

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/7059695>

# Health-related quality of life with lymphedema: A review of the literature

Article in *International Wound Journal* · April 2005

DOI: 10.1111/j.1742-4801.2005.00066.x · Source: PubMed

CITATIONS

188

READS

1,488

3 authors, including:



**Peter J Franks**

Centre for Research & Implementation of Clinical Practice

189 PUBLICATIONS 7,678 CITATIONS

[SEE PROFILE](#)



**Christine Moffatt**

Nottingham University Hospitals NHS Trust

205 PUBLICATIONS 5,667 CITATIONS

[SEE PROFILE](#)

Some of the authors of this publication are also working on these related projects:



Clinical Trial in Venous Ulceration [View project](#)



Assessment of pressure ulcer prediction tools [View project](#)

# Health-related quality of life with lymphoedema: a review of the literature

Philip A Morgan, Peter J Franks, Christine J Moffatt

Morgan PA, Franks PJ, Moffatt CJ. Health-related quality of life with lymphoedema: a review of the literature. *Int Wound J* 2005;2:47–62.

## ABSTRACT

This article reviews qualitative and quantitative studies that evaluate health-related quality of life (HRQoL) in lymphoedema. Qualitative studies reveal a number of factors that can affect HRQoL. These include a lack of understanding of lymphoedema by health professionals and poor information provided to patients. Emotional responses include shock, fear, annoyance, frustration and negative body image. Treatment can be costly in terms of time and disruption to lifestyle. Quantitative studies show that patients with lymphoedema experience greater levels of functional impairment, poorer psychological adjustment, anxiety and depression than the general population. Increased limb volume is poorly related to the impact of lymphoedema on the patient. Factors leading to deficits in quality of life include the frequency of acute inflammatory episodes, the presence of pain, skin quality, lymphoedema in the dominant hand and reduced limb mobility. There is some evidence that the adoption of patient-centred guidelines can improve quality of life in patients with breast-cancer-related lymphoedema. HRQoL is an important outcome in the management of patients with lymphoedema. Further studies must examine how lymphoedema impacts on patients other than those with breast-cancer-related lymphoedema and the consequences to patients of different approaches to care.

**Key words:** Lymphoedema • Patient experience • Physical and psychosocial effects • Quality of life

## INTRODUCTION

Lymphoedema is a chronic swelling arising from the accumulation of protein-rich fluid that would otherwise drain via the lymphatic system. It can be grossly disfiguring, and although it usually affects one or more limbs, it may involve the trunk, head or genital area. While it is recognised as a common complication of cancer and its treatment, for

example in breast cancer (1), it may occur for other reasons such as trauma (2), parasitic infection (3) or primary lymphoedema due to an intrinsic abnormality of the lymphatic system (4). A recent prevalence study in the United Kingdom (UK) (5) found lymphoedema, of various causes, to be more common than community health care professionals perceived it to be. The study estimates that 0.13% of the general population is likely to be affected rising to 0.5% in those over 65 years of age, giving an expected number of patients in the UK in excess of 80 000. In women with breast cancer, it affects one in four patients.

The swelling associated with lymphoedema can range from mild to severe. Untreated, or under-treated, lymphoedema can result in skin changes, fibrosis with thickened but fragile tissue, loss of normal sensation, impaired function, pain, discomfort and a sense of heaviness in the affected limb (6). The changes

## Key Points

- lymphoedema is a chronic swelling arising from a problem with the lymphatic system
- a prevalence study estimates that 0.13% of the general population is likely to be affected
- in the UK in excess of 80,000 individuals suffer from lymphoedema
- the swelling related to lymphoedema ranges from mild to severe

**Authors:** PA Morgan, RGN, EdD, Post-doctoral Research Fellow, Centre for Research and Implementation of Clinical Practice (CRICP), Thames Valley University, London, UK; PJ Franks, PhD, Professor of Health Sciences, Codirector of the Centre for Research and Implementation of Clinical Practice (CRICP), Thames Valley University, London, UK; CJ Moffatt, RGN, PhD, Professor of Nursing, Codirector of the Centre for Research and Implementation of Clinical Practice (CRICP), Thames Valley University, London, UK

**Address for correspondence:** Dr PA Morgan, Centre for Research and Implementation of Clinical Practice, Faculty of Health and Human Sciences, Thames Valley University, 32-38 Uxbridge Road, London W5 2BS, UK

**E-mail:** phil.morgan@tvu.ac.uk

### Key Points

- there is no cure for lymphoedema
- typically, the evaluation of HRQoL attempts to capture the impact of health and illness on a persons physical and mental well being
- the aim of this article is to review what is known about HRQoL
- information for this review was gathered from articles referenced through the medical and nursing systems
- research evidence was categorised and analysed

that take place within the tissues often bring a susceptibility to inflammation and recurrent infections known as acute inflammatory episodes (AIE) (7). There is no cure for lymphoedema, and its management involves the use of a combination of conservative treatment methods aimed at improving, and maintaining, the patient's quality of life. By definition, the management of this chronic condition is long-term, and Ganz (8) points out that treatment can be difficult and cumbersome and may be less effective than was perhaps hoped for.

Traditionally, lymphoedema has been viewed as a relatively unimportant and untreatable side effect of essential life-saving treatment for cancer and has been largely neglected by researchers (9). There is, however, evidence that this perception is changing and increasingly lymphoedema is recognised as a significant and complex problem and can represent a considerable challenge to a person's health-related quality of life (HRQoL) (6,10).

Typically, the evaluation of HRQoL attempts to capture the impact of health and illness on a person's physical and mental well-being as well as on their ability to function socially (11). Its importance lies in the shift away from traditional practitioner-determined outcome measures (12) to focus on the patient's perspective and how both illness and treatment impact on daily life (13). Equally important is that quality of life data have the potential to inform the physical, psychological, social, spiritual and financial aspects of caring (14,15). The aim of this article is to review what is known about the HRQoL of people with lymphoedema, to suggest directions for future research and to identify implications for the care and management of this patient group.

### METHODS

Information for this review was gathered from articles referenced through the medical (MedLine, EMBase) and nursing (Cinahl) systems using key words 'lymphoedema and quality of life', 'chronic oedema and quality of life', 'psychosocial and lymphoedema' and 'patient experience and lymphoedema'. Research evidence was categorised into four broad areas:

- Qualitative research
- Development and validation of disease-specific tools

- Cross-sectional quantitative research
- Longitudinal and outcome research

The criterion for inclusion was, in the case of quantitative studies, the investigation of quality of life for people suffering from lymphoedema. Only studies which have the effects of lymphoedema on quality of life as their primary focus were considered eligible. For qualitative studies, the criteria encompassed research that explored the quality of life of patients with lymphoedema, the patient experience of lymphoedema and the psychosocial implications of the condition. Specific exclusions were for individual case studies and studies that referred to quality of life but which gave no results for its evaluation or measurement.

## REVIEW OF THE LITERATURE

### Qualitative research

Qualitative research approaches attempt to achieve a deeper understanding of the impact that lymphoedema can have on the lives of patients. These studies act as a window on the experience of lymphoedema from the patient's perspective and provide powerfully subjective accounts which can contribute to more sensitive and effective treatment and care decisions. Of the six qualitative studies reviewed, one was conducted in Australia, three in the UK, one in the United States of America (USA) and one in Sweden (Table 1).

In order to gain insight into the depth and complexity of the problems experienced by women with breast-cancer-related lymphoedema and to explore changes in perceptions over time, Woods (16) conducted semi-structured interviews with 37 women on referral to a specialist lymphoedema service and again 6 months later. At the time of referral, 90% of the women had not received even basic information about the risk of developing lymphoedema. As a consequence, the appearance of swelling brought a feeling of shock and fear that the cancer had returned, or that something had gone wrong. For some, the swelling served as a reminder of the cancer and its treatment.

Coming to terms with their lymphoedema presented particular challenges and many expressed thoughts and feelings of annoyance

**Table 1** Qualitative analysis

Research question/aim	Design	Participants	Methods	Findings	Country and year	Reference
To explore patient's perceptions of breast cancer-related arm lymphoedema and the factors that may be associated with these perceptions.	Mixed qualitative/quantitative descriptive study	37 women with arm lymphoedema following breast cancer treatment referred to a specialist lymphoedema service.	Semi-structured interviews, one at beginning of 6-month study period and one at end. Thematic analysis.	<p>Main themes:</p> <p>Early on.</p> <ul style="list-style-type: none"> <li>- Swelling induced shock and fear that cancer had returned.</li> <li>- A reminder of treatment.</li> <li>- Poor information.</li> <li>- Changes in preferred style of</li> <li>- Poor body image.</li> <li>- Experiencing discomfort.</li> </ul> <p>Improvement over 6-month period in:</p> <ul style="list-style-type: none"> <li>- Coming to terms with the swelling. (linked to reduction in swelling).</li> <li>- Self-perception.</li> <li>- Discomfort.</li> </ul>	UK	(16)
To explore the influence of sociological factors and psychosocial implications that arm swelling has for the patient.	Descriptive study	40 women with arm swelling presenting at an established hospital-based lymphoedema service.	<ul style="list-style-type: none"> <li>- Semi-structured interviews with thematic analysis.</li> <li>- Limb measurement.</li> <li>- Demographic analysis.</li> </ul> <p>t-test of significance to explore relationship between limb size and demography.</p>	<p>Main themes:</p> <ul style="list-style-type: none"> <li>- Fear, anger and disappointment at appearance of swelling.</li> <li>- Lack of awareness.</li> <li>- Adaptation through experience, trial and error.</li> <li>- Importance of outward appearance.</li> <li>- Hiding the swelling.</li> <li>- Older women had significantly greater limb volume (<math>P &lt; 0.01</math>).</li> </ul>	UK 1995	(17)

Table 1 Continued

Research question/aim	Design	Participants	Methods	Findings	Country and year	Reference
To explore women's experiences of lymphoedema following breast cancer treatment.	Phenomenology	10 women: – Age 36–75 years. – All had completed treatment at least 1 year earlier. – Onset of lymphoedema at least 2 months after surgery. – Mean survival time since treatment = 7 years	Two semi-structure interviews and completion of the Demographic Data Sheet (DDS).	– Women working outside the home had significantly larger swollen arms ( $P < 0.01$ ) – Arm size significantly related to longer period of swelling ( $P < 0.05$ ). Three main themes: – Abandonment by medicine. – Concealing the imperfect image. – Living the interrupted life.	US 1997	(18)
To explore the meaning of surviving with breast cancer-related lymphoedema and to explore the psychological impact of living with lymphoedema.	Grounded theory	20 women aged 48–71 years. All had breast/axillary surgery and/or radiotherapy for breast cancer between 1 and 10 years previously with average being 5.5 years and had developed lymphoedema 1–8 years previously.	Random allocation of participants to one of four focus groups to discuss question: 'what is it like living with lymphoedema?'	Three main categories: – Finding information. – Suffering silently. – Counting blessings.  One main theme: Finding out information for women with breast cancer-related lymphoedema can help to ease their sense of anxiety and loss and increase ability to adapt to a changed life.	UK 2001	(19)

To explore employed women's experiences of light or moderate lymphoedema following breast cancer treatment.	Phenomenology	12 women representing all women attending lymphoedema clinic at University Hospital in Sweden <ul style="list-style-type: none"> <li>– Arm lymphoedema less than 40%</li> <li>– Had breast cancer treatment.</li> <li>– Work outside the home.</li> <li>– Lymphoedema for at least 1 year.</li> </ul>	One semi-structured interview. Phenomenological analysis based on Karlsson's approach.	Three themes: <ul style="list-style-type: none"> <li>– Reactions from others.</li> <li>– Being bound to a chronic disease.</li> <li>– Coping.</li> </ul>	Sweden 2003	(20)
To describe women's experiences with lower limb lymphoedema to inform both preventative and management clinical practice.	Retrospective survey	82 women with lower limb lymphoedema after surgical and radiation treatment for gynaecological cancers.	One structured interview.	Three main themes: <ul style="list-style-type: none"> <li>– Seeking help and receiving inappropriate advice.</li> <li>– Having to implement self-management strategies.</li> <li>– Impact on appearance, mobility, finances and self-image.</li> </ul>	Australia 2003	(21)

### Key Points

- negative body image and reduced self confidence were major impactors
- lack of awareness of the risk of lymphoedema and its continuing consequences was commonly expressed
- in this study, women spoke of the distress caused by the insensitivity and limited knowledge about lymphoedema by many physicians
- many studies showed significant impactors related to care

and frustration at the limitations imposed by the swelling. Negative body image and reduced self-confidence in their appearance were major effects forcing many to make a complete change to their preferred style of dress. The women in this study also commented that their self-confidence was negatively affected by the cumulative effects of seemingly harmless comments about their swelling by others. Woods notes that a reduction in limb volume was linked to a positive trend in the patient's perceptions of their lymphoedema. After 6 months of treatment, some improvement was reported in coming to terms with the swelling, problems with clothes and body image and the range of movement in the swollen arm.

In a study 2 years later, the same author (17) explored the psychosocial factors that were significant for a study group of 40 women with arm swelling related to breast cancer who were attending an established hospital-based lymphoedema clinic. Using semi-structured interviews, they found that for many women the appearance of the swelling had been unexpected and rapid, generating feelings of fear, anger and disappointment. Lack of awareness of the risk of lymphoedema and its continuing consequences was commonly expressed. Indeed, some thought that it would be short-lived and that it was an effect of the cancer treatment and would go once this phase was over. Adjustment to their swollen limb and its effects was often achieved through a process of trial and error. The depth of feeling associated with such adjustment, particularly with regard to the effect of the swelling on outward appearance, was for some women considerable.

A phenomenological study conducted in the USA by Carter (18) involved a self-selected sample of ten women aged between 36 and 75 years who had completed breast cancer treatment at least 7 years previously and had lymphoedema for an average of 4 years. Demographic data were collected, and patients were interviewed twice, 1 week apart, using semi-structured interviews. Three dominant themes emerged: abandonment by medicine, concealing the imperfect image and living the interrupted life.

In this study, women spoke of the distress caused by the insensitivity and limited knowledge about lymphoedema of many

physicians, the conflicting information they obtained (and the difficulty in obtaining it) and the paucity of specialist treatment centres. The time, financial cost, life-style disruption and difficulty associated with many aspects of lymphoedema treatment, as well as concerns regarding its efficacy, were identified as barriers to care and led many to develop their own treatment regime based on trial and error. Women in this study varied in their sensitivity to the appearance of their swollen arm, but all took measures to conceal what they saw as an imperfect image. In addition, managing lymphoedema was, for some women, more distressing than coping with the cancer itself and caused them to modify their personal, work and social life-styles. Carter (18) argues for sensitive and research-based care, more treatment centres and user-friendly treatment programmes to enhance concordance. She also suggests that women with lymphoedema would benefit from psychosocial assessment and support.

The lived experience of cancer-related lymphoedema and its psychological impact was explored by Hare (19) using a grounded theory approach. In this study, 20 women were randomly allocated to one of four focus groups to discuss 'what it is like to live with lymphoedema'. Three main categories emerged: finding information, suffering silently and counting blessings. Participants in this study described how receiving inadequate information left them unprepared for the shock of lymphoedema and prolonged their coming to terms with the condition. While the dominant strategy for coping with breast-cancer-related lymphoedema in this study group was to 'count one's blessings' and to 'feel lucky to be alive', the experience of lymphoedema involved much suffering. This suffering, often in silence, involved major life-style changes and feelings of loss, isolation, sadness, helplessness and anxiety.

A phenomenological study conducted in Sweden by Johanssen and colleagues (20) used a critical incident approach to explore 12 working women's experiences of mild or moderate lymphoedema following breast cancer treatment. Their findings indicate that there are many different practical and psychological problems related to arm lymphoedema and many of these echo those in the studies reviewed here. Two findings are worthy of

note. The first relates to work outside the home; heavy work, work that required precision, including word-processing, or long periods without rest became difficult or impossible. Coming to terms with such effects was problematic for many and was accompanied by feelings of sadness, anger and disappointment. The second is that while the women appeared to cope well using both problem-focused and, more commonly, emotion-focused strategies, analysis of critical incidents of everyday concerns related to lymphoedema, although few in number, was entirely negative. Eleven such critical incidents were identified and included irritation from the sleeve, slight swelling in the hand or arm and being told their lymphoedema had increased in volume by 50 ml. This contrasted to critical incidents related to their cancer which produced both positive and negative responses. An interpretation put forward is that while the women in this study appeared to cope well on a day-to-day basis, lymphoedema and its related problems were capable of inducing considerable levels of stress.

The experience of lower limb lymphoedema following surgery for gynaecological cancer is documented in a study by Ryan *et al.* (21), in which 82 women were interviewed using a structured interview schedule. Women in this study describe being unprepared for lower limb lymphoedema and shocked by its permanence and severity. They talk of the considerable delay in finding appropriate help and having to seek out information and treatment for themselves. Many considered the information and treatment they eventually received to be inadequate and in some cases inappropriate. Referral to specialist practitioners was slow and protracted, and a large number of women implemented their own self-management strategies as a consequence. For the women in this study, lower limb lymphoedema represented a major disruption to their lives and had an impact on appearance, mobility, finances and their self-image.

### Development and validation of disease-specific tools

Only one published example of the development of a disease-specific tool to evaluate HRQoL for patients suffering from lympho-

dema was identified (Table 2). In 2001, Launois *et al.* (22) published their results of the development of a tool (ULL-27) to assess the HRQoL for patients with upper limb lymphoedema. The ULL-27 was validated in a sample of 304 patients over a 28-day period. Data were gathered from a number of sources. These included volume differences between the healthy and affected arms, symptom scales completed from patient interviews, ULL-27 and SF-36 scales completed by the patients and the overall opinion of doctors and patients. Factor analysis isolated 27 items in three dimensions: a physical dimension (15 items), a psychological dimension (seven items) and a social withdrawal dimension (five items). At day 0, the physical and social withdrawal dimensions of the ULL-27 were significantly correlated with the severity of the illness but not the psychological dimension. Sensitivity between day 0 and day 28 in patients with active disease was good in all dimensions of the ULL-27. Trait validity was assessed by correlating the domains of the ULL-27 with the SF-36, but no results are given. Of particular note is that the findings suggest that the volume of the oedema suffered poorly reflects the impact of the condition on the patient.

### Cross-sectional studies

There are few cross-sectional studies that evaluate the impact of lymphoedema on HRQoL, and the four studies reviewed here use a variety of generic tools and methods (Table 3). For example, Tobin *et al.* (23) used a battery of tools to compare the psychological problems of 50 patients with breast cancer treatment-related arm swelling with 50 controls following breast cancer treatment but without arm swelling and matched for age, duration since treatment and type of treatment. Tools used include a modified Karnofsky scale to assess functional impairment, the Social Stress and Support Inventory, a Clinical Interview Schedule, the Hospital Anxiety and Depression Scale and the Psychological Adjustment to Illness Scale. Beaulac and colleagues (24) used the Functional Assessment of Cancer Therapy- Breast to assess the quality of life of 151 women with lymphoedema following either axillary lymph node dissection (ALND) and radiation or mastectomy without

### Key Points

- only one published example of the development of a disease-specific tool to evaluate HRQoL for lymphoedema was identified
- there are few cross-sectional studies that evaluate the impact of lymphoedema on HRQoL



**Table 2** Development of disease-specific tools

Subjects	Methods	Measures	Results	Conclusions	Country and year	Reference
304 patients with upper limb lymphoedema	Validation study using cross-sectional data and follow-up information after 28 days.	Validation of ULL-27, a 27-item questionnaire in three dimensions: physical, psychological and social withdrawal	At day 0, the physical and social dimensions of the ULL-27 were significantly correlated with the severity of the illness but not the psychological dimension. Sensitivity between day 0 and day 28 demonstrated significant differences between all ULL-27 dimensions.	Volume of oedema poorly reflects the impact of the illness upon the patient. The ULL-27 scale seems to be a consistent instrument.	France 2001	(22)

ULL-27: Upper Limb Lymphoedema 27 item questionnaire.

**Table 3** Cross-sectional studies

Subjects	Methods	Measures	Results	Conclusions	Country and year	Reference
50 female patients with breast cancer-related arm swelling.	Cross-sectional study comparing patients with breast cancer-related arm swelling with controls with breast cancer but without swelling matched for age, duration since treatment and type of treatment.	Modified Karnofski Performance Scale, CIS, SSSI, HAD and PAIS administered at one time point.	Modified Karnofski Scale indicated considerable functional impairment in patients with arm swelling; CIS indicated patients with arm swelling experienced greater psychiatric morbidity. SSSI showed no significant difference in concomitant life stressors. No significant differences in HAD scores between groups. Significant differences in five of seven domains of the PAIS.	Patients with breast cancer-related arm swelling experience greater functional impairment, poorer psychosocial adjustment to their illness and anxiety and depression resulting in considerable difficulty with the domestic and social environment and relationships within the family.	UK 1993	(23)
151 women surgically treated for early stage breast cancer.	Cross-sectional study comparing women with ALND and radiation and women with mastectomy without radiation controlled for demography, surgical factors and treatment types.	FACT-B administered at one time point.	Lymphoedema occurred in 27.8% of women. Similar lymphoedema rates in both types of surgery. Women with lymphoedema in both surgical groups scored significantly lower in four of five subsections of the FACT-B than women without lymphoedema.	Lymphoedema occurs at appreciable rates and its impact on long-term quality of life in survivors with early-stage breast cancer should not be underestimated.	USA 2002	(24)

Table 3 Continued

Subjects	Methods	Measures	Results	Conclusions	Country and year	Reference
23 patients with lymphoedema of upper and lower limbs.	Cross-sectional study comparing QoL of patients with and without lymphoedema.	SF-36 administered at one time point.	QoL of patients with lymphoedema was significantly reduced in both physical and mental health domains as well as social interaction.	QoL of patients with lymphoedema is poorer than in patients without lymphoedema particularly in ability to function physically, mentally and socially.	Brazil 2002	(25)
228 with chronic oedema of all causes.	Cross-sectional study comparing patients with published normative data. (mean age 71.4 years)	SF36 administered at one time point. McGill short form pain assessment tool.	Significant differences in role physical, role emotional, social functioning and physical functioning ( $P \leq 0.001$ ). 50% of patients suffered pain or discomfort.	Indications of poorer HRQoL in patients with lymphoedema compared with normative controls with particular emphasis on their ability to function physically and socially and the emotional consequences of the condition.	UK 2003	(5)

CIS, Clinical Interview Schedule; FACT-B, Functional Assessment of Cancer Therapy-Breast; HAD, Hospital Anxiety and Depression Scale; PAIS, Psychological Adjustment to Illness Scale; SF-36, Medical Outcomes Study – Short Form; SSI, Social Stress and Support Inventory.

radiation for early stage breast cancer. The remaining two studies used the SF-36. Moffatt *et al.* (5) compared the SF-36 scores of 228 patients with chronic oedema of a variety of causes with published normative data, while Pereira de Godoy and colleagues (25) used the SF-36 to compare the quality of life of 23 patients with lymphoedema of both upper and lower limbs with 23 patients without lymphoedema. Moffatt *et al.* (5) also used the McGill short form pain assessment tool to assess the pain symptoms experienced by patients.

Although the use of different tools and methodologies make comparison across studies difficult, it is possible to identify a number of common themes. The evidence from these cross-sectional studies indicates that patients with lymphoedema demonstrate poorer psychological adjustment, greater functional impairment and increased anxiety and depression than do patients without lymphoedema (5,23–25). Pain and discomfort was found to be an important factor in the lives of a significant number of people with lymphoedema (5). Also important is the disruption lymphoedema and its treatment can cause to the social, emotional and working lives of sufferers and the challenges it can place on relationships within families (5,23–25).

### Longitudinal and outcome studies

As with cross-sectional studies, longitudinal studies have favoured the use of an array of tools that assess a number of different aspects of quality of life as outcome measures for a variety of interventions. Across the eight studies reviewed here, ten such tools are used, often in combination, and in some cases, within complex methodologies (Table 4). Such variety and complexity, while in many ways reflecting the essential nature of lymphoedema, makes comparison between different research findings difficult. However, a number of broad as well as more focused findings can be identified. Broad findings include (a) the physically and emotionally disabling impact of lymphoedema and its negative effects on HRQoL following breast surgery for cancer (ALND) (26), (b) the relationship between the implementation of evidence-based, patient-centred guidelines for the management of lymphoedema and

improved HRQoL outcomes (27) and (c) the positive influence on HRQoL of a planned combination of intensive treatment, patient education and ongoing support for self-management identified in patients as diverse as those suffering with lymphoedema secondary to breast cancer treatment in a modern health facility in Australia (28) and lymphatic filariasis in a community with limited resources in Guyana (29) on their HRQoL.

More focused findings include the identification of factors associated with lymphoedema that can lead to deficits in HRQoL. These include the frequency of AIE (30), the presence of pain and discomfort (5,31,32), the condition of the skin (29,32), lymphoedema in the dominant hand (31) and reduced mobility of the limb (32). A common finding is that the volume of swelling, often used as a treatment outcome, is not correlated with improved HRQoL (31–33). Equally, Passik *et al.* (31) found that adjustment to lymphoedema was adversely affected by low levels of perceived social support and reliance on an avoidant coping style. Poor social support and avoidant coping were correlated with psychological and social distress and sexual difficulties and were associated with a negative impact on body image and the reporting of significantly greater pain. They argue that treatment and management decisions should not only focus on the severity of lymphoedema based on the volume of swelling and other clinical signs but also on a psychosocial assessment.

### DISCUSSION

The approaches to evaluate HRQoL reviewed in this article provide different perspectives on what is an important measure of the impact lymphoedema can have on a patient's life. Qualitative studies in particular have explored the lived experience of lymphoedema and add an important dimension to our understanding of the physical and psychosocial implications of this chronic condition. From these studies emerge accounts of patients receiving inadequate information, of poorly informed health professionals and of insufficient specialist resources. Patients also speak of shock, disappointment, anger and fear at the first appearance of the swelling, of challenges to their self-image, of the disruption to their personal, social and vocational lives and of prolonged periods of adjustment

### Key Points

- studies showed poorly informed health professionals and insufficient specialised resources
- self-image and disruption of their personal, social and vocational lives are common issues

**Table 4** Longitudinal and outcome studies

Subjects	Methods	Measures	Results	Conclusions	Country and year	Reference
25 patients with lymphoedema following surgery/radiotherapy for breast cancer.	Cohort evaluated pre-intensive versus postintensive treatment phase (4 weeks) and at 1, 6 and 12 months of a self-management phase.	FLIC and WCLS Need for assistance scale (devised by authors) and body image scale (devised by authors).	WCLS scores remained lower than FLIC throughout study with WCLS scores lowest during intensive treatment but surpassed pre-treatment scores during self-management phase. QoL scores did not reflect changes in oedema.	Study confirms that a combination of intensive treatment and education for self-management can reduce swelling and improve quality of life. WCLS appears to be sensitive and discriminating in monitoring patients receiving treatment for lymphoedema.	Australia 1995	(28)
69 women with upper limb lymphoedema seeking rehabilitation therapy following treatment for breast cancer.	Cohort evaluated at one time point — on referral to rehabilitation service of a lymphoedema clinic.	BSI, IES, DSFI, FIQ, SSQ6, ISEL, DWICI.	Women with upper limb lymphoedema had high levels of psychological distress and high levels of sexual, functional, and social dysfunction. These findings were increased for women with lymphoedema in the dominant hand and who had pain of any intensity. Those with pain also perceived lower levels of interpersonal support. Low social support and an avoidant coping style were correlated with psychological distress. No correlation between severity of lymphoedema and levels of distress.	Patients with upper limb lymphoedema may benefit from psychological and sexual therapy in addition to physical rehabilitation. Assessment of pain, social support and coping styles may be beneficial for this patient group as would a psycho-educational and support group within the lymphoedema clinic.	USA 1995	(31)

16 patients attending a breast unit following treatment for breast cancer.	Cohort evaluated pre-implementation versus post-implementation (12 weeks) of clinical guidelines for the management of breast-cancer-related lymphoedema	SF-36, EORTC QLQ-C30.	Stable or improved scores in all categories of physical, social, and emotional functioning. Stable or measured decrease in limb volume for 75% of cohort.	UK 1996	(27)
34 patients with unilateral or bilateral chronic oedema of upper or lower limbs attending a nurse-managed lymphoedema clinic.	Cohort evaluated pre-treatment versus post-treatment using a conservative treatment regime.	NHP-1 at baseline and 4 weeks after completion of initial treatment phase. Clinical assessment including skin condition and limb volume.	Significant improvement in energy, pain and physical mobility ( $P \leq 0.05$ ). Change in volume not associated with a change in any NHP-1 subscale. Significant correlation found between improvement in skin condition and improvement in pain subscale scores ( $P = 0.01$ ). Patients in -ALND and -LE groups had similar scores in all domains of SF-36. Patients in +LE group had significantly impaired quality of life in role-emotional ( $P = 0.03$ ) and bodily pain domains ( $P = 0.08$ ). Comparison with national norms showed that significantly higher percentage of +LE group was below one SD in domains of bodily pain ( $P = 0.005$ ), mental health ( $P = 0.01$ ) and general health ( $P = 0.04$ ).	UK 1997	(32)
101 consecutive, unselected patients who had undergone breast surgery for cancer.	Patients divided into three groups: 1. Surgery without ALND (-ALND) 2. With ALND, no lymphoedema (-LE) 3. With ALND, with lymphoedema (+LE) Evaluation time point ranged from 6 months to 4 years following surgery.	SF-36 at one time point.	Lymphoedema can produce significant impairments in the quality of life of post-operative breast cancer patients. Selective ALND or sentinel lymph node biopsy could reduce incidence of lymphoedema in this patient group.	US 1999	(26)

Table 4 Continued

Subjects	Methods	Measures	Results	Conclusions	Country and year	Reference
36 patients with lymphoedema of various causes.	Cohort evaluated pre-treatment and post-treatment with Complete Decongestive Therapy (CDT).	Disease-specific tool measuring physical, functional and psychosocial concerns (devised by authors).	Significantly greater improvement in QoL scores for patients with lower lymphoedema ( $P < 0.05$ ). No correlation between oedema volume reduction and post-treatment QoL improvement.	CDT can bring significant improvement in QoL of patients with lymphoedema which is not correlated with limb volume reduction.	USA 2002	(33)
54 patients with lower limb lymphoedema secondary to lymphatic filariasis in a clinic in Guyana.	Comparison of disease severity of lymphoedema secondary to lymphatic filariasis with DLQI score.	DLQI at one time point compared with disease severity using Dreyer score and number of AEs during last year.	Patients with a higher disease severity (Dreyer score) had a higher DLQI score (correlation coefficient 0.3). Increased number of AEs correlated with an increased DLQI score (correlation coefficient 0.56)	Confirms correlation between disease severity and DLQI scores and indicates DLQI as a useful tool for the measurement of QoL for limb lymphoedema secondary to lymphatic filariasis.	Guyana/UK 2003	(30)
11 patients with limb lymphoedema secondary to lymphatic filariasis in Guyana.	Cohort evaluated pre-introduction versus postintroduction of a nurse-led hygiene, skin care and education regimen.	DLQI, and disease severity using Dreyer score at baseline and after 1 year.	Significant improvement in DLQI scores ( $P \leq 0.0001$ ) for all patients and reported AEs reduced.	A nurse-led service combined with patient education in communities endemic for lymphatic filariasis is an effective intervention for improving HRQoL of patients with lymphoedema.	Guyana 2003	(29)

AE, acute inflammatory episode; ALND, axillary lymph node dissection; BSI, Brief Symptom Inventory; DLQI, Dermatology Life Quality Index; DWICI, Dealing With Illness-Coping Inventory; EORTC QLQ-C30, European Organization for Research of Cancer Core Quality of Life Questionnaire; FIQ, Functional Interference Questionnaire; FLC, Functional Living Index-Cancer; IES, Impact of Events Scale; ISEL, Interpersonal Support Evaluation List; NHP-1, Nottingham Health Profile Part 1; SF-36, Medical Outcomes Study-Short Form; SSQ6, Social Support Questionnaire – Short Form; WCLS, Wesley Clinic Lymphoedema Scale.

to their lymphoedema often achieved, in the absence of adequate information and support, by trial and error. They also give accounts of the costs and difficulty associated with treatment and how managing their lymphoedema can induce considerable levels of anxiety and stress.

The evidence from cross-sectional and longitudinal studies using generic tools is that patients with lymphoedema have poorer psychological adjustment, greater deficits in their ability to function physically and socially and increased anxiety and depression than do patients without lymphoedema. These studies also identify that pain is a more common and dominant characteristic than is often thought to be the case. The findings indicate that pain, the frequency of AIE, poor skin condition, lymphoedema in the dominant hand and reduced limb mobility are factors that can lead to deficits in HRQoL. Equally important is that the impact of lymphoedema on the patients and their HRQoL is not necessarily related to the volume of the swelling, although one qualitative study has suggested that it may contribute to more positive perceptions in self-image (16). Poor social support and maladaptive coping styles are associated with psychological and social distress as well as with reporting significantly greater pain. There is some evidence that the implementation of a coordinated approach to care and management based on evidence-based, patient-centred guidelines that include strategies for treatment, patient education and support for self-management can have a positive effect on HRQoL.

The studies reviewed in this article are representative of a growing trend towards efforts to understand how lymphoedema affects the lives of patients. However, the diversity of methodologies and number of tools used in these studies create problems of their own. Such a variety of approaches are used that replication and comparison across studies is virtually impossible. Clearly, research that takes this into account would contribute to the understanding of the impact of lymphoedema on HRQoL. In addition, there is a gap in our knowledge regarding the use of HRQoL as an outcome measure for interventions and therapies including. Equally, there is a need for large cross-sectional studies designed so that compari-

sons can be drawn not only across populations but also within populations, for example, comparing the HRQoL of patients with lymphoedema of upper and lower limbs and between patients with lymphoedema of different causes including, and especially, primary lymphoedema.

This review has a number of implications for practice. It draws attention to the need for clear, timely and ongoing information and support for the patient and their relatives and carers. It points to a need to adopt a broader definition of the severity of the condition and treatment outcomes that takes into account the multifaceted nature of lymphoedema. Such a measure would address not only the volume of swelling but also pain, skin condition, whether the swelling is in the dominant hand and the extent of limb movement as well as psychosocial factors such as psychological morbidity and levels of social support and coping strategies.

## CONCLUSION

Lymphoedema is a chronic, complex and multifaceted condition that has major physical, psychological and social implications for the HRQoL of patients. The primary aim of treatment and management is to improve and maintain HRQoL. If this is to be achieved, the evidence from this review points to the importance of having in place a coordinated approach to treatment and management that includes patient support. To be effective, such an approach must be underpinned by a comprehensive education programme for health professionals within an integrated, evidence-based, patient-centred framework of care. Clearly, the HRQoL of individuals must be a key element when evaluating the success of such approaches in the future.

## REFERENCES

- 1 Mortimer PS, Bates DO, Brassington HD, Stanton AWB, Strachan DP, Levick JR. The prevalence of arm oedema following treatment for breast cancer. *Q J Med* 1996;89:377-80.
- 2 Casley-Smith JR, Casley-Smith JR. *Modern treatment for lymphoedema*. 5th edition. Adelaide: Terrence Printing, 1997.
- 3 Penzer R. Lymphoedema. *Nurs Stand* 2003;17(35):45-53.
- 4 Todd JE. Lymphoedema: a challenge for all health care professionals. *Int J Palliat Nurs* 1998;4(5):230-9.

## Key Points

- the studies reviewed in this article are representative of a growing trend towards efforts to understand how lymphoedema affects the lives of patients
- review presents a number of implications for clinical practice



- 5 Moffatt CJ, Franks PJ, Doherty DC, Williams AF, Badger C, Jeffs E, Bosanquet N, Mortimer PS. Lymphoedema: an underestimated health problem. *Q J Med* 2003;96(10):731–8.
- 6 Passik SD, McDonald MV. Psychological aspects of upper extremity lymphoedema in women treated for breast carcinoma. *Cancer* 1998;83(28):17–20.
- 7 Franks AL, Jarrett H. Limb lymphoedema treatment: enhancing patient's quality of life. *Br J Ther Rehabil* 1997;4(9):500–6.
- 8 Ganz PA. The quality of life after breast cancer: solving the problem of lymphoedema. *N Engl J Med* 1999;340(5):383–5.
- 9 Sitzia J, Harlow W. Lymphoedema 4: research priorities in lymphoedema care. *Br J Nurs* 2002;11(8):531–41.
- 10 Farncombe M, Daniels G, Cross L. Lymphoedema: the seemingly forgotten complication. *J Pain Symptom Manage* 1994;9(4):269–76.
- 11 Fallowfield L. The quality of life: the missing dimension in health care. London: Souvenir, 1990.
- 12 Cheater F. Quality of life measures for the health-care environment. *Nurse Reser* 1998;5(3):17–30.
- 13 Hawthorn J. Measuring quality of life. *Eur J Cancer Care* 1993;2:77–81.
- 14 Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. Quality of life in breast cancer: part I: physical and social well-being. *Cancer Nurs* 1997;20(6):398–408.
- 15 Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. Quality of life in breast cancer: part II: psychological and spiritual well-being. *Cancer Nurs* 1998;21(1):1–9.
- 16 Woods M. Patient's perceptions of breast-cancer-related lymphoedema. *Eur J Cancer Care* 1993;2:125–8.
- 17 Woods M. Sociological factors and psychosocial implications of lymphoedema. *Int J Palliat Care* 1995;1(1):17–20.
- 18 Carter BJ. Women's experiences of lymphoedema. *Oncol Nurs Forum* 1997;24(5):875–82.
- 19 Hare M. The lived experience of breast cancer-related lymphoedema. *Cancer Nurs Prac* 2001:12–9.
- 20 Johansson K, Holmström H, Nilsson I *et al*. Breast cancer patients experiences of lymphoedema. *Scand J Caring Sci* 2003;17:35–42.
- 21 Ryan M, Stainton MC, Jaconelli C, Watts S, Mackenzie P, Mansberg T. The experience of lower limb lymphoedema for women after treatment for gynaecologic cancer. *Oncol Nurs Forum* 2003;30(3):417–23.
- 22 Launois R, Mègnigbèto A, LeLay K, Alliot F. A specific quality of life scale in upper limb lymphoedema: the ULL-27 questionnaire. *Value Health* 2001;4(6):407–8.
- 23 Tobin MB, Hubert JL, Meyer L, Mortimer PS. The psychological morbidity of breast cancer-related arm swelling. *Cancer* 1993;72(11):3248–52.
- 24 Beaulac SM, McNair LA, Scott TE, LaMorte WW, Kavanah MT. Lymphoedema and quality of life in survivors of early-stage breast cancer. *Arch Surg* 2002;137(11):1253–7.
- 25 Pereira de Godoy JM, Braile DM, de Fatima Goday M, Longo O Jr. Quality of life and peripheral lymphoedema. *Lymphology* 2002;35(2):44–5.
- 26 Velanovich V, Szymanski W. Quality of life of breast cancer patients with lymphoedema. *Am J Surg* 1999;177:184–7.
- 27 Kirshbaum M. The development, implementation and evaluation of guidelines for the management of breast cancer related lymphoedema. *Eur J Cancer Care* 1996;5:246–51.
- 28 Mirolo BR, Bunce IH, Chapman M, Olsen T, Eliadis P, Hennessy JM, Ward LC, Jones LC. Psychosocial benefits of post mastectomy lymphoedema therapy. *Cancer Nurs* 1995;18(3):197–205.
- 29 McPherson T. Impact on the quality of life of lymphoedema patients following introduction of a hygiene and skin care regime in a Guyanese community endemic for lymphatic filariasis: a preliminary clinical intervention study. *Filaria J* 2003:2–1 (available from <http://www.filiariajournal.com/content/2/1/1>).
- 30 McPherson T, Penzer R. A comparison of quality of life and disease severity in 54 patients with lymphoedema in Guyana. *Br J Dermatol* 2003;149 Suppl 64:34.
- 31 Passik SD, Newman ML, Brennan M, Tunkel R. Predictors of psychological distress, sexual dysfunction and physical functioning among women with upper extremity lymphoedema related to breast cancer. *Psychooncology* 1995;4:255–63.
- 32 Sitzia J, Sobrido L. Measurement of health-related quality of life of patients receiving conservative treatment for limb lymphoedema using the Nottingham Health Profile. *Qual Life Res* 1997;6:373–84.
- 33 Weiss JM, Spray BJ. The effect of complete decongestive therapy on the quality of life of patients with peripheral lymphoedema. *Lymphology* 2002;35(2):46–58.