

## ORIGINAL ARTICLE

# The impact of lower limb chronic oedema on patients' quality of life

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Chronic oedema; Gravitational/dependency oedema; Lipoedema; Lymphoedema; Lymphovenous oedema; Quality of life

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**Abstract**

This study aimed to explore patients' perceptions regarding the impact that lower limb chronic oedema has on their quality of life (QoL). A quantitative descriptive design was used to collect data from patients with lower limb chronic oedema. A condition-specific validated questionnaire was distributed to a purposive sample ( $n = 122$ ) through manual lymphatic drainage/vascular/health clinics in Ireland. Results indicated that patients with lower limb chronic oedema experience a wide range of physical problems such as limb heaviness (74%,  $n = 66$ ), weakness (44%,  $n = 40$ ) and pain (38%,  $n = 34$ ). Additionally, difficulties with walking (53%,  $n = 48$ ), standing (51%,  $n = 46$ ) and bending (45%,  $n = 40$ ) were reported. Concerns regarding poor body image were strongly evident (76%,  $n = 68$ ). Difficulties finding clothing/footwear to fit oedematous limb(s) were reported (59%,  $n = 53$ ), in addition to finding clothes that participants would like to wear (64%,  $n = 58$ ). Emotional symptoms of irritability (42%,  $n = 38$ ), anxiety (41%,  $n = 37$ ) and tension (40%,  $n = 36$ ) were reported. Over half of the participants (55%,  $n = 49$ ) stated that their chronic swelling affected their social functioning and their ability to engage in leisure activities. This study has identified that lower limb chronic oedema has significant psychological, social and physical implications for persons' QoL.

**Introduction**

Chronic oedemas of the lower limb(s) are incurable, debilitating and progressive conditions that can cause life-long physical, psychological and social problems (1–4). Chronic oedemas of the lower limb can be instigated by a number of different aetiologies and are generally characterised by persistent swelling that has been present for more than 3 months duration, which does not reduce on leg elevation alone (5–7). Chronic oedema can affect the limbs, hands/feet and more rarely the trunk, genitals, head, face, neck or a combination of these (5,8). In milder forms it can cause swelling of the affected body part, but in severe cases it can lead to gross distortion (9). Several types of chronic oedemas exist, including lymphoedema, lymphovenous oedema, lipoedema and gravitational/dependency oedema (7,10).

Lymphoedema is a form of chronic swelling arising from the accumulation of lymph fluid in the interstitial spaces as a result of an impaired lymphatic system. It is classified as either primary or secondary, depending on the underlying cause (10–12).

Lymphovenous oedema occurs as a result of a combination of both venous and lymphatic insufficiency and is

**Keyword Messages**

- patients with lower limb chronic oedema have a reduced quality of life (QoL) as a result of their chronic condition
- this study aimed to explore patients' perceptions regarding the impact that lower limb chronic oedema has on their QoL
- a quantitative descriptive design was used to collect data from patients with lower limb chronic oedema; using a purposive sample, 122 condition-specific questionnaires (LYMQOL) were distributed to patients attending various manual lymphatic drainage clinics ( $n = 21$ ), a vascular clinic and various public health centres ( $n = 14$ )
- this study has identified that lower limb chronic oedema has significant psychological, social and physical implications for the QoL of patients

commonly related to chronic venous disease, venous ulcers or post-thrombotic syndrome (13).

Lipoedema is a more unusual and distinct condition characterised by bilateral symmetrical enlargement of the buttocks and lower limbs (14,15). It can be caused by hormonal changes and genetic factors, resulting in an abnormal increase in adipose tissue (15,16).

Gravitational/dependency oedema develops as a result of an inactive muscle pump in the limb, resulting in reduced venous and lymphatic flow. It commonly develops in individuals who are immobile or who spend long periods sitting motionless in a chair (7,12).

Previous research studies have highlighted that chronic oedema can impact on an individual's physical, psychological, emotional and social well-being (3–5,17–22). In a society where people can feel pressurised to comply with a certain body image, people with chronic oedema often view their limbs as 'ugly' (20,21,23,24). This can often result in individuals concealing their limbs and lead to feelings of self-consciousness, embarrassment and depression (3,21,22,25,26). Furthermore, sourcing clothing and footwear to fit the oedematous limbs can be both challenging and frustrating for many individuals (6). As a result, chronic oedema can lead to social isolation and have a significant impact on patients' social functioning. Many patients suffering from chronic oedema also experience a range of physical symptoms including pain, discomfort and heaviness, and associated conditions including cellulitis, insomnia and immobility (3,5,22,27,28).

The majority of research studies that explore the impact of chronic oedema on quality of life (QoL) focus on the upper limb and lymphoedema, with a paucity of literature relating to the lower limb and on the broad concept of chronic oedema. Furthermore, the majority of quantitative studies conducted used generic QoL tools that may not be as informative or accurate as condition-specific tools (2). To date only two studies have been conducted exploring the impact of chronic oedema on QoL within the Irish context. Murray's (3) mixed method study provided a good insight into its impact on QoL; however, the majority of participants had upper limb lymphoedema. While Gethin *et al.* (4) focused on lower limb oedema, the study provided only superficial information on its impact on QoL because a generic QoL tool was used and the sample size was small ( $n = 13$ ).

## Aim

The aim of this study was to (i) ascertain patients' perceptions of the psychological, social and physical impact of lower limb chronic oedema on their QoL, (ii) examine the demographic variability of lower limb chronic oedema and (iii) investigate whether the socioeconomic status of patients with lower limb chronic oedema impacts on their perceived QoL. It was anticipated that results would inform a better understanding of the impact of lower limb chronic oedema on patients' QoL in order to focus symptom management interventions.

## Methods

A condition-specific postal questionnaire, the 'Lymphoedema Quality of Life' (LYMQOL), was chosen for data collection

purpose to explore the impact of lower limb chronic oedema on the QoL of patients in Ireland. The LYMQOL is comprised of two separate questionnaires: one for upper limb oedema and one for lower limb oedema (29). The questionnaire for lower limb oedema which can be used for patients with chronic oedema/lymphoedema of one or both leg(s) was used in this study.

## Study questionnaire

The LYMQOL is a validated questionnaire that consists of 27 questions: 26 multiple-choice questions (MCQs) and 1 rating question. It covers four domains: symptoms, body image or appearance, function and mood. Reliability of the LYMQOL questionnaire was tested using the test–retest technique. In addition, split-half testing was conducted for each domain which revealed that reliability was good for every domain ( $>0.9$ ) (29). Validation of the LYMQOL was based on face, content, criterion and internal validity criteria. Internal consistency within the LYMQOL using Cronbach's alpha was good ( $>0.8$  for all domains) (29).

The questions in the LYMQOL offer four response alternatives and scores, *Not at all* = 1; *A little* = 2; *Quite a bit* = 3; *A lot* = 4, for each of the four domains. A visual analogue scale (VAS) for 'overall QoL' is scored between 0 and 10 as the value marked by the respondent. If the item is not scored, left blank or not applicable, it is scored as zero. Domain totals are calculated by adding the individual scores and dividing the total by the number of questions answered. If greater than 50% of questions per domain are not answered, results cannot be calculated and are scored as zero (29). Within this study, an additional demographic section was added to the questionnaire, requesting details of age, gender, education and employment status to facilitate comparisons with other studies. Additionally, to facilitate exploration of the impact of the different types of chronic lower limb oedema, participants were asked to indicate their diagnosis. Consideration was given to the length of the questionnaire and the time required for completion, as completion time and response rates correlate (30). The questionnaire was piloted for readability, ambiguity of wording and comprehensibility with a cohort of patients ( $n = 3$ ) that met the inclusion criteria. After pilot evaluation, changes were made to the layout and presentation. Results of the pilot were not included in the main study.

Ethical approval was granted by the local hospital and university research ethics committee (REF CA: 830). The study protocol and conduct conformed to the ethical guidelines of the 1975 Declaration of Helsinki. All participants gave informed consent and were assured that their responses would remain anonymous.

## Setting and sampling

Details on the prevalence of lower limb chronic oedema are unavailable for Ireland and predictions on the actual size of the problem are rough estimates at best (3). Without a defined target population, purposive sampling was deemed the most appropriate strategy for this research (31), and patients who had chronic oedema of the lower limb(s) for more than 3 months

were invited to participate in the study. Information on the study aims and objectives was sent to Manual Lymphatic Drainage (MLD) Ireland who made the details available to MLD clinics throughout the country, with an invitation for participation from people in the services who met the study criteria. Details of the study were also sent to a large regional hospital and its related public health centres. Any person meeting the study criteria who expressed interest in participating was provided with an information pack.

Information packs included a covering letter, a participant information leaflet outlining the aims, purpose and process of the study, the questionnaire and a stamped addressed envelope for questionnaire return. Participants were recruited from MLD clinics ( $n = 21$ ), public health centres ( $n = 14$ ) and a vascular clinic ( $n = 1$ ). As large a sample size as possible was aimed at in order to increase generalisability, but the least requirements necessary for basic statistical analysis is 30 respondents (32). A total of 122 condition-specific questionnaires were distributed by MLD therapists, vascular nurses, and public health/community nurses who acted as gatekeepers. This increased the confidentiality of the survey as the researchers did not receive any names or addresses of participants. A total of 90 completed questionnaires were returned, giving a response rate of 74%.

## Analysis

Information from all questionnaire responses was entered into the Statistical Package for Social Sciences version 20 (IBM SPSS) for analysis. In addition, cross tabulation was used to investigate the relationship between variables and compare responses. Other statistical tests used within the study included one-way analysis of variance (ANOVA), Pearson correlation coefficient, independent simple  $t$ -test and Kruskal–Wallis test.

## Results

### Demographics

Of the 90 participants who took part in the study, the majority ( $n = 70$ , 77%) were female and 20 (23%) were male. The average age of the participants was 54 (SD 16.11) years. The majority (57.8%,  $n = 52$ ) lived with a spouse/partner, while 23% ( $n = 21$ ) of the sample lived alone. Over half (51%,  $n = 46$ ) of the patients recruited were living in the countryside, 26.7% ( $n = 24$ ) lived in a town and 22.2% ( $n = 20$ ) lived in a city. The results for status of employment found that almost a third of participants were retired (28.9%,  $n = 26$ ) or unable to work (25.6%,  $n = 23$ ) because of sickness or disability. Only 18.9% ( $n = 17$ ) of the participants were working full-time and 10% ( $n = 9$ ) were working part-time. The majority of participants reported having lymphoedema ( $n = 72$ , 79%), 8 (8.9%) participants reported having lipoedema and a further 5 (5.6%) indicated having chronic oedema secondary to other causes, which included cardiac failure, joint replacements, cancer and lymphovenous disease. Five of the participants did not answer this question which may indicate that they had not received a clinical diagnosis.

**Table 1** Body image\*

	<i>n</i>	Not at all (%)	A little (%)	Quite a bit (%)	A lot (%)
Impact on appearance	88	8.9	20.0	18.9	50.0
Impact on self confidence	88	8.9	20.0	18.9	50.0
Difficulties					
Finding clothes to fit	88	15.6	23.3	22.2	36.7
Finding nice clothes to wear	87	17.8	14.4	21.1	43.3
Finding shoes to fit	89	17.8	21.1	16.7	43.3
Finding socks/tights/stockings to fit	88	8.9	20.0	12.2	40.0

\*The impact of chronic oedema on body image.

**Table 2** Psychological and emotional consequences\*

	<i>n</i>	Not at all (%)	A little (%)	Quite a bit (%)	A lot (%)
Tension	89	36.7	22.2	25.6	14.4
Worry	88	28.9	27.8	21.1	20.0
Irritable	89	31.1	25.6	30.0	12.2
Depressed	89	37.8	24.4	15.6	21.1
Difficulty concentrating	89	44.4	30.0	15.6	8.9
Impact on relationships	89	34.4	24.4	15.6	24.4

\*The psychological and emotional impact of chronic oedema.

### Psychological and emotional consequences

The assessment of the psychological consequences of chronic oedema relates to two of the domains in the LYMQOL: appearance and mood. Concerns regarding poor body image were strongly evident (Table 1). In all, 76% of the participants ( $n = 68$ ) stated that their chronic swelling affected their appearance a lot or quite a bit. Furthermore, 69% ( $n = 62$ ) indicated that their oedematous limb(s) affected how they felt about themselves a lot or quite a bit. Over half the participants (64%,  $n = 58$ ) experienced difficulties finding clothes that they would like to wear, while 59% ( $n = 53$ ) reported having difficulty finding clothes to fit the oedematous leg(s). Problems with footwear were also identified by many participants with 60% ( $n = 54$ ) reporting difficulty finding shoes to fit the oedematous limb(s) and 52% ( $n = 47$ ) having difficulty finding socks or tights to fit the affected limb(s).

The emotional consequences of living with chronic oedema were also explored by asking the participants whether they felt tense, worried, irritable or depressed within the past week (Table 2). Many reported feeling tense (40%,  $n = 36$ ), worried (41%,  $n = 37$ ), irritable (42%,  $n = 38$ ) and depressed (37%,  $n = 33$ ) quite a bit/a lot in the previous week. Participants were also asked if they had difficulty concentrating on things such as reading and 25% ( $n = 22$ ) reported a lot/quite a bit of difficulty with their concentration. Results also suggest that chronic oedema can have a negative impact on personal relationships. In all, 40% ( $n = 36$ ) of the participants stated that their chronic condition affected their relationships with others a lot or quite a bit.

### Impact on social functioning

Questions in the function domain facilitated the assessment of the impact of chronic lower limb oedema on participants'

social functioning. In addition, participants were asked to provide examples of various leisure activities or aspects of their social life which may be impacted by their chronic condition. Over half of the participants (55%,  $n = 49$ ) indicated that their chronic swelling affected their social functioning and their ability to engage in leisure activities. In addition, 31% ( $n = 28$ ) of the respondents reported significant dependence on other people as a result of their condition. Difficulties performing household duties were highlighted by many participants, with 47% ( $n = 42$ ) of participants indicating that their swollen leg(s) affected their ability to do housework.

Quantitative results were supported by participants' written comments indicating that their chronic oedema restricted their ability to participate in many leisure activities including walking, swimming, dancing, cycling, horse riding, sailing and running. Difficulties shopping and gardening were also highlighted. Issues with going on holidays to sunny places were reported by participants, with many suggesting that heat exacerbated their swelling, while others felt too embarrassed to expose their oedematous legs. A few participants indicated difficulties going on skiing holidays because of their condition. Many participants reported difficulty socialising or avoidance of socialising because of their condition. Difficulties getting fashionable clothing and footwear to hide the swelling and fit the oedematous leg(s) were identified as the main contributing factor impacting on socialising. Female participants reported that being unable to wear dresses contributed to their reluctant to socialise to particular events.

Several factors impacted on participant's ability and motivation to socialise, including difficulty mobilising, treatment regimes and mood. Many participants identified the limiting and time-consuming nature of daily self-management regimes including simple lymphatic drainage, bandaging and exercise. They suggested that these regimes impacted on availability and motivation for social interaction. Additionally, several participants commented that their chronic condition resulted in them becoming housebound.

The study also explored whether chronic oedema impacted on an individual's occupation, and 29% ( $n = 26$ ) of participants reported that their chronic condition significantly negatively affected their work.

### Physical consequences

The physical consequences of chronic oedema were mainly examined using the symptom and function domains. To maintain consistency with findings in other studies, a question from the mood domain regarding difficulties with sleeping was also recorded as a physical consequence.

Findings in relation to the physical consequences of chronic oedema indicate that many participants suffer from symptoms such as pain (37.8%), heaviness (73.4%) and weakness (44.4%) (Table 3). The most frequent symptom reported by participants was heaviness, with 74% of participants ( $n = 66$ ) reporting significant difficulty in this area. This was followed by weakness, with 44% of participants ( $n = 40$ ) reporting significant problems. Pain was the third most common symptom, with 38% ( $n = 34$ ) reporting quite a bit/a lot of pain. Other symptoms experienced by participants included numbness (32%,

**Table 3** Physical consequences\*

	<i>n</i>	Not at all (%)	A little (%)	Quite a bit (%)	A lot (%)
Symptoms					
Pain	89	16.7	44.4	30.0	7.8
Numbness	88	34.4	34.4	21.1	7.8
Pins and needles/tingling	88	34.4	34.4	21.1	7.8
Weakness	86	26.7	24.4	22.2	22.2
Heaviness	89	3.3	22.2	26.7	46.7
Impact on physical functioning					
Walking	86	18.9	23.3	28.9	24.4
Standing	86	21.1	23.3	26.7	24.4
Bending	87	28.9	23.3	18.9	25.6
Getting up from chair	85	34.4	33.3	14.4	12.2
Sleeping	89	30.0	32.2	22.2	14.4

\*The physical impact of chronic oedema.

**Table 4** Mean domain scores of the LYMQOL\*

	Mean	SD
Domains		
Function	2.19	0.90
Appearance	2.76	0.91
Symptoms	2.34	0.75
Mood	2.14	0.90
Total score	67.10	17.19

LYMQOL, Lymphoedema Quality of Life.

\*The mean scores for each of the four domains of the LYMQOL.

$n = 29$ ) and pins and needles (29%,  $n = 26$ ). Exploration of the limitations put on physical functioning by the chronic leg oedema indicated that participants had difficulties walking (53%,  $n = 48$ ), standing (51%,  $n = 46$ ) and bending (45%,  $n = 40$ ). Furthermore, 26% ( $n = 24$ ) stated that their swollen limb(s) negatively affected their ability to get up from a chair. In addition, 36% ( $n = 33$ ) of participants reported having trouble sleeping.

### Impact on overall QoL

The impact of chronic oedema on overall QoL was measured using a 10-point Likert scale, where 0 = *poor* and 10 = *excellent*. The mean score for the participants' ratings of their overall QoL was 5.57 (SD 2.52) (Table 4).

The mean scores for each of the four domains of the LYMQOL – function, appearance, symptoms and mood – are presented in Table 4. Scores for each domain are scaled in a negative direction (i.e. the higher the score the poorer the QoL). All mean scores for each domain were below 3.0. Overall, the sample rated their QoL lowest in the appearance and symptoms domains. Participants rated their QoL highest in the function and mood domains. The mean for the total score of the domains is also included in Table 4 and also scaled in a negative direction. The total score suggests that overall participants rated their QoL as reasonably good.

A one-way ANOVA was conducted between groups to compare the effect of different types of chronic oedema on QoL. Results indicated no statistically significant differences

between group means [ $F(3, 86) = 0.361, P = 0.782$ ], suggesting that the cause of the chronic oedema is not a determinant of the effect on the QoL.

A Pearson correlation coefficient was performed to ascertain if the relationship between QoL and age was significant. There was a weak negative correlation between QoL and age ( $r = 0.011, n = 90, P = 0.915$ ); therefore, there is no significant relationship between QoL and age.

An independent simple *t*-test was conducted to compare the QoL of patients with chronic oedema between male and female patients. There was significant gender differences in the score of QoL for males [ $M = 55.53, SD = 11.90$ ] and females [ $M = 69.14, SD = 17.36, t(82) = (2.80), P = 0.001$ ]. Results suggest that the female participants perceive themselves to have a better QoL than their male counterparts.

A one-way ANOVA was conducted between groups to compare the effect of different living arrangements, such as living alone or living with someone, on QoL. Results indicated no statistically significant differences between group means [ $F(4, 85) = 0.322, P = 0.863$ ], suggesting that within this study living arrangements were not a determinant of the QoL. Similarly whether participants lived in an urban or rural setting had no significant impact on their QoL [ $F(2, 87) = 0.537, P = 0.586$ ].

A Kruskal–Wallis test revealed a statistically significant difference in QoL across employment groups (full-time work:  $n = 17, M = 57.00$ ; part-time work:  $n = 9, M = 56.00$ ; part-time course:  $n = 2, M = 70.00$ ; unemployed:  $n = 4, M = 70.50$ ; unable to work:  $n = 23, M = 83.00$ ; retired:  $n = 26, M = 63.50$ ; other:  $n = 7, M = 59.00$ ) ( $H = 29.367, P = 0.001$ ). Findings revealed that there were statistically significant differences between scores, particularly among those unemployed and those unable to work. Results indicate that participants with chronic oedema who are unemployed or unable to work have a poorer QoL.

There was no statistically significant difference in the QoL of patients with chronic oedema and the level of education they received across employment groups ( $H = 1.334, P = 0.513$ ), with a median of 74.50 for participants completing primary education, 63.00 for those completing secondary education and 70.00 for those completing third level education.

## Discussion

The results of this study indicate that patients with lower limb chronic oedema have a reduced QoL as a result of their chronic condition, and these results are supported by the results from other studies (1,4,19,21,23). Despite the relatively small sample size, the findings contribute to the existing knowledge surrounding the impact of lower limb chronic oedema on QoL within an Irish context, and allow international comparison to be made.

In keeping with identified trends this study found that the prevalence of chronic oedema is greater among those who are older than 50 years (4,5). Furthermore, findings from the current study suggest that the QoL of patients with lower limb oedema becomes poorer as they get older. This finding is not surprising considering that an increase occurs in physical illnesses as one becomes older (33).

This study had a clear gender difference with the majority (77%) of the participants being female. This is similar to Franks *et al.*'s (34) study on lower limb oedema in which 71% of the sample were females. Contrasting results were identified in Gethin *et al.*'s (4) study in which the majority of the sample were males. However, Gethin *et al.*'s (4) study had a small sample size (13 participants); therefore, findings cannot be generalised to a wider population (35).

Furthermore, findings from this study revealed significant gender differences in the QoL scores for male participants, with male participants reporting a poorer QoL. A possible explanation for this is the fact that female patients commonly have better compliance with treatments than male patients, and better compliance usually implies greater well-being (36–38). Evidence suggests that the success of any treatment regimen and concomitant improvement in QoL is dependent on patients' compliance with therapy (39,40).

The majority of the participants in this study lived with a spouse or partner, while a relatively small percentage lived alone. Contrasting findings were reported by Franks *et al.* (34) in which over half of the sample lived alone, while approximately a third lived with a partner or spouse. However, the differences in these findings may be because of the older age profile of participants in the study by Franks *et al.* (34).

Within this study over a quarter of participants identified an inability to work because of the debilitating and chronic nature of the condition, and these findings reflect results from similar studies (5,19,34). Additionally, findings from the current study revealed that QoL was poorer among those unemployed and unable to work compared with those working full-time, part-time or those retired. These findings are consistent with a report by the Health Inequality Framework (41) that also found that those who are unemployed have poorer QoL.

In contrast to Murray's (3) study, the majority of the participants in the current study lived in the countryside. However, this could possibly be due to the geographical distribution of the MLD clinics and public health centres involved in recruitment of participants.

## Types of chronic oedemas

Specific details concerning the incidence of the various types of chronic oedemas in Ireland is unknown (3). The majority of participants in this study had lower limb lymphoedema, with lipoedema and lymphovenous related oedema accounting for less than 16% of participants. The route of recruitment through lymphoedema clinics may have impacted this distribution.

## Impact on QoL

Results from this study, in keeping with earlier studies (3–5,19–21), strongly suggest that lower limb chronic oedema has a considerable impact on a person's QoL, resulting in detrimental psychological, social and physical implications.

## Psychological consequences

The impact of chronic swelling on participant's appearance and the resulting poor body image was consistently highlighted

regardless of age or gender. These findings are consistent with evidence from the literature in which many people with lower limb oedema report difficulties finding clothes that they like to wear or finding clothing and footwear to fit the oedematous limb(s) (17,19).

Participants in this study revealed that their condition had an impact on their emotional well-being and identified the subjective presence of anxiety, irritability, tension and depression. Participants' written comments identified feeling of self-consciousness, shame and embarrassment associated with the disfigurement of the swollen limb(s), and these feelings are consistent with evidence from other researchers (1,3,17,20,21).

Relationships were impacted by the chronic oedema. This could be because of the limitations created by the oedema or the changes in physical appearance, resulting in altered body image and reduced self-esteem, altering approaches to social and personal relationships (18,19,42). There was some evidence that chronic oedema can impact on an individual's concentration. This may result from psychological distress experienced by many patients or the physical impact of the condition in terms of pain and discomfort (5,19,21).

Despite the psychological consequences of chronic lower limb oedema, appropriate treatments and support can improve an individual's psychological well-being (43,44) and treatment compliance (45).

### Impact on social functioning

While the disfigurement of a limb can have devastating psychological consequences, it can also impact on social functioning (3,19,21). Over half of the participants in this study reported that their swollen limb(s) affected their social functioning and their ability to engage in leisure activities. The main issues of concern preventing socialisation were feelings of embarrassment and self-consciousness as a result of the distorted and swollen limb(s) and the restriction that lack of appropriate clothing and footwear had on an individual. Participants reported a restriction on their ability to participate in leisure activities, particularly walking, swimming, dancing, gardening, cycling, horse riding, sailing and running. In addition, there were issues around the feasibility and practicality of going on sun or skiing holidays. Many participants in this study experienced difficulties performing household duties, and this reflects evidence from other studies (3,19). Prevalence of reported difficulties may reflect on the type of chronic oedema experienced by the participants or indeed the extent to which their swelling is controlled (3). In addition to other reported difficulties, the time commitment required for daily self-management made significant inroads into available time for other pursuits either occupationally or socially. Participants' written comments highlighted that daily skin care and exercise regimens along with simple lymphatic drainage and possibly self-bandaging can be time-consuming and have a significant impact on day-to-day living, echoing results from other studies (3,20,25).

The debilitating nature of the chronic condition can cause patients to become practically housebound (46). Within this study the loss of independence was evident, with a third of the sample reporting being dependent on other people.

Several studies have identified the significant impact that chronic oedema can have on an individual's capacity to work and/or choice of employment (3,5,19,20). Within this study approximately one third of participants reported that their chronic condition affected their occupation.

The positive effects of MLD or simple massage and compression bandaging are well described in the literature and include improvements with psychological, social and physical symptoms (17,43,44). Furthermore, good social support has the potential to improve physical symptoms and thus improve social functioning (47).

### Physical consequences

Chronic oedema of the lower limb(s) can have significant physical consequences (3,5,19). Physical symptoms such as discomfort or pain, coupled with an increase in the size of the limb(s) can affect posture and physical functioning which consequently can make performing daily activities challenging or impossible (12,48). Within this study physical symptoms were prevalent with almost three quarters of participants reporting symptoms of limb heaviness. This is a significantly higher proportion than that reported in another study (5). In a similar pattern, symptoms of pain were more frequently reported in this study than other similar works (19).

Although a relatively high percentage complained of limb weakness within this study, similar findings have not been identified elsewhere. On the other hand, symptoms of tenderness, ache, fullness and tightness were identified by other studies (5,19,23). However, these variations of symptoms may be due to pain being a subjective experience (49). Sleep disturbances were a commonly reported symptom, reflecting findings elsewhere (3,5,27,28).

The limitations imposed on physical functioning were further explored. Over half of the participants reported difficulties walking and/or standing, and many found bending difficult, while some reported that they had difficulties getting up from a chair. These variables have not been reported elsewhere. However, there is consistent support for the improvements in QoL that appropriate treatment and management can have (17,43,44).

### Overall QoL score

The mean overall QoL score was 5.57, which indicates that their QoL was average. Comparisons were not possible because of the unavailability of corresponding data in other studies.

Scores at the level of the domains indicated that patients' QoL was poor across all four domains. Appearance and symptoms domains were most affected, while the function and mood domains were the least affected. Studies that have been performed on lower limb chronic oedema have also demonstrated deficits in physical, social and mental well-being (4,5,50). Similar to other studies, patient's emotional well-being was the least affected (4,5).

### Conclusion

Patients with lower limb chronic oedema have a reduced QoL as a result of their chronic condition, which can be compounded

by the lack of availability of appropriate services, impacting their ability to cope with the limitations of the condition (3). Best practice identifies that appropriate services include the development of specialised clinics where treatments would be conducted by a multidisciplinary team (51).

Within the Irish context, standardisation of practice for the management of chronic oedemas urgently requires the development, implementation and dissemination of clinical guidelines which are currently lacking in the system (3).

Patients with chronic oedema, especially those with non-cancer-related oedema, often experience a delayed diagnosis or even misdiagnosis (1,3,52). This can be due to the lack of education and awareness among health care professionals (53,54). Therefore, education on the various types of chronic oedemas, their treatments and available resources should be provided to members of the multidisciplinary team including primary care personnel who play a vital role in the appropriate referral of patients with chronic oedema (3,55). In addition, the educational gap in the undergraduate medical curriculum regarding lymphatic disease results in newly qualified doctors having little or no awareness of chronic oedema (56). A review of medical and allied health care curricula with the inclusion of subject matter around chronic oedemas should be undertaken.

Self-management is a significant aspect of the management of chronic oedemas. The wearing of compression garments is a life-time commitment and requires complete compliance in order to ensure effectiveness (57). Therefore, patient education is imperative to help them understand the importance of compliance in managing the chronic condition (58). Providing information on chronic oedema through a variety of strategies can help alleviate fear and anxiety and increase patient's sense of being in control (59). To enhance coping, it is important to encourage patients to take a sense of control over symptoms associated with their condition (60). Therefore, all patients with lower limb chronic oedema should be provided with the necessary training and support in, for example, SLD and self-bandaging.

Because of the detrimental psychological effects of chronic oedemas, patients require standardised psychological assessments so that depressive or psychiatric conditions can be diagnosed (21). Mandatory assessments of patients' psychological well-being should be introduced, so that patients who may need further psychological support can be recognised (3,21).

Lower limb chronic oedema can result in a loss of independence, with many patients being unable to function to their maximum capacity. Therefore, social support services should be made available to those who require additional assistance with day-to-day living. In addition, support groups, education and self-management programmes for chronic illnesses have been recognised as a means to improve QoL and cope with a chronic condition (7,58).

A lack of knowledge surrounding the incidence and prevalence of chronic oedema often results in the condition being underestimated, and as a result insufficient resources are channelled into support services to meet the patient needs (3,61). Research on the prevalence of all types of chronic oedemas is required. This would help to quantify the extent of the problem, and the information could subsequently inform the strategic planning of service developments.

Additional research needs to be conducted to examine the broad concept of chronic oedema and its impact on QoL. Of the small quantity of published studies that have been carried out on lower limb oedema, none have examined the impact of lipoedema on QoL despite being an extremely painful and debilitating condition (62). In addition, further research on lower limb chronic oedema using condition-specific measures needs to be conducted so that specific, rather than general, information is obtained (2,63). Also it would be of benefit if future research tools included a specific measure of psychological well-being so that clinical levels of distress could be measured.

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