Improving quality of life: Utilising patient perspectives to identify themes for a quality of life tool specific to obstetric fistula

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Introduction

Obstetric fistula (OF) is an injury that develops as a result of obstructed labour during childbirth[1]. Unless an emergency intervention (e.g. caesarean section) is performed, the prolonged pressure of the foetal head on the birthing person's pelvis can cause tissue necrosis, resulting in a hole between the vagina and bladder or rectum. An estimated two million people live with OF globally; another fifty- to one-hundred thousand develop the condition each year[2].

Quality of life (QoL) measures the standard of an individual's wellbeing. It is subjective and influenced by a number of physical and social factors, including disease and presence of social networks[3]. A number of tools exist to measure and quantify QoL. Measurement is particularly important in clinical settings where understanding a condition's impact on QoL can inform treatment. Existing tools range from generic measures of QoL in a scientifically average adult, to condition-specific (e.g., measuring the effect of incontinence on QoL).

A QoL tool specific to OF does not yet exist. Instead, researchers use generic tools to assess overall QoL and supplemental condition-specific tools to measure aspects of a patient's condition. Existing research acknowledges a relationship between OF and adverse QoL, and that QoL in OF patients is affected by a web of complex factors, some physical (e.g., incontinence) and others social (e.g., stigma, isolation).

This study sought to answer two research questions:
1. What aspects of QoL do existing tools prioritise in people living with OF?
2. How can patient perspectives be integrated with existing QoL metrics to create a condition-specific tool?

Study Design

A literature review of studies measuring QoL in OF populations was conducted to answer the first question and inform a semi-structured topic guide for interviews. The primary researcher reviewed studies measuring QoL in individuals with OF, and organised the tools used to identify shared themes. Five themes were identified: *General QoL, Emotional Health, Financial Health, Physical Health, and Social Health.*

The bulk of this research was a mixed-methods study. Descriptive statistics were gathered from a quantitative sample provided by Operation Fistula, a non-profit organisation in Madagascar, and participants interviewed for qualitative analysis. Descriptive statistics were used to contextualise the study population. Qualitative data were collected from semi-structured interviews with OF patients and analysed using content analysis.

Two rounds of coding were performed on interview transcripts for the qualitative analysis. The first round confirmed the relevance of the five themes identified in the literature review. Sub-themes for each were identified, which provided information about how each theme could be made condition-specific.

In the second round of coding, two additional themes were identified: *Sexual and Reproductive Health, and Barriers to Treatment.* These themes were absent from the tools used in existing research, which were analysed in the literature review.

Conceptual Model

Domain	Sub-theme	
General QoL	1)	Overall QoL
	2)	Knowledge of treatment
	3)	Cause of condition
Emotional health	1)	Shame
	2)	Trouble (depression)
	3)	Sadness
Financial health	1)	Money
	2)	Inability to work
	3)	Lack of money as a barrier to treatment
	4)	Return to work as a treatment expectation
Physical health	1)	Symptoms (losing weight, leaking, odour)
	2)	Changing symptoms over time
	3)	Treatment as a cure and return to pre-OF life
Social health	1)	Avoidance
	2)	Discrimination
	3)	Dependency
	4)	Expectation of treatment as end to discrimination
Sexual and reproductive health*	1)	Resumption of menstruation
	2)	Future fertility
Barriers to treatment*	1)	Lack of companion
	2)	Lack of funds
	3)	Lack of transportation
	4)	Previous unsuccessful treatment
	5)	Treatment availability

Results & Discussion

Univariate descriptive analyses indicated that the qualitative sample was a good approximation of the typical OF patient served by Operation Fistula in Madagascar.

Five initial themes were identified from the literature review, and the content analysis identified an additional two themes and seventy sub-themes in the qualitative interview transcripts. The number of new themes and sub-themes identified from the transcripts suggested that existing QoL tools do not capture effects on QoL specific to the disease. This might mean that generic QoL tools being utilised currently do not provide an accurate assessment of QoL in OF patients. A conceptual model that incorporates metrics from existing tools and themes identified from patient interviews would be more appropriate and was proposed.

The resulting conceptual model is a useful next step in the research needed to develop a condition-specific QoL tool for OF. Given that funding for the prevention and treatment of OF is limited relative to other issues of reproductive and maternal health, ensuring efficiency in treatment is key. Understanding how the condition affects an individual's QoL, and whether treatment improves QoL in the long-term, will be crucial to the future of decisions about fistula care.

1. Donnay & Weil, 2004. 2. WHO, 2002. 3. Kelleher, Cardozo, Khullar & Salvatore, 1997.