

PATIENT-REPORTED OUTCOME MEASUREMENT TOOLS USED TO ASSESS QUALITY OF LIFE FOR PATIENTS EXPERIENCING CANCER-RELATED LYMPHEDEMA – A SCOPING REVIEW

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Introduction

- Lymphedema refers to tissue swelling caused by an accumulation of protein-rich fluid, which often arises as a complication of oncological treatments and negatively affects patients’ quality of life (QoL).
- QoL assessment tools are important for assessing the effectiveness of current management strategies and providing direction for the development of new interventions to tackle unmet needs.
- This review attempts to assess the QoL issues in patients with cancer-related lymphedema and evaluate the existing lymphedema-specific tools in representing cancer patients’ experiences.

Methods

- MEDLINE, EMBASE and Google Scholar searched using keywords “**lymphedema**”, “**quality of life**” and “**validation**” to identify articles published that report on the validation of lymphedema-specific QoL tools in the literature from 1998 to 2022.
- Tools developed to screen for lymphedema-related physical symptoms rather than QoL were excluded. Superseded versions of QoL tools were also excluded.
- A separate search in the databases was performed to identify QoL issues of cancer survivors with lymphedema.

Results

- Seventeen validated lymphedema-specific tools were identified from 63 studies found in MEDLINE, EMBASE and Google Scholar
- Seven out of 17 (41.1%) were validated exclusively with cancer patients.
- Out of these tools, 5 out of 7 (71.4%) were specifically designed for breast cancer-related upper limb lymphedema.
- Ten categories of QoL issues were identified: physical symptoms, impairment of psychological well-being, functional impairment, body image concerns, sexual concerns, impairment in social relationships, information needs, financial stress, lymphedema treatment-related concerns and fear of recurrence (Table 1)
- None of the lymphedema-specific tools encompassed all ten categories** (Table 2)

Table 2: Summary of existing lymphedema specific patient reported outcome tools to assess quality of life

Tool	Validated with cancers only	Site of lymphedema validated	Physical	Mood	Function	Social	Body image	Sexual	Information needs	Treatment related	Finance	Fear of cancer recurrence
FACT-B +4	√(Breast)	UL	√	√	√	√	√	√	X	X	X	X
FLQA-LS	X	UL and LL	√	√	√	√	√	X	X	√	X	X
LLIS Ver. 2	X	UL and LL	√	√	√	√	X	√	√	X	X	X
LSIDS-A	√(Breast)	UL	√	√	√	√	√	√	X	X	√	X
LSIDS-H&N 2.0	√(H&N)	H&N	√	X	√	√	√	√	X	X	√	X
LSIDS-L	X	LL	√	√	√	√	√	√	X	X	√	X
LSIDS-T	Not mentioned	Trunk	√	X	√	√	√	√	X	X	√	X
Lymph-ICF -UL	√(Breast)	UL	√	√	√	√	√	X	X	X	X	X
Lymph-ICF -LL	X	LL	√	√	√	√	√	X	X	X	X	X
LYMPH-Q	√(Breast)	UL	√	√	√	X	√	X	√	√	X	X
LYMPROM	X	UL, LL	√	√	√	√	√	√	X	X	√	X
LYMQOL -Arm	X	UL	√	√	√	√	√	X	X	X	X	X
LYMQOL -Leg	X	LL	√	√	√	√	√	X	X	X	X	X
LyQLI	X	UL, LL, H&N	√	√	√	√	√	√	√	√	√	X
PBI-L	X	UL, LL (also includes lipedema)	√	√	√	√	√	X	√	√	√	X
ULL-27	√(Breast)	UL	√	√	√	√	√	X	X	X	X	X
ULLQoL	√(Breast, NHL)	UL	X	√	√	√	√	√	X	X	X	X

Abbreviations: UL = Upper limb, LL = lower limb, H&N = head and neck

Table 1: Quality of life issues in patients experiencing cancer related lymphedema

Quality of life domain	Examples of issues in domain
Physical symptoms	- Impaired mobility (range of motion affected, weakness), fluid reaccumulation (heaviness, swelling, stiffness), pain and altered sensation (pain, numbness, altered temperature), fatigue - Symptoms specific to head and neck internal lymphedema (difficulty in moving tongue, difficulty in chewing, difficulty in swallowing)
Impairment of psychological well-being	Depressed, angry or frustrated, anxious or nervous, helpless, tense / stressed, worried, discouraged, lack of concentration, poor sleep
Functional impairment	Impairment in self care, performing household activities, job related activities, leisure /recreational activities
Body image concerns	Lack of self confidence, negative self body image, concern about appearance
Sexual concerns	Impaired intimate / sexual relationship with partner, loss of sexual attractiveness or sexuality
Impairment in social relationships	Impaired relationships with others, increased dependence on others, reduced social activities, choice of clothing limited due to lymphedema
Information needs	Lack of knowledge about disease nature and treatment, frustration from lack of knowledge about lymphedema in healthcare team, frustration from lack of knowledge about lymphedema in general public
Financial stress	Increased financial costs from lymphedema treatment and self care appliances, impaired job productivity due to lymphedema
Lymphedema treatment-related concerns	Mobility affected due to compression garments, compression garments uncomfortable, finds difficulty in applying treatments, frustrated from ineffectiveness of treatment
Fear of recurrence	Interpreting symptoms of lymphedema as signs of recurrence

Conclusions

- Current QoL tools for the assessment of cancer patients with lymphedema are limited and are primarily focused on breast cancer related arm lymphedema.
- Resources should be directed towards developing tools which are body site specific, validated for patients of a variety of primary tumours and cover all areas of QoL domains