Living with Lymphoedema in Ireland: A Mixed Methods Exploration of Patient and Service Provider Perspectives

Author: Ms. Maeve I. Murray, BA

Supervisor: Dr. Pamela Gallagher

School of Nursing, Dublin City University

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of MSc is entirely my own work, that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Abbreviations

ALA	Australian Lymphology Association
ALND	Axillary Lymph Node Dissection
BC	Breast Cancer
BLS	British Lymphology Society
CREST	Clinical Resource Efficiency Support Team (Northern Ireland)
DHSSPS	Department of Health, Social Services and Public Safety (Northern Ireland)
DLT	Decongestive Lymphatic Therapy which is variously known as: Decongestive Lymphoedema or Lymphatic Therapy (DLT); Complete, Complex, Comprehensive or Combined Decongestive Therapy (CDT); Complex Decongestive Physiotherapy (CDP); or Complex Lymphoedema or Lymphatic Therapy (CLT)
HCP	Healthcare Professional
HSE	Health Service Executive
MEP	Medical Education Partnership (Authors of International Consensus: Best Practice in the Management of Lymphoedema)
MLD	Manual Lymphatic Drainage or Manual Lymph Drainage
MLLB	Multi-Layer Lymphoedema Bandaging
NCI	National Cancer Institute (United States of America)
NHS	National Health Service (UK)
NLN	National Lymphoedema Network (United Kingdom)
SD	Standard Deviation

SE	Standard Error
SLD	Simple Lymphatic Drainage
SLNB	Sentinel Lymph Node Biopsy
UK	United Kingdom

Glossary of Terms

Axillary Lymph Node Dissection	Procedure where all lymph nodes in the axilla, or armpit, are removed in order to reduce the likelihood of cancer spreading to other parts of the body.
Cellulitis	An infection in the layers of the skin, also known as an Acute Inflammatory Episode (AIE). The symptoms include redness of the skin, an elevated white blood count and/or an elevated temperature. Cellulitis is treated with antibiotics and in some cases hospitalisation may be required.
Compression Garments	Compression garments may take the form of sleeves, stockings or tights of various lengths, sizes and compression classes which are used to prevent an increase in swelling. They are carefully designed to provide a graduated pressure profile that reduces proximally, i.e. with more pressure at the end of limb to encourage lymph flow towards the trunk of the body.
Decongestive Lymphatic Therapy	Refers to the four cornerstones of care for lymphoedema: skin care, tailored exercise programmes, manual lymphatic drainage and containment using compression garments and/or bandages.
Hyperkeratosis	Condition resulting in thickened underlying tissue and skin.
Manual Lymphatic Drainage	Specialised gentle massage to encourage the redirection of fluid to better functioning lymph nodes.
Multi-layer Lymphoedema Bandaging	Short stretch inelastic bandages that produce graduated pressure which reduces proximally, i.e. more pressure is provided at the end of limb to encourage lymph flow towards the trunk of the

	body. The bandages provide low pressure when resting and high pressure when exercising. The bandages form a semi-rigid encasement, often including padding, which offers protection to fragile skin and tissues and ensures a uniform, cylindrical profile to a poorly shaped limb.
Oedema	Swelling
Papillomatosis	Skin condition resulting in cobblestone-like bumps.
Sentinel Lymph Node Biopsy	Procedure where lymph nodes in the axilla or armpit which have been shown to be cancerous, are removed in order to reduce the likelihood of cancer spreading to other parts of the body.
Simple Lymphatic Drainage	Specialised self-massage based on the principles of Manual Lymphatic Drainage.

Abstract

Lymphoedema is a chronic condition characterised by swelling. It results from impairment of the lymphatic system following cancer treatment, congenital malformation or other medical conditions. This study is the first conducted in Ireland to investigate lymphoedema service provision from practitioner and patient perspectives, in addition to exploring the impact of lymphoedema on patients' quality of life. Phase one involved a postal survey of 108 practitioners. Phase two involved five focus groups conducted throughout the country with a total of 33 patients. Phase three involved administering a postal survey and World Health Organisation (WHO) quality of life measure to 735 patients. Following integration of the mixed methods data, two super-ordinate themes emerged: lymphoedema - an unacknowledged condition; and the legacy of lymphoedema's association with cancer. The first theme related to poor awareness of lymphoedema resulting in under-resourced, insufficient service provision, and feelings of isolation for patients. The second theme related to inequitable service provision for patients with non-cancer-related lymphoedema; and lymphoedema as a constant reminder of patients' cancer treatment. Recommendations for lymphoedema service provision and patient support were made in light of these themes.

Chapter 1: Introduction

Introduction

In a healthy body, all tissues are kept alive by the circulatory system which provides a supply of oxygen, nutrients and water, and removes waste products. As blood does not reach every corner of the body a fluid known as interstitial fluid provides the supplies to each cell (British Lymphology Society, 2007). When there is an imbalance in the distribution of the fluid and particles in the space between the body's cells, smaller particles and approximately ninety percent of the fluid are reabsorbed into the blood capillaries to return to the heart through the veins (Clinical Resource Efficiency Support Team, 2008; Keeley, 2006). The remaining larger particles and fluid are absorbed by the lymphatic system (Keeley, 2006; Muscari, 2004; National Cancer Institute, 2008; Ridner, 2002).

Once the interstitial fluid enters the lymphatic system it is known as lymph or lymph fluid. Lymph fluid consists of water; protein; cellular debris; toxins; bacteria; dead, dying or mutant cells and enzymes; hormones; some fat cells and other macromolecules, as well as excess fluid (Sneddon & Lewis, 2007). The lymph fluid is collected into superficial vessels, known as initial lymphatics. Light skin pressure, muscle contraction or relaxation, and blood vessel pulsation assist the initial lymphatics in passing the lymph fluid through precollector vessels, collecting vessels and lymph nodes which are located progressively deeper under the skin (Ridner, 2002; Sneddon & Lewis, 2007). Finally the fluid is filtered by the lymph nodes and approximately forty percent of it is returned to the bloodstream (CREST, 2008; Lacovara & Yoder, 2006; Morrell et al., 2005). When this drainage by the lymphatic system is compromised, fluid accumulates in the space around the cells of the body. The resultant swelling is known as lymphoedema (Morrell et al., 2005).

The lymphatic system plays a major role in the body's immune system by producing white blood cells which are then carried throughout the body in response to inflammation signals

(CREST, 2008; Lacovara & Yoder, 2006). Therefore when the lymphatic system is impaired, as in lymphoedema, the body is much more susceptible to infection (CREST, 2008).

The Current Study

Lymphoedema refers to swelling or oedema which is comprised of lymph fluid. It is caused by damage to or malformation of the lymphatic system. It is a chronic, incurable condition believed to affect at least 1.33 per 1,000 of the population (Moffatt et al., 2003). Lymphoedema can lead to pain, discomfort, and increased susceptibility to skin infections such as cellulitis, which may require hospitalisation (Morgan, Franks & Moffatt, 2005). Lymphoedema can also have significant psychological and social consequences including depression, anxiety, isolation and disability (Morgan, Franks et al., 2005; McWayne & Heiney, 2005; Tobin et al., 1993; Williams et al., 2004).

Previous studies of lymphoedema service provision in Australia and the UK have found arbitrarily located, disjointed and under-resourced services (Australasian Lymphology Association, 2003; BreastCare Victoria, 2005; Department of Health Social Services and Public Safety, 2004; Morgan, 2006; Todd, 2006). While anecdotal evidence suggests that similar difficulties in lymphoedema service provision are present in Ireland, to date, there has been no research conducted on lymphoedema service provision or on patients' experiences of living with lymphoedema in the Republic of Ireland. Without a clear picture from both practitioners' and patients' perspectives coordination between services, planning on how to develop and expand services and formulation on how to address gaps and inequalities cannot take place.

The overall aims of the present study were to investigate current lymphoedema service provision from both service providers' and patients' perspectives, in addition to exploring patients' experiences of living with lymphoedema in Ireland, for the first time.

Specific objectives include:

- Providing an overall account of current service provision, documenting the range, location, funding, and referral pathways of services provided nationwide and exploring patients' experiences of obtaining a diagnosis, searching for appropriate treatment, accessing treatment and availing of ongoing lymphoedema services.
- Assessing service providers' and patients' recommendations for lymphoedema service development.
- Exploring patients' experiences of living with lymphoedema and the impact of the condition on daily life and quality of life.

Overview of Thesis

Literature Review

Previous research on lymphoedema, its prevalence and treatment, service provision and patients' experiences is outlined in the literature review in Chapter 2. In summary, studies on service provision in other countries have generally indicated arbitrarily located, disjointed and under-resourced services with inequitable service provision for those in rural areas and patients with non-cancer-related lymphoedema. Studies on patients' experiences of the condition have reported impairments of patients' physical wellbeing, capacity to engage in daily activities, psychosocial wellbeing and quality of life.

Design

A mixed methods design of service provider questionnaires, patient focus groups and patient questionnaires was chosen to explore the research aims. The rationale for choosing this methodology, and the sequence, priority and integration of methods is presented in Chapter 3.

Phase 1: Service Provider Survey

The first phase of the study involved a survey of service providers. The questionnaire explored treatments provided, funding sources, referral options, practitioners' level of training and recommendations for service development. The term 'service providers' is used interchangeably with 'practitioners' throughout the thesis and is intended to refer to those who provide information and/or treatment to lymphoedema patients. A total of 320 questionnaires were sent to physiotherapists, occupational therapists and breast care nurses working in university, regional and general hospitals; healthcare professionals working in private hospitals, homecare or palliative care teams, hospices, and cancer support services that provide a lymphoedema service; and private practitioners. There is no known nationally updated register of all professionals working with lymphoedema patients except the MLD Ireland listing of registered MLD therapists in Ireland. The intention was to distribute questionnaires to a wide variety of healthcare professionals who were known or potential lymphoedema practitioners. However it is likely that some healthcare professionals who were sent a questionnaire do not provide a lymphoedema service and therefore chose not to participate. 108 service providers returned a completed questionnaire. The results suggested that current lymphoedema service provision is insufficient and inequitable and that there are challenges to the continuation of services. The rationale for the inclusion of service provider surveys, the methodology, specific aims, results and discussion of the service provider phase are presented in Chapter 4.

Phase 2: Patient Focus Groups

The second phase of the study involved patient focus groups. A total of 33 lymphoedema patients participated in one of five focus groups conducted nationwide. Patients were recruited through hospitals in what were formerly known as the four Regional Health Authority Areas in Ireland, and through organisations which provide information and support to lymphoedema patients (e.g. Lymphoedema Ireland). The focus groups explored patients' experiences of obtaining a diagnosis, seeking and accessing treatment, lymphoedema services and practitioners, living with lymphoedema, the impact of the condition on their quality of life, and their recommendations for service development. Focus groups were analysed thematically. The emerging themes covered barriers to treatment; tension with healthcare professionals; lymphoedema affecting daily life; emotional factors; taking an active role in lymphoedema management; and deriving positives from living with lymphoedema. The rationale for the inclusion of patient focus groups, the methodology, specific aims, findings and discussion of the patient focus group phase are presented in Chapter 5.

Phase 3: Patient Survey

The final phase of the study involved a patient survey. The questionnaire explored patients' experiences of obtaining a diagnosis, seeking and accessing treatment, lymphoedema services and practitioners, living with lymphoedema, the impact of the condition on their quality of life, and their recommendations for service development. A total of 1,529 questionnaires were posted to patients accessed through hospitals, services and support organisations (e.g. Lymphoedema Ireland). Seven hundred and thirty-five questionnaires were returned. The main findings related to the inequitable nature of current service provision and the impact of the condition patients' quality of life. The rationale for the inclusion of patient questionnaires, the methodology, specific aims, results and discussion of the patient questionnaire phase are presented in Chapter 6.

Conclusion

Finally following the integration of the results from all three phases two super-ordinate themes emerged: lymphoedema – an unacknowledged condition and the legacy of lymphoedema's association with cancer. These super-ordinate themes in addition to recommendations for future research and policy developments are presented in the overall discussion in Chapter 7.

Chapter 2: Literature Review

Introduction

This thesis examines service providers' and patients' opinions of lymphoedema service provision in addition to exploring patients' experiences of living with lymphoedema. The following sections will outline the literature on the causes, classifications, prevalence, types, risk factors and treatment of lymphoedema. This is followed by sections detailing previous research on lymphoedema service provision in other countries, and on the impact of lymphoedema on patients' physical and psychological wellbeing and on their quality of life. Finally the last section outlines the aims of the current study

What is Lymphoedema

Lymphoedema is a progressive, chronic, incurable condition that is caused by damage to or malformation of the lymphatic system. Typically it occurs due to the removal, or impairment of part of the lymphatic system following cancer treatment, trauma, infection or congenital malformation (DHSSPS, 2004; Moffatt, Doherty, & Morgan, 2006). The underlying physical and chemical processes that lead to lymphoedema are still not fully understood (Okeke et al., 2004). However it is estimated that if lymphatic functioning is reduced below 20% of normal functioning, fluid which would normally be removed by the lymphatic system begins to accumulate in the tissues, causing noticeable swelling.

The swelling or oedema usually takes place in the limbs, and may include the associated trunk of the body. However swelling can occur in other parts of the body such as the head, neck, breast, and genitalia, depending on the location of the lymphatic impairment (Medical Education Partnership, 2006; Sneddon & Lewis, 2007). The affected area can become progressively larger and the skin and underlying tissue can become thickened or fibrosed (resulting in skin conditions such as hyperkeratosis and papillomatosis).

Generally lymphoedema is regarded as swelling caused by lymphatic impairment lasting longer than 3 months that is not relieved by the use of diuretics (Burns et al., 2003; Harris et al., 2001; National Lymphoedema Network, 2006; Revis, 2008). However, there is no consistent definition of clinically significant lymphoedema in the literature (Harris et al., 2001). The International Society of Lymphology (2003) argues that there is a subclinical stage of lymphoedema, Grade 0, when the transport of lymph fluid is impaired but overt oedema or swelling is not yet present. Indeed some patients experience symptoms of heaviness, aching and tightness long before visible signs of swelling develop (Muscari, 2004). Mild or clinically significant lymphoedema is frequently classified as a 2cm circumference or a 200ml volume difference between an affected and unaffected limb (Harris et al., 2001; Horning & Guhde, 2007). Grade 2 or moderate lymphoedema is often defined as a 20-40% volume differential. Grade 3 or severe lymphoedema is often defined as a greater than 40% volume disparity between an affected and unaffected limb (International Society of Lymphology, 2003). Advanced lymphoedema is referred to evocatively but perhaps insensitively as elephantiasis (Person et al., 2008). A positive Stemmer’s sign (i.e. the inability to pick up a fold of skin at the base of the second toe or of a finger due to thickening of the tissues) may only be present in moderate or severe stages of lymphoedema (CREST, 2008; Williams 2006).

Other indicators include tissue texture, skin condition (including thickness), subjective sensations, frequency of episodes of cellulitis, increased susceptibility to bacterial and fungal infections, psycho-social morbidity, movement, decrease in functionality, distortion in the shape of the affected area, and the reaction of the swelling to gravity or pressure (BLS, 2001b; Morrell et al., 2005, Williams 2003 cited in Hardy 2006). The only measures widely used are circumference or volume difference between the affected area and the contralateral limb, both of which relate to tissue swelling and are not appropriate for bilateral or midline swelling (i.e. swelling in the trunk of the body) (BLS, 2001b). The International Society of Lymphology (2003) has called for a lymphoedema classification based on an improved understanding of the mechanisms underlying lymphoedema development including underlying genetic disturbances which could encompass anatomic and functional characteristics. However there appears to have been little development on such a classification since then.

Prevalence and Types of Lymphoedema

There are many different types of lymphoedema i.e. primary lymphoedema arising from a congenital malformation of the lymphatic system and secondary lymphoedema arising from acquired damage or interference with the lymphatic system through a variety of medical conditions or treatments. As a result, there are cultural differences in the prevalence of lymphoedema as it is dependent on the type of lymphoedema most common in that region. The prevalence of lymphoedema in Ireland is not currently known. Therefore the prevalence rates presented in the following paragraphs, apart from those relating to lymphatic filariasis, are based on studies conducted in European countries.

Moffatt and colleagues in 2003 conducted a major epidemiological study in what was formerly known as the South West London Community Trust in the UK. Initially the research team contacted all health professionals in the area to ascertain potential patients for inclusion in the study. Patients who were known to health professionals as being affected by or receiving treatment for lymphoedema were invited to participate. These patients were clinically examined, questioned about their medical and treatment history and asked to complete a demographic and socio-economic questionnaire, the McGill short form pain assessment tool and the SF-36, a quality of life measure. On the basis of this, Moffatt et al. (2003) reported that lymphoedema is believed to affect 1.3 per 1,000 (or 0.13%) of the population. A similar figure of 0.14% was found by Petlund and colleagues in Norway in 1990 (Williams et al., 2005). However these figures are likely to underestimate the true prevalence of lymphoedema due to the lack of standardisation in diagnostic criteria and measurement practices, and the possibility that not all those with lymphoedema are receiving treatment (CREST, 2008; Moffatt et al., 2003; Rockson & Rivera, 2008).

Primary Lymphoedema

Primary lymphoedema refers to lymphoedema resulting from developmental abnormalities or malformations of the lymphatic system (DHSSPS, 2004; NCI, 2008). It can be evident in infancy or may develop at the onset of puberty or in adulthood. Primary lymphoedema can have a gradual onset with swelling subsiding at night but then reappearing the following day for up to three months. Following that some degree of swelling is permanently evident (Billingham, 2006). Primary lymphoedema usually affects lower extremities (i.e. the legs and feet) and is more common among females (Lacovara & Yoder, 2006; Revis, 2008). The CREST report (2008) was undertaken to provide guidelines on the management of lymphoedema in Northern Ireland. These guidelines were developed to assist healthcare practitioners in the development of appropriate referral and treatment pathways to ensure early identification and treatment of the condition. The report details that primary lymphoedema can also present as an aspect of a number of syndromes: Turner's syndrome, Milroy's disease, Meige's disease, and Klippel-Trenaunay syndrome, and the genetic basis of these syndromes is being investigated. The report also listed a series of studies which found varying prevalence rates of primary lymphoedema: 1 per 10,000, 1 in 33,000, and 1.5 per 100,000 (CREST, 2008). However methodological restrictions such as convenience sampling, lack of standardisation on diagnostic methods and classification issues would account for the wide variation. Furthermore, Mortimer (1998) argues that in truth, patients are often diagnosed with primary lymphoedema when a cause cannot be identified and with secondary lymphoedema when a cause (or a number of causes) can be identified.

Secondary Lymphoedema

Secondary lymphoedema refers to lymphoedema which occurs as a consequence of acquired damage or obstruction of the lymphatic system. Essentially the swelling results from an injury to the lymphatic system and as a result the lymphatic system is unable to manage even normal levels of lymph fluid (Lacovara & Yoder, 2006). The risk of developing lymphoedema following the interference with the lymphatic system is lifelong. Secondary lymphoedema is more common among women. While originally this was attributed to the prevalence of lymphoedema following breast cancer treatment, it was subsequently found that both primary and secondary lymphoedema are more common among women, although the reasons for this are not fully understood at present (Moffatt et al., 2003). Secondary lymphoedema can occur following infection (e.g. lymphatic filariasis), cancer or its treatment, trauma or tissue damage, venous disease, inflammatory conditions, and immobility or dependency (CREST, 2008; DHSSPS, 2004; Hardy, 2006; NCI, 2008; Williams et al., 2005).

Lymphatic Filariasis

Worldwide, the most common form of lymphoedema is lymphatic filariasis. It is caused by a parasitic infection transmitted by mosquitoes which damages the lymphatic system (DHSSPS, 2004; MEP, 2006). Filariasis is endemic in approximately 80 tropical and subtropical countries, and is particularly common in India, Africa, South-East Asia, the Pacific and the Americas (Wynd et al., 2007, World Health Organisation, 2000). The World Health Organisation (WHO) estimates that 120 million people are infected with the parasite and a billion are at risk of infection by living in endemic areas. The WHO counts lymphatic filariasis as the second most common cause of long-term disability after mental illness (Wynd et al., 2007).

Lymphoedema Secondary to Cancer or its Treatment

The most common cause of lymphoedema in countries were filariasis is not endemic is iatrogenic – i.e. inadvertently caused by treatment, usually cancer treatment (Rockson & Rivera, 2008). As cancer can metastasize to the lymph nodes, the treatment of cancer can include interference with, removal or radiation of lymph nodes. This is particularly relevant in breast cancer as metastatic spread to the axilla (i.e. the lymph nodes in the armpit) occurs in approximately 30% of breast cancer patients and is the strongest prognostic factor of a more advanced stage of breast cancer (Morrell et al., 2005; Thomas-MacLean et al., 2008). There is a higher risk of developing lymphoedema following more extensive surgical procedures – for example, axillary lymph node dissection (ALND) where all lymph nodes in the axilla, or armpit, are removed in the treatment of breast cancer; as opposed to more conservative techniques, such as sentinel lymph node biopsy (SLNB) where only cancerous nodes are removed (Flessig et al., 2006; Golshan et al., 2003; Lacovara & Yoder, 2006; Leitch et al., 1998; Mansel et al., 2006; Rietman et al., 2004; Sener et al., 2001). However it is important to note that people with advanced-stage breast cancer will still require ALND and some patients may request ALND if they greatly fear cancer recurrence. Furthermore it is possible that SLNB may reduce the severity rather than the prevalence of lymphoedema and as a result people in the SLNB group may be at a subclinical stage for a longer period of time (Richmond, 2003; Rockson, 2002).

Several studies have found that a combination of surgery and the irradiation of lymph nodes results in a greater risk of developing lymphoedema when compared with controls (Morrell et al., 2005; Williams et al., 2005). Radiation may result in an increased rate of fibrosis (hardened tissue) causing constriction of the lymphatic pathways, damage to the lymph nodes and a delay in the growth of new lymphatic vessels (Johansson et al., 2003; Morrell et al., 2005; Ridner, 2002). Essentially for cancer patients the risk of developing lymphoedema is increased by the surgical removal of nodes and tied off lymph vessels; scarring and fibrosis of lymph structures and surrounding tissues; and infection (Ridner, 2002).

Goltner et al. (1988) and Soran et al. (2006) argue that damage to the lymphatic system may be present for almost all patients who have had breast surgery. Therefore the question of why some patients develop cancer-related lymphoedema while others do not has not been explored in depth (Williams, 2006a). There is much confusion over the possibility of certain factors predisposing individuals to developing cancer-related lymphoedema. Some studies have identified body weight gain, number of nodes removed, tumour size, or surgical technique employed as potential predisposing factors whereas in other studies these were not significant (Morrell et al., 2005). Furthermore, in order to promote clarity and permit comparison across studies there is a need for standardisation on the definition of lymphoedema and methods of assessment employed by researchers (Morrell et al., 2005). Therefore it is unclear at present whether cancer-related lymphoedema can be prevented.

The majority of research on the prevalence of secondary lymphoedema refers to breast-cancer-related secondary lymphoedema. Indeed Moffatt et al. (2003) reported that 25% of the sample in their prevalence study had lymphoedema secondary to cancer treatment, but didn't indicate what type of lymphoedema the rest of the sample experienced. In terms of the proportion of breast cancer patients that develop lymphoedema, the figures range from 6% to 70%, with the majority of studies reporting its prevalence to be between 20% and 25%, (DHSSPS, 2004; Harris et al., 2001; Petrek & Heelan, 1998). Again, variations in prevalence are due to differences in the definition of lymphoedema used, the methods of assessment, the source of patients, and the length of follow up after patients' cancer treatment, which makes it difficult to compare prevalence across studies (CREST, 2008; DHSSPS, 2004; Harris et al., 2001; Petrek & Heelan, 1998; Williams et al., 2005). There is a lack of consensus on prevalence rates for lymphoedema secondary to other cancers but Williams and colleagues (2005) have produced a good review of findings to date.

Lymphoedema Secondary to Other Conditions

Other conditions which can result in lymphoedema include infections such as cellulitis (both a contributing factor and consequence of lymphoedema), severe acne, rosacea (a disorder of the skin causing flushing or redness of the face), surgical wound infection, and lymphadenitis (an infection of the lymph nodes) (CREST, 2008; Lu et al., 2008; Williams et al., 2005). Lymphoedema can also develop following significant scarring, large wounds and self harm (CREST, 2008). A retrospective study in a serious burns unit found a prevalence of 1% following trauma or tissue damage but additional research is required (CREST, 2008). Venous conditions such as deep vein thrombosis, chronic venous insufficiency, and intravenous drug use can also result in lymphoedema (Rockson & Rivera, 2008). Inflammatory conditions such as rheumatoid and psoriatic arthritis, dermatitis or eczema, and sarcoidosis can contribute to the development of secondary lymphoedema (CREST, 2008, DHSSPS, 2004). Immobility or dependency resulting from paralysis, chronic ill health, or obesity can result in lymphoedema as muscular contractions encourage the flow of lymph fluid through the lymphatic system

(CREST, 2008). However there is a paucity of research on the prevalence of lymphoedema secondary to these conditions.

Conclusion

The estimation of the population burden of disease has profound implications for strategic planning of service provision, and insurance and reimbursement issues but it also affects the motivation of pharmaceutical and biotechnology sectors to undertake the development of new treatment strategies (Rockson & Rivera, 2008). Therefore research estimating the prevalence of lymphoedema in the Republic of Ireland would be welcome.

Risk Factors for Developing Lymphoedema

As mentioned previously, lymphoedema can result from a number of medical conditions other than cancer. Therefore many of the risk factors for developing lymphoedema are often related to the causes, for example, the insertion of a pacemaker (which would indicate heart disease); and varicose vein stripping and vein harvesting (which would indicate venous disease) (Medical Education Partnership, 2006; Muscari, 2004).

One consistently reported risk factor is weight gain, or having a high body mass index or waist circumference (Doherty, 2006; McWayne & Heiney, 2005; Muscari, 2004; Petrek et al., 2001; Soran et al., 2006; Swenson et al., 2009). Age is another major risk factor as the overall prevalence of lymphoedema is 0.13% but for those over 65 years the prevalence is 0.54% (Moffatt et al., 2003). Both age and being overweight or obese can also have an indirect impact in that they increase the likelihood of other risk factors being present such as venous disease, heart disease, and reduced mobility (Doherty, 2006; Petrek et al., 2001).

Infection in the at-risk area greatly increases the chances of developing lymphoedema. Therefore skincare and risk avoidance is important (i.e. avoiding cuts, scrapes, burns, infection, extremes of temperature, restriction, carrying heavy loads, overuse, injections, blood pressure readings, and blood draws in the at risk area) (Horning & Guhde, 2007; MEP, 2006; NCI, 2008; NLN, 2005; Rinehart-Ayres, 1998). However as bilateral lymph node dissections are performed in some patients, it is important to be mindful that injections or blood draws in an at-risk area cannot always be avoided and do not necessarily lead to the development of lymphoedema (Muscari, 2004).

At present it is unclear what particular jobs or activities can predispose individuals to developing lymphoedema (Petrek et al., 2001). This may depend on what part of the body is affected by a lymphatic impairment and therefore at risk of developing lymphoedema. For example, individuals at risk of developing lymphoedema in their lower limbs are often discouraged from engaging in activities or jobs which require long periods of standing. Individuals at risk of developing lymphoedema in their upper limbs are often discouraged from engaging in activities or jobs requiring repetitive arm motion. However there is little direct evidence for this. Indeed some recommendations on avoiding the development of lymphoedema may appear to be contradictory. For example, too little exercise can exacerbate symptoms but too much vigorous exercise can have a similar effect. As a result the position paper of the National Lymphedema Network (2008) suggests that individuals at risk of developing lymphoedema should be able to perform aerobic and resistive exercises using the at-risk body part if they initiate exercise at a low intensity, increase it gradually and wear a properly fitted compression garment when exercising. Yet once again, these recommendations are generally based on anecdotal rather than robust evidence.

Air travel may also pose an additional risk and attention should be paid to sensations such as heaviness, fullness or aching in the at-risk area of the body during a flight (NLN, 2004). Ideally a compression garment recommended and sized by a trained and experienced garment fitter should be worn as a prophylactic measure (NLN, 2004). Individuals at risk of developing lymphoedema are advised to stay hydrated, walk around the cabin regularly (to prevent deep venous thrombosis), elevate and move the at risk area regularly (NLN, 2004). Again this advice is based on anecdotal rather than robust evidence.

In summary, the risk of developing lymphoedema is lifelong and patients and professionals need to be aware of risk reduction strategies (DHSSPS, 2004). A stronger evidence base on the risk factors for lymphoedema is required (Box et al., 2002; MEP, 2006; Muscari, 2004; Sitzia & Harlow, 2002). At present it is still unclear why individuals with the same medical history develop it and others do not, the wide variation in onset, progression and quality of tissue swelling and whether prior lymphatic system functioning has an impact (Sitzia & Harlow, 2002).

Treatment

Although lymphoedema is a chronic condition, there are treatment options for symptom control, maintenance of the affected area and prevention of complications. Lymphoedema treatment is not solely concerned with the alleviation of swelling, but also vigilance and treatment of aggravating conditions such as infection (Harris et al., 2001; Mondry et al., 2004). However it is important to note that essentially for patients a positive treatment outcome signifies improved quality of life as opposed to necessarily involving changes in volume (Williams, 2008).

Decongestive Lymphatic Therapy

Broadly speaking the consensus regarding the management of lymphoedema is to engage in the four cornerstones of care consisting of: skin care (to prevent infection), tailored exercise programmes (to encourage natural lymph flow), manual lymphatic drainage (specialised gentle massage to encourage the redirection of fluid to better functioning lymphatic pathways) and containment using compression garments and/or bandages (to encourage natural lymph flow and maintain any reduction in swelling) (DHSSPS, 2004; MEP, 2006; Morrell et al., 2005). The precise terminology relating to the four cornerstones of care is known by several names and acronyms. This reflects the fact that there are now several schools of lymphoedema treatment including the Casley-Smith, Földi, Klose, Leduc, and Vodder schools. Although the schools all follow the same basic principles, the precise techniques may vary (Casley-Smith et al., 1998; Williams, 2003; Williams, 2006b). For the purposes of this thesis the term Decongestive Lymphatic Therapy or DLT will be used to refer to the treatment approach that involves the four cornerstones of care for lymphoedema.

DLT is applied in two phases: an intensive phase and maintenance phase (Horning & Guhde, 2007). The intensive phase involves Manual Lymphatic Drainage (MLD) and in some cases Multilayer Lymphoedema Bandaging (MLLB), being provided once or even twice daily by a specifically trained therapist for up to 6 weeks (BLS, 2001b; CREST, 2008).

Manual Lymphatic Drainage (MLD) is a highly specialised form of massage involving slow and rhythmical movements with gentle pressure (Casley-Smith et al., 1998). The individual's unaffected side is treated first, and the therapist then moves fluid from the congested area to better functioning lymphatic pathways (MEP, 2006). It is recommended that MLD is followed with compression such as Multilayer Lymphoedema Bandaging (MLLB) and/or the wearing of compression garments in order to maintain the effects of the treatment (Casley-Smith et al., 1998).

In the maintenance phase the patient (or their carer) is encouraged to manage their condition using Simple Lymphatic Drainage (SLD, self-massage based on the principles of MLD), specific lymphoedema exercises and compression (garments or self-bandaging), all of which are designed to improve lymph flow. Daily skincare of the affected area is also encouraged to maintain the integrity of the skin and therefore avoid infection (Casley-Smith et al., 1998; MEP, 2006). If required the patient can seek intensive treatment if they experience a deterioration or sudden increase in swelling following an episode of cellulitis. Patients should be encouraged to attend follow up appointments for measurement for replacement compression garments (Williams, 2006a).

Evidence for the Effectiveness of Decongestive Lymphatic Therapy

There is little robust literature to support each of the components of Decongestive Lymphatic Therapy (Földi, Jünger & Partsch, 2005; Harris et al., 2001; Harris & Piller, 2003; MEP, 2006;

Partsch & Jünger, 2006; Sitzia & Harlow, 2002; Williams, 2006b). However Földi (1998) argues that each component of DLT is inadequate if applied in an isolated form; all four of the cornerstones of care should be applied and therefore evaluated as a systematic treatment.

In a prospective trial of 20 patients, DLT was associated with consistently decreasing pain scores on a visual analogue scale and increasing quality of life scores (Mondry et al., 2004). Boris et al. (1997) found that if patients are compliant with wearing compression garments in the maintenance phase, the effects of DLT can be maintained for up to three years (cited in Rinehart-Ayres, 1998). Yet evidence for the management of lymphoedema remains weak often based on anecdotal rather than empirical evidence (Lacovara & Yoder, 2006). Further work is required to assess the best practice and cost effectiveness of different management regimens (Moffatt et al., 2003). Therefore clinical decision making has been heavily influenced by ritual and individual trial and error (Sitzia & Harlow, 2002).

As a result the Lymphoedema Framework Project, a UK based research partnership, was established to raise the profile of lymphoedema and improve standards of care by involving specialist practitioners, patient groups and stakeholders in the wound care and compression garment industry. They consulted with an international panel of experts to produce an international consensus on lymphoedema management. In so doing, they found that there's little formal guidance on how to combine expert opinion and formal scientific evidence and there are added challenges in including the opinions of alternative perspectives, for example practitioners and patient groups (Morgan, Moffatt & Doherty, 2006). Nevertheless the resulting document "Best Practice for the Management of Lymphoedema" by the Medical Education Partnership (MEP, 2006) has been endorsed by lymphology societies due to its practicality and the credibility associated with being drawn from national and international consensus (Morgan & Moffatt, 2006). Yet the requirement for empirical research to guide clinical practice and support patients' claims for service provision and financial support for treatment remains.

Furthermore, for positive outcomes to be achieved in clinical practice, patients must be active in their care, have a high degree of vigilance, engage in preventive efforts and exhibit a high tolerance for treatment (for example, antibiotics for the treatment or prevention of infection, intensive daily MLD sessions, compression garments which are often uncomfortable, time consuming exercises and skin care, and the financial burden of seeking treatment and garments). Patient adherence to treatment plans is heavily affected by the consequences of noncompliance, the extent of the impact of living with uncontrolled lymphoedema and satisfaction with the treatment itself (Bogan et al., 1997). Satisfaction in turn is influenced by the thoroughness of preparation for the maintenance stage, the practitioner's affect and the patient's self efficacy (Bogan et al., 1997). As a result the effectiveness of DLT cannot be investigated in isolation from a consideration of the patient's adherence, the practitioner's competence, the practitioner-patient relationship, and the patient's psychological perspective.

Reviews of Service Provision

To date there have been no studies exploring current lymphoedema service provision in the Republic of Ireland. However a number of reports, reviews and empirical investigations of practitioners' and patients' perspectives on service provision have been produced in Australia, continental Europe and the UK. A summary of the findings is presented below.

Australia

The Australasian Lymphology Society (ALA) (2003) telephoned service providers to quantify lymphoedema service provision in Australia. They then surveyed an unspecified number of lymphoedema practitioners in order to explore current practice and details on topics such as compression garment provision. The ALA found that there is no pattern to the distribution of services between states, and even within states across urban and rural areas. Although they noted that this may be based on economic issues such as the distribution of a skilled workforce (ALA, 2003). Different hospitals provide different services not based on financial or epidemiological principles or therapeutic philosophy, and for little apparent reason (ALA, 2003). The report also identified the inequitable nature of compression garment provision with policies in Victoria and Tasmania guiding the appropriate prescription and equitable supply of garments to patients while patients in other states are required to pay for their garments. Overall the report indicated that lymphoedema services are provided with a serious lack of parity between the states, within states, and across individuals as a result (ALA, 2003). However the authors acknowledged that due to the lack of an existing register of lymphoedema services and the voluntary nature of respondents' participation it was possible that some services had been omitted from the study. The questionnaires employed by the researchers involved a small number of open questions. As a result it is possible that some respondents provided less detail than others thereby misrepresenting their service. Furthermore the study did not include patients' perspectives on lymphoedema service provision.

Subsequent to the ALA's study, BreastCare Victoria (2005) conducted a mixed methods study on lymphoedema service provision in Victoria, Australia. The study employed a survey of 276 patients; five focus groups with a total of 35 patients conducted by telephone to enable the participation of patients living in diverse locations; and a survey of 44 practitioners. In the terms of the results of the practitioner survey, the majority of services had the capacity to see approximately 1-15 patients per week. On average treatment sessions lasted 60 minutes and 79% of services provide home visits. The results also included an effective model of lymphoedema service provision in the Bendigo Health Service where a large, public lymphoedema service provides hub-and-spoke support to smaller, rural clinics through visiting clinicians and videoconferencing.

Regarding referral sources, practitioners indicated that although general practitioners were the most common referral source, many had poor knowledge of lymphoedema; as a result referral can be haphazard (BreastCare Victoria, 2005). Practitioners reported that on average there are 0.77 whole time equivalent practitioners per service. Most of practitioners' comments on compression garments related to the subsidisation programme being beneficial for patients and with prompt supply by compression garment providers. Although many noted that not all patients are eligible for such subsidies and that a wider range of garments should be available to patients under the scheme. Moreover practitioners reported that rural patients may be disadvantaged by the scheme as they are required to travel to specific garment suppliers in order to avail of the subsidies. Regarding practitioners' recommendations for service development, comments related to services being available in more public hospices, additional training of new practitioners, improving the affordability of treatments for patients, improving awareness of lymphoedema particularly among medical and allied health professionals and the compilation of a booklet containing information on the condition, treatment options, location of services, subsidy schemes, compression garment suppliers and education programmes.

In terms of the results from patient phases of the study, patients reported that diagnosis was made by a wide variety of health professionals or in several cases, by patients themselves or their family members. Some patients expressed dissatisfaction with the perceived lack of knowledge of lymphoedema and treatment alternatives among healthcare professionals as this could delay diagnosis and optimal management. Most had received information on lymphoedema either through their individual practitioner, group education sessions or through the lymphoedema association. Sixty percent of those who had sought treatment in the last year had received MLD in that time. Most of these treatments had been received once a week or less frequently. Fifty-nine percent of respondents reported being required to pay for their treatment and the minimum average charge for an individual treatment was \$39.75. Thirty-one percent reported that they replace their garments at least three times a year as recommended by practitioners. Several patients reported this was due to the cost with 40.5% spending \$1-\$200 per year and 41.6% spending \$201-\$500 per year on garments.

Eight-two percent of patients who had access to services expressed a high level of satisfaction with those services; however patients noted the gaps in provision in some suburban and rural areas (BreastCare Victoria, 2005). For example on average participants living in urban areas were required to travel 18.2 kilometres in a one way trip to their service whereas patients living in rural areas travelled on average 44.9 kilometres in a one way trip to their service. Additionally there was evidence of inequity according to type of lymphoedema For example, on average patients with breast-cancer-related secondary lymphoedema waited 0.6 years for a diagnosis following the onset of symptoms whereas patients with primary lymphoedema were waiting on average 9.4 years. In terms of their overall recommendations for service development, patients reiterated the recommendations of service providers in that both emphasised improved awareness of lymphoedema among healthcare professionals and the general public, an increased number of lymphoedema practitioners, improved affordability of treatments and compression garments and widespread dissemination of information about services, garments and eligibility for financial assistance.

While the study provided an interesting account of current service provision in Victoria, Australia, there were a number of limitations to the study. The authors noted that the views of practitioners working in some services and the views of patients not currently receiving treatment may not have been adequately represented (BreastCare Victoria, 2005). Moreover detailed information on the themes emerging from the patient focus groups was not provided. Nevertheless, the report’s lead author has indicated in private correspondence with the researcher that the work instigated by BreastCare Victoria has partly informed the development of strategies that are now being implemented across all cancer streams in Victoria.

Continental Europe

An empirical study on lymphoedema service provision in continental Europe could not be located. However MacLaren (2003) conducted a review on service provision in a number of countries in Europe. She reported that in Sweden and the Netherlands, a multidisciplinary team provides a range of services from outpatient care of mild and moderate lymphoedema to inpatient programmes for severe cases. The ethos is to maximise self-care through outpatient attendance at professionally-led self-management groups and group interventions on education and psychological support (MacLaren, 2003). These rehabilitation programmes are funded solely through health insurance. For those without health insurance, charitable organisations provide lymphoedema care (MacLaren, 2003).

MacLaren (2003) also reported that Austria and Germany are seen as centres of excellence for therapist training and treatment. There is a firm commitment to the four cornerstone approach (i.e. skin care, exercise, MLD and compression) with optional or prescribed extras such as attendance at fitness or dance class, weight loss programmes, therapeutic diets, and complementary health treatments (MacLaren, 2003). However despite the wide range of treatments available they are often not in close proximity to patient's homes. State certification is keenly sought by establishments wishing to provide rehabilitative or convalescent services in order that they are reimbursed to patients by the state.

The United Kingdom

The majority of the literature on lymphoedema service provision in the UK is derived from policy documents, reviews and reports rather than empirical investigations of service providers' or patients' experiences. However the few empirical studies that have been performed are outlined in subsequent sections.

Policy Documents and Reports

The Calman-Hine report of 1995, which set out the first overall policy for cancer care for England and Wales, stated that cancer centres and units should provide lymphoedema treatment for patients with breast-cancer-related secondary lymphoedema as a matter of course. Nevertheless many patients still do not have access to a full range of services. Charitable organisations have played an essential role in meeting the shortfall but as a result the provision of services can be uncoordinated (MacLaren, 2003). As the availability of MLD for National Health Service and hospice patients is limited, it is a lucrative area for private practice. While there are standards of care for lymphoedema services, they have yet to be enforced and the lack of national registration or licensing of therapists in the UK also complicates the reimbursement of patients by their health insurers (BLS, 2001a; MacLaren, 2003).

The report of the Lymphoedema Services Review Group in Northern Ireland noted that ad hoc investment and funding is generally provided by cancer or physiotherapy services with scant consideration given to the sustainability of lymphoedema services (Department of Health, Social Services and Public Safety, 2004). Moreover practitioners experience professional isolation, problems with cover for leave and long waiting lists (DHSSPS, 2004). Moffatt et al. (2003) observed that many existing lymphoedema services are based in hospices or oncology departments and are by their very location restricting access to alternative patient groups. In order to explore these issues further, the following section presents the results of empirical studies involving the opinions of various healthcare professionals involved in lymphoedema service provision in the UK.

Empirical Studies of Practitioners' Opinions of Service Provision

Tiwari et al. (2006) surveyed members of The Vascular Society of Great Britain and Ireland. Two hundred and fifty-one vascular consultants or 57% of members returned a completed questionnaire. Seventy-three percent of respondents believed that lymphoedema is managed inadequately in the UK and 72.9% of respondents believed that resources were insufficient (Tiwari et al., 2006). However this survey only included the opinions of vascular consultants who were members of the organisation and therefore did not involve a representative sample. The opinions of other healthcare professionals involved in the care of lymphoedema patients, such as oncology consultants, physiotherapists, occupational therapists, lymphoedema nurse specialists and nurses were also omitted.

Following on from their previous involvement in the lymphoedema prevalence study, Morgan, Moody and colleagues (2005) conducted an educational needs assessment of 55 community nurses working in South West London. This was intended to be a first step towards developing educational programmes thereby improving lymphoedema services in that region.

They employed focus groups on real-world lymphoedema practice and self-assessment questionnaires of participants' current knowledge and skill in the care of patients with lymphoedema. In only one category, skincare, a small majority of respondents (54%) rated themselves as having excellent or good knowledge and skill. In the remaining 10 categories the majority of respondents rated their knowledge and skill as poor or very poor. Participants reported that they often learned on the job from other nurses who had experience with lymphoedema which allows myths about the condition to be perpetuated (Morgan, Moody et al., 2005). While this study did provide information on the initiation of a model of educational needs assessment, it did not employ a representative sample rather a specific category of healthcare professionals working in a precise catchment area.

Empirical Studies Incorporating Patients' Experiences of Service Provision

Bulley (2007) incorporated both practitioners' and patients' experiences in a needs assessment of lymphoedema services in Fife, Scotland. A variety of methods were employed: a telephone survey of general practitioners regarding referral procedures and face-to-face interviews were conducted with a purposive sample of five lymphoedema patients from one hospital (two with primary lymphoedema, three with breast-cancer-related secondary lymphoedema) and with five lymphoedema practitioners (two physiotherapists, two nurses and one private practitioner).

The telephone survey of general practitioners revealed a lack of knowledge and awareness of lymphoedema, its management and of available services. Indeed one general practitioner said patients with lymphoedema 'just have to live with it' (Bulley, 2007, p.134). The patient interviews corroborated this as they reported how some healthcare professionals' lack of awareness acted as a barrier when they were seeking a diagnosis and access to treatment. Poor geographical access and a lack of home visits discouraged some patients from accessing treatment while practitioners reported that increasing caseloads offered the potential of further limiting patients' access to treatment. Additionally practitioners reported that they had been requested to engage in a prioritisation system by placing patients with non-cancer-related lymphoedema on the waiting list, resulting in inequity of care (Bulley, 2007).

While the needs assessment provides some insight into service provision in that area of Scotland, it was not conducted with representative samples of practitioners or patients. Indeed patients with non-cancer-related secondary lymphoedema (e.g. lymphoedema secondary to venous disease, infection, or inflammation) or patients with cancer-related but not breast-cancer-related secondary lymphoedema (e.g. lymphoedema secondary to lymphoma, gynaecological cancers or melanoma) were not included. Moreover patients were accessed through one hospital and the scope of the study was confined to a small region.

In terms of studies solely exploring patients' experiences of lymphoedema service provision, the Lymphoedema Services Review Group in Northern Ireland received questionnaires from a total of 32 lymphoedema patients who were members of lymphoedema support organisations (DHSSPS, 2004). Participants who could access treatment were generally satisfied with it although they did note the difficulties in accessing such treatment. People with primary and non-cancer-related secondary lymphoedema and people living in rural areas reported that they continue to experience greater difficulty in accessing services (DHSSPS, 2004). Participants who couldn't access initial and continuing care, reported that it can be "a constant struggle and I have no quality of life because of this" (DHSSPS, 2004 Page 32). However the report includes scant information on the results derived from this patient survey and as the survey was conducted only with patients accessed from support organisations it is unlikely to be representative of all lymphoedema patients in Northern Ireland.

Lam et al. (2006) conducted a postal survey of the members of the Lymphoedema Support Network and received responses from 1,449 individuals, which represent 60% of the membership at that time. 61% of respondents with a history of cancer and therefore at lifelong risk of developing lymphoedema had not been told that they could develop lymphoedema. Overall half of respondents were satisfied with the assistance they received at their first consultation. The proportion of those who were satisfied was lowest among those who consulted a GP initially (38%) and highest among those who consulted a nurse (77%).

Lam et al.'s (2006) study also detailed several differences in the experiences of patients with various types of cancer. Patients with non-cancer-related lymphoedema were less satisfied than patients with cancer-related lymphoedema with the professional they consulted when they first became concerned with their swelling. Fewer patients with non-cancer-related lymphoedema had received the various elements of decongestive lymphatic therapy (DLT) when compared with patients with cancer-related lymphoedema. Additionally, patients with cancer-related lymphoedema were more likely to experience continued monitoring of their lymphoedema (79%) when compared with patients with non-cancer-related lymphoedema (57%). However once again this study was conducted with patients accessed from a support organisation and as a result the sample is unlikely to be representative of all lymphoedema patients in the UK.

A series of qualitative studies have explored the difficulties lymphoedema patients' experience in adapting to their condition. For example Hare (2000) conducted four focus groups with a total of 20 women with breast-cancer-related secondary lymphoedema accessed from a hospice lymphoedema service in the UK. Williams et al. (2004) employed a phenomenological approach and interviewed 15 patients with various types of lymphoedema from a specialist clinic in London. Both revealed themes relating to the difficulties patients experience in sourcing information about lymphoedema and receiving the correct diagnosis. Williams et al. (2004) termed this 'fishing in the dark'. In a related point, both Hare (2000) and Williams et al. (2004) reported friction between patients and healthcare professionals when healthcare professionals failed to acknowledge the seriousness of the condition or the impact it has on patients' quality of life. While these studies add depth to our understanding of patients' experiences of lymphoedema service provision in the UK it is difficult to ascertain how representative participants' experiences are until a quantitative study is conducted with a larger sample of patients.

Conclusion

There is a considerable dearth of empirical research on lymphoedema service provision conducted with representative samples of practitioners and/or patients in Australia, continental Europe and in the UK. A derisory number of small scale quantitative studies have been conducted with specific groups of lymphoedema practitioners rather than considering input from multiple disciplines. While qualitative studies of patients' experiences have added depth, the few quantitative studies that involved patients generally relied on the opinions of particular categories of patients such as members of lymphoedema support groups. To date one study attempted to access a wide variety of practitioners and patients to ascertain their views on lymphoedema service provision, namely the BreastCare Victoria (2005) study. As mentioned previously, this study has assisted in developing guidelines that have prompted the development of lymphoedema services.

To date there has been no research conducted on service providers' and patients' experiences of lymphoedema service provision in the Republic of Ireland. Without a clear picture of current service provision in Ireland coordination between services, planning on how to develop and expand services, and formulation on how to address gaps and inequalities cannot take place. Therefore research that incorporates quantitative investigation of the experiences of a broad sample of practitioners and patients, in addition to qualitative findings to add depth, would be a first step in informing best practice in Ireland and an essential input to policy planning. Moreover such service development cannot be undertaken without an appreciation of patients' experiences of living with the condition. The following section outlines previous research on this area.

Patients' Experiences of Living with Lymphoedema

Lymphoedema affects many spheres of life, and is a unique and complex experience for each person (Woods, 1993). While bearing this in mind a number of researchers have attempted to explore general trends in patients' experiences of living with lymphoedema. Studies have focused on the physical consequences of lymphoedema, the impact of the condition on daily life, psychosocial consequences of living with lymphoedema and the impact on patients' quality of life. Researchers have also investigated the relationship between physical and psychological wellbeing, for example how physical consequences can act as exacerbating and protective factors to psychological consequences. An account of the findings to date is presented below.

Physical Consequences of Lymphoedema

Lymphoedema can lead to discomfort; pain; sensations of burning, itching, and tightness (even to the point of a bursting sensation); loss of feeling as the affected area becomes more solid; muscle wastage; increasing intolerance to changes in temperature; sleep disturbance and in a small number of cases loss of hair has also been reported (Morgan, Franks & Moffatt, 2005; Robertson Squire, 2000). The heaviness of the limb can lead to extreme fatigue, compromised posture, muscle tightness and musculoskeletal problems (Muscari, 2004; Passik & McDonald, 1998). Additionally fine motor movement may be affected as an upper limb increases in size (Carter, 1997, cited in Ridner, 2002). In terms of empirical studies, Moffatt and colleagues (2003) reported that 50% of patients in their prevalence study experienced pain or discomfort from their oedema and of those 56% were taking regular prescribed analgesia. Additionally, Lam et al. (2006) reported that 13% of participants indicated that pain, aching or tiredness affected their daily lives.

Moreover, the pooling of bacteria-laden lymph fluid in the body results in an increased susceptibility to infection, such as cellulitis an infection in the layers of the skin. Cellulitis is both a risk factor and consequence of lymphoedema. The symptoms of cellulitis include flushed skin and increased swelling in the affected area, an elevated white blood count or an elevated temperature (International Society of Lymphology, 2003; Lacovara & Yoder, 2006). If left untreated cellulitis can progress to systemic infection such as septicaemia (DHSSPS, 2004). Cellulitis is treated with antibiotics and in some cases requires hospitalisation (CREST, 2008; DHSSPS, 2004). Lymphoedema patients may experience recurring bouts of cellulitis and therefore patients may be advised to take low dose antibiotics as a preventative measure. Moffatt et al.'s (2003) reported that 29% of their sample had experienced at least once such acute infection in the previous year. Twenty-seven percent of those had been admitted to hospital for intravenous antibiotics. Over the course of their lymphoedema, 15% of their sample had experienced one or more hospital admissions for this purpose.

In summary, lymphoedema can involve symptoms such as pain, and tightness, but can also lead to associated conditions such as impaired mobility and cellulitis. However this literature should be considered in terms of the extent to which lymphoedema affects patients' daily lives. The results in relation to this are presented in the next section.

Impact of Lymphoedema on Daily Life

Lam et al. (2006) conducted a quantitative study of 1,449 members of the Lymphoedema Support Network in the UK and found that 75% of respondents considered lymphoedema to impinge on their daily living. This included limitations on their general mobility, restrictions on the clothes they could wear, limitations on the activities they could perform, the unsightly appearance of the affected area or the additional time they spent caring for the lymphoedematous area. Although as mentioned previously this study only involved lymphoedema support group members and did not include lymphoedema patients who were not involved with a support group.

Johansson et al. (2003) conducted a phenomenological study which involved interviews with twelve women experiencing breast-cancer-related secondary lymphoedema in Sweden. They reported themes relating to patients' discovery and subsequently acceptance of lymphoedema as a chronic disease with no cure. This reiterates Williams et al.'s (2004) findings on this topic. Meanwhile Bogan et al. (2007) interviewed 7 patients with non-cancer-related lymphoedema that had completed a lymphoedema rehabilitation programme in a hospital in the Pacific Northwest of America. All participants had extreme cases of swelling in order to provide information-rich experiences thereby illuminating both the unusual and the typical. Johansson et al.'s (2003) findings corresponded with Bogan et al.'s (2007) theme of patients ‘making room’ for their lymphoedema or Williams et al.’s (2004) theme of patients ‘getting on with it’. This can range from the physical effort of daily self-management practices, (such as exercises, simple lymphatic drainage and compression garment or bandage application) to dealing with the mental strain imposed by chronic illness (Bogan et al., 2007).

Additionally, lymphoedema can affect patients’ capacity to work. For example, as mentioned previously in the section on risk factors, patients with lymphoedema in their upper limb may be informed to avoid repetitive movements which might exacerbate symptoms; consequently work on a conveyor belt may be inadvisable. Patients with lymphoedema in their lower limb are advised to avoid prolonged periods of standing and therefore teaching may not be an ideal employment. More than 80% of respondents in Moffatt et al.’s (2003) prevalence study reported that they had taken time off work, 2% had to change occupation and 8% of respondents had to give up work entirely due to their lymphoedema. As a result lymphoedema may have a cumulative negative effect on patients’ wellbeing in that being impaired from working for a sustained period of time can result in psychological distress and depression due to financial pressures and challenges to an individual’s sense of self. Furthermore, an individual who is unemployed due to physical disability or incapacity rather than for other reasons is more likely to indicate symptoms within the range of a depressive disorder (Turner & Turner, 2004).

In summary, lymphoedema can affect patients’ daily lives through impaired mobility, following the daily management plan and in some cases ability to work. As a result lymphoedema can have significant psychosocial consequences which are explored further in the next section.

Psychosocial Consequences of Lymphoedema

Thomas-MacLean (2005) argues that lymphoedema can be explored in terms of the complexities of living with an altered, imperfect body. She suggests that many lymphoedema patients see their bodies through the eyes of others and as a result perceive it negatively.

This can lead to the adoption of practices such as concealing, underplaying, manipulating, or denying stigmatised differences which allows the "world of normals" to go unchallenged (Ellis, 1998 cited in Thomas-MacLean, 2005).

Participants' self-consciousness can be compounded by difficulties in finding clothing or shoes to cover the lymphoedematous area or being required to ask for help with daily chores (Johansson et al., 2003). Several qualitative studies reported how patients' self-consciousness was also heightened by the reactions of others to their swelling or compression sleeve. For example themes such as 'suffering silently', (Hare, 2000) 'alone and hiding from the world' (Bogan et al. 2007) and 'rehearsing the story and learning to open up' (Williams et al. 2004) were reported. Indeed in Lam et al.'s (2006) quantitative study approximately half of their respondents reported that their social life was affected by their insecurity and self-consciousness.

Findings in relation to self-consciousness also arose in studies of patients in regions endemic with filariasis, the parasitic infection transmitted by mosquitoes which damages the lymphatic system. Person and colleagues (2008) conducted a qualitative study of 28 women with lymphatic filariasis in their lower limbs in the Dominican Republic. They incorporated interviews, focus groups, field notes and photographs of participants in their homes. As understanding of the causes of lymphoedema among the general public can be poor, participants experienced considerable stigma, and social isolation, as others feared the condition was contagious. As a result many reported feelings of hopelessness and despair (Person et al., 2008).

Overall, in a review of eighteen quantitative and qualitative studies McWayne and Heiney (2005) reported that lymphoedema can lead to frustration, distress, depression and anxiety. Furthermore, for cancer survivors it may be difficult to separate the experiences of surviving cancer and living with lymphoedema as lymphoedema is often a constant reminder of cancer and its treatment (Carter, 1997 cited in Hare, 2000; Woods 1993). For some patients this can result in feelings of not being able to get on with life (Passik & McDonald, 1998) and heightened fears of cancer recurrence (Engel et al., 2003; Thomas-MacLean, 2005). Conversely Waters (2007) conducted autobiographical interviews with primary lymphoedema patients and reported that they can experience the added concern of the potential heritability of their condition.

While these studies offer some insight into the potential emotional difficulties experienced by patients, some studies have included actual psychological assessment in order to ascertain whether lymphoedema patients experience clinical levels of distress. Tobin and colleagues (1993) conducted formal psychiatric interviews and administered the Hospital Anxiety and Depression Scale (HADS), the Psychological Adjustment to Illness Scale (PAIS), and the Karnofsky Performance Scale, which measures physical functioning, to fifty patients with breast-cancer-related secondary lymphoedema and fifty matched control breast cancer survivors from The Royal Marsden Hospital in London. Tobin et al. (1993) found that lymphoedema patients showed greater psychological morbidity, impaired adjustment to illness and impaired physical functioning when compared with controls. However this was based on a relatively small sample of patients with one type of lymphoedema accessed from one hospital.

Similarly, Passik and colleagues (1995) administered a series of measures including the Brief Symptom Inventory (BSI), which provides a global severity index based on subscales measuring levels of depression, anxiety, obsessive compulsivity, paranoia and psychoticism, and the Derogatis Sexual Functioning Inventory (DSFI). Their sample was composed of 69 women with breast-cancer-related secondary lymphoedema from the lymphoedema clinic at the Memorial Sloan-Kettering Cancer Centre in New York. They found that women with lymphoedema had high levels of psychological distress, high level of body image disturbance and evidence of sexual dysfunction. Once more this study was based on patients with breast-cancer-related secondary lymphoedema and only included patients from one hospital.

Moreover both Tobin et al.'s (1993) study and Passik et al.'s (1995) study were conducted over ten years ago and as a result replication of these studies is required.

While bearing in mind the significant emotional and psychological difficulties some lymphoedema patients can experience it is important to consider the social consequences of living with lymphoedema. For example, Radina and Armer (2001) conducted an ethnographic study to explore how the impact of lymphoedema extends beyond the individual patient to the wider family group. They interviewed six women with breast-cancer-related secondary lymphoedema and two professionals – an oncology nurse and a physiotherapist before observing participants' interactions at a group meeting of a newly formed lymphoedema support group in central Missouri. Their first finding was that due to the limitations imposed by the condition, individuals with lymphoedema may modify their performance of particular household duties or request assistance in performing these tasks (Radina & Armer, 2001). This can be challenging as many individuals attribute part of their identity to being a homemaker, hands-on-parent or the person who repairs the home. In addition participants spoke of difficulties they experienced in asking for help given the importance they placed on being independent. The second finding was that the impact of lymphoedema on participants' ability to perform daily tasks required participants and their families to cope with changes in relation to family functioning and relationships. For example, participants spoke of how the family is required to adapt to repeated stressors (e.g. changes in limb volume and other symptoms, bouts of cellulitis, etc.). Some families rally around and support the person affected by lymphoedema to regain balance in the family, while other families are more rigid, and therefore do not make any adaptations perpetuating the imbalance (Radina & Armer, 2001). This study offers some insights into the psychosocial difficulties associated with lymphoedema; however the study would have been strengthened by interviews or focus groups involving participants' family members. Also further research is required in order to explore whether these difficulties are experienced in the families of lymphoedema patients in other settings with a view to extrapolating practical material from such findings to support patients in addition to the members of their family unit and social network.

Bearing in mind the studies identifying lymphoedema patients' self-consciousness, the impact of the condition on patients' psychological wellbeing and the potential affect on patients' wider social network, it is unsurprising that experiencing lymphoedema has been associated with lower quality of life scores. A summary of the results in relation to this is presented in the next section.

Impact of Lymphoedema on Quality of Life

Velanovich et al. (1999) requested 101 consecutive unselected patients who underwent breast surgery at the Henry Ford Hospital in Detroit, Michigan to complete the short form (SF-36) health survey. This measures eight domains of quality of life including physical functioning, role-physical, role-emotional, bodily pain, vitality, mental health, social functioning and general health. All scores in the SF-36 are standardised so that the worst possible score is 0 and the optimum level of health in that domain is scored as 100. Participants were divided into one of three groups: patients who had breast surgery involving axillary lymph node dissection (ALND) who had developed lymphoedema, patients who had breast surgery involving ALND who hadn't developed lymphoedema and patients who had breast surgery not involving ALND who hadn't developed lymphoedema. Velanovich et al. (1999) found that patients who had breast surgery involving ALND and had developed lymphoedema scored significantly lower in the domains of role-emotional and bodily pain when compared with patients in the two other groups. The percentage of patients who were below one standard deviation of the national norm was significantly higher among patients who had previously received ALND and had developed lymphoedema than patients in the other two groups. This occurred in the domains of bodily pain, mental health and general health and it was higher although not significantly so in the role-emotional domain.

Coster et al. (2001) administered the Functional Assessment of Cancer Therapy-Breast Cancer scale which assesses breast, emotional, functional, physical and social wellbeing with an additional four questions on arm morbidity (FACT-B+4) to 29 patients with breast-cancer-related secondary lymphoedema from a specific lymphoedema clinic in the UK. They found that lymphoedema patients had significantly lower scores on the FACT-B+4 when compared with 29 matched preoperative breast cancer patients.

Beaulac et al. (2002) also administered the FACT-B+4 in their study of 151 breast cancer patients from Boston University Medical Centre, or Jordan Hospital in Plymouth Massachusetts. They found that patients with breast-cancer-related secondary lymphoedema scored significantly lower on the breast, emotional, functional and physical wellbeing subsections of the scale, when compared with breast cancer survivors who hadn't developed lymphoedema. This was even after adjusting for other factors which can influence quality of life scores (e.g. range of motion of the limb, menopausal status and body mass index). However the results relating to the social wellbeing subsection were not statistically significant.

Mak et al. (2009) administered the FACT-B+4 and a self-devised Arm Symptom Distress Scale, which includes questions on pain, numbness, tingling, limitation of movement, infection and interference with daily life to a total of 202 patients from the Prince of Wales Hospital in Hong Kong. One hundred and one of their participants had breast-cancer-related secondary lymphoedema and 101 were breast cancer survivors who hadn't developed lymphoedema. They found that patients with breast-cancer-related secondary lymphoedema had significantly worse scores on the FACT-B+4 and Arm Symptom Distress Scale when compared with breast cancer survivors who hadn't developed lymphoedema, matched by patient demographics and clinical factors (e.g. surgery date, axillary radiotherapy and cancer stage). Moreover, patients with more severe lymphoedema scored significantly lower than those with mild lymphoedema. However the studies by Velanovich et al. (1999), Coster et al. (2001), Beaulac et al. (2002), and Mak et al. (2009) involved samples of patients with breast-cancer-related secondary lymphoedema accessed from one or two lymphoedema services and therefore did not involve broad samples of patients with other types of lymphoedema accessed from multiple settings.

Finally, as part of their lymphoedema prevalence study, Moffatt et al. (2003) compared 228 lymphoedema patients' scores on the SF-36 with published normative data for adults of working age and for elderly people. They found lymphoedema patients had clear deficits in all sub-scores of the SF-36 with the exception of the mental health and general health scores. The largest mean differences occurred in role-physical, role-emotional, social functioning and physical functioning subscales. All of these differences were significant at the $p<0.001$ level. Despite the psychological implications of lymphoedema outlined above, only 3% of participants received psychological support as a treatment strategy (Moffatt et al., 2003). While this study did consider patients with other types of lymphoedema sufficient information is lacking in that while the authors indicate that 25% of the sample had cancer-related secondary lymphoedema, the percentage with breast-cancer-related secondary lymphoedema, cancer-related (but not breast-cancer-related) secondary lymphoedema, non-cancer-related secondary lymphoedema or primary lymphoedema were not reported. Furthermore the quality of life aspect of the study involved a relatively small sample derived from a particular catchment area, namely South West London.

While these studies suggest that lymphoedema has a considerable impact on patients' quality of life, this is qualified by the considerable time period since some of the studies were conducted and the lack of studies involving a broad sample involving patients with various types of lymphoedema accessed from multiple services or locations. The previous sections have considered the physical conditions, daily limitations, psychosocial factors and quality of life issues associated with lymphoedema. The following section details research exploring the symbiotic relationship between these factors in exacerbating and protecting against the impact of lymphoedema on patients.

Exacerbating and Protective Factors

Regarding physical factors that may exacerbate the consequences of lymphoedema, Passik et al. (1995) found that severity of the swelling did not have a clear linear relationship with levels of distress; rather the associated symptoms of lymphoedema had more of an impact. Experiencing lymphoedema in the dominant arm; poor skin quality; frequent bouts of cellulitis; and pain have all been cited as significant predictors of sexual and psychosocial morbidity (see McWayne & Heiney, 2005; and Morgan, Franks & Moffatt, 2005 for a review of studies; and Passik & McDonald, 1998 for a brief review of general research trends). Pain is of particular importance as it can also spark intrusive thoughts about cancer recurrence, isolation, and an avoidant coping style and is associated with low perceived social support (Passik & McDonald, 1998). These findings suggest that effective treatment and maintenance of physical symptoms can have significant benefits to patients. Indeed Morgan, Franks and Moffatt (2005) cite a study by Kirschbaum (1996) indicating that the implementation of evidence-based, patient-centred guidelines for the management of lymphoedema can improve quality of life outcomes.

Regarding daily disturbances that can exacerbate the effects of lymphoedema, as previously mentioned, experiencing lymphoedema in the dominant arm has a significant effect on sexual and psychosocial morbidity (Passik et al., 1995). This may take place indirectly through greater functional limitations (Passik & McDonald, 1998).

Studies relating to psychosocial factors have generally focused on the benefits of being aware of the risk of developing the condition in advance and coping styles. As mentioned previously qualitative studies have found that a lack of knowledge about lymphoedema can be hugely frustrating for patients in the initial stages of the condition (Bogan et al., 2007; Williams et al., 2004). Therefore it is unsurprising that McWayne & Heiney (2005) found that a lack of prior knowledge of the features of lymphoedema and one’s susceptibility to developing it, compounded by poor illness adjustment predicted higher levels of anxiety and depression. Hare (2000) reported that prior knowledge about lymphoedema helped to ease patients’ sense of loss, mourning and anxiety, and increased patients’ sense of being in control when they did develop lymphoedema. Yet, the receipt of information in and of itself is not sufficient. Johansson et al. (2003) reported that patients considered much of the information they received as inappropriate and unhelpful, (e.g. being told that lymphoedema can only develop within 6 months of cancer treatment, whereas in reality the risk is lifelong). Widespread inconsistency in the timing and delivery of patient information to those at risk can lead to many gaining the impression that it is their fault if lymphoedema develops, resulting in considerable distress (Martlew, 1999; Tobin et al., 1993).

In terms of research on coping, an avoidant coping style was found to be a significant correlate of psychological distress as it is associated with greater body image concerns (Passik et al., 1995). Yet an active coping style didn't necessarily benefit patients as individuals with lymphoedema in their dominant arm still had increased difficulty in adjusting to their condition (Passik et al., 1995). Therefore exacerbating and protective factors cannot be viewed in isolation.

Johansson and colleagues (2003) identified problem-focused coping and emotion-focused coping as buffering patients against the negative consequences of living with the condition. Problem-focused coping related to patients using their unaffected arm to carry items, whereas emotion-focused coping related to patients regulating their emotional distress by consciously considering lymphoedema as a less important aspect of their lives. In their analysis of focus group data from a total of 20 women with breast-cancer-related secondary lymphoedema Hare (2000) identified emotion-focused coping. For example they reported how spirituality, 'counting blessings' and the sense of belonging and acceptance at the lymphoedema clinic acted as a defence against negative feelings associated with lymphoedema. Hare (2000) also reported the serendipitous finding that the focus groups themselves may have been beneficial for patients as several participants sent thank you cards to the researcher.

A cross cultural study involving German, Japanese and South Korean patients with breast-cancer-related secondary lymphoedema found that although there were no significant differences in terms of the impact of psychosocial factors between countries; depressive coping and problematic social support exerted a negative effect on quality of life (Shim et al., 2006 cited in CREST, 2008). Good social support may be protective by helping to counteract fears of abandonment and isolation, and have an indirect effect through treatment compliance and satisfaction thereby potentially improving physical symptoms (Passik et al., 1995).

Regarding protective factors within the family, in their secondary analysis of the data from their 2001 study, Radina and Armer (2004) reported the pattern that resiliency among lymphoedema patients (i.e. displaying good adjustment and adaptation to stressors) was associated with good prior family functioning (i.e. good adjustment and adaptation to previous stressors), family resources (i.e. individual, family and community characteristics and supports) and stressor appraisal (i.e. the meaning assigned to particular stressors such as spiritual beliefs, cultural values and past experiences). Further details and discussion of these findings is required. Also additional research on the experiences of patients and their wider social network is necessary in order to develop practical materials to support patients in addition to the members of their family unit and wider social network.

In summary, physical consequences, daily limitations, psychosocial consequences and quality of life have a complicated interrelationship acting as exacerbating and protective factors. Yet existing studies looking at these topics are either qualitative and therefore have limited generalisability or are cross-sectional and correlational and therefore causality cannot be determined. Longitudinal research is required to explore this further. As a result few definite conclusions can be reached as to the mechanisms and interrelations of exacerbating and protective factors.

Conclusions

Previous research on the potential impact of lymphoedema on patients' physical and psychosocial wellbeing, daily life and quality of life has been outlined. While these studies provide interesting insights into patients' experiences of living with lymphoedema, it is important to note their limitations. Several studies are retrospective and as a result patients' perceptions of their lives before they had lymphoedema are irrevocably influenced by their experiences since their diagnosis (McWayne & Heiney, 2005). As a result longitudinal studies are required to explore patients' experiences of lymphoedema as their level of swelling and other associated conditions fluctuate in severity. In addition, much of the research is ethnocentric and therefore there is a need for research which considers intra- and inter-ethnic diversity, gender issues and the compound effect of poverty (Sneddon & Lewis, 2007).

Qualitative studies have provided interesting insights but their generalisability is under question. Moreover most quantitative studies focused specifically on patients with breast-cancer-related secondary lymphoedema and most quality of life studies focused exclusively on comparing patients with breast-cancer-related secondary lymphoedema to breast cancer survivors who hadn't developed lymphoedema. Therefore quantitative research into the impact of lymphoedema on the quality of life of patients with other forms of lymphoedema has been neglected. Further research is needed to integrate these quantitative scales with clinical practice so that they are practical for use by practitioners at assessment and follow up (Williams, 2006a).

Moreover, existing studies on exacerbating and protective factors are either qualitative and therefore have limited generalisability or are cross-sectional and correlational and therefore causality cannot be determined. Longitudinal research is required to explore this further. As a result few definite conclusions can be reached as to the mechanisms and interrelations of exacerbating and protective factors.

Several researchers have called for evidence-based psychological interventions for lymphoedema patients on the basis that they would be cost-effective in the long term by improving treatment adherence, encouraging self-management, and therefore increasing the sustainability of lymphoedema services (McWayne & Heiney, 2005). In tandem with this, researchers have also called for the development of couple or family interventions in order to bring further benefits for patients (McWayne & Heiney, 2005; Morgan, Franks & Moffatt, 2005; Runowicz et al., 1998). However the methodological limitations of existing research suggest that this cannot take place until additional more robust research is conducted.

There has been no initial exploratory research conducted in the Republic of Ireland on lymphoedema patients' experiences of service provision and of living with the condition. Such research could serve as a first step to further explorations of the experiences of Irish patients and the members of their wider social networks, with a view to subsequently developing, piloting and rolling out effective evidence-based support programmes tailored for Irish patients, their families and friends. The following research outlines general arguments for the importance of research on lymphoedema and the aims of the present study.

Importance of Research on Lymphoedema and Aims of the Present Study

Traditionally lymphoedema was viewed as an unimportant and untreatable side effect of cancer, and therefore didn't receive a lot of attention within the research community (Morgan, Franks & Moffatt, 2005). However in recent years lymphoedema is increasingly viewed as a significant and complex problem which can present a significant challenge to a person's quality of life (Morgan, Franks & Moffatt, 2005). This has been coupled with the realisation that lymphoedema rates are likely to increase due to the widely predicted increase in the number of people affected by cancer, surviving cancer and experiencing longer cancer remissions (Földi, 1998; Martlew, 1999; Thomas-MacLean, 2005). Age is a significant risk factor in the development of lymphoedema. The increase in life expectancy rates, particularly among women who themselves are more likely to develop lymphoedema, also points towards increasing lymphoedema prevalence (Földi, 1998; Sneddon & Lewis, 2007). Incidence may also increase in a society where obesity is increasing and exercise levels are decreasing (DHSSPS, 2004; Sneddon & Lewis, 2007). In addition, the rates of lymphoedema are increasing worldwide due to lymphatic filariasis (Williams et al., 2005). Therefore as the number of people affected by lymphoedema increases, the need for additional research on lymphoedema becomes greater.

Apart from a general need for research on lymphoedema, as outlined above there is a need for more specific strands of research. As mentioned previously in the sections on service provision, much of the information on lymphoedema service provision is derived from reports based on consultations with a select group of stakeholders rather than empirical investigations of the opinions of representative samples of practitioners and patients. Moreover there is a need for additional research on patients' experiences of living with lymphoedema including the psychological consequences of the condition and the impact of lymphoedema on quality of life. The development of services and interventions cannot take place without such an assessment of the current level of service provision and of patients' needs. Specifically such research on service provision and the experiences of patients is required in the Republic of Ireland as no previous research has been conducted on lymphoedema to date.

It is against this background of a dearth of research on lymphoedema that the current study was undertaken. The specific purpose of this research is to investigate lymphoedema service provision and the impact of the condition on patients' lives in the Republic of Ireland for the first time. Given the chronic nature of lymphoedema, its impact on physical and psychological health and the potential increase in prevalence rates, it is imperative that lymphoedema patients have access to patient-centred, evenly distributed services. Moreover while practitioners are aware of the physical consequences of lymphoedema, until there is greater cognisance of the psychological and social implications of living with the condition, a comprehensive, multi-dimensional support service cannot be provided to patients. Therefore the overall aims of this study were to:

- Provide an overall account of current service provision: documenting the range, location, funding, and referral pathways of services provided nationwide and exploring patients' experiences of obtaining a diagnosis, searching for appropriate treatment, accessing treatment and availing of ongoing lymphoedema services.

- Ascertain service providers’ and patients’ recommendations for lymphoedema service development.
- Explore patients’ experiences of living with lymphoedema and the impact of the condition on daily life and quality of life.

The service provider survey, patient focus groups and patient survey phases of the study explored different aspects of these research aims and the specific aims of each phase are outlined in the relevant chapter. Chapter 3 outlines the rationale for choosing such a mixed methods approach to meet these aims.

Chapter 3: Mixed Methods Approach

This research study employed a mixed methods design to investigate patients' and service providers' experiences of lymphoedema service provision and to explore patients' experiences of living with lymphoedema. The study design had three elements: service provider survey, patient focus groups and patient survey. The rationale for choosing this mixed methods design is presented below.

Introduction to Mixed Methods

A mixed methods study is one which includes both quantitative and qualitative methods. Quantitative methods generally involve primarily closed-ended questions in a questionnaire format where participants are encouraged to provide numerical data or to choose between predetermined categories of responses (Creswell & Plano Clark, 2007; Maxwell & Loomis, 2003). The results are analysed statistically and may be generalisable if the statistical power of the method is deemed sufficient. The quantitative method is best suited to answering questions on the frequency or extent of certain experiences or phenomena (Maxwell & Loomis, 2003). However the limitations of quantitative methods include the poor expression of the context in which participants live; the participants' personal voice; and the personal biases and interpretations of researchers (Creswell & Plano Clark, 2007).

In contrast qualitative methods involve open-ended data which is usually gathered through textual analysis or discussion (Creswell & Plano Clark, 2007; Maxwell & Loomis, 2003). Each qualitative method has specific strengths. For example, focus groups are semi-structured group discussions. Participants are encouraged to respond with the idiosyncratic expression and interpretation of their experience. Focus groups capitalise on the interaction within a group and allow the comparison of participant's experiences and perceptions (Morgan, 1997). They can result in rich, experiential data if properly moderated and conducted in a non-threatening atmosphere (Morgan, Franks et al., 2005). Moreover, focus groups can result in serendipitous findings such as the empowerment of participants by making them feel like experts, which can in turn, benefit participants (Hare, 2000). Qualitative methods are strong on expressing findings in participants' own voices and exploring the reasons behind certain experiences. However they have been criticised for their subjectivity, the small samples involved and the consequent difficulties in generalising findings (Creswell & Plano Clark, 2007).

Historically there has been much debate in the research community over whether quantitative or qualitative methods are superior. This has been replaced by discussion on when it is most appropriate to use each method, and when quantitative and qualitative approaches should be combined within a single research study (Foster, 1997). By combining methods within a single study, the intention is not to homogenise the research methods but rather to synthesise and preserve the unique qualities and advantages of both quantitative and qualitative methods (Maxwell & Loomis, 2003). Each method is stronger at exploring the answers to different, but related, research questions. By integrating findings within a single study, a mixed methods design can capitalise on the strengths of both quantitative and qualitative methods to provide a more complete depiction of a phenomenon, than either method could provide alone (Creswell & Plano Clark, 2007; Erzberger & Kelle, 2003; Ivankova et al., 2006).

Rationale for Use of Mixed Methods Design in the Present Study

There are several reasons why a mixed methods design supported the aims of this research study. Firstly the study aimed to explore lymphoedema service provision from both service provider and patient perspectives in the Republic of Ireland for the first time. A mixed methods design complemented this aim as it promotes the integration of findings from multiple perspectives and methods (Creswell & Plano Clark, 2007).

Secondly this study aimed to explore patients' experiences of living with lymphoedema, for the first time. Therefore an exploratory approach where one can qualitatively explore and identify variables, constructs and wordings before measuring these quantitatively, corresponded with this research aim (Creswell & Plano Clark, 2007; Morgan, 1997). As a result the focus groups were intended to assist in identifying topics of particular relevance to Irish lymphoedema patients with a view to including these in the design of a patient questionnaire.

Thirdly, the use of a qualitative method was not solely to assist in the design of the quantitative patient questionnaire. One form of data would be insufficient in itself to explore patients' experiences of living with a complex condition such as lymphoedema. The original research questions were concerned not just with the frequency of specific occurrences but also the interpretation and meaning given to these experiences by patients. Therefore the qualitative aspect of the study was intended to assist in clarifying subtleties and cross-validating findings (Creswell & Plano Clark, 2007). While the use of more than one type of data does not guarantee internal or external validity, it does encourage the researcher to consider the findings more critically and thereby present a more measured account of the findings to the audience (Fielding & Fielding, 1987). Several researchers have termed this process as triangulation (Fielding & Fielding, 1987). By integrating the results from various methods super-ordinate themes can emerge. Therefore it is argued that interpretations based on these super-ordinate themes will be more credible, dependable and more likely to accurately represent the complexities of reality (Farmer et al., 2006). However the term triangulation has since become associated with the misconception that the goal of mixed methods integration is to reach a fixed point or convergent findings (Erzberger & Kelle, 2003). In reality the aim of mixed methods is to reveal infinite dimensions, angles and perspectives (Tobin & Begley, 2004). As a result there is a move within the mixed methods research community towards referring to this process as crystallisation, although the debate on nomenclature continues (Creswell & Plano Clark, 2007).

Finally mixed methods have been utilised in previous lymphoedema research, albeit in a different sequence to the current study. The study by BreastCare Victoria (2005) employed patient questionnaires, followed by patient focus groups and practitioner questionnaires. The findings from this mixed methods study have partly informed the development of strategies now being implemented across all cancer streams in Victoria, Australia. This study demonstrated the potential usefulness of a mixed methods design in addressing the aims of the study and in informing meaningful, practical recommendations.

Given that mixed methods corresponds with the specific aims of this study and has been shown to be a beneficial aspect of previous lymphoedema research a mixed methods approach was adopted.

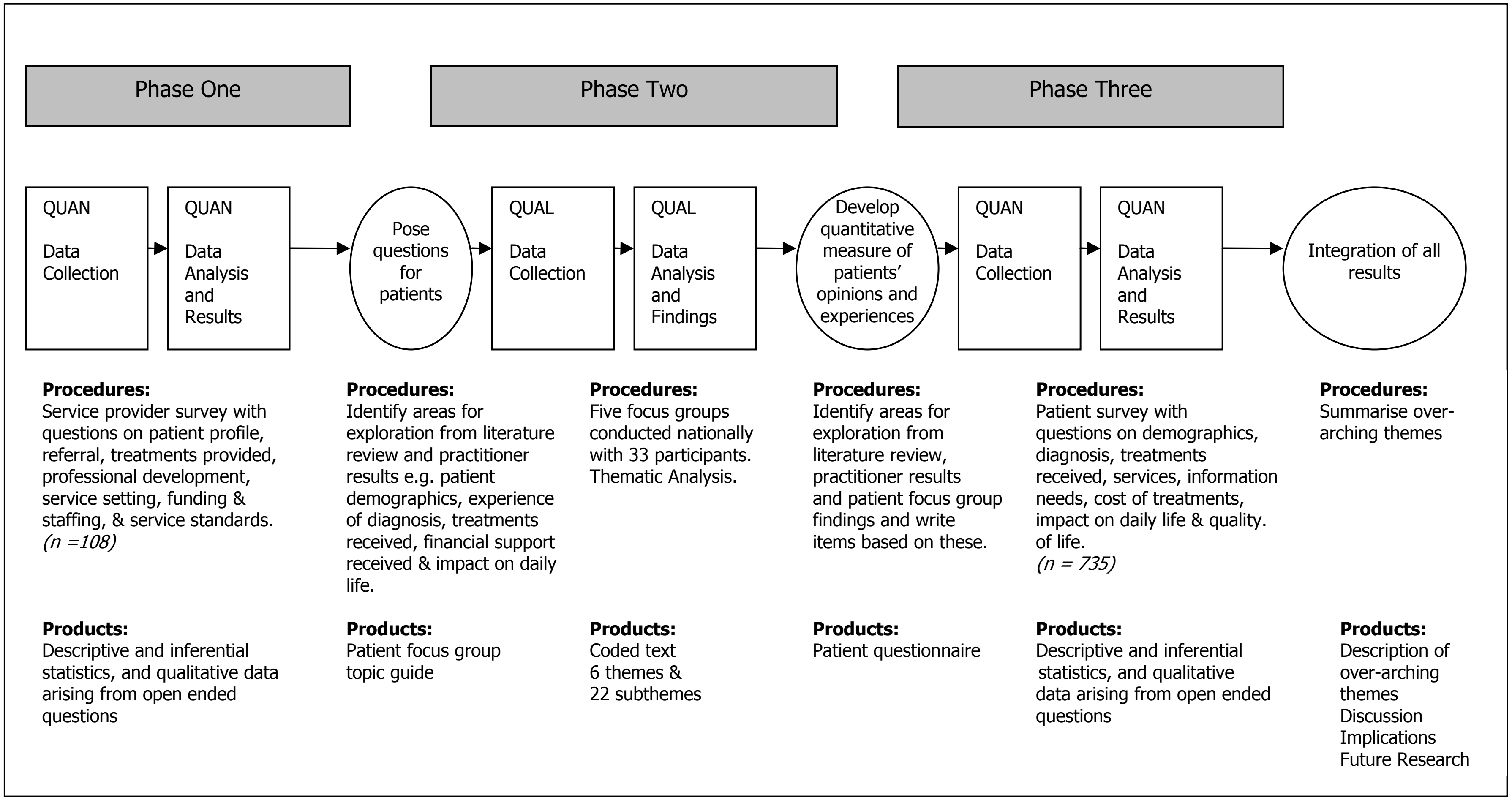
Sequence of Methods

This study involved three phases of data collection: service provider survey, patient focus groups, and patient survey.

The first phase of the research employed practitioner questionnaires to ascertain the opinions and recommendations of practitioners working in lymphoedema service provision, and to guide the design of the patient focus group topic guide. Furthermore this phase assisted in mapping current lymphoedema service provision in the Republic of Ireland thereby facilitating the identification of services or organisations that patients could be accessed from in subsequent phases of the study.

The second phase of the research involved focus groups conducted with patients. The focus group topic guide was influenced by the results of the service provider survey and a review of the literature. The intention of the focus groups was to explore patients' experiences of lymphoedema, service provision, and the impact of the condition on quality of life. Moreover the focus groups were intended to assist in identifying topics for inclusion in the patient questionnaires that hadn't arisen from the review of existing literature or practitioner questionnaires.

Finally the patient survey offered the potential to access a wider group of lymphoedema patients in order to calculate frequency data on patients' experiences in relation to lymphoedema service provision and the impact of lymphoedema on their quality of life. The sequence of methods is represented graphically in Figure 1 on page 50, which is based on Ivankova et al.’s (2006) guidelines for visual models of mixed methods studies.



Procedures:
Service provider survey with questions on patient profile, referral, treatments provided, professional development, service setting, funding & staffing, & service standards.
(n =108)

Products:
Descriptive and inferential statistics, and qualitative data arising from open ended questions

Procedures:
Identify areas for exploration from literature review and practitioner results e.g. patient demographics, experience of diagnosis, treatments received, financial support received & impact on daily life.

Products:
Patient focus group topic guide

Procedures:
Five focus groups conducted nationally with 33 participants. Thematic Analysis.

Products:
Coded text
6 themes &
22 subthemes

Procedures:
Identify areas for exploration from literature review, practitioner results and patient focus group findings and write items based on these.

Products:
Patient questionnaire

Procedures:
Patient survey with questions on demographics, diagnosis, treatments received, services, information needs, cost of treatments, impact on daily life & quality. of life.
(n = 735)

Products:
Descriptive and inferential statistics, and qualitative data arising from open ended questions

Procedures:
Summarise over-arching themes

Products:
Description of over-arching themes
Discussion
Implications
Future Research

Figure 1: Visual Diagram of the Research Design

Priority of Methods

The priority of methods refers to which approach (i.e. qualitative, quantitative or both) that the researcher gives more weight or attention to in the data collection and analysis stages of the research (Ivankova et al., 2006). In Figure 1, the use of capital letters (QUAN/QUAL) is used to signify that the methods have been given equal status. Therefore neither approach (i.e. qualitative or quantitative) has been given more weight or attention in the data collection or analysis stages of the research (Ivankova et al., 2006). Although it must be noted that due to the sequential nature of this study, earlier phases of the research did have a bearing on the content of subsequent data collection methods. For example, the results of the service provider survey informed the design of both the patient focus group topic guide and patient questionnaire. Likewise the findings of the patient focus groups also influenced the design of the patient questionnaire.

The perspectives of practitioners and patients have been given equal status in their views on lymphoedema service provision. Both samples provided a different viewpoint on the realities and interpretations of service provision and the study is richer for including both. However Farmer and colleagues (2006) suggest that certain samples or datasets may be more appropriate for answering different aspects of the research questions. For example in the BreastCare Victoria (2005) study, the service provider questionnaires provided information on topics, such as service structure, funding and level of staff training, that patients were likely to be less informed about. Conversely, patients were better placed to comment on other topics such as satisfaction with treatment. As a result, in the current study in cases when a particular sample is best placed to provide insight on a particular topic, emphasis has been given to the findings from that particular sample. The BreastCare Victoria (2005) study directed certain questions solely at patients (e.g. standards of care received). In the current study this topic was addressed to both service providers and patients in order to explore whether their perspectives differed considerably on this topic.

Within the patient data, the focus group findings and survey results were given equal status. The focus groups were intended to contribute more than merely influencing the content for the questionnaire. As mentioned previously, the complexity of participants' experience of lymphoedema and lymphoedema service provision could not have been captured solely through the questionnaire design. The patient survey offers the opportunity of ascertaining how representative various experiences of lymphoedema and lymphoedema service provision are among a broader sample of patients, and of quantitatively measuring the impact of lymphoedema on patients' quality of life in Ireland for the first time. Moreover, the patient survey provides additional information to correspond with, expand on or contradict the findings of the service provider survey and patient focus group phases.

Integration of Findings

Mixed methods research involves not just the inclusion of both quantitative and qualitative methods within a single research study but also the integration of the findings derived from both methods (Creswell & Plano Clark, 2007). As a result there is the potential for various outcomes: silence (where one dataset uncovers a theme or example whereas another dataset is silent about it); convergence (where all datasets produce the same findings on a theme or example); complementarity or divergence (where all sets of data feature a theme but have different perspectives on that theme); and contradiction or discrepancy (where datasets offer different findings on a theme) (Farmer et al., 2006; Johnson et al., 2007). Acceptance of each of these outcomes is legitimate as it involves admitting the complexity of the phenomenon under investigation (Slonim-Nevo & Nevo, 2009). Moreover it corresponds with the concept of crystallisation whereby a variety of perspectives and versions of the world are revealed (Erzberger & Kelle, 2003; Sandelowski, 1995 cited in Creswell & Plano Clark, 2007).

The process of integration can take place at various stages of the study (Johnson et al., 2007; Maxwell & Loomis, 2003). In the case of the current study, integration took place at the research planning, data collection and data analysis stages.

In terms of the research planning stage, research questions and sub-questions were related specifically to each phase of the research. Therefore it is to be expected that there may be silence regarding certain themes in one set of results when compared to others. For example, as mentioned previously, service providers are better placed to answer questions on the funding, staffing and staff educational levels within services whereas patients are unlikely to be as informed on these issues. Therefore questions have been tailored to the specific sample in question. Moreover as mentioned previously, the practitioner questionnaires were seen as integral to facilitating sampling in the patient phases of the research by assisting the research team in locating the lymphoedema services that patients could be accessed from.

Integration took place in the data collection stage, in that the quantitative and qualitative components influenced subsequent phases of the research. As mentioned previously, the practitioner questionnaire phase of the research informed both the patient focus group and patient questionnaire phases. For example issues that arose from the service provider questionnaires (e.g. waiting times for treatment, cost of treatments, cost of compression garments, waiting times for compression garments to be delivered etc.) were then integrated into the later phases of the research involving patients. Likewise the patient focus groups also influenced the patient questionnaire design. For example, in the focus groups, some participants reported that they didn’t wear their compression garment as often as they had been advised to by their lymphoedema practitioner. As a result questions on this topic and the reasons for this were included in the patient questionnaire.

Integration was also carried through into the data analysis stage. While the results of each phase of the research are explored in individual chapters, the final discussion chapter presents the overarching themes of this study. This structure is intended to promote clarity on the findings from each phase of the research while also providing space to integrate the findings from the three phases. Farmer and colleagues (2006) reported that while many researchers maintain that the integration of findings utilises mixed methods to their full advantage, few give details of the specific procedures undertaken. Their approach was to calculate how often various themes emerged from each datasets. However the intention in the current research was not to quantify qualitative findings. Therefore the themes arising from each phase of the research are explored separately in the relevant chapters and subsequently super-ordinate themes or metainferences are explored in the overall discussion in Chapter 7 (O'Catháin et al., 2007). Within the super-ordinate themes silence, convergence, complementarity and contradiction may be identified and where these arise each are discussed in turn.

Chapter 4: Service Provider Survey

Introduction

The first phase of the research was an exploration of service providers' perspectives on lymphoedema service provision in order to set the scene for the patient phases. The inclusion of service provider questionnaires in the study had several purposes.

Firstly, the questionnaires were utilised to map current lymphoedema service provision in Ireland for the first time, in order to identify the services or organisations that lymphoedema patients could be accessed from in subsequent phases of the study. The Australian Lymphology Association's (2002) National Service Equity Survey mapped lymphoedema service provision in Australia and this information was used to guide practitioner questionnaire distribution in the later BreastCare Victoria (2005) study. However there was no known listing of lymphoedema services in Ireland at the time the current study was conducted. Therefore the first phase not only provided important data on service providers' experiences but also facilitated the identification of a patient sample in later phases of the study.

Secondly practitioners could offer an additional perspective on lymphoedema service provision. As mentioned previously, the BreastCare Victoria (2005) study employed practitioner questionnaires to explore topics pertinent to lymphoedema service provision that patients would not necessarily be aware of such as the overall profile of patients attending services, descriptions of the full range of treatments provided, practitioners' training needs, referral pathways, and levels and sources of funding. As a result the contribution of service providers would help to inform the report's recommendations and ensure that they are based on current practice.

Finally the results of the service provider survey could inform later phases of the research, involving lymphoedema patients. As the people directly involved in the care of those affected by lymphoedema, service providers could enhance the research team's understanding of patients' experience of the condition, its management and the barriers to treatment. Thus the most pertinent topics could be emphasised during the development of measures of lymphoedema patients' experiences i.e. the focus group topic guide and questionnaire. Although the BreastCare Victoria (2005) study employed patient questionnaires and focus groups in advance of their practitioner survey, they were guided in the development of those patient measures by a prior study of practitioners' experiences by the Australian Lymphology Association (ALA). This earlier study conducted by the ALA in 2003 signposted some of the topics for inclusion in the BreastCare Victoria (2005) study, for example compression garment provision. However as the ALA study highlighted that lymphoedema service provision varies throughout the Australian states, the authors of the BreastCare Victoria study considered the inclusion of practitioners' views in a later part of the study to be required nevertheless. A study of Irish lymphoedema practitioners' experiences had not been conducted prior to the current study and as a result a practitioner phase was incorporated into the early stages of the current study to provide insights into their experiences and guide the development of later phases.

Specific Aims of Service Provider Survey

The broad aims of the service provider questionnaire phase were to investigate practitioners' experiences of lymphoedema service provision and explore their recommendations for lymphoedema service development. These general aims can be broken down into more specific objectives, which were to:

- Ascertain the type, setting and location of lymphoedema services and the type of healthcare professionals providing these services.
- Investigate service-based factors which may affect optimal lymphoedema service provision (e.g. practitioners' experience in treating lymphoedema patients, time spent per week treating lymphoedema patients, sources of funding, staffing levels, cover for leave, referral pathways).

- Determine the breakdown of lymphoedema patients being seen in lymphoedema services (e.g. type of lymphoedema, location of lymphoedema in the body, age range, gender etc.).
- Investigate what information and treatments are being provided and to explore potential barriers to treatment (e.g. distance to lymphoedema service, waiting times etc.) in order to inform subsequent patient phases of the research.
- Investigate potential inequalities in lymphoedema service provision (e.g. preferential acceptance of referrals by services, waiting list prioritisation systems and practitioners' ratings of the standard of care received by patients with different types of lymphoedema).
- Explore issues that may affect lymphoedema service development (e.g. practitioners' current level of training, barriers to accessing training).
- Ascertain practitioners' recommendations for lymphoedema service development.

Method

Identifying a Sample

There is no known nationally updated register of all professionals working with lymphoedema patients except the MLD Ireland listing of registered MLD therapists in Ireland. Additionally there has been no previous research conducted on lymphoedema service provision in the Republic of Ireland to date. Therefore the first task was to identify where lymphoedema treatments were being provided and by which practitioners. The intention was to initially contact as many potential lymphoedema practitioners as possible in order to include the experiences of as many lymphoedema practitioners working in a variety of settings and services. The inclusion criteria were healthcare professionals with specific experience and knowledge of lymphoedema that currently hold or have held a position in a hospital or service in the previous six months which provides advice and care specific to lymphoedema (rather than that provided to any patient with skin conditions or swelling of an unspecific cause). This enabled the inclusion of managers of lymphoedema services, physiotherapy departments or occupational therapy departments who would be aware of the funding structures and staffing levels in lymphoedema services but who may not personally treat lymphoedema patients. The exclusion criteria were healthcare professionals without specific experience and knowledge of lymphoedema working in services that provide advice and care that is not specific to lymphoedema and may be provided to patients with other forms of chronic oedema or related conditions. The exclusion criteria also applied to healthcare professionals with specific experience and knowledge of lymphoedema that did not currently hold or had not held a position in a hospital or service in the previous six months that provides advice and care specific to lymphoedema (rather than that provided to any patient with skin conditions or swelling of an unspecific cause).

All university, regional, general and private hospitals; palliative care and homecare teams; cancer support centres; and hospices were telephoned to ascertain whether they provided a lymphoedema service according to the above mentioned criteria. As a result the questionnaire was sent to the following groups:

- The managers in all physiotherapy and occupational therapy departments in university, regional and general hospitals; and named physiotherapists and occupational therapists in these departments who had previously been identified as having access to lymphoedema patients.
- Breast care nurses in teaching, regional and general hospitals. Breast-cancer-related secondary lymphoedema is the most prevalent form of lymphoedema in the UK and this was also expected to be the case in the Republic of Ireland. Therefore, breast care nurses would be more likely than general nurses to have access to patients at risk of or experiencing lymphoedema. Moreover breast care nurses are the only professionals who specifically mention the care of lymphoedema in their practice guidelines (Irish Breast Care Nurses Association, 2004). Breast care nurses working in Breastcheck (the national breast cancer screening programme) were not included as they do not see breast cancer patients postoperatively and therefore would be less likely to have access to patients with lymphoedema.

- Service providers in private hospitals, homecare and palliative care teams, hospices, and cancer support centres that identified themselves as providing lymphoedema treatment.
- Healthcare professionals of various professions (breast care nurses, physiotherapists, occupational therapists etc.) who had attended the introductory workshops on lymphoedema organised by Action Breast Cancer, a project of the Irish Cancer Society.
- Private practitioners specialising in lymphoedema treatment. These were identified from various sources, e.g. listings of practitioners based in the Republic of Ireland on the MLD (Manual Lymphatic Drainage) Ireland and MLD UK websites (as accessed on the 16th of June 2008), the listing of trained MLD therapists from Ireland on the websites of the Földi and Vodder lymphoedema schools (as accessed on the 16th of June 2008), and the listing of MLD therapists trained in Ireland up to the 29th of August 2008. In some cases hospitals supplied the research team with the names and contact details of the private practitioners that they referred lymphoedema patients to and these practitioners' names were also included in the database.

Physiotherapists or occupational therapists in smaller hospitals, general practitioners,, general nurses and public health nurses were not included. While some of these healthcare professionals may provide advice and potentially fit compression garments, they are unlikely to have the same high volume of lymphoedema patients. They are less likely to provide specific information on lymphoedema as opposed to chronic oedema in general. As a result they would be less appropriate for inclusion in a study specifically exploring current lymphoedema service provision and recommendations on lymphoedema service development.

Questionnaire Design

The development of the questionnaire was guided by the topics covered and recommendations made in previous international literature on lymphoedema service provision, the expert opinion of a research advisory group - composed of lymphoedema patients (one patient with primary lymphoedema since early adulthood and one patient with breast-cancer-related secondary lymphoedema), lymphoedema practitioners (a lymphoedema nurse specialist, occupational therapist and physiotherapist), consultants in related disciplines of venous disease and oncology, and research psychologists - and the practitioner questionnaire used in the BreastCare Victoria (2005) study. The Australian Lymphology Association's (2003) practitioner questionnaire included a variety of broad, open questions (e.g. please determine the following details: practice, workload and therapy for public patients). A more comprehensive approach was required considering this was the first study to explore current lymphoedema service provision in Ireland. As the BreastCare Victoria (2005) study included a comprehensive practitioner questionnaire approval was sought and granted for the use and amendment of that questionnaire. However the questionnaire employed in the current study included additional items such as practitioners' self-rating of their experience in relation to treating lymphoedema patients.

The questionnaire used in the current study includes sections on:

- General participant information (job title; whether the practitioner personally treats lymphoedema patients and if so for how long; and number of hours spent per week treating lymphoedema patients).
- Lymphoedema service (setting of service; funding sources; staffing levels; patient waiting lists; source of referrals; capacity to treat referred patients).
- Patient profile (number of patients currently being treated; duration of treatments; average number of treatments patients receive; percentage of patients with various types of lymphoedema and in various age ranges; and distances travelled by patients to access the service).
- Treatments provided (types of information provided to patients who are at-risk and affected by lymphoedema; types of treatment provided; and issues related to compression garment supply).
- Professional development (practitioners' self-rating of knowledge, competency, experience and confidence in relation to treating lymphoedema patients; level of

training and continuous professional development attained; recommendations for professional development).

- Service standards (ratings of the standard of care received by patients with various types of lymphoedema; and recommendations for service development).

The questionnaire was piloted with a lymphoedema nurse specialist, occupational therapist and physiotherapist. Amendments were made to ensure the questionnaire was as succinct and clear as possible. The questionnaire was then reviewed and approved by the entire research advisory group. A copy of the questionnaire employed in the current study is included in Appendix C.

Procedure

A cover letter, information sheet, questionnaire (see Appendix A, B and C respectively) and a FREEPOST envelope, with which to return the questionnaire, were posted to practitioners. A thank you/reminder letter was sent to practitioners approximately two weeks after the initial questionnaire mailing to thank those who had participated and to prompt those who had not participated but wished to do so. The letter reminded recipients that they were not obliged to participate and could contact the research team at any time. A copy of the thank you/reminder letter is presented in Appendix D.

Ethics

Consent

Approval was sought and granted from Dublin City University Research Ethics Committee to distribute the questionnaires to practitioners who met the inclusion criteria. All participants were over eighteen years of age and capable of informed consent. Participants were not requested to sign a consent form in order to protect their anonymity. Consent was assumed by the completion and return of the questionnaire. Participants were informed that they could decline the opportunity of completing the questionnaire and were not required to pay for the return of the questionnaire to the investigators.

Confidentiality

All participants were assured of confidentiality at all times and through all stages of the research. Although the number of professionals working with people affected by lymphoedema is relatively small, it is a heterogeneous group (e.g. nurses, occupational therapists, physiotherapists, cancer specialists, private practitioners etc.). Furthermore, results are presented in terms of the entire data set and any potentially identifying information has been omitted. Participants were invited to provide their contact details at the end of the questionnaire if they were agreeable to being contacted by the research team for further information. This was also to enable the research team to map current lymphoedema service provision in order to identify the services or organisations that lymphoedema patients could be accessed from in subsequent phases of the study. Eighty-seven percent of the sample chose to supply their details. However this information along with the anonymous questionnaires is being stored in a locked filing cabinet which only members of the research team have access to. Practitioners' contact details and data were inputted directly onto the researcher's computer, which is password protected to ensure confidentiality of all electronic records. All identifying information and anonymous questionnaires will be shredded and disposed of five years after completion of the study by Dr. Pamela Gallagher, supervisor of this study.

Risk Management

The majority of information requested on the questionnaire was factual (e.g. number of professionals working in the service, number and profile of patients attending the service etc.) thereby posing minimal risk to participants. All participants were supplied with the contact details of two of the investigators should they have any concerns or require additional information about the study.

Data Analysis

Questionnaire data was entered into the Statistical Program for the Social Sciences (SPSS) Version 17.0. Each participant did not respond to each item of the questionnaire. Therefore the results presented are based on the number of respondents to the individual question rather than on the overall sample of 108 participants. Descriptive statistics such as frequencies and means were performed (e.g. percentage of participants who personally treat lymphoedema patients, mean number of patients seen per month etc.). It was intended to perform a standard one-way ANOVA to ascertain whether practitioners' ratings of the standard of care received by patients with various types of lymphoedema differed significantly. However the Levene's test was significant indicating that the assumption of homogeneity of variance was violated. Therefore the non-parametric equivalent, the Welch one-way ANOVA and post-hoc Dunnett's T3 tests were performed. Where effect sizes were available, this information is provided in the text. Responses to open questions were typed into Microsoft Word (2003 Version) and analysed thematically. The findings are presented below in the results section.

Results

Participant and Service Information

A total of 320 questionnaires were distributed to practitioners. Of the 320 practitioners who were sent the questionnaire, 28 were private practitioners and the remaining 292 worked in a total of 88 services throughout the country. Twenty-six practitioners indicated that they wouldn't be returning questionnaires as they do not provide a lymphoedema service or were unable to complete the questionnaire at that time. Therefore out of a potential total of 294 questionnaires, 108 completed questionnaires were received, resulting in a completed questionnaire response rate of 36.73%.

Seventy-two practitioners, or 68.6% of respondents, personally treat lymphoedema patients *(n=105)*. Eighteen practitioners or 17% of respondents work in a dedicated lymphoedema service (i.e. services that solely treat lymphoedema patients and are not required to treat patients with other conditions) *(n=106)*. Participants who do not work in a dedicated service were asked whether their service is being developed. Twenty-seven practitioners or 37.5% of the 72 respondents to that question work in a service that is in the process of being developed. Participants who work in a service that is being developed were asked if their service is being expanded. Sixteen practitioners or 34.8% of the 46 respondents to that question work in a service that is in the process of being expanded. The majority of the results presented below focus on the responses of practitioners who personally treat lymphoedema patients, unless otherwise specified, as this section of the sample is viewed as most relevant for the purposes of the research. Table 1 on pages 65 and 66 provides a brief overview of the service type, setting, location and practitioner breakdown for all respondents, respondents who personally treat lymphoedema patients, those working in dedicated services and respondents working in services that are being developed or expanded. In terms of occupation, 'other' refers to practitioners who indicated that they have an occupation that wasn't listed on the original questionnaire (e.g. oncology nurse) or that they hold two occupations (e.g. MLD therapist and nurse, occupational therapist or physiotherapy manager).

In general most practitioners work in large, public hospitals situated in counties with major cities or towns (i.e. Dublin, Cork, Galway, Donegal). The vast majority of practitioners who personally treat lymphoedema patients are physiotherapists/physiotherapy managers, Manual Lymphatic Drainage (MLD) therapists, occupational therapists (OTs)/OT managers, and MLD therapists who are also nurses, physiotherapists or OTs.

Participants who personally treat lymphoedema patients have been doing so for an average of 56.33 months, over four and a half years (Range=1-360, SD=61.70, *n=70)* and spend on average 8.44 hours per week treating lymphoedema patients (Range=0.00-37.50, SD=8.95, *n=62)*. This may indicate that treating lymphoedema patients is only part of the majority of participants' caseloads. This may be due to practitioners purposely limiting the amount of time they spend per week treating lymphoedema patients as the measurement and intensive treatment of the affected area can be time consuming and physically demanding.

Table 1: Service Information and Practitioner Sample Breakdown

	All Respondents *(n=108)*	**Practitioners who personally treat Lymphoedema Patients** *(n=72)*	**Practitioners working in a Dedicated Service** *(n=18)*	**Practitioners working in a Service that's being Developed** *(n=27)*	**Practitioners working in a Service that's being Expanded** *(n=16)*
Service Type					
n	*106*	*71*	*18*	*26*	*16*
Public	62.3%	64.8%	72.2%	61.5%	75%
Private	17%	21.1%	16.7%	23.1%	6.3%
Public and Private	20.8%	14.1 %	11.1%	15.4%	18.8%
Service Setting					
n	*108*	*72*	*18*	*27*	*16*
University Hospital	30.6%	22.2%	27.8%	22.2%	43.8%
Regional Hospital	5.6%	5.6%	11.1%	7.4%	12.5%
General Hospital	20.4%	16.7%	11.1%	25.9%	25%
Private Hospital	7.4%	6.9%	5.6%	7.4%	-
Community Health Centre	1.9%	1.4%	-	-	-
Cancer Support Centre	2.8%	2.8%	11.1%	3.7%	-
Hospice	4.6%	6.9%	11.1%	7.4%	-
Private Practice	11.1%	16.7%	11.1%	14.8%	12.5%
Other (Domiciliary in community; Clinic in health centre & home visits; Specialist palliative care team; Primary care)	15.7%	20.8%	11.1%	11.1%	6.3%
County					
n	*108*	*72*	*18*	*27*	*16*
Cavan	3.7%	4.2%	-	7.4%	-
Clare	0.9%	1.4%	-	-	-
Cork	14.8%	12.5%	11.1%	14.8%	12.5%
Donegal	9.3%	13.9%	-	25.9%	18.8%
Dublin	33.3%	34.7%	50%	18.5%	43.8%
Galway	6.5%	4.2%	-	14.8%	-
Kerry	0.9%	1.4%	-	-	-
Kildare	0.9%	1.4%	-	-	-

Table 1: Service Information and Practitioner Sample Breakdown (continued)

	All Respondents *(n=108)*	**Practitioners who personally treat Lymphoedema Patients** *(n=72)*	**Practitioners working in a Dedicated Service** *(n=18)*	**Practitioners working in a Service that's being Developed** *(n=27)*	**Practitioners working in a Service that's being Expanded** *(n=16)*
County (continued)					
Kilkenny	1.9%	-	11.1%	-	-
Laois	3.7%	4.2%	5.6%	3.7%	-
Limerick	1.9%	-	5.6%	-	6.3%
Louth	2.8%	4.2%	-	3.7%	6.3%
Mayo	1.9%	1.4%	-	3.7%	-
Meath	2.8%	1.4%	-	-	-
Monaghan	1.9%	1.4%	-	3.7%	-
Sligo	0.9%	1.4%	-	-	-
Tipperary	3.7%	-	-	-	6.3%
Waterford	0.9%	1.4%	5.6%	-	-
Westmeath	2.8%	2.8%	-	-	6.3%
Wexford	2.8%	2.8%	11.1%	-	-
Wicklow	1.9%	2.8%	-	-	-
Occupation					
n	*107*	*72*	*18*	*26*	*16*
Breast Care Nurse	13.1%	2.8%	27.8%	19.2%	12.5%
Lymphoedema Nurse Specialist	1.9%	2.8%	11.1%	-	-
MLD Therapist	10.3%	15.3%	11.1%	7.7%	6.3%
Occupational Therapist	6.5%	8.3%	-	3.8%	6.3%
OT Manager	3.7%	1.4%	-	3.8%	-
Physiotherapist	39.3%	45.8%	16.7%	30.8%	31.3%
Physio Manager	10.3%	2.8%	5.6%	7.7%	6.3%
Other ~	15%	20.8%	27.8%	26.9%	37.5%

~Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.); or Oncology Nurse.

Funding of Services

Twenty-six participants reported that they didn't know the source of funding for their lymphoedema service and 5 practitioners indicated that their lymphoedema service received no funding. Sixty-two participants answered the question on what percentage of their services' funding was received from various sources and the results are presented in Table 2 below and continued on pages 68 and 69. The main source of funding for the majority of services is the physiotherapy budget, which is understandable given the high proportion of physiotherapists in the sample. 'Other' sources and patient contributions were the second and third most common sources of funding of respondents.

Table 2: Sources of Funding of Lymphoedema Services

Source of Funding	***n***	**Mean %**	**SD**	**Range**
Breast Care				
All Respondents	*62*	9.35	21.42	0-100
Breast Care Nurses	*4*	32.50	23.63	0-50
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	20.00	27.39	0-50
Physiotherapists/Physio Managers	*30*	8.33	23.06	0-100
Other ~	*12*	8.33	19.46	0-50
Oncology				
All Respondents	*62*	9.52	23.43	0-100
Breast Care Nurses	*4*	35.00	23.81	0-50
Lymphoedema Nurse Specialists	*2*	50.00	70.71	0-100
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	20.00	27.39	0-50
Physiotherapists/Physio Managers	*30*	3.33	12.69	0-50
Other ~	*12*	12.50	31.08	0-100
Physiotherapy				
All Respondents	*62*	31.85	44.93	0-100
Breast Care Nurses	*4*	27.50	37.75	0-80
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	58.83	47.30	0-100
Other ~	*12*	8.33	28.87	0-100

~ Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.) or Oncology Nurse.

Table 2: Sources of Funding of Lymphoedema Services (continued)

Source of Funding	*n*	**Mean %**	**SD**	**Range**
Occupational Therapy				
All Respondents	*62*	6.45	24.77	0-100
Breast Care Nurses	*4*	0	0	0
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	40.00	54.77	0-100
Physiotherapists/Physio Managers	*30*	0	0	0
Other ~	*12*	16.667	38.93	0-100
Vascular				
All Respondents	*62*	0	0	0
Breast Care Nurses	*4*	0	0	0
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	0	0	0
Other ~	*12*	0	0	0
Dermatology				
All Respondents	*62*	0.08	0.64	0-5
Breast Care Nurses	*4*	0	0	0
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	0	0	0
Other ~	*12*	0.42	1.44	0-5
Community Health				
All Respondents	*62*	2.26	12.98	0-90
Breast Care Nurses	*4*	0	0	0
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	1.67	9.13	0-50
Other ~	*12*	7.50	25.98	0-90
Patient Contributions				
All Respondents	*62*	15.32	34.35	0-100
Breast Care Nurses	*4*	5.00	10.00	0-20
Lymphoedema Nurse Specialists	*2*	0	0	0
MLD Therapists	*8*	65.63	42.38	0-100
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	10.00	30.51	0-100
Other ~	*12*	8.75	27.31	0-95

~ Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.) or Oncology Nurse.

Table 2: Sources of Funding of Lymphoedema Services (continued)

Source of Funding	***n***	**Mean %**	**SD**	**Range**
Grant				
All Respondents	*62*	1.05	5.95	0-45
Breast Care Nurses	*4*	0	0	0
Lymphoedema Nurse Specialists	*2*	5.00	7.07	0-10
MLD Therapists	*8*	0	0	0
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	0	0	0
Other ~	*12*	4.58	13.05	0-45
Other (i.e. Funding from Palliative Care, Private Donations, Community Fundraising etc.)				
All Respondents	*62*	22.66	39.93	0-100
Breast Care Nurses	*4*	2.50	5.00	0-10
Lymphoedema Nurse Specialists	*2*	45.00	63.64	0-90
MLD Therapists	*8*	39.29	43.25	0-100
OT/OT Managers	*5*	0	0	0
Physiotherapists/Physio Managers	*30*	17.83	37.69	0-100
Other ~	*12*	32.92	47.79	0-100

~ Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.) or Oncology Nurse.

Staffing of Services

Practitioners were asked to report how many practitioners from different backgrounds were employed in their service for the treatment of lymphoedema and the results are presented in Table 3.

Table 3: Average Number of Practitioners Employed in Each Service for the Treatment of Lymphoedema

Occupation (*n=88)*	**Mean**	**SD**	**Range**
Nurse	0.42	0.89	0-5.00
Occupational Therapist	0.29	0.52	0-2.00
Physiotherapist	0.95	1.16	0-8.50
Doctor	0.02	0.21	0-2.00
Masseur/Masseuse	0.11	0.58	0-5.00
Social Worker	0	0	0
Psychologist	0	0	0
Psychiatrist	0	0	0
Podiatrist	0	0	0
Administrative Staff	0.01	0.11	0-1.00
Other (Refers to 0.50 of an Assistant Physio or 2 MLD Therapists)	0.03	0.24	0-2.00

More physiotherapists are employed in the treatment of lymphoedema than any other profession, although it is worth noting that the average number of healthcare professionals employed in each service for the treatment of lymphoedema is low. No respondents reported working in a service that has a social worker, psychologist, or psychiatrist employed in the treatment of lymphoedema patients, despite the fact that psychosocial and mental health difficulties can be associated with lymphoedema.

Eight percent of respondents reported that their service had vacant posts *(n=90)*. This may reflect the HSE recruitment freeze when the funding for unfilled posts was no longer allocated and the posts were then lost. Moreover 76.5% of respondents reported that they didn't have cover for annual leave, sick leave or maternity leave *(n=81)*.

Referral Pathways

The 72 practitioners who personally treat lymphoedema patients were asked to indicate the most common sources of referrals to their lymphoedema service and the results are presented in Table 4.

Table 4: Referral Sources

Referral Source	***(n=71)***
Hospital Oncology Clinics	78.9%
Hospital General Surgical Clinics	40.8%
Hospital Physiotherapy Clinics	31.0%
Hospital Dermatology Clinics	19.7%
Hospital Leg Ulcer Clinics	15.5%
Hospital Vascular Clinics	31.0%
Hospital General Medical Clinics	15.5%
Hospital Tissue Viability Clinics	2.8%
Community Physiotherapy Clinics	18.3%
Community Leg Ulcer Clinics	2.8%
General Practitioners	53.5%
Patients Self-Referring	49.3%
Family/Friends of Patients	22.5%
Other (e.g. From Palliative Care Teams, MLD Ireland, Cancer Care Centre, Rheumatologists, Private Consultants & General Community Clinic)	32.4%

The most common referral sources were hospital oncology clinics, general practitioners and patients self-referring. Less than a third of respondents received referrals from the alternative potential referral sources. This suggests that poor awareness of lymphoedema and lymphoedema services among healthcare professionals in non-oncology settings results in low rates of referral. Indeed in comments to an open question on referrals, the following participants noted that a lack of knowledge on the part of other healthcare professionals, particularly general practitioners resulted in inappropriate or low numbers of referrals:

> *Participant 26 (Physiotherapist working in a service which does not solely treat lymphoedema patients):* We had to block GP referrals as they were incorrect referrals/wrong service/insufficient investigations into cause of swellings.
>
> *Participant 43 ('Other' Practitioner - MLD Therapist and Physiotherapy Manager working in a dedicated lymphoedema service):* Very low/little knowledge in GP clinics about lymphoedema and its treatment – referrals.

Seventy-seven percent of respondents who personally treat lymphoedema patients, knew where to refer a patient to if they weren't in a position to treat them *(n = 66).* The question of how often the practitioner refers on was left open ended. Twenty-two practitioners indicated that they had to refer patients on an occasional, frequent or weekly basis whereas 28 practitioners indicated it was rare or infrequent. This result, coupled with the results in Table 4, suggests that services do not receive referrals from all potential sources.

According to respondents who personally treat lymphoedema patients, the mean percentage of patients who have gone abroad for treatment was 1.55 (Range = 0-30, SD = 5.11, *n=64*).

Patient Profile

Patient Numbers

Table 5 on pages 72 and 73 presents the mean number of patients being seen and on the waiting lists of various types of practitioners who personally treat lymphoedema patients.

Table 5: Patient and Waiting List Numbers

	n	Mean	SD	Range
Patients Currently Being Seen by Practitioner				
Practitioners who personally treat Lymphoedema Patients	*68*	20.99	56.65	0-400
Breast Care Nurses	*2*	47.50	3.54	45-50
Lymphoedema Nurse Specialists	*2*	218.00	257.39	36-400
MLD Therapists	*9*	11.33	12.72	1-40
OT/OT Managers	*7*	8.00	9.71	1-24
Physiotherapists/Physio Managers	*33*	11.45	28.92	0-160
Other ~	*15*	24.00	50.69	0-200
Patients Seen by Practitioner for Initial Consultation per Month				
Practitioners who personally treat Lymphoedema Patients	*65*	4.94	5.32	0-30
Breast Care Nurses	*2*	19.50	14.85	9-30
Lymphoedema Nurse Specialists	*2*	10.00	0.00	10-10
MLD Therapists	*9*	6.44	3.47	2-12
OT/OT Managers	*7*	4.71	6.82	1-20
Physiotherapists/Physio Managers	*32*	3.13	2.61	0-10
Other ~	*13*	5.46	5.74	0-20
Patients Seen by Practitioner for Intensive Treatment per Month				
Practitioners who personally treat Lymphoedema Patients	*51*	3.24	4.97	0-25
Breast Care Nurses	*2*	0.00	0.00	0-0
Lymphoedema Nurse Specialists	*1*	25.00	0.00	25-25
MLD Therapists	*9*	5.00	4.09	1-12
OT/OT Managers	*5*	0.80	0.834	0-2
Physiotherapists/Physio Managers	*24*	2.67	4.72	0-20
Other ~	*10*	2.70	1.64	1-6
Patients Seen by Practitioner for Follow Up per Month				
Practitioners who personally treat Lymphoedema Patients	*62*	9.18	15.76	0-105
Breast Care Nurses	*1*	20.00	0.00	20-20
Lymphoedema Nurse Specialists	*2*	32.50	31.82	10-55
MLD Therapists	*10*	9.80	5.53	1-20
OT/OT Managers	*7*	4.43	4.28	1-11
Physiotherapists/Physio Managers	*30*	7.93	19.30	0-105
Other ~	*12*	9.75	11.79	1-40
Patients on Waiting List for Initial Consultation				
Practitioners who personally treat Lymphoedema Patients	*56*	2.95	8.31	0-50
Breast Care Nurses	*1*	0.00	0.00	0-0
Lymphoedema Nurse Specialists	*2*	1.50	2.12	0-3
MLD Therapists	*8*	1.13	2.10	0-5
OT/OT Managers	*4*	1.00	0.82	0-2
Physiotherapists/Physio Managers	*28*	1.68	3.67	0-15
Other ~	*13*	7.85	15.12	0-50

~Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.); or Oncology Nurse.

Table 5: Patient and Waiting List Numbers (continued)

	n	Mean	SD	Range
Patients on Waiting list for Intensive Treatment				
Practitioners who personally treat Lymphoedema Patients	*49*	3.29	7.78	0-40
Breast Care Nurses	*0*	-	-	-
Lymphoedema Nurse Specialists	*1*	3.00	0.00	3-3
MLD Therapists	*7*	5.71	15.12	0-40
OT/OT Managers	*4*	8.50	7.05	0-17
Physiotherapists/Physio Managers	*26*	0.77	1.93	0-7
Other ~	*11*	5.82	9.53	0-30
Patients on Waiting List for Follow Up				
Practitioners who personally treat Lymphoedema Patients	*52*	5.87	19.32	0-120
Breast Care Nurses	*0*	-	-	-
Lymphoedema Nurse Specialists	*2*	0	0.00	0-0
MLD Therapists	*7*	7.29	18.84	0-50
OT/OT Managers	*4*	2.00	2.83	0-6
Physiotherapists/Physio Managers	*27*	6.74	24.57	0-120
Other ~	*12*	5.33	9.59	0-30

~Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.); or Oncology Nurse.

According to the total number of respondents who personally treat lymphoedema patients, practitioners are currently treating approximately 21 patients. They see on average approximately 5 patients for initial consultation per month, 3 for intensive treatment and 9 for follow up, i.e. a total of approximately 17 patients. However there was considerable variation in how participants approached these questions. For example in the case of number of patients being currently seen, the range is from 0 to 400 patients, which suggests that some respondents included all patients on their caseload and waiting list.

Respondents who personally treat lymphoedema patients have on average approximately 3 patients on the waiting list for initial consultation, 3 patients on the waiting list for intensive treatment and 6 patients on the waiting list for follow up consultations i.e. a total of approximately 12 patients. Again there appears to be some variation in the interpretation of the question with a wide range being reported regarding the number of patients on the waiting list for follow up consultations. The numbers on waiting lists are quite low. However bearing in mind that the average number of patients seen per month for various consultations is low and as mentioned previously the number of hours practitioners spend per week treating lymphoedema patients was also low at an average of 8 hours per week, these results together suggests that services are not being accessed by all patients or that the capacity of services is quite depleted.

In terms of variations in responses according to type of healthcare professional, the average number of patients seen by breast care nurses is higher than the mean of the all respondents except in the case of patients seen each month for intensive treatment. This reflects the fact that breast care nurses' role with lymphoedema patients is often more involved at the identification of lymphoedema symptoms, fitting of compression garments and provision of advice and support rather than intensive consultation. Likewise the high number of patients being seen by lymphoedema nurse specialists per month reflects the fact that they are specialised in the treatment of lymphoedema and as a result their entire caseload consists of lymphoedema patients. 'Other' practitioners had the highest mean number of patients on a waiting list for initial consultation whereas MLD Therapists reported the highest mean number of patients on waiting lists for intensive treatment and follow up consultations.

Type of Lymphoedema Experienced by Patients

Tables 6a and 6b on page 75 and Table 6c on page 76 present the breakdown of patients, seen in the last year by practitioners who personally treat lymphoedema patients, according to type of lymphoedema, location of lymphoedema and age when first treated respectively. Lymphoedema secondary to breast cancer was the most predominant type of lymphoedema experienced by patients treated in the last year by practitioners who personally treat lymphoedema patients. Lymphoedema secondary to other types of cancer was the second most predominant type of lymphoedema experienced by patients. These other types of cancer included: gynaecological/genital cancers (e.g. cervical, penile, testicular, ovarian etc.), skin cancer, prostate cancer and head/neck/throat cancers. Although they accounted for a small proportion of their caseloads, practitioners reported that some of the patients they treated in the last year had previously experienced the following types of cancers: lymphoma, lung, sarcoma, mesothelioma (a form of cancer caused by exposure to asbestos), pancreatic, and bowel cancer. The third most predominant type of lymphoedema experienced by patients was primary lymphoedema. Patients with lymphoedema due to immobility, venous disease, tissue damage, infection and inflammation were rated as a much smaller percentage of respondents' caseloads.

Table 6a: Mean Percentages of Patients Treated in the last year, according to Type of Lymphoedema

Type of Lymphoedema *(n=70)*	**Mean %**	**SD**	**Range**
Primary lymphoedema	12.61	19.98	0-100
Lymphoedema Secondary to Breast Cancer	56.07	32.60	0-100
Lymphoedema Secondary to Other Types of Cancer	13.53	16.76	0-100
Lymphoedema Secondary to Trauma and Tissue damage (e.g. Burns, Scarring, Large Wounds, Self Harm etc.)	3.47	12.90	0-90
Lymphoedema Secondary to Venous Disease (e.g. DVT, Chronic Venous Insufficiency, Intravenous Drug Use etc.)	4.36	10.88	0-67
Lymphoedema Secondary to Infection (e.g. Cellulitis, Lymphadenitis, Filariasis etc.)	3.50	8.57	0-50
Lymphoedema Secondary to Inflammation (e.g. Rheumatoid/Psoriatic Arthritis, Eczema, Sarcoidosis etc.)	1.11	3.89	0-20
Lymphoedema Secondary to Immobility and Dependency (e.g. Dependency, Obesity, Paralysis etc.)	4.90	15.40	0-100

As breast-cancer-related-secondary lymphoedema was the most common type of lymphoedema experienced by patients it is unsurprising that the most common location of lymphoedema was in one arm.

Table 6b: Mean Percentage of Patients Treated in the last year, according to Location of Lymphoedema

Location of Lymphoedema *(n=69)*	**Mean %**	**SD**	**Range**
Unilateral Upper Limb (i.e. in one arm)	57.67	32.17	0-100
Bilateral Upper Limb (i.e. in both arms)	4.52	10.94	0-67
Unilateral Lower Limb (i.e. in one leg)	16.75	20.49	0-100
Bilateral Lower Limb (i.e. in both legs)	13.70	19.63	0-90
Face and/or Neck	1.65	5.58	0-40
Genitals	1.93	6.86	0-50
Other (Includes those with lymphoedema in bilateral upper limb and lower limb, in the trunk of the body, or in the breast)	0.88	3.87	0-25

As lymphoedema is more common among those who are middle aged and older it is unsurprising that the majority of patients were over 51 years old when first treated.

Table 6c: Mean Percentage of Patients Treated in the last year, according to Age when First Treated

Age Range ***(n=69)***	**Mean %**	**SD**	**Range**
Less than 18 years old	0.62	1.97	0-10
19-35 years	6.61	14.33	0-100
36-50 years	29.20	23.73	0-100
51-65 years	43.17	25.51	0-100
Over 66 years old	20.49	22.70	0-90

Information and Treatments Provided

To At-Risk Patients

Eighty-seven percent of respondents who personally treat lymphoedema patients provide advice to those at-risk of developing lymphoedema (*n = 68).* Fifty-nine practitioners responded to an open question on the type of advice practitioners provide and to what type of patient. The advice provided generally relates to skincare, avoidance of potential triggers of lymphoedema symptoms (e.g. cuts, abrasions, sunburn, air travel, blood pressure or injections in at risk arm etc.) and prophylactic measures (e.g. exercises, simple lymphatic drainage, compression garments etc.). The majority of respondents indicated this advice is provided to oncology patients, particularly breast cancer patients; however only three respondents provide this information to patients who were at risk of developing non-cancer-related-secondary lymphoedema (e.g. vascular patients, obese patients and at-risk palliative patients).

To Patients Affected by Lymphoedema

From Table 7 on page 77 it appears that almost all respondents who personally treat lymphoedema patients provide education on skincare; when to seek further medical attention; and how to perform simple lymphatic drainage and lymphoedema exercises. Roughly three quarters of respondents provide Manual Lymphatic Drainage (MLD) and compression such as Multi-Later Lymphoedema Bandaging (MLLB) or compression garment fitting, which are regarded as essential for the effective management of lymphoedema (MEP, 2006).

Table 7: Information and Treatments Provided

Information and Treatments	***(n=71)***
Education on Skincare	93%
Education on Diet	49.3%
Education on When to Seek Further Medical Attention	91.5%
Education on How to Perform Simple Lymphatic Drainage	85.9%
Education on How to Perform Exercises	93%
Manual Lymphatic Drainage	73.2%
Multi-Layer Lymphoedema Bandaging	76.1%
Education on Self-Bandaging	42.3%
Compression Garment Fitting	76.1%
Intermittent Pneumatic Compression Pump	11.3%
Other (e.g. Advice on how to use Pump, Lebed Method, Kinesio taping, Low Level Laser Therapy, Education on Overuse of Upper Limb)	9.9%

Practitioners who personally treat lymphoedema patients were asked a series of questions on the provision of compression garments. The results are presented in Table 8.

Table 8: Mean Number of Compression Garments Fitted and Mean Waiting Times for Garments

Mean Percentages regarding Compression Garment Fitting	**n**	**Mean %**	**SD**	**Range**
% of Patients Practitioners Fitted Compression Garments for	*64*	69.55	38.43	0-100
% of Patients Practitioners Fitted Off-The-Shelf Compression Garments for	*61*	53.30	36.12	0-100
% of Patients Practitioners Fitted Made-To-Measure Compression Garments for	*58*	30.10	33.24	0-100
	n	**Mean**	**SD**	**Range**
Number of Garments Fitted per Month	*55*	5.37	8.06	0-43
Average Waiting Time for Compression Garments to be Delivered (in weeks)	*46*	3.09	3.19	0-20

On average respondents fit almost 70% of the patients with a compression garment and fit 5.37 garments per month. Respondents fit more off-the-shelf compression garments than made-to-measure garments. The average time waiting is 3.09 weeks and 63% of respondents reported that the wait time for garments affected the treatment of patients *(n = 54).* Forty-two practitioners responded to an open question on the availability and delivery of compression garments. The themes and illustrative quotes from the open question on compression garments are presented in Table 9.

Table 9: Themes and Illustrative Responses from the Open Question on Compression Garments

Themes	**Illustrative Responses**
Custom-Made/ Made-to-Measure Garments take Longer to be Delivered	*Participant 14:* Made-to-measure can take 2-4 weeks.
	Participant 26: Limb shape may have changed by the time the garment arrives. I really try to avoid custom-made garments for this reason.
	Participant 39: Previously we have had huge difficulty with timely delivery of (made-to-measure)….garments, there is 3-4 week wait on garment adjustments which does interfere with patient care.
	Participant 84: One is inclined to fit the patient with an off-the-shelf garment rather than made-to-measure because of too long waiting and very expensive.
Delivery from the UK Takes Longer	*Participant 70:* The fact that garments are sent to local distributors before being sent out to us <u>really</u> slows down … UK delivery times for custom garments is 5 days.
HSE Approval Procedures Delay Delivery	*Participant 12:* Biggest problem is (for) medical card holders… patients need to supply (compression garment providers) with contact information from local HSE office, where nobody seems to know what to do or say regarding custom-made lymphoedema garments.
	Participant 34: Garment delivery is delayed by HSE red tape.
	Participant 40: Garments being paid privately arrive within 7-10 days. Garments being approved through medical card take up to 5 weeks.
	Participant 74: Garments requested on medical card can be anything from 4/52 (4 weeks) to > 5/12 (greater than 5 months) waiting time and then in the latter case – had to re-measure.
	Participant 107: Waiting for HSE approval of funding for garments can vary, sometime up to 6 weeks depending on the HSE office involved. Delivery of off-the-shelf garments is quick, but the quality is only fair.
Practitioner must continue To Treat the Patient Intensively until the Garment Arrives	*Participant 45:* Delay in receiving garments can result in changes in volume occurring between measurements taken following intensive (MLD) and supply of garment.
	Participant 85: Patient needs continued treatment during 2 week period (waiting for garment) – significant impact on service.
	Participant 98: Treatment must be continued until garment is supplied impacting on capacity to uptake new patients.
	Participant 108: Delays completion of client treatment therefore waiting lists expand as treatment must continue until garment is correctly fixed.

The main themes which emerged included delayed delivery for made-to-measure garments, garments manufactured in the UK or delayed approval of garments by the HSE for medical card holders. These delays coupled with the fact that the practitioner is required to continue intensive treatment of the patient until the garment arrives may discourage practitioners from recommending specific brands or types of garments (e.g. made-to-measure garments) to their patients or from recommending garments at all to medical card holders even though a well-fitting garment is a vital aspect of a lymphoedema management plan (MEP, 2006).

Duration, Frequency and Accessibility of Treatments

Lymphoedema is a chronic condition requiring ongoing monitoring, measurement and consultation yet practitioners who personally treat lymphoedema patients reported that patients are seen on average 11.43 times (SD = 14.16, Range = 0-68 times, *n = 47).* This is likely to be a conservative estimate as 3 practitioners gave their answer in terms of the amount of times a patient is seen per month, 6 practitioners gave their answer in terms of how many times a patient is seen per year, and 17 practitioners couldn't indicate an average for how many times patients are seen. For example:

> *Participant 39 ('Other' practitioner – MLD therapist and occupational therapist - working in a dedicated lymphoedema service):* No real average. New patient with lymphoedema will have initial assessment, follow up at 4-6 weeks possibly follow up at 3 months and 6 months if needed. Intensive treatment may be considered if patient taking an active role in managing lymphoedema. Majority of patients seen every 6 months if being re-measured for specialist garment will need to attend for fitting also. Complex patients or those requiring ongoing treatment – I have a number of patients who attend every 2 weeks and also undergo 6 monthly intensive treatments, some attend monthly – it varies!
>
> *Participant 72 (MLD therapist working in a service which does not solely treat lymphoedema patients):* Depends on condition – usually 8-10 treatments until plateau in reduction is achieved, if more severe – depends from patient to patient.

The average duration of consultations for upper limb patients is 54.26 minutes (SD = 18.22 Range = 0-90 minutes *n = 61)* and for lower limb patients is 61.53 minutes (SD = 27.27, Range = 0-120 minutes, *n = 58).* This reflects the time consuming nature of lymphoedema consultations as often discussion of symptoms and management plan, measurement of the affected area and in some cases treatment of the affected area are required. This finding should also be viewed with some caution as the consultation duration depended on whether several limbs were lymphoedematous and whether the purpose of the consultation was to review or intensively treat. For example:

> *Participant 25 (Physiotherapist working in a dedicated lymphoedema service):* 20-45 minutes (upper limb) 20-45 minutes (lower limb), MLD (manual lymphatic drainage) 90 minutes UL (upper limb), 90-120 minutes LL (lower limb).

Only 18.8% of respondents who personally treat lymphoedema patients provide home visits *(n = 69),* whereas only 12.3% provide inpatient services *(n = 65)* despite the fact that lymphoedema in the lower limb(s) can seriously affect patients' mobility*.*

According to respondents who personally treat patients, the mean greatest distance travelled by lymphoedema patients to get to their lymphoedema service was 71.44 km (SD = 64.84, Range = 0 – 350km, *n = 62)*. However the broad range implies that there is substantial variation in the distance patients are required to travel to access treatment. Participants were asked to indicate what percentage of their caseload lives within a 10 kilometre radius of their service and the average was 47.46 (SD = 33.11, Range = 0 – 100, *n = 63)*. Participants were also asked what percentage of their caseload lives more than 50 kilometres from their service and the average was 23.74 (SD = 24.96, Range = 0-100, *n = 58).* This suggests that travel distance may be a considerable barrier to treatment for a sizeable minority of patients.

Waiting Lists

Participants who personally treat lymphoedema patients were asked how long patients had to wait for treatment. According to respondents, on average patients spend 4.35 weeks waiting for lymphoedema treatment (Range = 0-16 weeks, SD = 4.94, *n=46)*. Thirty-seven percent of respondents who personally treat lymphoedema patients employed a prioritisation system for patients on the waiting list *(n=57)*. Participants who do employ a prioritisation system were asked to provide further details in response to an open question. Respondents indicated that patients were prioritised on the basis of the severity or type of lymphoedema (i.e. patients with cancer-related lymphoedema), being a newly-diagnosed or palliative patient, or being referred from an oncology department.

Professional Development

Practitioners who personally treat lymphoedema patients were asked to rate how knowledgeable, competent, experienced and confident they felt in treating lymphoedema on a Likert scale from 1 to 10 and the results are presented in Table 10 on page 82.

Overall practitioners who personally treat lymphoedema patients rated themselves highest in terms of how competent they feel and rated themselves lowest in terms of how experienced they feel. This may reflect the fact that treating lymphoedema patients represents only part of the caseload for some practitioners. Lymphoedema nurse specialists, whose role is dedicated to the treatment of lymphoedema, rated themselves as the most knowledgeable, competent, experienced and confident out of all healthcare professionals.

Table 10: Practitioners' Ratings of how Knowledgeable, Competent, Experienced and Confident they feel in the Treatment of Lymphoedema

	n	**Mean**	**SD**
Knowledgeable			
Practitioners who personally treat Lymphoedema Patients	*71*	7.38	1.768
Breast Care Nurses	*2*	6.00	0.000
Lymphoedema Nurse Specialists	*2*	9.00	0.000
MLD Therapists	*10*	8.30	1.567
OT/OT Managers	*7*	6.43	1.134
Physiotherapists/Physio Managers	*35*	6.89	1.906
Other ~	*15*	8.33	1.175
Competent			
Practitioners who personally treat Lymphoedema Patients	*71*	7.49	1.731
Breast Care Nurses	*2*	6.00	0.000
Lymphoedema Nurse Specialists	*2*	9.00	-
MLD Therapists	*10*	8.40	1.506
OT/OT Managers	*7*	6.86	1.345
Physiotherapists/Physio Managers	*35*	7.00	1.831
Other ~	*15*	8.33	1.345
Experienced			
Practitioners who personally treat Lymphoedema Patients	*71*	6.54	2.055
Breast Care Nurses	*2*	6.50	0.707
Lymphoedema Nurse Specialists	*2*	9.50	0.707
MLD Therapists	*10*	8.00	1.633
OT/OT Managers	*7*	5.86	1.574
Physiotherapists/Physio Managers	*35*	5.97	2.079
Other ~	*15*	6.80	1.971
Confident			
Practitioners who personally treat Lymphoedema Patients	*71*	7.17	1.912
Breast Care Nurses	*2*	6.00	0.000
Lymphoedema Nurse Specialists	*2*	8.50	0.707
MLD Therapists	*10*	8.30	1.494
OT/OT Managers	*7*	6.57	1.512
Physiotherapists/Physio Managers	*35*	6.60	2.018
Other ~	*15*	8.00	1.690

~ Please note 'other' occupation includes the following: MLD Therapist and other occupation (e.g. Hospice nurse, Staff Nurse, OT, Physio Manager, Clinical Nurse Manager, Therapeutic Massage Therapist etc.); or Oncology Nurse.

The 72 practitioners who personally treat lymphoedema patients were asked what training they have received and which methods they use to keep up to date with advances in lymphoedema research and treatments. All 72 practitioners responded and the results are presented in Table 11.

Table 11: Training and Methods of keeping up to date with Advances in Lymphoedema Research and Treatments

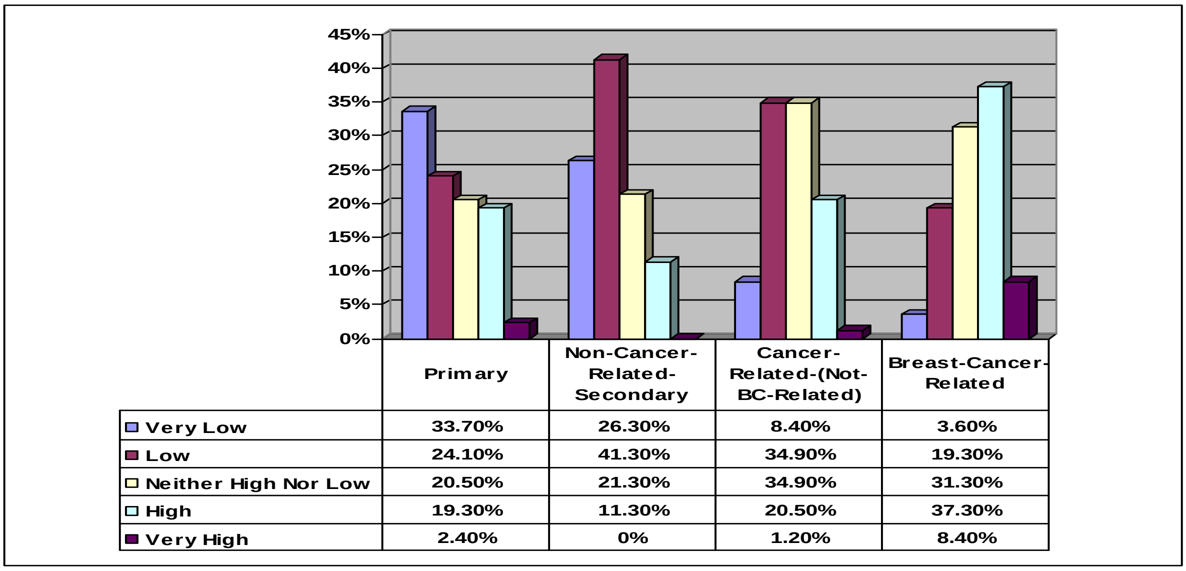
Level of Training	
Postgraduate Training in Lymphoedema Management	20.8%
Training by Casley-Smith School	12.5%
Training by Földi School	9.7%
Training by Klose School	12.5%
Training by Leduc School	8.3%
Training by Vodder School	34.7%
Training in Garment Fitting by Compression Garment Providers	56.9%
Introductory Workshops on Lymphoedema Provided by Action Breast Cancer	19.4%
Other (An Undergraduate Module, Training in Bandaging, Kinesio Taping, The Lebed Method, or Training provided by the British Lymphology Society, the Marie Curie, Cancercare or Macmillan Centres in the UK)	16.7%
Methods of Keeping Up- to-Date	
Read a Relevant Journal	66.7%
Read a Relevant Magazine	44.4%
Attend Conferences	51.4%
Attend Lectures, Meetings or Workshops on Lymphoedema	69.4%
Other (Online Searches or Search Engine Updates on Lymphoedema and Breast Cancer; Books; Reviews or Correspondence with a Lymphoedema School or Trainer; Collaborating With Colleagues, Sharing Expertise and Discussing Case Studies)	33.3%

Seventy-eight percent of respondents had received specialised training from one of the lymphoedema schools, which is deemed essential for the appropriate treatment of lymphoedema (BLS, 2001a). Just over half of practitioners who personally treat lymphoedema patients had received training by compression garment providers on fitting garments. Approximately half of respondents reported keeping up to date with developments through journals, magazines, conferences or workshops.

Practitioners were asked about opportunities for professional development. Sixty-nine participants or 94.5% of all respondents (*n=73)* indicated that they don't think there are sufficient opportunities for professional development. In terms of the training needs that practitioners felt should be addressed, 69.1% of the 68 respondents agreed that modules on the lymphatic system and lymphoedema should be taught to all relevant disciplines (e.g. nursing, occupational therapy, physiotherapy, medicine etc.) at undergraduate level; 61.8% agreed that postgraduate training on lymphatics and lymphoedema should be available. 79.4% indicated that more specialised training by the lymphoedema schools (such as Casley-Smith, Földi, Vodder, Klose etc.) should be available 95.6% agreed that continuous professional development courses should be provided to enable practitioners to keep abreast of lymphoedema research and treatment developments; and finally 13.2% reported that 'other' training needs should be addressed. The 'other' training needs suggested by participants included: removing the barriers for practitioners attending training (i.e. providing local, frequent, affordable training which practitioners are facilitated by their service to attend); providing specific types of training (garment fitting, unusual cases, collaborative multi-disciplinary, inter-departmental/hospital sessions led by a specialist team); and providing training available to other healthcare professionals (e.g. occupational therapists, general practitioners, physiotherapists, nursing staff).

Service Standards

Practitioners were asked to rate the standard of care received by patients with different types of lymphoedema on a Likert scale from 1- 'very low' to 5 - 'very high'. The percentage of all respondents who indicated each possible response category is presented in Figure 2 on page 85.



	Primary	Non-Cancer-Related-Secondary	Cancer-Related-(Not-BC-Related)	Breast-Cancer-Related
Very Low	33.70%	26.30%	8.40%	3.60%
Low	24.10%	41.30%	34.90%	19.30%
Neither High Nor Low	20.50%	21.30%	34.90%	31.30%
High	19.30%	11.30%	20.50%	37.30%
Very High	2.40%	0%	1.20%	8.40%

Figure 2: Practitioners' Ratings of the Standard of Care received by Patients with Different Types of Lymphoedema

The majority of respondents rated the standard of care received by primary lymphoedema patients as 'low' or 'very low' whereas the majority of respondents rated the standard of care received by patients with breast-cancer-related secondary lymphoedema as 'high'. The means of these ratings are presented in Table 12.

Table 12: Mean Practitioner Ratings of the Standard of Care received by Patients with Different Types of Lymphoedema

	n	**Mean**	**SD**
Primary Lymphoedema	*83*	2.33	1.201
Non-Cancer-Related-Secondary Lymphoedema	*80*	2.18	0.952
Cancer-Related-(Not-Breast-Cancer-Related)-Secondary Lymphoedema	*83*	2.71	0.931
Breast-Cancer-Related-Secondary Lymphoedema	*83*	3.28	0.992

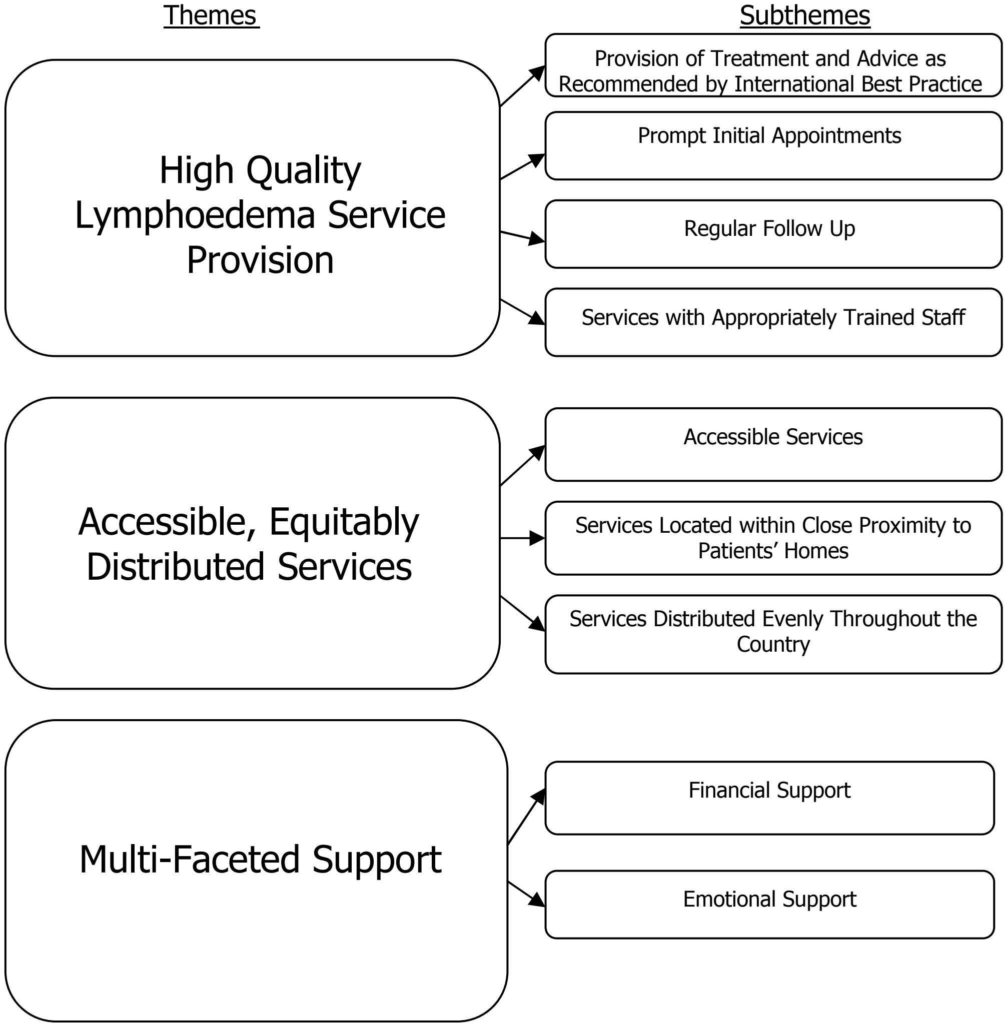
Patients with non-cancer-related secondary lymphoedema were rated as receiving the lowest standard of care by all respondents. Although patients with breast-cancer-related-secondary lymphoedema were rated as receiving the highest standard of care, the mean was closest to the midpoint score.

The Welch one-way ANOVA was performed to ascertain whether there was a difference in how respondents rated the standard of care received by patients with various types of lymphoedema and this was significant: F_w (3, 179.982) = 19.701, p=0.001. Dunnett's T3 post-hoc tests were performed to identify between which groups the significant differences occurred. Practitioners' ratings of the standard of care received by patients with non-cancer-related secondary lymphoedema was significantly lower than their ratings of the standard of care received by patients with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.002). Practitioners' ratings of the standard of care received by patients with primary lymphoedema (p=0.001), patients with non-cancer-related secondary lymphoedema (p=0.001), and patients with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.001) were significantly lower than their ratings of the standard of care received by patients with breast-cancer-related secondary lymphoedema.

Open Questions on Lymphoedema Service Development

Finally, practitioners were asked to complete two open questions. The first open question related to what factors they thought were important to patients attending lymphoedema services. The main themes were high quality service provision, accessible, equitable distributed services, and multi-faceted support. The themes, associated subthemes and illustrative responses are presented in Figure 3 on page 87.

The second open question related to what recommendations practitioners would make if they could influence policy on lymphoedema service development. The main themes were high quality, accessible, equitably distributed services, resources and increased awareness of lymphoedema. The themes, associated subthemes and illustrative responses are presented in Figure 4 on page 88.



Illustrative Quotes

Participant 32 (Physiotherapist working in a service which does not solely treat lymphoedema patients): A full time service which could provide patients with, for example, one hour daily of MLD or MLLB as indicated would be ideal, this would mean that up to 9 patients could be seen intensively for one week and studies have shown that if service is not consistent and intensive then benefit is minimal.

Participant 90 (Breast Care Nurse working in a service which does not solely treat lymphoedema patients): Rapid access to clinics…

Participant 72 (MLD Therapist working in a service which does not solely treat lymphoedema patients): A service that is available, comprehensive and regular in its treatment and management of their condition.

Participant 18 (OT Manager working in a service which does not solely treat lymphoedema patients): To have enough trained therapists to cater for the need … (and) give best practice service to all who require it.

Participant 51 (Breast Care Nurse working in a service which does not solely treat lymphoedema patients): It is important that they have easy access to treatment. This is not the situation. Some patients go privately to a practitioner to avail of treatment for lymphoedema.

Participant 89 (MLD Therapist working in a service which does not solely treat lymphoedema patients): Easy access to service e.g. parking, wheelchair access etc.

Participant 105 (Lymphoedema Nurse Specialist working in a dedicated lymphoedema service): The distance people have to travel for intensive treatment is a problem…

Participant 33 ('Other' MLD Therapist & OT working in a service which does not solely treat lymphoedema patients): ….Qualified therapists in all PCCC *(primary, community and continuing care)* areas…

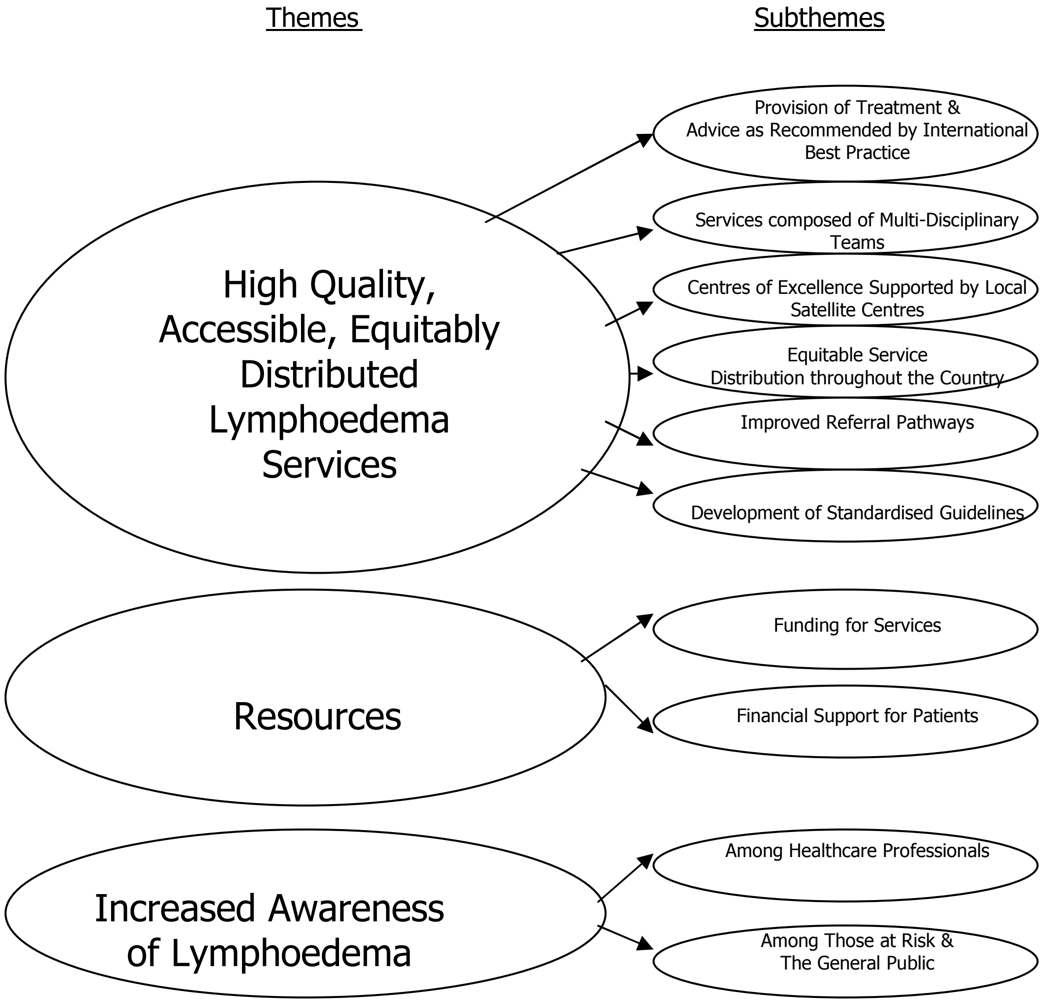
Participant 36 (OT working in a service which does not solely treat lymphoedema patients): …No inequalities of service provision within different geographical areas.

Participant 70 ('Other' Physio & MLD Therapist working in a service which does not solely treat lymphoedema patients): …Being covered by HSE/health insurer for treatment, bandages and compression hosiery. Entitlements to be clear and equitable.

Participant 26 (Physio working in a service which does not solely treat lymphoedema patients): I believe it is important to patients that they feel well supported in grieving the loss of non-lymphoedema status,.

Participant 38 (MLD Therapist&Hospice Nurse working in a service which does not solely treat lymphoedema patients): Support groups… Psychological support regarding altered body image.

Figure 3: Themes, Subthemes and Quotes from Practitioners in Response to the Question "What do you believe is important to patients of lymphoedema services?"



Illustrative Quotes

Participant 55 (Physio working in a service which does not solely treat lymphoedema patients): MLD should be available but maintenance treatment i.e. education, advice, skincare, positioning, exercises and diet should be absolutely available to all lymphoedema (patients).

Participant 63 (Physio working in a dedicated lymphoedema service): Patients (should) receive a complete treatment in a multi-disciplinary unit with dietician, technical imagery, medical testing, nursing for wound care and physiotherapy – MLD (manual lymphatic drainage), bandage, exercises etc…

Participant 5 (Physio working in a service which does not solely treat lymphoedema patients): Centres of excellence providing intensive treatment and satellite centres providing initial advice, garments, and SLD.

Participant 66 (Physio Manager working in a dedicated lymphoedema service): A centre is needed where patients with severe lymphoedema can be admitted for intense treatment and management. Regional centres for follow up care and local centres for maintenance checks and garments reissued.

Participant 38 ('Other' MLD Therapist & Hospice Nurse working in a service which does not solely treat lymphoedema patients): Every county should have a group of recognised specialists covering every area of Ireland…. Services at present are diabolical and if you're not living in the big cities, services are practically nil…

Participant 36 (OT working in a service which does not solely treat lymphoedema patients): …To create core pathways to allow for more effective referrals and assessment.

Participant 31 ('Other' MLD Therapist & Hospice Nurse working in a service which does not solely treat lymphoedema patients): …National standardised guidelines which provide lymphoedema management to all cancer and non-cancer related lymphoedema patients…

Participant 24 (Physio Manager working in a service which does not solely treat lymphoedema patients): Increase in resources to allow (1) staff training in effective fitting of garments etc. (2) computerised systems (3) all services provided in same area.

Participant 101 (Physio working in a service which does not solely treat lymphoedema patients): …To provide finance to support more specialists in this field...

Participant 57 (MLD Therapist working in a service which does not solely treat lymphoedema patients): Standardisation of provision of garments on drugs refund scheme….

Participant 72 (MLD Therapist working in a service which does not solely treat lymphoedema patients): That all costs involved in the treatment and maintenance /management of the condition, provided either in the public or private service, is completely reimbursed to the patient - including garments.

Participant 31 (Other' MLD Therapist & Hospice Nurse working in a service which does not solely treat lymphoedema patients): … Emphasis on training and education all HCPs (health care providers) in order to prevent lymphoedema occurring where possible….

Participant 71 (OT working in a service which does not solely treat lymphoedema patients): …Improved patient education – awareness campaigns.

Figure 4: Themes, Subthemes and Quotes from Practitioners in Response to the Question: "If you could influence government policy in this area, what recommendations would you make regarding lymphoedema services in general?"

Discussion of Service Provider Survey Results

The specific aims of the service provider survey were to: ascertain information about lymphoedema services and practitioners providing these services; investigate service-based factors which may affect optimal lymphoedema service provision (e.g. cover for leave etc.); determine the breakdown of lymphoedema patients being seen by practitioners; investigate the information and treatments being provided; explore potential barriers to treatment (e.g. distance to lymphoedema service etc.); investigate potential inequalities in lymphoedema service provision; explore issues that may affect lymphoedema service development (e.g. barriers to accessing training) and finally to ascertain practitioners' recommendations for lymphoedema service development.

Each of these aims has been met and a brief summary of the results is presented below in addition to examples of how these results compare with previous studies of lymphoedema service provision conducted in other countries. The results have been categorised and are presented under the following headings: insufficient service provision, inequitable service provision and challenges to the sustainability of services.

Insufficient Service Provision

Lymphoedema is believed to affect at least 1.33 per 1,000 of the population (Moffatt et al., 2003). Therefore if the population of Ireland is approximately four million people, potentially there are over 5,000 people experiencing lymphoedema symptoms in Ireland. Attempts were made to access as many lymphoedema practitioners as possible through a variety of means and yet the number of respondents who indicated that they personally treat lymphoedema patients was just 72 practitioners. The average number of healthcare professionals employed in each service for the treatment of lymphoedema was also low at less than one healthcare professional per service as in the BreastCare Victoria (2005) study. This indicates that there are an insufficient number of lymphoedema practitioners working in the treatment of these patients. Moreover of those who do work in the treatment of lymphoedema patients, many may be required to treat patients with other conditions. For example, only 18 practitioners reported working in a dedicated lymphoedema service (i.e. services that solely treat lymphoedema patients and are not required to treat patients with other conditions) and as a result lymphoedema patients comprise only part of the majority of practitioners' caseloads. This was reflected in the fact that on average practitioners spend just 8 hours per week treating lymphoedema patients. Moreover the average number of patients seen per month for various consultations is quite low at approximately 17 patients and likewise the average number of patients on waiting lists for these consultations is also quite low at 12 patients. These results considered together suggest that while the number of practitioners is low, the capacity of services also appears to be minimal. This is reminiscent of the BreastCare Victoria (2005) as the majority of services there had the capacity to see 1-15 patients per month.

The small number of dedicated services and the requirement of most lymphoedema practitioners to treat other patients could also be negatively influencing current service provision. For example when practitioners were asked to rate themselves in terms of their knowledgeability, competence, experience and confidence in treating lymphoedema patients, practitioners rated themselves lowest in terms of how experienced they feel. Additionally, only three quarters of respondents who personally treat lymphoedema patients provide time-consuming treatments such as Manual Lymphatic Drainage (MLD) and compression such as Multi-Later Lymphoedema Bandaging (MLLB) or compression garment fitting despite the fact that these which are regarded by international consensus as essential for the effective management of lymphoedema (MEP, 2006). Moreover only 19% of respondents indicated that their service provides home visits in comparison with 79% of services in the BreastCare Victoria (2005) study.

No respondents reported working in a service that has a social worker, psychologist, or psychiatrist employed in the treatment of lymphoedema patients, despite the fact that as outlined in the literature review psychosocial difficulties can be associated with lymphoedema (Tobin et al., 1993; Passik et al., 1995) and best practice suggests such multidisciplinary input (CREST, 2008; MEP, 2006). This is in contrast to the BreastCare Victoria (2005) study as practitioners reported that there were a total of 1.88 whole time equivalent social workers, and 0.2 whole time equivalent psychologists working in the state of Victoria.

The lack of practitioners personally treating patients, dedicated services and multidisciplinary input all point to practitioners' perception of inadequate service provision. This point was further emphasised in their ratings of the standard of care received by patients with various types of lymphoedema. The highest mean rating indicated by respondents was closest to the midpoint score and below a rating of 'high'. Finally practitioners' responses to open questions on lymphoedema service development also reiterated the need for additional resources to enable high quality service provision, incorporating psychological and financial support for patients.

In addition the finding of insufficient service provision extends beyond lymphoedema services to the service provided by compression garment manufacturers. Practitioners expressed their dissatisfaction with the delivery times particularly for made-to-measure garments and garments manufactured in the UK. This delay can affect practitioners as they are required to continue intensive treatment such as MLD until such garments arrive, by which time the level swelling may have altered and the garments are no longer appropriate, thereby diminishing the effectiveness of the treatment.

In summary, the theme of the insufficient, service provision is reflected in the low number of practitioners personally treating lymphoedema patients, practitioners working in dedicated lymphoedema services, practitioners providing treatment in each service, hours spent each week in the treatment of lymphoedema, and the low average rating of the standard of care received by patients in addition to the explicit reference to a need for an improvement in service provision in their recommendations for service development. This finding of insufficient service provision also incorporates the service provided by compression garment manufacturers as delays may compromise patient treatment and therefore the effective management of the condition. The second category under which these results can be presented is practitioners' perception of the inequitable nature of current lymphoedema service provision in Ireland.

Inequitable Service Provision

Lymphoedema services are mostly provided in large, public hospitals situated in counties with major towns and cities. However, as in the Australian Lymphology Association's (ALA) (2003) study and the report of lymphoedema services in Northern Ireland (DHSSPS, 2004), there does not appear to be any pattern to the distribution of services providing lymphoedema treatments. For example there were a relatively low proportion of practitioners from counties with large populations such as Meath and Kildare. In addition, practitioners reported that on average patients are required to travel over 71km to access their lymphoedema service and a sizeable minority patients are required to travel even lengthier distances to access services. This suggests that services are not located on the basis of population need. This is a considerably long travel distance when compared with the findings of the BreastCare Victoria (2005) study where patients reported being required to travel on average 18.2km in a one way trip in order to avail of treatment. Reports of service provision in the UK have also emphasised that patients living in rural areas may receive poorer lymphoedema service provision (DHSSPS, 2004; Moffatt et al., 2003; Morgan, 2006; Todd, 2006). Indeed in the UK, this has been referred to as a "postcode lottery of care" (Boris et al., 1997 cited in Rankin, 2001, page 3).

However such inequality in service provision applies not just in relation to the geographical location of services. For example, the results of the current study indicate that medical card holders may be receiving compromised treatment due to the delayed approval of their compression garments by the HSE. This is reminiscent of BreastCare Victoria's (2005) finding that rural patients may be disadvantaged by the compression garment subsidy scheme as they are required to travel to specific garment suppliers in order to avail of the subsidies.

Nevertheless the vast majority of results in relation to inequitable service provision from the current study relate to practitioners' perception that patients with non-cancer-related lymphoedema receive poorer service provision than patients with cancer-related lymphoedema. The most common referral source was hospital oncology clinics, and less than a third of respondents received referrals from alternative potential referral sources. Practitioners noted that in some cases this is due to poor awareness of lymphoedema among other healthcare professionals particularly general practitioners. This suggests that patients with non-cancer-related lymphoedema face barriers to service access. The BreastCare Victoria (2005) study and Bulley's (2007) study of services in Fife, Scotland, also indicated that poor awareness of lymphoedema and lymphoedema services among healthcare professionals may act as a barrier to service access particularly for those with non-cancer-related lymphoedema. However this finding can only be verified by the inclusion of patients' experiences.

Practitioners who provide advice to those at-risk of developing lymphoedema indicated that this information is generally provided to those at risk of cancer-related secondary lymphoedema. Again this suggests an inequality in service provision on the basis of lymphoedema aetiology. As in the BreastCare Victoria (2005) study the majority of the patients seen by the sample have breast-cancer-related secondary lymphoedema in the upper limb(s). This was expected given the greater prevalence of cancer-related secondary lymphoedema in this region of the world (Rockson & Rivera, 2008). Nevertheless the low number of practitioners' caseloads with non-cancer-related secondary lymphoedema in particular potentially signifies improved referral pathways for patients with cancer-related lymphoedema as mentioned above. However these results can only be corroborated by the inclusion of patients' experiences.

According to respondents, on average patients spend over 4 weeks waiting for lymphoedema treatment. As in Bulley's (2007) study of services in Fife, Scotland, some practitioners reported being required to employ prioritisation systems of patients on waiting lists in order to maximise their use of limited resources. Examples of the prioritisation systems employed by practitioners in Ireland include prioritisation based on being a newly-diagnosed or palliative patient, the severity of the lymphoedema, being a patient with cancer-related secondary lymphoedema or being referred from an oncology department. This again suggests that patients with non-cancer-related lymphoedema receive poorer service provision.

Further evidence that practitioners consider current lymphoedema service provision to be inequitable was evocatively provided by their ratings of the standard of care received by patients with various types of lymphoedema. Patients with breast-cancer-related-secondary lymphoedema were rated as receiving the highest standard of care, although the mean rating was still below a score of 'high', while patients with non-cancer-related secondary lymphoedema were rated as receiving the lowest standard of care. The differences in the ratings of the standard of care received by patients with various types of lymphoedema were statistically significant in all cases apart from the comparison between primary lymphoedema patients and patients with non-cancer-related secondary lymphoedema. Finally practitioners' recommendations for the development of services also signified their perception of an imbalance in service provision as they reiterated the need for equitably distributed service provision.

In summary, the inequitable nature of current lymphoedema service provision was illustrated by the location of practitioners, the great distances a sizeable minority of patients are required to travel to access services, the delays practitioners reported in the approval of compression garments for medical card holders and variations in service provision for patients with different types of lymphoedema. For example, the potential improved referral pathways for those from oncology sources, information about lymphoedema being provided preferentially to those at risk of developing cancer-related lymphoedema and the prioritisation of patients with cancer-related lymphoedema on waiting lists. The variations in practitioners' ratings of the standard of care received by patients with different types of lymphoedema coupled with their recommendation that services should be more equitable provided further emphasise the point. These results echo results from previous studies of service provision from Australia and the UK. However there is a need to corroborate the findings by the inclusion of patients' perspectives. The final category of results from the service provider survey relates to challenges to the sustainability of services.

Challenges to the Sustainability of Services

The majority of lymphoedema services' funding comes from general physiotherapy, oncology or palliative care budgets rather than an independent funding allocation. As the report on lymphoedema services in Northern Ireland pointed out such ad hoc investment and funding indicates scant consideration to the continuation of services for what is a chronic condition (DHSSPS, 2004). While the source of funding is a challenge to service sustainability, a more arduous challenge arises from the finding that 5 practitioners reported that their lymphoedema service received no funding at all.

Less than 8% of respondents reported that their service had vacant posts which may reflect the HSE recruitment freeze when the funding for unfilled posts was no longer allocated and posts were then lost. This is a considerable challenge to the stability of service provision. Additionally, as in the report from Northern Ireland a lack of cover for leave was a pervasive issue for respondents (DHSSPS, 2004).

While approximately 78% of practitioners have received specific training in the management of lymphoedema, almost all respondents requested additional training in order to keep abreast of developments in lymphoedema treatments as in the BreastCare Victoria (2005) study. However, low staffing levels in lymphoedema service and cutbacks throughout the health service present barriers to practitioners requesting continuous professional development. This in turn challenges the maintenance of service standards and the sustainability and development of services.

In summary, challenges to the sustainability of services relates to a lack of an independent funding stream or indeed of any funding at all for services, the loss of lymphoedema practitioner posts, the lack of cover for leave and the need and barriers to additional training.

In many cases these results correspond with previous studies on service provision conducted in other countries in addition to providing information on the unique challenges experienced by Irish lymphoedema services. However due consideration must be given to the methodological limitations of this phase of the study and these are presented in the next section.

Methodological Issues

In the survey distribution an attempt was made to balance the opposing aims of dispensing the questionnaire as widely as possible while specifically targeting questionnaire distribution at practitioners with precise knowledge of lymphoedema as opposed to other forms of chronic swelling. Nevertheless it must be noted that not all those receiving the survey were necessarily lymphoedema practitioners, not all lymphoedema practitioners were necessarily invited to participate and that due to personnel changes or some lymphoedema practitioners choosing not to participate, information on all lymphoedema services was not necessarily included. However given the lack of an existing register of lymphoedema services in Ireland, and the various procedures through which practitioners were sourced, the sample was as representative as possible at the time of questionnaire distribution.

Secondly once the results are broken down according to the practitioners who personally treat lymphoedema patients and according to various categories of healthcare professionals, the numbers of respondents are quite small. This reflects the low number of practitioners working in this field in Ireland, but it does make the comparison and generalisation of results within the study problematic.

Thirdly generalisation of these results beyond this study may also be problematic given the unique context of the Irish health service in general and specifically the unique context of Irish health service at present. For example the low number of practitioners reporting unfilled posts reflects the current financial pressures experienced within the health service rather than lymphoedema services operating with a full complement of staff.

Finally, the various departmental structures, funding and staffing situations in hospitals and services were difficult to explore fully in a questionnaire format. While the addition of service provider focus groups would have added further clarity in these matters it was not possible given the time constraints of the study.

From the Service Provider Survey to the Patient Perspective

While bearing these methodological limitations in mind, these results provide valuable insights into the perspective of service providers on current lymphoedema service provision in Ireland. Additionally as mentioned previously in the discussion, they signpost further questions on lymphoedema service provision and experiences of living with the condition which can only be answered by investigating patients' views, for example, differences in patients' opinions of lymphoedema services according to the type of lymphoedema patients experience. Therefore the next phase of the study explored patients' views through a series of nationally conducted focus groups.

Chapter 5: Focus Groups

Introduction

The overall aims of this study were to investigate lymphoedema service provision in Ireland, in addition to exploring patients' experiences of living with lymphoedema in Ireland. In meeting these aims, the second phase of the research employed focus groups to explore patients' experiences of living with the condition and of lymphoedema service provision. Patient focus groups were included in this study for several reasons.

Firstly focus groups offered the potential to clarify the results of the service provider survey. As mentioned previously, the results of the practitioner questionnaires flagged several topics for exploration which required the inclusion of another perspective on lymphoedema service provision. For example, practitioners provided information on the distance patients are required to travel to access services, delays in compression garment supply, waiting times in accessing lymphoedema services and differences in the standard of care received by patients with different types of lymphoedema. The information provided by practitioners could only be corroborated, explored further or contradicted by asking patients themselves about their experiences of services. This approach of tailoring specific questions to the most relevant sample was employed in the BreastCare Victoria (2005) mixed methods study on lymphoedema service provision.

Secondly, focus groups enable the exploration of patients' personal and subjective experiences of living with lymphoedema. As mentioned previously, the aims of this study were to explore patients' experiences of living with lymphoedema, not just to explore lymphoedema service provision. While previous studies conducted in the UK had investigated this topic, there was no information on how Irish patients feel about living with lymphoedema and its impact on their quality of life. As mentioned in the chapter on mixed methods, focus groups capitalise on the interaction within a group and allow the comparison of participant's experiences and perceptions (Morgan, 1997). Also focus groups are suitable when the intent is not to generalise findings but to gain a more complete understanding of a topic (Kreuger, 1997). Furthermore lymphoedema researchers have also argued that focus groups can be beneficial. For example Morgan, Franks and colleagues (2005) found that focus groups result in rich, experiential data if properly moderated and conducted in a non-threatening atmosphere. Hare (2000) suggests that focus groups can result in serendipitous findings such as the empowerment of participants, as they feel like experts, which can in turn be beneficial for participants.

Finally the findings of the focus groups could be employed to inform later phases of the research. Focus groups have previously been used successfully to identify appropriate language and questionnaires for new populations (e.g. McKinley et al., 1997; Gallagher and MacLachlan, 2000). Therefore the patient focus groups could assist in ascertaining the most pertinent and appropriate topics and wordings for the lymphoedema patient questionnaire.

Specific Aims of Focus Group Phase

The broad aims of the patient focus group phase were to explore patients' experiences of living with lymphoedema and of lymphoedema service provision. These general aims can be broken down into more specific objectives, which were to:

- Explore patients' experiences of seeking an explanation for their lymphoedema symptoms, obtaining a diagnosis and accessing information and treatment.
- Investigate barriers to patients' compliance with their lymphoedema management plans (e.g. difficulty in putting on compression garments; dissatisfaction with compression garments; difficulties with compression garment provision).
- Explore barriers in accessing treatment (e.g. distance to lymphoedema service, cost of treatments, level of financial support from private health insurers for treatment etc.).
- Assess the impact of lymphoedema on patients' daily life (e.g. limitations on employment, activities and socialising) and the impact of lymphoedema on their quality of life.

Method

Identifying a Sample

Drawing on the information from the service provider phase which mapped current lymphoedema service provision in Ireland, participants were recruited through hospitals in what were formerly known as the four Regional Health Authority Areas in Ireland, and through organisations which provide information and support to lymphoedema patients (e.g. Lymphoedema Ireland). The hospitals and organisations were contacted and permission was sought to purposively select volunteers to invite to focus group sessions held at a local venue. In hospitals, the cooperation of the manager of the lymphoedema clinic (or equivalent in physiotherapy, occupational therapy and/or vascular care department) was sought to facilitate the purposive sampling that allowed participants to be selected to participate in focus groups. The focus groups were also advertised in relevant newsletters and websites (e.g. Lymphoedema Ireland website and newsletter, MLD Ireland website) so that people who are not in direct contact with support organisations or hospitals but who were interested in the study could be sent information with a view to deciding if they would like to participate.

Purposive sampling was used to ensure that the focus groups reflected a variety of age ranges, types of lymphoedema and duration of lymphoedema symptoms. All participants had a diagnosis of lymphoedema, were over eighteen years of age and were deemed capable of informed consent by their lymphoedema practitioner. Patients who have chronic oedema (i.e. oedema of multiple origins with the original cause not being malformation, impairment or absence of part of the lymphatic system) were excluded in order to focus the research specifically on the experiences of lymphoedema patients. Patients under the age of eighteen were excluded as all participants were required to give their own informed consent. Palliative patients were also excluded from the study. Given the variety in health status among patients defined as receiving palliative care and the rate at which palliative patients' health status can change it was decided that they should not be sent information about the study in order to avoid unnecessary distress for either the patients themselves or their relatives.

A total of 5 focus groups were conducted, one in each of what were formerly known as the four Regional Health Authority Areas in Ireland, except in the east of the country where two groups were held, due to the density of the population there. Morgan (1997) suggests that it is advisable for focus groups to have between 6 and 8 participants in order to encourage interaction and contributions from all participants. With this in mind, each focus group was comprised of 5-8 participants.

Focus Group Topic Guide

In order to elicit information on patients' experiences predetermined open-ended questions were arranged into a focus group topic guide. Potential topics and question wordings were developed through three processes: the review of literature, expert opinion of the research advisory group (composed of lymphoedema patients, lymphoedema practitioners, consultants in related disciplines of venous disease and oncology, and research psychologists), and the results of the service provider survey. The topic guide covered subjects similar to those included in the study by Johansson et al. (2003) (e.g. first awareness of symptoms, ongoing management of lymphoedema) and the study by Williams, et al. (2004) (e.g. experiences of treatment, impact of lymphoedema on daily life). The focus group topic guide and sample questions are outlined in Table 13 on page 102.

The focus group topic guide was piloted in the first focus group. No changes were made to the topic guide on the basis of the pilot and therefore the topic guide was employed in the subsequent focus groups.

Table 13: Focus Group Topic Guide

Initial Reaction to Symptoms of Lymphoedema:

- Can you tell me what it was like for you when you first became aware of swelling in your body?
- What do you think triggered your lymphoedema?

Interaction with Services before Diagnosis:

- Can you tell me about your experience of services when you were seeking an explanation for your lymphoedema symptoms?

Diagnosis:

- Can you tell me about your experience of receiving a diagnosis?

Access to Information about Lymphoedema:

- Had you been told previously that you were at risk of developing lymphoedema?
- How did you find the process of accessing information about lymphoedema?

Experiences of Services since Diagnosis:

- Can you tell me about your experiences of services since you have been diagnosed with lymphoedema?

Experiences of Treatment:

- Please describe your experiences of lymphoedema treatment.
- When do you find it easier or more difficult to follow the recommended advice on the management of lymphoedema?
- What would make adjusting to lymphoedema treatment and self care easier?

Impact on Daily Life and Quality of Life:

- Tell me more about how lymphoedema has affected you and your daily life?
- What are the most difficult things about having lymphoedema?
- Can you tell me about any positive aspects associated with having lymphoedema?

Closing Questions:

- Is there anything that you feel should be included in our questionnaire that we haven't spoken about yet today?
- If you could change government policy on lymphoedema services in one way what would it be?
- What's the one message that you want us to take away with us and include in our report on the experiences of people with lymphoedema?

Procedure

Potential participants accessed through hospitals were advised verbally about the focus groups by their lymphoedema practitioner. Patients were asked if they would be willing to be put forward to receive further information about the focus groups. Those patients were then provided with a letter from their lymphoedema practitioner, an information sheet outlining the study and requesting their participation, and a consent form. Potential participants accessed through organisations providing support to lymphoedema patients (e.g. Lymphoedema Ireland) were posted the same letter but from a named person in the Irish Cancer Society, with an information sheet outlining the study and requesting their participation, and a consent form. Those willing to take part were asked to sign and return FREEPOST the informed consent form indicating their agreement to participate. As some research ethics committees required specific wordings in the cover letter, information sheet and/or consent form distributed to the patients under their remit there were slight variations in the text of these. However a sample cover letter, information sheet and consent form are presented in Appendix E, F and G respectively.

On receipt of the signed informed consent document, those agreeing to participate were sent information regarding their scheduled session. Participants had the option of choosing the focus group session that was located most conveniently for them. Participants were informed that they could withdraw from the study at any time in the research process and that they would not be required to provide a reason to do so. At the outset of the focus group, demographic information about the participants was gathered using a short demographic questionnaire for the purposes of transcription (see Appendix H). A trained oncology nurse familiar with the area and capable of dealing with any issues that may arise was present at all of the focus groups. Each focus group was audio-taped and written notes were taken by the two note-takers. Participants were assured of confidentiality at all times. The end point of the patient focus group phase was when there was saturation of the data (i.e. when no new information was emerging from additional focus groups). As a result a total of 5 focus groups were conducted nationwide.

Ethics

Ethical Approval

For this phase of the study, approval was sought and granted from Dublin City University Research Ethics Committee and from seven hospitals nationwide, to invite patients who met the inclusion criteria to participate in the focus groups.

Informed Consent

As mentioned previously, patients were provided with a letter from their lymphoedema practitioner or support organisation, an information sheet outlining the study and requesting their participation, and a consent form. Both the letter and information sheet invited patients to contact the researcher if they had any questions about the study. This option was available to patients at all stages of the research. Those willing to take part were asked to sign and return FREEPOST the informed consent form indicating their agreement to participate. As some research ethics committees required specific wordings in the consent form distributed to the patients under their remit there were slight variations in the text of this. However a sample consent form is presented in Appendix G.

Confidentiality

All participants were assured of confidentiality and anonymity at all times and through all stages of the research. All information divulged during the focus groups was treated confidentially. In transcribing the data from the focus groups, identification numbers were substituted for participants' names and their individual identities were not linked to the information they provided. The thesis does not contain any identifying information. Furthermore, only three previously identified people were allowed to view the data collected through the focus groups: the researcher, the oncology nurse present at the focus groups and the research supervisor. Furthermore, the tapes are being stored in a locked filing cabinet in the researcher's office which only members of the research team have access to and they will be destroyed on completion of the study. The transcripts were inputted directly onto the researcher's computer, which is password protected to ensure the confidentiality of all electronic records. Hard copies of the demographic questionnaires and signed consent forms are being stored in a locked filing cabinet in the researcher's office which only members of the research team have access to. All identifying information will be shredded and disposed of five years after completion of the study by Dr. Pamela Gallagher, supervisor of this study.

Risk Management

Since the research study employed focus groups which are a non-invasive data collection procedure, it was anticipated that there would be no adverse implications for the participants. However, there was the potential for raising anxiety given the sensitivity of discussing a chronic condition such as lymphoedema. Asking patients about their experience of first identifying swelling in their body, and being diagnosed or seeking treatment could have potentially caused the recollection of unpleasant memories or past negative experiences. This issue was acknowledged and safeguards were set up to deal with such situations and to minimise the risk of distress to participants.

In focus groups, there was a moderator/facilitator and two note-takers. This three person approach assisted with the sensitive handling of the group dynamics and individual issues that arose. An oncology nurse who has over 10 years first hand experience working with cancer patients and therefore has an understanding, awareness of and sensitivity to the needs of this group, was present at all focus groups. If any participants had displayed signs of discomfort or distress during the focus group then the option of withdrawing would have been automatically and immediately offered to them. The three person approach also facilitated the late arrival or early departure of participants as the second note-taker could assist in escorting participants to and from the venues where the focus groups were being held.

Participants were alerted to the Irish Cancer Society's Action Breast Cancer FREEFONE Helpline, through which all patients could receive information, support and counselling if required, and access to the support services provided by Lymphoedema Ireland in the patient information sheet. All participants at all stages of the research had this service available to them. The focus group topic guide was piloted at the first focus group to ensure that issues were explored in the most sensitive manner possible.

Data Analysis

The tapes of the discussions were transcribed verbatim. As the transcripts did not reflect non-verbal communication, they were supplemented with additional observational data obtained by the two note-takers during the session. The goal of the analysis was to identify themes as described by the participants and to describe the range of issues and experiences within each theme. These themes were identified both through the analysis of individuals' narratives and through the analysis of the dynamic construction of social meaning that occurs in focus group interactions (See Wilkinson, 1998a, 1998b). Data was analysed line by line to code for recurrent themes and coding categories. Following the coding of all transcripts, 60% of the transcripts were double coded to assess inter-rater reliability. The findings are presented below in the next section.

Findings

Focus Group Participant Information

Five focus groups were undertaken throughout Ireland each consisting of between 5 and 8 participants. The sample breakdown of the 33 focus group participants is presented in Figure 5. As expected the majority of participants were female, over 50 years old, with breast-cancer-related secondary lymphoedema in their upper limb(s). The rest of the sample reported that they have primary lymphoedema; lymphoedema secondary to gynaecological cancers, lymphoma or melanoma; or that they didn't know what type of lymphoedema they have.

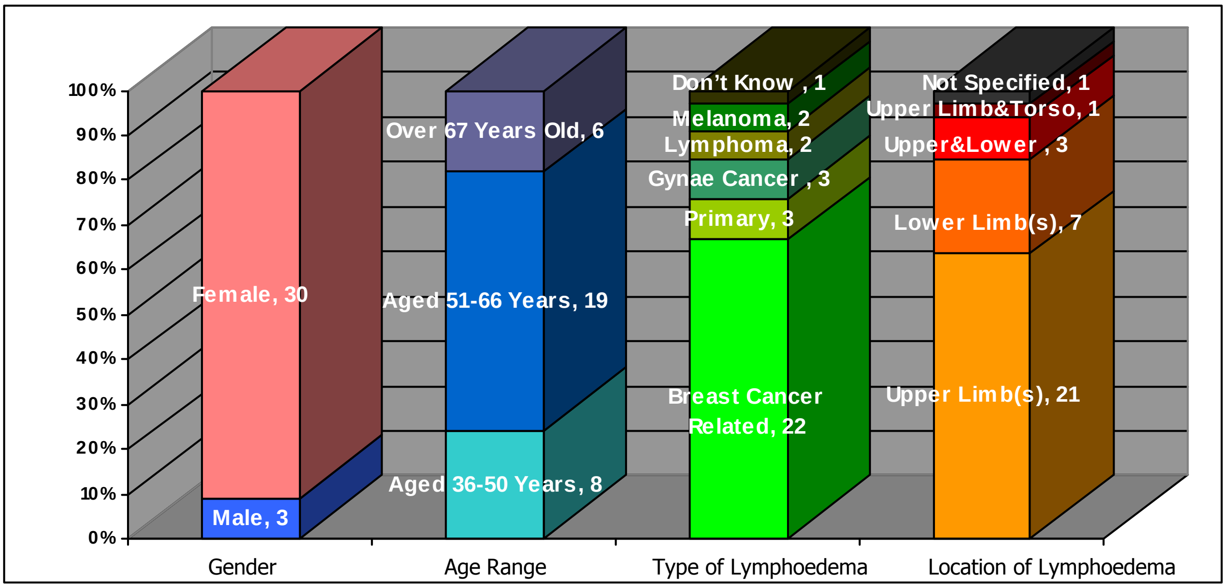


Figure 5: Focus Group Sample Breakdown

On average participants had experienced lymphoedema symptoms for 60.52 months (SD = 48.77, Range= 5-192, *n=33)* and had been diagnosed 57.76 months ago (SD = 46.55, Range= 3-192, *n=33)*. The demographic and clinical details of each of the focus group participants are presented in Appendix I.

The main themes and subthemes which arose from the analysis of the focus group transcripts are presented in Table 14 and are elaborated on with illustrative quotes in later sections.

Table 14: Main Themes and Subthemes from Patient Focus Groups

Main Themes	**Subthemes**
Barriers to Treatment	- Insufficient Services
	- Existing Services Overwhelmed
	- Cost of Treatment
	- Compression Garment Delays and Difficulties
Tension with Healthcare Professionals	- Not Pre-warned therefore not Prepared
	- Questions without Answers
	- Dismissive Attitude towards Lymphoedema
Lymphoedema Affecting Daily Life	- Making Space for Lymphoedema
	- Finding Clothes and Shoes to Cover Lymphoedema
	- Limitations imposed on Daily Activities
Emotional Factors	- Incapacity to Process Susceptibility to Developing Lymphoedema
	- Constant Reminder of Cancer Treatment
	- Adapting to the 'New Body'
	- Distress Following the Reactions of Others
	- Fears for an Uncertain Future
Taking an Active Role	- Taking Responsibility through Self-Management
	- Appealing for Treatment
Deriving Positives	- Preferable to an Advancing Cancer
	- Desire to Warn Others
	- Acceptance from Others who Speak the Language

Barriers to Treatment

The first theme that emerged from the focus groups was the various barriers for patients attempting to access appropriate, sufficient and continued treatment. The first subtheme related to the insufficient number of services available to meet the needs of lymphoedema patients. The second subtheme related to existing services being oversubscribed and under-resourced hampering access to continued treatment. The third subtheme related to how the cost of treatments discourages participants from supplementing public services with private treatment. Finally difficulties with the delivery, fit or appearance of compression garments were reported as lessening participants' adherence to lymphoedema management plans. Each of these subthemes is elaborated on with illustrative quotes below.

Insufficient Services

The insufficient number of services available to meet the needs of lymphoedema patients was a prominent concern among participants:

> I don't understand why the, you know, facilities are so limited really, (for) something that a lot of people seem to have.
> *FG 2, Participant 3*

> They sent me literally … a list of all the people who do (manual) lymphatic (drainage) and it's a very short list, there was nobody in (name of city) … there were 2 people in (name of town), which would have been the nearest place, but it's still an awful long drive with a leg, which you shouldn't be moving around and shouldn't really be driving … and I thought this is absolutely ridiculous, people are not being trained … but … it's impossible. You know the way we all fight for a slot with (name of practitioner).
> *FG 2, Participant 2*

As a result, some participants expressed concern regarding the sustainability of services:

> (Name of practitioner) is the only person … that's trained for this …I'm just worried because … I'm wondering who'd take over from (the practitioner, if the practitioner had to go on leave). There's nobody. There's nobody trained to fill (the practitioner's) place.
> *FG 3, Participant 4*

When participants were asked what final point they would like to make about current lymphoedema service provision before the end of the focus groups, the majority of responses related to the need for additional trained staff (e.g. Manual Lymphatic Drainage therapists) and services:

> (There's) still a lack of care and treatment…particularly (for) youngish people there's only one (practitioner) in (name of hospital; they need) someone on the wards going around…More people trained in manual lymph drainage.
> *FG 5, Participant 6*

One participant suggested the following:

> There is no one stop place, we're all having different experiences of where we went what we found out, there's nowhere you can go and say everything you need is there.
> *FG 3, Participant 6*

Existing Services are Overwhelmed

The subtheme of insufficient services is related to the second subtheme of existing services being oversubscribed and under-resourced. For example the following quote outlines that due to resource limitations they could not access prophylactic treatment at a preclinical stage, when the swelling may not have been visible but there was pain or other sensations present:

> I knew if I could get it seen quickly, ehm, I had read that if it was caught at an early stage to maybe keep it, keep it minimal, there was no real swelling, (but) it was painful … I knew that obviously there's a huge … lack of resources and huge lack of knowledge 'cause I have a friend who's a physio in this area and she works … in England … because … if you feel swelling or you get in pain in where she works you're immediately bandaged and you're immediately given treatment and in fact over there, the best practice, after surgery you're given 8-10 MLD (manual lymphatic drainage) sessions anyway, and you're given things, and you're measured and it's continuous education, and continuous heightening awareness of the fact that it can happen to anybody … I don't feel it was handled as well as it should've been because (the arm) wasn't huge but it was huge FOR ME, relative to ME it was huge, that's the problem and I think that's where the resource issue is.
> *FG 4, Participant 4*

For other participants the issue was that although they had accessed treatment they found that appointments were rushed and it was difficult to make contact with the practitioner to arrange follow up appointments:

> I was referred to (name of hospital)… from my experience it's massively understaffed, and massively overworked… quite a lot of the time a phone call isn't returned or it's very difficult to get an appointment … you know you've only got (the practitioner) while you're in there, (for) that few minutes, that half an hour because (the practitioner has) got a backlog out there, there was even a knock on the door when I was in there … we're also going from almost a one-on-one situation … when we're having our cancer treatment or whatever and you go from that to just (being) one of many, suffering, get in the queue it, it, it's hard to get used to the fact that this is what you've to get used to… you can go private but we can't all afford that.
> *FG 3, Participant 6*

As a result of the oversubscription of services, participants reported having difficulties accessing continued treatment:

> There's weeks in between (treatments), it's like a peanut to a monkey, having one therapy once every so often. Now (name of practitioner) tried the compression therapy on me but I need it everyday, and I'm in pain, I can't work, ehm, every afternoon my arm is sore, in fact it's getting worse, it upsets me.
> *FG 1, Participant 7*

Cost of Treatment

The cost of accessing ongoing private treatment to supplement what they perceived to be insufficient treatment from the public health service was a subtheme that featured prominently in all focus groups:

> I think that's a big issue, too … You have to pay. Everything…. You have to have the money. I think around the whole care and money and costs for people that you know that it's ongoing … that's not taken into account, like you know the ongoing difficulties and the ongoing costs.
> *FG 1, Participant 4*

> The services (are) very, very bad, yeah and with, you know with having lymphoedema you can, your tissues can get… hard, and (so) it's very important that you have your treatment, your, your massage treatment and to go privately it's €60 and €70 to go to somebody, you know. (Private health insurance company) don't cover it, at all.
> *FG 2, Participant 7*

> Well, ehm, can everybody afford €75 a week? That's what I'd like to know.
> *FG 1, Participant 7*

The cost of private treatment can extend beyond the private practitioners' fees to compression garments and bandaging:

> And it depends… some tights they're €400 for 2 pairs, and when I went to (a lymphoedema clinic in) Austria you could buy the tights, they were thick ones like these and they were €600 I think for one pair… It would cost me about €5,000 a year, to be honest…to keep my leg from becoming to the situation where it would get really bad.
> *FG 2, Participant 1*

The following interaction from Focus Group 5 illustrates that participants also incurred costs attending public lymphoedema services:

> *Participant 5:* At the end of the day, I went to (the practitioner)… (the practitioner) asked me to bring in the bandaging (for Multi-Layer Lymphoedema Bandaging) that I had actually gotten from (a private practitioner) that I had gotten privately, so I didn't want to say anything, I was glad to get in.
>
> *Participant 6:* They will wash (the bandages)… (the) HSE will not spend much money, as little as they can.

Compression Garment Delays and Difficulties

The final subtheme related to the barriers to treatment theme was compression garment delays and difficulties. Compression garments are an integral part of the self-management of lymphoedema as they contain the swelling and promote lymphatic drainage. However poorly fitting garments can be at best ineffectual and at worst counterproductive (MEP, 2006). Participants reported that their lymphoedema treatment was compromised by difficulties with compression garments, for example long delays in the ordering of garments due to HSE approval procedures or in the delivery of garments by garment suppliers.

> I got them from the medical card and I was waiting three months for it… three months I was waiting for the sleeve. I could've knitted it myself in that time.
> *FG 1, Participant 5*

This is further illustrated by the following exchange from the second focus group:

> *Participant 8:* (Name of practitioner) measured my arm this time last year for a sleeve and I still haven't got it… (Name of practitioner) hasn't forgotten it (practitioner) has ordered it but wherever they're ordered in from, from some other country, I'm not sure where… It's missing somewhere in the system….He hasn't forgotten it he has ordered it but wherever they're ordered in from, from some other country, I'm not sure where… It's missing somewhere in the system.
>
> *Participant 4:* It's in the system, the system, we know the system.

For others, the compression garments funded by the HSE were poor fitting and unlikely to be encouraging lymph flow.

> You can get (compression garments that)… look finer and they've better colour and I've said it to (practitioner) but (practitioner) said 'I can only get what the HSE is contracted

> with the company'… I had problems, they were rolling, the sleeve was rolling down and cutting into my arm here, so ehm, like these ones are made to fit … but what happens is it gets very loose after a while, it slips, slips, it doesn't cut in but it slips down … think this was my problem, I had two (garments) joined here, and the hand started swelling up it was actually quite like a golf ball there.
> *FG 3, Participant 5*

> First garment I got I more or less demanded, it was too big, I had asked pretty directly, to tighten up on it (as) I knew it had to be compressed but because it wasn't 3 times the size of this (other) arm (my arm) was too small to bother (with), maybe when you're in there, it wouldn't kill them to measure you… prevention could, could do it initially, (practitioners should) give you a garment that is tight enough which you could wear if you notice a change (increase in swelling).
> *FG 5, Participant 4*

> The (compression garments) the hospital gave me, they (weren't) self-supporting, they just used to roll over at the top, you pull them up like a pair of socks and they just used to roll over creating a thick band, and all I know about anatomy is you're supposed to have drainage, and this was like a tourniquet. So I found self-supporting ones which are absolutely marvellous because they don't have the same restriction or the bulge but I order them off the internet … because the hospital doesn't provide them. The two pairs cost me just over €100.
> *FG 3, Participant 4*

The following exchange from the first focus group illustrates that the discomfort participants experience while wearing compression garments can discourage them from wearing compression garments for sufficient amounts of time:

> *Participant 1:* I find by 5 o'clock in the evening I have to take (the compression garment) off, it's so painful.
> *Participant 7*: Yeah, it cuts.

Another aspect of this subtheme was that the uncomfortable nature of the garments coupled with how unsightly they can be makes it difficult for participants to wear them.

> The colour of the garments alone… (and) they're very heavy, and the heat … I find the garments are very cumbersome, or dry, they could be a bit finer and skin-like… (make) it into a skin-like stocking.
> *FG 5, Participant 5*

Tension with Healthcare Professionals

The second major theme was tension with healthcare professionals. This included participants' anger at not being pre-warned about the risk of developing lymphoedema and as a result they weren't prepared. The second subtheme was the perceived lack of knowledge of some healthcare professionals resulting in participants' questions being unanswered. The final subtheme related to this theme was the perceived dismissive attitude of some healthcare professionals towards their lymphoedema.

Not Pre-warned and therefore not Prepared

Participants expressed their frustration that they had not been warned that they were at risk of developing lymphoedema. As a result participants couldn't avoid risk factors or engage in preventative measures and weren't prepared for the development of their lymphoedema:

> Nobody told me about lymphoedema, which I, I feel a bit sore about now, that nobody told me … (I) feel sore I could've taken more precautions with the arm and I'm frustrated … that there isn't something else really … it just feels crazy that this is all there is, you know.
>
> *FG 2, Participant 3*

> You do go and you get diagnosed with cancer and they say 'we're going to do this operation on you' and …they don't tell you that the exercises… you do initially when you're feeling really, really, really bad, that if you don't do those exercises, you won't have the use of your arm, never mind you know lymph, lymphoedema…you're having to face the fact that you have cancer … you're left thinking… 'Am I the only one who gets this?' ...'Am I the only one who's sore after 8 years?' ...Nobody tells you, I have to ask people…does the pain ever go away and they say 'not really'… Six years later you're told this whereas you should be told everything.
>
> *FG 2, Participant 5*

> I didn't know what caused it; then they said it could've been the flight… I had a 4 hour flight, … I suppose what upset me was if I'd known in advance of going on the flight that I could've gotten a sleeve… the breast care nurse said it would have helped, but nobody had told me, and I had told everybody in the (oncology) unit, my own doctor, that I was going on this holiday … and is there anything I need to do and nobody mentioned (a sleeve), nobody really knows a lot about lymphoedema, nobody's sitting you down (to tell you), so I was a bit disappointed … so I always say to people who fly (to) wear a sleeve.
>
> *FG 4, Participant 3*

Participants spoke of their upset at not being advised that their condition is irreversible:

> I mean I was never told that it wouldn't go away… I thought we're going to get to the end of this and that'll be it, you know it took a while (for the healthcare professional) to say it's not going to go away, like the condition is going to be there, you know. Which was, which was awful really, very, very kind of depressing as well, you know, it can be, you know…
> *FG 3, Participant 2*

Participants who had been warned that they were at risk of developing lymphoedema reported that the risk of developing lymphoedema and the consequences of doing so should have been stressed more:

> We're not made aware of how serious it is… it's not made dramatic enough for the patients in the hospital and I genuinely feel we should be called back and reminded … you can never forget about it…
> *FG 4, Participant 4*

Questions without Answers

Tension also resulted from participants' perception that some healthcare professionals lacked knowledge about lymphoedema. As a result participants were left frustrated as their questions about their condition remained unanswered. The majority of quotes in relation to this subtheme referred specifically to participants' general practitioners:

> I was diagnosed almost by mistake I knew I had something wrong with my leg for about, 9, 8 or 9 or maybe even 10 years, I had a path worn to my GP… I was even having trouble really getting anyone to do anything definite with that… eventually I was sent by, I think, eventually, having battered them nearly, eh, the GP… I don't have any big hang up, except it took five years for it to be diagnosed and really it wasn't for want of ME trying to find out what the heck was wrong with my leg… medical people should get information… they know nothing… they don't take any notice.
> *FG 2, Participant 2*

> Especially the GPs, like I mean, your first port of call is your GP and in the main, most GPs don't know anything very much about it. Ok …surgeons might know a bit about lymphoedema but your ordinary GPs don't know anything about it.
> *FG 1, Participant 3*

> I went to my own GP and said I couldn't go anywhere, you know because you get tired listening to yourself… no-one knew nothing… I didn't know where to go or where to turn; I couldn't get them (garments) here. My GP wrote a letter to (the practitioner, and) they

> only heard of (lymphoedema) and (were) just beginning to learn about it and that was 6 years ago.
>
> *FG 5, Participant 2*

> (The GP) did the testing this way and (the GP) said 'oedema alright but it's not the usual swelling, em, it's probably lymphoedema and there's not a lot you can do about it' …. (The GP) wasn't unsympathetic but (the GP) wasn't offering anything.
>
> *FG 1, Participant 2*

Other participants referred to the lack of knowledge among healthcare professionals in general:

> I went to several doctors that I was attending for my check ups in (name of hospital) … I said it to one doctor, I said 'my arm is like an elephant's trunk' (the practitioner) said 'I don't know what what's wrong with you' … (I replied) 'somebody told me about lymphoedema' (the practitioner) said 'I never heard of it' - in a major hospital, you know what I mean?
>
> *FG 1, Participant 5*

> You're relying on the professionals, obviously … but they don't understand lymphoedema and they're not lymphoedema specialists because we're all surviving (cancer) so there's a huge need… I feel there's a huge lack of awareness and then when you do go in (to the hospital) there's a lack of a management programme.
>
> *FG 4, Participant 4*

> From the lymphoedema support group, the biggest problem (for most patients) was just to find a medical person who could do something for them, who could see if they had something wrong and guide them and tell them what to do. Lots of people absolutely didn't know what to do until they … came to the (Lymphoedema Ireland) meeting and saw what was there, their own GP or their own nurse… or whatever in most cases didn't seem to be able to help them, almost unable to identify what was wrong.
>
> *FG 1, Participant 2*

Dismissive Attitude towards Lymphoedema

The final subtheme related to the tension with healthcare professionals theme was participants' perceiving that some healthcare professionals had a dismissive attitude towards their lymphoedema. Essentially this related to participants' frustration that some healthcare professionals had underestimated the impact of the lymphoedema diagnosis or of living with the condition on patients:

> It's not life threatening (but) if you get these infections (cellulitis); you've all that to deal with. I think that's why (healthcare professionals are) not treating it as too important.
> *FG 4, Participant 1*

> (The doctor) said 'would you be very upset if it didn't go down', like this jollying you along as if you were an eegit, you know, like not treating you like an adult.
> *FG 1, Participant 3*

Later on in the same focus group another participant commented:

> Yes there's… a dismissiveness.
> *FG 1, Participant 4*

While some participants with cancer-related lymphoedema acknowledged the significance of their cancer survivorship, this did not negate the need for their current discomfort and distress to be adequately accepted and considered by others:

> I went back to (hospital) for a check up six months after and I did say to the doctor there and eh, (the doctor) said 'well aren't you lucky', that's what (the doctor) said, and that was it and I should be thankful that I only had lymphoedema after having the surgery. I felt that.
> *FG 1, Participant 5*

Lymphoedema affecting Daily Life

The third theme was lymphoedema affecting daily life. This referred to subthemes of making space for lymphoedema through the daily management plan; difficulties in finding clothes and shoes to cover the affected area of the body and the limitations imposed on daily activities or employment.

Making Space for Lymphoedema

The daily self-management of lymphoedema can involve time consuming skincare, exercises, simple lymphatic drainage, the use of compression garments and in some cases self-bandaging. The difficulty in dedicating the time to follow this daily self-management plan emerged from the focus groups:

> Life gets in the way.
> *FG 2, Participant 5*

Making space for lymphoedema extended beyond the self-management of lymphoedema to the actual treatments themselves. The difficulty of living with lymphoedema treatment was also highlighted:

> (Name of practitioner) wants me to go back for bandaging, but I can't for work. I couldn't bear that at all, it's just so cumbersome and I could not do a single thing at home.
> *FG 4, Participant 1*

Finding Clothes and Shoes to Cover Lymphoedema

The final subtheme of lymphoedema affecting daily life related to participants' difficulties in finding clothes and shoes to cover the lymphoedematous areas of their body:

> You buy a pair of trousers off the peg, and you get home and now they won't go over the knee and you have to go back into the shop to change it and they look at you, 'we've sold how many pairs of these trousers why are you bringing them back'. And you can't explain it to them, that one leg is different to the other. And eh, it's happened me, trying to buy gloves in the winter, I can buy woollen ones but they don't last too long, I can get normal ones or the nearest you can get to your size and you can get them on but you cant get them back off afterwards, and I don't bother … any more.
> *FG 1, Participant 6*

> (I) have to wear long skirts or long dresses, shoes, when you have (lymphoedema) in the foot, certain shoes, stocking that came to here (ankle) only so you didn't notice (the lymphoedema) … (but) going to a wedding or something, (you) couldn't wear high heels.
> *FG 5, Participant 5*

This was also illustrated in the following exchange from Focus Group 2:

> *Participant 3*: And, and I find like for clothes, you know, you go into a shop 'oh that's a nice jacket' and then you try it on.
> *Participant 5*: Won't fit this arm.
> *Participant 4*: Yeah you won't get it on, you won't get it on. Can't get the coat off.
> *Participant 3*: It's awful. It does affect your life you know.
> *Participant 7*: It's very hard.

Limitations Imposed on Daily Activities

The restrictions imposed by lymphoedema on participants' ability to engage in daily activities, hobbies and in some cases employment emerged as an important subtheme. In relation to restrictions on hobbies, this depended on the location of participants' swelling:

> I can't do any fine movements, I can't play golf, knit or sew; they're the pleasurable things, but even the daily, daily work.
>
> *FG 1, Participant 7*

> When you can't have the lifestyle … that you really did have, you miss it so much, the exercise I'd be talking about.
>
> *FG 2, Participant 2*

Difficulties performing household chores or taking care of children were also highlighted:

> Like you're trying to hoover and wash the floor in one go, it's impossible with one arm, like a lot of the time you have to treat it like you have one arm, and that's what I've been told, you know, but like if I hoover the floor and then have to wash it, I can't physically do both in one day… I suppose they're minor (things)… But it's irritating… Again you know, when you've small, a small child at home and (the child) doesn't understand, (the child) is jumping on top of you, you know, 'can you carry this mum?', 'no I cant'… (It's like) I've only one arm.
>
> *FG 1, Participant 1*

> I find it very upsetting at times… I can't lift (my siblings') children, I can't let them lean on this arm, they're important things to know, I mean my arm isn't genuinely that bad but what I'm hearing is that I need to be proactive …not to be upsetting yourself, you have the tears… with my nieces and nephews I can't look after them.
>
> *FG 4, Participant 4*

Participants with lymphoedema in their lower limb reported that their mobility can be affected:

> You can't stand in queues you know, going to the, if you're delayed in the airport or something like that and you feel 'oh my gosh', it starts the tingling and you know you want to sit down and people think 'what are you?', it is, it's just horrid.
>
> *FG 3, Participant 4*

A number of participants reported being required to accept significant lifestyle changes following the onset of lymphoedema. For example, a lessened capacity for work, being required to change job or being unable to return to work:

> I'm using my arm all the time and (name of practitioner) has said that I, I'm making it worse but you have to work….I should wear the sleeve when I'm working but I can't … I'm going to have to devise some sort of glove, waterproof glove or something but I know I'm making it worse but I have to work 'cause I'm, it's only me that's bringing in an income so I have no choice.
>
> *FG 2, Participant 3*

> It’s a massive transformation, I was self employed … and partly because of the lymphoedema … I was unable to continue, I had to completely reassess my life … downsize, get a smaller house, it completely and totally changed my life, but what can you do, I, I had a physical job and I’m no longer capable of doing it.
> *FG 3, Participant 6*

> I haven’t returned to my work yet and ehm, I don’t know when I’ll be able to because it’s (a) physical (job) … I don’t know when I’ll be able to return to that …
> *FG 3, Participant 7*

Emotional Factors

The fourth theme relates to emotional factors. This includes the subtheme that participants’ distress following their cancer diagnosis and treatment resulted in incapacity to process their susceptibility to developing lymphoedema. Other subthemes include lymphoedema as a constant reminder of cancer treatment; being required to adapt to a ‘new body’; distress in response to the reactions of others; and fears for an uncertain future.

Incapacity to Process Susceptibility to Developing Lymphoedema

Participants at risk of developing cancer-related secondary lymphoedema reported that emotions played a role at the very initial stages before they had developed lymphoedema. They described not being able to process the fact that they were at risk of lymphoedema because of their distress following their cancer diagnosis and treatment:

> You finish surgery; you’re facing treatment; the last thing you want to hear is another condition that you might get. I think no matter what they say to you, like I do remember (practitioner) coming round to us with a list, I put it in the drawer and left it there.
> *FG 1, Participant 1*

> I, I was very much in shock and in denial and I didn’t, didn’t, relate it at all to myself and didn’t take it on board…. a lot of information that you should get, you know, or make sure you absorb, you might’ve been given it but to make sure because of the psychological effect of the diagnosis on you…. I think to recognise that people don’t, you’re in denial, I didn’t want to know any more, your psychological effects of (the cancer) diagnosis, you’re very traumatised, you need to have somebody to come back to make sure did you hear it…. I’d normally read things but I was suffering, this hadn’t really hit me yet.
> *FG 1, Participant 4*

Constant Reminder of Cancer Treatment

Participants with cancer-related secondary lymphoedema reported that the difficulty of living with lymphoedema was compounded by the knowledge that lymphoedema would represent a constant reminder of their prior cancer treatment:

> Every time my arm swelled, it was like as if the water was being released through my eyes I would cry, like, you know, it had this effect on me, I think it had more effect on my than the cancer did, the lymphoedema, you know.
> *FG 1, Participant 3*

> It's initially very upsetting, desperately traumatic, because you've had cancer etc. and it's the last thing you need, you have your short sleeved t shirts and your high tops and then you lose that… you lose a breast, you lose everything…you're crumbling, I'm losing every option really…I thought I was fine. I thought I'd gotten away with it. It's very upsetting.
> *FG 4, Participant 4*

Adapting to the 'New Body'

Participants spoke of their self-consciousness as they adapt to their 'new body':

> My whole arm had swelled up and it was really like an elephant's trunk… Yes I hate wearing it (compression garment) I wouldn't wear short sleeves I never wear short sleeves, except if I'm going out maybe the odd time for dinner or a night out I might take it off but everyone says to you 'did you break your arm', … I just say 'yes'. I always say yes…. I never go into details, I just say I had an accident I don't tell anybody, I mean when people seem to say, 'what is that', 'it's something to do with, you know, an operation', very few people know what it is, I mean even, the name you don't realise, 'after effects of operation' I say.
> *FG 1, Participant 5*

> I'm very conscious of my arm, I am really.
> *FG 2, Participant 7*

> (People ask) 'What's wrong with you?'… constantly, constantly. I take that off (end of the compression sleeve covering bottom of hand) and shove it up my sleeve…. I say I've a sprain (or)… I say it's a little present from breast cancer.
> *FG 2, Participant 5*

> You have to get used to this new body…You're trying to live in this new body, it's not you anymore.
> *FG 3, Participant 5*

Distress in Response to the Reactions of Others

Participants' self-consciousness was heightened in response to the reactions of others:

> (In the) first few weeks you're very self conscious, I was very self conscious, no matter what I did because you knew it was there and you can see people looking but I don't notice anymore. But now for me personally the biggest bugbear is there's no quick answer is there… it's hard to tell them they just (yawns) and they say 'oh I get that', no you don't!
> *FG 3, Participant 6*

> When you go to socialise, that's when you really notice people pull their hand back (when you try to shake hands with them), and that was a complex I had when I was growing up, that was when I was a child in school and you know, you're different you're going to be picked on…
> *FG 1, Participant 6*

This lack of awareness about lymphoedema among the wider public can result in patients feeling isolated:

> Isolation, feeling that nobody else knows about it or understands it and it's not a major deal but it's just you've nobody to talk to about it, no-one understands, sufferers or people. I went to the doctor the other day and he said 'what's up with your hand' and I said 'oh lymphoedema', he said 'how come' and I said 'cause of treatment', wow, what a relief I was able to say it, and somebody understood and we could carry on. There is this feeling that no-one really knows.
> *FG 3, Participant 6*

Fears for an Uncertain Future

In some cases participants reported fears that a healthcare professional's lack of knowledge about lymphoedema meant they could inadvertently make the lymphoedema worse:

> I was in (hospital) a couple of weeks ago for a procedure and you know they, they bring you in now for a pre-op, a week before, (so I asked) 'will you put a note somewhere on the file (or) should I write on my arm do not touch' - and I was deadly serious - because the nurse just looked at me as if 'what do you mean, your arm' …I've often wondered about that (having blood or blood pressure taken or an injection into the arm) if I was knocked down (by a car).
> *FG 1, Participant 1*

Concerns regarding the progressive nature of lymphoedema were also highlighted:

> It is depressing because you know it's gonna get worse and worse and when I'm a little old lady and, trying to get these garments on which are really very difficult to get on…I'm

> doing everything by the book I think and yet (my leg is) still getting bigger, what's it going to be like, this, this is eight years now so what's it going to be like in sixteen (years)?
> *FG 3, Participant 4*

> Because people that come abroad to the (lymphoedema) clinic in Germany, international people are usually fairly end stage and it is scary stuff. When you see that stuff… When you see what's there, so it would motivate you to eh, keep yourself from getting that far.
> *FG 2, Participant 6*

For those with primary lymphoedema there was the added concern of the condition being passed on to their children:

> Long term worry with primary (lymphoedema)… I would be worried about hereditary, my children, is it going to come on them at a later stage… you don't know like if it's going to come they're all terrified.
> *FG 3, Participant 2*

Taking an Active Role

The fifth theme arising from the focus groups was participants taking an active role. This related to participants taking responsibility for the self-management of their lymphoedema and participants actively seeking and appealing for lymphoedema treatment.

Taking Responsibility through Self-Management

Participants taking responsibility for their lymphoedema referred to the adoption of measures to prevent an increase in swelling or the development of complications such as cellulitis:

> I keep (a compression garment) in my bag and I keep one in the glove box (of my car, in case) I see (my arm) start to (swell).
> *FG 3, Participant 5*

> I take one tablet for maintenance to keep the infection (cellulitis) out …. When I go anywhere the GP makes sure I have the emergency penicillin 'cause I could be anywhere and if there's nobody in reach… blood poisoning sets in very fast in about what within 5 hours I'm a hospital case, it's so bad. So I carry for emergencies everywhere I go.
> *FG 2, Participant 4*

This subtheme also related to participants conscientiously following their lymphoedema management plan:

> The whole management is boring you don't get any quick eh, solutions or results, but all I can say to you is when you stop the procedures, the problems start building up again and it'll take you twice as long… to get back to where you were before you started getting lazy… it involves very strict discipline… …. it's that boring thing of getting a routine going and sticking to it 'cause we're not robots, we're humans, and you cant do it everyday, everyday, yeah you cant, it'd just be impossible… I am a firm believer in this life, living in Ireland, of being responsible (for your health) as much as you can… for your own treatment.
> *FG 2, Participant 6*

Appealing for Lymphoedema Treatment

Participants also reported that they are required to actively seek and appeal for lymphoedema treatment:

> I think that it's very essential as you all have said that we continue to grab on to whoever we have to give us a bit of treatment.
> *FG 2, Participant 2*

> That's how I'm managing …just (by)… doggedly keeping pushing, pushing, pushing all the time to get myself into as much as I can of services…. How about kind of giving you 75% of a service rather that zero - 100% would be perfect… but how about 75% rather than zero.
> *FG 2, Participant 6*

> I haven't found the services that great for primary (lymphoedema patients), I have to say.… what are they doing like for me, nothing… since I started demanding stuff … they're offering me stuff now, because I informed myself … I went back and demanded it. But I don't find (service provision) the same for primary lymphoedema.
> *FG 3, Participant 2*

Deriving Positives

The final theme from the patient focus groups is participants deriving positives. This includes the subthemes such as living with lymphoedema is preferable to an advancing cancer; patients using their experiences to altruistically caution others about the risks of developing cancer and lymphoedema; and the benefits of meeting other lymphoedema patients.

Lymphoedema is Preferable to the Alternative of an Advancing Cancer

Several participants with cancer-related secondary lymphoedema expressed feeling thankful that they are living with lymphoedema rather than battling an advancing cancer:

> It's better than the alternative - dying from cancer.
> *FG 3, Participant 6*

> You've been through cancer, you've been through chemo, and you've been through the mental anguish, and you're on your feet again (so) I don't dwell on it.
> *FG 4, Participant 5*

> We're all lucky to be over the worst and moving on. If that's all I have I'm not going to be too worried about it.
> *FG 5, Participant 1*

Desire to Warn Others

Other participants reported that while their experiences of cancer and living with lymphoedema have been challenging, these experiences have motivated them to altruistically warn others about the risks of developing lymphoedema or cancer:

> This lady came in (to the hospital)…she hadn't got a sleeve on, but her hand was swollen, … I started to talk to her about it and she had never heard about (lymphoedema) … I gave her the little book about lymphoedema and was telling her about skincare and all the rest, and never, didn't have contact with her around that, but at least I told her, you know and eh, hopefully she did… do something about it… because she didn't know.
> *FG 1, Participant 3*

> I make a point of telling people who ask me (about my arm) because I think that then they know somebody else…who has an arm swelling that it may be, it may filter to, to them, to that person to go and talk to someone about it.
> *FG 1, Participant 7*

> I find if people ask me why am I wearing the sleeve, if they bring it up in conversation, depending on where it was, you know, I might just say I sprained my arm but if it was someone my own age who was at risk of breast cancer I would tell them what it was and why, and they didn't know it existed, because they didn't make the connection, they would always be totally amazed, but I think if it makes them do a breast self examination then it's worth telling them but you do shock them, that's what I find.
> *FG 3, Participant 5*

Benefits of Meeting Others who Speak the Language

Finally participants reported the benefits of meeting other lymphoedema patients in that they are not required to explain their condition and can freely share their experiences. This had a positive influence on participants by lessening their isolation and making them feel accepted and understood:

> (After going to the Lymphoedema Ireland meeting) I realised I wasn't on my own and it made a great difference, it didn't improve it or anything but you felt other people were out there with the same thing. You weren't a freak.
> *FG 1, Participant 3*

> I was at a Lymphoedema Ireland meeting… it was great; I felt I'm now part of a group.
> *FG 1, Participant 7*

Indeed some participants reported that attending the focus group itself was also beneficial as it involved the sharing of information and promoted feelings of belonging:

> It's funny it does show you that it's really worthwhile to have people talking (at the focus group) because if you're filling in a questionnaire (on your own) … and sometimes you just answer them in your own head, (but here) you're thinking and it widens your opinion.
> *FG 4, Participant 2*

> For me, personally meeting you guys (at the focus group)… knowing I'm not the only one… (having lymphoedema) is a bit like being an alien isn't it? (Laughter)… There're other people out there and you're not alone.
> *FG 3, Participant 6*

This was reflected in the fact that several of the participants at each focus group spontaneously exchanged numbers with each other so that they could keep in touch in the future.

Discussion of Focus Group Findings

The specific aims of the patient focus groups were to: explore patients' experiences of initial symptoms, diagnosis and treatment; explore barriers to patients' compliance with their lymphoedema management plans and in accessing treatment (e.g. difficulties with compression garments, cost of treatments etc.); and assess the impact of lymphoedema on patients' daily life and quality of life. Each of these aims has been met and a brief summary of the themes and subthemes is presented below in addition to examples of how these findings compare with previous literature and the results of the service provider surveys.

The first theme emerging from the data was barriers to treatment. This related to participants' perception of an insufficient number of services being provided, existing services being overwhelmed and as a result difficulties in accessing continued treatment. This corresponds with the review of lymphoedema services in Northern Ireland which also found that patients experience difficulties accessing continued treatment (DHSSPS, 2004). Additionally this subtheme is reminiscent of the results of the results of the service provider survey which emphasised the under-resourced and overstretched nature of current lymphoedema service provision in Ireland. Although the majority of the focus group participants had cancer-related lymphoedema, those with primary lymphoedema were vocal about the added difficulties they experienced in accessing treatment. This also corresponds with practitioners' opinions of the inequitable nature of service provision according to lymphoedema aetiology. Another barrier to treatment was the cost of private treatment discouraging those wishing to supplement their treatments from the public service. Delivery delays and discomfort associated with compression garments was another barrier as it impinged on participants' ability to wear the garments in accordance with their lymphoedema management plan. Problems with compression garment supply for rural patients in particular also featured in the results of the BreastCare Victoria (2005) study.

The second theme was tension with healthcare professionals. This resulted from participants not being warned that they were at-risk of developing lymphoedema and as a result they were not prepared for the condition. Similarly in a previous quantitative study conducted in the UK, 61% of respondents with a history of cancer had not been told that they could develop lymphoedema (Lam et al., 2006). Tension also resulted from some healthcare professionals being unable to answer participants' questions. This corresponds with the findings of the patient phases of the BreastCare Victoria (2005) study, Bulley's (2007) patient interviews and themes from previous qualitative studies, such as 'fishing in the dark' for information (Bogan et al., 2007) and 'nowhere to turn' (Williams et al., 2004). Another subtheme was tension resulting from healthcare professionals' dismissive attitude towards lymphoedema. This reiterates Hare's (2000) and William et al.'s (2004) findings that patients considered some healthcare professionals to underestimate the impact of living with the condition.

The third theme was lymphoedema affecting daily life. This theme included participants' difficulties in making space for lymphoedema and the daily management plan and this was also reported by Bogan et al. (2007) and Johansson et al. (2003). Focus group participants spoke of their difficulties in buying clothes and shoes to cover the lymphoedematous part of their bodies and this reiterates Johansson et al.'s (2003) findings. In addition, participants emphasised how lymphoedema limits their ability to engage in daily activities and employment. Similarly Johansson et al. (2003) reported patients' difficulties in asking for help with daily chores and Moffatt et al. (2003) found that lymphoedema affected more than 80% of their respondents' ability to work.

The fourth theme was emotional factors in living with lymphoedema. One subtheme related to this was participants' distress following cancer treatment resulting in incapacity to process their susceptibility to developing lymphoedema. Similarly Bogan et al. (2007) and Williams et al. (2004) found that a lack of knowledge about lymphoedema can be hugely frustrating for patients in the initial stages of the condition. Participants with cancer-related secondary lymphoedema also reported that the condition can act as a constant reminder of their cancer treatment. This has also been reported in previous studies (Carter, 1997 cited in Hare, 2000; Woods 1993). An additional subtheme was participants' self-consciousness as they adapt to their 'new body' and deal with reactions of others. Participants reported feeling isolated by others' lack of awareness much like the participants in Hare's (2000) study. This is also reminiscent of Williams et al.'s (2004) finding of participants rehearsing a reaction to other people's comments before learning to open up. This is reminiscent of the 'self-controlling' coping style identified by Folkman and Lazarus (1988), whereby individuals experiencing stressful circumstances try to keep their emotions to themselves (cited in Lazarus, 1999). Furthermore, participants reported their fears for an uncertain future regarding the risk of an uninformed healthcare professional inadvertently worsening the condition, the progressive nature of the condition or the risk of the condition being heritable. Primary lymphoedema patients concerns regarding the potential heritability of their condition had also been identified in a previous qualitative study (Waters, 2007).

The fifth theme was patients taking an active role in lymphoedema management for example through prophylactic or self-management measures. As mentioned previously, patients' difficulties with the daily management plan was also reported by Bogan et al. (2007) and Johansson et al. (2003). The 'active role' theme is reminiscent of the 'fighting spirit' coping style exhibited by some cancer patients (Greer et al., 1979 cited in Burton & Watson, 1988). The theme is also similar to the 'accepting responsibility' and 'planful problem solving' coping styles (Folkman & Lazarus 1988, cited in Lazarus, 1999). The 'active role' theme also included the subtheme of patients actively appealing for lymphoedema treatment. This subtheme had not been identified in previous studies of lymphoedema patients. However this subtheme is similar to the confrontive coping style identified by Folkman and Lazarus in 1988 (cited in Lazarus, 1999).

The final theme referred to participants deriving positives. Participants with cancer-related lymphoedema reported that they consoled themselves that lymphoedema is preferable to the alternative of an advancing cancer. This finding is reminiscent of Hare's (2000) theme of 'counting blessings'. Moreover it is similar to Johansson and colleagues' (2003) finding of patients consciously considering lymphoedema as a less important aspect of their lives in order to regulate their emotional distress. In turn these themes are related to Watson et al.'s (1994) finding that some cancer patients cope by engaging in cognitive avoidance by blocking off worrying thoughts or feelings rather than denying they have an illness (cited in Burton & Watson, 1998). Furthermore it is suggestive of the positive reappraisal coping style (Folkman & Lazarus, 1988, cited in Lazarus, 1999). Participants in the current study also reported that their experiences have motivated them to actively warn others about the risks of developing cancer and lymphoedema. This had not been reported in previous studies of lymphoedema patients. Finally participants reported that meeting others who understand their experiences and speak the same language as such, promotes feelings of acceptance. These benefits were derived from support group meetings and indeed from the focus group itself. This serendipitous finding of focus groups being beneficial for lymphoedema patients was also reported by Hare (2000). Moreover the 'seeking social support' coping style has previously been identified by Folkman and Lazarus in 1988 (cited in Lazarus, 1999).

These findings provide useful insights into patients' experiences of current lymphoedema service provision in Ireland and of living with the condition. In many cases the themes and subthemes correspond with findings from previous studies and with the service provider survey results. Moreover the findings present subthemes which have not previously been reported such as patients' fears of an uninformed healthcare professional inadvertently worsening their condition or patients' desire to warn others about the risks of developing cancer and lymphoedema. However due consideration must be given to the methodological limitations of this phase of the study and these are presented in the next section.

Methodological Issues

Firstly, while purposive sampling was employed in order to include both male and female participants with varied ages, types of lymphoedema and locations of lymphoedema, none of the focus group participants had non-cancer-related secondary lymphoedema, i.e. lymphoedema following infection, inflammation or venous disease.

Secondly, focus groups capitalise on interactions between participants encouraging the sharing and comparison of experiences. However given the sensitive nature of living with a chronic condition and the focus group setting, the investigators were careful not to explore topics which were too invasive. Therefore topics discussed in previous studies such as the impact of lymphoedema on patients' sexuality were not explored (Passik et al., 1995). Therefore it is possible that individual qualitative interviews would be more appropriate to explore the more personal consequences of living with lymphoedema.

Finally, focus groups or interviews involving patients' families and friends would have added a further dimension to this phase of the study by appreciating the effects of lymphoedema beyond the individual patient. However this was not possible given the time constraints of the study and is recommended in future research.

From Focus Groups to the Patient Survey

The focus groups have provided valuable information on patients' experiences of lymphoedema service provision in Ireland and of living with the condition. As mentioned previously their intention was not to generalise but to explore patients' experiences of lymphoedema. Yet the findings do pose questions as to how frequent these participants' experiences are among a broader sample of lymphoedema patients. As such, an alternative quantitative data collection approach is required to answer this question. Therefore the next phase of the study involved a survey of a wider group of lymphoedema patients to explore these topics further.

Chapter 6: Patient Survey

Introduction

The overall aims of this study were to investigate lymphoedema service provision in Ireland from both service provider and patient perspectives, in addition to exploring patients' experiences of living with lymphoedema in Ireland. The final phase of the research employed patient questionnaires for the following reasons.

Firstly, as mentioned previously the patient survey offered the potential to ascertain how representative various experiences of lymphoedema and lymphoedema service provision are among a broader sample of patients. This facilitated the comparison of Irish lymphoedema patients' experiences with those of lymphoedema patients in other countries.

Secondly a patient survey format was compatible with quantitatively measuring the impact of lymphoedema on patients' quality of life in Ireland for the first time. As mentioned previously in the literature review, most of the studies on the impact of lymphoedema on patients' quality of life focused on comparing the experiences of patients with breast-cancer-related secondary lymphoedema with breast cancer survivors who hadn't developed lymphoedema (e.g. Velanovich et al., 1999; Coster et al., 2001; Beaulac et al., 2002; Mak et al., 2009). Conversely the intention of the current study was to explore the impact of lymphoedema on the quality of life of patients with all types of lymphoedema.

Finally the results of a patient survey would provide additional information to correspond with, expand on or contradict the findings of the service provider survey and patient focus group phases.

Specific Aims of Patient Surveys

The broad aims of the patient survey phase were to explore patients' experiences of living with lymphoedema and of lymphoedema service provision. These general aims can be broken down into more specific objectives, which were to:

- Explore patients' experiences of seeking an explanation for their lymphoedema symptoms, obtaining a diagnosis and accessing information and treatment. This would enable the investigation of whether patients with different types of lymphoedema have quantitatively or significantly different experiences of diagnosis and treatment (e.g. waiting time between first symptoms and diagnosis, waiting time for first treatment, awareness of being at-risk prior to developing lymphoedema, waiting time since last treatment etc.).
- Explore patients' perspective on lymphoedema service provision by investigating patients' experiences of service providers and treatments, and their ratings of the standard of care they are receiving.
- Investigate barriers to patients' compliance with their lymphoedema management plans (e.g. dissatisfaction with compression garments; difficulties with compression garment provision; availability of written or audiovisual material to enable the revision of techniques in lymphoedema exercises, SLD and self-bandaging).
- Explore barriers in accessing treatment (e.g. distance to lymphoedema service, cost of treatments, level of financial support from private health insurers for treatment etc.).
- Assess the impact of lymphoedema on patients' daily life (e.g. limitations on employment, activities and socialising; hospitalisation for the treatment of associated infections) and on the physical health, psychological health, social relationships and environment domains of the WHOQOL-BREF quality of life measure.

Method

Identifying a Sample

Using the information from the service provider phase which mapped current lymphoedema service provision in Ireland, participants were recruited through a total of sixteen hospitals, services and organisations. Participants were recruited through teaching, regional or general public hospitals that currently or have previously provided a dedicated lymphoedema service and therefore have a patient list or waiting list on file. Participants were also recruited through cancer support services that provide lymphoedema treatment and through organisations which provide information and support to lymphoedema patients (e.g. Lymphoedema Ireland). The hospitals, services and organisations were contacted and permission was sought to post questionnaires to their patients. The survey was also advertised in relevant newsletters and websites (e.g. the Lymphoedema Ireland website and newsletter, and the MLD Ireland website) so that people who are not in direct contact with hospitals, services or support organisations but who would like to participate could be sent a copy of the questionnaire for inclusion in the study.

In hospitals and services, the cooperation of the manager of the lymphoedema clinic (or equivalent in the physiotherapy or occupational therapy department) was sought to act as gatekeeper by facilitating the identification of patients who met the inclusion criteria.

The inclusion criteria were patients over eighteen years of age with a diagnosis of lymphoedema that were deemed capable of informed consent by their lymphoedema practitioner. Patients under the age of eighteen were excluded as all participants were required to give their own informed consent. Patients with chronic oedema (i.e. oedema of multiple origins with the fundamental cause not being malformation or impairment of the lymphatic system) were excluded in order to focus the research specifically on the experiences of lymphoedema patients. Palliative patients were also excluded from the study. Given the variety in health status among patients defined as receiving palliative care and the rate at which palliative patients' health status can change it was decided that they should not be sent a questionnaire in order to avoid causing unnecessary distress either to the patients themselves or their relatives.

Questionnaire Design

As a means of avoiding false or irrelevant structures and ensuring the full range of possible responses, questionnaire content and subsequent item selection was developed through four processes: the review of literature, expert opinion (of the research advisory group which is composed of lymphoedema patients, lymphoedema practitioners, consultants in related disciplines of venous disease and oncology, and research psychologists), the findings of the service provider phase of the research and the themes arising from the focus groups that revealed issues requiring further exploration. The majority of previous studies on service provision did not involve patient questionnaires. Rather they asked specific groups of service providers or a small group of patients with a specific type of lymphoedema for their experiences. The BreastCare Victoria (2005) study measured opinions of lymphoedema service provision and impact on daily living and as a result approval was sought and granted for the use and amendment of the questionnaire used by that research team. However the questionnaire employed in the current study included additional items (such as the rating of healthcare professionals on various characteristics such as knowledge, experience and overall satisfaction) and a quality of life measure.

The majority of research on the impact of lymphoedema on patients' quality of life has compared the scores of patients with breast-cancer-related secondary lymphoedema with survivors of breast cancer who hadn't developed lymphoedema. The exception was Moffatt et al.'s (2003) prevalence study. However as mentioned previously they didn't indicate what proportion of their sample had various types of lymphoedema and didn't compare them as a result. Therefore these studies offered less guidance to the current study as the intention was to explore the impact of lymphoedema on the quality of life of all lymphoedema patients and compare across patients with different types of lymphoedema.

The content of the survey includes the following:

- First identification of lymphoedema symptoms, experience of diagnosis, and location and type of lymphoedema.
- Treatment: experience of seeking treatment, factors influencing access to treatment, average cost, personal expense, treatments received, and experiences of treatment.
- Perception of practitioners (e.g. knowledge, competency, experience, attitude etc.).
- Satisfaction with funding and treatment.
- Implications of lymphoedema on daily life and quality of life.
- Recommendations for lymphoedema service development.

In exploring the impact of lymphoedema on patients' quality of life, the World Health Organisation (WHO)'s definition of quality of life was employed. The WHO has defined quality of life as:

> Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment
>
> (WHO, 1997, Page 1).

As a result, the World Health Organisation's abbreviated Quality of Life measure (WHOQOL-BREF) was included at the end of the questionnaire. The WHOQOL-BREF is a 26 item measure that assesses four major domains: physical, psychological, social relationships and environment (WHO, 1996). The physical domain includes items on activities of daily living; dependence on medical treatment; energy and fatigue; mobility; pain and discomfort; sleep and rest; and work capacity. The psychological domain includes items on bodily image and appearance; positive and negative feelings; self-esteem; spirituality; thinking, learning, memory and concentration. The social relationships domain includes items on personal relationships; social support and sexual activity. Finally the environment domain includes items on financial resources; freedom, physical safety and security; accessibility and quality of health and social care; home environment; opportunities for acquiring new information; opportunities for and participation in leisure activities; aspects of the physical environment such as pollution, noise, traffic and climate; and transport (WHO, 1996). The WHOQOL-BREF was designed to facilitate the understanding of medical conditions and therefore is appropriate for use in the current study (WHO, 1996).

While previous studies exploring the impact of lymphoedema on quality of life have not employed the WHOQOL-BREF, these studies have provided guidance as to the domains of quality of life which may be impacted upon by the experience of lymphoedema. For example, as mentioned previously in the literature review, lymphoedema patients' physical wellbeing can be affected by their experience of lymphoedema whether through altered sensation, pain or acute infection (Lam et al., 2006; Muscari, 2004; Moffatt et al., 2003; Passik & McDonald, 1998). Additionally previous studies have shown that the experience of lymphoedema may compromise psychological wellbeing through self consciousness, distress, impaired body image and depression (Lam et al, 2006; McWayne & Heiney, 2005; Passik et al., 1995; Tobin et al., 1993). The social relationships domain may also be of relevance given previous findings on the impact of the condition on the wider family group and on patients' social lives through the mediating variable of self consciousness (Lam et al., 2006; Radina & Armer, 2001). Finally the environment domain may also be of relevance as the physical limitations of lymphoedema may require patients to rely more on public services.

The WHOQOL-BREF domain scores demonstrate good discriminant validity. This was measured by t tests between 'ill' and 'well' participants' scores on the four domains with resulting p values of between 0.001 and 0.01 (The WHOQOL Group, 1998). The measure also demonstrates good internal consistency with alpha levels for the four domains ranging between 0.66 and 0.84. Finally the WHOQOL-BREF's test-retest reliability was measured by correlations of scores on the four domains at two time points ranging between 0.66 and 0.87 (The WHOQOL Group, 1998).

The questionnaire was piloted with six lymphoedema patients. The pilot participants varied in terms of gender, age range, county of residence, type of lymphoedema, duration of lymphoedema symptoms and time since diagnosis. Subsequent to the pilot, amendments were made to ensure the questionnaire was as succinct and clear as possible. The questionnaire was then reviewed and approved by the research advisory group (composed of lymphoedema patients, lymphoedema practitioners, consultants in related disciplines of venous disease and oncology, and research psychologists) prior to its distribution. A copy of the questionnaire employed in the current study is included in Appendix L.

Procedure

In hospitals and services, the cooperation of the manager of the lymphoedema clinic (or equivalent in the physiotherapy or occupational therapy department) was sought to act as a contact person by facilitating the identification of patients who met the inclusion criteria. In keeping with data protection, the research team did not request hospitals or organisations to provide the research team with the names and addresses of lymphoedema patients. This was in order to ensure that the questionnaires remained anonymous and confidentiality wasn't breached. However, assistance was offered to the hospital or organisation when required, with mail-merging patients' names and addresses onto the cover letters and envelopes, in order to minimise any disruption to the hospital or organisation. The electronic database containing the patients' details was saved by the hospital or organisation and was not retained by the researcher.

Potential participants accessed through hospitals were posted a cover letter from their lymphoedema practitioner with an information sheet, questionnaire and a FREEPOST envelope, with which to return the questionnaire. Potential participants accessed through organisations providing support to lymphoedema patients (e.g. Lymphoedema Ireland) were posted the same cover letter but from a named person in the support organisation. As some research ethics committees required specific wordings in the cover letters and/or information sheets distributed to the patients under their remit there were slight variations in the text of these. However a sample cover letter, sample information sheet, and the actual patient questionnaire employed in this study are presented in the Appendix J, K and L respectively.

A thank you/reminder letter was sent to patients approximately two weeks after the initial questionnaire mailing to thank those who had participated and to prompt those who had not participated but wished to do so. The letter reminded recipients that they were not obliged to participate and could contact the research team at any time. These reminder letters were mail-merged at the time of the original cover letters. The letters were retained for approximately two weeks by the contact person in the particular organisation and subsequently posted to patients by the contact person. This was to ensure that the research team did not leave the hospital, service or organisation with the contact details of patients, thereby preserved the confidentiality of patients' details. A sample thank you/reminder letter is presented in Appendix M.

Ethics

Consent

Approval was sought and granted from thirteen hospitals nationwide to invite patients who met the inclusion criteria to participate in the focus groups. Approval was also sought and granted from Dublin City University Research Ethics Committee to enable the research team to invite patients from three services and organisations outside the remit of a hospital ethics committee. This was to ensure that participants who might not be currently receiving treatment from a hospital or service were included in the sample. Participants were not requested to sign a consent form in order to protect their anonymity. Consent was assumed by the completion and return of the questionnaire. Participants were informed that they could decline the opportunity of completing the questionnaire and were not required to pay for the return of the questionnaire to the investigators.

Confidentiality

All participants were assured of confidentiality and anonymity at all times and through all stages of the research. The research team did not record the names and addresses of patients that were sent the questionnaire. The research team had no way of tracking which individuals were sent the questionnaire or which individuals chose to participate. The questionnaires did not request participants to include their name on them and consent was assumed from the completed questionnaire and it was intended that the questionnaires would be anonymous. However fifty-nine participants chose to provide their name and/or contact details at the end of the questionnaire and invited the research team to contact them if further clarification of their responses was required. Therefore the questionnaires are being stored in a locked filing cabinet which only members of the research team have access to. Anonymous data was inputted directly onto the researcher's computer, which is password protected to ensure confidentiality of all electronic records. All identifying information and questionnaires will be shredded and disposed of five years after completion of the study by Dr. Pamela Gallagher, supervisor of this study.

Risk Management

Since the research study employed questionnaires which are a non-invasive data collection procedure it was anticipated that there would be minimal adverse implications for the participants. However there was the potential for raising anxiety given the sensitivity of discussing a chronic condition such as lymphoedema. Asking patients about their experience of first identifying swelling in their body, being diagnosed or seeking treatment could have potentially caused the recollection of unpleasant memories or past negative experiences. This issue was acknowledged and safeguards were set up to deal with such situations and to minimise the risk to participants.

Participants were alerted to the Irish Cancer Society's Action Breast Cancer FREEFONE Helpline on the information sheet, through which all patients could receive information, support and counselling if required, and access to the support services provided by

Lymphoedema Ireland. All participants at all stages of the research had this service available to them. As mentioned previously the questionnaire was piloted by six lymphoedema patients to ensure that issues were also explored in the most sensitive manner possible.

Data Analysis

Questionnaire data was entered into the Statistical Program for the Social Sciences (SPSS) Version 17.0. Each participant did not respond to each item of the questionnaire. Therefore the results presented are based on the number of respondents to the individual question rather than on the overall sample of 735 participants. Descriptive statistics such as frequencies and means were performed to present trends in the data. Due to space limitations some information is presented in the Appendices and where that occurs, reference is made in the main results section.

In terms of inferential statistics, correlations were performed to explore relationships between variables - for example whether there was a relationship between those who had been diagnosed less recently and the time they had to wait for their first treatment. The Chi-square test of independence was performed to explore whether a particular category of participants were more likely to indicate a particular response - for example whether there is an association between patients who knew they were at-risk of developing lymphoedema and the type of lymphoedema they subsequently developed. Independent sample t tests were performed to explore differences by comparing the means of two groups - for example whether gender had an influence on participants' scores on the various domains of the quality of life measure. However in some cases the Levene's test for homogeneity of variance was significant and as a result the non-parametric equivalent, the Mann Whitney U was performed. Standard one-way analyses of variance (ANOVAs) were performed to explore differences by comparing the means of more than two groups – for example whether participants in various age ranges responded differently to quality of life items. Tukey post hoc tests were subsequently performed to identify between which groups any significant differences occur. In comparing the means of patients with different types of lymphoedema –

for example whether participants with different types of lymphoedema responded differently to time between first symptoms and treatment - the Levene's test for homogeneity of variance was significant. As a result the Welch one-way ANOVA and Dunnett's T3 post hoc test were performed as these are more robust when this assumption has been violated (Field, 2005; Pallant, 2007; Roth, 1983). Where effect sizes were available, this information is provided in the text. Responses to open questions were typed into Microsoft Word (2003 Version) and analysed thematically. The findings are presented below in the results section.

Results

Sample Characteristics

A total of 1,529 questionnaires were posted to patients. As questionnaires were sent to patients from a total of sixteen hospitals, services and organisations, some patients may have received multiple copies of this questionnaire. If this arose, patients were advised to complete one questionnaire and return the completed questionnaire and the additional blank questionnaire(s) in each of the FREEPOST envelopes provided. The overall response rate was 55.79%. One hundred and eighteen of the responses involved patients who were unable to complete the questionnaire due to having received more than one copy, ill health or various other reasons. Therefore out of a potential total of 1,411 questionnaires, 735 completed questionnaires were received, resulting in a completed questionnaire response rate of 52.09%. Table 15 on pages 142 and 143, presents a breakdown of the sample in terms of gender, age range, and type and location of lymphoedema and county of residence.

Table 15: Sample Characteristics

Gender ***(n=732)***	
Female	93.2%
Male	6.8%
Age Range ***(n=728)***	
18-35 Years Old	3.0%
36-50 Years Old	22.7%
51-66 Years Old	45.6%
Over 66 Years Old	28.7%
Type of Lymphoedema ***(n=726)***	
Primary Lymphoedema	
Primary Lymphoedema	6.5%
Cancer-Related Secondary Lymphoedema	
Lymphoedema Secondary to Breast Cancer	73.1%
Lymphoedema Secondary to Gynaecological Cancers	3.9%
Lymphoedema Secondary to Melanoma	3.0%
Lymphoedema Secondary to Other Cancer (Unspecified)	0.8%
Lymphoedema Secondary to Lymphoma	0.7%
Lymphoedema Secondary to Bladder Cancer	0.4%
Lymphoedema Secondary to Throat Cancer	0.4%
Lymphoedema Secondary to Sarcoma	0.4%
Lymphoedema Secondary to Bowel Cancer	0.1%
Lymphoedema Secondary to Skin Cancer	0.1%
Lymphoedema Secondary to Leukaemia	0.1%
Secondary to Breast & Gynaecological Cancer	0.1%
Primary and Cancer-Related Secondary Lymphoedema	
Primary Lymphoedema & Lymphoedema Secondary to Breast Cancer	0.6%
Primary Lymphoedema & Lymphoedema Secondary to Lymphoma	0.1%
Non-Cancer-Related Secondary Lymphoedema	
Lymphoedema Secondary to Infection (e.g. Cellulitis, Lymphadenitis, Filariasis etc.)	2.9%
Lymphoedema Secondary to Trauma/Tissue Damage (e.g. Burns, Scarring, Wounds etc.)	1.2%
Lymphoedema Secondary to Gland Removal (unspecified whether due to cancer)	0.6%
Lymphoedema Secondary to Venous Disease (e.g. DVT, Chronic Venous Insufficiency etc.)	0.4%
Lymphoedema Secondary to Infection & Inflammation (e.g. Arthritis, Sarcoidosis etc.)	0.1%
Lymphoedema Secondary to Infection & Injury	0.1%
Lymphoedema Secondary to Infection & Venous Disease	0.1%
Lymphoedema Secondary to Venous Disease, Infection & Immobility	0.1%
Don't Know	
Don't Know Type of Lymphoedema	3.1%

Table 15: Sample Characteristics (continued)

Location of Lymphoedema ***(n=733)***	
Left Upper Limb	43.8%
Right Upper Limb	35.1%
Left Lower Limb	19.5%
Right Lower Limb	19.3%
Chest/Breast	5.0%
Abdomen	2.6%
Head/Neck/Face	1.8%
Groin/Genitals	0.6%
Back/Shoulders	0.4%
Other - Not Specified	0.1%
County ***(n=708)***	
Carlow	1.6%
Cavan	0.7%
Clare	2.3%
Cork	12.7%
Donegal	4.5%
Dublin	36.4%
Galway	2.0%
Kerry	0.7%
Kildare	4.9%
Kilkenny	1.8%
Laois	2.8%
Leitrim	0.4%
Limerick	3.8%
Longford	0.3%
Louth	2.0%
Mayo	1.0%
Meath	4.7%
Monaghan	1.1%
Offaly	2.1%
Roscommon	0.6%
Sligo	0.7%
Tipperary	3.0%
Waterford	3.5%
Westmeath	0.9%
Wexford	3.0%
Wicklow	2.7%

Ninety-three percent of the sample was female and 6.8% was male. The majority of the present sample (74.3%) was aged over 50 years of age which was expected given the greater prevalence of the condition among those who are middle aged and older. Indeed the mean age of participants in the current study was 58.89 years (SD=12.65, Range=18-97 years, *n=728)*.

There were a much higher proportion of patients with breast-cancer-related secondary lymphoedema (73.1%) than patients with cancer-related (but not breast-cancer-related) secondary lymphoedema (9.9%), patients with non-cancer-related secondary lymphoedema (5.5%) and patients with primary lymphoedema (6.5%). A greater proportion of participants indicated that they have lymphoedema in the upper limb(s) than in any other part of their bodies. The majority of the sample lives in Dublin, which reflects the high population density there. However there was a representation of patients from all counties in the Republic of Ireland.

Obtaining a Lymphoedema Diagnosis

On average, participants had experienced lymphoedema symptoms for 78.45 months (SD = 101.94, Range = 2-804, *n=689)*. Participants had received a diagnosis on average 62.08 months ago (SD = 77.00, Range = 0-600, *n=668)*. As a result, it was possible to calculate how long in months patients were waiting from the time they became aware of symptoms to the time when they received a diagnosis of lymphoedema for those symptoms. The findings for all respondents and for patients with various categories of lymphoedema are presented below in Table 16. Please note a number of participants could not be placed in the following categories of type of lymphoedema as they had experienced two forms of lymphoedema or they indicated that they had glands removed but not whether this was part of cancer treatment or treatment for another condition.

Table 16: Average Time Spent Waiting for a Diagnosis

	n	**Mean (Months)**	**SD**	**Range**
All Respondents	*654*	14.36	53.76	0-624
Primary Lymphoedema	*42*	78.17	131.78	0-528
Non-Cancer-Related Secondary Lymphoedema	*40*	20.55	39.18	0-228
Cancer-Related (but not BC-Related) Lymphoedema	*64*	8.17	17.00	0-77
Breast-Cancer-Related Secondary Lymphoedema	*474*	4.84	17.69	0-240

From Table 16 it appears that patients with primary lymphoedema spent much longer waiting for a diagnosis when compared with patients with other types of lymphoedema. Patients with non-cancer-related secondary lymphoedema were waiting longer than patients with cancer-related (but not breast-cancer-related) secondary lymphoedema. Patients with breast-cancer-related secondary lymphoedema received a diagnosis in nearly half the time that patients with cancer-related-(but not breast-cancer-related)-secondary lymphoedema received a diagnosis. The Welch one-way ANOVA was performed and found to be highly significant: F_W (3, 81.441) = 6.855, p=0.001. Post hoc analysis revealed that primary lymphoedema patients waited significantly longer than patients with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.008) and patients with breast-cancer-related secondary lymphoedema (p=0.005).

Forty-two percent of respondents indicated that they knew they were at-risk of developing lymphoedema *(n=716)*. Yet while 51.6% of patients with breast-cancer-related secondary lymphoedema knew they were at-risk *(n=519);* only 23.5% of those with cancer-related (but not breast-cancer-related) lymphoedema *(n=68)*; 6.7% of primary lymphoedema patients *(n=45)* and just 4.8% of those with non-cancer-related secondary lymphoedema *(n= 42)* knew they were at-risk of developing the condition. A Chi-square test for independence indicated there was a highly significant association between patients who knew they were at-risk of developing lymphoedema and the type of lymphoedema they subsequently developed, x^2(3, *n*=674) = 75.658, p=0.001. The test also indicated a medium effect size, Cramer's V=0.335 (Pallant, 2007). Based on the odds ratio patients with breast-cancer-related secondary lymphoedema were 3.47 times more likely than patients with cancer-related (but not breast-cancer-related) secondary lymphoedema, 21.35 times more likely than patients with non-cancer-related secondary lymphoedema, and 14.95 times more likely than primary lymphoedema patients to know they were at-risk of developing lymphoedema (Field, 2005).

Participants were asked to indicate all of the various healthcare professionals they consulted when they were originally seeking an explanation for their lymphoedema symptoms. Out of the 704 respondents 44.9% went to a consultant, 27.6% went to a general practitioner, 23.3% went to a breast care nurse, 20.2% went to a physiotherapist, 19.3% went to a lymphoedema nurse specialist, 9.2% went to a manual lymphatic drainage therapist, 5.1% went to an occupational therapist and 1.8% contacted another healthcare professional (i.e. general nurse, helpline nurse or radiotherapist). This suggests a wide variety of healthcare professionals are required by patients to be informed about lymphoedema and lymphoedema services.

Participants were also asked to rate the healthcare professional(s) they consulted at that time in terms of attitude, knowledge, support, time taken to diagnose, and overall satisfaction on a Likert scale from 1 - 'very dissatisfied' to 5 - 'very satisfied'. The frequencies of various responses are presented in Table 17. Apart from in the case of emotional support and time to diagnose, over 60% of respondents were satisfied or very satisfied with the healthcare professionals they consulted when they were seeking an explanation of their symptoms. However a sizeable minority of approximately 20-30% were 'dissatisfied' or 'very dissatisfied' with the healthcare professionals on all measures.

Table 17: Frequency Data on Participants' Ratings of Satisfaction with the Healthcare Professionals (HCPs) they consulted when they were seeking an explanation of their symptoms

	n	**V Dissatisfied**	**Dissatisfied**	**Neutral**	**Satisfied**	**V Satisfied**
Attitude	*605*	12.6%	10.7%	13.4%	34.2%	29.1%
Knowledge	*596*	11.9%	11.9%	10.2%	33.6%	32.4%
Practical Support	*573*	11.7%	12.9%	12.2%	31.4%	31.8%
Emotional Support	*549*	15.3%	14.8%	20.4%	23.5%	26.0%
Time to Diagnose	*557*	12.6%	14.2%	13.8%	30.2%	29.3%
Overall Satisfaction	*607*	13.8%	11.5%	12.4%	32.8%	29.5%

The mean ratings of each of the healthcare professionals are presented in Table 18 on pages 147 and 148. The lowest rated healthcare professionals were general practitioners and in almost all cases, lymphoedema nurse specialists were rated the highest. Most participants, regardless of which healthcare professional they were rating, rated them highest in terms of knowledge and lowest in terms of emotional support. However even the highest overall rating was still below a rating of 'satisfied'.

Table 18: Average Ratings of Healthcare Professionals Consulted when Seeking Explanation of Symptoms, according to Type of Healthcare Professional

	n	**Mean**	**SD**
Attitude			
Mean Rating of all Healthcare Professionals	*605*	3.57	1.341
General Practitioner	*171*	3.06	1.355
Breast Care Nurse	*146*	3.78	1.262
Consultant	*276*	3.51	1.344
Physiotherapist	*125*	3.59	1.345
Occupational Therapist	*31*	4.06	1.031
Lymphoedema Nurse Specialist	*109*	3.90	1.209
MLD Therapist	*55*	3.47	1.359
Other (Nurse, Helpline Nurse, Radiotherapist)	*13*	3.77	1.536
Knowledge			
Mean Rating of all Healthcare Professionals	*596*	3.63	1.356
General Practitioner	*157*	2.97	1.450
Breast Care Nurse	*143*	3.90	1.165
Consultant	*278*	3.54	1.387
Physiotherapist	*129*	3.64	1.385
Occupational Therapist	*28*	3.93	1.184
Lymphoedema Nurse Specialist	*111*	4.04	1.228
MLD Therapist	*55*	3.20	1.520
Other (Nurse, Helpline Nurse, Radiotherapist)	*13*	3.77	1.536
Practical Support			
Mean Rating of all Healthcare Professionals	*573*	3.59	1.357
General Practitioner	*153*	2.94	1.382
Breast Care Nurse	*140*	3.87	1.240
Consultant	*270*	3.53	1.373
Physiotherapist	*125*	3.53	1.400
Occupational Therapist	*28*	3.89	1.197
Lymphoedema Nurse Specialist	*107*	4.02	1.141
MLD Therapist	*54*	3.37	1.418
Other (Nurse, Helpline Nurse, Radiotherapist)	*13*	3.38	1.660

Table 18: Average Ratings of Healthcare Professionals Consulted when Seeking Explanation of Symptoms, according to Type of Healthcare Professional (continued)

	n	**Mean**	**SD**
Emotional Support			
Mean Rating of all Healthcare Professionals	*549*	3.30	1.396
General Practitioner	*145*	2.74	1.339
Breast Care Nurse	*137*	3.64	1.283
Consultant	*261*	3.19	1.442
Physiotherapist	*122*	3.18	1.342
Occupational Therapist	*28*	3.54	1.374
Lymphoedema Nurse Specialist	*96*	3.80	1.303
MLD Therapist	*51*	3.14	1.312
Other (Nurse, Helpline Nurse, Radiotherapist)	*13*	2.92	1.498
Time Taken to Diagnose			
Mean Rating of all Healthcare Professionals	*557*	3.49	1.370
General Practitioner	*151*	3.00	1.400
Breast Care Nurse	*135*	3.67	1.327
Consultant	*261*	3.39	1.414
Physiotherapist	*120*	3.39	1.416
Occupational Therapist	*27*	3.52	1.282
Lymphoedema Nurse Specialist	*103*	3.89	1.267
MLD Therapist	*51*	3.22	1.433
Other (Nurse, Helpline Nurse, Radiotherapist)	*13*	3.23	1.536
Overall Satisfaction			
Mean Rating of all Healthcare Professionals	*607*	3.53	1.380
General Practitioner	*170*	2.99	1.406
Breast Care Nurse	*140*	3.80	1.259
Consultant	*284*	3.43	1.411
Physiotherapist	*129*	3.40	1.417
Occupational Therapist	*31*	3.77	1.309
Lymphoedema Nurse Specialist	*112*	3.94	1.232
MLD Therapist	*53*	3.21	1.446
Other (Nurse, Helpline Nurse, Radiotherapist)	*13*	3.38	1.446

Participants' satisfaction with the healthcare professional they consulted when they were seeking an explanation for their lymphoedema symptoms were then broken down according to the type of lymphoedema that the respondents experience. These results are presented in Table 19 on page 149.

Table 19: Average Ratings of Healthcare Professionals Consulted when Seeking Explanation of Symptoms, according to Type of Lymphoedema

	n	Mean	SD
Attitude			
All Respondents	*605*	3.57	1.341
Primary Lymphoedema	*43*	2.93	1.421
Non-Cancer-Related Secondary Lymphoedema	*34*	3.09	1.334
Cancer-Related (but not BC-Related) Lymphoedema	*58*	3.45	1.404
Breast-Cancer-Related Secondary Lymphoedema	*435*	3.70	1.292
Knowledge			
All Respondents	*596*	3.63	1.356
Primary Lymphoedema	*42*	2.74	1.449
Non-Cancer-Related Secondary Lymphoedema	*34*	2.94	1.324
Cancer-Related (but not BC-Related) Lymphoedema	*56*	3.29	1.423
Breast-Cancer-Related Secondary Lymphoedema	*432*	3.82	1.279
Practical Support			
All Respondents	*573*	3.59	1.357
Primary Lymphoedema	*41*	2.68	1.404
Non-Cancer-Related Secondary Lymphoedema	*32*	2.97	1.231
Cancer-Related (but not BC-Related) Lymphoedema	*53*	3.34	1.400
Breast-Cancer-Related Secondary Lymphoedema	*415*	3.77	1.298
Emotional Support			
All Respondents	*549*	3.30	1.396
Primary Lymphoedema	*38*	2.42	1.244
Non-Cancer-Related Secondary Lymphoedema	*33*	2.70	1.311
Cancer-Related (but not BC-Related) Lymphoedema	*53*	2.98	1.366
Breast-Cancer-Related Secondary Lymphoedema	*394*	3.52	1.352
Time Taken to Diagnose			
All Respondents	*557*	3.49	1.370
Primary Lymphoedema	*40*	2.73	1.414
Non-Cancer-Related Secondary Lymphoedema	*32*	2.50	1.586
Cancer-Related (but not BC-Related) Lymphoedema	*54*	3.28	1.406
Breast-Cancer-Related Secondary Lymphoedema	*401*	3.69	1.271
Overall Satisfaction			
All Respondents	*607*	3.53	1.380
Primary Lymphoedema	*42*	2.69	1.352
Non-Cancer-Related Secondary Lymphoedema	*35*	2.91	1.358
Cancer-Related (but not BC-Related) Lymphoedema	*60*	3.28	1.403
Breast-Cancer-Related Secondary Lymphoedema	*436*	3.73	1.318

Participants with breast-cancer-related secondary lymphoedema were more satisfied with the healthcare professionals they consulted than participants with other types of lymphoedema. Participants with primary lymphoedema rated the healthcare professionals lowest on measures of attitude, knowledge, practical and emotional support and overall satisfaction, whereas patients with non-cancer-related secondary lymphoedema rated the healthcare professionals lowest in terms of time taken to diagnose them.

It was intended to perform one-way ANOVAs to explore whether the difference in participants' ratings were significantly different according to the type of lymphoedema they experience. The data did not violate the homogeneity of variance assumption of ANOVAs in the case of ratings of the professional's attitude, practical support, emotional support and overall satisfaction. Therefore standard one-way ANOVAs were performed and are presented in Table 20 in addition to the associated effect sizes, calculated using eta squared. Given the discrepancy in the sample size in the groups the Welch one-way ANOVAs for these items are also presented. In the case of knowledge and time taken to diagnose the Levene's test indicated that the homogeneity of variance assumption had been violated. Therefore Welch one-way ANOVAs were performed and these are also presented below in Table 20. The results were highly significant in all cases indicating that participants' ratings of these items were associated with the type of lymphoedema that they're experiencing.

Table 20: Inferential Statistics on Difference in Average Ratings of Healthcare Professionals of Healthcare Professionals Consulted when Seeking Explanation of Symptoms, according to Type of Lymphoedema

	Standard ANOVA	**Effect Size**	**Welch One-Way ANOVA**
Attitude	F (3,566) = 6.543 *	0.03 Small-Medium	F_W (3, 80.131) = 5.907 *
Knowledge			F_W (3, 78.422) = 12.386 *
Practical Support	F (3,537) = 12.186*	0.06 Medium	F_W (3, 75.662) = 11.440 *
Emotional Support	F (3,514) = 11.999 *	0.06 Medium	F_W (3, 76.211) = 12.773 *
Time Taken to Diagnose			F_W (3, 73.705) = 11.196 *
Overall Satisfaction	F (3,569) = 12.055*	0.06 Medium	F_W (3, 81.783) = 11.537 *

*Significance at 0.001 level

A series of post hoc analyses were conducted in order to explore between which types of patients these significant differences occurred. Where the assumption of homogeneity of variance was not violated (i.e. in the case of professional's attitude, practical support, emotional support and overall satisfaction) Tukey post-hoc tests were performed and where the assumption was violated (i.e. in the case of knowledge and time taken to diagnose) Dunnett's T3 post-hoc tests were performed.

The analyses revealed that primary lymphoedema patients (p=0.001 and p=0.001 respectively) and patients with non-cancer-related secondary lymphoedema (p=0.04 and p=0.003 respectively) rated healthcare professionals significantly lower in terms of their attitude and overall satisfaction than patients with breast-cancer-related secondary lymphoedema. Primary lymphoedema patients (p=0.001) and patients with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.005) rated healthcare professionals significantly lower in terms of their practical support than patients with breast-cancer-related secondary lymphoedema. Primary lymphoedema patients (p=0.001), patients with non-cancer related secondary lymphoedema (p=0.004) and patients with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.033) rated healthcare professionals significantly lower in terms of their emotional support than patients with breast-cancer-related secondary lymphoedema. Primary lymphoedema patients (all had a significance level of p=0.001) and patients with non-cancer-related secondary lymphoedema (p=0.004 and p=0.001 respectively) rated healthcare professionals significantly lower in terms of their knowledge and time taken to diagnose than patients with breast-cancer-related secondary lymphoedema.

Participants were asked to indicate which practitioner suggested that their symptoms might be indicative of lymphoedema. Although participants were asked to indicate only one practitioner, 80 participants ticked more than one box. The results are presented in Table 21 on page 152.

Table 21: Healthcare Professionals who Diagnosed Participants

Diagnosing Healthcare Professionals ***(n=714)***	
Consultant	50.3%
Breast Care Nurse	15.0%
Lymphoedema Nurse Specialist	14.3%
Physiotherapist	13.6%
General Practitioner	10.4%
Occupational Therapist	3.6%
Self-Diagnosed	2.4%
Oncology Nurse	1.0%
Friend/Relative	0.8%
Radiotherapist	0.6%
MLD Therapist	0.4%
Radiologist	0.3%
Other (e.g. Compression Garment Fitter or Unspecified)	0.3%

Just over half of respondents were diagnosed by a consultant whereas a relatively low proportion of the sample was diagnosed by other healthcare professionals. This may reflect the relatively high proportion of the sample with breast-cancer-related secondary lymphoedema as these patients are more likely to be seeing a consultant. Once again a wide array of healthcare professionals is being consulted regarding this condition requiring many groups of healthcare professionals to be aware of lymphoedema, its treatment and the location of services.

Information

Participants were asked whether they had received information about lymphoedema from various sources following their diagnosis and if so, what types of information they had received. Participants were also asked how satisfied they were with this information. The results of these questions are presented in Table 22 on page 153.

Table 22: Sources, Types and Satisfaction with Information Received Following Diagnosis

Sources of Information *(n=690)*	
Lymphoedema Practitioner (i.e. Physiotherapist, OT, MLD Therapist etc.)	60.3%
MLD Ireland Website	13.5%
Other Lymphoedema Patients	13.0%
Lymphoedema Ireland Website	12.2%
General Practitioner	11.2%
Lymphoedema Ireland Support Group Meetings	9.6%
Lymphoedema Ireland Newsletters	9.6%
Irish Cancer Society Helpline	6.2%
Other Websites (e.g. UK, German, Australian, US websites)	5.7%
Other (e.g. Booklet, Encyclopaedia, Books etc.)	4.3%
Types of Information *(n=713)*	
Education on Skincare	69.0%
Education on When to Seek Further Medical Attention	39.3%
Education on Diet	22.4%

Satisfied with Information Received *(n=700)*				
Very Dissatisfied 9.4%	Dissatisfied 12.3%	Midpoint 18.0%	Satisfied 37.4%	Very Satisfied 22.9%

The main source of information for patients following their diagnosis was their lymphoedema practitioner, while very small proportions of the sample had received information from MLD Ireland, Lymphoedema Ireland, the Irish Cancer Society, their general practitioner, other websites and other sources. In terms of the content of the information received, over two-thirds of the sample had received education on skincare, almost 40% had received education on when to seek further medical attention but only about one-fifth of the sample had received education on diet and how this can affect lymphoedema symptoms. Regarding satisfaction with information received, the majority of respondents were satisfied or very satisfied, however sizeable minority of 21.7% were dissatisfied or very dissatisfied with the information they received and the mean satisfaction rating was 3.52 which is close to the midpoint (SD=1.23, *n=700)*.

Participants were asked an open question on how the information lymphoedema patients receive could be improved and 357 participants responded. One of them main themes was that patients should be told in advance of medical treatment, specifically cancer treatment, that it may predispose them to developing lymphoedema. In addition some participants noted that the repetition of this information is important as patients' distress following cancer diagnosis and treatment can result in them not being able to process that information initially:

> *Participant 105 (with breast-cancer-related secondary lymphoedema):* To tell us before cancer treatment that it can happen and not only in the arm.
>
> *Participant 339 (with breast-cancer-related secondary lymphoedema):* More information throughout the cancer journey/procedures. It is such an emotionally stressful time that it may take time to absorb the information.

The second theme related to the presentation and content of the information in that it shouldn't solely focus on the physical consequences of lymphoedema, for example:

> *Participant 55 (with breast-cancer-related secondary lymphoedema):* Information pack including Lymphoedema Ireland DVD could be given to patients at time of diagnosis.
>
> *Participant 580 (with breast-cancer-related secondary lymphoedema):* On diagnosis a simple booklet should be available, written in plain English, covering topics on (1) the diagnosis (2) what to expect ongoing (3) how you can help yourself through diet, skincare, exercise etc.
>
> *Participant 731 (with non-cancer-related secondary lymphoedema):* By being put in touch with other sufferers, given more all round information.

The final theme related to the importance of informing healthcare professionals about lymphoedema to enable them to impart accurate information on the condition, for example:

> *Participant 443 (doesn't know type of lymphoedema):* Probably informing GPs about lymphoedema so they could treat patients at local level and be more aware of the complaint.

Lymphoedema Services

Eighty-nine percent of respondents indicated that they have received lymphoedema treatment *(n=720).* However of the 76 participants who reported that they haven't received lymphoedema treatment and who responded to items relating to types of treatment, 89.7% have had a compression garment prescribed for them *(n=58)*, 77.6% use compression garments *(n=58)*, 65.5% have been taught lymphoedema exercises *(n=55),* 43.6% have been taught simple lymphatic drainage (SLD) *(n=55)*, 12.5% have received manual lymphatic drainage *(n=56)*, and 5.4% have received multi-layer lymphoedema bandaging *(n=56)*. Therefore it is possible that this item was not accurately answered or that participants who have received compression garments, or have been taught exercises or SLD do not consider themselves to have received lymphoedema treatment as such. Many of the following results in this section are based on the 644 participants who indicated that they have received treatment unless otherwise specified.

Sixty-five percent of respondents who indicated that they have received treatment received it in a public service, 15.2% in a private service and 20% attended a mix of public and private services *(n=626)*. Participants were asked what setting their main lymphoedema service is in. Although participants were asked to tick one box, 28 participants ticked more than one. Seventy-eight percent reported that their lymphoedema service is in a hospital, 13.8% indicated that it is in a cancer support centre, 10.8% private practice, 2.3% community health centre and 0.2% indicated that it is in a lymphoedema clinic abroad *(n=632)*.

One potential barrier to accessing treatment is distance. Participants reported that on average they had to travel 27.88 kilometres in a one way trip to their lymphoedema service (SD=34.27, Range=1-250km, *n=550)*. Nineteen percent of respondents reported that travel distance did limit their ability to avail of lymphoedema treatment *(n=610)*.

Participants were asked what type of practitioner provides the treatment in their main lymphoedema service. Forty respondents ticked more than one box. Thirty-seven percent indicated that a physiotherapist is their main lymphoedema practitioner, 30.6% ticked lymphoedema nurse specialist, 23.6% MLD therapist, 12.7% occupational therapist, 0.5% general practitioner, 0.3% garment distributors, 0.2% consultant, 0.2% breast care nurse, 0.2% an amatsu massage therapist, 0.2% chemist, 0.2% tissue viability nurse, 0.2% nurse in health centre, 0.2% and other – not specified *(n=614)*. Again this indicates that a number of healthcare professionals can be involved in the care and treatment of lymphoedema patients.

Participants who had received treatment were asked to rate the practitioner in their main lymphoedema service on a Likert scale from 1 to 10 in various categories and the frequencies are presented in Table 23. Over 78% of respondents rated the practitioner in their main lymphoedema service as 7 or higher on all measures.

Table 23: Frequency Responses in Ratings of Practitioners in Main Lymphoedema Service

	n	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Knowledgeable	*598*	1.8%	0.7%	1.0%	1.8%	2.7%	1.8%	5.9%	11.5%	11.7%	61.0%
Competent	*589*	0.8%	0.7%	1.2%	1.4%	2.0%	1.9%	4.4%	10.9%	13.6%	63.2%
Experienced	*591*	1.5%	1.2%	1.2%	1.4%	2.4%	2.0%	5.2%	9.5%	13.9%	61.8%
Confident	*592*	0.7%	1.0%	1.0%	1.4%	2.2%	1.7%	5.1%	9.5%	13.2%	64.4%
Attitude	*586*	1.2%	1.0%	0.9%	0.7%	2.7%	2.0%	3.4%	8.9%	11.6%	67.6%
Practical Support	*586*	2.7%	1.2%	1.4%	1.4%	2.7%	3.1%	6.5%	12.1%	12.8%	56.1%
Emotional Support	*564*	5.3%	2.5%	1.6%	1.4%	5.9%	5.3%	7.1%	9.9%	9.6%	51.4%
Time Available	*586*	2.4%	1.7%	2.0%	2.2%	6.8%	3.2%	5.3%	9.2%	12.5%	54.6%
Overall Satisfaction	*598*	2.8%	1.1%	1.3%	0.7%	4.4%	3.1%	3.8%	11.7%	12.5%	58.6%

The means and the breakdown according to those who indicated one of the three main professions associated with the treatment of lymphoedema - physiotherapist, occupational therapist or MLD therapist, are presented in Table 24 on pages 157 and 158. Overall, practitioners were rated highest in terms of their attitude, confidence and competence; and lowest in terms of emotional support, time taken to diagnose and practical support.

Table 24: Patients' Mean Ratings of their Main Lymphoedema Practitioners

	n	Mean	SD
Knowledgeable			
All Respondents	*581*	8.89	1.929
Physiotherapist	*196*	8.85	1.914
Occupational Therapist	*69*	8.74	1.899
MLD Therapist	*115*	9.19	1.420
Competent			
All Respondents	*571*	9.07	1.696
Physiotherapist	*194*	8.96	1.675
Occupational Therapist	*65*	9.18	1.424
MLD Therapist	*115*	9.24	1.455
Experienced			
All Respondents	*575*	8.95	1.909
Physiotherapist	*194*	8.86	1.992
Occupational Therapist	*65*	8.83	1.701
MLD Therapist	*115*	9.23	1.512
Confident			
All Respondents	*574*	9.09	1.702
Physiotherapist	*193*	8.99	1.718
Occupational Therapist	*66*	8.98	1.767
MLD Therapist	*115*	9.33	1.275
Attitude			
All Respondents	*569*	9.14	1.722
Physiotherapist	*193*	9.09	1.731
Occupational Therapist	*62*	9.23	1.453
MLD Therapist	*115*	9.26	1.499
Practical Support Provided			
All Respondents	*568*	8.69	2.135
Physiotherapist	*189*	8.72	2.008
Occupational Therapist	*65*	8.32	2.251
MLD Therapist	*111*	8.94	1.744
Emotional Support Provided			
All Respondents	*548*	8.14	2.637
Physiotherapist	*185*	7.93	2.760
Occupational Therapist	*57*	7.56	3.082
MLD Therapist	*110*	8.37	2.334

Table 24: Patients' Mean Ratings of their Main Lymphoedema Practitioners (continued)

	n	Mean	SD
Time Available to Deal with You			
All Respondents	*568*	8.46	2.328
Physiotherapist	*192*	8.35	2.477
Occupational Therapist	*65*	8.35	2.146
MLD Therapist	*110*	8.51	2.204
Overall Satisfaction			
All Respondents	*591*	8.74	2.146
Physiotherapist	*200*	8.67	2.082
Occupational Therapist	*69*	8.65	1.939
MLD Therapist	*117*	8.93	1.874

A series of one-way ANOVAs were performed to ascertain whether there was a difference in participants' ratings according to which type of healthcare professional is their main lymphoedema practitioner however none of these were significant.

All participants were asked to rate the standard of care they are receiving on a Likert scale from 1 – 'very low' to 5 – 'very high'. The frequency of various responses is presented in Table 25. While 74.3% of respondents with breast-cancer-related secondary lymphoedema rated the standard of care they're receiving as high or very high, 47.8% of respondents with primary lymphoedema rated likewise.

Table 25: Frequencies of Participants' Ratings of the Standard of Care They are Receiving

	n	V Low	Low	Midway	High	V High
All Respondents	*645*	7.4%	5.1%	18.3%	36.4%	32.7%
Participants Who Have Received Lymphoedema Treatment	*586*	5.8%	4.3%	17.6%	37.7%	34.6%
Participants Who Haven't Received Lymphoedema Treatment	*52*	23.1%	9.6%	26.9%	26.9%	13.5%
Primary Lymphoedema	*44*	25.0%	2.3%	25.0%	27.3%	20.5%
Non-Cancer-Related Secondary Lymphoedema	*34*	11.8%	8.8%	26.5%	26.5%	26.5%
Cancer-Related (not-BC-Related) Secondary Lymphoedema	*56*	10.7%	5.4%	17.9%	32.1%	33.9%
Breast-Cancer-Related Secondary Lymphoedema	*475*	4.8%	3.4%	17.5%	38.9%	35.4%

The mean ratings are presented in Table 26 on page 159.

Table 26: Patients' Ratings of the Standard of Care they are receiving

	n	**Mean**	**SD**
All Respondents	*645*	3.82	1.163
Participants Who Have Received Lymphoedema Treatment	*586*	3.91	1.100
Participants Who Haven't Received Lymphoedema Treatment	*52*	2.98	1.365
Patients with Primary Lymphoedema	*44*	3.16	1.462
Patients with Non-Cancer-Related Secondary Lymphoedema	*34*	3.47	1.308
Patients with Cancer-Related (not-BC-Related) Secondary Lymphoedema	*56*	3.73	1.286
Patients with Breast-Cancer-Related Secondary Lymphoedema	*475*	3.97	1.049

Consistent with previous findings, patients with breast-cancer-related secondary lymphoedema gave the highest rating of the standard of care they are receiving whereas patients with primary lymphoedema gave the lowest rating of the standard of care they are receiving when compared with patients with other forms of lymphoedema. However the highest mean rating is still below the score of 4, which represents a high standard of care.

The Welch one-way ANOVA was performed to ascertain whether there was a significant difference in ratings of standard of care according to type of lymphoedema. This was found to be highly significant: F_W (3, 75.630) = 5.838, p=0.001. Post hoc analysis revealed that participants with primary lymphoedema rated their standard of care significantly lower than participants with breast-cancer-related secondary lymphoedema (p=0.005).

Lymphoedema Treatments

Participants were asked how soon after their lymphoedema diagnosis they received treatment and how many months since they last received lymphoedema treatment. The results are presented below in Table 27 on page 160.

Table 27: Time between Diagnosis and First Treatment and Time since Last Treatment

	n	Mean	SD	Range
Time between Diagnosis and First Treatment (in Weeks)				
All Respondents	*536*	42.80	142.62	0-1560
Participants Who Have Received Lymphoedema Treatment	*514*	41.63	143.15	0-1560
Patients with Primary Lymphoedema	*35*	199.83	388.72	0-1560
Patients with Non-Cancer-Related Secondary Lymphoedema	*25*	94.40	163.24	0-676
Patients with Cancer-Related (not-BC-Related) Secondary Lymphoedema	*51*	34.39	64.12	0-364
Patients with Breast-Cancer-Related Secondary Lymphoedema	*396*	24.62	86.40	0-1040
Time since Last Treatment (in Months)				
All Respondents	*579*	10.17	33.51	0-540
Participants Who Have Received Lymphoedema Treatment	*554*	9.13	25.54	0-360
Patients with Primary Lymphoedema	*43*	34.05	99.09	0-540
Patients with Non-Cancer-Related Secondary Lymphoedema	*29*	10.21	17.30	0-72
Patients with Cancer-Related (not-BC-Related) Secondary Lymphoedema	*52*	7.40	11.22	0-68
Patients with Breast-Cancer-Related Secondary Lymphoedema	*424*	7.68	19.09	0-229

Overall respondents were waiting 42 weeks, approximately 10 months, for treatment following their lymphoedema diagnosis. However if we consider how long participants with various types of lymphoedema were waiting, participants with primary lymphoedema were waiting on average nearly 4 years for treatment while participants with breast-cancer-related secondary lymphoedema were waiting on average nearly 25 weeks– still a considerable length of time at approximately 6 months. The Welch one-way ANOVA was performed to ascertain if there was a significant difference in waiting time according to type of lymphoedema. This was highly significant: F_W (3, 60.198) = 3.943, p=0.012. Post hoc analysis revealed that primary lymphoedema patients were waiting longer than patients with breast-cancer-related secondary lymphoedema and this result approached significance (p=0.067). However it is worth noting the very large ranges and standard deviations associated with these means, which suggests that there is huge variation in time spent waiting even among patients with the same category of lymphoedema.

A Pearson product-moment correlation coefficient was performed to ascertain if the relationship between time since diagnosis and time between diagnosis and first treatment was significant. There was a strong positive correlation between the two variables, r=0.558, *n=499*, p=0.01 and time since diagnosis helped to explain 34.57% of the variance in time between diagnosis and first treatment. This indicates that participants who have been diagnosed more recently are seen quicker. This may suggest a greater availability of services and practitioners which enables quicker treatment. Alternatively participants who have been diagnosed more recently may have more accurate recall of the time taken to receive treatment following their diagnosis.

On average respondents received their last treatment 10.17 months ago. Patients with primary lymphoedema had their last treatment on average 34.05 months ago whereas patients with cancer-related (but not breast-cancer-related) secondary lymphoedema had their last treatment 7.4 months ago. Again the ranges and standard deviations are quite large particularly for patients with primary lymphoedema which suggests that there is huge variation in the time since treatment has been received even among patients with the same type of lymphoedema. The Welch one-way ANOVA was performed to ascertain if there was a significant difference in time since last treatment according to type of lymphoedema. The result was not significant: F_W (3, 74.889) = 1.198, p=0.317.

Compression Garments

Ninety-five percent of respondents reported that they had been prescribed a compression garment *(n=705).* Eighty-eight percent of respondents reported that they currently use garments *(n=694)*. Participants who currently use garments reported that they are using on average 2.47 garments (SD=1.46, Range=0-12, *n=573)*. The broad range may reflect the fact that several participants have lymphoedema in several limbs or that some participants experience greater fluctuation in their swelling and therefore require a greater number of garments.

Forty-five percent of respondents who currently use garments are using off-the-shelf garments, 31.1% are using custom-made or made-to-measure garments, 18.6% are using both types of garments and 5.1% didn’t know what type of garments they are using *(n=591)*. Participants who currently use garments reported that they have to wait on average 22.82

days for garments to be delivered (SD=51.41, Range=0-730, *n=439)*. When type of garment is taken into consideration, participants who currently use off-the-shelf garments have to wait on average 15.62 days (SD=37.58, Range=0-365, *n=181)* whereas those using custom-made garments have to wait on average 25.87 days (SD=29.05, Range=0-210, *n=156)*. Given the huge ranges and standard deviations, this again suggests that different patients have very different experiences of garment provision which could interfere with their ability to follow their lymphoedema management plan.

One potential barrier to using compression garments, particularly for ageing patients with arthritis can be the application of the garments. Eighteen percent of participants who currently use garments reported that they need another person to help them put on and take off their garments *(n=593),* while 15.5% use an assistive device for this purpose *(n=595)*.

When asked how often they wear their garments, 63.8% of participants who currently use garments wear them daily but not at night, 22.5% wear them some of the time, when doing chores etc., 6.8% wear them rarely, 4.3% wear them all the time 24 hours a day, 0.7% wear them only when swelling is bad or when travelling or on a flight, and 0.2% wear them for each of the following: for 6 hours during the day, for 1-2 hours daily, when walking, every other day, or never *(n=605)*.

Participants who currently use garments were asked if they wear their garment during various activities. The results for those who currently use garments and for when the activity was deemed relevant are presented in Table 28 on page 163. There appears to be relatively high use of compression garments during chores or flights but relatively low use of compression garments while socialising, child minding and during employment, sports or hobbies among respondents.

Table 28: Use of Compression Garments during Various Activities

	n	**% who wear a Garment**
Walking	*506*	72.1%
Swimming	*349*	14.0%
Other Sports Activities	*337*	49.6%
Social Activities (e.g. Visiting Friends)	*530*	61.5%
Daily Household Indoor Chores (e.g. Cleaning, Hoovering)	*548*	82.5%
Daily Household Outdoor Chores (e.g. Shopping, Gardening)	*535*	81.9%
Taking Care of Children	*333*	51.7%
Personal Care (e.g. Taking a Shower, Combing Hair etc.)	*508*	14.0%
Taking a Flight	*501*	84.2%
When on Holidays	*497*	70.6%
Employment/Occupation	*353*	56.7%
Other (e.g. While Driving, Playing Musical Instruments, Doing Craftwork, When Standing for Long Periods or When Sleeping)	*170*	18.8%

Participants who currently use garments were also asked if they wear their compression garment as often as they have been advised to and 75.1% indicated that they do *(n=571)*. The 142 participants, who don't wear the compression garment as often as they have been advised to, were asked for the reasons why, in order to explore the barriers to compliance with recommendations that compression garments should be worn. Fifty-four percent reported that they find the compression garment uncomfortable, 33.6% consider the garment unsightly, 22.9% find the garment difficult to put on or take off, 38.6% reported that they don't need to wear the garment all the time to maintain the swelling at a comfortable level and 25.7% gave another reason - the compression garment is too tight, too hot or a poor fit; causes pain or additional swelling; isn't practical for activities or chores; the garment is reminder that they have been ill or had cancer and invites questions from others; and because they have forgotten to wear it *(n=140)*.

Participants who currently use garments were asked to rate their satisfaction with various aspects of their compression garments on a Likert scale from 1 – 'very dissatisfied' to 5 – 'very satisfied'. The frequency of the various responses is presented in Table 29 on page 164. Although the majority of respondents scored the garments as neutral or better, a sizeable minority of approximately or greater than 20% in almost all cases were dissatisfied or very dissatisfied, particularly with compression garments' appearance and temperature.

Table 29: Frequency of Participants who are currently using Garments' Responses in Ratings of Compression Garments

	n	V Dissatisfied	Dissatisfied	Neutral	Satisfied	V Satisfied
Colour	*567*	7.4%	13.6%	22.0%	44.4%	12.5%
Appearance	*551*	12.3%	18.5%	27.4%	33.8%	8.0%
Comfort	*557*	7.0%	16.0%	18.1%	48.8%	10.1%
Fit	*548*	4.0%	10.9%	12.6%	59.3%	13.1%
Texture	*535*	6.5%	13.3%	21.7%	48.4%	10.1%
Temperature	*528*	6.8%	20.5%	22.3%	43.6%	6.8%
Quality	*526*	3.6%	7.4%	21.5%	54.4%	13.1%
Value for Money	*455*	6.6%	10.8%	25.5%	41.8%	15.4%
Overall	*534*	4.7%	8.8%	20.0%	52.1%	14.4%

The mean results are presented in Table 30. Participants rated the compression garments lowest in terms of appearance when worn, temperature and comfort, and rated them highest in terms of fit, quality and overall satisfaction. However all of the scores clustered around 3, the midpoint score.

Table 30: Mean Ratings of Compression Garments

	n	Mean	SD
Colour	*567*	3.41	1.100
Appearance when Worn	*551*	3.07	1.155
Comfort	*557*	3.39	1.087
Fit	*548*	3.67	0.973
Texture	*535*	3.42	1.052
Temperature	*528*	3.23	1.065
Quality	*526*	3.66	0.924
Value for Money	*455*	3.49	1.082
Overall Satisfaction	*534*	3.63	0.990

The international consensus of lymphoedema practitioners is that an individual with one lymphoedematous limb should receive a minimum of two garments every three to six months or even more frequently if the patient is active (MEP, 2006). This permits the washing of one garment while another is worn and ensures that the level of compression provided by the garment is optimal. Thirty-four percent of respondents who currently use compression garments receive two garments per year from their main lymphoedema service, 25.9% receive two every six months, 14.6% don't receive any, 14.3% receive one per year, 3.4% only ever received two garments, 3.2% only ever received one garment, 2.6% receive garments as needed, 0.8% receive 2 every 4 months, 0.6% receive 2-3 every 3 months, 0.4% receive 3 per year, 0.2% receive 3 over 6 years, 0.2% receive 4 every 6 months, and 0.2% originally received 2 every 6 months but has received none since *(n=533)*. A relatively high proportion of respondents (70.1%) do not receive the minimum amount of compression garments from their main lymphoedema service.

Sixty-one percent of those who currently use garments have a medical card *(n=599)*, and of those approximately one-fifth (18%) considered that HSE approval procedures for the expenses of medical card holders slowed down the delivery of their compression garments *(n=311)*.

Participants who currently use garments were asked how much they spend of their own money per calendar year on compression garments. Fifty-eight percent of the 366 respondents to that question don't pay anything towards their compression garments. Those who do pay reported that they spend on average €165.94 of their own money per calendar year on compression garments (Range=2-1000, SD=164.01, *n=154*). Given the large range and standard deviation, it appears that there is a huge variation in the financial burden on patients. For example the participant who reported spending €1,000 per year explained that due to weight loss and difficulties in getting an appropriate fit for her swelling meant that she regularly needs new compression garments. Furthermore, only 5 participants who currently use garments have private health insurance that contributes towards the cost of compression garments and on average these respondents receive €188 from their insurer (SD=141.67, Range=50-410, *n=5)*.

Participants were asked how often they replace their garments. Fifteen percent of respondents replace their garments less than once a year, 20.7% replace them once a year, 50.8% replace twice a year, 6.5% three times a year, 5.1% four times a year, and 1.8% more than four times a year *(n=508)*. Seventeen percent indicated that the cost of garments affected whether they replaced them, 33.3% reported that cost didn't affect whether they replaced their garments and 49.5% reported that it wasn't applicable as they don't pay for garments *(n=550)*. However as mentioned previously those relying purely on garments from their main lymphoedema service may not be receiving a sufficient number of garments to the appropriately manage their condition.

Nine percent of respondents who currently use garments reported having difficulties getting re-measured *(n=524).* The reasons for this included practitioners being too busy to measure patients; lymphoedema services being discontinued, patients not knowing where to go to be re-measured and finally that due to cutbacks in hospital services there is no funding for the appropriate custom-made compression garment.

Finally participants who currently use garments were asked to rate their satisfaction with the process of receiving garments on a Likert scale from 1 – 'very dissatisfied' to 5 – 'very satisfied'. The mean ratings are presented below in Table 31.

Table 31: Ratings of Satisfaction with the Process of Receiving Compression Garments

	n	**Mean**	**SD**
Participants who currently use Compression Garments	*575*	3.62	1.189
Patients with Primary Lymphoedema	*41*	3.17	1.395
Patients with Non-Cancer-Related Secondary Lymphoedema	*28*	3.25	1.323
Patients with Cancer-Related (not-BC-Related) Secondary Lymphoedema	*53*	3.09	1.148
Patients with Breast-Cancer-Related Secondary Lymphoedema	*417*	3.74	1.136

The mean rating of the total group of those who currently use compression garments was 3.62, which is above the midpoint level. It is interesting to note the disparity between the ratings of patients with breast-cancer-related secondary lymphoedema when compared with patients with other types of lymphoedema. Patients with cancer-related (but not breast-cancer-related) secondary lymphoedema rated their satisfaction with the process of getting compression garments the lowest. Again the homogeneity of variance assumption was violated so a Welch one-way ANOVA was performed and found to be highly significant: F_W (3, 72.254) = 6.916, p=0.001. Post hoc analysis revealed that participants with cancer-related (but not breast-cancer-related) secondary lymphoedema rated their satisfaction significantly lower than participants with breast-cancer-related secondary lymphoedema (p=0.002).

Lymphoedema Exercises and Simple Lymphatic Drainage

Eighty-one percent of respondents reported that they had been taught how to perform specific lymphoedema exercises *(n=695)*, whereas 52.8% of respondents reported that they had been taught how to perform specific simple lymphatic drainage (SLD) or self-massage *(n=684)*. The 563 participants who had been taught exercises and the 361 participants who had been taught SLD were asked to tick one box to indicate how they were taught these exercises or SLD. However 46 of respondents who were taught exercises and 22 participants who were taught SLD ticked more than one box. Participants were also asked in an open question how often they perform the specific lymphoedema exercises and SLD. The results of these questions are presented in Table 32 on page 168.

The majority of respondents were taught lymphoedema exercises or SLD in a once-off individual consultation whereas a very small proportion had been taught in repeated consultations or provided with a book, leaflet or DVD to enable them to revise their technique. The majority of respondents indicated that they perform exercises or SLD on a daily basis.

Table 32: Lymphoedema Exercises and Simple Lymphatic Drainage

	Lymphoedema Exercises	**Simple Lymphatic Drainage**
Method that Exercises/SLD were taught to Participants	*(n= 519)*	*(n=326)*
Once-Off Individual Consultation with Practitioner	52.0%	60.4%
Repeated Individual Consultations with Practitioner	30.1%	29.8%
Written Format	17.9%	9.5%
DVD	7.7%	4.9%
Group Consultation	2.1%	2.5%
How often Exercises/SLD are performed by Participants	*(n= 511)*	*(n=335)*
Daily	51.5%	40.3%
'Very Often'	0.2%	0.3%
'As Often as Possible'	1.0%	0.6%
Twice a Week	1.6%	2.7%
3-4 Times a Week	10.0%	-
Once a Week	3.9%	6.6%
Once Every Two Weeks	-	0.3%
Occasionally	4.9%	5.1%
Once a Month	-	0.9%
When the Swelling is Bad	6.8%	7.5%
Twice a Year	0.4%	0.4%
Not Performed Often	13.7%	16.1%
Before Leaving the Hospital Only	0.2%	-
Never	5.9%	10.4%

Manual Lymphatic Drainage and Multi-Layer Lymphoedema Bandaging

Fifty-six percent of respondents reported that they had received manual lymphatic drainage (MLD) a specialised form of massage of the treatment of lymphoedema (*n=670)*. 35.4% of respondents reported that they had received multi-layer lymphoedema bandaging (MLLB) (*n=667)*. The number of times respondents have received MLD and MLLB are presented in Table 33 on page 169.

There appears to be considerable variation in lymphoedema patients' access to MLD and MLLB. The most common responses were that participants receive MLD every 2-3 months and have received MLLB only 1-3 times.

Table 33: Manual Lymphatic Drainage and Multi-Layer Lymphoedema Bandaging

How Often Participants have Received These Treatments	**MLD** *(n=361)*	**MLLB** *(n=208)*
Not Received Regularly or Intensively		
1-3 Times	13.0%	31.3%
4-9 Times	4.6%	2.9%
10-19 Times	0.6%	0.5%
Received Regularly		
Once a Year	5.6%	9.6%
Once Every 6 Months	9.6%	8.7%
Once Every 4 Months	0.3%	-
Once Every 2-3 Months	23.1%	5.3%
Once Every 6 Weeks	1.2%	0.5%
Once a Month	16.1%	6.8%
2-3 Times a Month	7.6%	3.8%
Once a Week	4.3%	2.4%
Intensive Treatment Once or Twice		
Intensive Treatment of 3-5 Times for One Week Once	0.6%	0.5%
Intensive Treatment of 3-5 Times for More than One Week Once	6.0%	5.4%
Intensive Treatment of 3-5 Times for More than One Week Twice	-	0.5%
Intensive Treatment Once a Year or Less Frequently		
Twice a Week for 6 Weeks Every Other Year	0.3%	0.5%
Intensive Treatment of 3-5 Times for One Week, Once a Year	2.9%	5.8%
Intensive Treatment of 3-5 Times for More than One Week, Once a Year	3.2%	3.9%
Intensive Treatment Every Four/Six Months		
Intensive Treatment of 3-5 Times for One Week, Every Four Months	0.3%	-
Intensive Treatment of 3-5 Times for One Week, Every Six Months	1.7%	3.4%
Intensive Treatment of 3-5 Times for More than One Week, Every Four Months	-	0.5%
Intensive Treatment of 3-5 Times for More than One Week, Every Six Months	0.8%	1.4%
Other Intensive Treatment		
5 Times Per Week for 2 Months, 4 Times Per Week for 3 Months etc.	0.3%	-
Once a Week for One Month or 6 Weeks Twice a Year	0.9%	-
Other		
Twice a Week in November, January and February Abroad	0.3%	-
As Needed – When Swelling is Bad	0.9%	2.4%
When MLD doesn't work sufficiently after an infection	-	0.5%
Privately - As Required; In Hospital Only in Extreme Circumstances	-	0.5%
As Often as I can afford it	0.3%	0.5%

Participants who have received MLLB reported that on average they spent €39.80 of their own money on bandages to enable them to receive MLLB from their lymphoedema practitioner (SD=116.96, Range=0-1000, *n=125)*. Only 1.5% of these participants reported that they had received assistance from their private health insurer to assist them in paying for these bandages *(n=199)*. None of these participants indicated how much money they have received from their private health insurer.

Sixty-four participants or 29.1% of respondents who have received MLLB reported that they had been taught how to self-bandage *(n=220)* and of those, 48.3% had been taught in a once-off individual consultation with their lymphoedema practitioner, 44.8% had been taught in repeated individual consultations, and 6.9% were taught in a group consultation *(n=58)*. None of the respondents reported being provided with a book, leaflet or DVD to enable them to revise their technique.

Cost of Treatments

Ten percent of respondents reported that they pay a fee to see the practitioner in their main lymphoedema service *(n=634)*. The mean amounts paid by participants for initial and review consultations, sessions of intensive treatments of MLD or MLLB, or home visits varied between €60 and €75. Eighty-six percent of respondents who pay a fee to see their lymphoedema practitioner reported having private health insurance *(n=62)* and of those 25.5% indicated that their health insurer pays money towards their consultation fees *(n=51)*. However financial support from private health insurers were subject to certain stipulations, e.g. the lymphoedema treatment being classified as 'physiotherapy', and a limit to how much could be claimed.

Participants were then asked an open question on the cost of lymphoedema treatments in general. A total of 307 participants responded. While the majority of respondents indicated that they don't pay for treatment, the first theme related to the difficulties these patients would encounter if they were required to pay for their treatment:

> *Participant 105 (with breast-cancer-related secondary lymphoedema):* During the first 1.5 years when I was waiting to be treated in the hospital I saw private physios to do MLD. I spent approximately €2,000 on treatment – it nearly bankrupted us.
>
> *Participant 133 (with breast-cancer-related secondary lymphoedema):* Luckily I have my treatment at the hospital. The one time I went to an MLD private person it cost €60. If there wasn't any other person to go to I would not be able to afford private treatment.
>
> *Participant 178 (with breast-cancer-related secondary lymphoedema):* I am lucky to receive treatment in the hospital … I could not pay for this privately – it should be available to all in need.
>
> *Participant 585 (with breast-cancer-related secondary lymphoedema):* For someone on average 3 day/week employment with other health problems as well, it could become costly, once the medical card is no longer available!

The second theme related to respondents who do pay for their treatment viewing the treatment as essential to their wellbeing:

> *Participant 260 (with breast-cancer-related secondary lymphoedema):* Expensive but well worth the money in terms of service provided…
>
> *Participant 522 (with cancer-related but not breast-cancer-related secondary lymphoedema):* Recognise the value in what I receive but wonder about which could be covered/contribution from insurance.
>
> *Participant 524 (with breast-cancer-related secondary lymphoedema):* They are expensive but these therapists paid for their own training and had to get it abroad, so for the relief of discomfort and body distortion I would pay anything to look NORMAL in my clothes.

The final theme related to the views of the sizeable minority of respondents who reported experiencing great difficulty in paying for the treatment of this chronic condition:

> *Participant 15 (with breast-cancer-related secondary lymphoedema):* Very expensive, couldn't afford it so didn't go anymore.
>
> *Participant 87 (with breast-cancer-related secondary lymphoedema):* As a life-time condition, one will never be finished with treatment so costs are ongoing.
>
> *Participant 195 (with cancer-related but not breast-cancer-related secondary lymphoedema):* I have had to borrow to pay €300 per week for intensive treatment and €285 for made to measure stockings and €100+ for bandages. I'm disgusted and won't be able to do this on an ongoing basis.

> *Participant 310 (with primary lymphoedema):* Costs other than treatment significant – have to have trousers (custom) made etc.
>
> *Participant 511 (with breast-cancer-related secondary lymphoedema):* It is prohibitive. I have to think really hard before going for treatment and go less often and receive fewer garments than I would like to/need.

Treatment Abroad

Twenty-two participants or 3.3% of respondents reported having gone abroad for lymphoedema treatment *(n=662)*. Forty-two percent of those who had gone abroad for treatment had done so once, 10.5% had gone abroad for treatment twice, 21.1% went three times, 10.5% went four times, 10.5% went five times and 5.3% went 6 times *(n=19)*. On average participants had gone abroad for treatment 2.53 times *(n=19)*. Sixty-three percent reported having received financial assistance for their trip from the HSE, whereas the remaining 36.8% reported receiving no assistance *(n=19)*. Fourteen participants wrote comments about the financial assistance they had received for accessing lymphoedema treatment abroad or the difficulties they had experienced in accessing treatment abroad:

> *Participant 618 (with breast-cancer-related secondary lymphoedema):* The HSE funded me completely. I only paid my flight and for my compression garment and daily rate for accommodation.
>
> *Participant 54 (with primary lymphoedema):* Had to chase HSE/put a very strong case forward/numerous letters and follow up required as well as medical letter of referral.
>
> *Participant 418 (with primary lymphoedema):* (Funding) was very difficult to obtain and did not cover the full cost.
>
> *Participant 217 (with cancer-related but not breast-cancer-related secondary lymphoedema):* Very expensive, airport runs, phone calls home and very lonely abroad!

While other participants who hadn't accessed treatment abroad commented that accessing treatment abroad is not a suitable solution for patients:

> *Participant 463 (with non-cancer-related secondary lymphoedema):* Very hard to get, first you have to get a lot of forms fill in by doctors and the HSE could take weeks (to approve it). But going abroad is not the answer; we could (provide treatment) a lot better here in (this) country (rather) than going abroad (for treatment).

General Comments on Lymphoedema Treatments

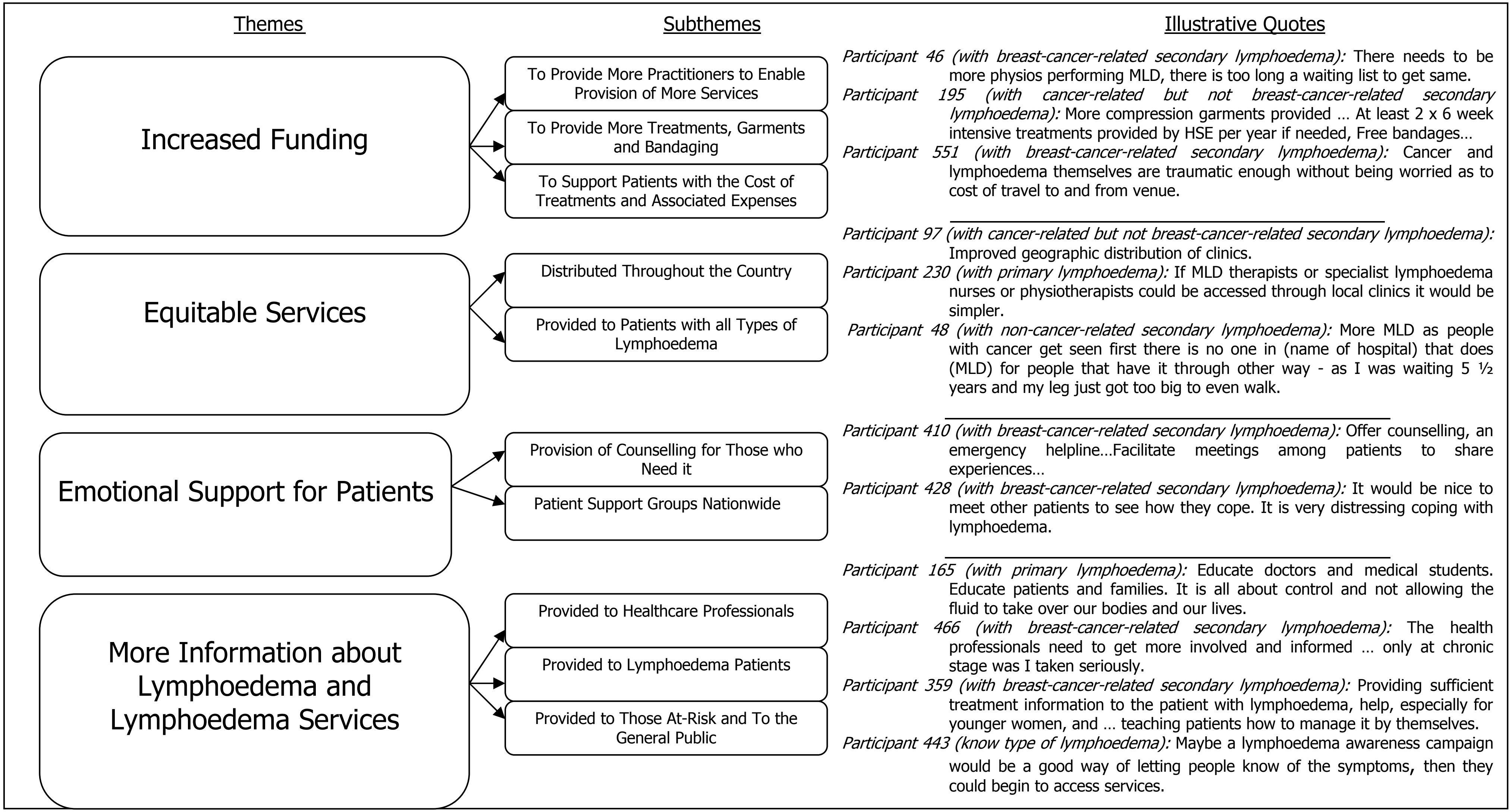
Participants were asked whether they receive sufficient treatment to manage their lymphoedema effectively. The results are presented below in Table 34.

Table 34: Participants who Indicated that They Receive Sufficient Treatment to Manage Their Lymphoedema Effectively

	n	**%**
All Respondents	*598*	61.2%
Participants Who Pay a Fee to See their Lymphoedema Practitioner	*60*	40.0%
Patients with Primary Lymphoedema	*46*	47.8%
Patients with Non-Cancer-Related Secondary Lymphoedema	*33*	48.5%
Patients with Cancer-Related (not-BC-Related) Secondary Lymphoedema	*54*	48.1%
Patients with Breast-Cancer-Related Secondary Lymphoedema	*426*	67.1%

Sixty-seven percent of patients with breast-cancer-related secondary lymphoedema considered themselves as receiving sufficient treatment whereas 47.8% of primary lymphoedema patients considered themselves as receiving sufficient treatment. A Chi-square test for independence was performed and indicated a significant association between type of lymphoedema and whether participants considered themselves to be receiving sufficient treatment: $x^2(3, n=559) = 15.660$, p=0.001, Cramer's V=0.167 indicating a small-medium effect size (Pallant, 2007). This represents the fact that based on the odds ratio patients with breast-cancer-related secondary lymphoedema were 2.20 times more likely than patients with cancer-related (but not breast-cancer-related) secondary lymphoedema, 2.17 times more likely than patients with non-cancer-related secondary lymphoedema, and 2.11 times more likely than primary lymphoedema patients to indicate that they receive sufficient treatment (Field, 2005).

Participants were asked an open question on how lymphoedema services could be improved and 439 participants responded. The themes, subthemes and illustrative responses are presented in Figure 6 on page 174. The themes related to the need for more practitioners and services, equitably distributed and provided services, emotional support and increased awareness of lymphoedema and lymphoedema services among various groups.



Participant 46 (with breast-cancer-related secondary lymphoedema): There needs to be more physios performing MLD, there is too long a waiting list to get same.

Participant 195 (with cancer-related but not breast-cancer-related secondary lymphoedema): More compression garments provided … At least 2 x 6 week intensive treatments provided by HSE per year if needed, Free bandages…

Participant 551 (with breast-cancer-related secondary lymphoedema): Cancer and lymphoedema themselves are traumatic enough without being worried as to cost of travel to and from venue.

Participant 97 (with cancer-related but not breast-cancer-related secondary lymphoedema): Improved geographic distribution of clinics.

Participant 230 (with primary lymphoedema): If MLD therapists or specialist lymphoedema nurses or physiotherapists could be accessed through local clinics it would be simpler.

Participant 48 (with non-cancer-related secondary lymphoedema): More MLD as people with cancer get seen first there is no one in (name of hospital) that does (MLD) for people that have it through other way - as I was waiting 5 ½ years and my leg just got too big to even walk.

Participant 410 (with breast-cancer-related secondary lymphoedema): Offer counselling, an emergency helpline…Facilitate meetings among patients to share experiences…

Participant 428 (with breast-cancer-related secondary lymphoedema): It would be nice to meet other patients to see how they cope. It is very distressing coping with lymphoedema.

Participant 165 (with primary lymphoedema): Educate doctors and medical students. Educate patients and families. It is all about control and not allowing the fluid to take over our bodies and our lives.

Participant 466 (with breast-cancer-related secondary lymphoedema): The health professionals need to get more involved and informed … only at chronic stage was I taken seriously.

Participant 359 (with breast-cancer-related secondary lymphoedema): Providing sufficient treatment information to the patient with lymphoedema, help, especially for younger women, and … teaching patients how to manage it by themselves.

Participant 443 (know type of lymphoedema): Maybe a lymphoedema awareness campaign would be a good way of letting people know of the symptoms, then they could begin to access services.

Figure 6: Themes, Subthemes and Quotes from Patients in Response to the Open Question on How Lymphoedema Services could be improved

Impact of Lymphoedema on Daily Life and Quality of Life

Impact of Lymphoedema on Daily Life

Participants were asked how much lymphoedema affected various aspects of their daily lives. The results of those who responded to the question and considered the activity relevant to their lives are presented in Table 35.

Table 35: Impact of Lymphoedema on Daily Life

	n	**Limited a Lot**	**Limited a Little**	**Not Limited at All**
Walking	*509*	16.5%	28.9%	54.6%
Swimming	*349*	18.9%	29.5%	51.6%
Other Sports Activities	*324*	35.8%	39.5%	24.7%
Daily Indoor Chores (Cleaning)	*641*	28.9%	48.8%	22.3%
Daily Outdoor Chores (Gardening)	*614*	35.0%	45.9%	19.1%
Taking Care of Children	*317*	24.0%	37.5%	38.5%
Buying Clothes/Shoes	*562*	38.6%	32.7%	28.6%
Wearing Clothes/Shoes	*590*	38.0%	39.8%	22.2%
Social Activities (Visiting Friends)	*506*	11.3%	19.0%	69.8%
Work/Employment	*389*	32.4%	30.8%	36.8%
Sexual Activity	*368*	12.8%	24.2%	63.0%
Sleeping	*574*	16.6%	44.3%	39.2%
Going on Holidays	*543*	25.4%	42.7%	31.9%
Other (Driving, Repetitive Tasks)	*65*	36.9%	15.4%	47.7%

The limitations that lymphoedema imposes on patients' lives were more keenly felt with regard to their ability to perform indoor and outdoor chores, wear clothes/shoes, and go on holidays. Table 36 on pages 176 and 177 presents the results of Chi-square tests for independence which were performed to ascertain if there is a difference in the limitations lymphoedema presents for participants with different types of lymphoedema, in different age ranges, or of different genders.

Table 36: Impact of Type of Lymphoedema, Age or Gender on the Limitations Lymphoedema Presents

	Chi Square Test of Independence	Effect Size	
Walking			
Type of Lymphoedema	x^2(6, *n=473)* = 129.219 *	Cramer's V=0.370	Large Effect
Age Group	x^2(6, *n=506)* = 6.093	Cramer's V=0.078	
Gender	x^2(2, *n=508)* = 8.378 ^	Cramer's V =0.128	Small-Medium Effect
Swimming			
Type of Lymphoedema	x^2(6, *n=332)* = 16.367 ^	Cramer's V=0.157	Medium-Large Effect
Age Group	x^2(6, *n=345)* = 24.257 *	Cramer's V=0.187	Small-Medium Effect
Gender	x^2(2, *n=348)* = 6.533 ^	Cramer's V=0.137	Small-Medium Effect
Other Sports Activities			
Type of Lymphoedema	x^2(6, *n=309)* = 25.264 *	Cramer's V=0.202	Medium-Large Effect
Age Group	x^2(6, *n=321)* = 20.189 ~	Cramer's V=0.177	Small-Medium Effect
Gender	x^2(2, *n=323)* = 3.503	Cramer's V=0.104	
Daily Indoor Chores (Cleaning)			
Type of Lymphoedema	x^2(6, *n=609)* = 28.192 *	Cramer's V=0.152	Small-Medium Effect
Age Group	x^2(6, *n=636)* = 20.503 ~	Cramer's V=0.127	Small-Medium Effect
Gender	x^2(2, *n=639)* = 13.214 ~	Cramer's V=0.144	Small-Medium Effect
Daily Outdoor Chores (Gardening)			
Type of Lymphoedema	x^2(6, *n=585)* = 29.579 *	Cramer's V=0.159	Small-Medium Effect
Age Group	x^2(6, *n=609)* = 18.195 ~	Cramer's V=0.122	Small-Medium Effect
Gender	x^2(2, *n=613)* = 10.046 ^	Cramer's V=0.128	Small-Medium Effect
Taking Care of Children			
Type of Lymphoedema	x^2(6, *n=301)* = 14.229 ^	Cramer's V=0.154	Small-Medium Effect
Age Group	x^2(6, *n=314)* = 7.125	Cramer's V=0.107	
Gender	x^2(2, *n=315)* = 8.384 ^	Cramer's V=0.163	Small-Medium Effect
Buying Clothes/Shoes			
Type of Lymphoedema	x^2(6, *n=526)* = 59.198 *	Cramer's V=0.237	Medium-Large Effect
Age Group	x^2(6, *n=557)* = 4.228	Cramer's V=0.062	
Gender	x^2(2, *n=561)* = 0.582	Cramer's V=0.032	
Wearing Clothes/Shoes			
Type of Lymphoedema	x^2(6, *n=552)* = 53.136 *	Cramer's V=0.219	Medium-Large Effect
Age Group	x^2(6, *n=584)* = 3.476	Cramer's V=0.055	
Gender	x^2(2, *n=589)* = 3.884 ^	Cramer's V=0.081	Small-Medium Effect

* p=0.001 ~ p<0.009 ^ p<0.05 ! Violated Minimum Expected Cell Frequency Assumption

Table 36: Impact of Type of Lymphoedema, Age or Gender on the Limitations Lymphoedema Presents (Continued)

	Chi Square Test of Independence	**Effect Size**	
Social Activities (Visiting Friends)			
Type of Lymphoedema	$x^2(6, n=480) = 36.293$ *	Cramer's V=0.194	Medium-Large Effect
Age Group	$x^2(6, n=502) = 14.517$ ^	Cramer's V=0.120	Small-Medium Effect
Gender	$x^2(2, n=505) = 3.279$	Cramer's V=0.081	
Work/Employment			
Type of Lymphoedema	$x^2(6, n=369) = 6.447$	Cramer's V=0.093	
Age Group	$x^2(6, n=385) = 24.320$ *	Cramer's V=0.178	Small-Medium Effect
Gender	$x^2(2, n=387) = 2.095$	Cramer's V=0.074	
Sexual Activity			
Type of Lymphoedema	$x^2(6, n=349) = 36.182$ *	Cramer's V=0.228	Medium-Large Effect
Age Group	$x^2(6, n=365) = 12.781$ ^	Cramer's V=0.132	Small-Medium Effect
Gender	$x^2(2, n=367) = 8.968$ ^	Cramer's V=0.156	Small-Medium Effect
Sleeping			
Type of Lymphoedema	$x^2(6, n=542) = 17.865$ ^	Cramer's V=0.128	Small-Medium Effect
Age Group	$x^2(6, n=570) = 12.927$ ^	Cramer's V=0.106	Small-Medium Effect
Gender	$x^2(2, n=572) = 8.935$ ^	Cramer's V=0.125	Small-Medium Effect
Going on Holidays			
Type of Lymphoedema	$x^2(6, n=515) = 42.173$ *	Cramer's V=0.202	Medium-Large Effect
Age Group	$x^2(6, n=539) = 19.371$ ^	Cramer's V=0.134	Small-Medium Effect
Gender	$x^2(2, n=542) = 0.017$	Cramer's V=0.006	
Other (Driving, Repetitive Tasks)			
Type of Lymphoedema	$x^2(6, n=61) = 6.030$!	Cramer's V=0.222	
Age Group	$x^2(6, n=65) = 2.641$!	Cramer's V=0.143	
Gender	$x^2(2, n=64) = 0.164$!	Cramer's V=0.051	

* $p=0.001$ ~ $p<0.009$ ^ $p<0.05$! Violated Minimum Expected Cell Frequency Assumption

In relation to the 'other' category in all cases over 50% of cells had an expected count of less then 5, violating a basic assumption of Chi-Square. As a result these analyses were not reliable (Pallant, 2007).

The results for type of lymphoedema were significant in all cases apart from work/employment. Participants with non-cancer-related secondary lymphoedema experienced greater limitation than participants with other types of lymphoedema in walking, swimming, performing other sports, performing outdoor chores, taking care of children, buying clothes/shoes, wearing clothes/shoes, socialising, sexual activity, sleeping, and going on holidays. For example based on the odds ratio, participants with non-cancer-related secondary lymphoedema were 3.33 times more likely to experience limitations in walking than participants with primary lymphoedema, 6.57 times more likely to experience limitations in walking than participants with cancer-related (but not breast-cancer-related) secondary lymphoedema, and 32.55 times more likely to experience limitations in walking than participants with breast-cancer-related secondary lymphoedema.

Participants with breast-cancer-related secondary lymphoedema experienced greater limitation than participants with other types of lymphoedema in performing indoor chores. For example based on the odds ratio, participants with breast-cancer-related secondary lymphoedema were 2.79 times more likely to experience limitations in performing indoor chores than participants with primary lymphoedema, 1.13 times more likely to experience limitations in performing indoor chores than participants with non-cancer-related secondary lymphoedema, and 3.49 times more likely to experience limitations in performing indoor chores than participants with cancer-related (but not breast-cancer-related) secondary lymphoedema.

The results for age range were significant in all cases apart from walking, taking care of children, buying clothes/shoes, and wearing clothes/shoes. Participants in the 18-35 age range experienced greater limitation than participants in other age ranges in terms of going on holidays. For example based on the odds ratio participants in the 18-35 age range were 1.29 times more likely to be limited in going on holidays than participants in the 36-50 age range, 1.62 times more likely to be limited in going on holidays than participants in the 51-66 age range and 1.87 times more likely to be limited in going on holidays than participants in the 67+ age range.

Participants in the 36-50 age range experienced greater limitation than participants in other age ranges in terms of performing other sports, and working. For example based on the odds ratio participants in the 36-50 age range were 2.31 times more likely to be limited in performing other sports than participants in the 18-35 age range, 1.06 times more likely to be limited in performing other sports than participants in the 51-66 age range and 3.42 times more likely to be limited in performing other sports than participants in the 67+ age range.

Participants in the 51-66 age range experienced greater limitation than participants in other age ranges in terms of swimming and performing outdoor chores. For example based on the odds ratio participants in the 51-66 age range were 3.95 times more likely to be limited in swimming than participants in the 18-35 age range, 1.15 times more likely to be limited in swimming than participants in the 36-50 age range and 1.88 times more likely to be limited in swimming than participants in the 67+ age range.

Finally, participants in the 67+ age range experienced greater limitation than participants in other age ranges in terms of performing indoor chores, socialising, sexual activity, and sleeping. For example based on the odds ratio participants in the 67 + age range were 4.06 times more likely to be limited in performing indoor chores than participants in the 18-35 age range, 1.37 times more likely to be limited in performing indoor chores than participants in the 36-50 age range and 1.05 times more likely to be limited in performing indoor chores than participants in the 51-66 age range.

The results in relation to gender were significant in all cases apart from other sports activities, buying clothes/shoes, social activities, work/employment and holidays. Male participants experienced greater limitation than female participants in terms of walking, swimming, and sexual activity whereas female participants experienced greater limitations than male participants in terms of performing indoor and outdoor chores, taking care of children, wearing clothes/shoes, and sleeping. For example based on the odds ratio male participants were 3.10 times more likely to be limited in walking than female participants, whereas female participants were 2.83 times more likely to be limited in indoor chores than male participants.

Therefore in summary, the degree of limitation participants experienced in swimming, indoor chores, outdoor chores, sexual activity and sleeping was influenced by the type of lymphoedema they experienced, their age and their gender. The degree of limitation participants experienced in other sports, social activities and going on holidays was influenced by the type of lymphoedema they experienced and their age but not their gender. The degree of limitation participants experienced in walking, taking care of children and wearing clothes or shoes was influenced by the type of lymphoedema they experienced and their gender but not their age. Finally, the degree of limitation participants experienced in buying clothes and shoes was influenced by the type of lymphoedema they experienced and but not their age or gender while the degree of limitation participants experienced in their ability to work was influenced by their age rather than the type of lymphoedema they experienced or their gender.

In terms of other factors associated with lymphoedema which may affect patients' daily lives, participants were asked whether they had ever had cellulitis, an infection in the layers of the skin, commonly associated with lymphoedema. Twenty-nine percent of all respondents reported that they had experienced a bout of cellulitis *(n=682)*. However eleven participants wrote in the margins that they didn't know what cellulitis is. As cellulitis can require hospitalisation for its treatment, the 200 participants who reported that they had experienced a bout of cellulitis were asked how often they had been hospitalised for its treatment. Thirty-nine percent of respondents had never been hospitalised for the treatment of their cellulitis, 30.5% had been hospitalised once, 7.9% had been hospitalised twice, 10.7% had been hospitalised three times and the remaining 12.2% had been hospitalised 4 or more times *(n=177).* On average respondents had been hospitalised for the treatment of their cellulitis 1.69 times. (SD=2.88, Range=0-20, *n=177)*. However the large range suggests that this associated condition of lymphoedema can have a significant impact on some patients' lives.

Impact of Lymphoedema on Quality of Life

Participants were then asked to fill in the World Health Organisation's shorter Quality of Life measure (WHOQOL-BREF). The percentage responses for each item of the WHOQOL-BREF are presented in Appendix N. Interestingly one item asked participants "whether physical pain prevents you from doing what you want to do" and 42.5% reported that it did prevent them doing what they want to do either to a moderate extent, very much or an extreme degree.

The first two items of the WHOQOL-BREF asked participants to rate their quality of life and their satisfaction with their health on a Likert scale from 1 – 'very poor/dissatisfied' to 5 – 'very good/satisfied'. The frequencies of responses to these items are presented in Table 37.

Table 37: Frequency of Responses to Items on Quality of Life and Satisfaction with Health

	n	**V Poor**	**Poor**	**Neither**	**Good**	**V Good**
Quality of Life						
All Respondents	*718*	1.4%	8.1%	17.4%	49.9%	23.3%
Primary Lymphoedema	*47*	2.1%	19.1%	21.3%	44.7%	12.8%
Non-Cancer-Related Secondary Lymphoedema	*42*	7.1%	19.0%	26.2%	33.3%	14.3%
Cancer-Related (not-BC-Related) Secondary Lymphoedema	*66*	-	18.2%	13.6%	42.4%	25.8%
Breast-Cancer-Related Secondary Lymphoedema	*518*	0.6%	4.8%	15.1%	53.3%	26.3%
Satisfaction with Health						
All Respondents	*715*	3.4%	15.0%	18.9%	48.7%	14.1%
Primary Lymphoedema	*47*	6.4%	27.7%	19.1%	38.3%	8.5%
Non-Cancer-Related Secondary Lymphoedema	*42*	7.1%	28.6%	31.0%	21.4%	11.9%
Cancer-Related (not-BC-Related) Secondary Lymphoedema	*69*	3.0%	15.2%	13.6%	50.0%	18.2%
Breast-Cancer-Related Secondary Lymphoedema	*531*	2.1%	12.3%	17.1%	53.3%	15.2%

Approximately 20% of respondents with primary, non-cancer-related-secondary or cancer-related (but not breast-cancer-related) secondary lymphoedema reported that their quality of life was poor or very poor. Less than 7% of patients with breast-cancer-related secondary lymphoedema rated their quality of life as poor or very poor. Likewise, in relation to satisfaction with their health approximately 35% of patients with primary or non-cancer-related-secondary lymphoedema rated their satisfaction negatively compared with 14.4% of patients with breast-cancer-related secondary lymphoedema.

The means for these items are presented in Table 38. Participants with non-cancer-related secondary lymphoedema rated their quality of life and satisfaction with their health lowest whereas participants with breast-cancer-related secondary lymphoedema rated their quality of life and satisfaction with their health highest.

Table 38: Participants' Ratings of their Quality of Life and Satisfaction with their Health, according to Type of Lymphoedema, Age Range and Gender

	n	Mean	SD
Quality of Life			
All Respondents	*718*	3.86	0.91
Patients with Primary Lymphoedema	*47*	3.47	1.02
Patients with Non-Cancer-Related Secondary Lymphoedema	*42*	3.29	1.15
Patients with Cancer-Related (not-BC-Related) Lymphoedema	*66*	3.76	1.04
Patients with Breast-Cancer-Related Secondary Lymphoedema	*518*	4.00	0.81
Patients in the 18-35 Age Range	*22*	3.73	1.08
Patients in the 36-50 Age Range	*164*	3.93	0.92
Patients in the 51-65 Age Range	*328*	3.88	0.88
Patients in the 67 + Age Range	*198*	3.80	0.93
Male Participants	*48*	3.56	1.09
Female Participants	*667*	3.88	0.90
Satisfaction with Health			
All Respondents	*715*	3.55	1.02
Patients with Primary Lymphoedema	*47*	3.15	1.12
Patients with Non-Cancer-Related Secondary Lymphoedema	*42*	3.02	1.14
Patients with Cancer-Related (not-BC-Related) Lymphoedema	*66*	3.65	1.05
Patients with Breast-Cancer-Related Secondary Lymphoedema	*514*	3.67	0.95
Patients in the 18-35 Age Range	*22*	3.23	1.23
Patients in the 36-50 Age Range	*162*	3.50	0.99
Patients in the 51-65 Age Range	*329*	3.59	1.04
Patients in the 67 + Age Range	*196*	3.59	0.96
Male Participants	*48*	3.33	1.26
Female Participants	*664*	3.57	1.00

Inferential statistics were performed to ascertain if the variation in responses to these items were significantly different according to type of lymphoedema, age range and gender.

The Welch one-way ANOVA was performed to explore whether participants with different types of lymphoedema rated their quality of life differently. The result was highly significant: F_W (3, 89.500) = 9.270, p=0.001. Post hoc analysis revealed that participants with primary lymphoedema (p=0.006) and participants with non-cancer-related secondary lymphoedema (p=0.002) rated their quality of life significantly lower than participants with breast-cancer-related secondary lymphoedema. Regarding age range the assumption of homogeneity of variance was not violated and therefore a standard one-way ANOVA was performed. It was not found to be statistically significant: F (3, 708) = 0.749, p=0.523. The effect size, calculated using eta squared was also poor at 0.003. In relation to gender, the Levene's test indicated that the assumption of homogeneity of variance had been violated. Therefore the non-parametric Mann Whitney U was performed. Males (median = 4) did not significantly differ in their ratings of their quality of life from females (median = 4), U = 13,566.00, ns, r = -0.07. Thus the difference in participant's responses to this item on quality of life is influenced by type of lymphoedema rather than other factors, namely age range or gender.

In terms of ratings of satisfaction with health the Welch one-way ANOVA was performed to explore whether participants with different types of lymphoedema rated their satisfaction differently on this item. The result was also highly significant: F_W (3, 91.596) = 7.012, p=0.001. Post hoc analysis revealed that participants with non-cancer-related secondary lymphoedema rated their satisfaction with their health lower than participants with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.029) and participants with breast-cancer-related secondary lymphoedema (p=0.005). Participants with primary lymphoedema (p=0.019) rated their satisfaction with their health significantly lower than participants with breast-cancer-related secondary lymphoedema. Regarding age range the assumption of homogeneity of variance was not violated and therefore a standard one-way ANOVA was performed. It was not found to be statistically significant: F (3, 705) = 1.142, p=0.331. The effect size, calculated using eta squared was also poor at 0.004. In relation to gender, the assumption of homogeneity of variance was violated and as a result the non-parametric Mann Whitney U was performed. Males (median = 4) did not significantly differ in their ratings of their satisfaction with their health from females (median = 4), U = 14,541.00, ns*,* r = -0.04. This suggests that the difference in participant's responses to the item on satisfaction with health is influenced by type of lymphoedema rather than other factors, namely age range or gender.

The domain scores for each of the four domains of the WHOQOL-BREF – physical health, psychological health, social relationships and environment - of all respondents are presented in Table 39. The domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The first transformation method converts scores to range between 4 and 20. As a result the domains are comparable with each other and with scores ascertained with the longer version of the scale, the WHOQOL-100 (WHO, 1996).

Table 39: Mean Domain Scores of the WHO QOL-BREF

	n	**Range**	**Mean**	**SD**
Physical Health Domain Raw Score	*678*	4-20	14.27	3.16
Psychological Health Domain Raw Score	*697*	7-20	14.76	2.69
Social Relationships Domain Raw Score	*680*	5-20	15.10	3.45
Environment Domain Raw Score	*692*	5-20	15.24	2.67

Overall the sample rated themselves lowest on the physical and psychological health domains and these scores were quite close to the midpoint score. The sample rated their quality of life highest on the environment and social relationships domains. The mean scores on these domains according to the type of lymphoedema that patients experience are presented in Table 40 on page 185.

Table 40: Mean Domain Scores of the WHO QOL-BREF, according to Type of Lymphoedema

	n	**Mean**	**SD**
Physical Health Domain Raw Scores			
Patients with Primary Lymphoedema	*46*	13.34	3.81
Patients with Non-Cancer-Related Secondary Lymphoedema	*39*	12.39	3.60
Patients with Cancer-Related (not-BC-Related) Lymphoedema	*65*	14.71	3.57
Patients with Breast-Cancer-Related Secondary Lymphoedema	*489*	14.56	2.90
Psychological Health Domain Raw Scores			
Patients with Primary Lymphoedema	*46*	13.88	2.92
Patients with Non-Cancer-Related Secondary Lymphoedema	*41*	13.80	2.94
Patients with Cancer-Related (not-BC-Related) Lymphoedema	*67*	14.76	2.93
Patients with Breast-Cancer-Related Secondary Lymphoedema	*499*	14.98	2.60
Social Relationships Domain Raw Scores			
Patients with Primary Lymphoedema	*46*	14.42	3.59
Patients with Non-Cancer-Related Secondary Lymphoedema	*38*	14.02	3.88
Patients with Cancer-Related (not-BC-Related) Lymphoedema	*67*	14.41	3.91
Patients with Breast-Cancer-Related Secondary Lymphoedema	*488*	15.40	3.31
Environment Domain Raw Score			
Patients with Primary Lymphoedema	*46*	13.90	2.70
Patients with Non-Cancer-Related Secondary Lymphoedema	*40*	13.62	3.25
Patients with Cancer-Related (not-BC-Related) Lymphoedema	*66*	14.90	3.12
Patients with Breast-Cancer-Related Secondary Lymphoedema	*498*	15.60	2.47

In order to ascertain whether the type of lymphoedema participants experience influenced their scores on these domains, one-way ANOVAs were performed. With regard to the physical health and environment domains, the Levene's test indicated that the assumption of homogeneity had been violated and therefore Welch one-way ANOVAs and Dunnett's T3 post hoc tests were performed. In the case of the psychological health and social relationships domains the Levene's test indicated that the assumption of homogeneity had not been violated and therefore standard one-way ANOVAs and post hoc Tukey tests were performed.

With regard to the physical health domain, the Welch one-way ANOVA was highly significant: F_W (3, 86.485) = 5.814, p=0.001 indicating that there was a significant difference in how participants with various types of lymphoedema rated their physical health. Post hoc analysis revealed that participants with non-cancer-related secondary lymphoedema scored significantly lower on the physical health domain than participants with cancer-related (but not breast-cancer-related) secondary lymphoedema (p=0.012), and participants with breast-cancer-related secondary lymphoedema (p=0.004).

In relation to the psychological health domain, the standard one-way ANOVA was highly significant F (3,649) = 4.474, p=0.004 indicating that there was a significant difference in how participants with various types of lymphoedema rated their psychological health. The effect size, calculated using eta squared was small at 0.02. Post hoc analysis revealed that while participants with primary lymphoedema (p=0.039) and participants with non-cancer-related secondary lymphoedema (p=0.035) scored significantly lower on the psychological health domain than participants with breast-cancer-related secondary lymphoedema.

With regard to the social relationships domain, the standard one-way ANOVA was highly significant F (3,635) = 3.976, p=0.008 indicating that there was a significant difference in how participants with various types of lymphoedema rated their social relationships. The effect size, calculated using eta squared was small at 0.02. Post hoc analysis revealed that participants with non-cancer-related secondary lymphoedema scored lower on the social relationships domain than participants with breast-cancer-related secondary lymphoedema but this only approached significance (p=0.080).

In relation to the environment domain, the Welch one-way ANOVA was highly significant: F_W (3, 88.365) = 10.142, p=0.001 indicating that there was a significant difference in how participants with various types of lymphoedema rated their environment. Post hoc analysis revealed that participants with primary lymphoedema (p=0.001) and participants with non-cancer-related secondary lymphoedema (p=0.003) scored significantly lower on the environment domain than participants with breast-cancer-related secondary lymphoedema.

Therefore in summary, the type of lymphoedema participants experience influenced their scores on the physical health domain as participants with non-cancer-related secondary lymphoedema scored significantly lower than patients with cancer-related (but not breast-cancer-related) secondary lymphoedema and patients with breast-cancer-related secondary lymphoedema. The type of lymphoedema participants experience influenced their scores on the psychological health domain as participants with primary lymphoedema and participants with non-cancer-related secondary lymphoedema scored significantly lower than patients with breast-cancer-related secondary lymphoedema. The type of lymphoedema participants' experience influenced their scores on the social relationships domain. Participants with non-cancer-related secondary lymphoedema scored lower on the social relationships domain than participants with breast-cancer-related secondary lymphoedema but this only approached significance. Finally, type of lymphoedema also influenced participants' scores on the environment domain as participants with primary lymphoedema and participants with non-cancer-related secondary lymphoedema scored significantly lower than participants with breast-cancer-related secondary lymphoedema. The mean scores on these domains according to patients' age ranges are presented in Table 41.

Table 41: Mean Domain Scores of the WHO QOL-BREF, according to Age Range

	n	**Mean**	**SD**
Physical Health Domain Raw Scores			
Patients in the 18-35 Age Range	*22*	14.52	3.53
Patients in the 36-50 Age Range	*162*	14.41	3.24
Patients in the 51-65 Age Range	*317*	14.43	3.04
Patients in the 67 + Age Range	*171*	13.87	3.20
Psychological Health Domain Raw Scores			
Patients in the 18-35 Age Range	*22*	14.82	2.51
Patients in the 36-50 Age Range	*164*	14.34	2.79
Patients in the 51-65 Age Range	*321*	14.96	2.57
Patients in the 67 + Age Range	*185*	14.87	2.74
Social Relationships Domain Raw Scores			
Patients in the 18-35 Age Range	*22*	14.97	3.44
Patients in the 36-50 Age Range	*163*	14.37	3.59
Patients in the 51-65 Age Range	*319*	15.13	3.43
Patients in the 67 + Age Range	*172*	15.81	3.21
Environment Domain Raw Score			
Patients in the 18-35 Age Range	*22*	14.52	3.06
Patients in the 36-50 Age Range	*163*	14.84	2.69
Patients in the 51-65 Age Range	*321*	15.43	2.50
Patients in the 67 + Age Range	*181*	15.44	2.81

In order to test whether respondents' scores on these domains were also affected by age range, further inferential statistics were performed. The assumption of homogeneity was not been violated and therefore standard one-way ANOVAs and post hoc Tukey tests were performed.

With regard to the physical health and psychological health domains, the standard one-way ANOVAs were not significant: F (3,668) = 1.352, p=0.256, and F (3,688) = 2.045, p=0.106 respectively. The effect sizes, calculated using eta squared were also low, 0.006 and 0.009 respectively. This indicates that there was no significant difference in how participants in various age ranges scored on the physical and psychological health domains.

In relation to the social relationships domain, the standard one-way ANOVA was highly significant: F (3,672) = 4.985, p=0.002 indicating that there was a significant difference in how participants in various age ranges rated their social relationships. The effect size, calculated using eta squared was small at 0.02. Post hoc analysis revealed that participants in the 36-50 age range (p=0.001) scored significantly lower on the social relationships domain than participants in the 67 + age range.

With regard to the environment domain, the standard one-way ANOVA was significant F (3,683) = 2.677, p=0.046 indicating that there was a significant difference in how participants in various age ranges rated their environment. The effect size, calculated using eta squared was small at 0.01. Post hoc analysis revealed that participants in the 36-50 age range scored lower on the environment domain than participants in the 51-66 age range (p=0.092) however this test only approached significance.

In summary, participants' age did not influence their scores on the physical health and psychological health domains. However there was a significant difference in how participants in various age ranges rated their social relationships as participants in the 36-50 age range scored significantly lower on the social relationships domain than participants in the 67 + age range. There was also a significant difference in how participants in various age ranges rated their environment. Participants in the 36-50 age range scored lower on the environment domain than participants in the 51-66 age range but this only approached significance. Finally the mean scores on these domains according to patients' gender are presented in Table 42.

Table 42: Mean Domain Scores of the WHO QOL-BREF, according to Gender

	n	Mean	SD
Physical Health Domain Raw Scores			
Male Participants	*46*	13.77	3.70
Female Participants	*629*	14.30	3.12
Psychological Health Domain Raw Scores			
Male Participants	*46*	14.27	3.08
Female Participants	*648*	14.79	2.66
Social Relationships Domain Raw Scores			
Male Participants	*46*	14.03	3.60
Female Participants	*631*	15.18	3.43
Environment Domain Raw Score			
Male Participants	*47*	14.18	2.97
Female Participants	*643*	15.32	2.63

In order to test whether gender influenced participants' scores on these domains, further inferential statistics were performed. In the case of the physical health, social relationships and environment domains the Levene's test indicated that the assumption of homogeneity had not been violated and therefore independent sample t tests were performed. However with regard to the psychological health domain, the Levene's test indicated that the assumption had been violated and therefore a non-parametric Mann Whitney U was performed.

With regard to the physical health domain, the independent sample t test indicated that on average, females (mean = 14.30, SE= 0.124) scored higher than males (mean = 13.77, SE = 0.546) and this difference was not significant t (673) = -1.093, p = 0.275. In relation to the psychological health domain, the non-parametric Mann Whitney U was performed. Females (median = 15.33) did not significantly differ in their scores on this domain from males (median = 15.33), U = 13,679.500, ns, r= -0.04. With regard to the social relationships domain, the independent sample t test indicated that on average, females (mean = 15.18, SE = 0.136) scored higher than males (mean = 14.03, SE = 0.531) and this difference was significant t (675) = -2.185, p = 0.029. With regard to the environment domain, the independent sample t test indicated that on average, females (mean = 15.32, SE = 0.104) scored higher than males (mean = 14.18, SE = 0.433) and this difference was significant t (688) = -2.822, p = 0.005.

Therefore in summary, gender did not influence participants' scores on the physical and psychological health domains but did in the case of the social relationships and environment domains, where females scored significantly higher than males.

Overall, participants' scores on the physical health and psychological domains were influenced by the type of lymphoedema they experienced, rather than their age or their gender. Participants' scores on the social relationships and environment domains were influenced by the type of lymphoedema participants experienced, their age and their gender.

Open Question on Patients' Experiences of Lymphoedema Services and of Living with the Condition

The final question of the questionnaire asked participants whether there were any other comments that they would like to make with regard to seeking a lymphoedema diagnosis, lymphoedema services, compression garments, the standard of care they're receiving, or living with lymphoedema. A total of 428 participants responded to the open question. While the majority of responses were patients' accounts of their experiences of cancer treatment, explanations for the delay in returning the questionnaire or expressions of thanks to their lymphoedema practitioner and the research team, the remaining responses related either to lymphoedema services or the impact of the condition on patients' lives.

With regard to comments on lymphoedema service provision, 76 respondents referred to the need for healthcare professionals to be better informed about lymphoedema and its impact on patients:

> *Participant 109 (with breast-cancer-related secondary lymphoedema):* I think lymphoedema is not given enough publicity and doctors do not know much about it.
>
> *Participant 142 (with non-cancer-related secondary lymphoedema):* Lymphoedema as a medical problem is not highlighted enough. Awareness of this condition should be made more easily available to the general public and in some cases to the local GPs. I have had this swelling for years and my GP never referred to anyone!
>
> *Participant 152 (with breast-cancer-related secondary lymphoedema):* …All anaesthetists and nurses should be adequately trained to deal with mastectomy patients and be aware of the dangers of causing lymphoedema in patients by mistreating those at-risk.
>
> *Participant 382 (with breast-cancer-related secondary lymphoedema):* Lymphoedema is definitely on the back burner… (it) needs to be brought to the fore medically.
>
> *Participant 524 (with breast-cancer-related secondary lymphoedema):* What it all boils down to is – in medical circles CANCER (TREATABLE), is an easier word than LYMPHOEDEMA (NOT TREATABLE) to talk about and many a time I felt like telling my surgeons that if they suffered from it their jobs would be over and life as they enjoyed <u>ENDED.</u>

Seventy respondents indicated that services should be coordinated, accessible, continued and regular, standardised and available to all lymphoedema patients:

> *Participant 7 (with breast-cancer-related secondary lymphoedema):* Lymphoedema services should be available at local level, i.e. (at a) local health clinic and should be free for everybody.
>
> *Participant 548 (with primary lymphoedema):* I feel that people with primary lymphoedema in my area are really neglected, because there may not be very many of us. We may not be so visible. Have been to a few open days I think oncology patients are getting on better because of their overall treatment. We seem to be with vascular or general departments who I feel do not know enough about the problem. I support a few people (with lymphoedema) who do not leave the house anymore and this scares me.

> *Participant 516 (with primary lymphoedema):* Why should primary lymphoedema (patients) be treated differently now (to those with lymphoedema) brought on by trauma/surgery…

Fifty-nine comments related to the need for additional lymphoedema services and funding for those services:

> *Participant 45 (with breast-cancer-related secondary lymphoedema):* … The bottom line is there are lack of facilities and resources for the professionals to do their job properly.
>
> *Participant 60 (with breast-cancer-related secondary lymphoedema):* … I feel there are an appalling lack of services available and a huge shortage of specialist nurses.

Thirty-six comments related to the necessity of informing patients that they are at-risk of developing the condition:

> *Participant 1 (with breast-cancer-related secondary lymphoedema):* … Patients should be made aware of (the) possibility (of developing lymphoedema) and shown how to prevent and/or treat it.
>
> *Participant 175 (with breast-cancer-related secondary lymphoedema):* People like me should be TOLD before surgery that there is a great risk of this condition as there is no cure for it, only how to maintain it.

Comments that didn't relate to service provision, focused on the impact of lymphoedema on patients. Thirty-nine participants wrote about the impact of lymphoedema on their self-image and self-confidence:

> *Participant 104 (with breast-cancer-related secondary lymphoedema):* …The very hard part of it is the altered body image. I found it hard to accept wearing the compression garments…
>
> *Participant 77 (doesn't know type of lymphoedema):* I have lymphoedema in my left foot and lower leg. This makes it impossible for me to wear shoes other than hiking boots. This has a huge effect on how I can dress, compromising my self expression and image. Have you ever tried going to a wedding in hiking boots?!
>
> *Participant 43 (with breast-cancer-related secondary lymphoedema):* I am reluctant to have photos taken now and if I do have to I try to ensure they are taken on my left side so that my right arm isn't visible...don't like wearing sleeveless outfits without a cardigan to cover my arm… (I am) self conscious.

Thirty-four comments focused on the financial implications of living with lymphoedema:

> *Participant 40 (with breast-cancer-related secondary lymphoedema):* The price of compression garments is way too high €162 for 1 sleeve made to measure.
>
> *Participant 442 (with primary lymphoedema):* …I have tried to get the HSE in (name of county) to repay my bills for my stockings and toe-caps, but have been unsuccessful. I got a letter to say I wasn't entitled to payment as I didn't have a medical card and they weren't a prescribed medication. It seems very unfair to be penalised when there's no other cure for the condition.

Thirty-two comments explained the frustration, sadness and depression some participants feel as a result of living with lymphoedema:

> *Participant 65 (with non-cancer-related secondary lymphoedema):* (It) can get you down, no matter how happy and outgoing you are. Spells of these feelings need to be got over as soon as possible or depression sets in.
>
> *Participant 252 (with cancer-related but not breast-cancer-related secondary lymphoedema):* …Every evening I cry with pain - secretly.
>
> *Participant 707 (with primary lymphoedema):* I get very low with not being able to wear shoes like every other woman, having to go out in long skirts to cover the shape of my leg, not being able to go up stairs as the leg is so hard to lift, not being able to dance, so many things I cant do for the last 30 years, things other people can do. Sometimes I wish I were not here. I feel like a freak. I am crying just writing this. I am sure people like me say <u>why me.</u> They say we have to carry a cross but mine is a heavy cross that no one ever wants. I hope things are better for young people who get lymphoedema now. I hope no one has to go through the things and heartache that I have.

Thirteen participants wrote about their feelings of isolation as they feel others can not understand their experiences:

> *Participant 14 (with breast-cancer-related secondary lymphoedema):* … (It is) tedious… explaining to people why the sleeve is being worn. I feel like wearing a sandwich-board explaining the facts!
>
> *Participant 384 (with cancer-related but not breast-cancer-related secondary lymphoedema):* (I have) feelings of isolation as so few people know what it is.

> *Participant 202 (with breast-cancer-related secondary lymphoedema):* We are 'Third World' patients and without the help of all you good people would be consigned to the 'scrap heap of life'.

Three participants reported viewing lymphoedema as inconsequential compared to their experiences of surviving cancer:

> *Participant 100 (with breast-cancer-related secondary lymphoedema):* I consider lymphoedema a small price to pay, having survived cancer. Lymphoedema seems a trivial complaint. I am happy to be alive!
>
> *Participant 561 (with breast-cancer-related secondary lymphoedema):* I am coping well with lymphoedema as I think it's a small price to pay after breast cancer…

Whereas for eleven participants lymphoedema signifies a constant reminder of their cancer diagnosis and treatment:

> *Participant 149 (with breast-cancer-related secondary lymphoedema):* I can accept my cancer and all the treatment I received. I find having lymphoedema the worst aspect of my condition. It is a daily reminder when I have to wear my compression garment that I have had cancer and this is the souvenir – it is difficult to find shirts to cover the whole arm – people often ask me what happened to my arm – I hate it!!!!
>
> *Participant 269 (with breast-cancer-related secondary lymphoedema):* … Now I realise that after the scars of surgery heal and chemotherapy is finished that the lymphoedema will remain.
>
> *Participant 195 (with cancer-related but not breast-cancer-related secondary lymphoedema):* … I feel that I have now swapped a death sentence for a life sentence. … It's so bad now that that it affects every aspect of my life. … I'm so annoyed and frustrated that lymphoedema sufferers are forgotten about by our health system. … I'm embarrassed about my appearance. I can't get nice clothes to wear and getting shoes are a nightmare - can't get any to fit and any I do get aren't nice or trendy. I'm only 39 I don't want to wear granny shoes!! …I can't emphasise enough how angry I feel about the whole system.

Consequently, sixteen participants expressed their desire for support groups or counselling:

> *Participant 64 (with breast-cancer-related secondary lymphoedema):* …Group sessions it may help knowing you're not alone and you're not the only

> one who lives with a bandage. You can pick up tips and can talk to others who know really how you're feeling.
>
> *Participant 55 (with breast-cancer-related secondary lymphoedema):* (Patients need) support groups and counselling…At the very least, just one person who has the time to explain what is going on. I realise my answers paint a very negative picture but for the first time since January 2007 I have been honest with both you and myself and this exercise has been very helpful. Most of the time I just pretend all is well and carry on.

While nine participants' responses related to thoughts of a cure for lymphoedema:

> *Participant 89 (with breast-cancer-related secondary lymphoedema):* … I would travel to the end of the world for cure and worry everyday about it getting worse…
>
> *Participant 105 (with breast-cancer-related secondary lymphoedema):* … I am considering having my breast removed if that would mean the lymphoedema would go away (this participant has lymphoedema in one breast).
>
> *Participant 321 (with breast-cancer-related secondary lymphoedema):* … MAYBE A CURE MIGHT BE FOUND! PLEASE!!!!

Finally, seven patients that had accessed appropriate, effective treatment reported deriving huge benefits to their quality of life from this:

> *Participant 3 (with non-cancer-related secondary lymphoedema):* My life has completely changed for the better over the past year since I discovered my lymphoedema practitioner, who has made enormous improvements in my quality of life.
>
> *Participant 524 (with breast-cancer-related secondary lymphoedema):* The real heroes here are the poor unfortunate, kind, considerate therapists who through their own expense and expertise are the silver lining in an otherwise very, very dark cloud… You have found someone who cares and can do what they can to make your life bearable again – And once you've met one you leave with a smile and some happiness, AT LAST! Although getting there can be a frightening, lonely and desperate journey.

Discussion of Patient Survey Results

The specific aims of the patient survey were to: explore patients' experiences of seeking an explanation for their lymphoedema symptoms, obtaining a diagnosis and accessing information and treatment; explore patients' experiences of service provision; explore barriers in accessing treatment; and assess the impact of lymphoedema on patients' daily life and quality of life. Each of these aims has been met and a brief summary of the results is presented below.

There is no existing data on the prevalence of lymphoedema in Ireland and as a result the breakdown of the current sample is compared with that of the BreastCare Victoria (2005) sample and Moffatt et al.'s (2003) UK prevalence study in order to give a sense of how it compares with the patients being seen for treatment in Victoria, Australia and in South West London. Ninety-three percent of the current sample was female and 7% was male which was almost identical to the gender breakdown of the patient sample in the BreastCare Victoria (2005) study (94% female; 6% male). In Moffatt et al.'s (2003) prevalence study 82.99% of their sample was female and 17.01% was male. In the present sample there were a much higher proportion of patients with breast-cancer-related secondary lymphoedema (73.1%) when compared with the BreastCare Victoria sample (46.5%) and a much lower proportion of primary lymphoedema patients (6.5%) than in the BreastCare Victoria sample (18.5%). This may reflect the location of many lymphoedema services in hospitals providing cancer treatment and the requirement of some lymphoedema services in the Republic of Ireland to primarily or solely treat patients with cancer-related lymphoedema. Comparison with Moffatt et al.'s (2003) study on this point is not possible as the authors did not indicate what proportion had various types of lymphoedema beyond reporting that 25% had cancer-related secondary lymphoedema. Due to the higher proportion of primary lymphoedema patients in the BreastCare Victoria sample, their sample also had a greater proportion of patients with lymphoedema in the lower limb(s). In Moffatt et al.'s (2003) study 41% had lymphoedema in their upper limb(s) and 58% had lymphoedema in their lower limb(s).

The majority of the present sample is aged over 50 years of age which was expected given that while the overall prevalence of lymphoedema has been reported 1.33 per 1,000, 5.4 per 1,000 of those over 65 years old and 10.3 per 1,000 of those over 85 years old were found to experience lymphoedema (Moffatt et al., 2003). Indeed the mean age of participants in the current study was 58.89 years (Range=18-97 years, SD=12.65, *n=728)* while the mean age of participants in the BreastCare Victoria study was 61.0 years. The majority of the sample lives in Dublin, which reflects the high population density there. However there was a representation of patients from all counties in the Republic of Ireland.

In relation to service provision, participants reported that they waited a substantial amount of time for diagnosis and treatment. Additionally there was huge variation in patients' experiences of services particularly across patients with different types of lymphoedema and also among patients with the same type of lymphoedema.

Regarding the impact of the condition on participants' daily life and quality of life, participants reported that the limitations imposed by the condition were more keenly felt with regard to their ability to perform chores, wear clothes/shoes, and go on holidays. Participants' ratings of their quality of life and satisfaction with their health were significantly influenced by the type of lymphoedema they had but not by other factors such as age range or gender. Participants' scores on the physical health and psychological domains were influenced by the type of lymphoedema they experienced, rather than their age or their gender. Participants' scores on the social relationships and environment domains were influenced by the type of lymphoedema participants experienced, their age and their gender.

The next sections provide a more detailed analysis of the results, and how they compare with the results of previous studies and with previous phases of this study, is presented below under the headings: inequitable service provision and impact on daily life and quality of life.

Inequitable Service Provision

The majority of data on the inequitable nature of current lymphoedema service provision in Ireland related to inequality based on the greater prevalence of cancer-related lymphoedema in this part of the world. Although lymphatic filariasis is the most common cause of lymphoedema worldwide, cancer treatment is the most common cause in the Western world. The questionnaire results starkly present the inequitable nature of current lymphoedema service provision based on lymphoedema aetiology. For example, patients with breast-cancer-related secondary lymphoedema waited approximately 5 months for a diagnosis while patients with primary lymphoedema waited over six and a half years for a diagnosis. This difference was significant and comparable with the BreastCare Victoria (2005) study which found that patients with breast-cancer-related secondary lymphoedema waited 0.6 years for a diagnosis whereas patients with primary lymphoedema waited on average 9.4 years for diagnosis following the onset of symptoms. Patients with non-cancer-related lymphoedema were also less likely to know they were at-risk of developing lymphoedema and rated the healthcare professionals they consulted when they were seeking a diagnosis lower than patients with breast-cancer-related secondary lymphoedema. However it is worth noting the wide variety of healthcare professionals consulted by patients when they were seeking a diagnosis and the lack of dedicated lymphoedema clinics or designated patient streams or pathways may have inhibited the prompt assessment and treatment of their lymphoedema.

Patients with non-cancer-related lymphoedema waited a longer time period between diagnosis and first treatment, had a longer time period since their last treatment; rated the standard of care they are receiving as lower, and rated themselves lower in terms of their quality of life, satisfaction with their health and on all domains of the WHOQOL-BREF than patients with breast-cancer-related secondary lymphoedema. All of these results were statistically significant. These results correspond with the study by Sitzia, Woods et al. (1998) which found that people with non-cancer-related lymphoedema generally wait longer for diagnosis, have greater severity or swelling and consequently have considerable management problems exacerbated by their later referral (cited in Bogan et al., 2007). Furthermore a study in the UK by Lam et al. (2006) also found that patients with non-cancer-related lymphoedema were less likely to have ongoing monitoring of their condition when compared with patients with cancer-related lymphoedema.

While patients with breast-cancer-related secondary lymphoedema scored better on these items the results indicate that the service they receive is far from adequate or optimal. They also experience relatively long periods to be diagnosed and treated. Moreover even within categories of patients with the same type of lymphoedema the ranges in responses were very large.

Similarly there was evidence of inequity in terms of the distribution of services, delays for medical card holders and the financial burden experienced by some patients. For example, a sizeable minority of approximately one fifth reported that travel distance limited their ability to avail of lymphoedema treatment. This issue also arose in the results of the service provider survey. Additionally one-fifth of medical card holders reported that HSE approval procedures delayed the delivery of their compression garments. This was a point previously raised in both the service provider survey and patient focus groups. While some patients aren't required to spend money on their lymphoedema treatments, bandages and compression garments others go to great personal expense to receive adequate treatment and supplies to effectively manage their symptoms. This also emerged strongly from the patient focus groups. While the majority of survey respondents indicated that they do not pay for their treatments 42% pay money towards their compression garments and 10% pay for consultations with their lymphoedema practitioner. The cost per calendar year can range from €2 to €1,000 for compression garments alone with only 5 participants indicating that they receive financial support from their private health insurers for such costs.

In summary, the inequitable nature of service provision generally related to patients with non-cancer-related lymphoedema receiving poorer service provision than patients with cancer-related lymphoedema. Yet even among participants with the same type of lymphoedema, there was huge variation in experiences. Further inequalities were also reported with some patients being required to travel long distances, wait long periods for the approval of compression garments or pay large sums of money to access treatment. The final category of results from the patient surveys relates to the impact of lymphoedema on patients' daily life and quality of life. The results in relation to this are discussed below in the next section.

Impact on Daily Life and Quality of Life

The results of the patient survey also emphasise the significant impact of the condition on patients' daily lives and quality of life. As mentioned previously, this can take the form of considerable financial expense for some patients. For many participants this can involve the use of compression garments which were rated as mediocre on all measures by the current sample. The results indicated that participants' dissatisfaction with the mediocrity of compression garments can lead to them not wearing garments as often as they have been advised to. Previous studies of patients' experiences of living with lymphoedema have not explored their experiences of compression garments as an example of how the condition affects their daily lives.

Regarding the limitations imposed by lymphoedema on daily activities, participants reported that restriction was more keenly felt with regard to their ability to perform chores, wear clothes/shoes, and go on holidays. Type of lymphoedema, age range and gender also had a significant impact on participants' responses to these items. For example, participants with non-cancer-related secondary lymphoedema experienced greater limitation than participants with other types of lymphoedema in walking, swimming, performing other sports, performing outdoor chores, taking care of children, buying clothes/shoes, wearing clothes/shoes, socialising, sexual activity, sleeping, and going on holidays. Participants with breast-cancer-related secondary lymphoedema experienced greater limitation than participants with other types of lymphoedema in performing indoor chores. This variation in restriction may reflect the location of the swelling experienced by participants with various types of lymphoedema, or the extent to which their swelling and associated symptoms are controlled through self-management and access to regular treatments. As mentioned in the previous section, participants with various types of lymphoedema may experience disparity in their access to services.

Participants’ responses regarding the impact of the condition on daily life also differed significantly in terms of their age. Participants in the 18-35 age range experienced greater limitation in terms of going on holidays when compared with participants in other age ranges. Participants in the 36-50 age range experienced greater limitation in terms of performing other sports, and working when compared with participants in other age ranges. Participants in the 51-66 age range experienced greater limitation than participants in other age ranges in terms of swimming and performing outdoor chores. Participants in the 67+ age range experienced greater limitation in terms of performing indoor chores, socialising, sexual activity, and sleeping when compared with participants in other age ranges.

Gender differences to responses to these items were also reported. Male participants experienced greater limitation than female participants in terms of walking, swimming, and sexual activity. Female participants experienced greater limitation than male participants in terms of performing indoor and outdoor chores, taking care of children, wearing clothes/shoes, and sleeping. Previous studies of living with lymphoedema have not measured the impact of the condition according to type of lymphoedema, age or gender therefore direct comparison cannot be made. The results may relate to the greater prioritisation of certain activities by certain groups. For example women may place greater emphasis on feeling comfortable when wearing clothes and shoes and therefore experience greater limitation when this is impeded by their swelling. Further investigation is required in order to explore why individuals of various age ranges or genders experience greater difficulties on some activities rather than other activities.

Lymphoedema can also affect participants’ daily lives and quality of life through physical symptoms and associated medical conditions. For example, 42.5% of respondents reported that physical pain prevents them from doing what they want to do. This is a much higher proportion than in Lam et al.’s (2006) study where 13% of their participants indicated that pain, aching or tiredness affected their daily lives. This may be due to differences in the phrasing of the question. Alternatively the discrepancy may be due to participants in the current sample having insufficient access to lymphoedema treatments which offer the potential to manage or reduce swelling (thereby reducing associated musculoskeletal pain for example) and to prevent infection (thereby reducing pain associated with these infections).

An associated physical condition of lymphoedema is cellulitis an infection in the layers of the skin. Twenty-nine percent of respondents reported that they had experienced a bout of cellulitis which is identical to the proportion of Moffatt et al.'s (2003) sample that reported experiencing at least one such acute infection. Sixty-one percent of the respondents in the current sample who had experienced cellulitis reported that they had been hospitalised at least once for its treatment whereas only 15% in Moffatt et al.'s (2003) study reported that the infection(s) resulted in one or more hospital admissions. This may suggest that respondents in the current sample experience more serious infections due to insufficient treatment provision or self-management of the condition which both aim to prevent such serious infection.

Regarding the impact of the condition on participants' quality of life, the first two items of the WHOQOL-BREF asked participants to rate their quality of life and satisfaction with their health. Participants' ratings on these items were significantly influenced by the type of lymphoedema they experienced but were not influenced by other factors such as age or gender. In terms of the domain scores of the WHOQOL-BREF, participants' scores on the physical health and psychological health domains were influenced by the type of lymphoedema they experienced, rather than their age or their gender. Participants' scores on the social relationships and environment domains were influenced by the type of lymphoedema participants experienced, and their age and gender.

Previous studies exploring the quality of life of patients with chronic illness have reported different quality of life scores according to the type of chronic illness experienced by patients (Schlenk et al., 1998). Lymphoedema is a condition which can involve sometimes fluctuating symptoms in various parts of the body leading to diverse implications and impairments. Moreover, as mentioned previously there is considerable evidence in the current study to suggest that individuals with different types of lymphoedema experience varying levels of service provision. Therefore it is reasonable to expect that the type of lymphoedema participants experience influenced their scores on the WHOQOL-BREF. Indeed, participants with non-cancer-related secondary lymphoedema scored lowest on all domains whereas participants with breast-cancer-related secondary lymphoedema scored highest on almost all domains. Previous studies of quality of life among lymphoedema patients have generally not included patients with all types of lymphoedema. Although Moffatt et al.'s (2003) study did include patients with various types of lymphoedema; comparison between them in terms of their scores on the quality of life measure was not undertaken. This study contributes considerably to the literature on lymphoedema patients' quality of life as it is the first to compare quality of life scores across patients with different types of lymphoedema. Therefore this information could be utilised to increase healthcare professionals' understanding of patients' experiences and to develop tailored support programmes for patients with various types of lymphoedema.

Previous quality of life research has reported differences in quality of life scores according to age and gender. In the current study, age and gender did not significantly influence scores on the physical health and psychological health domains but did influence scores on the social relationships and environment domains. In a study of general population scores on the WHOQOL-BREF younger participants scored highest on all domains while participants in the 51-60 age range scored lowest on the physical and psychological domains and participants in the 31-40 age range scored lowest on the social and environmental domains (Skevington et al., 2004). Conversely, in the current study while participants in the 18-35 age range scored highest in the physical health domain, participants in the 51-65 age range scored highest in the psychological health domain and participants in the 67+ age range scored highest in the social relationships and environment domains. In terms of gender differences in quality of life, previous studies have reported that women score more poorly than men (Guallar-

Castillón et al., 2005; Schwarz & Hinz, 2001). In the current study, women scored higher on all domains than men. Therefore in summary, the type of lymphoedema participants experienced was consistently associated with their quality of life scores, whereas age and gender did not have a significant association with all domains. Moreover where age and gender did appear to influence quality of life scores, the results were not in line with previous general literature on age, gender and quality of life.

As a result it appears that it is the experience of lymphoedema rather than age or gender that is consistently associated with participants' quality of life. Indeed researchers have argued that the experience of illness itself alters patients' perception of the concept of quality of life. Sprangers and Schwartz (1999) have termed this 'response shift'. Following a catalyst or the development of a condition, individuals may utilise affective, behavioural and cognitive processes to accommodate the catalyst. This can lead to individuals changing their standards of measurement or the values they place on certain components of quality of life or alternatively to individuals reconceptualising their personal definition of quality of life. The mechanism of this change can involve coping strategies, social comparison, social support, goal reordering, reframing of expectations or spiritual practices. Therefore it may be possible that the experience of lymphoedema has prompted many in the current sample to undertake such a response shift and that this has superseded the impact that age or gender would typically have on quality of life scores. Further investigation and exploration of the mechanisms of response shift and how this theory can be applied and utilised to support lymphoedema patients is required.

Finally in their responses to a broad, open question, participants reiterated the considerable impact lymphoedema has on their wellbeing. Respondents wrote about the effect of the condition on their self-image and confidence, feelings of frustration, depression and isolation, and how lymphoedema can serve as a constant reminder of their prior cancer diagnosis and treatment for some participants. These responses reiterated the findings of the patient focus groups in the current study and the findings of previous qualitative studies of patients' experiences (e.g. Bogan et al., 2007; Hare, 2000; Johansson et al., 2003; Williams et al., 2004). Participants expressed their desire for support groups and counselling and those that had accessed appropriate, effective treatment reported deriving huge benefits to their quality of life from such treatment. The lower rating of lymphoedema practitioners' emotional support in comparison to ratings of their other characteristics suggests that practitioners have the ability to improve patients' wellbeing in other ways rather than through the treatment of the swelling. This suggests that there are practical ways that the impact of lymphoedema can be minimised.

In summary, the implications of living with lymphoedema can be multi-faceted – financial (e.g. cost of treatment, compression garments, and bandaging), physical (e.g. pain, cellulitis), social (e.g. activity level, socialising), emotional (e.g. sadness, frustration) and psychological (e.g. poor self-image, self-confidence, depression, isolation). The results suggest that there are huge variations in the impact of lymphoedema and that appropriate levels of treatment and the provision of support groups and counselling may offer the potential of lessening the consequences of lymphoedema for those who feel it most keenly.

While these results add to our understanding of patients' experiences of lymphoedema service provision and of living with the condition, they cannot be presented without due consideration of the methodological issues of this phase of the research. These are presented in the next section.

Methodological Issues

Firstly, for ethical and logistical reasons it was not possible to include individuals who had not been diagnosed with lymphoedema. Moreover, although attempts were made to access patients who may not be receiving treatment through lymphoedema support organisations, in reality the majority of participants were accessed through hospitals and services. As a result lymphoedema patients who are not or have never received treatment were less likely to be invited to participate and may be underrepresented. Therefore there is a possibility that the experiences presented may not reflect all individuals' experiences. Unless such an investigation was conducted as part of a prevalence study, accessing those who are not receiving treatment represents a significant challenge.

Secondly, this was a postal survey and the majority of participants were accessed through hospitals and services. Consequently, there was the regrettable possibility of unwittingly posting surveys to individuals who had passed away where this information might not yet have been known to hospital personnel or where patient records had not been updated. Although it is recognised that this is a small possibility, it is an extremely sensitive area and it is of paramount importance to avoid causing unnecessary distress to their families. To minimise the possibility of sending research correspondence to people who may have passed away, it is recommended that all research using hospital or health service records to access potential participants should have a member of the relevant healthcare team identify people who meet the inclusion criteria from the available records and lists. This emerging list should be subsequently reviewed by other key personnel on the team as different members of the team may be more aware of individual patient circumstances than others. Furthermore it is also strongly recommended that the emerging list is crosschecked by making contact with patients' general practitioners and by reviewing death notices (in newspapers and/or online (e.g. www.rip.ie).

Thirdly, previous studies on the impact of lymphoedema on quality of life have compared lymphoedema patients' scores with matched controls, for example breast cancer survivors who haven't developed lymphoedema or with population norms. As the intention of this study was to concentrate specifically on lymphoedema patients the opportunity of comparing their scores with matched controls or population norms was not explored.

Finally, while many participants reported in responses to open questions that they are distressed by their lymphoedema, a specific clinical measure of psychological wellbeing was not included in order to keep the questionnaire as succinct as possible. Therefore it is difficult to ascertain what proportion of the sample experience clinical levels of distress.

Conclusion

The intention of the patient survey was to ascertain how representative various experiences of lymphoedema service provision and of living with lymphoedema are among a broader sample of patients. While the results provide information on how common particular experiences are – namely inequitable service provision and difficulties in living with lymphoedema – the next chapter of the thesis will present an integration of the findings from all three phases of the study with a view to making recommendations on the development of lymphoedema service provision in Ireland and the support of patients.

Chapter 7: Discussion

Introduction

The results of each phase of the research have previously been explored in individual chapters. The results of the service provider survey indicated that lymphoedema services are insufficient and inequitably provided, and that there are challenges to the sustainability of services. The findings of the patient focus groups included themes of barriers to treatment, tension with some healthcare professionals, the difficulties of living with lymphoedema and emotional factors. Other themes included participants taking an active role in their lymphoedema management and deriving positives out of their experiences. The patient questionnaires reiterated the inequitable nature of current lymphoedema service provision and further explored the impact of the condition on patients' daily life and quality of life.

This final discussion chapter presents the metainferences of the study derived from the integration of the findings of the three phases. There is a lack of well-known exemplars in order to guide the integration of mixed methods data in order to develop such metainferences (Bryman, 2007). As a result the approach undertaken by the researcher was not to focus on difficulties directly associated with the condition of lymphoedema (e.g. difficulties associated with swelling, a chronic condition, time consuming treatment etc.) but rather to identify super-ordinate themes which compound the difficulties of living with lymphoedema in Ireland at present. While the initial aims of the study were separated into questions on lymphoedema service provision; and patients' experiences of living with the condition, the super-ordinate themes transcend these aims.

The individual results from each phase have previously been discussed in the relevant chapters with details and references provided so as to compare them with the findings of previous studies. As a result those details and references will not be repeated in this chapter. No previous study on lymphoedema has employed the integration of mixed methods data in this way. Therefore this study had the scope to see a broader perspective. As a result the super-ordinate themes may not been identified or defined in the same way in previous studies although where similar points have been made by other researchers, reference will be made to them. As mentioned previously in Chapter 2, by integrating results from various methods there is the potential for various outcomes: silence (where one dataset uncovers a theme or example whereas another dataset is silent about it); convergence (where all datasets produce the same findings on a theme or example); complementarity or divergence (where all sets of data feature a theme but have different perspectives on that theme); and contradiction or discrepancy (where datasets offer different findings on a theme) (Farmer et al., 2006; Johnson et al., 2007). While no example of contradiction or discrepancy could be found, the outcomes of silence, convergence, and complementarity are discussed in the following sections. The super-ordinate themes, their subthemes and examples of silence, convergence, and complementarity where they occur are briefly summarised in diagrams in order to simplify the findings.

Super-Ordinate Themes

The super-ordinate themes that arose from this mixed methods study are lymphoedema as an unacknowledged condition and the legacy of lymphoedema's association with cancer.

Lymphoedema – An Unacknowledged Condition

The first super-ordinate theme is lymphoedema – an unacknowledged condition. Lymphoedema has been termed a 'forgotten complication' (Farncombe et al., 1994 cited in McWayne & Heiney, 2005) or an 'underestimated health problem' (Moffatt et al., 2003) by previous researchers. The intention of this part of the study is not merely to identify prevalent issues but also to provide evidence from the data as to why such a metainference has been reached.

This super-ordinate theme includes the sub-themes that lymphoedema is inappropriately acknowledged among healthcare professionals; within the HSE; among private health insurers; among compression garment manufacturers; and that there are emotional consequences of living with an unacknowledged condition. The first super-ordinate theme, its subthemes and examples of silence, convergence, and complementarity are briefly summarised in Figure 7 on page 211. Each of the subthemes along with the evidence supporting them from the various stages of the current study and examples of silence, convergence, and complementarity are presented in subsequent sections.

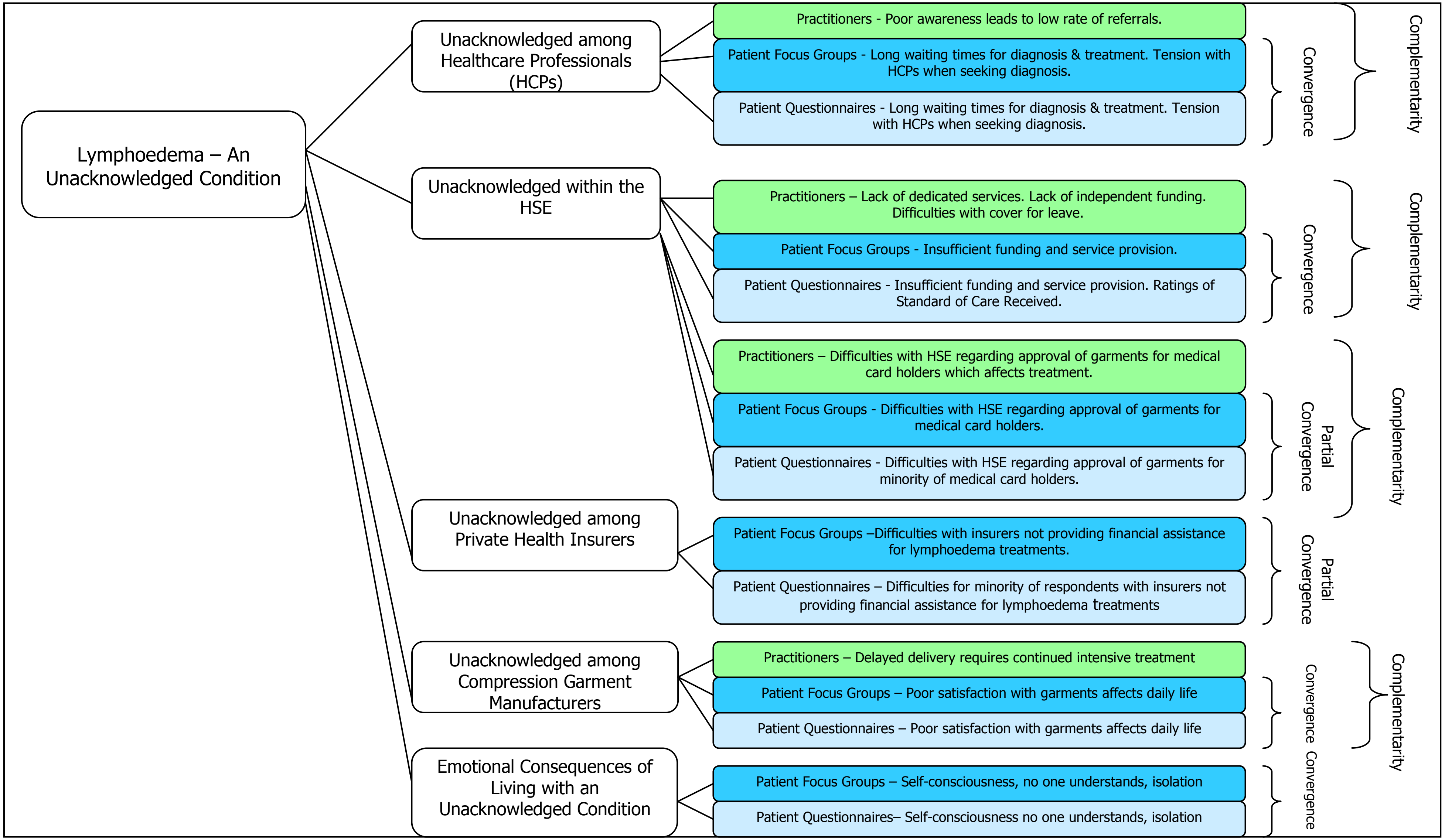


Figure 7: First Super-Ordinate Theme, Subthemes and Examples of Silence, Convergence and Complementarity Following Integration

Lymphoedema Not Appropriately Acknowledged Among Healthcare Professionals

This subtheme referred to the condition still not being appropriately acknowledged among some healthcare professionals. For example, practitioners reported that poor awareness of the condition among other healthcare professionals leads to low numbers of referrals. A complementary finding was that participants from both the focus groups and patient survey reported waiting significant periods for diagnosis and treatment. This emerged particularly for patients with non-cancer-related lymphoedema, where recognition of lymphoedema and its diagnosis is even poorer. Furthermore, focus group and to a lesser extent questionnaire participants reported tension with healthcare professionals when they were seeking an explanation of their lymphoedema symptoms regarding their lack of knowledge about lymphoedema and their attitude towards the condition. Indeed patient survey participants' mean ratings of the healthcare professionals they consulted when they were seeking a diagnosis were all below a rating of 4 – 'satisfied' on measures of attitude, knowledge, practical and emotional support, time taken to diagnose and overall satisfaction. However while bearing these results in mind it is important to note the wide range of healthcare professionals consulted by patients when they were seeking a diagnosis. Therefore an improved awareness of lymphoedema is required not just within one discipline but across a wide spectrum of healthcare professionals.

Lymphoedema Not Appropriately Acknowledged Within the HSE

Both service providers and patients converged in reporting their frustration that lymphoedema is not sufficiently acknowledged within the HSE. For practitioners this referred to the low number of dedicated clinics, practitioners being required to treat patients with other conditions, the lack of a specific allocation of funding for lymphoedema services and difficulties in getting cover for leave - all challenges for practitioners treating an unacknowledged condition. Practitioners' difficulty with cover for leave also results in difficulties in practitioners accessing continuous training which would ensure the maintenance of treatment standards. Moreover the large proportion of practitioners indicating a need for more training corresponds with this. A complementary finding from patients in both focus groups and questionnaires was that the HSE's poor funding of services has lead to an insufficient level of services being provided. This has lead to delays in diagnosis and lengthy waiting times for patients. Indeed focus group participants spoke of the need to appeal for treatment and patient survey participants reiterated this with mediocre ratings of the standard of care they are receiving.

Another example of the HSE inappropriately acknowledging lymphoedema related to the HSE's delayed approval of medical card holders' compression garments. This arose in practitioner surveys as they noted such delays affected patients' treatment. A complementary theme arose among the patient data. Participants in patient focus groups were very vocal that the HSE's poor acknowledgement of lymphoedema has resulted in some medical card holders being required to wait an inordinate amount of time for the approval of compression garments. Moreover the results of the patient survey indicated that a sizeable minority of 20% of respondents who are medical card holders considered HSE approval procedures to have delayed the delivery of their compression garments.

Lymphoedema Not Appropriately Acknowledged Among Private Health Insurers

Patient focus groups and questionnaire results partially converged in relation to private insurance companies failing to sufficiently acknowledge lymphoedema. While this theme featured strongly in focus groups, a small minority of patient questionnaire participants pay for treatment and therefore can claim for the cost from their private health insurance. However patients who do pay for treatment were again very communicative on the financial burden this places on them in their responses to the open questions on the questionnaire. Service providers were silent on this topic as they are less likely to be informed on patients' health insurance status and claims.

Lymphoedema Not Appropriately Acknowledged Among Compression Garment Manufacturers

Service providers indicated in their responses to an open question on compression garments that delayed delivery of made-to-measure compression garments and garments manufactured in the UK can affect patient treatment. Complementarily, patient focus group and survey results converged in relation to compression garment manufacturers not sufficiently acknowledging the difficulties in living with lymphoedema and therefore for many, living with compression garments. Focus group participants spoke about this topic at length. Moreover questionnaire participants rated compression garments as mediocre on measures of comfort, fit, colour, temperature etc. and many of them wrote negative comments about their experiences of garments.

Emotional Consequences of Living with an Unacknowledged Condition

Living with a chronic condition often places great strain on patients' emotional wellbeing. However with lymphoedema there is the added burden of coping with an unacknowledged condition. Patient focus group and questionnaire results converged in relation to the powerful emotional consequence of living with an unacknowledged condition. Many focus group and questionnaire participants indicated that they tried to hide their lymphoedema but still felt self-conscious, upset and in some cases depressed. As a result, some patients in the focus group and questionnaire results reported feeling isolated. This may also reflect patient survey respondents' poor rating of the level of emotional support received from their main lymphoedema practitioners. The patient survey results in relation to participants' ratings on the quality of life item and overall scores on the domains of the WHOQOL-BREF correspond with this. Furthermore, both focus group and patient survey participants' recommendations for the provision of support groups and counselling further emphasise this point.

The emotional difficulties associated with living with an unacknowledged condition may relate particularly well to patients with non-cancer-related lymphoedema. As mentioned previously they were less likely to be informed that they were at-risk of developing the condition and experienced greater delays in their diagnosis and treatment. Therefore patients with non-cancer-related lymphoedema may consider their condition to be acknowledged to an even lesser extent than patients with cancer-related lymphoedema. Interestingly patients with non-cancer-related lymphoedema also scored significantly lower on all domains of the quality of life measure than patients with cancer-related lymphoedema.

However this is not to imply that the experience of patients with cancer-related lymphoedema does not present considerable difficulties. Indeed the next super-ordinate theme relates to the legacy of lymphoedema's association with cancer.

Lymphoedema and the Legacy of its Association with Cancer

Although lymphatic filariasis is the most common cause of lymphoedema worldwide, cancer treatment is the most common cause in the Western world. The second super-ordinate theme relates to the legacy of lymphoedema's association with cancer. It includes the subthemes that there is inequality in service provision based on the greater prevalence of cancer-related lymphoedema and some patients not being able to process their risk of developing lymphoedema due to their distress from their cancer diagnosis and treatment. Other subthemes include that patients' prior cancer experience has affected others' perceptions of the difficulties of living with lymphoedema and that for some patients lymphoedema can be a constant reminder of cancer diagnosis and treatment. The second super-ordinate theme, its subthemes and examples of silence, convergence, and complementarity are briefly summarised in Figure 8 on page 216. Each of the subthemes along with the evidence supporting them from the various stages of the current study and the examples of silence, convergence, and complementarity are presented in subsequent sections.

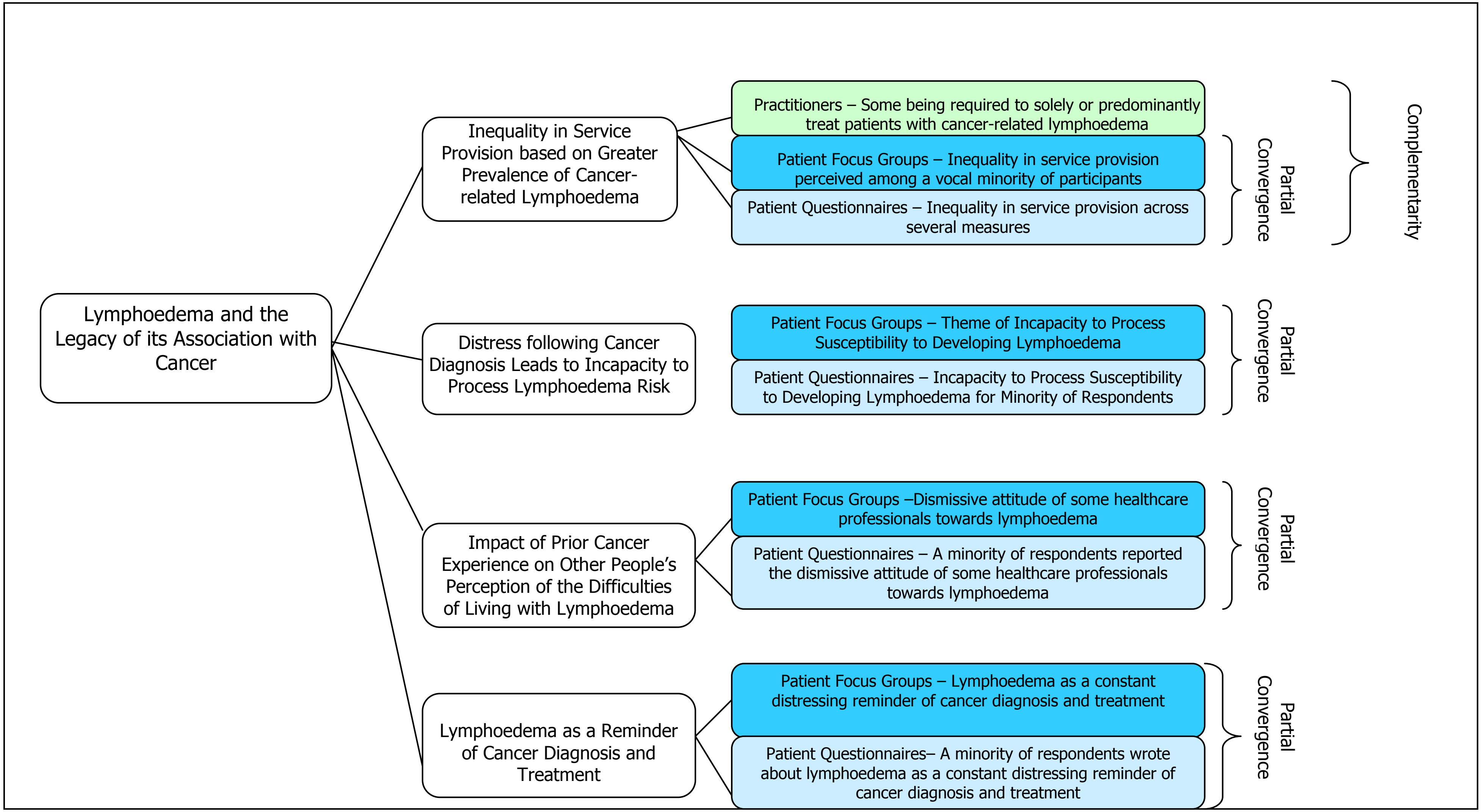


Figure 8: Second Super-Ordinate Theme, Subthemes and Level of Silence, Convergence and Complementarity Following Integration

Inequality based on Greater Prevalence of Cancer-Related Lymphoedema

For service providers the first subtheme relates to many practitioners being required to predominantly or solely treat patients with cancer-related lymphoedema to ensure limited resources are allocated according to the service's remit. Therefore some practitioners are required to overlook patients with non-cancer-related lymphoedema. Practitioners' poor ratings of the standard of care received by patients with non-cancer-related lymphoedema, further underscores their perceptions of this inequality.

A complementary finding from patient questionnaires was patients' perception of the inequality in service provision. Patients with non-cancer-related lymphoedema were less likely to know they were at-risk of developing the condition, waited longer to be diagnosed and receive their first treatment, were less satisfied with the healthcare professional they consulted when they were seeking a diagnosis, had a longer time period since their last treatment, were less satisfied with the process of getting compression garments, rated the standard of care they receive as poorer, and rated their quality of life and satisfaction with their health poorer than patients with cancer-related lymphoedema. This did not feature as strongly in the patient focus groups as the majority of focus group participants had cancer-related lymphoedema. However patients with primary lymphoedema were vocal about the greater difficulties they experienced in accessing continued treatment, which suggests a partial convergence of findings.

Distress following Cancer Diagnosis Leads to Incapacity to Process Lymphoedema Risk

The second subtheme arose particularly in relation to focus group participants and a minority of questionnaire participants who recounted the difficulty they experienced in processing information about lymphoedema at a time of great personal distress. As a result these participants recommended that information on lymphoedema should be repeated to patients at-risk of developing cancer-related lymphoedema. Service providers were silent on this topic as they are less well placed to comment in subjective experiences of cancer diagnosis and treatment and subsequent predisposition to lymphoedema development.

Impact of Prior Cancer Experience on Other People's Perception of the Difficulties of Living with Lymphoedema

The third subtheme arose particularly in relation to focus group participants and a minority of questionnaire participants that recounted how some healthcare professionals in particular underestimated the impact of lymphoedema on their lives as a result of their prior cancer diagnosis and treatment. Participants who reported this experience indicated their hurt and anger at insufficient weight being placed on the difficulties of living with this chronic condition. This point arose to a lesser extent in patient questionnaire results suggesting a partial convergence of findings. Service providers were silent on this topic as they are less well placed to comment on patients' subjective experiences of previous interactions with healthcare professionals. Furthermore, this subtheme may be related to the super-ordinate theme of lymphoedema being an unacknowledged condition in its own right.

Lymphoedema as a Reminder of Cancer Diagnosis and Treatment

The final subtheme was that the stress of living with lymphoedema can be heightened among those who perceive the condition as a constant, distressing reminder of their cancer diagnosis and treatment. This arose very strongly in the findings of the patient focus groups and among a minority of responses to open questions in the patient survey where participants wrote of swopping "a death sentence for a life sentence" (*Participant 195 with cancer-related but not breast-cancer-related secondary lymphoedema*). This suggests a partial convergence of findings. Service providers were again silent on this subtheme as they are less well placed to comment on patients' subjective experience of developing lymphoedema subsequent to cancer treatment.

While these super-ordinate themes and subthemes are intended to add further depth to the overall findings of the study, due consideration must be given to the overall limitations of the study which are presented in the next section.

Overall Limitations

The overall results and findings of this study should be considered in light of its limitations. Firstly, it is possible that the inclusion of additional data collection methods would have offered further insights into experiences of lymphoedema service provision and living with the condition. As mentioned previously the various departmental structures, and the funding and staffing situations in hospitals and services were difficult to explore fully in a practitioner questionnaire format. While the addition of service provider focus groups would have added further clarity in these matters it was not possible given the time constraints of the study. Furthermore, individual patient interviews would have been appropriate to investigate sensitive topics such as the impact of living with lymphoedema on patients' sexuality. Moreover, while many participants reported in responses to open questions that they are distressed by their lymphoedema, a specific measure of psychological wellbeing was not included to keep the questionnaire as succinct as possible. Therefore it is difficult to ascertain what proportion of the sample is experiencing clinical levels of distress. These are areas that could be further explored in future research.

Secondly, the generalisability of these findings is also open to question. Given the unique structure of the Irish healthcare system and the current changes in that system it is uncertain whether the results and recommendations can be applied to other countries. Furthermore, the pervasive media coverage on the challenges facing the Irish healthcare system and indeed the Irish economy at present may have affected practitioners' and patients' responses to certain items. For example the following quote was a response to the final open question of the patient survey which requested any additional comments:

> (*Participant 714 with breast-cancer-related secondary lymphoedema):* Because lymphoedema requires regular assessment and treatment, it is important and reassuring to know that you have a reliable, high standard lymphoedema service within reasonable access. I think (name of city) is perhaps fairly well serviced, but the less populated counties are probably experiencing problems. Unfortunately with the economic downturn I cannot see improvements being made in this regard, at least not in the immediate future.

Therefore it is unclear whether participants would have responded differently if this study had been conducted at a different juncture.

Notwithstanding these limitations, the findings have important implications. A number of recommendations in terms of future research and policy can be made based on the findings and these are presented below in the next section.

Recommendations

The recommendations arising from this thesis have been categorised as either research or policy recommendations and are presented below. Some of these recommendations echo those made in previous reports or studies and these are referenced where appropriate.

Research Recommendations

As mentioned previously in the literature review, there is a paucity of research on lymphoedema. It is intended that this study will encourage a general stimulation of research on lymphoedema and lymphoedema service provision. However there are a number of streams of research which are required and these are briefly outlined below.

Firstly additional research on the lymphatic system and lymphoedema is required. Researchers are still uncertain as to the normal range of lymphatic variation in terms of lymph vessel numbers, functional capabilities and locations. Research is also required on the mechanisms of lymphatic system functioning, the aetiology and progression of lymphoedema, and the extent to which prior lymphatic functioning further predisposes some individuals to developing secondary lymphoedema (Morrell et al., 2005; Williams, 2006a). Some investigations into the genetic basis of primary lymphoedema have been undertaken but identified mutations only account for less than half the cases of primary lymphoedema and therefore further exploration is required (see Ferrell and Finegold, 2008 for a review of findings to date). This research would add weight to evidence for treatment approaches and enable individuals who are at a heightened risk of developing lymphoedema to adopt prophylactic measures and to access treatments promptly (Piller, 2006).

Secondly, the International Society of Lymphology (2003) called for a lymphoedema classification based on an improved understanding of the mechanisms underlying lymphoedema development including underlying genetic disturbances which could encompass anatomic and functional characteristics. Following the development of such a classification system further research on the prevalence of all types of lymphoedema is required. A study on the prevalence of lymphoedema in Ireland would be particularly welcome as it would assist with the acknowledgement and awareness of the condition, and the strategic planning of lymphoedema service development.

Thirdly, evidence for the effectiveness of particular treatment strategies when used singularly and in tandem with other treatment approaches is also sorely lacking. Furthermore, research into emerging treatments, such as microsurgery to repair lymphatic pathways, is required to ascertain whether they are effective and if so under what circumstances. More robust research on the effectiveness of lymphoedema treatments including their ability to prevent the development of cellulitis and therefore costly inpatient treatment would support the provision of maintenance lymphoedema treatment. A study in the UK calculated that the average cost of managing lymphoedema with information and advice, an exercise programme, MLD and SLD training for patient, MLLB and compression garments as £468.09 for six months treatment per patient including professional time, clinic facility and administrative support (Todd, 1999). The cost of such a programme in an Irish healthcare context needs to be calculated and offset against the alternative costs of inpatient treatment for cellulitis, lost workdays, disability benefits, and the subsequent reduction in revenue contributions, in order to bolster the argument that the provision of lymphoedema services would be cost effective (DHSSPS, 2004; Moffatt et al., 2003). Research into the effectiveness of lymphoedema treatments would also increase awareness of these treatments among the wider healthcare community and consolidate patients' claims for financial support from private health insurance companies.

Fourthly, while this study aimed to contribute to research on the impact of lymphoedema, further research is required. For example the impact of lymphoedema on particular groups that were not included in the current study, such as palliative patients with lymphoedema, children with primary lymphoedema and their carers. While the impact of lymphoedema on patients' sexuality was explored to a certain extent by two items of the patient questionnaire, the topic could not be explored in the group setting of the focus groups. Individual interviews would allow for a more comprehensive investigation of the impact of the condition on sensitive aspects of patients' lives. Alternatively a multi-element study could explore the impact of the condition from the perspectives of the patient, their partner or significant other, children, friends etc. (McWayne & Heiney, 2005). Furthermore as mentioned previously, the current study did not include a measure of psychological wellbeing and therefore it is uncertain what proportion of the sample of Irish lymphoedema patients are experiencing clinical levels of distress.

Finally, research on the impact of the condition on patients must be practically employed (McWayne & Heiney, 2005). For example, studies should be undertaken to ascertain appropriate methods of promoting patients' self-management. Furthermore specific quality of life measures and measures of psychological wellbeing should be developed for use in applied settings so that patients who may require additional support can be identified and supported. The results of the current study correspond with previous studies which reported that lymphoedema patients may experience difficulties with their self-image, isolation and distress. Undoubtedly interventions can be adapted or specifically developed in order to support these patients. Further research is required to develop, pilot and assess them with a view to integrating such evidence-based psychosocial interventions into lymphoedema service provision (Rockson, 2002).

Policy Recommendations

To encourage acknowledgement of lymphoedema among healthcare professionals, private health insurers, compression garment manufacturers, all other relevant stakeholders, and within the HSE, information on lymphoedema, and the results of the current study should be presented to them. As mentioned in the previous section on research recommendations private health insurance companies would be assisted in acknowledging lymphoedema by the dissemination of research on the prevalence of lymphoedema in Ireland, and studies indicating the cost-effectiveness of lymphoedema treatments. Regarding compression garment manufacturers, a forum should be provided whereby manufacturers interact with professionals and patients to improve understanding between the various parties.

With the intention of improving the HSE's acknowledgement of lymphoedema, the results of this study should be provided to the relevant bodies, for example the Health Information and Quality Authority (HIQA) and the National Cancer Control Programme (NCCP). In order for the HSE to demonstrate that lymphoedema has been sufficiently acknowledged, a number of recommendations need to be realised. These recommendations would focus heavily on the initiation and continuation of independent streams of funding to enable the strategic planning and provision of coordinated, equitably-located, nationally-provided, comprehensive services. This strategic planning would be based on the current study, a lymphoedema prevalence study conducted in Ireland, the recommendations of the international consensus on the best practice for the management of lymphoedema (MEP, 2006) and analysis of population distribution in Ireland.

With the intention of reducing current inequalities in service provision, the capacity of existing lymphoedema services should be increased in order to enable services to treat all lymphoedema patients. Where possible, lymphoedema services should be independent and not branches located within cancer clinics. This would encourage the use of lymphoedema services among all lymphoedema patients. Patients with non-cancer-related lymphoedema would not assume that the service was exclusively for patients with cancer-related lymphoedema. Furthermore patients with cancer-related lymphoedema would not have the negative association of being required to attend lymphoedema consultations in the same department that they attended consultations relating to their previous cancer treatment.

Previous reports on lymphoedema service provision have recommended the hub-and-spoke model whereby intensive treatment is provided in specialised clinics by a multi-disciplinary team including breast care nurses, occupational therapists, physiotherapists, psychologists, podiatrists, dermatologists, tissue viability nurses or dieticians as required, as each has a particular perspective to bring (CREST, 2008). Maintenance of the condition would then be delivered more locally in satellite services (MacLaren, 2003). The specialist services would require project management and regular audits to ensure goals and targets are set and reached (DHSSPS, 2004). An example would be the audit conducted by Jeffs (2006), which monitored the presenting characteristics of patients, treatments undertaken and a follow up of outcomes. Ideally these lymphoedema services would form a network, liaising with each other, working from shared protocols and standards (DHSSPS, 2004; Martlew, 1999; Richmond, 2003) This would complement the Irish Department of Health and Children's (DOHC), and the World Health Organisation's (WHO) aims of developing local services and the reorientation of health services into the community, where appropriate (DOHC, 2008; MacLaren, 2003).

Once the establishment of multi-disciplinary teams in lymphoedema services has taken place lymphoedema patients should be offered individual and/or group psychological support, where required, in order to assist them in adapting to living with lymphoedema. Psychological support would not only improve patients' wellbeing but also offers the potential to assist in patients' compliance with lymphoedema management plans (Rockson, 2002). In addition, such psychological support would assist patients in dealing with the specific difficulties they may have. For example, patients with cancer-related lymphoedema may need assistance with dealing with feelings that lymphoedema is a constant reminder of their previous cancer diagnosis and treatment while for primary lymphoedema patients there are the added concerns of heritability.

Furthermore in order to encourage the acknowledgement of lymphoedema among healthcare professionals and appropriate referral of patients, a series of educational programmes is required. Given the wide range of healthcare professionals patients reportedly contacted when they were seeking a diagnosis and treatment, education on the lymphatic system and lymphoedema should be provided across the spectrum of healthcare professionals, from primary care teams (e.g. general practitioners, community nurses etc.) and secondary health professionals (e.g. those working in areas such as cancer, vascular surgery, wound care or tissue viability, dermatology, palliative care, plastic surgery etc.) to lymphoedema specialists themselves (Augustine et al., 1998; Bogan et al., 1997; Runowicz, 1998). The anatomy, physiology and pathophysiology of the lymphatic system, and the prevention, development and treatment of lymphological disorders should be included in the undergraduate curricula of these professionals (CREST, 2008; DHSSPS, 2004).

Information on lymphoedema, its treatment and available services should also be provided through continuous professional development programmes for existing healthcare professionals. Moreover in order to ensure the standardised treatment of all patients, publication of precise patient streams in addition to general practice guidelines are required, such as the guidelines produced by CREST (2008) in Northern Ireland. A cadre of lymphoedema practitioners could cascade their training to facilitate and monitor the awareness of lymphoedema by their colleagues, improving service-wide lymphoedema awareness, which would in turn improve referral pathways and healthcare professionals' appreciation of the difficulties of living with the condition (DHSSPS, 2004). General practitioners and those in primary care should be specifically targeted as they are in a privileged position to identify patients with non-cancer related lymphoedema. For example, resources such as the CREST (2008) decision tree would assist healthcare professionals in identifying the type of chronic oedema patients are experiencing and therefore the most appropriate referral option. Moreover lymphoedema practitioners themselves require repeated training to ensure that the standard of treatment patients receive is optimal. Guidelines on the level of training required by practitioners feature in the British Lymphology Society's (BLS) (2001a) framework for education.

Standardised prevention programmes should be provided for all patients who may be at-risk including those at risk of non-cancer-related secondary lymphoedema and those with a genetic risk of developing primary lymphoedema (McWayne & Heiney, 2005). These programmes would the provision of information on the condition and of available services and baseline measurements of the at risk area. Participants with cancer-related lymphoedema in the focus groups especially spoke about the difficulties of processing the information about lymphoedema when they were distressed following their cancer surgery or treatment. Therefore the provision of repeated group information sessions following patients' discharge from hospital and the inclusion of patients' spouses, friends, or children at these information sessions could assist with this (Runowicz et al., 1998).

Treatment should be available to all lymphoedema patients at least at a subsidised rate through the HSE. As mentioned previously research on the cost of a lymphoedema maintenance programme as opposed to inpatient treatment for cellulitis, lost revenue and disability benefit payments would assist in lobbying for the provision of this essential care. Moreover timely interventions could hinder the development of many of the physical, functional, social and economic consequences of lymphoedema thereby benefiting not just the patients themselves but also limiting the financial implications of the condition on the economy (Person et al., 2008).

However while the above mentioned proposals are undoubtedly required, recommendations cannot be made without consideration of the present economic situation. The Irish healthcare system is currently under enormous financial pressure and cutbacks are being made to what many consider to be essential services. While bearing this in mind, there is scope for recommendations which would be relatively cost-neutral by increasing coordination between lymphoedema practitioners thereby resulting in negligible financial cost while nonetheless benefitting to patients.

Firstly, the information provided to patients at-risk of developing lymphoedema, to lymphoedema patients and to their families should be standardised across lymphoedema services. Practitioners' resources and time are limited so through the collaboration of practitioners perhaps through a lymphoedema support organisation, various information packs could be produced including general information on lymphoedema and tailored information for patients with different needs. This information could also be provided in audiovisual formats, e.g. a DVD or audio CD of general instructions for performing lymphoedema exercises for those with upper limb and lower limb lymphoedema.

Secondly patients need to be empowered to take ownership of their lymphoedema care. While some patients reported taking responsibility for their lymphoedema through daily simple lymphatic drainage, exercises and skincare, many participants indicated they would like additional support from their lymphoedema service. Conversely, practitioners reported that their services lacked the capacity to provide frequent follow up appointments to all patients. At a minimum, the international consensus document states that patients should receive follow up appointments on a six-monthly basis (MEP, 2006). Through the use of the above mentioned information leaflets and audiovisual resources, patients should be encouraged to continue with the self-management of their condition while retaining the option of contacting the service for advice or a prompt appointment in the intervening period if required.

Finally, in a related point, patients also need to be empowered and mobilised to initiate local fora for patients to share experiences, information and ideas and to encourage and support each other on a regional and regular basis. Lymphoedema patients are the most appropriate individuals to support other lymphoedema patients as they best understand the realities of the condition. Additionally, local practitioners could be invited on a rota basis to discuss particular topics with such support groups where possible and required (for example, a workshop on how to perform specific lymphoedema exercises). Family members and friends could be included in these psycho-educational programmes to train them in lymphoedema management techniques (e.g. compression garment and bandage application, simple lymphatic drainage etc.). This could encourage them to support their loved ones, thereby improving patients' adherence to their management plan and increasing the level of involved, informed social support patients receive (Person et al., 2008). Such a support group would not only ensure patients and their families are informed and encouraged it would also have the benefits of combating feelings of isolation and maximising the use of limited resources.

Overall Conclusions

Lymphoedema rates are likely to increase worldwide due to the widely predicted increase in the number of people affected by cancer, surviving cancer and experiencing longer cancer remissions; the increase in life expectancy rates, particularly among women; the increase in obesity levels and decrease in exercise levels; and the increase in lymphatic filariasis infections in endemic countries. One of the outcomes of this report is to highlight the dearth of research in lymphoedema and given the predicted rising lymphoedema prevalence rates, gaps in service provision and the impact of the condition on patients' quality of life it is of paramount importance that the recommended areas of research are investigated promptly. It is intended that the current study, the first conducted in this country, will stimulate research on lymphoedema in the Republic of Ireland and further afield.

Lymphoedema is one of many conditions that require investment to enable the development of appropriate service provision in Ireland. While bearing this in mind, it is intended that by highlighting the pressures endured by practitioners working with limited resources and the challenges endured by patients, lymphoedema will no longer be perceived as an unacknowledged condition.

References

Augustine E, Corn M, Danoff J. (1998). Lymphedema management training for physical therapy students in the United States. Cancer 83(12):2869-2873

Australasian Lymphology Association. (2003). Lymphoedema national service equity survey 2002. Australasian Lymphology Association: Milton, Queensland, Australia

Beaulac SM, McNair LA, Scott TE, LaMorte WW, Kavanagh MT. (2002). Lymphedema and quality of life in survivors of early-stage breast cancer. Archives of Surgery 137:1253-1257

Billingham R. (2006). An unusual case of primary lymphoedema praecox. Journal of Lymphoedema 1(1):73-76 Retrieved 9th of July 2008 from http://www.journaloflymphoedema.com/journal/0101_praecox.pdf

Bogan LK, Powell JM, Dudgeon BJ. (2007). Experiences of living with non-cancer-related lymphoedema: Implications for clinical practice. Qualitative Health Research 17(2)213-224

Box RC, Reul-Hirche HM, Bullock-Saxton JE, Furnival CM. (2002). Physiotherapy after breast cancer surgery: results of a randomised controlled study to minimise lymphoedema. Breast Cancer Research and Treatment 75:51-64

BreastCare Victoria. (2005). A review of lymphoedema services in Victoria. Victorian Government Department of Human Services: Melbourne, Victoria, Australia

British Lymphology Society (BLS). (2001a). Framework for Education. BLS: Gloucester, England

British Lymphology Society (BLS). (2001b). Clinical Definitions. BLS: Gloucester, England

British Lymphology Society (BLS). (2007). Strategy for Lymphoedema Care. BLS: Gloucester, England

Bryman A. (2007). Barriers to integrating quantitative and qualitative research. Journal of Mixed Methods Research 1(1): 8-22

Bulley C. (2007). A needs assessment of lymphoedema services in Fife and resulting recommendations. Primary Health Care Research and Development 8:128-140

Burns F, Micke O, Bremer M. (2003). Current status of selenium and other treatments for secondary lymphedema. Journal of Supportive Oncology 1(2):121-130

Burton M, Watson M. (1988). Counselling People with Cancer. John Wiley & Sons Ltd.: Chicester, West Sussex, England

Casley-Smith JR, Boris M, Weindorf S, Lasinski B. (1998). Treatment for lymphedema of the arm – the Casley-Smith method. Cancer 83(12):2843-2860

Clinical Resource Efficiency Support Team (CREST) (2008). Guidelines for the diagnosis, assessment and management of lymphoedema. CREST: Belfast, Northern Ireland

Coster S, Poole K, Fallowfield LJ. (2001). The validation of a qualify of life scale to assess the impact of arm morbidity in breast cancer patients post-operatively. Breast Cancer Research and Treatment 68:273-282

Creswell JW, Plano Clark VI. (2007). Designing and Conducting Mixed Methods Research. Sage Publications: London, England

Department of Health, Social Services and Public Safety (DHSSPS) (2004). Lymphoedema services: Report of the Lymphoedema Services Review Group. DHSSPS: Belfast, Northern Ireland

Department of Health and Children. (DOHC) (2008). Tackling Chronic Disease: A Policy Framework for the Management of Chronic Diseases. DOHC: Dublin, Ireland

Doherty D. (2006). Assessment of lymphoedema of the lower limbs by the community nurse. British Journal of Community Nursing 11(10):S9-S11

Engel J, Kerr J, Schlesinger-Raab A, Sauer H, Hölzel D. (2003). Axilla surgery severely affects quality of life: results of a 5-year prospective study in breast cancer patients. Breast Cancer Research and Treatment 79:47-57

Erzberger C, Kelle U. (2003). Chapter 16: Making inferences in mixed methods: The rules of integration. In A Tashakkori & C Teddlie (Eds.) Handbook of Mixed Methods in Social and Behavioural Research. Sage Publications: Thousand Oaks, California, United States of America

Farmer T, Robinson K, Elliott SJ, Eyles J. (2006). Developing and implementing a triangulation protocol for qualitative health research. Qualitative Health Research 16(3):377-394

Ferrell RE, Finegold DN. (2008). Research perspectives in inherited lymphatic disease: An update. Annals of the New York Academy of Sciences 1131:134-139

Field A. (2005). Discovering Statistics Using SPSS. Second Edition. Sage Publications: London, England, UK

Fielding NG, Fielding JL. (1987). Linking Data. Sage University Paper Series on Qualitative Research Methods Series 4. Sage Publications: Beverley Hills, California, United States of America

Földi E. (1998). The treatment of lymphedema. Cancer 83(12):2833-2834

Földi E, Jünger M, Partsch H. (2005). The science of lymphoedema bandaging. Pp.2-4 In European Wound Management Association (EWMA). Focus document: Lymphoedema bandaging in practice. MEP Limited: London

Foster RL. (1997). Addressing epistemologic and practical issues in multimethod research: A procedure for conceptual triangulation. Advances in Nursing Science 20(2):1-12

Franks PJ, Moffatt CJ, Doherty DC, Williams AF, Jeffs E, Mortimer PS. (2006). Assessment of health-related quality of life in patients with lymphedema of the lower limb. Wound Repair and Regeneration 14:110-118

Gallagher P, & MacLachlan M. (2000). The development and psychometric evaluation of the Trinity Amputation and Prosthesis Experience Scales (TAPES). Rehabilitation Psychology 45:130-155

Golshan M, Martin WJ, Dowlatshahi K. (2003). Sentinel lymph node biopsy lowers the rate of lymphoedema when compared with standard axillary lymph node dissection. The American Surgeon 69:209-212

Guallar-Castillón P, Sendino ÁR, Banegas JR, López-Garcia E, Rodríguez-Artalejo F. (2005). Differences in quality of life between women and men in the older population of Spain. Social Science and Medicine 60:1229-1240

Hardy D. (2006). Managing long-term conditions: Non-cancer-related lymphoedema. British Journal of Nursing 15(8):444-452

Hare M. (2000). The lived experience of breast cancer-related lymphoedema. Nursing Standard 15(7):35-39

Harris SR, Hugi MR, Olivotto IA, Levine M. (2001). Clinical practice guidelines for the care and treatment of breast cancer: 11 lymphedema. Canadian Medical Association Journal 164(2):191-199

Horning KM & Guhde J. (2007). Lymphedema: An under-treated problem. Medical-Surgical Nursing 16(4):221-227

International Society of Lymphology. (2003). The diagnosis and treatment of peripheral lymphedema. Lymphology 36:84-91

Irish Breast Care Nurses Association (IBCNA) (2004). Guidelines for Practice. IBCNA: Dublin, Ireland

Ivankova NV, Creswell JW, Stick SL. (2006). Using mixed-methods sequential explanatory design: From theory to practice. Field Methods 18(1):3-20

Jeffs E. (2006). Treating breast cancer-related lymphoedema at the London Haven: clinical audit results. European Journal of Oncology Nursing 10:71-79

Johnson RB, Onwuegbuzie AJ, Turner LA. (2007). Toward a definition of mixed methods research. Journal of Mixed Methods Research 1(2):112-133

Johansson K, Holmström H, Nilsson I, Ingvar C, Albertsson M, Ekdahl C. (2003). Breast cancer patients' experiences of lymphoedema. Scandinavian Journal of Caring Sciences 17:35-42

Keeley V. (2006). The use of lymphoscintigraphy in the management of chronic oedema. Journal of Lymphoedema 1(1):42-57 Retrieved 9th of July 2008 from http://www.journaloflymphoedema.com/journal/0101_lymphoscintigraphy.pdf

Krueger RA. (1997). Analyzing and Reporting Focus Groups Results. Focus Group Kit (Vol. 6) London: Sage.

Lacovara JE, Yoder LH (2006) Secondary lymphoedema in the cancer patient. Medsurg Nursing 15(5):302-306

Lam R, Wallace A, Burbidge B, Franks P, Moffatt C. (2006). Experiences of patients with lymphoedema. Journal of Lymphoedema 1(1):16-21 Retrieved 9th of July 2008 from http://www.journaloflymphoedema.com/journal/0101_experiences.pdf

Lazarus RS. (1999). Stress and Emotion: A New Synthesis. Springer Publishing Company: New York, USA

Leitch AM, Meek AG, Smith RA, Boris M, Bourgois P, Higgins S, Pressman PI, Stevens J, Stevens RE. (1998). Workgroup 1: Treatment of the axilla with surgery and radiation – preoperative and postoperative risk assessment. Cancer 83(12):2877-2879

Lu S, Anh Tran T, Jones DM, Meyer DR, Ross JS, Fisher HA, Carlson JA. (2008). Localised lymphedema (elephantiasis): a case series and review of the literature. Journal of Cutaneous Pathology 1-20

MacLaren J-A. (2003). Models of lymphoedema service provision across Europe: sharing good practice. Journal of Palliative Nursing 9(12):538-543

Maxwell JA, Loomis DM. (2003). Chapter 9: Mixed methods design: An alternative approach. In A Tashakkori & C Teddlie (Eds.) Handbook of Mixed Methods in Social and Behavioural Research. Sage Publications: Thousand Oaks, California, United States of America

Mak SS, Mo KF, Suen JJS, Chan SL, Ma WL, Yeo W. (2009). Lymphedema and quality of life in Chinese women after treatment for breast cancer. European Journal of Oncology Nursing 13:110-115

Mansel RE, Fallowfield L, Kissin M, Goyal A, Newcombe RG, Dixon JM, Tiangou C, Horgan K, Bundred N, Monypenny I, England D, Sibbering M, Abdullah TI, Barr L, Chetty U, Sinnett DH, Flessig A, Clark D, Ell PJ. (2006). Randomised multicenter trial of sentinel node biopsy versus standard axillary treatment in operable breast cancer: the ALMANAC trial. Journal of the National Cancer Institute 98(9):599-609

Martlew B. (1999) Mapping lymphoedema service provision in the Mount Vernon cancer network. Retrieved 26th May 2008 from http://www.lymphoedema.org/bls/pdf_docs/martlew.pdf

McKinley RK, Manku-Scott T, Hastings AM, French D P, Baker R. (1997). Reliability and validity of a new measure of patient satisfaction with out of hours primary medical care in the United Kingdom: Development of a patient questionnaire. British Medical Journal 314:193-8.

McWayne J, Heiney SP. (2005). Psychologic and social sequelae of secondary lymphedema: A review. Cancer, 104(3):457-466

Medical Education Partnership (MEP). (2006). International Consensus Best Practice for the Management of Lymphoedema. Medical Education Partnership LTD.: London, UK

Moffatt CJ, Franks PJ, Doherty DC, Williams AF, Badger C, Jeffs E, Bosanquet N Mortimer PS. (2003). Lymphoedema: An underestimated health problem. Quarterly Journal of Medicine 96:731-738

Mondry TE, Riffenburgh RH, Johnstone PAS. (2004). Prospective trial of complete decongestive therapy for upper extremity lymphoedema after breast cancer therapy. The Cancer Journal 10(1):42-48

Morgan DL. (1997). Focus groups as qualitative research. Second Edition. Sage Publications: California, USA

Morgan PA. (2006). Health professionals' ideal roles in lymphoedema management. Journal of Community Nursing 11(8):5-8

Morgan PA, Moffatt CJ. (2006). An update on the lymphoedema framework project. British Journal of Community Nursing 11(10):20-21

Morgan PA, Franks PJ, Moffatt CJ. (2005). Health-related quality of life with lymphoedema: A review of the literature. International Wound Journal 2:47-62

Morgan PA, Moffatt CJ, Doherty DC. (2006). Achieving consensus in lymphoedema care. Journal of Lymphoedema 1(1):22-31 Retrieved 30th of June 2008 from http://www.journaloflymphoedema.com/journal/0101_consensus.pdf

Morgan PA, Moody M, Franks PJ, Moffatt CJ & Doherty DC. (2005). Assessing community nurses' level of knowledge of lymphoedema. British Journal of Nursing 14(1):8-13

Morrell RM, Halyard MY, Schild SE, Ali MS, Gunderson LL, Pockaj BA. (2005). Breast cancer-related lymphoedema. Mayo Clinic Proceedings 80(11):1480-1484

Mortimer PS. (1998). The pathophysiology of lymphedema. Cancer 83(12):2798-2802

Muscari E. (2004). Lymphedema: Responding to our patients' needs. Oncology Nursing Forum 31(5):905-912

National Cancer Institute (NCI). (2008). Lymphedema. Retrieved 29th May 2008 from http://www.nci.nih.gov/cancertopics/pdq/supportivecare/lymphedema

National Lymphedema Network (NLN). (2004). Position Statement of the National Lymphedema Network: Air Travel. Retrieved 29th May 2008 from http://www.lymphnet.org/pdfDocs/nlnairtravel.pdf

National Lymphedema Network (NLN). (2005). Position Statement of the National Lymphedema Network Lymphedema: Risk Reduction Practices. Retrieved 29th May 2008 from http://www.lymphnet.org/pdfDocs/nlnriskreduction.pdf

National Lymphedema Network (NLN). (2006). Position Statement of the National Lymphedema Network: Treatment. Retrieved 29th May 2008 from http://www.lymphnet.org/pdfDocs/nlntreatmeht.pdf

O'Catháin A, Murphy E, Nicholl J. (2007). Integration and publications as indicators of "yield" from mixed methods studies. Journal of Mixed Methods Research 1(2):147-163

Okeke AA, Bates DO, Gillatt DA. (2004). Lymphoedema in urological cancer. European Urology 45:18-25

Pallant, J. (2007) SPSS Survival Manual: A Step by Step Guide to Data Analysis using SPSS for Windows. Third Edition. McGraw Hill Open University Press: Maidenhead, Berkshire, England, UK.

Partsch H, Jünger M. (2006). Evidence for the use of compression hosiery in lymphoedema. In Lymphoedema Framework. Template for Practice: compression hosiery in lymphoedema. MEP Limited: London, UK

Passik SD, McDonald MV. (1998). Psychosocial aspects of upper extremity lymphedema in women treated for breast carcinoma. Cancer 83(12): 2817-2820

Passik SD, Newman ML, Brennan M, Tunkel R. (1995). Predictors of psychological distress, sexual dysfunction and physical functioning among women with upper extremity lymphedema related to breast cancer. Psycho-oncology 4-255-263

Person B, Addiss D, Bartholomew LK, Meijer C, Pou V, Gonzálvez G, van den Borne B. (2007). A qualitative study of the psychosocial and health consequences associated with lymphedema among women in the Dominican Republic. Acta Tropica 103:90-97

Person B, Addiss D, Bartholomew LK, Meijer C, Pou V. (2008). "Can it be that God does not remember me": A qualitative study on the psychological distress, suffering, and coping of Dominican women with chronic filarial lymphedema and elephantiasis of the leg. Health Care for Women International 29:349-365

Petrek JA, Heelan MC. (1998). Incidence of breast carcinoma-related lymphedema. Cancer. 83:2776-2781

Petrek JA, Senie RT, Peters M, Rosen PP. (2001). Lymphedema in a cohort of breast carcinoma survivors 20 years after diagnosis. Cancer 92(6):1368-1377

Piller N. (2006). Understanding lymphoedema in the new millenium. Journal of Lymphodema 1(1):60-65 Retrieved 9th of July 2008 from http://www.journaloflymphoedema.com/journal/0101_millenium.pdf

Radina ME, Armer JM. (2001). Post-breast cancer lymphedema and the family: a qualitative investigation of families coping with chronic illness. Journal of Family Nursing 7(3):281-299

Radina ME, Armer JM (2004). Surviving breast cancer and living with lymphedema: Resiliency among women in the context of their families. Journal of Family Nursing 10(4):485-505

Rankin J, (2001). Regional Audit of Training in Lymphoedema Care. Belfast City Hospital Trust: Belfast, Northern Ireland

Revis DR. (2008). Lymphedema. Retrieved 29th May 2008 from http://www.emedicine.com/med/topic2722.htm

Richmond K. (2003). A review of lymphoedema services in Wales. Received in private correspondence from the Welsh Association of Lymphoedema Services (WALS).

Ridner SH. (2002). Breast cancer lymphedema: pathophysiology and risk reduction guidelines. Oncology Nursing Forum 29(9):1285-1293

Rietman JS, Dijkstra PU, Geertzen JHB, Baas P, de Vries J, Dolsma WV, Groothoof JW, Eisma WH, Hoekstra HJ. (2004). Treatment-related upper limb morbidity 1 year after sentinel lymph node biopsy or axillary lymph node dissection for stage I or stage II breast cancer. Annals of Surgical Oncology 11(11):1018-1024

Rinehart-Ayres ME. (1998). Conservative approaches to lymphedema treatment. Cancer 83(12):2828-2832

Robertson Squire M. (2000). Chapter 1: The patient's perspective. pp. 1-10 In R Twycross, K Jenns, J Todd. (Eds.) Lymphoedema. Radcliffe Medical Press: Abingdon, Oxon, England, UK

Rockson SG. (2002). Lymphedema after surgery for cancer: The role of patient support groups in patient therapy. Disease Management and Health Outcomes 10(6):345-347

Rockson SG, Rivera KK. (2008). Estimating the population burden of lymphedema. Annals of the New York Academy of Sciences 1131:147-154

Roth AJ. (1983). Robust trend tests derived and simulated: Analogs of the Welch and Brown-Forsythe tests. Journal of the American Statistical Association 78(384):972-980

Runowicz CD, Passik SD, Hann D, Berson A, Chang H, Makar K, Moss R, Osuch J, Petrek JD, Vaillant-Newman A-M. (1998). Workgroup 2: Patient education - pre- and posttreatment. Cancer 83(12): 2880-2881

Schlenk EA, Erlen J, Dunbar-Jacob J, McDowell J, Engberg S, Sereika SM, Rohay JM, Bernier MJ. (1998). Health-related quality of life in chronic disorders: A comparison across studies using the MOS SF-36. Quality of Life Research 7(1):57-65

Schwarz R, Hinz A. (2001). Reference data for the quality of life questionnaire EORTC QLQ-C30 in the general German population. European Journal of Cancer 37:1345-1351

Sener SF, Winchester DJ, Martz CH, Feldman JL, Cavanaugh JA, Winchester DP, Weigel B, Bonnefoi K, Kirby K, Morehead C. (2001). Lymphedema after sentinel lymphadenectomy for breast carcinoma. Cancer 92(4):748-752

Sitzia J, Harlow W. (2002). Lymphoedema 4: research priorities in lymphoedema care. British Journal of Nursing 11(8):531-541

Skevington SM, Lotfy M, O'Connell KA. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial a report from the WHOQOL Group. Quality of Life Research 13:299-310

Slonim-Nevo V, Nevo I. (2009). Conflicting findings in mixed methods research: An illustration from an Israeli study on immigration. Journal of Mixed Methods Research 3(2):109-128

Sneddon MC, Lewis M. (2007). Lymphoedema: A female health issue with implications for self care. British Journal of Nursing 16(2):76-81

Soran A, D'Angelo G, Begovic M, Ardic F, Harlak A, Wieand HS, Vogel VG, Johnson RR. (2006). Breast cancer-related lymphedema – What are the significant predictors and how they affect the severity of lymphedema? The Breast Journal 12(6):536-543

Sprangers MAG, Schwartz CE. (1999). Integrating response shift into health-related quality of life research: A theoretical model. Social Science and Medicine 48:1507-1515

Swenson KK, Nissen MJ, Leach JW, Post-White J. (2009). Case-control study to evaluate predictors of lymphedema after breast cancer surgery. Oncology Nursing Forum 36(2):185-193

The WHOQOL Group (1998). Development of the World Health Organisation WHOQOL-BREF quality of life assessment. Psychological Medicine 28:551-558

Thomas-MacLean R. (2005). Beyond dichotomies of health and illness: Life after breast cancer. Nursing Inquiry 12(3):200-209

Thomas-MacLean RL, Hack T, Kwan W, Towers A, Miedema B, Tilley A. (2008). Arm morbidity and disability after breast cancer: new directions for care. Oncology Nursing Forum 35(1):65-71

Tiwari A, Myint F, Hamilton G. (2006). Management of lower limb lymphoedema in the United Kingdom. European Journal of Vascular and Endovascular Surgery 31:311-315

Tobin GA, Begley CM. (2004). Methodological rigour within a qualitative framework. Journal of Advanced Nursing 48(4):388-396

Tobin MB, Lacey HJ, Meyer L, Mortimer PS. (1993). The psychological morbidity of breast cancer-related arm swelling. Cancer 72:3248-3252

Todd JE. (1999). A study of lymphoedema patients over their first six months of treatment. Physiotherapy 85(2):65-76

Todd M. (2006). Lymphoedema: sizing up the problem. British Journal of Community Nursing 11(8):3-4

Turner JB, & Turner RJ. (2004). Physical disability, unemployment and mental health. Rehabilitation Psychology 49(3):241-249

Velanovich V, Szymanski W. (1999). Quality of life of breast cancer patients with lymphedema. The American Journal of Surgery 1777:184-188

Waters, B. (2007). Unknown Stories: Biographies of Adults with Primary Lymphoedema. Progress Article for British Lymphology Society. Received in Private Email Correspondence.

Williams A. (2003). An overview of non-cancer related chronic oedema – a UK perspective. World Wide Wounds Electronic Wound Management Journal. Retrieved on 14th of May 2008 from
http://www.worldwidewounds.com/2003/april/Wiliams/Chronic-Oedema.html

Williams A. (2006a). Lymphoedema: Care in the community. Primary Health Care 16(6):25-29

Williams A. (2006b). Patient self-massage for breast cancer-related lymphoedema. Journal of Community Nursing 20(6):24-28

Williams A. (2006c). Breast and trunk oedema after treatment for breast cancer. Journal of Lymphoedema 1(1):32-39 Retrieved 9th of July 2008 from http://www.journaloflymphoedema.com/journal/0101_breasttrunk.pdf

Williams A. (2008). Managing arm lymphoedema due to advanced cancer. Journal of Community Nursing 22(05):24-30

Williams AF, Moffatt CJ & Franks PJ. (2004). A phenomenological study of the lived experiences of people with lymphoedema. International Journal of Palliative Nursing 10:279-286

Williams AF, Franks PJ, Moffatt CJ. (2005). Lymphoedema: estimating the size of the problem. Palliative Medicine 19:300-313

Woods M. (1993). Patients' perceptions of breast-cancer-related lymphoedema. European Journal of Cancer Care 2:125-128

World Health Organisation (1996). WHOQOL-BREF: Introduction, Administration, Scoring and Generic Version of the Assessment. Field Trial Version. World Health Organisation: Geneva, Switzerland

World Health Organisation (1997). WHOQOL: Measuring Quality of Life. World Health Organisation: Geneva, Switzerland

World Health Organisation (2000). Media Centre FactSheet No. 102: Lymphatic Filariasis. Revised September 2000. Retrieved 27th of August 2009 from http://www.who.int/mediacentre/factsheets/fs102/en/

Wynd S, Melrose WD, Durrheim DN, Carron J, Byapong M. (2007). Understanding the community impact of lymphatic filariasis: A review of the sociocultural literature. Bulletin of the World Health Organisation. 85(6):493-498

Appendix A

Service Provider Questionnaire Cover Letter

<Address of Practitioner>

<Date>

Dear <Mr. / Ms. Surname of Practitioner>,

The Irish Cancer Society, in conjunction with the School of Nursing, Dublin City University is conducting research into patients' experience of living with lymphoedema and of lymphoedema service provision in Ireland. The overall aim is to learn more about the experiences of people affected by all types of lymphoedema in order to influence the development of nationwide service provision and policy guidelines, which directly respond to an identified need.

The research team are involving people affected by lymphoedema and the people who provide the service to give them the opportunity to voice their opinion on this area, so that improvements can be made.

We are contacting you and requesting your participation in this research because you are working in a service which treats lymphoedema patients and consequently, your views are extremely important in enhancing our understanding of current lymphoedema service provision in Ireland. If you are unaware of the treatments available to lymphoedema patients in your service, please pass this questionnaire on to the most appropriate person in your department or service.

You will find an Information Sheet and Questionnaire enclosed with this letter. Please answer all questions in the Questionnaire and post it back, as soon as possible, in the enclosed FREEPOST envelope to FREEPOST, Susan O'Carroll, Irish Cancer Society, 43–45 Northumberland Road, Dublin 4.

Participation is on a voluntary basis. You are under no obligation to take part in this research study. All your answers to the Questionnaire will remain strictly confidential.

If you would like further information about the study please don't hesitate in contacting Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2310594. We would greatly appreciate your support in this project.

Yours sincerely,

Susan O'Carroll

Clinical Coordinator
Irish Cancer Society

Appendix B

Service Provider Survey Information Sheet

1. Title of research project:

Exploring the Provision of Lymphoedema Services in Ireland.

2. Introduction:

You are being invited to take part in a study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, please contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

Lymphoedema is a chronic, incurable condition that can lead to pain, susceptibility to infections as well as compromised mobility. However, with early diagnosis and intervention, the condition can be well controlled. As a result, prompt diagnosis and appropriate treatment is an essential part of the management process. However, in Ireland there has been no research on lymphoedema service provision to date.

The overall aim of this research is to learn more about the experiences of patients in the diagnosis, treatment and management of lymphoedema. People affected by lymphoedema and professionals who provide the service will be involved in the research, so that improvements in this area can be made. This research is funded by Action Breast Cancer (a project of the Irish Cancer Society); and was devised by a research team consisting of Ms. Susan O'Carroll, Irish Cancer Society, and Dr. Pamela Gallagher and Ms. Maeve Murray, the School of Nursing, Dublin City University.

3. Procedures:

You are being contacted about this study because you currently hold or have held a position in a hospital/service that treats lymphoedema patients in the past six months.

You are being asked to take part in a survey about the lymphoedema treatments and support services available by filling out a questionnaire.

If you would like to take part, you are asked to complete the questionnaire and to return it to FREEPOST, Susan O'Carroll, Irish Cancer Society, 43-45 Northumberland Road, Dublin 4.

4. Benefits:

There are no direct benefits to taking part in this study. However, the information that will be collected will help develop guidelines to improve equity, availability and quality in lymphoedema service provision. Research that helps develop policy in this way will, in turn, benefit professionals working in the services.

5. Risks:

Asking you about your experiences of treating lymphoedema may bring about unpleasant or upsetting memories. If you feel uncomfortable or distressed at any stage, you can withdraw without any consequences. You can also contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

6. Exclusion from participation:

If you have not held a position in a hospital/service that treats lymphoedema patients in the past six months, you will be unable to take part in the study.

7. Confidentiality:

If you agree to take part, all information collected will be kept strictly confidential.

The study findings will form the basis for preparation of policy documents, reports, academic publications, conference papers and other scientific publications.

8. Voluntary participation:

You have volunteered to take part in this study. You may withdraw your participation at any time. If you decide not to participate, or if you quit, you will not be penalised. There will be no penalty for withdrawing before all stages of the research study have been completed.

9. Permission:

This research project has been approved by Dublin City University Research Ethics Committee.

10. Further Information:

If you need more information about your participation in the study, your rights, or answers to your questions about the study, contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

If participants have concerns about this study and wish to contact an independent person, please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9. Tel 01-7008000

Appendix C

Service Provider Questionnaire

This is a questionnaire designed to investigate different aspects of lymphoedema service provision. We are interested in **all** types of lymphoedema, primary and secondary.

Please answer every item as honestly as you can. There are no right or wrong answers. Your responses will remain completely confidential.

SECTION 1: GENERAL INFORMATION

1. What position do you hold?
[ ] Breast Care Nurse
[ ] Lymphoedema Nurse Specialist
[ ] MLD Therapist
[ ] Occupational Therapist
[ ] Occupational Therapy Manager
[ ] Physiotherapist
[ ] Physiotherapy Manager
[ ] Other, please specify___________________________

2. Do you personally treat people with lymphoedema? [ ] Yes [ ] No
(IF NO, GO TO SECTION 6)

2b. If yes, how long have you been treating people with lymphoedema?
______ years_____ months

2c. If yes, how many hours per working week do you spend in activities related to the treatment of lymphoedema patients (please state number of hours)?
_____________hours

SECTION 2: PATIENT PROFILE

3. Please estimate how many patients you are currently treating? ____________ patients

4. On average, how many patients do you treat in a month?
Initial Consultation–Education, Skin Care, SLD ____________ patients
Intensive Treatment – MLD/MLLB ____________ patients
Follow up appointments ____________ patients

5. On average, how many times is each patient seen?
____

6. On average, how long does each consultation last? _____________ Upper limb patients
_____________ Lower limb patients

7. Please estimate what percentage of the patients you have treated in the last year experience the following forms of lymphoedema (Please write the approximate percentage next to each type of lymphoedema. Leave the others blank. Your answers should total 100%):

________% Primary lymphoedema

________% Lymphoedema secondary to breast cancer

________% Lymphoedema secondary to other types of cancer

_______% Lymphoedema secondary to trauma and tissue damage (e.g. burns, varicose vein surgery, scarring, large wounds, self harm etc.)

_______% Lymphoedema secondary to venous disease (e.g. DVT chronic venous insufficiency, intravenous drug use etc.)

_______% Lymphoedema secondary to infection (e.g. cellulitis, lymphadenitis, filariasis etc.)

_______% Lymphoedema secondary to inflammation (e.g. rheumatoid arthritis, psoriatic arthritis, dermatitis/eczema, sarcoidosis etc.)

_______% Lymphoedema secondary to immobility and dependency (e.g. dependency lymphoedema, obesity, paralysis etc.)

7b. Please estimate what are the five most common types of cancers that the patients you have treated in the last year have experienced which have caused their lymphoedema (from most to least common)? (Please write the approximate percentage next to each type of cancer. Leave the others blank. Your answers should total 100%):

Type of cancer	% of your patients who have lymphoedema as a result
1.	_______%
2.	_______%
3.	_______%
4.	_______%
5.	_______%

8. Please estimate what percentage of the patients you have treated in the last year have lymphoedema in the following parts of their bodies?

_______% Unilateral upper limb

________% Bilateral upper limb

_______% Unilateral lower limb

_______% Bilateral lower limb

_______% Face and/or neck

_______% Genitals

_______% Other, please specify ____

9. Please estimate what percentage of the patients you have treated in the last year were in the following age ranges when you first began to treat them?

_______% Less than 18 years old

________% 19-35 years

________% 36-50 years

_______% 51-65 years

_______% Over 66 years old

10. What is the greatest distance a patient would travel to get to your service (approximately)? ____km

11. Please estimate what percentage of the patients you have treated in the last year live within a 10km radius of your service (approximately)? _____%

12. Please estimate what percentage of the patients you have treated in the last year live more than 50km from your service (approximately)? _____%

SECTION 3: PATIENT REFERRAL

13. Do you receive referrals from the following sources?

			If yes, can you treat them?	
	Yes	No	Yes	No
Hospital oncology clinics	[ ]	[ ]	[ ]	[ ]
Hospital general surgical clinics	[ ]	[ ]	[ ]	[ ]
Hospital physiotherapy clinics	[ ]	[ ]	[ ]	[ ]
Hospital dermatology clinics	[ ]	[ ]	[ ]	[ ]
Hospital leg ulcer clinics	[ ]	[ ]	[ ]	[ ]
Hospital vascular clinics	[ ]	[ ]	[ ]	[ ]
Hospital general medical clinics	[ ]	[ ]	[ ]	[ ]
Hospital tissue viability clinics	[ ]	[ ]	[ ]	[ ]
Community physiotherapy clinics	[ ]	[ ]	[ ]	[ ]
Community leg ulcer clinics	[ ]	[ ]	[ ]	[ ]
General Practitioners	[ ]	[ ]	[ ]	[ ]
Patients self referring	[ ]	[ ]	[ ]	[ ]
Family/friends of patients	[ ]	[ ]	[ ]	[ ]
Other (please specify) ______________________			[ ]	[ ]

14. Please indicate the 3 most common referral sources.

1.______________________________________

2.______________________________________

3.______________________________________

15. If you get a referral for a lymphoedema patient that your service cannot treat at that time do you know where you can refer them to? [ ] Yes [ ] No

16. How often does this happen? ______________________

17. Please estimate what percentage of the patients you have treated in the last year has gone abroad for treatment? _____%

18. Please add additional comments on the referral options for lymphoedema patients?

____

____

____

SECTION 4: MINIMISING RISK AND TREATMENTS PROVIDED

19. Do you provide advice on how to minimise the risk of developing lymphoedema to those who may have compromised lymphatic functioning?

[ ] Yes [ ] No

19b. If yes, please give details about the content of the information you provide and to what types of patients.

____

____

20. Do you provide the following treatments in the management of lymphoedema?

			If no, is the treatment available within your service?	
	Yes	No	Yes	No
Education on skincare	[ ]	[ ]	[ ]	[ ]
Education on diet	[ ]	[ ]	[ ]	[ ]
Education on when to seek further medical attention	[ ]	[ ]	[ ]	[ ]
Education on how to perform simple lymphatic drainage	[ ]	[ ]	[ ]	[ ]
Manual lymphatic drainage	[ ]	[ ]	[ ]	[ ]
Education on how to perform exercises	[ ]	[ ]	[ ]	[ ]
Multi-layer lymphoedema bandaging	[ ]	[ ]	[ ]	[ ]
Education on self-bandaging	[ ]	[ ]	[ ]	[ ]
Compression garment fitting	[ ]	[ ]	[ ]	[ ]
Intermittent pneumatic compression pump	[ ]	[ ]	[ ]	[ ]
Other, Please specify________________________	[ ]	[ ]	[ ]	[ ]

21. Please estimate what percentage of the patients you have treated in the last year have you fitted lymphoedema compression garments for: _____%

21b. Please estimate what percentage of the patients you have treated in the last year use off-the-shelf garments? _____%

21c. Please estimate what percentage of the patients you have treated in the last year use custom-made garments? _____%

21d. On average, how many compression garments would you fit each month?

____

21e. What is the average length of time for a garment to be delivered by a supplier?

____

21f. Does the length of time waiting for the delivery of a garment interfere with the treatment of patients? [ ] Yes [ ] No

21g. Please add additional comments on the availability of garments and the duration spent waiting for the delivery of garments.

____

____

____

SECTION 5: PROFESSIONAL DEVELOPMENT

22. How would you rate yourself on each of the following characteristics when thinking about treating patients with lymphoedema?

		Not at all ←								→ Extremely
(i)	Knowledgeable.	1	2	3	4	5	6	7	8	9	10
(ii)	Competent	1	2	3	4	5	6	7	8	9	10
(iii)	Experienced	1	2	3	4	5	6	7	8	9	10
(iv)	Confident	1	2	3	4	5	6	7	8	9	10

23. Do you keep up to date with current advances in lymphoedema research by…?

	Yes	No
(i) Reading a relevant journal?	[ ]	[ ]
(ii) Reading a relevant magazine?	[ ]	[ ]
(iii) Attending conferences?	[ ]	[ ]
(iv) Attending lectures/meetings/workshops on the subject?	[ ]	[ ]
(v) Other (please specify)____________________________________	[ ]	[ ]

24. Have you completed any of the following forms of additional training in lymphoedema management?

	Yes	No
Postgraduate training in lymphoedema management	[ ]	[ ]
Training provided by the Casley-Smith School	[ ]	[ ]
Training provided by the Földi School	[ ]	[ ]
Training provided by the Klose School	[ ]	[ ]
Training provided by the Leduc School	[ ]	[ ]
Training provided by the Vodder School	[ ]	[ ]
Training in garment fitting by compression garment providers	[ ]	[ ]
Introductory workshops on lymphoedema provided by Action Breast Cancer	[ ]	[ ]

Other (please specify) ____

25. Do you think there is sufficient opportunity for professional development in the field of lymphoedema treatment? [ ] Yes [ ] No

25b. If no, which of the following training needs do you feel should be addressed *(please tick one or more boxes)*?

[ ] Modules at undergraduate level on the lymphatic system and lymphoedema for all relevant disciplines (e.g. nursing, occupational therapy, physiotherapy, medicine etc.)

[ ] Postgraduate training on lymphatics and lymphoedema

[ ] Provision of specialised training for those working with lymphoedema patients (e.g. as provided by the Casley Smith, Főldi, Klose, Leduc and Vodder schools)

[ ] Provision of Continual Professional Development lymphoedema courses to enable practitioners to keep abreast of lymphoedema research and treatment developments

[ ] Other, please specify____
____
____

SECTION 6: YOUR SERVICE

26. How long have you been working in the hospital/service that you currently work in?
______ years_____ months

27. In what county in Ireland is your service located? ______________________________

28. How would you best describe your service?
[ ] Public [ ] Private [ ] Mix of public/private

28b. If you are a private practitioner, have you been funded by the HSE to treat people in your private practice? [ ] Yes [ ] No

29. In what setting is your service located?

[ ] University/Teaching Hospital
[ ] General Hospital
[ ] Community Health Centre
[ ] Hospice
[ ] Regional Hospital
[ ] Private Hospital
[ ] Cancer Support Centre
[ ] Private Practice
[ ] Other, Please specify________________________________

30. Is your service a dedicated service for lymphoedema patients? [ ] Yes [ ] No

30b. Please give further details.

____
____
____
____

30c. If no (to Question 30), are you in the process of developing a lymphoedema service? [ ] Yes [ ] No

Please give further details on the number of full time equivalent staff that is required by your service.

____
____
____
____

30d. If yes (to Question 30), are you in the process of expanding an existing lymphoedema service? [ ] Yes [ ] No

Please give further details on the number of full time equivalent staff that is required by your service.

____
____
____
____

31. Please estimate approximately what percentage of your <u>service's funding</u> comes from each of the following <u>sources</u>? (Please write the approximate percentage next to each of your funding sources. Leave the others blank. Your answers should total 100%)

____% Breast Care
____% Oncology
____% Physiotherapy
____% Occupational Therapy
____% Vascular
____% Dermatology
____% Community health
____% Patient contributions
____% Grant (please specify source) _________________________
____% Other (please specify) ________________________________
[ ] Don't Know

32. How many people employed in your service, <u>work in the treatment of lymphoedema</u>**,** in the following occupations?

	Number of Staff Members
(i) Nurses	
(ii) Occupational Therapists..	
(iii) Physiotherapists	
(iv) Doctors	
(v) Masseurs	
(vi) Social workers	
(vii) Psychologists	
(viii) Psychiatrists	
(ix) Podiatrists	
(x) Administration Staff	
(xi) Other *(Please specify)* _______________________	

33. Does your service have any vacant posts for lymphoedema practitioners that have not been filled?

[ ] Yes [ ] No

33b. If yes, what is the reason for the vacant posts not being filled?

[ ] Financial constraints within the service
[ ] Lack of qualified staff
[ ] Other, please give details____
____

34. Do the lymphoedema practitioners in your service have cover for annual leave, sick leave or maternity leave? [ ] Yes [ ] No

34b. If no, please comment on this.

____
____
____
____

35. How many patients are on the waiting list for the following?

Initial Consultation–Education, Skin Care, SLD ____________ patients
Intensive Treatment – MLD/MLLB ____________ patients
Follow up appointments ____________ patients

36. Is there a prioritisation system of patients with specific types of lymphoedema on the waiting list? [ ] Yes [ ] No

36b. If yes, please give details.

____
____
____
____

37. How long (in time) is the waiting list for patients requiring lymphoedema treatment in your service? __________________

38. Approximately how many lymphoedema patients per month does your service have the capacity to manage?

Initial Consultation–Education, Skin Care, SLD ____________ patients
Intensive Treatment – MLD/MLLB ____________ patients
Follow up appointments ____________ patients

39. On average, how many patients does your service treat in a month?

Initial Consultation–Education, Skin Care, SLD ____________ patients
Intensive Treatment – MLD/MLLB ____________ patients
Follow up appointments ____________ patients

40. Does your service offer home visits? ☐ Yes ☐ No

40b. If yes, please give details.

____
____

41. Does your service offer inpatient services specifically for the management of lymphoedema (that is where a person is admitted as an inpatient for the management of their lymphoedema, not admitted for another condition but also has lymphoedema)? ☐ Yes ☐ No

41b. If yes, how many inpatients can you accommodate in a month? ____________

SECTION 7: SERVICE STANDARDS

42. Please tick the standard of care you believe primary lymphoedema patients are receiving?

☐	☐	☐	☐	☐
Very low standard of care	Low standard of care	Neither high nor low standard of care	High standard of care	Very high standard of care

43. Please tick the standard of care you believe non-cancer-related secondary lymphoedema patients are receiving?

☐	☐	☐	☐	☐
Very low standard of care	Low standard of care	Neither high nor low standard of care	High standard of care	Very high standard of care

44. Please tick the standard of care you believe cancer-related (but not breast-cancer-related) secondary lymphoedema patients are receiving?

☐	☐	☐	☐	☐
Very low standard of care	Low standard of care	Neither high nor low standard of care	High standard of care	Very high standard of care

45. Please tick the standard of care you believe breast-cancer-related secondary lymphoedema patients are receiving?

☐	☐	☐	☐	☐
Very low standard of care	Low standard of care	Neither high nor low standard of care	High standard of care	Very high standard of care

46. What do you believe is important to patients of lymphoedema services?

47. If you could influence government policy in this area, what recommendations would you make regarding lymphoedema services in general?

48. In order to ensure we accurately map lymphoedema services in the Republic of Ireland it is important that we have the contact details of your service. Any of your details used in the final report will only be those ordinarily available to members of the public. Sensitive information you have provided in this questionnaire such as patient numbers etc. will be treated in a highly confidential manner.

Under these conditions, are you agreeable to providing your details? If yes, could you please complete the following:

Your name: ______
Name of your lymphoedema service: ______
Address: ______
Phone number: ______
Email: ______
Other: ______

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.

PLEASE RETURN THE QUESTIONNAIRE IN THE FREEPOST ENVELOPE PROVIDED AS SOON AS POSSIBLE.

Appendix D

Service Provider Survey Thank You/Reminder Letter

< Address of Practitioner>

<Date>

Dear <Mr. / Ms. Surname of Practitioner>,

On the <date>, the Irish Cancer Society posted out questionnaires as part of their research, in conjunction with the School of Nursing, Dublin City University, into patients' experiences of living with lymphoedema and of lymphoedema service provision in Ireland. The overall aim is to learn more about the experiences of people affected by <u>all types</u> of lymphoedema in order to influence the development of nationwide service provision and policy guidelines, which directly respond to an identified need.

A cover letter, information sheet and questionnaire were sent to you to request your participation in this research because you are working in a service which treats lymphoedema patients. Consequently, your views are extremely important in enhancing our understanding of current lymphoedema service provision in Ireland.

If you have completed the questionnaire and sent it back to us, thank you for your participation in the research study.

If you have not completed the questionnaire and are working in a service which treats lymphoedema patients we would appreciate it if you would complete the questionnaire and return it as soon as possible to: FREEPOST, Susan O'Carroll, Irish Cancer Society, 43–45 Northumberland Road, Dublin 4. Participation is on a voluntary basis. You are under no obligation to take part in this research study. All your answers to the questionnaire will remain strictly confidential.

If you would like further information about the study or would like an additional questionnaire please don't hesitate in contacting Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606. We would greatly appreciate your support in this project.

Yours sincerely,

Susan O'Carroll

Clinical Coordinator
Irish Cancer Society

Appendix E

Patient Focus Group Cover Letter

<Date>

Dear Sir/Madam,

The Irish Cancer Society, in conjunction with the School of Nursing, Dublin City University is conducting research into patients' experiences of living with lymphoedema and of lymphoedema service provision in Ireland. The overall aim is to learn more about the experiences of people affected by all types of lymphoedema – in particular the diagnosis, treatment and management of the condition. People affected by lymphoedema and professionals who provide the service will be involved in the research, so that improvements in this area can be made.

Previously you indicated your interest in receiving further information about the study with a view to considering whether you would like to participate.

Please take the time to read the enclosed information sheet about the first stage of the research which will involve focus groups.

Please note that you are not obliged to participate in this research, but if you would like to participate please complete the enclosed consent form and return it as soon as possible to FREEPOST, Susan O'Carroll, Irish Cancer Society, 43-45 Northumberland Road, Dublin 4.

If you would like further information about the study please contact Maeve Murray from the School of Nursing in Dublin City University on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

Yours sincerely,

Susan O'Carroll

Clinical Coordinator
Irish Cancer Society

Appendix F

Patient Focus Group Information sheet

1. Title of research project:

Exploring the Provision of Lymphoedema Services in Ireland.

2. Introduction:

You are being invited to take part in a study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, please contact Maeve Murray from the School of Nursing in Dublin City University on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

Lymphoedema is a chronic, incurable condition that can lead to pain, susceptibility to infections as well as compromised mobility. However, with early diagnosis and intervention, the condition can be well controlled. As a result, prompt diagnosis and appropriate treatment is an essential part of the management process. However, in Ireland there has been no research of lymphoedema service provision to date.

The overall aim is to learn more about the experiences of people affected by all types of lymphoedema - in particular their experiences of the diagnosis, treatment and management of the condition. People affected by lymphoedema and professionals who provide the service will be involved in the research, so that improvements in this area can be made. This research is funded by Action Breast Cancer (a project of the Irish Cancer Society); and was devised by a research team consisting of Ms. Susan O'Carroll, Irish Cancer Society, and Dr. Pamela Gallagher and Ms. Maeve Murray, the School of Nursing, Dublin City University.

3. Procedures:

You are being contacted about this study because you have a diagnosis of lymphoedema and are over eighteen years of age.

You are being asked to take part in a group discussion about your experiences of living with lymphoedema, and lymphoedema services. The group discussion will be led by an oncology nurse who has over 10 years experience working with cancer patients. The group will consist of 6-8 people who have a diagnosis of lymphoedema and will last approximately one hour. This discussion will be tape recorded and transcribed so that the data can be analysed. No one will listen to these tapes except the members of the research team. Information will be kept confidential at all times.

If you are willing to take part, you are asked to sign and return a consent form informing you of the research, indicating that you agree to take part and for the session to be tape recorded to FREEPOST, Susan O'Carroll, Irish Cancer Society, 43-45 Northumberland Road, Dublin 4. When we receive your consent form, you will be sent information regarding your scheduled session.

4. Benefits:

There are no direct benefits to taking part in this study. However, the information that will be collected will help develop guidelines to improve equity, availability and quality in lymphoedema service provision. Research that helps develop policy in this way will, in turn, benefit patients availing of those services.

5. Risks:

Asking you about your experiences of living with lymphoedema may bring about unpleasant or upsetting memories. If you feel uncomfortable or distressed at any stage, you can withdraw without consequences. You can also contact the Irish Cancer Society's Action Breast Cancer FREEFONE Helpline 1800 30 90 40 through which all patients can receive information, support and counselling if required, and access to the support services provided by Lymphoedema Ireland, who can be contacted directly on 087 693 4964.

6. Exclusion from participation:

If you do not have a diagnosis of lymphoedema, or are under eighteen years of age, you will be unable to take part in the study.

7. Confidentiality:

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law. All information will have your name and address removed so as to preserve confidentiality. Any information that will identify you in any way will also be removed. The focus group tapes will be destroyed once the anonymous transcripts have been completed. All data will be stored in a locked filing cabinet which only members of the research team can access.

The study findings will form the basis for preparation of policy documents, reports, academic publications, conference papers and other scientific publications.

8. Voluntary participation:

You have volunteered to take part in this study. You may quit at any time. If you decide not to participate, or if you quit, you will not be penalised. There will be no penalty for withdrawing before all stages of the research study have been completed.

9. Permission:

This research project has been approved by Dublin City University Research Ethics Committee.

10. Further Information:

If you need more information about your participation in the study, your rights, or answers to your questions about the study, contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

If participants have concerns about this study and wish to contact an independent person, please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9. Tel 01-7008000

Appendix G

Patient Focus Group Consent Form

Title of Research Project:
Exploring the Provision of Lymphoedema Services in Ireland

This study and this consent form have been explained to me. The researchers have answered all my questions to my satisfaction. I believe I understand what will happen if I agree to be part of this study.

I have read, or had read to me, this Consent Form. I have had the opportunity to ask questions about the Consent Form and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, which respects my legal and ethical rights. I am aware that I may withdraw at any time, without giving reason, and without this decision affecting my future treatment or medical care. I have received an Information Sheet.

Participant's Name: ____________________________

Participant's Signature: _________________________ **Date:** _________________

Date on which the participant was first given this form: ____________________

Statement of investigator's responsibility:
I have explained the nature, purpose, procedures, benefits, risks of, or alternatives to, this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Investigator's Signature: ________________________ **Date:** _________________

Appendix H

Patient Focus Group Demographic Questionnaire

Gender:

Male [ ]
Female [ ]

Age Range:

19-35 Years Old [ ]
36-50 Years Old [ ]
51– 66 Years Old [ ]
66 + Years Old [ ]

Cause/Type of Lymphoedema:

Primary Lymphoedema [ ]
Lymphoedema Secondary to Breast Cancer [ ]
Lymphoedema Secondary to Other Types of Cancer [ ]
Non-Cancer-Related Secondary Lymphoedema (e.g. trauma etc.) [ ]
Don’t know [ ]

Location of Lymphoedema:

Upper Limb [ ]
Lower Limb [ ]
Other ____________________________ [ ]

How long have you had lymphoedema symptoms for? ______________________

How long since you were diagnosed with lymphoedema? ___________________

Appendix I

Demographic and Clinical Details of Each Focus Group Participant

Table: Demographic and Clinical Details of Each Focus Group Participant

FG1, Participant 1	Female, Aged 36-50, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 10 months, Diagnosed 6 months ago
FG1, Participant 2	Female, Aged 51-66, Primary Lymphoedema in Lower Limb, Symptoms for 10-15 years, Diagnosed 10-12 years ago
FG1, Participant 3	Female, over 66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 15 years, Diagnosed 15 years ago
FG1, Participant 4	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 4 years, Diagnosed 4 years ago
FG1, Participant 5	Female over 66 years old, Lymphoedema Secondary to Breast Cancer in Upper & Lower Limb, Symptoms for 7 years, Diagnosed 6 years ago
FG1, Participant 6	Male, 36-50 years old, Primary Lymphoedema in Upper & Lower Limb, Symptoms since birth, Diagnosed at birth
FG1, Participant 7	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 2 years, Diagnosed 2 years ago
FG2, Participant 1	Female, Lymphoedema Secondary to Cervical Cancer in Lower Limb, Symptoms for 8 years, Diagnosed 8 years ago
FG2, Participant 2	Female, Aged over 66 Years Old, Doesn't Know Type of Lymphoedema, Swelling in Lower Limb, Symptoms for 8/9 years, Diagnosed about 5 years ago
FG2, Participant 3	Female, 51- 66 Years Old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 6 years, Diagnosed 6 years ago
FG2, Participant 4	Male, 51-66 years old, Lymphoedema Secondary to Lymphoma in Upper Limb & under Arms, Symptoms for 16 years, Diagnosed 16 years ago
FG2, Participant 5	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 6 years, Diagnosed 6 years ago
FG2, Participant 6	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper & Lower Limb, Symptoms for 8 years, Diagnosed 8 years ago
FG2, Participant 7	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 6 years, Diagnosed 6 years ago

Table: Demographic and Clinical Details of Each Focus Group Participant (continued)

FG2, Participant 8	Female, Aged 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 4 years, Diagnosed 4 years ago
FG3, Participant 1	Female, 36-50 years old, Lymphoedema Secondary to Lymphoma in Lower Limb, Symptoms for 3 years, Diagnosed 3 years ago
FG3, Participant 2	Female, 36-50 years old, Primary Lymphoedema in Lower Limb, Symptoms for 4 years, Diagnosed 3 ½ years ago
FG3, Participant 3	Female, over 66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 2 years, Diagnosed 3 ½ years ago
FG3, Participant 4	Female, 51-66 years old, Lymphoedema Secondary to Melanoma in Lower Limb, Symptoms for 8 years, Diagnosed 8 years ago
FG3, Participant 5	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 5 years, Diagnosed 5 years ago
FG3, Participant 6	Male, 51-66 years old, Lymphoedema Secondary to Melanoma in Upper Limb, Symptoms for 2 years, Diagnosed 2 years ago
FG3, Participant 7	Female, 36-50 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 10 months, Diagnosed 10 months ago
FG4, Participant 1	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 16 months, Diagnosed 16 months ago
FG4, Participant 2	Female, over 66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 16 months, Diagnosed 16 months ago
FG4, Participant 3	Female, 36-50 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 6 months, Diagnosed 6 months ago
FG4, Participant 4	Female, 36-50 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 5 months, Diagnosed 5 months ago
FG4, Participant 5	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 5 years, Diagnosed 5 years ago
FG5, Participant 1	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 1 and a ½ years, Diagnosed 1 and a ½ years ago
FG5, Participant 2	Participant 2, Female, 51-66 years old, Lymphoedema Secondary to Gynaecological Cancer in Lower Limb, Symptoms for 10 years, Diagnosed 9 years ago

Table: Demographic and Clinical Details of Each Focus Group Participant (continued)

FG5, Participant 3	Female, over 66 years old, Lymphoedema Secondary to Breast Cancer in Upper and Lower Limb, Symptoms for 6 years, Diagnosed 5 years ago
FG5, Participant 4	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb, Symptoms for 6 months, Diagnosed 3 months ago
FG5, Participant 5	Female, 51-66 years old, Lymphoedema Secondary to Gynaecological Cancer in Leg & Abdomen, Symptoms for 2 years, Diagnosed 2 years ago
FG5, Participant 6	Female, 51-66 years old, Lymphoedema Secondary to Breast Cancer in Upper Limb , Symptoms for 5 years, Diagnosed 5 years ago

Appendix J

Patient Survey Cover Letter

<Patient's Address>

<Date>

Dear <Mr. / Ms. Surname of Patient>,

You are being invited to take part in a research study currently being undertaken on lymphoedema. Your name has been taken from the list of patients who <have previously been referred to or attended the lymphoedema service/ are members of this organisation>.

The overall aim of this research is to learn more about the experiences of patients in the diagnosis, treatment and management of lymphoedema. In Ireland, the most common type of lymphoedema is lymphoedema following cancer treatment. However lymphoedema can result from a number of other conditions or can develop independently. Although this research is being conducted with the Irish Cancer Society, it is important to note that lymphoedema is not a form of cancer. The purpose of this research is to investigate the experiences of people with all types of lymphoedema, not just those with cancer-related-lymphoedema. People affected by all types of lymphoedema and professionals who provide the service will be involved in the research, so that improvements in this area can be made.

You are being asked to take part in a survey about lymphoedema treatment and the support services available by filling out a questionnaire. You will find an information sheet about the research and a questionnaire enclosed in this envelope. Please note that you are not obliged to participate in this study but if you would like to participate please complete the enclosed questionnaire and return it in the enclosed envelope to FREEPOST, Susan O'Carroll, Irish Cancer Society, 43-45 Northumberland Road, Dublin 4.

As the research team is sending questionnaires to patients from a number of different hospitals and organisations, it is possible that you may receive multiple copies of this questionnaire in the coming weeks. If this is the case, we would appreciate it if you could fill in one questionnaire and return the completed questionnaire and the additional blank questionnaire(s) in each of the FREEPOST envelopes provided.

The research team does not have any record of the individuals that are being sent the questionnaire and therefore there is no way of tracking who has and has not participated in this aspect of the study.

If you would like further information about the study please contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

Regards,

<Name of Lymphoedema Practitioner/ Named Person from Lymphoedema Organisation>

Appendix K

Patient Survey Information Sheet

1. Title of research project:

Exploring the Provision of Lymphoedema Services in Ireland.

2. Introduction:

You are being invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, please contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

Lymphoedema is a chronic, incurable condition that can lead to pain, susceptibility to infections as well as compromised mobility. However, with early diagnosis and intervention, the condition can be well controlled. As a result, prompt diagnosis and appropriate treatment is an essential part of the management process. However, in Ireland there has been no research of lymphoedema service provision to date.

The overall aim of this research is to learn more about the experiences of patients in the diagnosis, treatment and management of lymphoedema. In Ireland, the most common type of lymphoedema is lymphoedema following cancer treatment. However lymphoedema can result from a number of other conditions or can develop independently. Although this research is being conducted with the Irish Cancer Society, it is important to note that lymphoedema is not a form of cancer. The purpose of this research is to investigate the experiences of people with all types of lymphoedema, not just those with cancer-related-lymphoedema.

People affected by <u>all types of lymphoedema</u> and professionals who provide the service will be involved in the research, so that improvements in this area can be made. This research is funded by Action Breast Cancer (a project of the Irish Cancer Society). It was devised by a research team consisting of Ms. Susan O'Carroll, Irish Cancer Society; Dr. Pamela Gallagher and Ms. Maeve Murray, the School of Nursing, Dublin City University; and a research steering group composed of lymphoedema patients and a number of lymphoedema practitioners.

3. Procedures:

You are being contacted about this study because you have a diagnosis of lymphoedema and are over eighteen years of age.

You are being asked to take part in a survey about lymphoedema treatment and support services available by filling out a questionnaire.

If you would like to take part, you are asked to complete the questionnaire and to return it in the enclosed envelope to FREEPOST, Susan O'Carroll, Irish Cancer Society, 43-45 Northumberland Road, Dublin 4. By completing and returning the questionnaire you are consenting to participate in this study.

As the research team is sending questionnaires to patients from a number of different hospitals and organisations, it is possible that you may receive multiple copies of this questionnaire in the coming weeks. If this is the case, we would appreciate it if you could fill in <u>one</u> questionnaire and return the completed questionnaire and the additional blank questionnaire(s) in each of the FREEPOST envelopes provided.

The questionnaire includes items on the various types of treatment you may have received. Please note that although you have a diagnosis of lymphoedema, there are many different stages of lymphoedema and your symptoms may be so mild that you have not required treatment or certain types of treatment, as yet.

4. Benefits:
There are no direct benefits to taking part in this study. However, the information that will be collected will help develop guidelines to improve equity, availability and quality in lymphoedema service provision. Research that helps develop policy in this way will, in turn, benefit patients availing of those services.

5. Risks:
Asking you about your experiences of living with lymphoedema may bring about unpleasant or upsetting memories. If you feel uncomfortable or distressed at any stage, you can withdraw without consequences. You can also contact the Irish Cancer Society's Action Breast Cancer FREEFONE Helpline 1800 30 90 40 through which through which all patients can receive information, support and counselling if required, and access to the support services provided by Lymphoedema Ireland on 087 6934964.

6. Exclusion from participation:
If you do not have a diagnosis of lymphoedema, or are under eighteen years of age, you will be unable to take part in the study.

7. Confidentiality:
Only anonymous data, that is, information that does not identify you by name, will be collected in the questionnaire.

The study findings will form the basis for preparation of policy documents, reports, academic publications, conference papers and other scientific publications.

8. Voluntary participation:
You have volunteered to take part in this study. You may quit at any time. If you decide not to participate, or if you quit, you will not be penalised. There will be no penalty for withdrawing before all stages of the research study have been completed.

9. Permission:
This research project has been approved by Dublin City University and <name of hospitals> Research Ethics Committees.

10. Further Information:
If you need more information about your participation in the study, your rights, or answers to your questions about the study, contact Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

If participants have concerns about this study and wish to contact an independent person, please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9. Tel 01-7008000

Appendix L

Patient Questionnaire

This is a questionnaire designed to investigate different aspects of lymphoedema service provision. We are interested in **all types of lymphoedema**, primary and secondary. Please answer every item as honestly as you can. There are no right or wrong answers. Your responses will remain completely confidential.

SECTION 1: GENERAL INFORMATION

1. Are you male or female? [ ] Male [ ] Female

2. What age are you? ____________years

3. In what county in Ireland do you live? ________________________________

4. What type of lymphoedema do you have *(Please tick only one box)?*

- [ ] Primary lymphoedema
- [ ] Lymphoedema following treatment for breast cancer (e.g. surgery, radiotherapy etc.)
- [ ] Lymphoedema following treatment for another type of cancer, Please specify type of cancer_________________
- [ ] Lymphoedema following trauma or tissue damage (e.g. burns, varicose vein surgery etc.)
- [ ] Lymphoedema following venous disease (e.g. deep vein thrombosis, chronic venous insufficiency, etc.)
- [ ] Lymphoedema following infection (e.g. cellulitis etc.)
- [ ] Lymphoedema following inflammation (e.g. rheumatoid/psoriatic arthritis, dermatitis/eczema etc.)
- [ ] Lymphoedema following immobility or dependency
- [ ] Don't Know

5. Where in your body do you have lymphoedema *(Please tick all that apply)?*

- [ ] Left arm
- [ ] Right arm
- [ ] Head/neck/face
- [ ] Chest/breast
- [ ] Abdomen
- [ ] Left leg
- [ ] Right leg
- [ ] Other, Please specify ____

6. How long have you had lymphoedema symptoms for? _______years _______months

7. How long have you been diagnosed with lymphoedema? _______years _______months

SECTION 2: GETTING A LYMPHOEDEMA DIAGNOSIS

8. Do you think any of the following brought on or triggered your initial lymphoedema symptoms? *(You may have a specific cause of your lymphoedema e.g. the removal of lymph nodes during cancer treatment, but some of the following may have triggered your initial symptoms, Please tick all that apply)*

- [ ] Sunburn
- [ ] Insect bite
- [ ] Injection/Receiving chemotherapy into at-risk arm
- [ ] Overuse of the at-risk limb (e.g. through over-exercise, carrying a heavy load)
- [ ] Other, Please Specify____
- [ ] Other burn
- [ ] Flight
- [ ] Blood pressure taken from at-risk arm
- [ ] Cut, graze or bang to at-risk area
- [ ] Don't know

9. Did you know before you were diagnosed with lymphoedema that you were at risk of developing lymphoedema? [ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q10 ON THIS PAGE)***

9b. If you were told that you were at risk, which of the following healthcare professionals told you that you were at risk of developing lymphoedema?

	Yes	No
General Practitioner	[ ]	[ ]
Breast Care Nurse	[ ]	[ ]
Consultant (e.g. Surgeon, Oncologist etc.)	[ ]	[ ]
Physiotherapist	[ ]	[ ]
Occupational Therapist	[ ]	[ ]
Lymphoedema Nurse Specialist	[ ]	[ ]
Manual Lymphatic Drainage Therapist	[ ]	[ ]
Other, Please Specify ______________________________	[ ]	[ ]

9c. When you were told you were at risk of developing lymphoedema, were you given the following types of information?

	Yes	No	If yes, how was this information presented? Written Only	Verbal Only	Both Written & Verbal
General information about the symptoms of lymphoedema	[ ]	[ ]	[ ]	[ ]	[ ]
Education on skincare	[ ]	[ ]	[ ]	[ ]	[ ]
Education on how to perform specific lymphoedema exercises	[ ]	[ ]	[ ]	[ ]	[ ]
Education on how to perform simple lymphatic drainage	[ ]	[ ]	[ ]	[ ]	[ ]
Education on when to seek further medical attention...................	[ ]	[ ]	[ ]	[ ]	[ ]
Other, Please specify_____________________________________	[ ]	[ ]	[ ]	[ ]	[ ]

9d. If you were provided with any of the above information was the timing of this:

[ ] Too soon [ ] Just right [ ] Too late [ ] I did not receive any information

10. Which of the following types of healthcare professionals did you go to when you were originally looking for an explanation of your lymphoedema symptoms?

	Yes	No
General Practitioner	[ ]	[ ]
Breast Care Nurse	[ ]	[ ]
Consultant (e.g. Surgeon, Oncologist etc.)	[ ]	[ ]
Physiotherapist	[ ]	[ ]
Occupational Therapist	[ ]	[ ]
Lymphoedema Nurse Specialist	[ ]	[ ]
Manual Lymphatic Drainage Therapist	[ ]	[ ]
Other, Please Specify ______________________________	[ ]	[ ]

11. In general, how satisfied were you with these healthcare professionals with regard to EACH of the following when you were originally looking for an explanation of your lymphoedema symptoms?

		Very Dissatisfied	**Dissatisfied**	**Neither Dissatisfied nor Satisfied**	**Satisfied**	**Very Satisfied**
(i)	Healthcare Professional's Attitude. .	[ ]	[ ]	[ ]	[ ]	[ ]
(ii)	Healthcare Professional's Knowledge of Lymphoedema	[ ]	[ ]	[ ]	[ ]	[ ]
(iii)	Practical Support given by Healthcare Professional.	[ ]	[ ]	[ ]	[ ]	[ ]
(iv)	Emotional Support given by Healthcare Professional	[ ]	[ ]	[ ]	[ ]	[ ]
(v)	Time taken to receive an appropriate diagnosis	[ ]	[ ]	[ ]	[ ]	[ ]
(vi)	Overall satisfaction	[ ]	[ ]	[ ]	[ ]	[ ]

12. Who suggested that your diagnosis was lymphoedema? *(Please tick only <u>one</u> box)*

- ☐ General Practitioner
- ☐ Breast Care Nurse
- ☐ Consultant (e.g. Surgeon, Oncologist etc.)
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Lymphoedema Nurse Specialist
- ☐ Other, Please Specify ____________________________________

SECTION 3: INFORMATION NEEDS

13. Have you received information about lymphoedema from the following sources?

	Yes	No
Lymphoedema Practitioner	☐	☐
General Practitioner	☐	☐
Other Lymphoedema Patients	☐	☐
Lymphoedema Ireland Website	☐	☐
Lymphoedema Ireland Support Group Meetings	☐	☐
Lymphoedema Ireland Newsletters	☐	☐
Irish Cancer Society Helpline	☐	☐
Manual Lymph Drainage (MLD) Ireland	☐	☐
Other Websites, Please Specify __________________________	☐	☐
Other, Please Specify ___________________________________	☐	☐

14. Have you received education on any of the following topics?

	Yes	No
Education on skincare	☐	☐
Education on diet	☐	☐
Education on when to seek further medical attention	☐	☐

15. How <u>satisfied</u> are you with the <u>information on lymphoedema</u> that you have received?

Very Dissatisfied	Dissatisfied	Neither Dissatisfied nor Satisfied	Satisfied	Very Satisfied
☐	☐	☐	☐	☐

16. In your opinion, how could the lymphoedema information patients receive be improved?

____

____

SECTION 4: LYMPHOEDEMA AND DAILY LIFE

17. For <u>EACH</u> of the following, does having lymphoedema limit you in these activities?

	Yes, limited a lot	**Yes, limited a little**	**No, not limited at all**	**Not relevant**
(i) Walking	☐	☐	☐	☐
(ii) Swimming	☐	☐	☐	☐
(iii) Other Sports Activities	☐	☐	☐	☐
(iv) Daily household indoor chores (cleaning)	☐	☐	☐	☐
(v) Daily outdoor chores (shopping, gardening)	☐	☐	☐	☐
(vi) Taking care of children	☐	☐	☐	☐
(vi) Buying clothes/shoes.	☐	☐	☐	☐
(vii) Wearing clothes/shoes	☐	☐	☐	☐
(vi) Social Activities (visiting friends etc.)	☐	☐	☐	☐
(vii) Work/employment.	☐	☐	☐	☐
(vi) Sexual Activity	☐	☐	☐	☐
(vii) Sleeping	☐	☐	☐	☐
(vii) Going on holidays.	☐	☐	☐	☐
(vii) Other – please specify _______________	☐	☐	☐	☐

SECTION 5: YOUR LYMPHOEDEMA SERVICE AND SERVICE NEEDS

18. Have you ever received treatment for your lymphoedema?
[ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q 26 ON THIS PAGE)***

19. How would you best describe the service that you mainly visit for treatment of your lymphoedema?
[ ] Public [ ] Private [ ] Mix of public/private

20. In what setting is your main lymphoedema service located? *(Please tick only one box)*

[ ] Hospital
[ ] Community Health Centre
[ ] Cancer Support Centre
[ ] Private Practice/ Private Practitioner
[ ] Other, Please specify____

21. How far do you have to travel to get to your main lymphoedema service (one way trip)? _______km

22. Does travel distance limit your ability to avail of lymphoedema treatments? [ ] Yes [ ] No

23. How long do you have to wait between making an appointment and being seen for the following consultations?

Initial Consultation	______Weeks ______ Days	[ ] Not Applicable
Review Consultation	______Weeks ______ Days	[ ] Not Applicable
Intensive treatment of bandaging and/or Manual Lymphatic Drainage	______Weeks ______ Days	[ ] Not Applicable
Group Consultation	______Weeks ______ Days	[ ] Not Applicable
Home visit	______Weeks ______ Days	[ ] Not Applicable

24. What type of practitioner provides your lymphoedema treatment in your main lymphoedema service? *(Please tick only one box)*

[ ] Physiotherapist
[ ] Occupational Therapist
[ ] Lymphoedema Nurse Specialist
[ ] Manual Lymphatic Drainage Therapist
[ ] Other, Please Specify ______________________________________

25. How would you rate the practitioner in your main lymphoedema service on EACH of the following characteristics? *(Please circle one number on each line)*

		Not at all ←									→ **Extremely**
(v)	Knowledgeable.	1	2	3	4	5	6	7	8	9	10
(vi)	Competent	1	2	3	4	5	6	7	8	9	10
(vii)	Experienced	1	2	3	4	5	6	7	8	9	10
(viii)	Confident	1	2	3	4	5	6	7	8	9	10
(ix)	Attitude	1	2	3	4	5	6	7	8	9	10
(x)	Practical Support given	1	2	3	4	5	6	7	8	9	10
(xi)	Emotional Support given	1	2	3	4	5	6	7	8	9	10
(xii)	Time available to deal with you	1	2	3	4	5	6	7	8	9	10
(xiii)	Overall satisfaction	1	2	3	4	5	6	7	8	9	10

26. Please tick the standard of care you believe you are receiving, on average.

Very Low Standard of Care	Low Standard of Care	Neither High nor Low Standard of Care	High Standard of Care	Very High Standard of Care	Don't Know
[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

(IF YOU DO NOT RECEIVE ANY LYMPHOEDEMA TREATMENT, PLEASE GO TO SECTION 7 ON PAGE 10)

SECTION 6: LYMPHOEDEMA TREATMENTS

27. How soon after your lymphoedema diagnosis did you receive treatment? ________________

28. When was the last time you received treatment for your lymphoedema? *(Please specify month and year)* ________________

COMPRESSION GARMENTS (E.G. SLEEVES OR STOCKINGS WITH GRADUATED PRESSURE TO MANAGE SWELLING)

29. Have you ever been prescribed a Compression Garment for the treatment of lymphoedema?
☐ Yes ☐ No

29b. If you have, who measured you for your last Compression Garment? *(Please tick only one box)*

☐ General Practitioner
☐ Breast Care Nurse
☐ Physiotherapist
☐ Occupational Therapist
☐ Lymphoedema Nurse Specialist
☐ Manual Lymphatic Drainage Therapist
☐ Other, Please Specify ____________________________________

30. Do you use Compression Garments for the treatment of lymphoedema?
☐ Yes ☐ No ***(IF NO, PLEASE GO TO Q47 ON PAGE 7)***

31. How many Compression Garments are you currently using?
(You may have two garments for the same part of the body (e.g. a glove and sleeve) and you might have one to wash and one to wear, if this is the case please include all garments)?
________________garments

32. What type of Compression Garment do you use?
☐ Off-the-shelf
☐ Custom-made/made-to-measure
☐ Both off-the-shelf and made-to-measure garments
☐ Don't know

33. On average, how long do you have to wait for your Compression Garments to be delivered?
_________Weeks__________ Days

34. Do you need help from another person to get your Compression Garments on? ☐ Yes ☐ No

35. Do you use an assistive device or aid to help you to get your Compression Garments on?
☐ Yes ☐ No

36. How often do you wear your Compression Garment?
☐ All of time (24 hours a day, including night time)
☐ Most of the time (e.g. daily but not at night)
☐ Some of the time (when doing activities, chores etc.)
☐ Rarely
☐ Other, please specify __________________________

37. In general, do you wear a Compression Garment for <u>EACH</u> of the following activities?

		Yes	**No**	**Not relevant to me**
(i)	Walking	[ ]	[ ]	[ ]
(ii)	Swimming	[ ]	[ ]	[ ]
(iii)	Other sport activities	[ ]	[ ]	[ ]
(iv)	Social activities (e.g. visiting friends, going to the theatre)	[ ]	[ ]	[ ]
(v)	Daily household indoor chores (e.g. cleaning, hoovering etc.).	[ ]	[ ]	[ ]
(vi)	Daily outdoor chores (e.g. shopping, gardening).	[ ]	[ ]	[ ]
(vii)	Taking care of children	[ ]	[ ]	[ ]
(viii)	Personal care (taking showers, combing hair etc.)	[ ]	[ ]	[ ]
(ix)	Taking a flight	[ ]	[ ]	[ ]
(x)	When on holidays	[ ]	[ ]	[ ]
(xi)	Employment/occupation	[ ]	[ ]	[ ]
(xii)	Other, please specify ______________________________	[ ]	[ ]	[ ]

38. Do you wear your Compression Garment <u>as often as you have been advised to</u>? [ ] Yes [ ] No

38b. If <u>no</u>, please explain why. *(Please tick <u>all</u> that apply)*

[ ] The garment is uncomfortable

[ ] The garment is unsightly

[ ] It's too difficult to put on and take off

[ ] I don't need to wear it all the time to maintain the swelling at a comfortable level

[ ] Other, Please specify____

39. Please *<u>tick the box</u>* that represents the extent to which you are satisfied with <u>EACH</u> of the following aspects of the Compression Garment(s) that you <u>wear most regularly</u>.

		Very Dissatisfied	**Dissatisfied**	**Neither Dissatisfied nor Satisfied**	**Satisfied**	**Very Satisfied**
(i)	Colour	[ ]	[ ]	[ ]	[ ]	[ ]
(ii)	Appearance when worn . .	[ ]	[ ]	[ ]	[ ]	[ ]
(iii)	Comfort	[ ]	[ ]	[ ]	[ ]	[ ]
(iv)	Fit	[ ]	[ ]	[ ]	[ ]	[ ]
(v)	Texture	[ ]	[ ]	[ ]	[ ]	[ ]
(vi)	Temperature	[ ]	[ ]	[ ]	[ ]	[ ]
(vii)	Quality	[ ]	[ ]	[ ]	[ ]	[ ]
(viii)	Value for money	[ ]	[ ]	[ ]	[ ]	[ ]
(ix)	Overall satisfaction	[ ]	[ ]	[ ]	[ ]	[ ]

40. How many Compression Garments are provided by your <u>main lymphoedema service</u>?

[ ] I do not receive any garments from my lymphoedema service, I pay for all my garments myself
[ ] One per year
[ ] Two per year
[ ] Two every six months
[ ] Other, Please Specify ____________________________________

41. Do you have a Medical Card? [ ] Yes [ ] No

41b. If you have a Medical Card, does this <u>delay/slow down the delivery</u> of your Compression Garments? [ ] Yes [ ] No

42. On average, how much of your own money do you spend per calendar year on Compression Garments? €______

42b. If you have Private Health Insurance, do you receive any assistance from your insurer in paying for your Compression Garments? [ ] Yes [ ] No [ ] Not applicable

42c. If you receive assistance from your insurer how much does your insurer pay towards your Compression Garment costs per calendar year? €_____

43. Have you ever had any difficulty getting re-measured for replacement Compression Garments?
[ ] Yes [ ] No

43b. If you have had difficulty getting re-measured, please give further details.
____
____

44. On average how many times per year do you replace your Compression Garments?
[ ] Less than Once a Year [ ] Once a Year
[ ] Twice a Year (i.e. Every 6 months) [ ] Three Times a Year (i.e. Every 4 months)
[ ] Four Times a Year (i.e. Every 3 months) [ ] More than Four Times a Year

45. Does the cost of Compression Garments influence how often you replace them?
[ ] Yes [ ] No [ ] Not applicable

46. How satisfied are you with the process of getting Lymphoedema Compression Garments?

Very Dissatisfied	Dissatisfied	Neither Dissatisfied nor Satisfied	Satisfied	Very Satisfied
[ ]	[ ]	[ ]	[ ]	[ ]

LYMPHOEDEMA EXERCISES

47. Have you ever been given specific lymphoedema exercises to do?
[ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q50 ON THIS PAGE)***

48. How were you taught these specific lymphoedema exercises? *(Please tick only one box)*
[ ] Once-off individual consultation
[ ] Repeated individual consultations
[ ] Group consultation
[ ] Written format only
[ ] Instructional DVD
[ ] Other, Please Specify ________________________________

49. How often do you do these specific lymphoedema exercises? ____________________________

SIMPLE LYMPHATIC DRAINAGE (SELF-MASSAGE FOR THE MANAGEMENT OF LYMPHOEDEMA)

50. Have you ever been taught how to perform Simple Lymphatic Drainage (self-massage)?
[ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q53 ON PAGE 8)***

51. How were you taught to perform Simple Lymphatic Drainage (self-massage)? *(Please tick only one box)*

[ ] Once-off individual consultation
[ ] Repeated individual consultations
[ ] Group consultation
[ ] Written format only
[ ] Instructional DVD
[ ] Other, Please Specify ____________________________________

52. How often do you perform Simple Lymphatic Drainage (self-massage)? ______________________

MANUAL LYMPHATIC DRAINAGE (SPECIALISED MASSAGE FOR THE TREATMENT OF LYMPHOEDEMA)

53. Have you ever received Manual Lymphatic Drainage (specialised massage for the treatment of lymphoedema)? [ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q56 ON THIS PAGE)***

54. On average, how often do you receive Manual Lymphatic Drainage (specialised massage)?

[ ] Once
[ ] Once a year
[ ] Once every 6 months
[ ] Once every 2-3 months
[ ] Once a month
[ ] 2-3 times a month
[ ] Once a week
[ ] Intensive treatment of 5 times per week for one week once a year
[ ] Intensive treatment of 5 times per week for one week every 6 months
[ ] Intensive treatment of 5 times per week for more than one week once a year
[ ] Intensive treatment of 5 times per week for more than one week every 6 months
[ ] Other, please specify ____

55. How long, on average, does your Manual Lymphatic Drainage session last *(i.e. how long is a session of specialised massage for lymphoedema that doesn't include bandaging)*?

[ ] 30 minutes or less
[ ] 31 to 60 minutes
[ ] 61 to 90 minutes
[ ] 91 to 120 minutes
[ ] More than 2 hours
[ ] Other, please specify _________________________

MULTI-LAYER LYMPHOEDEMA BANDAGING

56. Have you ever received Multi-Layer Lymphoedema Bandaging?
[ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q60 ON PAGE 9)***

57. On average, how often does your practitioner provide you with Multi-Layer Lymphoedema Bandaging?

[ ] Once
[ ] Once a year
[ ] Once every 6 months
[ ] Once every 2-3 months
[ ] Once a month
[ ] 2-3 times a month
[ ] Once a week
[ ] Intensive treatment of 5 times per week for one week once a year
[ ] Intensive treatment of 5 times per week for one week every 6 months
[ ] Intensive treatment of 5 times per week for more than one week once a year
[ ] Intensive treatment of 5 times per week for more than one week every 6 months
[ ] Other, please specify ____

58. On average, how much of your own money do you spend per calendar year on these bandages?
€______

58b. If you have Private Health Insurance, do you receive any assistance from your insurer in paying for these bandages? [ ] Yes [ ] No [ ] Not applicable

58c. If you do receive assistance, how much does your insurer pay towards your bandage costs per calendar year? €______

59. Have you been taught how to self-bandage? [ ] Yes [ ] No

59b. If yes, how were you taught to self-bandage?

- [ ] Once-off individual consultation
- [ ] Repeated individual consultations
- [ ] Group consultation
- [ ] Written format only
- [ ] Instructional DVD
- [ ] Other, Please Specify ____________________________________

COST OF TREATMENTS

60. Do you pay a fee to see the practitioner in your main lymphoedema service?[ ] Yes [ ] No

60b. If yes, how much do you pay for each of the following, where applicable?

Initial Consultation	€______	[ ] Not Applicable
Review Consultation	€______	[ ] Not Applicable
Intensive Treatment of Bandaging and/or Manual Lymphatic Drainage	€______	[ ] Not Applicable
Group Consultation	€______	[ ] Not Applicable
Home Visit	€______	[ ] Not Applicable

61. Do you have Private Health Insurance? [ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q62 ON THIS PAGE)***

61b. If you have Private Health Insurance, do you receive any assistance from your insurer in paying for appointments with the practitioner in your main lymphoedema service?
[ ] Yes [ ] No

61c. If you do receive assistance, how much does your insurer pay towards each of the following, where applicable?

Initial Consultation	€______	[ ] Not Applicable
Review Consultation	€______	[ ] Not Applicable
Intensive Treatment of Bandaging and/or Manual Lymphatic Drainage	€______	[ ] Not Applicable
Group Consultation	€______	[ ] Not Applicable
Home Visit	€______	[ ] Not Applicable

62. Have you ever gone abroad for lymphoedema treatment?
[ ] Yes [ ] No ***(IF NO, PLEASE GO TO Q63 ON PAGE 10)***

62b. If you have, how many times have you gone abroad for lymphoedema treatment? ___________

62c. Do you receive any assistance from the following sources in paying for lymphoedema treatment abroad?

[ ] Private Health Insurance [ ] HSE
[ ] Both Private Health Insurer and HSE [ ] I don't receive any financial assistance for my treatment abroad
[ ] Other, Please specify____

62d. If you receive assistance, how much do you receive towards the cost of lymphoedema treatment abroad? €_____

62e. Please comment on the availability of financial assistance for lymphoedema treatment abroad.

____
____

63. Please comment on the cost of lymphoedema treatments, in general.

____
____

64. Do you believe you receive sufficient treatment to manage your lymphoedema effectively?
[ ] Yes [ ] No

65. Please discuss how lymphoedema services could be improved.

____
____
____
____

SECTION 7: FINAL QUESTIONS

66. The following questions ask how you feel about your quality of life, health, or other areas of your life. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks**.

(Please circle a number on each line)

		Very poor	Poor	Neither poor nor good	Good	Very good
a	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
b	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
c	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
d	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
e	How much do you enjoy life?	1	2	3	4	5
f	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
g	How well are you able to concentrate?	1	2	3	4	5
h	How safe do you feel in your daily life?	1	2	3	4	5
i	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
j	Do you have enough energy for everyday life?	1	2	3	4	5
k	Are you able to accept your bodily appearance?	1	2	3	4	5
l	Have you enough money to meet your needs?	1	2	3	4	5
m	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
n	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
		Very poor	Poor	Neither poor nor good	Good	Very good
o	How well are you able to get around?	1	2	3	4	5
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
p	How satisfied are you with your sleep?	1	2	3	4	5
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
q	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
r	How satisfied are you with your capacity for work?	1	2	3	4	5
s	How satisfied are you with yourself?	1	2	3	4	5
t	How satisfied are you with your personal relationships?	1	2	3	4	5
u	How satisfied are you with your ability to perform your sex life?	1	2	3	4	5
v	How satisfied are you with the support you get from your friends?	1	2	3	4	5
w	How satisfied are you with the conditions of your living place?	1	2	3	4	5
x	How satisfied are you with your access to health services?	1	2	3	4	5
y	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
z	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

67. Have you ever had cellulitis? [ ] Yes [ ] No

67b. If you have had cellulitis, how many times have you been admitted to hospital to have the cellulitis treated? ______________

68. If there are any other comments that you would like to make with regard to seeking a lymphoedema diagnosis, lymphoedema services, compression garments, the standard of care you're receiving, or living with lymphoedema, please do so here. *(Please use the back of this page to continue your comments if necessary)*

Thank you for taking the time to complete this questionnaire

Appendix M

Sample Patient Survey Thank You/Reminder Letter

<Address>

<Date>

Dear <Mr. / Ms. Surname of Patient>,

The Irish Cancer Society and the School of Nursing, Dublin City University are conducting a study into patients' experiences of living with lymphoedema and of lymphoedema service provision in Ireland. The overall aim is to learn more about the experiences of people affected by all types of lymphoedema in order to influence the development of nationwide service provision and policy guidelines, which directly respond to an identified need.

On <date>, a questionnaire was sent to you to request your participation in this study. If you have completed the questionnaire and sent it back to the research team they would like to thank you for your participation in the research study.

If you have not completed the questionnaire and would like to participate, the research team would appreciate it if you would complete the questionnaire and return it as soon as possible to: FREEPOST, Susan O'Carroll, Irish Cancer Society, 43–45 Northumberland Road, Dublin 4. Participation is on a voluntary basis.

You are under no obligation to take part in this research study. All your answers to the questionnaire will remain strictly confidential.

If you would like further information about the study or would like an additional questionnaire please don't hesitate in contacting Maeve Murray from the School of Nursing in DCU on 01 7007793 or Susan O'Carroll from the Irish Cancer Society on 01 2316606.

The research team would greatly appreciate your support in this project.

Regards,

<Name of Lymphoedema Practitioner/ Named Person in Lymphoedema Organisation>

Appendix N

Percentage Responses to Each Item of the WHOQOL-BREF

		n	Very poor	Poor	Neither poor nor good	Good	Very good
a	How would you rate your quality of life?	*718*	1.4%	8.1%	17.4%	49.9%	23.3%
			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
b	How satisfied are you with your health?	*715*	3.4%	15.0%	18.9%	48.7%	14.1%
			Not at all	A little	A moderate amount	Very much	An extreme amount
c	To what extent do you feel that physical pain prevents you from doing what you need to do?	*696*	26.3%	31.2%	27.7%	11.2%	3.6%
d	How much do you need any medical treatment to function in your daily life?	*673*	30.6%	26.3%	27.6%	11.6%	3.9%
e	How much do you enjoy life?	*699*	0.6%	6.2%	25.3%	50.9%	17.0%
f	To what extent do you feel your life to be meaningful?	*688*	1.9%	5.7%	20.6%	44.6%	27.2%
g	How well are you able to concentrate?	*714*	1.3%	7.4%	36.8%	42.0%	12.5%
h	How safe do you feel in your daily life?	*707*	1.1%	4.1%	27.3%	47.0%	20.5%
i	How healthy is your physical environment?	*704*	0.7%	4.1%	21.0%	49.0%	25.1%
j	Do you have enough energy for everyday life?	*713*	5.9%	10.8%	33.1%	41.1%	9.1%
k	Are you able to accept your bodily appearance?	*715*	5.5%	11.3%	22.4%	40.3%	20.6%
l	Have you enough money to meet your needs?	*713*	7.0%	6.3%	24.1%	41.1%	21.5%
m	How available to you is the information that you need in your day-to-day life?	*671*	4.8%	8.5%	24.7%	44.7%	17.3%
n	To what extent do you have the opportunity for leisure activities?	*683*	7.3%	15.7%	32.9%	32.9%	11.1%
			Very poor	Poor	Neither poor nor good	Good	Very good
o	How well are you able to get around?	*706*	2.5%	6.7%	13.5%	35.6%	41.8%
			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
p	How satisfied are you with your sleep?	*698*	5.9%	22.9%	22.3%	34.2%	14.6%
			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
q	How satisfied are you with your ability to perform your daily living activities?	*705*	2.7%	13.8%	19.9%	48.7%	15.0%
r	How satisfied are you with your capacity for work?	*662*	8.2%	18.4%	22.2%	39.9%	11.3%
s	How satisfied are you with yourself?	*690*	2.2%	10.1%	21.9%	47.4%	18.4%
t	How satisfied are you with your personal relationships?	*677*	3.1%	6.4%	16.0%	41.8%	32.8%
		n	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
u	How satisfied are you with your ability to perform your sex life?	*550*	15.3%	12.7%	28.0%	29.5%	14.5%
v	How satisfied are you with the support you get from your friends?	*685*	2.6%	4.5%	16.2%	37.7%	39.0%

			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
w	How satisfied are you with the conditions of your living place?	*703*	0.7%	3.0%	9.0%	32.9%	54.5%
x	How satisfied are you with your access to health services?	*699*	5.0%	7.6%	21.3%	39.6%	26.5%
y	How satisfied are you with your transport?	*690*	3.8%	4.8%	11.9%	39.0%	40.6%
			Never	Seldom	Quite often	Very often	Always
z	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	*711*	8.6%	54.4%	28.6%	7.7%	0.7%