



Conceptualizing and measuring health-related quality of life in critical care



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ABSTRACT

Introduction: When assessing health-related quality of life (HRQL), critical care outcomes research generally uses generic measures in the absence of a suitable critical care-specific measure. Our aims were to construct a conceptual framework of survivors' HRQL and assess the extent to which the 2 most commonly used generic measures (the Short Form 36 Health Survey and EuroQol-5D) covered the framework.

Methods: A preliminary framework for survivors' HRQL was constructed based on a systematic literature review and on a secondary analysis of 40 existing in-depth interviews with adult, critical care survivors. Its adequacy was then tested using new in-depth interviews with a maximum variation sample of critical care survivors. The extent of coverage of the final framework by the 2 generic HRQL instruments was then evaluated in 2 ways: by comparison with critical care survivors' accounts from the new in-depth interviews and by eliciting survivors' views on the adequacy of the 2 generic HRQL instruments using cognitive debriefing.

Results: The final framework recognized 3 aspects of health status that affected 9 areas of life. The 2 most commonly used generic measures had substantial gaps in their coverage of the framework of survivors' HRQL.

Conclusions: The findings argue strongly for a new critical care-specific HRQL measure.

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1. Introduction

Health-related quality of life (HRQL) is an important end point when evaluating the effectiveness and cost-effectiveness of critical care. However, unlike in many other fields of health care, which use both generic and specific HRQL measures, critical care outcomes research has typically used only generic measures. This reflects a lack of consensus regarding a critical care-specific measure, which is in turn partly due to a lack of understanding of those aspects of quality of life (QoL) most pertinent for critical care survivors. Instead, most studies that encompass HRQL [1–18] use 1 of the 2 generic measures recommended by expert consensus [19]—the Short Form 36 Health Survey (SF-36) [20] and EuroQol-5D (EQ-5D) [21].

The SF-36 contains 36 questions, divided into 11 sections that cover 8 health concepts: physical functioning, role limitations because of physical health problems, bodily pain, general mental health (psychological distress and psychological well-being), role limitations because of emotional problems, social functioning, vitality (energy/fatigue), and

general health perceptions [22]. The EQ-5D consists of a descriptive system and a visual analog scale. The descriptive system covers 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The visual analog scale asks an individual to score his/her overall health.

This study sought to understand the concept of HRQL from the perspective of adult, general critical care survivors and use this knowledge to assess the adequacy of using only generic measures in this population. It aimed to generate a preliminary conceptual framework covering all aspects of HRQL that are of greatest relevance to adult, general critical care survivors; test its comprehensiveness with an independent sample of survivors; and use the final, patient-based framework to assess the extent to which the SF-36 and EQ-5D covered all aspects of concern to survivors.

2. Methods

2.1. Constructing the preliminary framework

Relevant literature was identified via Medline and EMBASE searches using Ovid Gateway using several terms, as follows: intensive care, critical care, outcome measure, follow-up, health status, HRQL, morbidity, recovery experiences, aftercare, qualitative research, interviews, and questionnaires. Snowballing from reference lists of relevant articles was also undertaken, with 72 studies and book chapters included in the final scientific review.

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A review of the gray literature was also conducted using a Google search of the World Wide Web with search terms similar to those used in the searches of the scientific literature. The review covered Web sites on critical illness (www.icusteps.org, www.i-canuk.com, www.ics.ac.uk/icf/patients-and-relatives/, www.ardsusa.org), personal accounts on the Web, and information booklets on critical care.

In addition, secondary analysis of 40 existing, narrative interviews previously conducted in 2005 with a maximum variation sample of critical care survivors [23,24] was undertaken. Relevant HRQL data were extracted (by W.L.) from listening to these interviews and reading the written transcripts, guided by the themes obtained from the literature review.

The literature review and secondary analysis of existing interview data were used to identify 6 domains/dimensions for the preliminary framework: physical, psychological, cognitive, spiritual, social functioning, and activities and role functioning (Table 1).

Table 1
Preliminary conceptual framework for HRQL in critical care survivors

Possible dimensions/domains for HRQL of critical care survivors
<ul style="list-style-type: none"> • Physical <ul style="list-style-type: none"> – Mobility/exercise tolerance (muscle weakness) – Muscle dysfunction in other areas such as swallowing and cough – Fatigue – Numbness/paraesthesia (neuropathy/nerve palsies) – Itching/pruritus – Balance – Pain/stiffness – Communication/speech (long term tracheostomy) – Appetite/nutrition – Sleep – Sexualfunctioning – Specific organ dysfunction such as breathlessness or need for long-term organ support such as dialysis – Cosmetic concerns (alopecia, tracheostomy scars, scars from invasive monitoring, etc) • Psychological <ul style="list-style-type: none"> – Anxiety/panic attacks – Depression – Guilt about putting family through the experience – Anger and conflict within family – Nightmares – Post-traumatic stress (flashbacks, anxiety/panic attacks, traumatic memories of critical care, etc) – Amnesia of events/loss of time causing stress – Moving on, looking into future • Cognitive <ul style="list-style-type: none"> – Memory – Concentration • Spiritual <ul style="list-style-type: none"> – Outlook in life – Support from spirituality/church • Social <ul style="list-style-type: none"> – Relationships with family and friends including any changes in how survivors relate to others and how others relate to survivors – Support from family and friends, medical/nursing/auxiliary staff, work (degree of dependency) – Social integration and whether they feel isolated from their social networks – Living arrangements/residence – Finances • Activities and role functioning <ul style="list-style-type: none"> – Ability to look after themselves <ul style="list-style-type: none"> ▪ Getting around, including getting to the toilet, etc ▪ Washing/showering ▪ Personal grooming ▪ Dressing ▪ Eating and drinking – Ability to run their own lives <ul style="list-style-type: none"> ▪ Shopping ▪ Handling money ▪ Preparing meals ▪ Driving – Work

2.2. Testing the preliminary framework

2.2.1. Interview sample

New, in-depth, face-to-face, largely semistructured qualitative interviews were conducted with a sample of survivors to elicit their views on the important changes that had occurred and/or were still occurring in relation to the impact of their critical illness on their QoL. This method of data collection is consistent with current recommended practice to inform the development of QoL measures [25–28].

To maximize the chances of identifying the full range of features contributing to, or influencing the HRQL of critical care survivors, a maximum variation sample [29] of survivors in terms of age, sex, duration of stay in critical care, and reason for emergency admission were recruited from English National Health Service adult critical care units. For practical reasons (the fieldwork was undertaken by a single researcher), sampling was confined to 2 units—Wythenshawe Hospital, Manchester, and Whiston Hospital, Liverpool—but both have a typical case mix for units in England. Interviews with participants were conducted between December 2007 and May 2009, 6 to 15 months after critical care discharge to allow for sufficient recovery time but without significantly compromising recall of early events. Sampling of participants and data collection continued until no new themes emerged from the data (the point of “data saturation”), and in this study, this occurred after 25 participants had been interviewed.

2.2.2. Structure and format of interviews

Interviews, which lasted 0.5 to 5 hours and were conducted by W.L., were semistructured in the first part. They were based on a topic guide (Appendix A) focusing on the consequences of critical illness that survivors regarded as important for their HRQL. This was followed by a “questerview” [30], a form of cognitive debriefing, in which either the SF-36 ($n = 12$) or the EQ-5D ($n = 13$) was given to the participant to complete. Participants were then questioned about how well they believed the instrument they completed captured their perceptions of their HRQL and any gaps they could identify. Only one measure was given to each survivor to minimize respondent fatigue.

The semistructured interview was administered before the questerview to minimize any influence of completing the generic measure on their views. Interviews were conducted in participants' homes, with them setting its pace and length. Before starting the interviews, considerable time was spent building rapport and putting participants at ease to encourage them to be as open and honest as possible. The interviewer minimized interruptions, steering, or prompting.

2.2.3. Data analysis

All interviews were audiotaped, following participant consent, and transcribed as soon as possible after interview completion. Transcripts were checked and amended where necessary by the interviewer (W.L.).

The transcripts were scrutinized for established and emergent themes (thematic analysis) [31], so that the various factors impacting on survivors' HRQL could be identified. Thematic analysis was also undertaken on the opinions expressed by participants during the questerview component. All interview data were coded systematically using a detailed coding frame that was constructed with help from 2 other qualitative researchers (N.M. and an experienced qualitative researcher who was also a critical care survivor), both of whom had nonclinical backgrounds, unlike W.L. When all the data had been coded using NVivo 8 (QSR International Pty Ltd in Australia), analysis was carried out using an established method in which the issues identified under one code were noted on an “OSOP” (“one sheet of paper”) and then grouped together into broader themes (a process known as “axial coding”) [31]. Once emergent domains of QoL had been extracted from the analysis, they were used to revise the preliminary framework to produce the final framework.

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