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A QUALITY OF LIFE MEASURE FOR LIMB LYMPHOEDEMA (LYMQOL)

Vaughan Keeley, Sue Crooks, Jane Locke, Debbie Veigas, Katie Riches, Rachel Hilliam

Abstract

Background: This paper describes the validation of a ‘condition-specific’ quality of life (QoL) assessment tool for lymphoedema of the limbs (LYMQOL). Aim: To ascertain whether the tool could accurately assess QoL in this patient group. Methods: Face and content validity were assessed by patient questionnaires; criterion validity by comparison with European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30 questions (EORTC QLQ-C30); internal validity by Cronbach’s Alpha and split half-testing of each domain; reliability by the test-retest method; construct validity by comparing LYMQOL score with initial limb volume and responsiveness by measuring changes in score following treatment. Results: The tool was validated in a total of 209 patients. Face, content, criterion and internal validity were supported. However, there was no correlation between initial limb volume and LYMQOL score (construct validity), a finding which is similar to that from other studies. The validation of responsiveness was limited by the small numbers of responses at three and six months after the initial assessment. Conclusions: LYMQOL is a validated condition-specific QoL assessment tool which can be used for lymphoedema of the limbs both in clinical assessment and as an outcome measure. Declaration of interest: The authors are not aware of any conflicts of interest.

Key words

QoL assessment tool
Symptom
Body image/appearance
Function
Mood

The impact of lymphoedema on a patient’s quality of life (QoL) has generally been underestimated. However, it is now clear that it can cause physical symptoms, impaired physical and social function and emotional effects (Moffatt et al, 2003).

A number of attempts have been made to define QoL (Higginson and Carr; 2001) and it is a very personal issue. However, in healthcare it usually incorporates physical and social health and functioning and psychological and emotional wellbeing (Bowling, 1997).

This paper describes the validation of a condition-specific QoL measure for lymphoedema of the limbs (LYMQOL) which could be used routinely in clinical services.

QoL measures can be used to assess the impact of chronic oedema on the individual and also to demonstrate changes as a result of treatment (Keeley, 2008). They can be used as practical clinical tools influencing treatment decisions and measuring outcome, as well as in research studies assessing the effectiveness and cost-effectiveness of interventions (Higginson and Carr; 2001).

Health-related quality of life measures that have been used in studies of lymphoedema have been either ‘general’, e.g. Medical Outcome Study 36-item short form (SF-36) (Ware and Sherbourne, 1992), which assesses functional health status, or ‘condition-specific’, e.g. European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30 questions (EORTC QLQ-C30) (Aaronson et al, 1993) and QLQ-BR23, a 23-question tool specifically for breast cancer (Sprangers et al, 1996). However, general health-related measures may not be as accurate or informative as condition-specific tools (Morgan et al, 2005).

In the recent literature, a number of lymphoedema/chronic oedema-specific QoL assessment tools have been reported. For some, the validation has been published, e.g. ULL-27 for upper limb lymphoedema (Launois and Alliott, 2000) and FLQA-L for lymphoedema of arms and legs (Augustin et al, 2005). For others, the tools have been used in studies without a formal validation being reported, e.g. Wesley Clinic Lymphoedema Scale (WCLS) or post mastectomy lymphoedema (Mirolo et al, 1995) and an un-named tool for...
peripheral lymphoedema (Weiss and Spray, 2002).

This paper describes the validation of a condition-specific QoL measure for lymphoedema of the limbs (LYMQOL) which could be used routinely in clinical services, Interim stages of the validation process have been previously reported (Keeley et al, 2004).

Methods
Development of the tool
LYMQOL was developed by experienced healthcare professionals in the lymphoedema service in Derby, UK in consultation with service users. Separate tools were developed for arm and leg lymphoedema. The tools were designed as patient-completed questionnaires with a structure similar to the EORTC QLQ-C30 (Appendices 1a and 1b).

The questions cover four domains:
- Symptoms
- Body image/appearance
- Function
- Mood.

There is an overall QoL rating. The mood questions were taken from the previously validated EORTC QLQ-C30 with permission.

Scoring of LYMQOL
Each item in each domain was scored:
- Not at all = 1
- A little = 2
- Quite a bit = 3
- A lot = 4.

A total score for each domain was calculated by adding all scores together and dividing by the total number of questions answered. If fewer than 50% of the items were answered, the whole domain was scored as 0. The ‘overall QoL’ item was scored 0–10.

In some of the analyses, the domain scores were calculated as a percentage to facilitate comparison with other measures (see below).

Validation
The study was designed to measure (Fallowfield, 1990):
- Validity, i.e. is the scale measuring what it was designed to do?
- Reliability, i.e. to what extent can the scale be reproduced under different conditions?
- Responsiveness, i.e. is the scale sensitive enough to record significant changes following treatment?

Specific aspects of these elements were measured as follows.

Face validity
The subjective assessment of the presentation of the questionnaire and its relevance was measured using a short questionnaire that was given to patients who took part in the study (Appendix 2).

Content validity: does the content address all the important issues
This was assessed from the patient questionnaire and by a separate study (Veigas and Keeley, 2004). The study was a phenomenological interview of 22 patients. The main themes that emerged were loss, both actual and potential, relating to the individual’s role, work, body image, self-esteem and embarrassment.

Criterion validity: how does the new measure compare with a ‘gold standard’ tool?
No such condition-specific tool was available at the time the study was carried out. Therefore, the results were compared with relevant sections of the EORTC QLQ-C30 in the first 50 patients, using the Spearman or Pearson correlation coefficient and intra-class correlation coefficient.

Internal validity
This includes:
- Internal consistency: by Cronbach’s Alpha and split half-testing of each domain. The latter tests for homogeneity, i.e. the extent to which the questions relating to a particular domain measure only that and no other. Split half-testing was carried out in two ways, the first comparing first and second half items and the second comparing odd and even numbered items. The Spearman-Brown coefficient was used to test for similarities between the two halves
- Reliability: by the test re-test method in a subgroup of patients. The first measure was carried out at the initial assessment and the second before intensive treatment with bandaging, i.e. repeated in individual patients before any treatment had been given, and therefore it was unlikely that there would have been any significant change in QoL. Results were compared using Pearson’s correlation coefficient.

Construct validity: to what extent does the tool test the theory it is measuring?
It was postulated that patients with more severe lymphoedema (i.e. larger limb volumes) would have a ‘lower’ QoL, i.e. higher scores in LYMQOL domains. Therefore, initial limb volume was compared with LYMQOL scores in each domain, using the paired T test.

Responsiveness: is the tool sensitive to change?
This was assessed by measuring changes in QoL scores following treatment, using the Pearson correlation coefficient.

Inclusion criteria:
- New patients presenting to the lymphoedema clinic in Derby who consented to take part
- Patients over 18 years of age with unilateral or bilateral swelling of upper or lower limbs.

Exclusion criteria:
- Those with active malignancy
- Those undergoing chemotherapy.

Data was collected as follows:
- First visit:
  - demographics, i.e. gender, age, site of lymphoedema, cause of lymphoedema
  - LYMQOL score
  - Patient questionnaire
  - EORTC QLQ-C30 (first 50 patients)
  - Limb volume measurement.
- Follow-up at one week, one month, three months and six
months after treatment either
with a compression garment or
multilayer lymphoedema bandaging
± manual lymphatic drainage
(MLD). This involved:
• LYMQOL score
• Limb volume measurement.

The study was approved by the
Southern Derbyshire Local Research
Ethics Committee (Reference No:
SDLREC 02/02/438).

Results
A total of 209 patients took part
in the study, of which 78.7% were
women. The mean age of participants
was 58 years (SD 16.4 years). Bilateral
leg swelling was the most frequently
reported site of swelling (43.8%).
Approximately one quarter of the
sample reported unilateral arm swelling
(26.8%) or unilateral leg swelling
(27.7%). 1.5% of patients reported that
a combination of arms and legs was
swollen.

Face validity
Face validity was confirmed (Table 1).
Patients found LYMQOL clear, easy to
complete and not too long.

Content validity
There were 90 patient questionnaires
returned. Although 92% of respondents
felt that no questions could be left out,
20% felt that there were important
areas missing. The main themes of these
are shown in Table 2.

Criterion validity
The LYMQOL results for the domains
‘function’, ‘symptoms’, ‘mood’ and ‘overall
QoL’ showed good correlation with
those for comparable domains in the
EORTC QLQ-C30 for both arm and
leg questionnaires (Tables 3 and 4).
There was no comparable domain
in the EORTC QLQ-C30 for that
of ‘appearance’ in LYMQOL, so no
comparison could be made.

Internal validity
Internal consistency — Cronbach’s alpha
Cronbach’s alpha was >0.8 for all
domains in both the arm and leg
versions of LYMQOL, thus confirming
internal consistency (Tables 5 and 6).

Deleting any of the items did not
appear to increase the value of alpha
by a large amount, i.e. did not improve
internal consistency and therefore
supported the reliability.

The small number in the ‘symptom’
domains included in the analysis
reflects the relatively large number of
incomplete responses in this domain.

Split half-testing of each domain
Reliability was adequate (a0.8) or
good (a0.9) for each of the domains
with the exception of ‘symptoms’
for LYMQOL (arm) when first and
second halves were compared (Tables
7 and 8). This is likely to be because
the questions in the first half are all
part of Q11 and relate to the site and
degree of pain. The second method of
testing is therefore more appropriate
for this domain. Reliability was found
to be adequate or good for all of the
domains tested.

Reliability
Reliability was supported using the
test-retest method for 15 patients who
had leg oedema (Table 9). This number
is relatively small and reflects the fact
that most patients were treated at the
first clinic appointment and the test-
retest method could only be used in
those who returned for treatment at
a later date. Nevertheless, there was
good correlation between the mean
scores for each domain at visit one and
two, i.e. with no intervening treatment
in this subgroup.

Construct validity
It was postulated that patients with
more severe swelling, i.e. larger limb
volume would have a ‘lower’ quality of
life. Therefore, LYMQOL scores were
compared with initial limb volume.

There was no significant correlation
between any of the domains of
LYMQOL and the initial limb volume.

Responsiveness
Scores at the time of presentation
were compared with those at one
week and one month later to see how
the questionnaire responded over time.
Too few responses were received at
later times after presentation to allow
meaningful analysis.

There were no significant
differences in scores after one week
and one month for LYMQOL (arm)
domains.

For LYMQOL (leg), the ‘appearance’
scores were significantly lower, i.e.
improved at one week and one month,
whereas the ‘function’, ‘symptoms’

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Face validity. Response to questionnaires (n=90)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was it easy to complete?</td>
<td>Yes (%)</td>
</tr>
<tr>
<td>Was it too long?</td>
<td>93</td>
</tr>
<tr>
<td>Were the questions clear?</td>
<td>99</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Examples of comments on what was missed out</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity of legs</td>
<td></td>
</tr>
<tr>
<td>Redness and soreness</td>
<td></td>
</tr>
<tr>
<td>Burning/hot feelings</td>
<td></td>
</tr>
<tr>
<td>Effect of other conditions, e.g. previous knee injury</td>
<td></td>
</tr>
<tr>
<td>Impact of cellulitis</td>
<td></td>
</tr>
<tr>
<td>Embarrassment</td>
<td></td>
</tr>
<tr>
<td>Effect of compression garment</td>
<td></td>
</tr>
</tbody>
</table>
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within each domain using Spearman’s
correlation coefficient (rho).

If two items have a high correlation,
they may be measuring the same thing
and, therefore, one could be removed
in the development of a revised version
of LYMQOL. From a statistical point of
view, a correlation of \( \geq 0.7 \) was applied
as the ‘cut off’ for a significant value in
determining whether a particular item
could be considered superfluous.

Items with a poor correlation to
the overall domain score may equally
not contribute much to the domain as
a whole. These could also be removed
to shorten the tool without affecting its
value.

However, in the application of
this methodology, consideration has
also to be given to whether the items
are particularly relevant clinically. If
LYMQOL is to be used as part of
clinical assessment and outcome
measurement, keeping some potentially
‘redundant’ items may be appropriate if
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Finally, consideration was given to
whether some items were frequently
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particularly relevant to the ‘symptom’
domain where the number of complete
responses was low (Tables 5
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Using this approach, LYMQOL arm
and LYMQOL leg were modified and
the new versions contain 28 and 27
items respectively (Appendix 3a, 3b).

The scoring system is also included in
Appendix 3a and 3b.

The details of this modification
process are included in Appendix 4.

Discussion
This paper has demonstrated the face
validity, content validity, criterion validity
and internal validity of LYMQOL.

The aim was to produce a condition-
specific QoL tool for lymphoedema
which could be used in routine clinical
practice for assessment and as an
outcome measure, as well as in research.

and ‘mood’ domains showed no
difference. The ‘overall QoL’ scores
were significantly higher; i.e. better
at one week but no different at one
month from presentation (Table 10),
although the difference at one week
was small and not likely to be of clinical
significance.

<table>
<thead>
<tr>
<th>Function</th>
<th>0.689</th>
<th>0.005</th>
<th>0.686</th>
<th>0.001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>0.688</td>
<td>0.005</td>
<td>0.643</td>
<td>0.003</td>
</tr>
<tr>
<td>Mood</td>
<td>0.860</td>
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</table>

ICC=Intraclass correlation coefficient

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### Table 4
Correlation between LYMQOL (leg) and EORTC QLQ-C30 domains

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<tr>
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<tr>
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</tr>
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</table>

### Table 5
Cronbach’s alpha for the domains of LYMQOL (arm)

Reducing the number of items
Although the LYMQOL tool is not
particularly lengthy (38 items for
arm; 40 items for leg), analysis was
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Table 6
Cronbach’s alpha for the domains of LYMQOL (leg)

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>45</td>
<td>0.945</td>
</tr>
<tr>
<td>Appearance</td>
<td>78</td>
<td>0.874</td>
</tr>
<tr>
<td>Symptoms</td>
<td>12</td>
<td>0.917</td>
</tr>
<tr>
<td>Mood</td>
<td>100</td>
<td>0.875</td>
</tr>
</tbody>
</table>

Table 7
Spearman-Brown coefficients for split half-testing for LYMQOL (arm) domains

<table>
<thead>
<tr>
<th></th>
<th>1st/2nd half</th>
<th>Odd/even</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>0.923</td>
<td>0.933</td>
</tr>
<tr>
<td>Appearance</td>
<td>0.853</td>
<td>0.830</td>
</tr>
<tr>
<td>Symptoms</td>
<td>0.642</td>
<td>0.859</td>
</tr>
<tr>
<td>Mood</td>
<td>0.801</td>
<td>0.871</td>
</tr>
</tbody>
</table>

Table 8
Spearman-Brown coefficients for split half-testing for LYMQOL (leg) domains

<table>
<thead>
<tr>
<th></th>
<th>1st/2nd half</th>
<th>Odd/even</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>0.897</td>
<td>0.964</td>
</tr>
<tr>
<td>Appearance</td>
<td>0.835</td>
<td>0.936</td>
</tr>
<tr>
<td>Symptoms</td>
<td>0.887</td>
<td>0.964</td>
</tr>
<tr>
<td>Mood</td>
<td>0.855</td>
<td>0.923</td>
</tr>
</tbody>
</table>

As such, it is important that the tool is easy to use and not too lengthy. Although patients did not feel it was too long, and indeed suggested further items which should be added (Table 2), it was also clear that there was a degree of “fatigue” in repeatedly completing the questionnaire during the course of the study, as the numbers responding decreased over time. Indeed, there were insufficient responses at three and six months to examine statistically.

On reviewing the issues raised in Table 2, it was felt that some could perhaps be addressed by existing items, e.g. impact on holidays covered by the item on leisure activities and embarrassment by the ‘appearance’ domain.

The question of the effect of comorbidity on the scores is more complex. For example, mobility may be affected by other conditions, e.g. arthritis, lung disease and neurological problems, rather than the lymphoedema itself. This needs to be considered when using the tool to assess individual patients, since treating the lymphoedema successfully may not necessarily result in an improvement in mobility (as measured by the ‘function’ domain) in these situations.

Taking the above into account, it was felt important to try to reduce the size of LYMQOL to make it more acceptable to users. This process was supported by the statistical analysis, which had demonstrated that some items were potentially redundant. The revised versions of LYMQOL should also address the problem of incomplete responses to the symptom domain (Tables 5, 6, 7 and 8). It seems that the issue here related to the ‘sites of pain’, particularly in LYMQOL (arm) as described in Table 7 and, therefore, the revised version has been amended accordingly (Appendices 3a, 3b and 4).

The decline in ‘response rate’ at three and six months may reflect patient ‘fatigue’, however it is also possible that not all patients received questionnaires to complete at these times if the research nurse was not present at the follow-up appointment. Regardless of this, a less frequent use, e.g. six-monthly or annually may be appropriate when LYMQOL is employed in routine clinical practice to fit in with follow-up assessment appointments.

Construct validity was not fully confirmed in that there seemed to be no significant correlation between initial limb volume and quality of life. Interestingly, other studies have reported a lack of relationship between improved QoL and a reduction in limb volume after treatment (e.g. Sitzia and Sobrindo, 1997; Weiss and Spray, 2002). Thus, the initial construct that limb volume and quality of life are inversely related may be erroneous. Nevertheless, this could suggest that QoL measures may add a different dimension to patient assessment beyond the routine measurement of limb volume currently carried out by most lymphoedema services. Hence,
this strengthens the case for using a condition-specific QoL assessment tool as a clinical outcome measure.

Unfortunately, the data available in this study have not conclusively demonstrated the responsiveness of LYMQOL over time, although the ‘appearance’ scores of LYMQOL (leg) were significantly improved at one week and one month. This is largely due to the fact that few patients completed questionnaires at three and six months. More data is to be collected on this using the revised LYMQOL, but asking patients to complete questionnaires less frequently (six-monthly), with the aim of improving the response rate.

LYMQOL seems to be a potentially useful tool in assessing and monitoring patients with chronic limb oedema. One limitation in its use, however, is that it does not specifically address ‘midline’ oedema, e.g. trunk, genital and head and neck oedema.

A number of other condition-specific QoL tools for lymphoedema have been developed and reported. Only two other groups have published the validation of the tools — ULL-27 for upper limb lymphoedema (Launois and Alliott, 2000) and FLQA-L for lymphoedema of the arms and legs (Augustin et al, 2005).

The former is a 27-item tool specifically designed for upper limb lymphoedema. The latter is a 92-item questionnaire derived from a previously validated tool (FLQA vein questionnaire). LYMQOL represents an alternative to these, being a relatively short tool, covering both arm and leg oedema.

LYMQOL has not been designed for use in children, therefore it is not recommended for this age group. In addition, as described above, it does specifically address ‘mid-line’ lymphoedema. This is going to be the subject of future work.

Conclusions
LYMQOL is a validated QoL assessment tool for use with people with limb lymphoedema. Further work is underway to confirm its responsiveness over time. Readers who are interested in using LYMQOL are invited to contact vaughan.keeley@derbyhospitals.nhs.uk for further information and to share experiences of its use.

Acknowledgement
The authors thank the EORTC for their
Appendix 2

Lymphoedema quality of life questionnaire responses

(1) Was it easy to complete?
If no, please say why:

(2) Was it too long?

(3) Were all the questions clear?
If no please record the relevant question numbers, and state why:

(4) Were there any important areas where your swollen limb(s) affects the quality of your life that were not covered?
If yes please comment:

(5) Were there any questions which you feel we could have left out?
If yes please give examples:

(6) Any other comments?

References


Appendix 1a

Lymphoedema Quality of Life Study (LYMQOL)  ARM

If any of the items are not applicable to you, please write N/A in the relevant answer box(es).

(1) How much does your swollen arm affect the following daily activities?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) occupation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) housework</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) combing hair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) dressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) doing up/undoing buttons</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) writing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) eating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h) washing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) cleaning teeth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j) putting on make-up/shaving</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(2) How much does it affect your leisure activities/social life?

Please give example(s) of this.

(3) How much do you have to depend on other people?

(4) How much do you feel the swelling affects your appearance?

(5) How much difficulty do you have finding clothes to fit?

(6) How much difficulty do you have finding clothes you would like to wear?

(7) Have you had difficulty wearing jewellery, e.g. wedding ring?

(8) Does the swelling affect how you feel about yourself?

(9) Does it affect your relationship with your partner?

(10) Does it affect your relationships with other people?

(11) Does your lymphoedema cause you pain?

If so, do you have pain in the arm:

- shoulder
- back
- neck
- elsewhere — if so, where?

(12) Do you have any numbness in your swollen arm?

(13) Do you have any feelings of ‘pins and needles’ or tingling in your swollen arm?

(14) Does your swollen arm feel weak?

(15) Does your swollen arm feel heavy?

(16) Does your hand feel ‘cold’?

(17) Do you feel tired?

In the past week

(18) Have you had trouble sleeping?

(19) Have you had difficulty concentrating on things, e.g. reading?

(20) Have you felt tense?

(21) Have you felt worried?

(22) Have you felt irritable?

(23) Have you felt depressed?

(24) Overall, how would you rate your quality of life at present? Please mark your score on the following scale:

<table>
<thead>
<tr>
<th>Poor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Excellent</th>
</tr>
</thead>
</table>

Thank you for completing this form.

If you have any comments or queries about it, please discuss these with Dr Vaughan Keeley, Consultant in Palliative Medicine, Nightingale Macmillan Unit, 117A London Road, Derby DE1 2QS.

Questions 18 to 24 have been reproduced with permission from the EORTC.

These questions are only a part of the QLQ-C30 Questionnaire.

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## Lymphoedema Quality of Life Study (LYMQOL)  
### LEG

If any of the items are not applicable to you, please write N/A in the relevant answer box(es).

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Has your swollen leg(s) affected:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) your walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) your ability to go up and down stairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) your ability to bend, e.g. to tie shoelaces or cut toenails</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) your ability to kneel</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) your ability to stand</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) your ability to get into/out of a car</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>g) Your ability to get on/off public transport, e.g. trains/buses</td>
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<td></td>
</tr>
<tr>
<td>h) your ability to get up from a chair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) your ability to drive a car</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j) your occupation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k) your ability to do housework</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(2) Does the swelling affect your leisure activities/social life?

Please give example(s) of this.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) How much do you have to depend on other people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) How much do you feel the swelling affects your appearance?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(5) How much difficulty do you have finding clothes to fit?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(6) How much difficulty do you have finding clothes you would like to wear?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(7) Do you have difficulty finding shoes to fit?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Do you have difficulty finding socks/tights/stockings to fit?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(9) Does the swelling affect how you feel about yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10) Does it affect your relationship with your partner?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(11) Does it affect your relationships with other people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(12) Does your lymphoedema cause you pain?</td>
<td></td>
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<tr>
<td>If so, do you have pain in the leg/feet</td>
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<tr>
<td>leg/legs</td>
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<tr>
<td>hip(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>back</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>elsewhere —— if so, where?</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

(13) Do you have any numbness in your swollen leg(s)?

(14) Do you have any feelings of ‘pins and needles’ or tingling in your swollen leg(s)

(15) Does (do) your swollen leg(s) feel weak?

(16) Does (do) your swollen leg(s) feel heavy?

(17) Does (do) your swollen foot (feet) feel ‘old’?

(18) Have you had any leakage of fluid from your leg(s)

In the past week

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>(19) Have you had trouble sleeping?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(20) Have you had difficulty concentrating on things, e.g. reading?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(21) Have you felt tense?</td>
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<tr>
<td>(22) Have you felt worried?</td>
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<tr>
<td>(23) Have you felt irritable?</td>
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<tr>
<td>(24) Have you felt depressed?</td>
<td></td>
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</tbody>
</table>

(25) Overall, how would you rate your quality of life at present? Please mark your score on the following scale:

| Poor | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Excellent |

Thank you for completing this form.

If you have any comments or queries about it, please discuss these with Dr V L Keeley, Consultant

Questions 19 to 25 have been reproduced with permission from the EORTC. These questions are only a part of the QLQ-C30 Questionnaire.
**LYMQOL ARM-Screening System**

Lymphoedema Quality of Life Tool

The score for the individual responses are given below. If the item is not scored and left blank or not applicable this is scored with a 0. Domain totals are calculated by adding the individual scores and dividing the total by the number of questions answered. (If >50% of questions per domain are not answered this cannot be calculated and =0). The four domains and their corresponding questions are: Function 1 (a–h); Appearance 4, 5, 6, 7, 8; Symptoms 9, 10, 11, 12, 13, 14; and Mood 15, 16, 17, 18, 19, 20. Overall quality of life (Q21) is scored as the value marked by the patient, between 0–10.

<table>
<thead>
<tr>
<th>Question</th>
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<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) How much does your swollen arm affect the following daily activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) occupation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b) housework</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c) combing hair</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d) dressing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e) writing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f) eating</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g) washing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h) cleaning teeth</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(2) How much does it affect your leisure activities/social life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tbody>
</table>

Please give example(s) of this.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) How much do you have to depend on other people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) How much do you feel the swelling affects your appearance?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(5) How much difficulty do you have finding clothes to fit?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(6) How much difficulty do you have finding clothes you would like to wear?</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>(7) Does the swelling affect how you feel about yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Does it affect your relationships with other people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(9) Does your lymphoedema cause you pain?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10) Do you have any numbness in your swollen arm?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(11) Do you have any feelings of ‘pins and needles’ or tingling in your swollen arm?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(12) Does your swollen arm feel weak?</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>(13) Does your swollen arm feel heavy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14) Do you feel tired?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past week</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(15) Have you had trouble sleeping?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16) Have you had difficulty concentrating on things, e.g. reading?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(17) Have you felt tense?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(18) Have you felt worried?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(19) Have you felt irritable?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(20) Have you felt depressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(21) How would you rate your quality of life at present?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Poor | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Excellent |

Thank you for completing this form.

If you have any comments or queries about it, please discuss these with Dr V L Keeley, Consultant in Palliative Medicine.

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LYMQOL LEG-Scoring System
Lymphoedema Quality of Life Tool

The score for the individual responses are given below. If the item is not scored and left blank or not applicable this is scored with a 0. Domain totals are calculated by adding the individual scores and dividing the total by the number of questions answered. (If >50% of questions per domain are not answered this cannot be calculated and =0).

The four domains and their corresponding questions are: Function (a–f), Appearance (4, 5, 6, 7, 8, 9, 10), Symptoms (11, 12, 13, 14, 15) and Mood (16, 17, 18, 19, 20, 21).

Overall quality of life (Q22) is scored as the value marked by the patient, between 0–10.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) How much does your swollen leg affect the following daily activities?</td>
<td>[\text{Please give example(s) of this.}]</td>
<td>[\text{Please give example(s) of this.}]</td>
<td>[\text{Please give example(s) of this.}]</td>
<td>[\text{Please give example(s) of this.}]</td>
</tr>
<tr>
<td>a) your walking</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b) your ability to bend, e.g. to tie shoelaces or cut toenails</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c) your ability to stand</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d) your ability to get up from a chair</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e) your occupation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f) your ability to do housework</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(2) Does the swelling affect your leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(3) How much do you have to depend on other people?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(4) How much do you feel the swelling affects your appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(5) How much difficulty do you have finding clothes to fit?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(6) How much difficulty do you have finding clothes you would like to wear?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(7) Do you have difficulty finding shoes to fit?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(8) Do you have difficulty finding socks/leggings to fit</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(9) Does the swelling affect how you feel about yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(10) Does it affect your relationships with other people?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(11) Does your lymphoedema cause you pain?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(12) Do you have any numbness in your swollen arm?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(13) Do you have any feelings of ‘pins and needles’ or tingling in your swollen arm?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(14) Does (do) your swollen leg(s) feel weak?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(15) Does (do) your swollen arm(s) feel heavy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>In the past week</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(16) Have you had trouble sleeping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(17) Have you had difficulty concentrating on things, e.g. reading?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(18) Have you felt tense?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(19) Have you felt worried?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(20) Have you felt irritable?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(21) Have you felt depressed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>(22) (24) Overall, how would you rate your quality of life at present?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Thank you for completing this form.
If you have any comments or queries about it, please discuss these with Dr V.L Keeley, Consultant (89).

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Appendix 4

**LYMQOL Modifications after further analysis**

**LYMQOL arm:**

*Arm function: questions 1(a–j)–3*
- Question 1e: doing up/undoing buttons demonstrated high correlations to dressing, eating and putting on make up and shaving, all were >0.7. This question was therefore removed as it was felt that this action was covered by these questions.
- Question 1j: Putting on make up/shaving was also highly correlated with writing, eating and washing, all >0.68. This question was also removed.
- Questions 1a and i: Occupation and cleaning teeth were poorly correlated to the other questions and the domain as a whole. Despite this it was decided that these questions should be kept. Despite a maximum of 37 participants answering Q1a it was felt to have clinical significance if recognised as a problem by the patient. Q1i was not omitted as it was felt that this activity required a level of dexterity and actions not covered by the other questions.

*Arm appearance: questions 4–10*
- On the whole the individual questions in this section were poorly correlated with each other; however, they were correlated to the domain as a whole. There were two questions that were not correlated to the domain 7 and 9: difficulty wearing jewellery and whether the swelling affects the relationship with their partner. Both of these questions were removed.

*Arm symptoms: questions 11–17*
- Question 11 asks whether the lymphoedema causes pain and the five subsequent questions detailed specific areas. It was felt that the presence of pain was the significant question and knowing the specific area did not add to this, as further questions regarding the presence of pain would be covered in a clinical assessment. These five questions have been removed from the modified version of LYMQOL.
- Question 16 asked whether the hand felt cold and this was poorly correlated with the other questions and also the domain as a whole. This question was therefore removed.

*Arm mood: questions 18–23*
- These questions were taken from the EORTC questionnaire and therefore have been previously validated. However, they have been taken from different domains in the EORTC. They are all correlated to the domain and therefore all remain in the modified version.

**LYMQOL leg:**

*Leg function: questions 1(a–k)–3*
- The majority of the questions correlated well with each other and the domain as a whole. There was one aspect, however, that did not demonstrate any significant correlations with any other aspect or to the domain. This was the ability to drive a car (1i). This has subsequently been removed in the modified version.
- Question 1j: The effect of the swelling on the patient’s occupation did not demonstrate a high correlation with the other functional aspects but was correlated with the domain. Similarly to the arm LYMQOL, this was perceived as having clinical significance and was retained.
- As a result of the high correlations each question was reviewed and questions 1b (the ability to go up and down stairs), d (the ability to stand), f (the ability to get into/out of a car), g (the ability to get on/get off public transport) have been removed, as it was felt that these aspects were covered by the remaining questions.

*Leg appearance: questions 4–11*
- Similarly to the arm questionnaire, question 10, ‘relationship with your partner’ was poorly correlated and it was felt that this could be answered by the following question, relationship with others. Therefore this has been removed.

*Leg symptoms: questions 12–18*
- Once more the relationships demonstrated in the analysis of the arm questionnaire were mirrored in the leg questionnaire. The sub-questions relating to the areas of pain (12 a–e) and also the feeling of coldness (17) have been removed.
- Question 18, leakage of fluid was not correlated with any of other questions and did not add to the domain as a whole, therefore it been removed. This symptom can be addressed in the clinical assessment.

*Leg mood: questions 19–24*
- These questions were taken from the EORTC questionnaire and therefore have been previously validated. However, they have been taken from different domains in the EORTC. They are all correlated to the domain and therefore all remain in the modified version.