



Living with Lymphoedema in Ireland: Patient and Service Provider Perspectives

Maeve Murray, BA, MSc¹, Pamela Gallagher, PhD¹, Susan O'Carroll, RGN²;
¹ School of Nursing, Dublin City University, Ireland; ² Irish Cancer Society

This project was funded by the Irish Cancer Society.

The executive summary and full research report are available on www.cancer.ie / www.lymphireland.com

For further information, please contact pamela.gallagher@dcu.ie or socarroll@irishcancer.ie

Executive Summary

February 2010

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 was 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 are 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.