

Living with Lymphoedema in Ireland: Patient and Service Provider Perspectives

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Abbreviations Used in this Report

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)
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

Executive Summary

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 frequently develops after treatment for cancer, most often breast cancer but also cervical, prostate, bladder and bowel cancer. Furthermore it can occur as a complication of non-cancer related conditions or can develop independently. The swelling usually occurs in the limbs. However, it can also occur in other parts of the body such as the head, neck, breast and genitalia, depending on the location of the lymphatic impairment (Moffatt et al., 2006). 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 (Morgan, Franks et al., 2005; McWayne & Heiney, 2005; Tobin et al., 1993; Williams et al., 2004).

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. 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; DHSSPS, 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.

These aims were achieved through a three-stage project. The first phase of the study involved a postal survey of lymphoedema practitioners to explore their perspective on current lymphoedema service provision in Ireland, thereby setting the scene and informing subsequent phases of the research. The second phase of the study employed focus group methodology to explore patients' experiences of accessing treatment and living with lymphoedema. Finally the third phase of the study involved a postal survey of lymphoedema patients to investigate the experiences of a wider group of lymphoedema patients. The findings from all three phases were integrated in order to provide a more complete depiction of lymphoedema service provision and patients' experiences of living with lymphoedema, and to inform recommendations.

Phase One: Service Provider Perspectives - Survey

Service provider questionnaires were conducted to attain their perspective on current lymphoedema service provision. 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. 108 service providers returned a completed questionnaire. The main results are presented below.

General Participant and Service Information

- In general most practitioners work in large, public hospitals situated in counties with major cities or towns. 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 over 4 1/2 years on average, and spend on average 8 hours per week treating lymphoedema patients. This suggests that treating lymphoedema patients is only part of the majority of participants' caseloads. This is compounded by the fact that the average number of healthcare professionals employed in each service for the treatment of lymphoedema is low at less than one healthcare professional per service.
- 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.
- 76.5% of respondents reported that they did not have cover for annual leave, sick leave or maternity leave and this was generally due to a lack of appropriately trained practitioners available in the service or a general lack of provision by the HSE for cover for leave.
- The most common referral sources were hospital oncology clinics, general practitioners and patients self-referring.
- 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.

Patient Profile

- Lymphoedema secondary to breast cancer was the most predominant type of lymphoedema experienced by patients treated in the last year, followed by lymphoedema secondary to other types of cancer and 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 (all < 5%).

- The most common location of lymphoedema was in a unilateral upper limb. Although the percentages for face, neck, genitals and 'other' are low (all <2%), it is worth noting that practitioners in Ireland are treating patients with lymphoedema in parts of the body which requires considerable specialised training and experience.
- Age profile corresponded with prevalence data which indicates that lymphoedema is more common in individuals who are middle aged and older.

Information and Treatments Provided

To Those At-Risk

- 87% of respondents who personally treat lymphoedema patients provide advice to those at-risk of developing lymphoedema.

To Lymphoedema Patients

- 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-Layer Lymphoedema Bandaging (MLLB) or compression garment fitting, which are regarded as essential for the effective management of lymphoedema.

Compression Garments

- 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 3.1 weeks and 63% of respondents reported that the wait time for garments affected the treatment of patients.

Consultations

- 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 11.4 times, although this is likely to be a conservative figure as some participants found this difficult to estimate.
- The average duration of consultations for upper limb patients is 54.3 minutes and for lower limb patients is 61.5 minutes. This reflects the time consuming nature of lymphoedema consultations.
- Only 19% of respondents who personally treat lymphoedema patients provide home visits, whereas only 12% provide inpatient services despite the fact that lymphoedema in the lower limb(s) can seriously affect patients' mobility.

Potential Barriers for Patients Accessing Treatment

- While on average 47% of respondents' caseload live within a 10km radius of the service, almost a quarter live more than 50km from the service. This suggests that travel distance may be a considerable barrier to treatment for a sizeable proportion of patients.
- On average patients spend 4.7 weeks waiting for lymphoedema treatment. 38% of respondents employed a prioritisation system for patients on the waiting list and the prioritisation is generally

according to the severity or type of lymphoedema, being a newly-diagnosed or palliative patient, or the source of the referral.

Professional Development

- 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.
- 78% of respondents had received specialised training from one of the lymphoedema schools, which is deemed essential for the appropriate treatment of lymphoedema. 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.
- 94% of respondents reported insufficient opportunities for professional development.

Service Standards

- Practitioners were asked to rate the standard of care received by patients with different types of lymphoedema on a scale from 1- 'very low' to 5 - 'very high'. More than one out of every two people (58%) rated the standard of care for people with primary lymphoedema as very low or low; two out of every three people (68%) rated the standard of care for people with non-cancer related secondary lymphoedema as very low or low; 43% rated the standard of care as low or very low for people with cancer (non BC related) lymphoedema; and 23% rated the standard of care for BC related lymphoedema as very low or low.
- Practitioners were asked what factors they thought were important to patients attending lymphoedema services. The main themes were high quality service provision; accessible, equitably distributed services; and multi-faceted support.
- Practitioners were asked an open question on the recommendations they would make if they could influence policy on lymphoedema service development. The main themes were high quality, accessible, equitably distributed services; additional resources and increased awareness of lymphoedema.

The findings from the service provider can be presented under the following headings: insufficient service provision, inequitable service provision and challenges to the sustainability of services.

- 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 inequitable nature of current lymphoedema service provision was illustrated by the location of practitioners, the percentage of patients required to travel greater than 50km 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 better 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 emphasises the point.
- 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.

Phase Two: Patient Perspectives - Focus Groups

The second phase of the study involved patient focus groups which encouraged patients to explore their experiences of lymphoedema service provision and of living with the condition in their own words. Five focus groups were undertaken throughout Ireland each consisting of between 5 and 8 participants. One group took place in each of the four regional health authority areas, except in Dublin where two focus groups were held. 33 patients in total participated and the majority were female, over 50 years old, with breast-cancer-related 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 did not know what type of lymphoedema they have. On average participants had experienced lymphoedema symptoms for 60.5 months (Range= 5-192) and had been diagnosed 57.8 months ago (Range= 3-192).

Six main themes, each with their own subthemes, emerged and are presented below:

- *Barriers to treatment:* The first theme related to the various barriers encountered by patients attempting to access appropriate, sufficient and continued treatment. It referred to the insufficient number of services available to meet the needs of lymphoedema patients; the existing services being oversubscribed and under-resourced hampering access to continued treatment; the cost of treatments discouraging participants from supplementing public services with private treatment;

and difficulties with the delivery, fit or appearance of compression garments lessening participants' adherence to lymphoedema management plans.

- *Tension with healthcare professionals:* This included participants' anger at not being pre-warned about the risk of developing lymphoedema and as a result they were not prepared, the perceived lack of knowledge of some healthcare professionals resulting in participants' questions being unanswered and the perceived dismissive attitude of some healthcare professionals towards their lymphoedema.
 - *Lymphoedema affecting daily life:* This referred to 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.
 - *Emotional factors:* This incorporated participants' distress following their cancer diagnosis and treatment resulting in incapacity to process their susceptibility to developing lymphoedema; 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.
 - *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
 - *Deriving positives:* This included living with lymphoedema as 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.
- In summary, these findings provide useful insights into patients' experiences of current lymphoedema service provision in Ireland and of living with the condition. In particular they highlight the barriers to treatment, tension with healthcare professionals, the affect of lymphoedema on daily life, the emotional factors, taking an active role and deriving positives. 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.

Phase Three: Patient Perspectives - Survey

The final phase of the study involved patient questionnaires. A total of 1,529 questionnaires were posted to patients accessed through sixteen hospitals, services and support organisations (e.g. Lymphoedema Ireland). 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. 735 completed questionnaires were returned. The main results from this phase of the study are presented below.

General Participant Information

- 93% of the sample is female and 7% is male. The majority of the sample is aged over 50 years of age which was expected given the greater prevalence of the condition among those who are middle aged and older. The mean age of participants in the current study was 58.9 years.
- 7% of participants have primary lymphoedema, 6% have non-cancer-related secondary lymphoedema, 10% have cancer-related (but not breast-cancer-related) secondary lymphoedema and 73% have breast-cancer-related lymphoedema. Approximately 40% have lymphoedema in the upper limb(s), and 20% have lymphoedema in the lower limb(s).
- 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 an average of 6.5 years and had received a diagnosis on average just over 5 years ago.
- Patients with primary lymphoedema spent much longer waiting for a diagnosis when compared with patients with all other types of lymphoedema. Patients with primary lymphoedema waited on average 78.2 months for a diagnosis, patients with non-cancer-related secondary lymphoedema waited on average 20.6 months, and patients with cancer-related (but not breast-cancer-related) secondary lymphoedema waited an average of 8.2 months, while patients with breast-cancer-related lymphoedema waited on average 4.8 months for a diagnosis.
- Only 42% of respondents indicated that they knew they were at-risk of developing lymphoedema. 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. While 52% of patients with breast-cancer-related secondary lymphoedema knew they were at-risk; only 24% of those with cancer-related (but not breast-cancer-related) lymphoedema; 7% of primary lymphoedema patients and just 5% of those with non-cancer-related secondary lymphoedema knew they were at-risk of developing the condition.
- Participants were asked to indicate all of the various healthcare professionals they consulted when they were originally seeking an explanation of their lymphoedema symptoms. The majority of respondents, approximately 45%, went to a consultant however 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. The lowest rated healthcare professionals were general practitioners and in almost all cases, lymphoedema nurse specialists were rated the highest – which is unsurprising considering that they are specialised in the treatment of lymphoedema.

- 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'.
- Patients with primary lymphoedema and non-cancer-related secondary lymphoedema rated these healthcare professionals lower whereas patients with breast-cancer-related lymphoedema rated them higher. This difference was highly significant.

Information

- The main source of information for patients following their diagnosis was their lymphoedema practitioner. However, only two-thirds of the sample had received education on skincare, 40% had received education on when to seek further medical attention and only about one-fifth of the sample had received education on diet and how this can affect lymphoedema symptoms.
- Approximately one in five people were dissatisfied with the information that they received.
- When asked how the information lymphoedema patients receive could be improved, patients reported that they should be told in advance of medical treatment, specifically cancer treatment, that it may predispose them to developing lymphoedema. Patients recommended that information should be presented in audiovisual and written format and that the content of the information should not solely focus on the physical consequences of lymphoedema. The final theme related to the importance of informing healthcare professionals about lymphoedema to enable them to impart accurate information on the condition.

Lymphoedema Services

- 89% of respondents indicated that they have received lymphoedema treatment. However some participants who have received compression garments, or have been taught exercises or SLD may not have considered themselves as having received lymphoedema treatment. The majority of respondents indicated that their main lymphoedema service is in a public service (65%) and 78% indicated that the setting was a hospital.
- Participants reported that on average they had to travel 27.9 kilometres in a one way trip to their lymphoedema service. Yet participants were travelling between 1 and 250 km to their lymphoedema service. Almost a fifth of respondents reported that travel distance limited their ability to avail of lymphoedema treatment.
- The most commonly cited lymphoedema practitioner was a physiotherapist (37%) but a wide variety of healthcare professionals are involved in the care and treatment of lymphoedema.
- Participants who had received treatment were asked to rate the practitioner in their main lymphoedema service on a scale from 1 to 10 in various categories. Over 78% of respondents rated the practitioner as 7 or higher on all measures. 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.

- All participants were asked to rate the standard of care they are receiving on a scale from 1 – ‘very low’ to 5 – ‘very high’. While 74% of respondents with breast-cancer-related secondary lymphoedema rated the standard of care they’re receiving as high or very high, 48% of respondents with primary lymphoedema rated likewise. 27% of patients with primary lymphoedema rated the standard of care as very low or low; 21% of patients with non-cancer related secondary lymphoedema, 16% of patients with cancer (not BC) related secondary lymphoedema and 8% of patients with BC related secondary lymphoedema rated the standard of care as very low or low.

Lymphoedema Treatments

- Overall respondents were waiting approximately 10 months, for their first treatment following their lymphoedema diagnosis. Patients with primary lymphoedema were waiting on average approximately 4 years for treatment while patients with breast-cancer-related lymphoedema were waiting on average approximately 6 months. This difference was significant.
- There was a positive correlation between time since diagnosis and first treatment indicating that participants who have been diagnosed more recently are seen quicker.
- On average respondents had received their last treatment 10.2 months ago. Patients with primary lymphoedema received their last treatment on average 34.1 months ago whereas patients with cancer-related (but not breast-cancer-related) secondary lymphoedema received their last treatment 7.4 months ago.

Compression Garments

- 95% of respondents reported that they had been prescribed a compression garment and 88% of respondents currently use garments. On average participants use 2.5 garments. 45% of respondents use off-the-shelf garments, 31% use custom-made or made-to-measure garments, 19% use both types of garments and 5% do not know what type of garments they are using. Participants have to wait on average 22.8 days for garments to be delivered. Although the large range and standard deviation 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 and arthritic patients can be the application of the garments. 18% of participants who currently use garments reported that they need another person to help them put on and take off their garments, while 16% use an assistive device for this purpose.
- A higher percentage of people wore their compression garment doing daily household indoor (83%) or outdoor chores (82%) or during flights (84%) than while socialising (62%), child minding (52%), during employment (57%), sports (50%) or swimming (14%).
- A quarter of respondents indicated that they do not wear garments as often as they have been advised to. Of those, 54% reported that they find the compression garment uncomfortable, 34% consider the garment unsightly, 23% find the garment difficult to put on or take off, 39%

reported that they do not need to wear the garment all the time to maintain the swelling at a comfortable level and 26% gave another reason.

- Participants who currently use garments were asked to rate their satisfaction with the colour, appearance, comfort, fit, texture, temperature, quality, value for money and overall satisfaction of their compression garments on a scale from 1-‘very dissatisfied’ to 5-‘very satisfied’. Although the majority of respondents scored the garments as neutral or better, a sizeable proportion of between 20-30% were dissatisfied or very dissatisfied with the colour, appearance, comfort, texture and temperature of compression garments.
- 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. A high proportion of respondents (70%) do not receive the minimum amount of compression garments from their main lymphoedema service.
- 61% of those who currently use garments have a medical card and of those 18% indicated that having a medical card slowed down the delivery of their compression garments.
- 42% of respondents pay for their compression garments and on average spend €165.94 of their own money per calendar year on compression garments (Range €2-1000). However there was huge variation in the financial burden on patients.
- 57% of respondents replace their garments the recommended two-three times a year. 17% indicated that the cost of garments affected whether they replaced them. 9% of respondents who currently use garments reported having difficulties getting re-measured because practitioners are too busy to measure patients; lymphoedema services have been discontinued, and patients do not know where to go to be re-measured.

Lymphoedema Exercises and Simple Lymphatic Drainage

- 81% of respondents reported that they had been taught how to perform specific lymphoedema exercises, whereas 53% of respondents reported that they had been taught how to perform specific simple lymphatic drainage (SLD) or self-massage. The majority of respondents were taught lymphoedema exercises or SLD in a once-off individual consultation (52% v 60%) 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. Only 52% and 40% respondents indicated that they perform exercises or SLD respectively on a daily basis.

Manual Lymphatic Drainage and Multi-Layer Lymphoedema Bandaging

- 56% of respondents reported that they had received manual lymphatic drainage (MLD) a specialised form of massage for the treatment of lymphoedema whereas 35% of respondents reported that they had received multi-layer lymphoedema bandaging (MLLB).

- There appears to be considerable variation in lymphoedema patients' access to MLD and MLLB. The most common responses were that 23% of respondents receive MLD every 2-3 months and 31% have received MLLB only 1-3 times. (Table 33).
- 29% of respondents who have received MLLB reported that they had been taught how to self-bandage and none of the respondents reported being provided with a book, leaflet or DVD to enable them to revise their technique in self-bandaging.

Cost of Treatments and Service Recommendations

- 10% of respondents reported that they pay a fee to see the practitioner in their main lymphoedema service and the mean fee for various types of consultations varied between €60 and €75.
- 86% of respondents who pay a fee to see their lymphoedema practitioner reported having private health insurance and of those 26% indicated that their health insurer pays money towards their consultation fees. However financial support from private health insurers was subject to certain stipulations, e.g. the lymphoedema treatment being classified as 'physiotherapy', and a limit to how much could be claimed.
- Participants were asked their opinion on the cost of lymphoedema treatments in general. While the majority of respondents indicated that they do not pay for treatment, they recognised the difficulties they would encounter if they were required to pay. For respondents who do pay for their treatment they highlighted how essential it was to their wellbeing. The final theme related to respondents who reported experiencing great difficulty in paying for the treatment of this chronic condition.
- 61% of respondents considered the treatment they receive as sufficient to manage their lymphoedema effectively. 67% of patients with breast-cancer-related lymphoedema considered the level of treatment they receive as sufficient whereas 48% of primary lymphoedema patients considered themselves as receiving sufficient treatment. There was a significant association between type of lymphoedema and whether participants considered the treatment they receive as sufficient.
- Participants were asked an open question on how lymphoedema services could be improved. Many of the patients' recommendations echo comments made previously by the focus group participants about the need for increased funding to provide more practitioners, treatments and services and to support patients with the costs of treatments; equitable services that are distributed throughout the country and provided to patients with all types of lymphoedema; emotional support in the form of counselling for those who need it and nationwide patient support groups; and increased awareness of lymphoedema and lymphoedema services among healthcare professionals, lymphoedema patients, those at risk and the general public.

Impact of Lymphoedema on Daily Life and Quality of Life

- At least 30% of respondents experienced limitation across each of the specified aspects of their daily lives. The limitations that lymphoedema imposes on patients' lives were more keenly felt

with regard to their ability to perform indoor (77.7%) and outdoor (80.9%) chores, wear clothes/shoes (77.8%), and go on holidays (68.1%).

- 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.
- 29% of all respondents reported that they had experienced a bout of cellulitis, an infection in the layers of the skin commonly associated with lymphoedema. On average respondents had been hospitalised for the treatment of their cellulitis twice (Range=0-20). However the large range suggests that cellulitis can have a significant impact on some patients' lives.
- The first two items of the QoL measure asked participants to rate their quality of life and their satisfaction with their health on a scale from 1 – 'very poor/dissatisfied' to 5 – 'very good/satisfied'. 21%, 26% and 18% 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 6% 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 34% and 36% of patients with primary or non-cancer-related-secondary lymphoedema rated their satisfaction negatively compared with 14% of patients with breast-cancer-related secondary lymphoedema.
- In looking at the scores across the four QoL domains, the sample rated themselves lowest on the physical and psychological health domains and highest on the environment and social relationships domains.
- With regard to the physical health domain, 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, and participants with breast-cancer-related secondary lymphoedema. With regard to the psychological health domain, participants with primary lymphoedema and participants with non-cancer-related secondary lymphoedema scored significantly lower on the psychological health domain than participants with breast-cancer-related secondary lymphoedema. With regard to the social relationships domain, there were no significant differences between groups. Finally, in relation to the environment domain, participants with primary lymphoedema and with non-cancer-related secondary lymphoedema scored significantly lower on the environment domain than participants with breast-cancer-related secondary lymphoedema.
- The results of the patient survey can be summarised into two themes which broadly correspond with the findings of the service provider questionnaire and patient focus group phases: inequitable service provision and the impact of lymphoedema on patients' quality of life. 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 implications of living with lymphoedema emerged as 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.

Recommendations

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. Policy recommendations arising from the study include:

Service Development

1. Appropriate services should be available for people with all types of lymphoedema, primary and secondary, and cancer and non-cancer related lymphoedema.
2. To address the current inequalities in service provision and to encourage the uptake of lymphoedema service among all lymphoedema patients, lymphoedema services should be independent and not solely located within cancer clinics. Drawing on international experience, the hub-and-spoke model of service delivery is recommended. This involves intensive treatment being provided in specialised clinics by a multi-disciplinary team (CREST, 2008) whereas maintenance of the condition would be delivered in local satellite services (MacLaren, 2003). Ideally these lymphoedema services would form a network, liaising with each other, working from shared protocols and standards (DHSSPS, 2004; Martlew, 1999; Richmond, 2003).
3. To ensure the standardised treatment of all patients, publication of precise patient streams and general practice guidelines are required, such as those produced by CREST (2008) in Northern Ireland.
4. To assist in adapting to living with lymphoedema and the self management of the condition, individual and/or group psychological support should be promoted and be made more readily available. Measures of quality of life and psychological well-being should also be introduced so that patients who may require additional support can be identified.

5. To effectively manage lymphoedema, a dedicated and independent stream of funding is required to enable the strategic planning and provision of coordinated, equitably-located, nationally-provided, comprehensive services.
6. To ensure timely interventions and the prevention of costly complications, it is recommended that the option of subsidising treatment for lymphoedema patients is explored.

Raising Awareness of Lymphoedema & Training amongst Healthcare Professionals

7. To raise awareness of the difficulty of living with lymphoedema and to influence policy, relevant stakeholders such as healthcare professionals, private health insurers, compression garment manufacturers, the Health Information and Quality Authority (HIQA) and the National Cancer Control Programme (NCCP), need to be targeted with information on lymphoedema.
8. To raise awareness and to ensure a baseline level of understanding, appropriate material on lymphoedema should be included in the undergraduate curricula across the spectrum of healthcare professionals.
9. To raise awareness among and to promote appropriate referral of patients by key practicing health professionals, information on lymphoedema, its treatment and available services should be provided through continuous professional development programmes.
10. Healthcare professionals in primary care, especially General Practitioners, play an important role in the appropriate referral of lymphoedema patients. In particular, general practitioners have an important role to play in identifying primary and non cancer related lymphoedema. It is recommended that raising awareness and training amongst these healthcare professionals should be prioritised.
11. 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 (2001a) framework for education and these should be reviewed for initial guidance.
12. 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).

Raising Awareness of Lymphoedema amongst People at Risk and Patients with Lymphoedema

13. For all patients who may be at-risk of developing lymphoedema, it is recommended that standardised information and prevention programmes are developed and provided.
14. All lymphoedema patients and their families across all lymphoedema services should have access to standardised information such as general information on lymphoedema, available services, treatment, exercises, and compression garments, or tailored information for patients with different needs. This information should be available in packs, online and in audiovisual formats, e.g. DVD of instructions for performing lymphoedema exercises.

15. Self management is an important aspect of lymphoedema care and patients should be provided with the training and information to take ownership of their lymphoedema care. For example, 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.
16. To maximise the use of limited resources, to combat feelings of 'being the only one', and to inform patients and families, local fora such as those set up by Lymphoedema Ireland should be expanded and initiated in new areas for patients to share experiences, information and ideas and to encourage and support each other on a regional and regular basis.

Chapter 1: Introduction

What is Lymphoedema?

The lymphatic system works in tandem with the body's circulatory system to drain water, cellular debris, toxins, bacteria, dead, dying or mutant cells and enzymes, and other macromolecules from the space around the body's cells. The lymphatic system filters this lymph fluid and returns some of the filtered fluid to the circulatory system (Sneddon & Lewis, 2007). When the lymphatic system is compromised, the lymph fluid accumulates in the space around the cells of the body. The resultant swelling is known as lymphoedema (Morrell et al., 2005).

Lymphoedema is a chronic, incurable condition believed to affect at least 1.33 per 1,000 of the population (Moffatt et al., 2003). However this figure is 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 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. 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. Worldwide, the most common cause of lymphoedema is lymphatic filariasis, a parasitic infection that is transmitted by mosquitoes and damages the lymphatic system (DHSSPS, 2004; MEP, 2006). However the most common type of lymphoedema in the western world is lymphoedema secondary to cancer most notably breast cancer. As cancer can metastasize to the lymph nodes, the treatment of cancer can include interference with, removal or radiation of lymph nodes. Secondary lymphoedema can also occur following infection, trauma or tissue damage, venous disease, inflammatory conditions, and immobility or dependency (CREST, 2008; DHSSPS, 2004; Hardy, 2006; NCI, 2008; Williams et al., 2005).

Lymphoedema usually takes place in the limbs and may include the associated trunk of the body. However it can occur in other parts of the body such as the head, neck, breast and genitalia, depending on the location of the lymphatic impairment (Moffatt et al., 2006). 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). Some patients report a loss of normal sensation, impaired functioning, pain and a sense of heaviness in the affected area (BLS, 2001; Lu et al., 2008; Morgan, Franks & Moffatt, 2005; Morrell et al., 2005; Williams et al., 2005). Due to the fact that the fluid can contain bacteria and waste products, the lymphoedematous area is susceptible to skin infections such as cellulitis, which may require hospitalisation (CREST, 2008).

Treatment

Although lymphoedema is a chronic condition, with early diagnosis and intervention the condition can be well controlled through skincare to prevent infection, specific exercises, a specialised form of massage to encourage lymph flow (Manual Lymphatic Drainage - MLD) and compression (such as compression garments or Multi-Layer Lymphoedema Bandaging - MLLB) to contain the swelling (MEP, 2006). This is generally referred to as decongestive lymphatic therapy (DLT) or the four cornerstones of care. 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 this report 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.

It is important to note that the evidence for the management of lymphoedema remains weak often based on anecdotal rather than empirical evidence (Lacovara & Yoder, 2006). As a result the Lymphoedema Framework Project, a UK based research partnership, consulted with an international panel of experts to produce an international consensus on lymphoedema management. 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 & Moffat, 2006; Morgan, Moffat & Doherty, 2006).

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, 2001; CREST, 2008). 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.

Previous Research on Lymphoedema Service Provision

The literature on service provision in Sweden, the Netherlands, Austria and Germany indicates that lymphoedema services are generally coordinated, relatively standardised and provided by multidisciplinary teams (MacLaren, 2003). Conversely in Australia and the UK the research indicates poor knowledge of lymphoedema among referring agents and haphazardly located service provision.

There are often delays to diagnosis and barriers to treatment for patients, particularly those with non-cancer-related lymphoedema (Bogan, Powell, Dudgeon, 2007; BreastCare Victoria, 2005; DHSSPS, 2004; Moffatt et al., 2003; Williams et al., 2004). In the UK, prophylactic care and education is often not routinely available (Sneddon & Lewis, 2007). Patients who could access treatment were generally happy with it whereas for those who could not access initial and continuing care, it can be “a constant struggle and I have no quality of life because of this” (DHSSPS, 2004 Page 32). Many patients have to travel long distances to get access to treatment (Todd, 2006) in what has been referred to as a “postcode lottery of care” (Boris et al., 1997 cited in Rankin, 2001 page 3). As the availability of MLD for National Health Service and hospice patients is limited, it is a lucrative area for private practice.

Anecdotal evidence within the Irish context suggests that comprehensive treatment services are few in Ireland and that there is a lack of co-ordination between the different agencies involved. Inequities in access to services have also been reported. However to date there has been no research conducted in the Republic of Ireland on lymphoedema service provision. Without a clear picture from both practitioners’ and patients’ perspectives, co-ordination between services, planning on how to develop and expand services and formulation on how to address gaps and inequalities cannot take place. Indeed it is useful to note that correspondence with the authors of the BreastCare Victoria report revealed that their research partly informed the development of strategies that are now being implemented across all cancer streams in Victoria to improve care for patients with lymphoedema.

Impact 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 limb becomes more solid, muscle wastage, increasing intolerance to changes in temperature, sleep disturbance and loss of hair have also been reported (Morgan, Franks & Moffatt, 2005; Okeke et al., 2004; Robertson Squire 2000). The heaviness of the limb can lead to extreme fatigue, compromised posture, muscle tightness and musculoskeletal problems (Muscarì, 2004; Okeke et al., 2004; Passik & McDonald, 1998).

In terms of the impact of lymphoedema on patients’ lives, qualitative studies have reported themes such as patients being required to ‘fish in the dark’ for information on lymphoedema, tension with healthcare professionals, feelings of stigma, shame, anxiety and isolation (Bogan et al., 2007; Hare, 2000; Johansson et al., 2003; Williams et al., 2004). 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. Quantitative studies using overall quality of life measures have found

that lymphoedema patients score poorly when compared with breast cancer survivors who have not developed lymphoedema (Beaulac et al., 2002; Coster et al., 2001; Mak et al., 2009; Velanovich et al., 1999) and when compared with appropriate normative data (Moffatt, Franks, Doherty et al., 2003). Furthermore, Tobin and colleagues (1993) and Passik and colleagues (1995) found that lymphoedema patients had poorer psychological wellbeing and higher levels of functional, social and sexual dysfunction than breast cancer survivors who had not developed lymphoedema. There has been no research conducted to date on the impact of lymphoedema on patients' quality of life in the Republic of Ireland.

Aims of the Current Study

The prevalence of lymphoedema is likely to rise due to the widely predicted increases in the number of people affected by cancer, in life expectancy rates, in obesity and in lymphatic filariasis. Given this potential increase in prevalence rates, the chronic nature of lymphoedema, and its impact on physical and psychological health, 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. Indeed, the development of services and interventions cannot take place without an assessment of the current level of service provision and of patients' needs. Therefore the 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.

These aims were achieved through a three-stage project. The first phase of the study involved a postal survey of lymphoedema practitioners to explore their perspective on current lymphoedema service provision in Ireland, thereby setting the scene and informing subsequent phases of the research. The second phase of the study employed focus group methodology to explore patients' experiences of accessing treatment and living with lymphoedema. Finally the third phase of the study involved a postal survey of lymphoedema patients to investigate the experiences of a wider group of lymphoedema patients. The findings from all three phases were integrated in order to provide a more complete depiction of lymphoedema service provision and patients' experiences of living with lymphoedema, in order to best inform the recommendations.

Chapter 2: Service Provider Perspectives

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, 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.

Methodology

Identifying the 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. There has also 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 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 who provide 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 who do not currently hold or have not held a position in a hospital or service in the previous six months.

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 (IBCNA, 2004).
- 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

In developing the questionnaire, the investigators were assisted by the research steering group; and guided by the topics covered and recommendations made in previous international literature on lymphoedema service provision. Approval was sought and granted from the BreastCare Victoria study (2005) for the use and amendment of the questionnaire used by the BreastCare Victoria research team. The questionnaire used in the current study includes sections on:

- General participant information (job title; 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 steering group.

Procedure

Having sought and received ethical approval, a cover letter, information sheet, questionnaire and a FREEPOST envelope 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.

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 for closed ended questions. Relevant tables are included in the Appendices. Responses to open questions were analysed thematically.

Results

General Participant and Service Information

- 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. The overall response rate was 41.88%. 26 practitioners indicated that they would not 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 personally treat lymphoedema patients. Eighteen practitioners work in a dedicated lymphoedema service (i.e. services that solely treat lymphoedema patients and are not required to treat patients with other conditions).
- Most practitioners work in large, public hospitals (62.3%) situated in counties with major cities or towns (e.g. Dublin (33.3%); Cork (14.8%)). The most common types of practitioners who personally treat lymphoedema patients are physiotherapists/ physiotherapy managers (48.6%), Manual Lymphatic Drainage (MLD) therapists (15.3%), occupational therapists (OTs)/OT managers (9.7%), and MLD therapists who are also nurses, physios or OTs (20.8%). (Table 1)
- 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 suggests that treating lymphoedema patients is only part of the majority of participants' caseloads.
- The main source of funding 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)
- More physiotherapists are employed on average in the treatment of lymphoedema than any other profession (mean 0.95, SD 1.16, Range 0-8.5), 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. (Table 3)
- 76.5% of respondents reported that they did not have cover for annual leave, sick leave or maternity leave and this was generally due to a lack of appropriately trained practitioners available in the service or a general lack of provision by the HSE for cover for leave.

- The most common referral sources were hospital oncology clinics, general practitioners and patients self-referring. 78.9% of respondents received referrals from hospital oncology clinics, 53.5% received referrals from GPs and 49.3% had patients self-referring (Table 4)

Patient Profile

- Lymphoedema secondary to breast cancer was the most predominant type of lymphoedema experienced by patients treated in the last year (56.1%), followed by lymphoedema secondary to other types of cancer (13.5%) and primary lymphoedema (12.6%). Patients with lymphoedema due to immobility, venous disease, tissue damage, infection and inflammation were rated as a much smaller percentage of respondents' caseloads (all < 5%). (Table 6)
- The most common location of lymphoedema was in a unilateral upper limb (57.7%). Although the percentages for face, neck, genitals and 'other' are low (all < 2%), it is worth noting that practitioners in Ireland are treating patients with lymphoedema in parts of the body, which requires considerable specialised training and experience. (Table 6)
- The findings on the percentage of patients in each age range broadly correspond with prevalence data which indicate that lymphoedema is more common in individuals who are middle aged and older (63.7% older than 50 years of age). (Table 6).

Information and Treatments Provided

To Those At-Risk

- 86.8% of respondents who personally treat lymphoedema patients provide advice to those at-risk of developing lymphoedema. The advice provided generally relates to skincare, avoidance of potential triggers of lymphoedema symptoms and prophylactic measures. The majority of respondents indicated this advice is provided to oncology patients, particularly breast cancer patients.

To Lymphoedema Patients

- Almost all respondents who personally treat lymphoedema patients provide education on skincare (93%); when to seek further medical attention (91.5%); and how to perform simple lymphatic drainage (85.9%) and lymphoedema exercises (93%). However, only half provide information on diet. Roughly three quarters of respondents provide Manual Lymphatic Drainage (MLD) and compression such as Multi-Layer Lymphoedema Bandaging (MLLB) or compression garment fitting, which are regarded as essential for the effective management of lymphoedema. (Table 7).

Compression Garments

- On average respondents fit almost 70% of their 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. (Table 8)
- Participants were asked an open question about compression garments and the main themes that emerged were 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). (Table 9)

Consultations

- 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), although this is likely to be a conservative figure as some participants found this difficult to estimate.
- The average duration of consultations for upper limb patients is 54.26 minutes (SD = 18.22 Range = 0-90 minutes) and for lower limb patients is 61.53 minutes (SD = 27.27, Range = 0-120 minutes). 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.
- Only 18.8% of respondents who personally treat lymphoedema patients provide home visits, whereas only 12.3% provide inpatient services despite the fact that lymphoedema in the lower limb(s) can seriously affect patients' mobility.

Potential Barriers for Patients Accessing Treatment

- According to respondents who personally treat patients, the mean greatest distance travelled by the lymphoedema patients to get to their lymphoedema service was quite substantial at 71.44 km (SD = 64.84, Range = 0 – 350km). While on average 47% (SD = 33.11, Range = 0 – 100) of respondents' caseload live within a 10km radius of the service, 23.7% on average (SD = 24.96, Range = 0-100) live more than 50km from the service. This suggests that travel distance may be a considerable barrier to treatment for a sizeable minority of patients.
- On average patients spend 4.68 weeks waiting for lymphoedema treatment (SD=4.94, Range=0-16 weeks). 38% of respondents employed a prioritisation system for patients on the waiting list and the prioritisation is generally according to the severity or type of lymphoedema, being a newly-diagnosed or palliative patient, or the source of the referral.

Professional Development

- Practitioners who personally treat lymphoedema patients rated themselves highest in terms of how competent they feel and 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)

- 77.7% of respondents had received specialised training from one of the lymphoedema schools (Casley-Smith, Foldi, Klose, Leduc, Vodder), which is deemed essential for the appropriate treatment of lymphoedema. 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 magazines and conferences. Approximately two thirds kept up to date with reading relevant journals and attending lectures or workshops on lymphoedema. (Table 11)
- 94% of respondents indicated that they do not think there are sufficient opportunities for professional development.
- In terms of the training needs that practitioners felt should be addressed, 69.1% of the 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; and 95.6% agreed that continuous professional development courses should be provided to enable practitioners to keep abreast of lymphoedema research and treatment developments

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'. When reviewing average ratings, 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. (Table 12). When reviewing the frequency of response categories, more than one out of every two people (57.8%) rated the standard of care for people with primary lymphoedema as very low or low; two out of every three people (67.6%) rated the standard of care for people with non-cancer related secondary lymphoedema as very low or low; 43.3% rated the standard of care as low or very low for people with cancer (non BC related) lymphoedema; and 22.9% rated the standard of care for BC related lymphoedema as very low or low (See Figure 1 below).

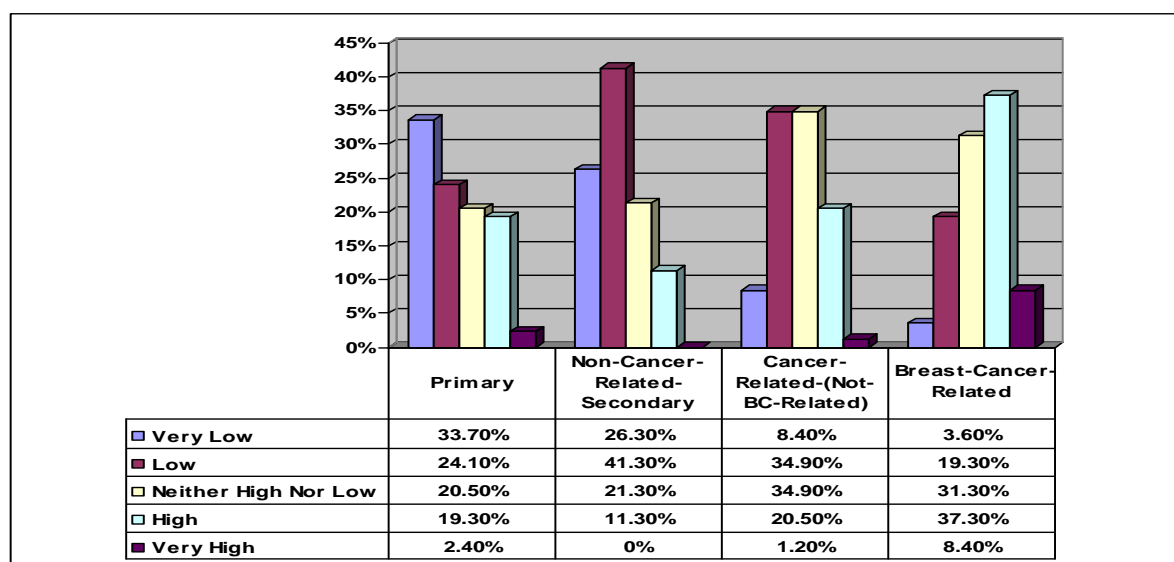


Figure 1: Practitioners' Ratings of the Standard of Care received by Patients with Different Types of Lymphoedema

- 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 (1) high quality lymphoedema service provision; (2) accessible, equitably distributed services; and (3) multi-faceted support. The themes, associated subthemes and illustrative responses are presented in Figure 2 in the appendix.
- The second open question related to what recommendations practitioners would make if they could influence policy on lymphoedema service development. The main themes were (1) high quality, accessible, equitably distributed services; (2) resources and (3) increased awareness of lymphoedema. The themes, associated subthemes and illustrative responses are presented in Figure 3 in the appendix.

Discussion

The discussion of the service provider results is presented under the following headings: insufficient service provision, inequitable service provision and challenges to the sustainability of services.

Insufficient Service Provision

The average number of healthcare professionals employed in each service for the treatment of lymphoedema was low at less than one healthcare professional per service. 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. The average number of patients seen per month for various consultations is also 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 only see 1-15 patients per month.

The small number of dedicated services and the necessity 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 knowledge, 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 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.

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. 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 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. While this would be expected given the prevalence rates of lymphoedema, 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.

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. This corresponds with a recurring theme across studies in England, Northern Ireland and Fife in Scotland that a lack of knowledge and awareness of lymphoedema and lymphoedema services on the part of non-oncology related health professionals and patients is a substantial barrier to diagnosis and referral for patients with non-cancer-related lymphoedema (Bulley, 2007; DHSSPS, 2004; Lam et al., 2006; MEP, 2006). Despite the greater prevalence of cancer-related secondary lymphoedema in this region of the world (Rockson & Rivera, 2008), the low number of practitioners' caseloads with non-cancer-related secondary lymphoedema in particular potentially signifies better referral pathways for patients with cancer-related lymphoedema as mentioned above.

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 percentage of patients required to travel greater than 50km 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 better 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.

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. This may indicate less than optimal funding security. 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.

The absence of cover for leave for the vast majority of practitioners corresponds with those from the UK and represents a considerable challenge to the stability of lymphoedema service provision (DHSSPS, 2004; Morgan, 2006). Indeed several practitioners have informed the research team anecdotally during the course of this study that departing lymphoedema practitioners have not been replaced, effectively resulting in services being suspended, leaving patients without a service.

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. These findings

suggest that many practitioners are striving to provide a sufficient standard of care to their patients but that services are provided on an ad hoc and uncertain basis.

- In summary, challenges to the sustainability of services relates to a lack of an independent funding stream or indeed 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.

From the Service Provider Perspective to the Patient Perspective

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 inclusive as possible at the time of questionnaire distribution.

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 3: Patient Perspectives – Focus Groups

The second phase of the study involved patient focus groups, which are semi-structured, group discussions. Focus groups capitalise on the interaction within a group and allow the comparison of participants' experiences and perceptions (Morgan, 1997). 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, 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;
- Explore barriers in accessing treatment;
- Assess the impact of lymphoedema on patients' daily life and on their quality of life.

Methodology

Identifying a Sample

Participants were recruited through hospitals and 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 were 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 upsetting either the patients themselves or their relatives.

A total of 5 focus groups, with approximately 5-8 participants in each, were conducted nationwide. One group took place 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.

Focus Group Topic Guide

To elicit 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 steering group, and the findings of the service provider phase of the research. The topic guide covered similar subjects as those asked in the studies by Johansson et al., (2003) and Williams, Moffatt and Franks, (2004). The focus group topic guide included: Initial Reaction to Symptoms of Lymphoedema; Interaction with Services before Diagnosis; Diagnosis; Access to Information about Lymphoedema; Experiences of Services since Diagnosis; Experiences of Treatment; Impact on Daily Life and Quality of Life; Changing government policy. The focus group topic guide was piloted in the first focus group and no changes were required.

Procedure

Having received ethical approval from each participating organisation, 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 receive further information about the focus groups. Those patients were then provided with a letter from their lymphoedema practitioner, an information leaflet 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 leaflet outlining the study and requesting their participation, and a consent form. Those willing to take part were asked to sign and return FREEPOST to the research team an informed consent form indicating their agreement to participate.

On receipt of the signed informed consent document, those agreeing to participate were sent information regarding their scheduled session. Participants were given 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. The facilitator of the focus groups was a trained oncology nurse familiar with the area and capable of dealing with any issues that might arise. 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 5 focus groups were conducted nationwide.

Data Analysis

The tapes of the discussions were transcribed verbatim. 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 group interaction. To ensure consistency two analysts coded the focus group transcripts independently for recurrent themes and coding categories.

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 4. See Table 13 in Appendix 3 for the demographic and clinical details of each focus group participant

As expected the majority of participants were female, over 50 years old, with breast-cancer-related 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 did not know what type of lymphoedema they have.

On average participants had experienced lymphoedema symptoms for 60.52 months ($n=33$, Range= 5-192, SD = 48.767) and had been diagnosed 57.76 months ago ($n=33$, Range= 3-192, SD = 46.554).

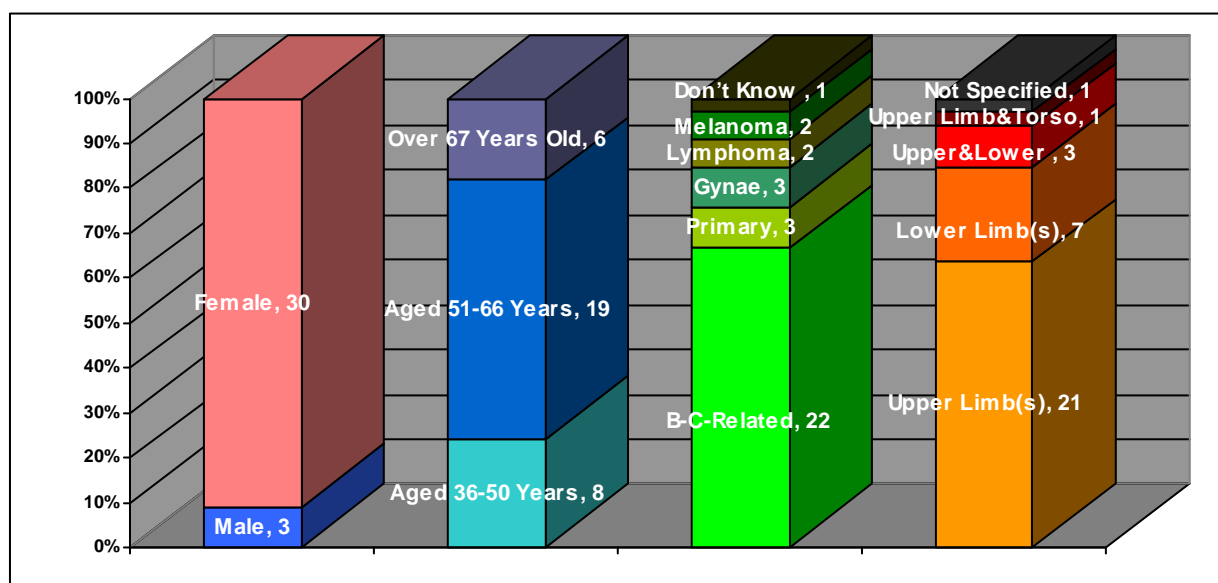


Figure 4: Focus Group Sample Breakdown

Themes and Subthemes

Six main themes, each with their own subthemes, emerged and are presented in Table 14 below.

Table 14: Main Themes and Subthemes from Patient Focus Groups

Main Themes	Subthemes
Barriers to Treatment	<ul style="list-style-type: none"> - Insufficient Services - Existing Services Overwhelmed - Cost of Treatment - Compression Garment Delays and Difficulties
Tension with Healthcare Professionals	<ul style="list-style-type: none"> - Not Pre-warned therefore not Prepared - Questions without Answers - Dismissive Attitude towards Lymphoedema
Lymphoedema Affecting Daily Life	<ul style="list-style-type: none"> - Making Space for Lymphoedema - Finding Clothes and Shoes to Cover Lymphoedema - Limitations imposed on Daily Activities
Emotional Factors	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - Taking Responsibility through Self-Management - Appealing for Treatment
Deriving Positives	<ul style="list-style-type: none"> - Preferable to an Advancing Cancer - Motivation to Inform Others - Acceptance from Others who Speak the Language

Barriers to Treatment

The first theme emerging 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 services* available to meet the needs of lymphoedema patients.

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)

The second subtheme related to *existing services being overwhelmed* as they are oversubscribed and under-resourced hampering access to continued treatment. For example, one person outlined 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. 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 got 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)

The third subtheme related to *the cost of treatment* and in particular how the cost of accessing ongoing private treatment to supplement what they perceived to be insufficient treatment from the public health service featured prominently in all focus groups. The cost of private treatment also extends beyond the private practitioners' fees to compression garments and bandaging.

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)

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. (FG 5, Participant 5).

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, poor 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)

For others, the compression garments funded by the HSE were poor fitting and unlikely to be encouraging lymph flow. Furthermore, the discomfort participants experience while wearing compression garments can make it difficult for participants to wear them.

I find by 5 o'clock in the evening I have to take (the compression garment) off, it's so painful. (FG 1, Participant 1).

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 and frustration at not *being pre-warned and therefore not being prepared* about the risk of developing 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)

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)

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)

The second subtheme was the tension arising from the perceived lack of knowledge of some healthcare professionals resulting in participants having *questions without answers*.

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)

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)

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 jollyng you along as if you were an eegit, you know, like not treating you like an adult. (FG 1, Participant 3)

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. 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 and in *making space for lymphoedema* 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.

(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)

The second subtheme of lymphoedema affecting daily life related to participants' difficulties in *finding clothes and shoes to cover the lymphoedema*:

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)

The *limitations imposed by lymphoedema on daily activities* emerged as the final 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... (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, for example, standing in queues posed difficulties. 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)

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*. 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:

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)

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 cancer treatment*:

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)

Participants spoke of their self-consciousness in *adapting to their 'new body'*:

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)

Participants spoke about their *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)

Another subtheme related to *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)

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.

Participants *taking responsibility through self-management* for their lymphoedema referred to the adoption of measures to prevent an increase in swelling (e.g. keeping a compression garment in their bag) or the development of complications such as cellulitis (e.g. taking medication for maintenance or having an emergency supply of penicillin). 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)

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

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.... (FG 2, Participant 6)

I haven't found the services that great for primary, 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*. Several

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

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)

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

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)

Finally participants reported the *benefits of meeting other lymphoedema patients who speak the language* 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)

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:

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)

Discussion

The findings of the patient focus groups broadly correspond with the results of the service provider phase as both emphasised the under-resourced, overstretched, and inequitable nature of current lymphoedema service provision in Ireland. This was particularly reflected in the first theme emerging from the data, which referred to the 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). With regard to the inequitable nature of lymphoedema service provision, 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. 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 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 Williams 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 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 peoples' comments before learning to open up. 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 whether through prophylactic or self-management measures or by actively appealing for lymphoedema treatment. As mentioned previously, patients reporting difficulties with their daily management plan was also reported by Bogan et al., (2007) and Johansson et al. (2003). However, previous studies have not identified themes relating to patients actively appealing for treatment.

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 is related to Hare's (2000) theme of 'counting blessings' and Johansson and colleagues' (2003) finding of patients consciously considering lymphoedema as a less important aspect of their lives to regulate their emotional distress. Participants 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. 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).

- In summary, these findings provide useful insights into patients' experiences of current lymphoedema service provision in Ireland and of living with the condition. In particular they highlight the barriers to treatment, tension with healthcare professionals, the affect of lymphoedema on daily life, the emotional factors, taking an active role and deriving positives. 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.

From Focus Groups to the Patient Survey

While purposive sampling was employed to include 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. Nonetheless, the focus groups 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, a 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 4: Patient Perspectives - Survey

The final phase of the study employed patient questionnaires in order to explore how representative various experiences of lymphoedema and lymphoedema service provision are among a broader sample of patients; to quantitatively measure the impact of lymphoedema on patients' quality of life in Ireland for the first time and to provide additional information to correspond with, expand on or contradict the findings of the service provider questionnaire and patient focus group phases. These general aims can be broken down into more specific objectives, 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.

Methodology

Identifying a Sample

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 had previously provided a lymphoedema service and therefore had a patient list or waiting list on file. Participants were also recruited through cancer support services that provided lymphoedema treatment and through organisations, which provided 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. In hospitals and services, the cooperation of the manager of the lymphoedema clinic (or equivalent in physiotherapy or occupational therapy department) was sought to act as gatekeeper by facilitating the identification of patients who met the inclusion criteria. The survey was also advertised in relevant newsletters and websites (e.g. the Lymphoedema Ireland website and newsletter, and MLD Ireland website) so that people who were 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.

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 upsetting either the patients themselves or their relatives.

Questionnaire Design

Questionnaire content and subsequent item selection was developed through four processes: the review of literature, expert opinion, the findings of the service provider phase of the research and the themes arising from the focus groups that revealed issues requiring further exploration. Approval was also sought and granted for the use and amendment of the questionnaire used in the BreastCare Victoria study (2005).

The final content of questionnaire included the following:

- 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.
- Recommendations for lymphoedema service development.
- Implications of lymphoedema on daily life and quality of life.
- The World Health Organisation's abbreviated Quality of Life measure (WHOQOL-BREF) was included to measure the impact of the condition on patients' quality of life. The WHOQOL-BREF is a 26 item measure that assesses four major domains: physical, psychological, social relationships and environment (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).

The questionnaire was piloted with six lymphoedema patients. 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 prior to its distribution.

Procedure

Ethical approval was sought and granted from fourteen Ethics Committees that covered the sixteen participating hospitals, services and organisations. In hospitals and services, the cooperation of the manager of the lymphoedema clinic (or equivalent in physiotherapy or occupational therapy department) was sought to facilitate 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 was not breached. Instead a member of the research team went to the hospital or organisation to assist when requested, 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 but was not retained by the research team.

Potential participants accessed through hospitals were posted a cover letter from their lymphoedema practitioner with an information leaflet, questionnaire and a FREEPOST envelope, with which to return the questionnaire to the research team. Potential participants accessed through organisations providing support to lymphoedema patients were posted the same cover letter but from a named person in the support organisation. 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.

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. Inferential statistics such as correlations, the Chi-square test of independence, one-way analysis of variance (ANOVAs) and Brown-Forsythe test were performed to assess the statistical significance of relationships between variables and differences between groups. Tables and Figures are presented in Appendix 4. Responses to open questions were thematically analysed.

Results

General Participant Information

- A total of 1,529 questionnaires were posted to patients. As the research team sent questionnaires 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 55.8%. 118 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 52.1%.
- 93.2% of the sample is female and 6.8% is male. The majority of the sample (74.3%) is aged over 50 years of age, which was expected given the greater prevalence of the condition among those who are middle aged and older. The mean age of participants in the current study was 58.89 years (SD=12.7, Range=18-97). (Table 15)
- 6.5% of participants have primary lymphoedema, 5.5% have non-cancer-related secondary lymphoedema, 10% have cancer-related (but not breast-cancer-related) secondary lymphoedema and 73.1% have breast-cancer-related lymphoedema. Approximately 40% have lymphoedema in their upper limb(s), and 20% have lymphoedema in their lower limb(s). (Table 15)
- 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. (Table 15)

Obtaining a Lymphoedema Diagnosis

- Participants had experienced lymphoedema symptoms for an average of 6.5 years (mean 78.45 months, SD = 101.9, Range 2-804 months) and had received a diagnosis on average just over 5 years ago (mean 62.08 months, SD=77.0, Range 0-600).
- Patients with primary lymphoedema spent much longer waiting for a diagnosis when compared with patients with all other types of lymphoedema. Patients with primary lymphoedema waited on average 78.2 months for a diagnosis, patients with non-cancer-related secondary lymphoedema waited on average 20.6 months, and patients with cancer-related (but not breast-cancer-related) secondary lymphoedema waited an average of 8.2 months, while patients with breast-cancer-related lymphoedema waited on average 4.8 months for a diagnosis. (Table 16).
- Only 41.5% of respondents indicated that they knew they were at-risk of developing lymphoedema. 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. While 51.6% of patients with breast-cancer-related secondary lymphoedema knew they were at-

risk; only 23.5% of those with cancer-related (but not breast-cancer-related) lymphoedema; 6.7% of primary lymphoedema patients and just 4.8% of those with non-cancer-related secondary lymphoedema knew they were at-risk of developing the condition.

- Overuse of the at-risk limb was the main trigger for lymphoedema symptoms (30.1%), followed by a cut/graze or bang to the at-risk area (8.1%) and taking a flight (6.0%). 28.2% of respondents did not know what had triggered their initial lymphoedema symptoms.
- Participants were asked to indicate all of the various healthcare professionals they consulted when they were originally seeking an explanation of their lymphoedema symptoms. 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'. Apart from 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 20-30% were 'dissatisfied' or 'very dissatisfied' with the healthcare professionals on all measures. (Table 17)
- The lowest rated healthcare professionals were general practitioners and in almost all cases, lymphoedema nurse specialists were rated the highest – which is unsurprising considering that they are specialised in the treatment of lymphoedema. 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).
- When looking at participants' satisfaction broken down according to the type of lymphoedema they experience, 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. These differences were significant which indicated that participants' ratings of these items were associated with the type of lymphoedema that they're experiencing. (Table 19 & 20)
- Participants were asked to indicate which practitioner suggested that their symptoms might be indicative of lymphoedema. Just over half of respondents had a consultant suggest

lymphoedema. However, it is important to note that 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. (Table 21)

Information

- The main source of information for patients following their diagnosis was their lymphoedema practitioner (60.3%). Just over two-thirds had received education on skincare, almost 40% had received education on when to seek further medical attention and only about one-fifth of the sample had received education on diet and its impact on lymphoedema symptoms. (Table 22)
- While the majority of respondents were satisfied or very satisfied with the information they receive, 21.7% were dissatisfied or very dissatisfied. (Table 22).
- Participants were asked an open question on how the information lymphoedema patients receive could be improved. Patients reported that they should be told in advance of medical treatment, specifically cancer treatment, that it may predispose them to developing lymphoedema. Patients recommended that information should be presented in audiovisual and written format and that the content of the information should not solely focus on the physical consequences of lymphoedema. Patients also highlighted the importance of informing healthcare professionals about lymphoedema to enable them to impart accurate information on the condition.

Lymphoedema Services

- 89.4% of respondents indicated that they have received lymphoedema treatment. However some participants who have received compression garments, or have been taught exercises or SLD may not have considered themselves as having received lymphoedema treatment. The majority of respondents indicated that their main lymphoedema service is in a public service (64.9%) and 77.7% indicated that the setting was a hospital.
- Participants reported that on average they had to travel 27.9 kilometres in a one-way trip to their lymphoedema service. Yet participants were travelling between 1 and 250 km to their lymphoedema service. Almost a fifth of respondents reported that travel distance limited their ability to avail of lymphoedema treatment.
- The most commonly cited lymphoedema practitioner was a physiotherapist (37.1%) but a wide variety of healthcare professionals are involved in the care and treatment of lymphoedema.
- 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. Over 78% of respondents rated the practitioner as 7 or higher on all measures. 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 23).
- 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'. 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. 27.3% of patients with primary lymphoedema rated the standard of care as very low or low; 20.6% of patients with non-cancer related secondary lymphoedema, 16.1% of patients with cancer (not BC) related secondary lymphoedema and 8.2% of patients with BC related secondary lymphoedema rated the standard of care as very low or low. (Table 25)

Lymphoedema Treatments

- Overall respondents were waiting approximately 10 months for their first treatment following their lymphoedema diagnosis. Patients with primary lymphoedema were waiting on average approximately 4 years for treatment while patients with breast-cancer-related lymphoedema were waiting on average approximately 6 months – still a considerable period of time. However there were large ranges and standard deviations associated with these means suggesting a wide variation in waiting time even among patients with the same type of lymphoedema. (Table 27)
- There was a strong positive correlation between time since diagnosis and time between diagnosis and first treatment ($r=0.558$, $p=0.01$). This indicates that participants who have been diagnosed more recently are seen quicker.
- On average respondents had received their last treatment 10.2 months ago. Patients with primary lymphoedema received their last treatment on average 34.1 months ago whereas patients with cancer-related (but not breast-cancer-related) secondary lymphoedema received their last treatment 7.4 months ago. Again the ranges and standard deviations were quite large particularly for patients with primary lymphoedema which suggests that there is huge variation even among patients with the same type of lymphoedema. (Table 27).

Compression Garments

- 95.3% of respondents reported that they had been prescribed a compression garment and 87.6% of respondents currently use garments. On average participants use 2.5 garments (SD=1.5, Range=0-12). 45.2% of respondents use off-the-shelf garments, 31.1% use custom-made or made-to-measure garments, 18.6% use both types of garments and 5.1% do not know what type of garments they are using. Participants have to wait on average 22.8 days for garments to be delivered (SD=51.4, Range 0-730 days). Although the large range and standard deviation 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 can be their application. 18.2% of participants who currently use garments reported that they need another person to help them put on and take off their garments, while 15.5% use an assistive device for this purpose.
- A higher percentage of people wore their compression garment doing daily household indoor (82.5%) or outdoor chores (81.9%) or during flights (84.2%) than while socialising (61.5%), child minding (51.7%), during employment (56.7%), sports (49.6%) or swimming. (Table 28)
- 24.9% of respondents indicated that they do not wear garments as often as they have been advised to. Of those, 54.3% 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 do not need to wear the garment all the time to maintain the swelling at a comfortable level and 25.7% gave another reason.

- Participants who currently use garments were asked to rate their satisfaction with the colour, appearance, comfort, fit, texture, temperature, quality, value for money and overall satisfaction of their compression garments on a scale from 1-'very dissatisfied' to 5-'very satisfied'. Although the majority of respondents scored the garments as neutral or better, a sizeable proportion of between 20-30% were dissatisfied or very dissatisfied with the colour, appearance, comfort, texture and temperature of compression garments. (Table 29 & 30)
- 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. A high proportion of respondents (70.1%) do not receive the minimum amount of compression garments from their main lymphoedema service.
- 60.9% of those who currently use garments have a medical card and of those 18% indicated that having a medical card slowed down the delivery of their compression garments.
- 42.1% of respondents pay for their compression garments and on average spend €165.94 of their own money per calendar year on compression garments (SD=164.01, Range €2-1000). However there was huge variation in the financial burden on patients.
- 57.3% of respondents replace their garments the recommended two-three times a year. 17.3% indicated that the cost of garments affected whether they replaced them. 8.8% of respondents who currently use garments reported having difficulties getting re-measured because practitioners are too busy to measure patients; lymphoedema services have been discontinued, and patients do not know where to go to be re-measured.

Lymphoedema Exercises and Simple Lymphatic Drainage

- 81% of respondents reported that they had been taught how to perform specific lymphoedema exercises, whereas 52.8% of respondents reported that they had been taught how to perform specific simple lymphatic drainage (SLD) or self-massage. The majority of respondents were taught lymphoedema exercises or SLD in a once-off individual consultation (52% v 60.4%) 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. 51.5% and 40.3% of respondents indicated that they perform exercises or SLD on a daily basis. (Table 32)

Manual Lymphatic Drainage and Multi-Layer Lymphoedema Bandaging

- 56.4% of respondents reported that they had received manual lymphatic drainage (MLD) a specialised form of massage of the treatment of lymphoedema whereas 35.4% of respondents reported that they had received multi-layer lymphoedema bandaging (MLLB).

- There appears to be considerable variation in lymphoedema patients' access to MLD and MLLB. The most common responses were that 23.1% of respondents receive MLD every 2-3 months and 31.1% have received MLLB only 1-3 times. (Table 33).
- 29.1% of respondents who have received MLLB reported that they had been taught how to self-bandage and none of the respondents reported being provided with a book, leaflet or DVD to enable them to revise their technique in self-bandaging.

Cost of Treatments and Service Recommendations

- 9.8% of respondents reported that they pay a fee to see the practitioner in their main lymphoedema service and the mean fee for various types of consultations varied between €60 and €75.
- 85.5% of respondents who pay a fee to see their lymphoedema practitioner reported having private health insurance and of those 25.5% indicated that their health insurer pays money towards their consultation fees. However financial support from private health insurers was 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. While the majority of respondents indicated that they do not pay for treatment, the first theme was the difficulties these patients would encounter if they were required to pay for their treatment. The second theme related to respondents who do pay for their treatment viewing the treatment as essential to their wellbeing '*for the relief of discomfort and body distortion I would pay anything to look NORMAL in my clothes*' (P524). 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.
- 3.3% of respondents reported having gone abroad for lymphoedema treatment, On average participants had gone abroad for treatment 2.53 times. 63.2% reported having received financial assistance for their trip from the HSE, whereas the remaining 36.8% reported receiving no assistance ($n=19$).
- 61.2% of respondents considered the treatment they receive as sufficient to manage their lymphoedema effectively. 67% of patients with breast-cancer-related lymphoedema considered the level of treatment they receive as sufficient whereas 47.8% of primary lymphoedema patients considered themselves as receiving sufficient treatment. There was a significant association between type of lymphoedema and whether participants considered the treatment they receive as sufficient. (Table 34)
- Participants were asked an open question on how lymphoedema services could be improved. Many of the patients' recommendations echo comments made previously by the focus group participants about the need for increased funding to provide more practitioners, treatments and services and to support patients with the costs of treatments; equitable services that are distributed throughout the country and provided to patients with all types of lymphoedema;

emotional support in the form of counselling for those who need it and nationwide patient support groups; and increased awareness of lymphoedema and lymphoedema services among healthcare professionals, lymphoedema patients, those at risk and the general public. (Figure 5)

Impact of Lymphoedema on Daily Life and Quality of Life

- At least 30% of respondents experienced limitation across each of the specified aspects of their daily lives. The limitations that lymphoedema imposes on patients' lives were more keenly felt with regard to their ability to perform indoor (77.7%) and outdoor (80.9%) chores, wear clothes/shoes (77.8%), and go on holidays (68.1%). (Table 35)
- 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. (Table 36)
- 29.3% of all respondents reported that they had experienced a bout of cellulitis, an infection in the layers of the skin a condition commonly associated with lymphoedema. On average respondents had been hospitalised for the treatment of their cellulitis 1.7 times (SD=2.9, Range=0-20). However the large range suggests that cellulitis can have a significant impact on some patients' lives.
- The first two items of the QoL measure 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'. 21.2%, 26.1% and 18.2% 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 6% 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 34.1% and 35.8% 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. (Table 37)
- In looking at the scores across the four QoL domains, the sample rated themselves lowest on the physical and psychological health domains and highest on the environment and social relationships domains. (Table 39)
- With regard to the physical health domain, 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, and participants with breast-cancer-related secondary lymphoedema. With regard to the psychological health domain, participants with primary lymphoedema and participants with non-cancer-related secondary lymphoedema scored significantly lower on the psychological health domain than participants with breast-cancer-related secondary lymphoedema. With regard to the social relationships domain, there were no significant differences between groups. Finally, in relation to the environment domain, participants with primary lymphoedema and with non-cancer-related

secondary lymphoedema scored significantly lower on the environment domain than participants with breast-cancer-related secondary lymphoedema.

Final Question

A total of 428 participants responded to a final open question on their additional comments. 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 382:..Lymphoedema is definitely on the back burner... (it) needs to be brought to the fore medically.

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

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

59 comments related to the need for additional lymphoedema services and funding for those services:

Participant 45: ... The bottom line is there are lack of facilities and resources for the professionals to do their job properly.

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

Participant 1: ... Patients should be made aware of (the) possibility (of developing lymphoedema) and shown how to prevent and/or treat it.

Comments that did not relate to service provision, focused on the impact of lymphoedema on patients. 39 participants wrote about the impact of lymphoedema on their self-image and self-confidence:

Participant 104: ...The very hard part of it is the altered body image. I found it hard to accept wearing the compression garments...

34 comments focused on the financial implications of living with lymphoedema:

Participant 442: ...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.

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

Participant 707: 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 why me. 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 cannot understand their experiences:

Participant 384: (I have) feelings of isolation as so few people know what it is.

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

Participant 64: ...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.

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

Participant 561: 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 195: ... 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. ...

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

Participant 89: ... I would travel to the end of the world for cure and worry everyday about it getting worse...

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

Participant 524: 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

The results of the patient questionnaires can be summarised into two themes which broadly correspond with the findings of the service provider questionnaire and patient focus group phases: inequitable service provision and the impact of lymphoedema on patients' 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. 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 6 and 1/2 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. 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. However, while patients with breast-cancer-related secondary lymphoedema scored more favourably 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.

There was also 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, 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 are not 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.

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, for some this can take the form of considerable financial expense. For others this can involve the use of compression garments with which patients are dissatisfied. The results indicated that participants' dissatisfaction with 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 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.

Lymphoedema can also affect participants' daily lives and quality of life through physical symptoms and associated medical conditions. An associated physical condition of lymphoedema is cellulitis an infection in the layers of the skin. 29% 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. 61% 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.

Lymphoedema is a condition that 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 nor comparisons therein. This study 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.

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. These 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.

Conclusion

It is important to note that, 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 under-represented. Nonetheless, the findings are a key step in documenting the experiences of lymphoedema service provision and of living with lymphoedema among an Irish sample for the first time and provide information on how common particular experiences are – namely inequitable service provision and difficulties in living with lymphoedema

Chapter 5: Conclusion & Recommendations

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.

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.

- 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 further inform the strategic planning of lymphoedema service development.
- Evidence for the clinical effectiveness of particular treatment strategies when used singularly and in tandem with other treatment approaches is required to increase awareness of these treatments among the wider healthcare community and consolidate patients' claims for financial support from private health insurance companies.
- While this study aimed to contribute to research on the impact of lymphoedema, further research is required with groups that were not included in the current study, such as palliative patients with lymphoedema, children with primary lymphoedema and their carers.
- 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. Future research should include such a measure to ascertain what proportion of the sample of Irish lymphoedema patients is experiencing clinical levels of distress.

- Future studies on the impact of lymphoedema on quality of life should compare lymphoedema patients' scores with matched controls, for example breast cancer survivors who have not 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.
- Research on the impact of the condition on patients must also 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.
- Finally, with postal surveys of potential participants accessed through hospital and service records, there is the regrettable possibility of unwittingly posting surveys to individuals who are deceased and where this information might not yet have been known to hospital personnel or where patient records have 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 families. To minimise the possibility of sending research correspondence to people who may be deceased, it is recommended that all research using hospital or health service records to potential participants should not only have a member of the relevant healthcare team identify people who meet the inclusion criteria from the available records and lists and subsequently have the emerging list reviewed by other key personnel on the team (different members of the team may be more aware of individual patient circumstances than others), but it is also strongly recommended that the emerging list is crosschecked by making contact with the patient's GP and reviewing death notices (paper and/or online (e.g. www.rip.ie)).

Policy Recommendations

These recommendations are categorised under three headings: Service Development; Raising Awareness of Lymphoedema & Training amongst Healthcare Professionals; Raising Awareness of Lymphoedema amongst People at Risk and Patients with Lymphoedema.

Service Development

- 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).
- 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.
- Once the establishment of multi-disciplinary teams in lymphoedema services has taken place, measures of quality of life and psychological well-being should be introduced so that patients who may require additional support can be identified. Subsequently, 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 order for the HSE to address the gaps in lymphoedema service provision, 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.
- The option of at least subsidising treatment should be explored to ensure timely interventions and the prevention of costly complications.

Raising Awareness of Lymphoedema & Training amongst Healthcare Professionals

- 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. 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).
- 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 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 et al., 1998). The anatomy, physiology and pathophysiology of the lymphatic system, and the prevention, development and treatment of lymphatic 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. 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.

Raising Awareness of Lymphoedema amongst People at Risk and Patients with Lymphoedema

- 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).

- 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, information packs could be produced including general information on lymphoedema and tailored 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.
- Patients should 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 policy change, service development, increased awareness and further national and international research.

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
- 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
- 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
- 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
- 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 quality of life scale to assess the impact of arm morbidity in breast cancer patients post-operatively. *Breast Cancer Research and Treatment* 68:273-282
- 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
- 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
- Jeffs E. (2006). Treating breast cancer-related lymphoedema at the London Haven: clinical audit results. *European Journal of Oncology Nursing* 10:71-79
- 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
- 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

- 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
- 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
- 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
- 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
- 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
- Morrell RM, Halyard MY, Schild SE, Ali MS, Gunderson LL, Pockaj BA. (2005). Breast cancer-related lymphoedema. *Mayo Clinic Proceedings* 80(11):1480-1484
- 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). (2006). Position Statement of the National Lymphedema Network: Treatment. Retrieved 29th May 2008 from <http://www.lymphnet.org/pdfDocs/nlntreatment.pdf>
- Okeke AA, Bates DO, Gillatt DA. (2004). Lymphoedema in urological cancer. *European Urology* 45:18-25
- 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. (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
- 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).
- 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
- 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
- Sneddon MC, Lewis M. (2007). Lymphoedema: A female health issue with implications for self care. *British Journal of Nursing* 16(2):76-81
- Tobin MB, Lacey HJ, Meyer L, Mortimer PS. (1993). The psychological morbidity of breast cancer-related arm swelling. *Cancer* 72:3248-3252
- Todd M. (2006). Lymphoedema: sizing up the problem. *British Journal of Community Nursing* 11(8):3-4
- Velanovich V, Szymanski W. (1999). Quality of life of breast cancer patients with lymphedema. *The American Journal of Surgery* 177:184-188
- 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 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

Appendix 1

Glossary of Terms Used in this Report

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.
Lymphoedema	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; NLN, 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.

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.

Appendix 2

Service Provider/Practitioner Tables & Figures

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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)
Service Type			
<i>n</i>	106	71	18
Public	62.3%	64.8%	72.2%
Private	17%	21.1%	16.7%
Public and Private	20.8%	14.1 %	11.1%
Service Setting			
<i>n</i>	108	72	18
University Hospital	30.6%	22.2%	27.8%
Regional Hospital	5.6%	5.6%	11.1%
General Hospital	20.4%	16.7%	11.1%
Private Hospital	7.4%	6.9%	5.6%
Community Health Centre	1.9%	1.4%	-
Cancer Support Centre	2.8%	2.8%	11.1%
Hospice	4.6%	6.9%	11.1%
Private Practice	11.1%	16.7%	11.1%
Other (Domiciliary in community; Clinic in health centre & home visits; Specialist palliative care team; Primary care)	15.7%	20.8%	11.1%
County			
<i>n</i>	108	72	18
Cavan	3.7%	4.2%	-
Clare	0.9%	1.4%	-
Cork	14.8%	12.5%	11.1%
Donegal	9.3%	13.9%	-
Dublin	33.3%	34.7%	50%
Galway	6.5%	4.2%	-
Kerry	0.9%	1.4%	-
Kildare	0.9%	1.4%	-
Kilkenny	1.9%	-	11.1%
Laois	3.7%	4.2%	5.6%
Limerick	1.9%	-	5.6%
Louth	2.8%	4.2%	-
Mayo	1.9%	1.4%	-
Meath	2.8%	1.4%	-
Monaghan	1.9%	1.4%	-
Sligo	0.9%	1.4%	-
Tipperary	3.7%	-	-
Waterford	0.9%	1.4%	5.6%
Westmeath	2.8%	2.8%	-
Wexford	2.8%	2.8%	11.1%
Wicklow	1.9%	2.8%	-

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)
Occupation			
<i>n</i>	107	72	18
Breast Care Nurse	13.1%	2.8%	27.8%
Lymphoedema Nurse Specialist	1.9%	2.8%	11.1%
MLD Therapist	10.3%	15.3%	11.1%
Occupational Therapist	6.5%	8.3%	-
OT Manager	3.7%	1.4%	-
Physiotherapist	39.3%	45.8%	16.7%
Physio Manager	10.3%	2.8%	5.6%
Other ~	15%	20.8%	27.8%

~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

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
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

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

Source of Funding	<i>n</i>	Mean %	SD	Range
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
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.

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

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

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%

Table 5: Patient and Waiting List Numbers

	<i>n</i>	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)

	<i>n</i>	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.

Table 6: Mean Percentages of Patients Treated in the last Year, in Relation to Type and Location of Lymphoedema and Age Range when First Treated

Type of Lymphoedema	n	Mean %	SD	Range
Primary lymphoedema	70	12.61	19.98	0-100
Lymphoedema Secondary to Breast Cancer	70	56.07	32.60	0-100
Lymphoedema Secondary to Other Types of Cancer	70	13.53	16.76	0-100
Lymphoedema Secondary to Trauma and Tissue damage (e.g. Burns, Scarring, Large Wounds, Self Harm etc.)	70	3.47	12.90	0-90
Lymphoedema Secondary to Venous Disease (e.g. DVT, Chronic Venous Insufficiency, Intravenous Drug Use etc.)	70	4.36	10.88	0-67
Lymphoedema Secondary to Infection (e.g. Cellulitis, Lymphadenitis, Filariasis etc.)	70	3.50	8.57	0-50
Lymphoedema Secondary to Inflammation (e.g. Rheumatoid/Psoriatic Arthritis, Eczema, Sarcoidosis etc.)	70	1.11	3.89	0-20
Lymphoedema Secondary to Immobility and Dependency (e.g. Dependency, Obesity, Paralysis etc.)	70	4.90	15.40	0-100
Location of Lymphoedema				
Unilateral Upper Limb (i.e. in one arm)	69	57.67	32.17	0-100
Bilateral Upper Limb (i.e. in both arms)	69	4.52	10.94	0-67
Unilateral Lower Limb (i.e. in one leg)	69	16.75	20.49	0-100
Bilateral Lower Limb (i.e. in both legs)	69	13.70	19.63	0-90
Face and/or Neck	69	1.65	5.58	0-40
Genitals	69	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)	69	0.88	3.87	0-25
Age Range				
Less than 18 years old	68	0.62	1.97	0-10
19-35 years	69	6.61	14.33	0-100
36-50 years	69	29.20	23.73	0-100
51-65 years	69	43.17	25.51	0-100
Over 66 years old	69	20.49	22.70	0-90

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%

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

	n	Mean %	SD	Range
Mean Percentages regarding Compression Garment Fitting				
% 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
<hr/>				
	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

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	<p><i>Participant 14:</i> Made-to-measure can take 2-4 weeks.</p> <p><i>Participant 26:</i> Limb shape may have changed by the time the garment arrives. I really try to avoid custom-made garments for this reason.</p> <p><i>Participant 39:</i> 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.</p> <p><i>Participant 84:</i> 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.</p> <p>-----</p>
Delivery from the UK Takes Longer	<p><i>Participant 70:</i> 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.</p> <p>-----</p>
HSE Approval Procedures Delay Delivery	<p><i>Participant 12:</i> 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.</p> <p><i>Participant 34:</i> Garment delivery is delayed by HSE red tape.</p> <p><i>Participant 40:</i> Garments being paid privately arrive within 7-10 days. Garments being approved through medical card take up to 5 weeks.</p> <p><i>Participant 74:</i> 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.</p> <p><i>Participant 107:</i> 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.</p> <p>-----</p>
Practitioner must continue To Treat the Patient Intensively until the Garment Arrives	<p><i>Participant 45:</i> Delay in receiving garments can result in changes in volume occurring between measurements taken following intensive (MLD) and supply of garment.</p> <p><i>Participant 85:</i> Patient needs continued treatment during 2 week period (waiting for garment) – significant impact on service.</p> <p><i>Participant 98:</i> Treatment must be continued until garment is supplied impacting on capacity to uptake new patients.</p> <p><i>Participant 108:</i> Delays completion of client treatment therefore waiting lists expand as treatment must continue until garment is correctly fixed.</p>

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

	<i>n</i>	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.

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%

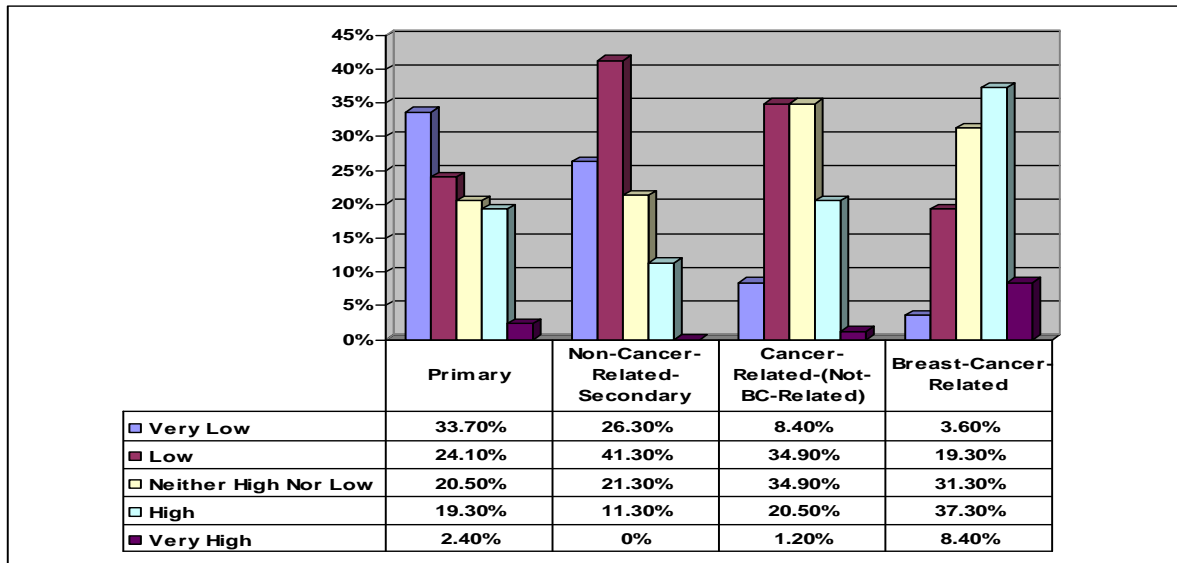


Figure 1: Practitioners' Ratings of the Standard of Care received by Patients with Different Types of Lymphoedema

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

	<i>n</i>	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

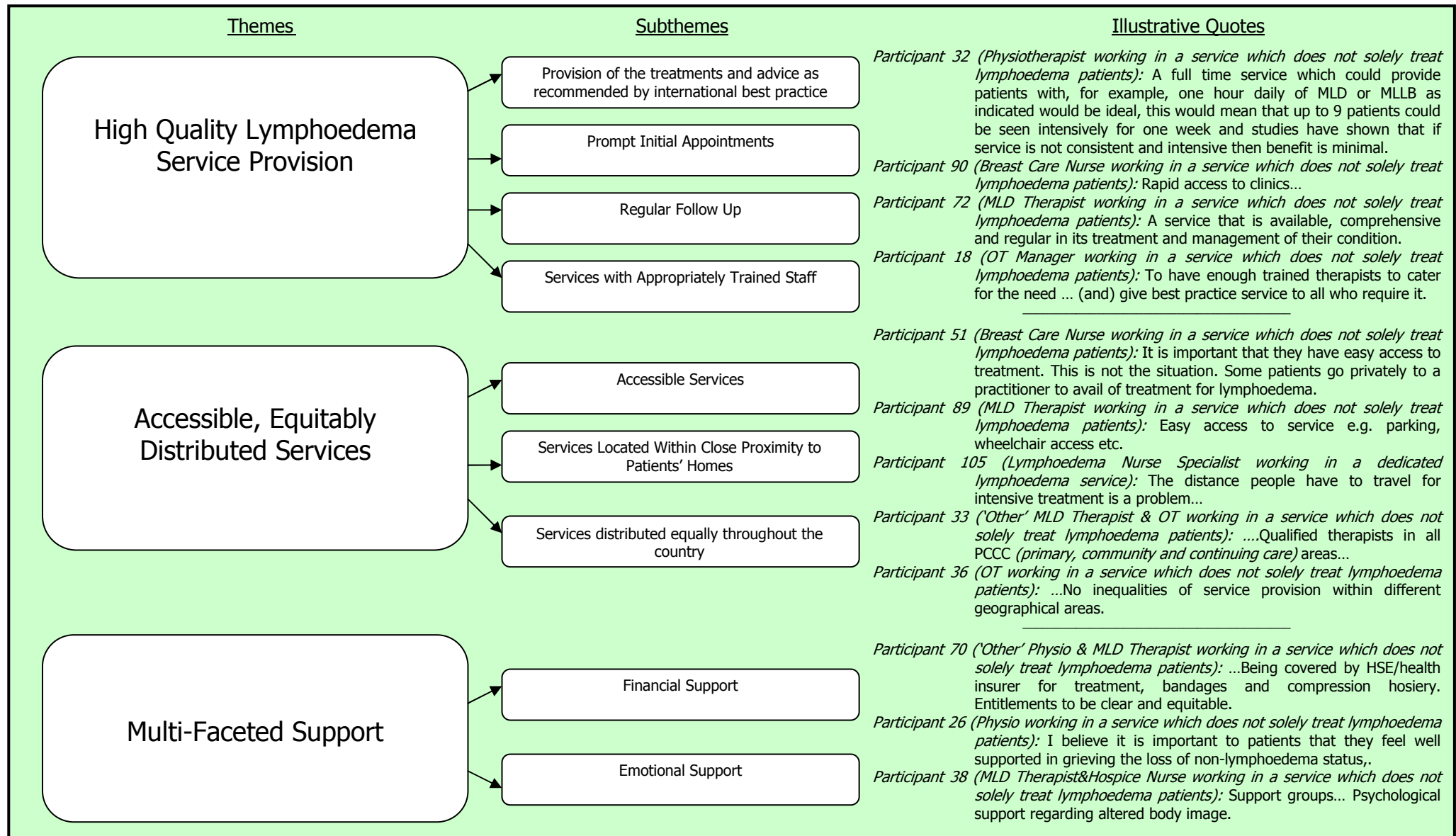


Figure 2: Themes, Subthemes and Quotes from Practitioners in Response to the Question "What do you believe is important to patients of lymphoedema services?"

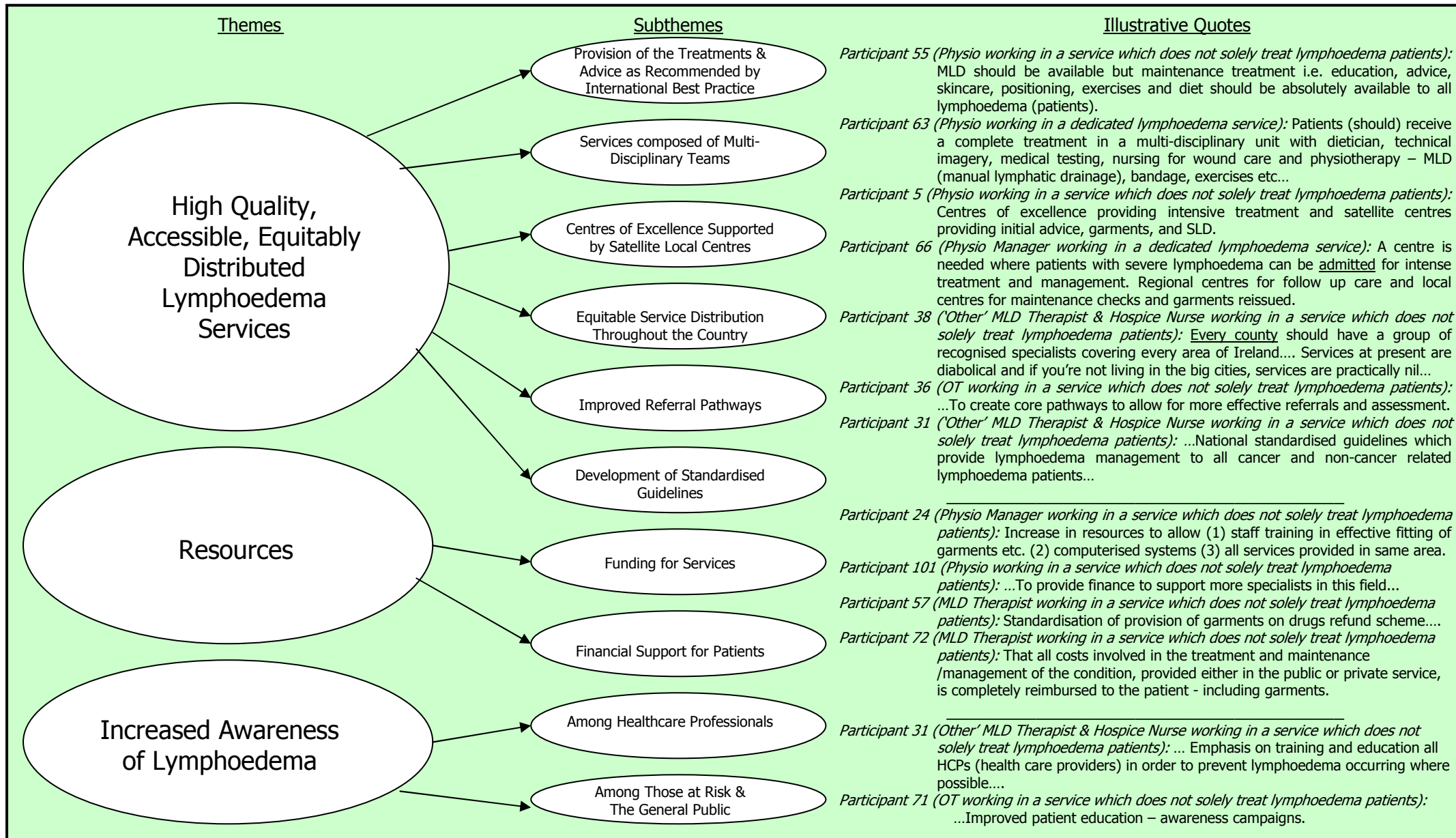


Figure 3: Themes, Subthemes and Quotes from Practitioners in Response to the Question: "If you could influence government policy in this area, what recommendations would you make regarding lymphoedema services in general?"

Appendix 3

Demographic and Clinical Details of Each Focus Group Participant

Table 13: 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 13: 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 13: 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 4

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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)	
<i>Primary Lymphoedema</i>	
Primary Lymphoedema	6.5%
<i>Cancer-Related Secondary Lymphoedema</i>	
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%
<i>Primary and Cancer-Related Secondary Lymphoedema</i>	
Primary Lymphoedema & Lymphoedema Secondary to Breast Cancer	0.6%
Primary Lymphoedema & Lymphoedema Secondary to Lymphoma	0.1%
<i>Non-Cancer-Related Secondary Lymphoedema</i>	
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%
<i>Don't Know</i>	
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%

Table 16: Average Time Spent Waiting for a Diagnosis

	<i>n</i>	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

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

	<i>n</i>	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%

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

	<i>n</i>	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)

	<i>n</i>	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

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

	<i>n</i>	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

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

	Welch One-Way ANOVA
Attitude	$F_w(3, 80.131) = 5.907 *$
Knowledge	$F_w(3, 78.422) = 12.386 *$
Practical Support	$F_w(3, 75.662) = 11.440 *$
Emotional Support	$F_w(3, 76.211) = 12.773 *$
Time Taken to Diagnose	$F_w(3, 73.705) = 11.196 *$
Overall Satisfaction	$F_w(3, 81.783) = 11.537 *$
*Significance at 0.001 level	

Table 21: Healthcare Professionals who suggested a diagnosis of lymphoedema

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%

*Although participants were asked to indicate only one practitioner, 80 participants ticked more than one box.

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%

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

	<i>n</i>	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%

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

	<i>n</i>	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)

	<i>n</i>	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

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%

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

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

	<i>n</i>	Mean	SD	Range
Time between Diagnosis and First Treatment (in Weeks)				
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)				
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

Table 28: Use of Compression Garments during Various Activities

	<i>n</i>	% 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%

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

	<i>n</i>	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%

Table 30: Mean Ratings of Compression Garments

	<i>n</i>	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

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

	<i>n</i>	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

Table 32: Lymphoedema Exercises and Simple Lymphatic Drainage

	Lymphoedema Exercises	Simple Lymphatic
Drainage		
Method that Exercises/SLD were taught to Participants	<i>(n= 519)</i>	<i>(n=326)</i>
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	<i>(n= 511)</i>	<i>(n=335)</i>
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%

*Having been asked to tick one box to indicate how they were taught these exercises or SLD, 46 of respondents who were taught exercises and 22 participants who were taught SLD ticked more than one box.

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

How Often Participants have Received These Treatments	MLD <i>(n=361)</i>	MLLB <i>(n=208)</i>
<i>Not Received Regularly or Intensively</i>		
1-3 Times	13.0%	31.3%
4-9 Times	4.6%	2.9%
10-19 Times	0.6%	0.5%
<i>Received Regularly</i>		
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%
<i>Intensive Treatment Once or Twice</i>		
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%
<i>Intensive Treatment Once a Year or Less Frequently</i>		
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%
<i>Intensive Treatment Every Four/Six Months</i>		
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%
<i>Other Intensive Treatment</i>		
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%	-
<i>Other</i>		
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%

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

	<i>n</i>	%
All Respondents	598	61.2%
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%

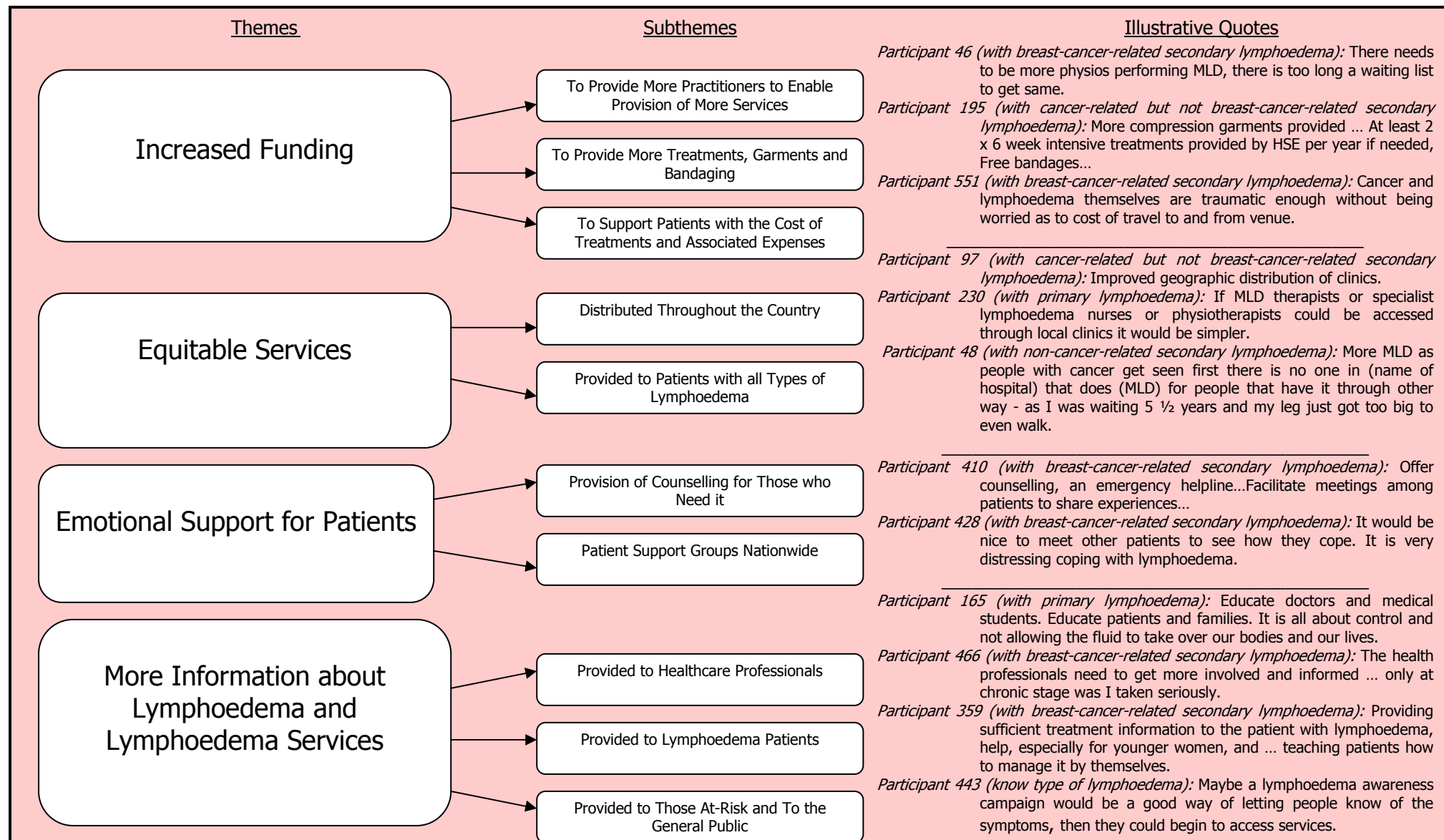


Figure 6: Themes, Subthemes and Quotes from Patients in Response to the Open Question on How Lymphoedema Services could be improved

Table 35: Impact of Lymphoedema on Daily Life

	<i>n</i>	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%

Table 36: Impact of Type of Lymphoedema on the Limitations Lymphoedema Presents

	Chi Square Test of Independence	Effect Size
Walking	$\chi^2(6, n=473) = 129.219^*$	Cramer's V=0.370 Large Effect
Swimming	$\chi^2(6, n=332) = 16.367^{\wedge}$	Cramer's V=0.157 Medium-Large Effect
Other Sports Activities	$\chi^2(6, n=309) = 25.264^*$	Cramer's V=0.202 Medium-Large Effect
Daily Indoor Chores (Cleaning)	$\chi^2(6, n=609) = 28.192^*$	Cramer's V=0.152 Small-Medium Effect
Daily Outdoor Chores (Gardening)	$\chi^2(6, n=585) = 29.579^*$	Cramer's V=0.159 Small-Medium Effect
Taking Care of Children	$\chi^2(6, n=301) = 14.229^{\wedge}$	Cramer's V=0.154 Small-Medium Effect
Buying Clothes/Shoes	$\chi^2(6, n=526) = 59.198^*$	Cramer's V=0.237 Medium-Large Effect
Wearing Clothes/Shoes	$\chi^2(6, n=552) = 53.136^*$	Cramer's V=0.219 Medium-Large Effect
Social Activities (Visiting Friends)	$\chi^2(6, n=480) = 36.293^*$	Cramer's V=0.194 Medium-Large Effect
Work/Employment	$\chi^2(6, n=369) = 6.447$	Cramer's V=0.093
Sexual Activity	$\chi^2(6, n=349) = 36.182^*$	Cramer's V=0.228 Medium-Large Effect
Sleeping	$\chi^2(6, n=542) = 17.865^{\wedge}$	Cramer's V=0.128 Small-Medium Effect
Going on Holidays	$\chi^2(6, n=515) = 42.173^*$	Cramer's V=0.202 Medium-Large Effect
Other (Driving, Repetitive Tasks)	$\chi^2(6, n=61) = 6.030^{\dagger}$	Cramer's V=0.222

* p=0.001 \sim p<0.009 \wedge p<0.05 \dagger Violated Minimum Expected Cell Frequency Assumption

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

	<i>n</i>	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%

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

	<i>n</i>	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
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

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

	<i>n</i>	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

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

	<i>n</i>	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

Table 41: 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%

