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From Stories to Scores: Tracking Quality of Life in Lymphoedema

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Introduction

Lymphoedema is a chronic condition caused by a failure of the lymphatic system, leading to swelling/discomfort [1] It is a lifelong condition that affects people's physical, emotional, and social well-being. Yet across the world, swelling is the major measure. This narrow focus misses the bigger picture of how people cope day to day.

Patients and carers lack a clear way to track wellbeing, and have little evidence to guide improvements in care. Without this, the true impact of services remains invisible [2]

This project set out to address this challenge by creating a new Quality of Life Tool that captures the full experience of living with lymphoedema and turns patients' voices into meaningful evidence of change.

Methodology

Reviewed 15 published studies and found that no widely used tool exists anywhere in the world to track overall well-being.

Existing approaches focus mainly on limb size or physical symptoms, leaving out emotional and social aspects.

PPIE (Patient And Public Engagement)

- I spoke directly with patients in consultations and support groups, listening to their experiences of living with lymphoedema.
- Their voices shaped the questions and scoring system, ensuring the tool reflects real life.
- Worked alongside the clinical team, sitting in on clinics to learn about lymphoedema care from their perspective. Ensuring the tool fits naturally into their routine.
- Drawing on both patients' stories and clinicians' years of experience meant the tool was designed to work for everyone
- (patients, carers, and healthcare staff)
- I shared scores back with patients, and they confirmed the tool reflected their own experiences, building trust and accuracy.

Result and Impact

The New Tool measures:

Work and service impact
Physical Impact (daily limitations)
Social Life (relationships, activities)
Emotional Well-being (coping, confidence)
Digital tool makes results easy to track/share.

Importance:

Patients and carers now have a way to see progress beyond limb size.
Clinicians gain clearer evidence of how their care improves lives.
The hospice can use results to show impact to funders and commissioners.
Provides a model for services that currently lack any widely used measure.

Future implications

- Trial the tool in other clinical settings, expanding beyond lymphoedema to quantify other qualitative aspects of hospice care.
- Enable more robust evaluations, supporting stronger funding conversations with commissioners.
- Provide hospices with the evidence they need to secure resources and articulate the value of their services.

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