et al., 2008) included male and female participants with other types of secondary lymphoedema following cancer treatment, however the majority of the participants in both studies had breast cancer related lymphoedema and results were sufficiently similar to other BCRL studies.

Qualitative Literature

Within qualitative research, Carter (1997) was one of the original researchers to highlight the wider issues of the experience of lymphoedema. Carter interviewed 10 women with BCRL in the Midwest of the United States. Next, Hare (2000) examined the lived experience of 20 women with BCRL in Bath, England with focus groups; and Johansson et al. (2003) analysed the experience of 12 working women with light to moderate arm lymphoedema in Sweden. More recently, three Canadian studies were conducted: Thomas-MacLean, Miedema and Tatemichi

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4 Symptomatic relief is a subjective measure of the perceived effectiveness of treatment from the patient’s perspective (Sierla et al, 2013).
(2005) interviewed 15 women with lymphoedema; Greenslade and House (2006) questioned 13 women with lymphoedema; and Towers et al. (2008) took a psychosocial focus to interview 11 participants and their 8 spouses with secondary lymphoedema and. Fu and Rosedale (2009) considered the experience of lymphoedema symptoms of 34 women in the US; Ridner et al. (2012) analyzed the expressive writings of 39 women with lymphoedema in the US, and Meiklejohn et al. (2013) considered the experience of lymphoedema in the context of daily life in Australia.

Similar themes emerged in all the studies, which could be categorised into four broad areas. The first common theme was how shocked and scared the patients felt when they first experienced swelling in the arm. Some thought the cancer was returning. Patients were unprepared for lymphoedema, having felt they received little or no information about its risk following cancer surgery and treatment (Fu & Rosedale, 2009; Thomas-MacLean et al., 2005). They were further shocked and grieved when they realised the permanence and severity of this life long condition. Some reporting it was worse than cancer, and expressing surprise at the sheer volume of lymphoedema symptoms (Fu & Rosedale, 2009). A denial of the severity of the lymphoedema was reported by Meiklejohn et al. (2013), and difficulty of maintaining the commitments to self-care (Meiklejohn et al., 2013).

The second main theme was the search for information and treatment. Carter (1997), described this theme bluntly as a rejection by medicine and Meiklejohn et al. (2013) described the interaction with the health system for lymphoedema as an accidental journey with considerable financial, time and emotional costs to find treatment. Patients in most studies were frustrated by health professionals’ lack of interest, awareness and knowledge. Some felt denigrated and belittled by physicians’ comments, such as “it’s nothing” or “it will clear up” (Carter, 1997, p. 876). Some were given inappropriate advice and information described as a failure in disease management (Ridner, Bonner, et al., 2012) and some required two or three visits before obtaining referral for treatment (Towers et al., 2008). In contrast, specialist lymphoedema services were praised by participants in England (Hare, 2000). When a knowledgeable and caring health professional was found they became essential for management of lymphoedema (Hare, 2000; Meiklejohn et al., 2013; Ridner, Bonner, et al., 2012).

A third key theme was the profound impact lymphoedema had on individuals’ daily lives. Patients were bound to a chronic condition that affected the ability to use their arm, with significant changes in appearance, finances and self-image. They felt stigmatised by others, and the experience of altered normalcy and “yearning to return to normal” (Ridner, Bonner, et al., 2012, p. 7) led to deficits in self-care such as avoiding wearing a compression garment.
(Meiklejohn et al., 2013; Ridner, Bonner, et al., 2012). Multiple losses were noted in roles of partner, parent, occupation and home life (Ridner, Bonner, et al., 2012; Thomas-MacLean et al., 2005; Towers et al., 2008). The symptom distress of living with “perpetual discomfort” and “losing pre-lymphoedema being” left women feeling handicapped as they went about their daily lives (Fu & Rosedale, 2009, pp. 5 & 7). Treatments were time-consuming, cumbersome, and costly; compression garments were found to be uncomfortable and ugly. Some had suffered silently (Hare, 2000).

Coming to terms with the swelling and coping with it was the fourth common theme in this review. Patients adapted by trial and error, making changes in their lifestyle. They adjusted their values to change the meaning of lymphoedema, reappraising what they hoped for in terms of function and health (Thomas-MacLean et al., 2005) and learned to get on with it. Coping strategies were having a positive outlook, commitment to treatment and adapting one’s life. Some spoke of the importance of a lymphoedema clinic and of social support (Hare, 2000; Meiklejohn et al., 2013; Ridner, Bonner, et al., 2012) especially helpful were activities that invited open discussion about lymphoedema and cancer.

The studies of the lived experience of lymphoedema begin to describe the context of the reduced quality of life that has been reported in individuals with lymphoedema. They give insights into the real difficulties faced, particular needs that should be addressed, and ways of giving practical help. The next section looks further into the experience of treatment, and how this may contribute context to the experience of lymphoedema.

**Patient Experience in Health Care Research**

This section considers the experience of treatment from the patient’s perspective and how this can contribute to clinical recommendations and lymphoedema care. Due to the lack of studies considering patient experience of lymphoedema treatment, the more general area of rehabilitation after breast cancer is also considered (Lattanzi et al., 2010), as well as occupational therapy for lymphoedema related deficits (McGrath, 2013). Osteopathy and manual therapy is then considered from the perspective of treatment experience or a patient-centered perspective. A closer look at these studies highlights how focusing on patient experience can provide simple clinical recommendations and context to the experience of lymphoedema.
The Experience of Treatment for Lymphoedema

The literature on the patient's view of treatment for lymphoedema is limited in both qualitative and quantitative literature. Despite the lack of evidence, or perhaps because of, women with lymphoedema appear to be open to trying a number of different treatments from conservative to alternative for lymphoedema. In a cohort of 154 Australian women with lymphoedema, 66% had tried four or more modalities and 9% had tried seven or more (Sierla et al., 2013). This suggests that they are looking for, or hoping for, better solutions.

The benefits of treatment or symptomatic relief have been repeatedly overlooked in favour of outcome measures focusing on physical changes (Devoogdt et al., 2010; Huang et al., 2013; Torres Lacomba et al., 2010). At present most treatment for lymphoedema is recommended or tried on a trial and error basis. One study that considers symptomatic relief from treatment is from Sierla et al. (2013). This study suggests that combinations of treatment may be required to obtain optimal benefits. Of the 149 women that were surveyed across 10 different treatment modalities,5 benefits were reported from all modalities that had been tried, but with varying levels of satisfaction and with no one modality that was of benefit to all the women. Considering the amount of treatments tried by women with lymphoedema, and the variability in efficacy of treatment it appears that data on symptomatic relief may give additional insight into the effectiveness of treatment and treatment combinations for different stages of lymphoedema.

The experience of treatment is mentioned within qualitative literature on lymphoedema. As mentioned in the previous section, treatment for lymphoedema has been described as time consuming and costly, delayed, mismanaged and characterised by a lack of information (Hare, 2000; Meiklejohn et al., 2013; Ridner, Bonner, et al., 2012). Positive experiences have been associated with care at specialist lymphoedema clinics (Hare, 2000). Nonetheless, the patient’s experience of physical therapy treatment for lymphoedema has not been addressed directly in the qualitative literature.

Two studies consider the experience of other forms of treatment, firstly rehabilitation after breast cancer (Lattanzi et al., 2010) and secondly occupational therapy for lymphoedema.

5 Treatment modalities surveyed by Sierla et al. (2013): simple lymphatic drainage, compression garment, MLD, exercise, CDT, laser, self-bandaging, complementary and alternative medicine, diet and external pneumatic device.
(McGrath, 2013). The former did not deal with lymphoedema directly, but discussed the importance of a specialised environment for rehabilitation after breast cancer, and particularly screening for lymphoedema. Key recommendations for clinicians from patient experience were the importance of a specialised breast cancer rehabilitation environment, which contributed to a positive experience of care, similar to what was mentioned above by Hare (2000). In particular, having a therapist that was knowledgeable in the management of all impairments and functional limitations associated with breast cancer treatment such as lymphoedema was considered invaluable (Lattanzi et al, 2010).

The McGrath study spoke to participants who were part of a craft group for women with lymphoedema (2013). Results focused on the distress caused by lymphoedema due to reduced upper limb function. Women reported conflicting emotions and distress at adhering to lymphoedema guidelines, such as avoiding lifting heavy items when it threatened their identities, for instance as a caregiver or parent. Occasions were reported where women knowingly defied lymphoedema care and advice to lift children and experienced worsening symptoms. A key outcome of this study was to address the distress at this loss of arm function through supportive adaptations. Despite not being directly related to manual therapy or OMT, the McGrath (2013) and Lattanzi et al. (2010) studies emphasise the contributions of patient-centered research to clinical practice.

**Osteopathy and Treatment Experience**

Recent expert opinion on research methods used within osteopathy notes a reliance on quantitative methods. The authors highlight that a “weakness of this approach is its failure to acknowledge the values, expectations and illness experience of the individual patient” (Thomson et al., 2011, p. 4). They suggest that qualitative research exploring patients’ experiences, and disability from their perspective, can inform collaborative decision-making. This can help osteopaths care for their patients more effectively, and enhance their clinical practice.

The original case study of OMT for lymphoedema did not comment on the experience of treatment from the patient’s perspective, or give any indication as to the patient's satisfaction with the treatment approach, creating a gap in the understanding of the effectiveness of treatment from the patient’s perspective (Bradshaw & Snider, 2006). In addition, there is a lack of more general research on the experience of OMT from the patient’s perspective (Thomson et al., 2011). Therefore, the lack of research in this area highlights the space in the literature for
this study to contribute to not only the understanding of the experience of lymphoedema, but also the experience of OMT as a novel treatment for lymphoedema.

Within the field of osteopathy and manual therapy, the contribution of patient views and experiences of health care is increasingly an important aspect of investigation (Thomson et al., 2011). Literature in the field of manual therapy also supports gathering the patient perspective of treatment outcomes and experiences (Carlesso, Cairney, Dolovich, & Hoogenes, 2011; Johnson & Waterfield, 2004; Strutt, Shaw, & Leach, 2008). For instance a qualitative inquiry into the experience of adverse events from Carlesso et al. (2011) illustrates the difference in patient and practitioner experience of adverse events in manual therapy (physiotherapy, chiropractic and osteopathy). The exploratory study found that patients categorised the experience differently from the practitioner and frequently did not verbalise or show what they were experiencing to the practitioner. This is concerning because manual therapists rely heavily on patient feedback for indications of positive or negative outcomes of treatment (Johnson & Waterfield, 2004). In response to these findings, the standard definition for adverse events underwent refinement to encompass the patient’s experience and viewpoint. Despite not being directly related to lymphoedema, this study also stresses the clinical relevance of patient-centered research.

In conclusion, this review of literature has highlighted that lymphoedema after breast cancer treatment is a complex and multifaceted condition. The lack of a standardised diagnosis has led to immensely variable reports of the incidence and prevalence, as well as the effectiveness of treatment. Addressing subjective, experiential aspects of lymphoedema is increasingly valued in the literature, and emphasises the variable effects of lymphoedema on wider aspects of well-being, beyond just a swollen limb. Qualitative literature also provides context, depth and new information to describe the breadth of this variable condition. Treatment for lymphoedema lacks consensus in the literature, however is a burgeoning area of study including OMT as a relatively new treatment for lymphoedema. Patient-centered inquiry on treatment can also contribute to understanding the experience of lymphoedema. This study aimed to provide additional insight into the experience of lymphoedema and the experience of OMT. It is hoped conclusions drawn from these data will benefit health practitioners who treat women with lymphoedema, and contribute to the knowledge base on the experience of OMT.
CHAPTER THREE

Methodology, Methods and Analysis
Methodology, Methods and Analysis

This chapter explores the methodological framework and methods used in the research project. It begins with an overview of qualitative research and how it has been used to address the stated research questions. It then gives further detail about the chosen analysis method of interpretative phenomenological analysis (IPA) (Smith, 1996). Aspects of rigour in qualitative research are examined, followed by the methods used to gather the data.

Methodology

A Qualitative Approach

Qualitative inquiry offers many tools for gathering subjective and experiential data. This study employed a qualitative approach to investigate the lived experience of women with lymphoedema undergoing osteopathic care. Although numerous studies have investigated the experience of lymphoedema (Carter, 1997; Ridner, Bonner, et al., 2012; Thomas-MacLean et al., 2005) and the efficacy of treatment for lymphoedema (Huang et al., 2013; Preston et al., 2008), there is little published research considering the experience of treatment from the perspective of the patient. The current study therefore sets out to examine the lived experience of women undergoing osteopathic manual therapy (OMT) for breast cancer related lymphoedema.

This study was carried out in partnership with a project examining OMT as an adjunct or complementary treatment for lymphoedema (Eydt, 2014). The data collected in the Eydt study is primarily quantitative and relates to the volume of both affected and unaffected limbs throughout a three week treatment programme. Recent research, however, suggests that there is no clear evidence that the amount of swelling correlates with the amount of distress caused by lymphoedema (Bulley et al., 2013). While arm size may decrease, patients may not feel noticeably better, demonstrating the multifaceted nature of this condition. Therefore, the present study proposed to explore the experience of lymphoedema treatment with a focus on the subjective, lived experience. The inductive nature of qualitative research such as this can
provide a useful platform for highlighting and providing context to quantitative studies (Bryman, 2006).

Because of the limited understanding of the experience of treatment for lymphoedema or OMT and lymphoedema, this study uses an exploratory approach. Qualitative research is suitable where little is known about a phenomenon, as it allows the researcher to explore the topic in detail without the constraints of prior assumptions (Van Manen, 1997). The qualitative approach taken in this study facilitates the collection of rich data to contribute to understanding the experience of lymphoedema and the experience of osteopathic care.

The purpose of the research and the research question are important in determining the research method (Morse & Field, 1996). Given that this project is examining lived experience, it was considered important to use an approach that acknowledges and respects the individual’s understanding and perspective. Cohen (2006) supports this, stating that the goal of qualitative methods is “to be able to see the world in the same way as those men and women undergoing the experience” (p. 132). The qualitative approach taken here explores the experience of osteopathic treatment for lymphoedema, hoping to provide descriptions useful for researchers and health professionals.

There are a variety of approaches to qualitative research. For this study, interpretative phenomenological analysis (IPA) (Smith, 1996) has been chosen to answer the research questions regarding the lived experience of lymphoedema and osteopathic treatment. IPA is a method increasingly used to understand the participant’s personal view of the phenomena being investigated. The theoretical principles underlying IPA are described in the following section.

**Interpretative Phenomenological Analysis: illuminating the general by delineating the particular**

The aim of IPA is to understand and make sense of another person’s sense-making activities, with regard to a given phenomenon and in a given context (Smith, 1996). The basis of analysis in phenomenology is how these experiences are perceived and related through language. The theoretical foundations of IPA provide a basis for the researcher to interpret meaning through questions, discussion, conversation, story telling, and other uses of language.

IPA as a process can be informed by theory and does not have the development of a model as its primary focus. As an inductive approach, IPA tends not to test hypotheses and prior
assumptions are avoided, making it ideal for exploring topics where little is known (Reid, Flowers, & Larkin, 2005). As outlined in the literature review, there is a gap in the research around the lived experience of lymphoedema and the experience of treatment for lymphoedema. As the Eydt (2014) study is also of an exploratory nature, the qualitative data of the present study provides additional context for analysing the objective data of the Eydt (2014) study.

The three main philosophical underpinnings of IPA are phenomenology, hermeneutics, and ideography (Smith, 1996). As such, IPA draws on sources such as Giorgi (Smith, 1996), Heidegger (Larkin, Watts, & Clifton, 2006; Smith, 2007) Solomon, Merleau-Ponty, Van Manen (Smith, Flowers, & Larkin, 2009), and Gadamer and Schleiermacher (Smith, 2007) to articulate the conceptual foundations of the approach. These sources share a commitment to a hermeneutic understanding of people’s experiences and to situating their concerns in the context of the lived world. The next section describes these three main influences on IPA and explains why they are appropriate to answer the research questions posed by this study.

**Phenomenology**

In phenomenological inquiry the researcher seeks a truth that resonates and adds understanding to the phenomenon (Pringle, Drummond, McLafferty, & Hendry, 2011). Phenomenology asks for the nature of the phenomenon (Van Manen, 1997) and assists with uncovering meaning (Pringle et al., 2011). This approach is concerned with the individuals’ perceptions or accounts of a particular phenomenon as opposed to an attempt to produce an objective statement of the object or event itself (Smith & Osborn, 2008). Thus, this approach is useful when little is known about the phenomenon.

**Hermeneutics**

The interpretative aspect of IPA is informed by hermeneutics, primarily through the work of Schleiermacher, Heidegger, and Gadamer (Smith et al., 2009). Hermeneutics is the study of interpretation, and acknowledges that the researcher has to make sense of, and interpret, the participant's personal world, thus impacting on the research process (Smith et al., 1999). IPA is concerned with examining how a phenomenon appears, and the researcher is implicated in facilitating and making sense of this appearance as they work with the data (Smith et al., 2009). Acknowledging the role and subjectivity of the researcher in interpreting a phenomenon such as the lived experience of lymphoedema is integral to IPA and provides rigour to the study.
**Ideography**

IPA argues for a focus on the particular, making ideography the third major influence. Goethe states that "the particular eternally underlies the general; the general eternally has to comply with the particular" (cited in Hermans, 1988, p. 12). In IPA the researcher commits to situating participants in their particular contexts and exploring their personal perspectives. In doing so, they seek to understand how participants conceptually interpret or represent their experience of the phenomenon. In this study, ideographic principles were followed by beginning with a detailed examination of each case before moving to more general claims of the whole group. The lived experience of lymphoedema and OMT creates an opportunity to consider how we and other people might deal with lymphoedema, with the potential to reveal how at the deepest level we share a great deal with a person whose personal circumstances may, at face value, seem entirely separate and different from our own (Smith et al., 2009).

**Addressing Rigour in Qualitative Research**

As with all research investigation, qualitative inquiry is concerned with standards of quality, or rigour/trustworthiness. This section defines rigour and gives four criteria for measuring rigour, and explains how it has been achieved in this study.

Tobin and Begley (2004, p. 3) define rigour as "a way of demonstrating the legitimacy of the research process." The definition of rigour or trustworthiness in qualitative research is therefore open to debate, because there are many ways to assess the legitimacy of the research process. However, rigour can be achieved within qualitative research methods if the researcher understands the way in which different paradigms and philosophical beliefs influence the research process (Koch, 1996). The aims of a study must be consistent with the philosophical and methodological approach taken (Laverty, 2008). As outlined above, the theoretical concepts underlying IPA are consistent with the aims of this study.

Rigour may also be assisted if the research process is clearly outlined. The trustworthiness of a qualitative study depends not only on stating what was found, but also explaining how it was done (Ryan-Nicholls & Will, 2009). Systematically collecting, analysing, and presenting data means that findings and the interpretation of those findings are open to evaluation, and are available for future research. Unsubstantiated results can also be identified and reviewed or contested. Koch and Harrington (1998) argue that reflective, self-critiquing research with
detailed explanations of how themes were identified and developed form the basis for rigour in qualitative research.

A wide range of criteria for evaluating rigour exists (de Witt & Ploeg, 2006). Houghton, Casey, Shaw & Murphy (2013) suggest the following criteria as a guideline for rigour or trustworthiness: dependability, credibility, confirmability, and transferability. These criteria are discussed below in relation to the current study.

**Dependability**

Dependability encompasses the degree to which a reader can rely or depend on the data presented. Koch and Harrington (1998) argue that the reader should be able to audit the events, influences, and actions that guided the researcher, so that even if they do not share a researcher's interpretation, they can discern the means by which it has been reached. Auditability and transparency of the data and the researcher's thought process is therefore important.

Particularly in IPA the researcher is considered an instrument of the research (Houghton et al., 2013). It is very important then for dependability, and rigour, to record personal responses and acknowledge the researcher's ongoing interpretative thought processes (Houghton et al., 2013). Dependability can also be achieved through the use of an audit trail of decision-making and through reflexivity (researcher self-reflection).

Dependability in this study is achieved by including examples of the inquiry to analysis process. For instance Appendix E details the questions used during initial inquiry and Appendix G demonstrates methods of individual and over all theme development using a mind mapping technique.

**Credibility**

Credibility of the research describes demonstrating consistent findings and is associated with conducting the research in a believable manner (Houghton et al., 2013). Several ways to enhance credibility include prolonged engagement and persistent observation with the topic of interest, triangulation by using different methods to collect data, peer debriefing, and member checking (Houghton et al., 2013).
Credibility in this study was established through analysis over a 12-month period, observation in the field (observation of three participants’ OMT treatments), support from experienced supervisors, and discussion with peers. Preliminary findings were also presented to a wider research forum, which allowed opportunities to “test” the credibility of data interpretation with an audience from a broad research background. Triangulation through using individual interviews and a focus group to gather data also demonstrated consistency in findings.

**Confirmability**

Confirmability concerns the degree to which results can be confirmed or corroborated by others (Trochim, 2006). Confirmability can be enhanced in a number of ways. The researcher can document the procedures for checking and rechecking the data throughout the study. Another researcher can deliberately challenge the results, or the researcher can purposefully search for and describe aspects that contradict prior observations (Trochim, 2006).

For this study, confirmability was addressed primarily through continual reflection and return to the transcript and at times the audio data for clarification of meaning and tone. This was documented in an ongoing reflexive journal that was kept throughout the research process. Discussion with peers and supervisors also served to corroborate and challenge the researcher’s interpretation of the data.

**Transferability**

Transferability relates to whether the findings of the study can be generalised or applied to other contexts (Trochim, 2006). Although the nature of qualitative research does not allow for outright transferability of findings, by providing context and rich description the reader can decide whether or not findings are transferable to another context. Initial feedback received from presentation of this data to an audience of clinicians and researchers indicated application of results beyond this topic and into clinical practice.

This section has outlined the methodological and theoretical underpinnings of the current study. The discussion began with an outline of why a qualitative approach was appropriate to consider the phenomenon of interest. Following this, an overview of the theoretical principles of IPA was discussed and how they fit with the aims and questions to be answered by this study. The
section concluded with the role of rigour in qualitative research and how the current study has practiced the principles of rigour.

The following section will detail the methods used to undertake the study.

**Methods**

This section discusses details of the larger project including participant recruitment and ethical considerations. The chapter concludes with a discussion of data collection, data management, and data analysis.

**Sampling and Inclusion Criteria**

The aim of this exploratory phenomenological study is to gain insight into the lived experience of lymphoedema and osteopathic care. Consistent with the exploratory nature of the study and the principles of IPA (Smith et al., 2009) a small sample of participants was recruited with an emphasis on obtaining the appropriate depth and richness within the data (Van Manen, 1997). Purposive sampling was used to recruit seven participants for the Eydt study (2014), who were then invited to join the present study.

The inclusion criteria consisted of participants being part of the OMT for lymphoedema study (Eydt, 2014), an understanding of the activities involved in the research process, and demonstrating a willingness to express experiences and opinions about lymphoedema and osteopathic care. Details of the Edyt (2014) study, can be found in Appendix F.

**Recruitment**

Following acceptance into the Eydt study, participants were given a brief information sheet about the current study by the OMT intervention researcher. Participants were asked to express their interest in the qualitative study to the primary researcher of the Eydt study. Following their expression of interest, they were contacted by phone or email to outline the study, details of their participation and given an in depth information sheet on the research process (refer to Appendix B for brief and full information sheets). Once preliminary agreement was obtained, a convenient meeting time was organised. This was a focus group for the first cohort and
treatment or phone interviews for the second cohort. One interview was also conducted in person at the participant’s home, as this was most convenient for her. Recorded verbal consent was given at the beginning of each focus group or interview. Signed consent was obtained by post for individual phone interviews or at the time of the focus group and face to face interview. Refer to Appendix C for consent forms.

**Ethical Considerations**

The research was granted ethical approval by the Unitec Research Ethics Committee for completion of data collection between 27 July 2012 and 27 July 2013 (see Appendix A). Ethical considerations for this study related to informed consent, data collection, anonymity and confidentiality, data security, and withdrawal from the study.

The possibility of psychosocial or emotional harm was outlined when ethical approval for the study was sought (and to participants), and participants were advised of the availability of a free counselling service. No situation arose that appeared to necessitate referral to this service, and no participants indicated an interest in accessing counseling.

**Data Collection**

Two methods were used to gather data. An initial focus group was conducted with three participants, followed by four individual interviews (three by phone and one in person). Initially all data was intended to be derived from focus groups, however due to difficulty coordinating the second focus group, individual interviews were used (as per the research proposal). This approach was justified with the premise that the data contained strong, detailed experiential content, essential for a phenomenological approach (Palmer, Larkin, de Visser, & Fadden, 2010). Both modes of data collection provided rich experiential data, which is discussed further in the following section.

**Use of a Focus Group and Interviews**

In IPA, interviews are generally the first method of data collection. They are ideally suited to facilitating collection of the in-depth experiential data on which analysis is based. Focus groups
are increasingly common in nursing research and can be considered a useful source of information and guidance for approaching research into patient experience of treatment (Streubert & Carpenter, 1999). The primary goal of focus groups is to use data resulting from discussion among participants, for instance where participants question one another or comment on each other’s experiences (Lambert & Loiselle, 2008).

Focus groups are less common within previous IPA research. Smith (2004) suggests that issues may arise around group dynamics such as the emergence of dominant perspectives and the possibility of assumed consensus. These factors have been considered potential impediments to gathering the detailed experiential content required for IPA. Despite this, it is possible that the discussion within focus groups will facilitate personal disclosure more than individual interviews (Wilkinson, 2003). Smith (2004) suggests that discussion of personal experiences in sufficient detail and intimacy, within the presence of the group, provides adequate data for IPA. Having only three participants in the focus group also enabled further space for experiential accounts to emerge.

Both the focus group and the individual interviews utilised a semi-structured interview approach, consisting of identical questions and prompts (refer to Appendix E). A pilot interview was conducted with a peer who was also doing semi-structured interviews, allowing the researcher to rehearse questioning, prompts and to receive feedback. The interviews ranged from 30 minutes to 60 minutes while the focus group lasted for 90 minutes. All were audio recorded. The interview ceased once the participants had shared their experience of the phenomenon and the conversation came to a natural close. The final data set for analysis included five transcripts with a total recording time of four hours and 33 minutes. All data collection took place within three weeks of finishing the OMT intervention.

**Data Analysis**

Interviews were transcribed verbatim by a paid transcriptionist who had completed a confidentiality agreement (Appendix D). Completed transcriptions were then checked for accuracy and anonymised by the researcher. The opportunity to review the transcripts was offered to each participant, but was not taken up.

Analysis and interpretation of the data aimed to consider the participants’ experiences and their attempts to make sense of these experiences. The process of data analysis was guided by IPA, as outlined by Smith, Flowers, and Larkin (2009):
1. Reading and re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving on to the next case
6. Looking for patterns across cases.

After initial analysis of each transcript the extensive process of writing, re-writing and reflecting on the developing themes enabled the analysis to grow and the interpretation of the data to take shape. Mind maps were used to summarise each transcript, to look for patterns across cases, and to develop final themes. Examples of the mind maps can be viewed in Appendix G. Global themes and inter-connections emerged through the process of discussing with supervisors, presenting at a research forum, continual questioning of the findings, and the writing process itself. The gradual clarifying of the themes allowed a deeper and more comprehensive understanding of the lived experience of lymphoedema and osteopathic care.

This chapter has discussed the IPA methodology that guided the research process and outlined the methods and practical steps used to collect and analyse the data. The following chapter will present results of the analysis process, and discussion in the form of a manuscript for publication.
References


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CHAPTER FOUR

Manuscript
Note: This manuscript was prepared in general accordance with the Instructions for Authors (See thesis Appendix I) for the International Journal of Osteopathic Medicine, however, there are three main deviations: i) the manuscript exceeds the prescribed word count in the journal guidelines in order to address the learning outcomes as part of a research thesis; ii) for ease of reading the tables and figures are typeset in the text; and iii) the style of the headings and subheadings also differs from that prescribed for ease of reading. A final note: extended findings not included in the manuscript can be found in Appendix H.
The Continual Search for a Sense of Control:
The lived experience of breast cancer related lymphoedema
and osteopathic care

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Abstract

The continual search for a sense of control: The lived experience of lymphoedema and osteopathic care

Background: Despite numerous studies evaluating interventions to manage breast cancer related lymphoedema (BCRL), patients’ experiences of these interventions have received limited attention. This qualitative phenomenological study explores the lived experience of individuals who participated in a partner study investigating osteopathic manual therapy (OMT) as an adjunct treatment to manage BCRL.

Objective: To investigate the lived experience of women with lymphoedema whilst under osteopathic care.

Method: Seven participants were recruited following the completion of the OMT intervention study. Data were gathered via semi-structured interviews and a focus group and analysed using interpretative phenomenological analysis.

Results: Qualitative analysis produced three major themes: (1) the continual search for a sense of control, (2) uncertainty of lymphoedema progression, and (3) novel treatments and miraculous cures. Much of the experience of BCRL is characterised by feelings of a lack of control, particularly in relation to support received from the health system and the uncertainty of lymphoedema progression. Osteopathic care highlighted the potential benefits from expanding the treatment and self-management focus beyond the affected limb, and the participants’ desire for an intervention to support self-care in the long term. There were high expectations for osteopathy as a new treatment for lymphoedema and narratives of curative treatment for lymphoedema were common in the group.

Conclusion: Results suggest that women with lymphoedema are continually searching for a sense of control. A sense of control for some may be enhanced by self-management that is wider than the affected arm. Infrequent self-care may also be related to a sense of control. Osteopathic treatment for lymphoedema was approached with high expectations. Self-management may be supported through symptomatic relief from treatment.

Keywords: Lymphoedema; Breast cancer; Osteopathy; Qualitative research; Patient experience
**Introduction**

Breast cancer related lymphoedema* is the one of the most problematic and unanticipated side effects of treatment for breast cancer. Lymphoedema is believed to result from damage to the lymphatic system from treatments for breast cancer such as radiotherapy, lymph node dissection and surgery. It is characterised by swelling caused by the accumulation of fluid in body tissues, affecting predominantly the upper limb, but also the trunk and breast. Although generally characterised by upper limb swelling, lymphoedema has profound impacts on psychosocial as well as physical well-being. Physical symptoms may include limb swelling, pain, fatigue, impaired limb mobility and recurrent episodes of infection or inflammation. Psychosocial consequences involve symptom distress, anxiety, anger, fear, change in role function, lack of social support, loss of confidence in the body and social avoidance. The multifaceted nature of lymphoedema can have a detrimental effect on quality of life compared with breast cancer survivors without lymphoedema.

Lymphoedema is primarily a self-managed condition, and as such relies heavily on the motivation of those affected to prevent progression with thorough self-care. Daily tasks may include wearing a compression garment, avoiding activities that increase the risk of developing swelling or infection in the arm, self-massage, and skin care.

Treatment for lymphoedema aims to decrease swelling and prevent additional accumulation of fluid, ideally slowing or reversing effects. International guidelines on management recommend compression, massage, skin care, exercise and elevation. The efficacy of interventions to manage lymphoedema remain inconclusive and primarily guided by clinical experience. Although some interventions can significantly reduce swelling, individuals with lymphoedema still remain tied to daily self-care to manage the progression of swelling.

Arm volume or circumference is a common outcome used to determine significant and reproducible change following treatment. Research suggests, however that the severity of swelling in the affected limb has little correlation with the level of symptom-related distress experienced by those with lymphoedema. In addition, the extent of psychological and

*There are several different forms of lymphoedema, for the purposes of this article breast cancer related lymphoedema will be referred to as lymphoedema.
emotional distress appears to be more related to how successfully individuals adapt to and manage their illness complications, rather than swelling severity.\textsuperscript{4,13} Within the literature there is growing acknowledgement of the psychosocial and emotional burden of lymphoedema and the impact this has on the ability to manage illness complications.\textsuperscript{13}

Existing qualitative literature paints lymphoedema as a complex phenomenon, with wide-ranging effects. Four key categories of experience emerge from the literature. The first category identified is the shock of initial swelling and diagnosis. This is characterised by feeling unprepared for the potential development of lymphoedema, and a lack of information on the risks following cancer treatment.\textsuperscript{14,15} Shock of the permanence of the condition and the sheer volume of symptoms\textsuperscript{15} has been reported, alongside a denial of severity and difficulty maintaining self-care.\textsuperscript{16} The search for information and treatment is the second main theme. Patients report feeling belittled, and frustrated by the lack of knowledge from health professionals.\textsuperscript{17} Inappropriate or delayed advice are also discussed.\textsuperscript{18,19} Specialist lymphoedema services when accessed were praised and relied upon.\textsuperscript{16,20}

A third key theme is the profound impact on daily life. Individuals report a decreased function of their arm. They experience a loss of normalcy in appearance, self-image, occupation and relationships\textsuperscript{14,18,19} and ongoing discomfort.\textsuperscript{15} Coming to terms with swelling and coping is a fourth area. Individuals with lymphoedema learn to get on with things, reappraise functionality and health\textsuperscript{14} and practice coping strategies such as maintaining a positive outlook, commitment to treatment and adapting to change.\textsuperscript{16,18,20}

Despite a wide range of studies on the causes, experience, and treatment of lymphoedema, to date there is little specific research on the experience of treatment for lymphoedema. Treatment experiences mentioned within qualitative literature suggest that treatment for lymphoedema is often time-consuming and costly.\textsuperscript{19,20}

Preliminary evidence suggests OMT may provide a unique and effective treatment for lymphoedema alongside self-management.\textsuperscript{21} The current study shared participants with an intervention study considering OMT to manage lymphoedema alongside participants’ usual self-care routines.\textsuperscript{21} The outline of the Edyt study can be found in Figure 1.

\textit{The Purpose of the Article}

This paper provides insight into the experience of lymphoedema and the experience of OMT. Conclusions drawn from this data may benefit women with lymphoedema, health practitioners who treat women with lymphoedema and also contribute to the knowledge on experience of OMT.
Methods

Methodology
This study was guided by an interpretative phenomenological analysis (IPA) approach. IPA is concerned with the perception of the individual experiencing the phenomenon, as opposed to an attempt to produce an objective statement of the phenomenon. The hermeneutic aspect of IPA also acknowledges the inherent subjectivity of the researcher in interpreting the participant's perception of a phenomenon. This methodology guides the researcher to focus on the essence of the lived experience, making it ideal for exploring topics where little is known, which is the case with the experience of OMT for lymphoedema.

Participants
All participants in the intervention study were invited to take part in this qualitative study. Recruitment involved the main researcher of the Edyt study passing on an information sheet indicating the aims of the study and participation details. All seven participants of the intervention agreed to take part, later signing a consent form specific to this study. Ages ranged from 51 to 72 and all had unilateral breast cancer related lymphoedema of varying onset and duration. See Table 1 for participant demographics.

Table 1. Participant demographics, LO = lymphoedema

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Difference in volume between arms</th>
<th>Reported onset post surgery</th>
<th>LO duration at time of study</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>51</td>
<td>27%</td>
<td>1 month</td>
<td>2 years, 3 months</td>
</tr>
<tr>
<td>2.</td>
<td>56</td>
<td>8%</td>
<td>1 month</td>
<td>10 years, 6 months</td>
</tr>
<tr>
<td>3.</td>
<td>61</td>
<td>18%</td>
<td>4 months</td>
<td>2 years, 7 months</td>
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<tr>
<td>4.</td>
<td>67</td>
<td>39%</td>
<td>6 years</td>
<td>1 year, 10 months</td>
</tr>
<tr>
<td>5.</td>
<td>51</td>
<td>27%</td>
<td>1 year 7 months</td>
<td>2 years, 5 months</td>
</tr>
<tr>
<td>6.</td>
<td>72</td>
<td>15%</td>
<td>1 year</td>
<td>10 years, 5 months</td>
</tr>
<tr>
<td>7.</td>
<td>54</td>
<td>62%</td>
<td>3 years</td>
<td>1 year</td>
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Data Collection
One focus group (90 minutes) and four individual interviews (30 to 60 minutes) were conducted, with the data collection method based on participant availability. Three interviews were by phone and one in person. All data collection took place within three weeks of finishing the OMT intervention.
Using a combination of data collection methods added diversity and depth to the data set. In phenomenological research, interviews are a common way of collecting rich experiential data. Focus groups are increasingly used in nursing literature on patient experience, and can facilitate more personal disclosure than interviews. An identical semi-structured interview protocol was conducted with the focus groups and interviews (refer to Table 2). The broad guiding questions led into in-depth discussion of the areas most relevant to the participants.

Table 2. Semi-structured interview protocol

What are your thoughts on osteopathic treatment?
- Initial impressions of the treatment?
- Any concerns about the treatment?
- How did you feel during/after treatment?
- Has the treatment influenced the management of your lymphoedema?

How would you describe your experience of lymphoedema?
- What is unknown about this condition?
- What do you think health professionals don’t know about the experience of lymphoedema?
- What are some of the key things that define your experience of lymphoedema?

Ethics

The study was approved by the Unitec Research Ethics Committee. Informed consent was obtained in person at the focus group, or verbally and then by post for the interviews by phone. Participants were reminded at the beginning of the interview or focus group of confidentiality amongst the focus group members and researcher, the right to withdraw, and the availability of counselling services if needed (no participant requested this service). The transcriptionist also signed a confidentiality agreement.

Data Analysis and Rigour

Analysis and interpretation of the data focused on the participants’ experiences and their attempts to make sense of these. This process was guided by IPA as detailed by Smith, Flowers & Larkin. Each transcript was coded individually for emerging themes, before looking for patterns across cases. The focus group data were also considered individually and as a group,
to ensure detailed experiential data. Four main themes were developed out of initial coding then further analysis lead to theme interpretation and final three themes and subthemes.

Initially, in analysis the lived experience of lymphoedema and the lived experience of osteopathic treatment were considered separately. In considering the summarised transcripts for connections between themes, the experience of the osteopathic care developed into a lens or magnifying glass for the lived experience of lymphoedema rather than a separate part. Both of these aspects could have been reported separately, however when considered together both illuminate part of the lived experience of breast cancer related lymphoedema. Thus, in the following section the results of both aspects of the study are presented and discussed together.

**Results**

Three major themes were identified: the search for a sense of control, uncertainty of lymphoedema progression, and novel treatments and miraculous cures. Themes and subthemes are presented in Table 3. All quotes are followed by an identifying participant number and page reference to the raw data.

**Table 3. Themes and subthemes**

<table>
<thead>
<tr>
<th>Theme 1: The continuing search for a sense of control</th>
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<tbody>
<tr>
<td>Subtheme: “to have a sense of control”</td>
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<tr>
<td>Subtheme: lack of support from the health system</td>
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<tr>
<td>Subtheme: it’s not just about the arm</td>
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<td>Subtheme: longing for effective treatment and long-term support</td>
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<tr>
<th>Theme 2: Uncertainty of lymphoedema progression</th>
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<tr>
<td>Subtheme: damage from treatment</td>
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<tr>
<td>Subtheme: everyday risks</td>
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<td>Subtheme: concerns about the future</td>
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<th>Theme 3: Novel treatments and miraculous cures</th>
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<tr>
<td>Subtheme: looking for the quick fix</td>
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<tr>
<td>Subtheme: high hopes for osteopathic care</td>
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**Theme 1: The Continuing Search for a Sense of Control**

Control in the context of health, suggests the ability to influence a health condition. Much of the experience of lymphoedema that was reported by participants was characterised by feelings of a lack of control, for instance in accessing appropriate support from the health system, and in a fear of further progression of lymphoedema through treatment, daily life and aging. For the participants of this study finding ways to cope with lymphoedema to gain a sense of control showed itself in several different ways.

**Subtheme: “To have a sense of control.”**

Developing a sense of control over lymphoedema was a theme that emerged strongly from six of the seven participants. The search for a sense of control was present in several different expressions. Some participants responded with a detailed whole-body approach to managing their lymphoedema, while others sought to distance themselves from their experience of lymphoedema. Three participants reported actively identifying and even recording factors that appeared to influence their symptoms. Influencing factors ranged from things that affected the arm directly such as wearing a compression sleeve, driving and self-care activities, to wider influences from fluctuation in symptoms according to the time, dietary changes, exercise, and stress levels. Being aware of these factors was seen as an important part of their self-management and enhanced a feeling of control over lymphoedema.

To have a sense of control...and that, I think it, for me it’s about being able to link the status of my arm with things that are within my control. Like, what have I done, what have I eaten, how stressed have I been, what have been my activities, what could have been the things that I do have control over, what has been the impact on my lymphoedema. [ ] So you have a sense that you can change the things that are modifiable whereas with lymphoedema a lot of it feels unmodifiable (P3, 26).

Alternatively, creating distance from the symptoms of lymphoedema emerged as the primary strategy for creating a sense of control over lymphoedema for three of the participants.

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† [ ] – indicates some text omitted.
I could take it more seriously but then you waste time worrying about yourself and I'm not into that... I don't want to get worried about it. If you start getting concerned about it you get a bit of a thing about it and I don’t want that... They take over (P6, 10).

Focusing or dwelling on the experience through self-management tasks, or thinking about the condition worsening, seemed to threaten a potential loss of control.

You've got a choice that you either get on with it or you are in a foetal position under the bed for the rest of your life (P7, 12).

For these participants, keeping on with life as normally as possible increased a sense of control over lymphoedema.

**Subtheme: Lymphoedema - it's not just about the arm.**

The search for a sense of control was also evident in the experience of OMT. Participants commented on benefits from the treatment that ranged from improved shoulder movement, rib movement and breathing, increased flexibility in areas of scarring, as well as changes in skin texture and decreased heaviness; an experience that emphasised how management of the lymphoedema was about more than just the affected arm.

With the osteopathy, the day, the evening that I had it and the next day I was really, really tired, really tired, and then the next day after that I felt fantastic. So whatever she was doing, I did find really a lot of benefit. I needed to rest quite a bit the day after but I also felt there was quite a bit of healing happening, it wasn’t just my arm. It was my body (P5, 3).

Education and reassurance also appeared to be key components of the therapeutic encounter, which brought new perspectives and options for how lymphoedema could be managed for some participants. Participant two describes the advice on breathing she received:

[The practitioner] practiced some of that [breathing] with me and told me about this book so I think it, that is helping me manage, it’s not exactly the lymphoedema I suppose... so that's sort of what I got out of it, that's what I’m now carrying on with trying to improve (P2, 23).

At least through the treatment you notice that maybe there's something that could be done about it (P4, 13).

The osteopathic care reinforced an approach to managing lymphoedema that addressed wider areas of the body, as well as the arm. This appeared to align well with the approach of some
participants who gained a sense of control managing their lymphoedema from strategies that engaged the whole body.

**Subtheme: Feeling a lack of support from the health system.**

Five of the seven participants recounted stories of delayed support, poor and inconsistent advice, and lack of knowledge about lymphoedema from some health professionals involved in their care.

> When I was new, I found it incredibly frustrating and I felt that it [lymphoedema] was very minimised. It’s not something that can be cured or someone can do something about. So they don’t have a sense of ... okay let’s get on top of this (P3, 36).

One participant describes her symptoms and experience of care after the initial onset of lymphoedema that followed shortly after her breast cancer treatment:

> Why even tell me that its treatable if they catch it early enough when they don’t give a toss... this is my arm, this is my job, this is my life, and I have to ring them, it was urgent with lymphoedema but I don’t think they realised the urgency and how you can’t sleep, you can’t function ’cause your arm’s killing you (P1, 38).

A lack of control over accessing appropriate and timely support services for lymphoedema was a source of despair and alienation for some participants.

**Subtheme: Longing for effective treatment and long-term support.**

The search for a sense of control over lymphoedema was also evident in the participants looking for treatment that could be relied upon. Five of the seven participants enquired after the efficacy of long term osteopathic care, and queried whether the frequency of treatment for long term care had been studied. The intervention study provided a new treatment for lymphoedema that highlighted a longing and an ongoing search for more effective care.

> I had this big reduction in my arm and I suppose that was over, it was probably over six months that I was with the hospital... So I wasn’t expecting a lot more but I did get a little bit more, but if I had this for six months what I’m thinking is well I wonder what that would be like? (P2, 12).
I have had my arm bound as well for a week and it nearly killed me… it was excruciatingly uncomfortable and painful… I actually felt well this [osteopathic treatment] would be more beneficial for me to do this longer term than having it bound… (P1, 13).

These quotes represent the consideration of regular osteopathic care as a viable option to help them manage lymphoedema, and may also be representative of a wider longing for long-term individualised support to help manage their lymphoedema.

**Theme 2: Uncertainty of Lymphoedema Progression**

Concerns for damage to the affected arm and fear of the further progression of the lymphoedema were voiced by all of the participants. For some this was expressed as fears that osteopathic treatment could potentially increase swelling. For others, activities of daily living such as lifting and gardening represented potential threats to developing infection and increasing swelling. Several participants also mentioned aging with lymphoedema, with concerns about financial status and uncertainty over lymphoedema worsening with age.

**Subtheme: Damage from treatment.**

Some participants approached osteopathic treatment with trepidation. Two participants reflected on concerns that the arm might be damaged by the treatment and worsen their symptoms and swelling. These apprehensions were addressed and discussed by the primary researcher of the intervention study. Anxiety appeared related to a further loss of function, and loss of the hard work that was put in to contain the swelling. Wider well-being and health was also seen as at risk if the lymphoedema progressed.

*I was a little bit apprehensive… I didn’t want to go backwards as far as my health or my arm was concerned… I didn’t want it to do any damage and yeah, I’m a little bit over protective of it probably (P1, 2).*

Osteopathic treatment was described as firmer and more direct, than other treatments such as manual lymphatic drainage (MLD), it was also more vigorous with aching and soreness noted, particularly in the pectoral region. For most this was perceived as novel, rather than threatening. However, participant three reported a worsening of her symptoms after five treatments and did not complete the sixth treatment. The participant communicated full support for the research, despite the withdrawal. The osteopathic treatment she experienced on
her affected arm increased her symptoms and contrasted with how she expected the affected arm to be treated.

I definitely have been really careful in the way its [the arm] treated and very gentle, only stroking and this [osteopathic treatment] was kind of climbing in and getting into other structures (P3, 5).

**Subtheme: Everyday risks**

Activities of daily living were also a source of physical threats to the progression of swelling. Concern was associated with activities such as lifting, gardening, typing and walking. Participant five describes her reaction after the everyday action of picking up a tea-towel lead to being stung by a bee, illustrating the underlying vulnerability of the arm to infection and the difficulty of protecting the arm from damage:

I freaked because I realised that could be quite serious for the hand and then when I managed to get the sting out [ ] it was fine and it didn’t swell up, you kind of go wow, okay, so it’s quite precarious 'cause you know, who knows? Who knows what would really damage [the arm], you know, if the medics are saying don’t have an injection, which is the tiniest of skin openings in sterile surroundings then you think oh god… (P5, 18).

**Subtheme: Concerns about the future**

Concern for the progression of lymphoedema was linked with aging and the raised questions and uncertainty about the ability to cope with lymphoedema in the future.

I sometimes do wonder, if it’s like this now, will it go further…[ ] it’s not that I’m worried about it but yes it does cross my mind, where is it going to end up (P4, 7).

Appropriate management of lymphoedema for some of the participants required considerable personal financial resources to supplement or substitute what was available through the public healthcare system. Aging also represented a loss of financial resources and changing circumstances, with a loss of health and wellbeing alongside the inability to appropriately manage lymphoedema.

I need a compression garment. I wear mine every day, they are worn out within three months but they cost $600 and through the DHB [District Health Board] you only get two a year. So really after three months is it that effective or am I going backwards? ...I sort of
think well next time I'll buy two but as I get older and maybe when you eventually retire you're never going to be able to afford that (P1, 33).

**Theme 3. Novel Treatments and Miraculous Cures**

Attitudes toward treatment for lymphoedema were highlighted by inquiry into the osteopathic care. One particular attitude that emerged was the high expectations for osteopathy as a new treatment for lymphoedema. Six of the participants had tried a range of treatment approaches such as bandaging, MLD, kinesio-taping, naturopathy, and homeopathy. Hope for a new and miraculous treatment to fix lymphoedema was something that both the participants and their friends and families contributed to.

**Subtheme: The continual search for the quick fix**

Hoping for a “miracle cure” or “quick fix” was a common theme among all the participants, no matter how pragmatic their approach to lymphoedema. The tantalising idea of returning to a pre-lymphoedema state was typified by stories of lymph node transplants, laser therapy and liposuction for lymphoedema. Five participants mentioned a local story that had caught their imagination and also those of their friends and family:

_They had this story about this one woman who has, had very severe lymphoedema and she had it treated with liposuction. I mean, god, I mean I don't know... What I'm saying is that there are treatments coming out all the time... this woman reckoned that it sort of cured her lymphoedema (P5,16)._ 

**Subtheme: High hopes for osteopathic care**

All the participants appeared to have high hopes of osteopathic treatment although their definitions of success differed. For some success was related to osteopathy as an effective management option:

_Well I was hoping I could ditch my compression garment, for life!... oh is this the answer! [laughter]. " (P1, 12)._ 

For others this expectation appeared to be hope for long term reduction of swelling:
I had fully believed that it would just go away, it would be sorted, but it didn’t, but I think it is probably better than it was but it is not back to what I would like it to be (P7, 4).

Those that hoped for a curative approach for lymphoedema were faced with disappointment for the lack of a lasting change from the treatment. Symptomatic relief appeared less important and did not fit into their definition of a successful treatment for lymphoedema. These high expectations and hopes for a new treatment for lymphoedema left some women vulnerable to suggestion and unrealistic beliefs about lymphoedema treatment.

**Discussion**

Theme one: the continual search for a sense of control, brought up the constant tension between experiencing a lack of control over the condition, and the ways in which participants tried to establish control over the condition. A study from Meiklejohn et al.\(^\text{16}\) also discuss the concept of fluctuations in a sense of control in the experience of lymphoedema, highlighting congruence in the findings of this study to similar research.

Osteopathic care complemented the active, whole-body approach that some participants took to managing their lymphoedema. The discussion of the experience of treatment emphasised how the OMT practitioner addressed physical compensations and incorporated education to manage dysfunction beyond the arm. Meiklejohn et al.\(^\text{16}\) discuss the all-encompassing nature of lymphoedema, referring to its effects beyond the affected limb. These effects create an altered sense of normalcy, lack of independence and disability.\(^\text{16}\) The results of the present study, however, provide an alternative perspective on the all-encompassing nature of lymphoedema. They suggest that the whole body can be implicated in improving symptoms of lymphoedema. As much of the focus in lymphoedema is on reducing the size of the limb, emphasising the wider aspects of lymphoedema management may provide a sense of control, enhancing self-management.

For some participants focusing on the effects of lymphoedema made them worry that they might lose the ability to cope. This is identified in the results as a loss of sense of control over lymphoedema. Distancing themselves from the experience of symptoms and daily self-care appeared to give them a sense of control over lymphoedema. Ridner et al.\(^\text{18}\) present a similar theme of ‘damaging attempts to regain a sense of normalcy’ describing how the wish to return normal results in a reluctant approach to self-care. These findings suggest that infrequent self-
care may be associated with women who wish to separate or disconnect themselves from the experience of lymphoedema.

A feeling of a lack of support from the health system was a source of frustration and despair and contributed to feelings of a lack of control over lymphoedema. Such issues have been reported extensively in the literature. Lack of support from traditional health care resources may be a motivating factor for the willingness to try new treatments such as OMT.

The participants’ longing for an effective treatment and ongoing support for self-management of their condition was highlighted by the experience of osteopathic care. This was considered by the majority of the participants as a long-term management option, perhaps as it reportedly provided symptomatic relief as well as wider support such as education and reassurance from the osteopathic practitioner.

There is a lack of emphasis in the lymphoedema intervention literature on symptomatic relief from treatment. However, symptomatic relief alongside regular practitioner support could have a positive impact in supporting self-management. The theme of searching for a long-term management option suggests that symptomatic relief may complement standard self-care. These aspects may contribute to a sense of control over lymphoedema.

The fear and uncertainty of lymphoedema progression threatened the ability to cope with daily life and permeated thoughts of the future. These concerns are reflected in similar findings in two recent studies with the fear of deterioration, permanent uncertainty of lymphoedema status and the fear of infection causing deterioration or progression of lymphoedema.

Concerns about osteopathic treatment causing damage to the arm were mentioned. These concerns may arise from self-care guidelines regarding the fragile and inflammatory nature of lymphoedema and the experience of gentler treatments such as MLD. Some participants experienced OMT as firmer and more dynamic than expected, however concerns were only expressed by two participants. Participant three reported an adverse reaction to the treatment. The literature reports this is not uncommon in the area of treatment for lymphedema and is discussed further in Eydt’s study.

Distrust or trepidation regarding treatment is also seen in a similar theme of disease management failure highlighted by Ridner et al’s study, drawn from experiences of the failure of some health professionals to manage lymphoedema appropriately. Similar to the Ridner study, several participants interviewed for this study remarked on incidences (in the wider healthcare community) of a lack of appropriate management and inconsistent knowledge about lymphoedema. Whether there is actual or perceived harm occurring from some treatment for
lymphoedema, both studies suggest that the concerns for further progression of lymphoedema through mismanagement requires acknowledgement and further investigation from a patient-centred approach.

Despite some concerns about progression of lymphoedema, many of the participants had tried many treatments for lymphoedema, both conventional and unconventional approaches. Literature suggests that trying several treatments may not be uncommon for women with lymphoedema. There were high expectations for the effectiveness of osteopathic treatment. The effectiveness or success of the treatment was for some related to symptomatic relief and management of their condition and for others related to fixing or curing their lymphoedema for good. Clearly, those that were expecting a permanent decrease in arm volume were disappointed.

Osteopathy was a treatment option that none of the participants had previously experienced for lymphoedema. Whether all new or untried treatments for lymphoedema are also approached with high expectations is not clear in the available literature at this time. These expectations highlight the vulnerability of this population to suggestion about new treatments for lymphoedema. The role of practitioners in contributing to treatment expectations is also a topic for further investigation.

As well as high expectations, the hope for a novel treatment that could dramatically benefit or cure lymphoedema was a common narrative. This theme was differentiated from the subtheme of "longing for effective treatment and long-term support" through the connection to less realistic hopes. Hoping for exploratory or novel treatments can be interpreted as a coping strategy for managing a chronic condition. From a theoretical perspective, Giddens’ concept of authority vs. uncertainty is applied to further interpret hope as a coping strategy in this context.

Authority represents the reality of the diagnosis of lymphoedema, which is chronic and progressive. However, there is uncertainty, which is encompassed by doubting reality – for instance, hope that a successful treatment will be found. In this sense hope becomes an essential part of coping with a chronic illness like lymphoedema; it becomes a place of retreat and a means by which the future is constructed. A person without hope becomes trapped in the present because of an inability to project toward a future that looks any different from reality. The theme of 'novel treatments and miraculous cures' embodies hope for considering a better future. Acknowledging the role of hope in management of lymphoedema may require some reflection about the purpose of what may at first appear as unrealistic beliefs. Where these beliefs may be damaging is when regular self-care practices are neglected in favour of 'holding
out’ for a miraculous cure. Further consideration of the practitioner’s role in moderating these beliefs is beyond the scope of this project.

**Limitations:**

There are several limitations to this study. The small number of individuals means that transferability of the findings is limited. The variability of lymphoedema onset and duration of the participants also limit the transferability of the research. Bias toward osteopathy may also be present as the researcher is an osteopathic student. The participants’ gratitude for research investigating lymphoedema was noted in this study and another. The wish to increase awareness and support of lymphoedema may be a motivating factor for their participation.

**Conclusions**

Results of this study suggest that women with lymphoedema are continually searching for a sense of control. A sense of control for some may be enhanced by self-management that is wider than the affected arm. Self-management may be supported through symptomatic relief from treatment coupled with regular practitioner support. Importantly, infrequent self-care may also be related to a sense of control. Women who wish to separate or disconnect themselves from the experience of lymphoedema may avoid regular self-care.

Osteopathic treatment for lymphoedema was approached with high expectations, which emphasises the importance of discussing treatment expectations with women with lymphoedema. Finally, narratives of novel treatments for lymphoedema may represent a coping strategy for dealing with this chronic condition.

**Clinical Recommendations**

- Self-management may be supported by emphasising a whole body approach to care beyond just the affected arm
- Practitioners are advised to enquire into patient expectations of treatment to establish what they expect to receive.

**Further Research**

The place of symptomatic relief in supporting self-management needs to be explored further alongside interventions for lymphoedema. Further research could also address attitudes to treatment, use of multiple treatments, and what is considered a successful treatment from the
patient’s point of view. Lastly, women’s concerns about further damage due to treatment, and the experience of medical mismanagement also warrant further investigation.

**Relevance of the Study**

This study is relevant for practitioners working within the field of breast cancer related lymphoedema and osteopathy.
References


APPENDICES
Appendices

Appendix A

Ethics Approval

Kate Henderson
25 Hakanoa St
Grey Lynn
Auckland, 1021

23.8.12

Dear Kate,

Your file number for this application: 2012-1043
Title: The lived experience of women with arm lymphedema related to previous breast cancer treatment, and those who are under osteopathic care.

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and has been approved for the following period:

Start date: 27.7.2012
Finish date: 27.7.2013

Please note that:

1. The above dates must be referred to on the information AND consent forms given to all participants.

2. You must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.

You may now commence your research according to the protocols approved by UREC. We wish you every success with your project.

Yours sincerely,

Gillian Whalley
Deputy Chair, UREC

cc: Elizabeth Niven
Cynthia Almeida
Appendix B

Participant Information Sheets:
Brief initial information sheet

Would you like to talk about your treatment experience?

OSTEOPATHIC TREATMENT FOR Lymphoedema

My name is Kate Henderson, I am doing research conducted within the Master of Osteopathy programme at Unitec, Auckland and I am interested in hearing your experiences and thoughts about osteopathic treatment for lymphoedema.

Why this topic?
Osteopaths (and other health professionals) can gain a lot from understanding what it’s like to experience treatment for lymphoedema – such as improve elements of techniques, or the information they provide to their patients.

Participating in this research means you help us understand a little bit more about what it is like for you to have lymphoedema, and how osteopathy can help. You may also find it useful to hear about the experiences of other women who have lymphoedema, and are receiving osteopathic care.

What is expected of you as a participant?
- A willingness to talk about your experience of osteopathic treatment in a group setting of between three to six women who have lymphoedema.
- Being able to share, discuss and listen to other women talk about their thoughts and experiences of osteopathic treatment.

Logistics
- The focus group will be up to 90 minutes and take place at Unitec Institute of Technology on Carrington Rd in Mt Albert, within two weeks after you finish treatment.
- You may be invited for an individual interview to clarify ideas or discuss your experience further.
- The discussions and interviews will be audio recorded, transcribed, and you will remain anonymous outside of the group.

I’m interested, what next?
- Please call or text me on 021 029 61401, or email me at kate.henderson2@gmail.com and we can talk more about what is involved in this project.
Title of Research Study:

“The lived experience of women with arm lymphoedema related to previous breast cancer treatment, and those who are under osteopathic care”

INFORMATION SHEET FOR PARTICIPANTS

Dear Participant,

You are invited to take part in a research study to examine the experiences of living with lymphoedema associated with breast cancer treatment. I invite you to take part in a focus group or interviews to ask you about what it is like to have lymphoedema and receive osteopathic treatment. This research is part of a Masters thesis at Unitec for the Masters of Osteopathy.

Before you decide whether to take part in the study it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information and discuss it with others if you wish. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep. You will also be asked to sign a consent form. You can change your mind up to 10 days after receiving the transcript and withdraw from the study without giving a reason.

You are welcome to phone me if you would like any further information.

The purpose of the research study is to examine / explore your experiences living with lymphoedema whilst receiving osteopathic treatment. I would like to ask questions in a focus group with up to five other women with lymphoedema about what it is like for you, your thoughts, your feelings as well as situations, events, places and people connected with your experience.

The study will involve up to nine participants, who take part in focus groups of up to six, but most likely three per group. The focus group discussion will take approximately 90 minutes. The location of the focus group will be at the Unitec Mt Albert Campus, Carrington Rd, Mt Albert.

In addition to taking part in a focus group, there will also be an option of individual interviews offered to some participants. Interviews will be used to clarify areas of interest to the researcher that may arise out of discussions in the focus group. Interviews will be conducted at a location convenient to the participants involved and last approximately 30 minutes.

The information gained from this research will be used to make recommendations for best practice for osteopaths and other health practitioners and will offer insights into the experiences of what it is
like to live with the condition of lymphoedema. The results of the study may also lead onto further studies into lymphoedema.

Talking about what it is like to have lymphoedema may be upsetting for you. You are free to stop the focus group at any time if you do not wish it to continue. If the discussion or questions upset you and you feel you would like some additional help after the focus group and / or interview, free counselling is available through the Auckland branch of the Cancer Society.

The focus group and interview will be recorded on audio tape and then transcribed onto a computer by a transcriber who has signed a non-disclosure agreement. The audio tapes will be stored in a locked secure place at all times and the computer data will be protected from intrusion also. The audio tapes will be destroyed at the end of the study. Your response will be treated with full confidentiality and only code numbers or false names will identify anyone who takes part in the research. You can request a copy of the transcript if you wish. The interviews will be analysed by Kate Henderson. At the end of the research I will write a report and the results may be published in peer reviewed journals and conference presentations. No research participant will be identifiable from any publications. This study has been reviewed and approved by the Unitec Research Ethics Committee.

Please do not hesitate to contact me if you would like further information - contact details are provided below.

Many thanks for taking the time to consider being part of this research project.

Yours sincerely,

Kate Henderson

Primary Researcher
021 02961401
kate.henderson2@gmail.com

Supervisor:
Elizabeth Niven
eniven@unitec.ac.nz
Appendix C

Participant Consent Forms: Interviews consent form

Thank you for agreeing to participate in this research project being undertaken for the Master of Osteopathy programme at Unitec New Zealand.

Consent Form for Interviews

The lived experience of women with arm lymphedema related to previous breast cancer treatment, and those who are under osteopathic care.

Name of Participant:______________________________

I have had the research project explained to me and I have read and I understand the information sheet given to me.

I have had the opportunity to ask questions and have them answered.

I understand that I don't have to be part of this if I don't want to and I may withdraw from the interview at any time.

I may withdraw or edit any or all of my contribution to the focus groups and/or interview within ten days of receiving the transcript.

I understand that everything I say is confidential with the researcher and none of the information I give will be used in a way that identifies me. I understand that the only persons who will know what I have said will be the researcher, the researcher’s supervisors and Erin Eydtt who is conducting a related study. I also understand that all the information that I give will be stored securely on a computer and in hard copy for a minimum period of five years.

I understand that my discussion within the interview will be recorded and then transcribed by a hired transcriber who has signed a confidentiality form.

I understand that I will receive a copy of the transcript and I will be provided with a copy of the finished research document.

I have had time to consider everything and I give my consent to be a participant in this study.

Participant Signature: ………………………… Date: ……………………………

Project Researcher: ………………………… Date: ……………………………

Participant/Researcher Copy

This study has been approved by the Unitec Research Ethics Committee from (27/07/12) to (27/07/13). If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (Ph: 09 815 4321 ext.7254). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

66
Focus Group Consent Form

Thank you for agreeing to participate in this research project being undertaken for the Master of Osteopathy programme at Unitec New Zealand.

Consent Form for Focus Groups

The lived experience of women with arm lymphedema related to previous breast cancer treatment, and those who are under osteopathic care.

Name of Participant: ____________________________________________________

I have had the research project explained to me and I have read and I understand the information sheet given to me.
I have had the opportunity to ask questions and have them answered.
I understand that I don't have to be part of this if I don't want to and I may withdraw from the focus group at any time.
I may withdraw or edit any or all of my contribution to the focus groups within ten days of receiving the transcript.

I understand that everything I say is confidential with the researcher and none of the information I give will be used in a way that identifies me. I understand that the only persons who will know what I have said will be the researcher, the researcher’s supervisors and Erin Eydt who is conducting a related study. I also understand that all the information that I give will be stored securely on a computer and in hard copy for a minimum period of five years.

I understand that my discussion within the focus group will be recorded and then transcribed by a hired transcriber who has signed a confidentiality form.

I understand that I will receive a copy of the transcript and I will be provided with a copy of the finished research document.

I have had time to consider everything and I give my consent to be a participant in this study.

Participant Signature: ___________________________ Date: ___________________________

Project Researcher: ___________________________ Date: ___________________________

Participant/Researcher Copy

This study has been approved by the Unitec Research Ethics Committee from (27/07/12) to (27/07/13). If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (Ph: 09 815 4321 ext.7254). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix D

Transcriptionist Confidentiality Form

NON-DISCLOSURE OF INFORMATION

The lived experience of women with arm lymphoedema related to previous breast cancer and those who are under osteopathic care

Transcribing Typist

I ______________________________ agree not to disclose the names of, or any information that would lead to the identification of the participants in the research study being undertaken by Kate Henderson.

The audio-recordings, transcription hard copies, and computer files will not be made available to anyone other than the researchers and will be kept securely while in my possession.

I will not retain any copies of the audio-recordings, computer files, or transcriptions.

Signed: ______________________

Name: ______________________

Date: ______________________
Appendix E

Question Protocol

Experience of osteopathic treatment

- What are your thoughts about osteopathic treatment?
- What were your initial impressions?
- Do you have any concerns about osteopathic treatment for lymphoedema?
- How did you feel during/after the treatment?
- Has the treatment influenced your management of your lymphoedema?

Lymphoedema experience

- How would you describe your experience of lymphoedema?
- What is unknown about this condition?
- What do you think health professionals/osteopaths/physical therapists/lymphoedema therapists, don't know about the experience of lymphoedema?
- What are some key things that define your experience of lymphoedema?
  - Prompt: imagine you had to describe it to someone who had never experienced a chronic condition
- What are some of the key things that define your experience of lymphoedema?
Appendix F

Outline of Eydt (2014) study:

Osteopathic manual therapy (OMT) as an adjunct treatment for management of breast cancer related lymphoedema: A prospective case series.

Osteopathic treatment aims:

- To improve lymphatic drainage of the affected arm to reduce arm volume

Research structure:

- 2 weeks baseline, 3 weeks intervention, 2 weeks withdrawal

Intervention:

- 30 minute OMT treatment alongside standard care twice a week for three weeks

Outcomes measured:

- **Time series data (7 weeks):** daily measurement of bilateral arm volume, arm symptoms and function and weekly measurement of quality of life
- **Pre and post treatment data:** bilateral arm volume, arm symptoms, bilateral shoulder range of motion

Techniques used:

- Muscle energy technique, soft tissue, myo-fascial release, articulation, high velocity low amplitude manipulations, specific lymphatic pumping techniques

Inclusion criteria:

- Stage 1 or 2 unilateral arm lymphoedema associated with past breast cancer, which was currently in remission.

Exclusion criteria:

Numerous conditions were considered to warrant exclusion from the study, including fractures, heart failure, pregnancy, anaemia, history of deep vein thrombosis, acute infection, active malignancy, renal insufficiency, and history of contra-lateral breast cancer or arm lymphoedema.

Written permission was sought from the relevant oncologist for the inclusion of one woman not considered to be in remission.
Appendix G

Additional notes on analysis

Mind map 1. Example of key themes from participant 4.
Mind map 2. Bringing together overall themes with three main areas: control, vulnerability and competence/coping

Note: the theme of ‘vulnerability’ – developed into the final themes of ‘novel treatments and miraculous cures’ and ‘uncertainty of lymphoedema progression’,
Appendix H

Additional findings:
This theme was not included in the final manuscript version. Even though this theme was developed to the same extent as the rest of the results, it does not relate specifically to the experience of OMT for lymphoedema which is a key purpose of the article. Despite this, it is a strong theme and does contribute context and further description to the experience of lymphoedema.

Theme 4: Gaining Perspective on Managing Lymphoedema
Coping is defined as the cognitive processes where an individual learns how to tolerate the effects of an illness (Bury, 1991). All of the participants reflected positively on their personal ability to cope with the stresses associated with lymphoedema. This success was defined through comparison to other women with lymphoedema and reflecting on previous experiences with breast cancer and other illnesses. Favourable attributes participants used to emphasise the ability to cope included, fielding questions about visible differences in arm size, being younger, confidence levels, and the ability to independently manage lymphoedema through seeking information and finding support. Reflecting on the experience of breast cancer and those they had seen succumb to cancer, was a reminder that even with the daily challenges of lymphoedema they were fortunate.

Subtheme: Comparison and coping.
A sense of personal competence in dealing with lymphoedema was enhanced by comparison with others perceived as less fortunate due to age, confidence or the ‘right’ personal attributes to cope with lymphoedema. The comparison was made with an imagined contemporary, who they perceived as less competent, and served to validate their own coping skills.

I don’t care really that people ask me all the time and I don’t care that people think god she has got a big fat swollen arm, I am reasonably confident about that. But if you were a shy person and you had to wear that arm or you are older or you were, you know, that would be really hard I think, but it really doesn’t bother me that much (P7, 25).
I feel, really feel for people who don’t have the sort of personality or the opportunity in their life to be able to focus on themselves and work out how to manage it (P3, 36).

**Subtheme: Putting Lymphoedema in Perspective.**

Four participants also compared the experience of lymphoedema and breast cancer survivorship. The breast cancer experience was reflected on both as a reminder of their ability to cope with challenging circumstances and also being fortunate to be alive and well in comparison to friends and acquaintances who had not survived.

*When I feel pissed off that I have lymphoedema I really remind myself of the fact that well I’m here and I buried three friends from breast cancer in the last four years and none of them got lymphoedema [ ] I’m sure every single one of those women would have loved to have been living with lymphoedema (P5, 21).*
Appendix I

International Journal of Osteopathic Medicine: Research Submission Guidelines


Author Guidelines (abridged form):

Reviews and Original Articles (2,000 - 5,000 words)
These should be either (i) reports of new findings related to osteopathic medicine that are supported by research evidence. These should be original, previously unpublished works; or (ii) a critical or systematic review that seeks to summarise or draw conclusions from the established literature on a topic relevant to osteopathic medicine.

(C) GENERAL GUIDANCE

Review Process
The decision to publish a paper is based on an editorial assessment and peer review. Initially all papers are assessed by an editor of the journal. The prime purpose is to decide whether to send a paper for peer review and to give a rapid decision on those that are not.

Manuscripts going forward to the review process are reviewed by members of an international expert panel. All such papers will undergo a double blind peer review by two or more reviewers. All papers are subject to peer review and the Journal takes every reasonable step to ensure author identity is concealed during the review process. The Editors reserve the right to the final decision regarding acceptance.

Author Enquiries
For enquiries relating to the submission of articles (including electronic submission where available) please visit this journal’s homepage at http://www.elsevier.com/ijosm. You can track accepted articles at http://www.elsevier.com/trackarticle and set up e-mail alerts to inform you of when an articles status has changed. Also accessible from here is information on copyright, frequently asked questions and more.

Contact details for questions arising after acceptance of an article, especially those relating to proofs, will be provided by the publisher.

(D) PREPARATION OF THE MANUSCRIPT

Submitted papers should be relevant to an international audience and authors should not assume knowledge of national practices, policies, law, etc. Authors should consult a recent issue of the journal for style if possible. Since the journal is distributed all over the world, and as English is a second language for many readers, authors are requested to write in plain English and use terminology which is internationally acceptable.

Abbreviations - Avoid the use of abbreviations unless they are likely to be widely recognised. In particular you should avoid abbreviating key concepts in your paper where readers might not already be familiar with the abbreviation. Any abbreviations which the authors intend to use should be written out in full and followed by the letters in brackets the first time they appear, thereafter only the letters without brackets should be used.

Manuscript Layout
The manuscript with a font size of 12 or 10 pt double-spaced with wide margins (2.5 cm at least) and number pages consecutively beginning with the Title Page. Depending on the paper type (see above) this should include the title, abstract, key words, text, references, tables, figure legends, figures, appendix. Microsoft Word or similar programme should be used.

Papers should be set out as follows, with each section beginning on a separate page:

Title page

Keywords

Abstract
Both qualitative and quantitative research approaches should be accompanied by a structured abstract of no more than
250 words. All original articles should include the following headings in the abstract as appropriate: Background, Objective, Design, Setting, Methods, Participants, Results, and Conclusions. As an absolute minimum: Objectives, Methods, Results, and Conclusions must be provided for all original articles.

Text
The text of observational and experimental articles is usually, but not necessarily, divided into sections with the headings; introduction, methods, results, results and discussion. In longer articles, headings should be used only to enhance the readability. Three categories of headings should be used:

- major headings should be typed in capital letter in the centre of the page and underlined (i.e. INTRODUCTION)
- secondary ones should be typed in lower case (with an initial capital letter) in the left hand margin and underlined (i.e. Participants).
- minor ones typed in lower case and italicised (i.e. questionnaire).

Statement of Competing Interests
When submitting a manuscript you will need to consider if you, or any of your co-authors, are an Editor or Editorial Board member of the International Journal of Osteopathic Medicine.

References
Responsibility for the accuracy of bibliographic citations lies entirely with the authors.

Citations in the text: Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Avoid using references in the abstract. Avoid citation of personal communications or unpublished material. Citations to material “in press” is acceptable and implies that the item has been accepted for publication. Citation of material currently under consideration elsewhere (e.g. “under review” or “submitted”) is not.

Text: Indicate references by superscript numbers in the text. These should generally appear at the end of the relevant sentence and should be directly after punctuation. The actual authors can be referred to, but the reference number(s) must always be given.

Implications for Clinical Practice
At submission stage, authors of reviews and original research articles are required to provide three to four bullet points outlining the manuscript implications for clinical practice.

Submission Checklist
Please check the manuscript carefully before it is sent off to the Editorial Office, both for correct content and typographical errors, as it is not possible to change the content of accepted typescripts during the production process. As a guide, please ensure the following had been included:

- One copy of manuscript and;
- Tables, figures and illustrations, uploaded separately and correctly labelled;
- Reference list in correct style and correct in-text referencing;
- Written permission from original publishers and authors to reproduce any borrowed any borrowed material (where relevant).