**Conceptualising 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 two most commonly used generic measures (the SF-36 and EQ-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 two generic HRQL instruments was then evaluated in two ways: by comparison with critical care survivors’ accounts from the new in-depth interviews; and by eliciting survivors’ views on the adequacy of the two generic HRQL instruments using cognitive debriefing.

*Results*

The final framework recognised three aspects of health status that affected nine areas of life. The two 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.

**Keywords**

Health related quality of life; generic measures; critical care; intensive care; qualitative research; cognitive debriefing.

**Introduction**

Health related quality of life (HRQL) is an important endpoint when evaluating the effectiveness and cost-effectiveness of critical care. However, unlike in many other fields of health care, which employ both generic and specific HRQL measures, critical care outcomes research has typically employed 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 one of the two generic measures recommended by expert consensus (19) - the Short Form 36 Health Survey (SF-36) (20) and EQ-5D (21).

The SF-36 contains 36 questions, divided into 11 sections that cover eight health concepts: physical functioning (PF); role limitations because of physical health problems (RP); bodily pain (BP); general mental health (psychological distress and psychological well-being) (MH); role limitations because of emotional problems (RE); social functioning (SF); vitality (energy/fatigue) (VT); and general health perceptions (GH) (22). The EQ-5D consists of a descriptive system and a visual analogue scale. The descriptive system covers five dimensions: mobility; self-care; usual activities; pain/discomfort; and anxiety/depression. The visual analogue 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 utilise 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.

**Methods**

Constructing the preliminary framework

Relevant literature was identified via Medline and EMBASE searches using Ovid Gateway using several terms: intensive care; critical care; outcome measure; follow-up; health status; health-related quality of life; 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.

A review of the grey 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 websites on critical illness ([www.icusteps.org](http://www.icusteps.org), [www.i-canuk.com](http://www.i-canuk.com), [www.ics.ac.uk/icf/patients-and-relatives/](http://www.ics.ac.uk/icf/patients-and-relatives/), [www.ardsusa.org](http://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 WL) 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 six domains/dimensions for the preliminary framework: physical; psychological; cognitive; spiritual; social functioning; and activities and role functioning (Table 1).

Testing the preliminary framework

*Interview sample*

New, in-depth, face-to-face, largely semi-structured 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 maximise 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 was 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 two 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, 6-15 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.

*Structure and format of interviews*

Interviews, which lasted 0.5-5 hours and were conducted by WL, were semi-structured 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 minimise respondent fatigue.

The semi-structured interview was administered before the ‘questerview to minimise 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 minimised interruptions, steering or prompting.

*Data analysis*

All interviews were audio-taped, following participant consent, and transcribed as soon as possible after interview completion. Transcripts were checked and amended where necessary by the interviewer (WL).

The transcripts were scrutinised 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 two other qualitative researchers (NM and an experienced qualitative researcher who was also a critical care survivor), both of whom had non clinical backgrounds, unlike WL. When all the data had been coded using NVivo 8, 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.

Ethical considerations

Ethics approval for the study was obtained from the Stockport Research Ethics Committee (REC reference number: 07/H1012/55) and the London School of Hygiene and Tropical Medicine Ethics Committee (application number: 5201). Local, NHS research and development governance approval was obtained at the two study sites.

For the small number of participants who disclosed highly specific information, all recordings, field notes and transcripts had no personal identifiers attached to prevent possible identification. Any details that could identify a participant were also removed from quotes used in this paper.

The interviews involved participants recounting topics that could, conceivably, cause marked distress. Measures to deal with such a situation were put in place. The interviewer offered support in the form of empathic listening in the first instance, and checked whether the participant preferred that the interview be terminated and audio recording stopped. If still concerned, then with the participant's permission, WL referred the interviewee back to the critical care unit from which the survivor had been recruited. Both units had existing follow-up clinics to address any issues survivors might have had. In addition, with their permission, the survivor’s general practitioner was also informed.

Content mapping between the generic measures and the conceptual framework for HRQL

The extent to which the generic measures captured all aspects of HRQL encompassed in the final framework was considered. In addition, thematic analysis (31) was undertaken of the opinions that survivors expressed during the ‘questerview’ about the comprehensiveness of the SF-36 and EQ-5D (Appendices). The results from these two approaches were collated to strengthen the analysis of any gaps in the coverage of the two instruments.

**Results**

The results, reported here, are from the 25 new interviews undertaken for this study. Characteristics of the interview participants, including details of their critical illnesses, were self-reported, with their reason for admission and duration of stay (in ICU and in hospital) verified by their clinician (Table 2).

Final conceptual framework

The final conceptual framework, generated after analysing the 25 new interviews, is set out in Figure 1. Colour coding has been used to highlight the domains of survivors’ health status affecting each category. To reflect the way that survivors viewed the impact of critical illness on their lives, the six domains in the preliminary framework needed to be restructured such that the final framework recognised two distinct aspects that the participants highlighted during the interviews conducted for this study: their health status; and the impact of their health status.

*Survivors’ health status*

Survivors’ health status fell into three domains: physical status; emotional/psychological status; and cognitive status. These were interdependent, as changes in one domain often affected the others. These three domains are briefly discussed, with illustrations from interview data (pseudonyms are used in all cases).

*Physical status*

Reflecting the heterogeneity of the critical care population, there was considerable variation in physical status among the participants, with diversity in the kind of physical changes experienced. Examples included sensory problems, tremors, joint contractures, stomas, incontinence, shortness of breath, alopecia, weakness and fatigue:

“I just didn’t have the strength to walk about. And I tired very quickly…I found it difficult in the earlier months when I first come out to lift things. I didn’t have the strength to lift: even a two pint of milk seemed heavy, and I have no grip.”

*Emotional/psychological status*

Several participants experienced considerable emotional/psychological upheaval during the experience of critical illness and recovery. This ranged from positive feelings, like gratitude at being alive, to neutral responses such as altered priorities and expectations, to distressing changes such as depression, anger, frustration, guilt, loneliness, nightmares, intrusive memories and flashbacks, phobias:

”[it] completely changed, ruined my life, absolutely ruined my life. I wouldn’t go out. I had unrealistic fears, such as I wouldn’t go on a bus, I wouldn’t drive the car, I didn’t like the smell of grass; all peculiar things. And nightmares were unbelievable.”

*Cognitive status*

Many participants suffered a cognitive decline which included: disorientation; memory problems such as amnesia, forgetfulness and disruption of procedural memory; problems with attention and concentration; executive dysfunction such as difficulty in completing tasks, multitasking, problem solving and decision making; language issues such as word finding difficulties; decreased visual-spatial awareness/abilities; and mental slowness:

“I struggle at work because I can’t remember things…if I’m going to explain something, the words just aren’t there and people ask me stuff that I used to be able to just recall straightaway and I have to go, “Well, I’m thinking,” if you know what I mean…I forget things that I’ve done or I think I’ve done things that I haven’t done…And it’s the same at home; I’ve locked my car keys in the car five times since I got out of hospital and had to call people out to break into the car. So the memory thing’s hard.”

*Impact of survivors’ health status*

Each domain of health status had an impact on various areas of their lives, which in turn affected their QoL. When delineating impacts, the goal was to be inclusive so every effect is included if at least one participant mentioned it. The extent of the impact varied because each participant perceived a given impact differently.

Some areas were affected by all three health status domains (activities and behaviour; physical zone of comfort and/or activity; interactions and relationships). Other areas were only affected by the domains of emotional and cognitive status (perception of, interpretation of and responses to life; personality) or only by the physical status domain (appearance, clothing; place of residence; finances)

The details of these impacts are presented below, with the relevant illustrations from interview data (pseudonyms are used in all cases).

*Activities and behaviour*

The types of activities and behaviour affected were: posture and mobility; sleep/rest; communication; self-care; social roles; and other activities such as recreational and leisure activities, social activities and sexual activity. One participant was so incapacitated that even holding a pen was a problem:

“Since my admission to intensive care, my walking’s not so good. I am getting stronger but that’s one thing that has been affected and holding a pen. That was affected as well because I was lying still for so long, for five weeks I was unconscious, everything sort of seized up and my doctor explained it like saying all the muscle wastes away so I was very, very weak so it’s taken me quite a long time to build up…”.

Another talked about being ‘dubious about climbing’ (stairs) while someone else commented on being unable to multitask during driving:

“...when I’m in the front of a car, going anywhere, I can’t take in everything around me and process it like I could before, and like street signs, I’ll miss things and cars...really I can’t see myself, you know coordinating everything like the gears and the clutch and being aware of it.”

In contrast, others had to do more of an activity. Some slept or rested more, others did a lot more cleaning due to worry about getting ill again:

“..like washing me hands, I do it three times, even though I know they’re clean. And anti-bacterial, that wash, I’ve got them in every room and I do it constantly when I’m walking round…And like cleaning, everything’s got to be clean because I think I’ll get ill if it’s not clean.”

*Physical zone of comfort and/or activity*

For many participants, their physical zone of comfort and/or activity diminished, with the extent of the restriction varying among participants. It ranged from one participant’s anxiety about her critical illness recurring making her hesitant about going abroad to some participants who were confined to their homes.

Participants’ physical mobility was not always the key determinant of their physical zone of comfort and/or mobility. For example, a participant who was almost wheelchair bound had a greater physical zone than some participants who could walk because she could navigate the steps outside the front door with help and ride a car when the other participants could not.

*Interactions and relationships*

The frequency of relationships and interactions was often affected. One participant, because of leg amputations, had to live in a nursing home after her discharge and she could spend only 30 minutes each day with her spouse and children. Consequently, some participants were left very isolated, which was difficult for some, but others welcomed it, especially in the early stages of their recovery. Conversely, some participants increased their interactions within existing relationships and/or built new relationships, often with the clinical staff providing support for them:

“…I used to get uptight about things, if I hadn’t done something, I mean I always did spend a lot of time with my grandchildren, but if, say, Sally (her daughter) will say, “Do you fancy going somewhere to…?” If I’ve got a mound of washing waiting to be ironed up to the ceiling, I’ll say, “Yeah, okay.” Whereas before I’d say, “Oh, no, I’ve got all these jobs to do.””

Some existing relationships also changed in nature, sometimes with no consistent pattern. First, the attachment a number of participants felt towards others changed. Some felt alienated. For example, one participant could not remember the feelings she had had for her partner and, consequently, she also pushed him away when he tried to be physically more intimate with her. Others drew closer to certain people, usually those who provided emotional/psychological support for them.

Second, many participants shifted their degree of dependence on others. A number became more reliant. For example, several participants needed help with remembering crucial information like when to take their medication and attend their appointments. Some also required reminders for events and occasions like birthdays. In contrast, others became more independent of the people around them:

“And it’s bizarre because I used to need Adeline’s (her daughter) dad, Carl (her ex partner), more than he needed me...I’d have been devastated if we’d split up before this….I feel like I should be sad but I’m not-- about a relationship...he used to say, “Did you miss me?” you know, if he hadn’t been round a couple of-- “No.”, just go, “No.” And he’s so hurt and I say “I’m sorry, I don’t mean to hurt you.” So he said, “So did you miss me?” And I just couldn’t lie ‘cause I’m useless at lying. I used to say, “Well, no, I didn’t because I was busy,” but it wasn’t that.”.

Third, conflict was often more prevalent. One participant talked about being upset with her husband because she was being treated like “one of the children” when before the illness, she “won most of the arguments” and had more say. Others reported that their poor memory meant that they often disagreed with friends and family over facts such as the places they had visited.

Fourth, some participants became more guarded and less honest in their interactions. One participant spoke about having to ‘act differently’, ‘put a brave face on’ and ‘show the world something differently to what you actually are’. Another lied to buy time to do what others expected her to be able to do, rather than admitting that she could not do it:

“I just assumed that the tutor would give us the forms to take away to fill out. She wants it doing on the spot. Oh I can’t do it on the spot. I can’t recall. But I can’t say to her, “I can’t actually recall, you know.” So I said, “I’m really sorry. I’ve got a lunchtime appointment at the doctor’s…I’ll have to email you it tomorrow.” Just all those things to stop yourself looking incompetent and stupid.”

Fifth, a number of participants functioned less effectively. Some were less able to form accurate judgments and opinions:

”…after I’d sat and spoke to someone for a bit, I knew right away whether I liked them or not and I could tell what their nature was like and everything, I don’t do that anymore.”

Moreover, several participants were unable to remember pertinent information about the people they knew while for others, their ability to communicate suffered. They had word-finding problems or they could not follow a conversation because of inadequate concentration:

“Concentration was minimal...I didn’t want people to talk to me because, after a while, a short while, I’d just wander off into my own little world anyway and I wouldn’t really know what they were talking about.”

Lastly, for some participants, their resultant health status adversely affected how they were treated by the people around them. For instance, one participant’s partner exploited her memory issues and blamed her for not giving him relevant messages even when she had done so. She had to resort to writing down what she had said to him to avoid his continual abuse of this gap in her recall.

*Perception of, interpretation of, and responses to life.*

One participant spoke of having a bleak outlook, feelings that further limited him in his daily activities. His more accepting stance towards his limitations, later on in his recovery, helped contribute directly to his sense of well-being which was increased further by activities he started to participate in. Some others commented that not being able to remember their critical illness made it difficult for them to accept that their lives had changed. One participant, who was preparing for an overseas trip at the time she became ill, came round from her critical illness wanting to go on the trip. She could not grasp the fact that she had been ill and expected to carry on with life as usual. Other participants failed to understand the extent of their limitations:

“…I thought I could just come out the hospital and I’d be fine in two or three weeks’ time...I think that’s ‘cause I just didn’t realise how ill I was.”

Furthermore, in a number of cases, participants’ reactions to aspects of daily life changed. One participant was wary of standing pools of water as a result of contracting Legionnaires’ pneumonia. For some, these reactions became generalised and sometimes extremely limiting. For instance, one participant, due to what she knew to be a false belief that nurses had poured water into her mouth while washing her hair in critical care, panicked whenever she tried to visit her hairdresser. In addition, she could not stand physical closeness of any kind and avoided crowded places. Even hugging her children ‘turned her stomach’ and ‘made her skin crawl’.

Besides these more intense emotional/psychological responses, some participants experienced diminished emotions. One participant described herself as being numbed and gave several examples of the things that left her unruffled when they would have bothered her before, from news about benefit cheats to her relationship with her partner not working out.

*Personality*

Participants’ personality was sometimes altered. For example, some participants reported being reclusive when they had been sociable before:

“I was really outgoing; had a very dry sense of humour; got on with everyone. And now I won’t make an effort to, to see the people that I used to see, or, friends.”

Another talked about “being lost and in a shell” because of amnesia about her illness. Lack of information to fill in the gaps left her with no way of making sense of what had happened to her. She found this very difficult to cope with and consequently, it “changed everything”, including her personality:

“I can’t remember and that worries me and scares me…And I just don’t know where to get them answers from…It’s changed me, me personality, it’s changed everything. And that’s why I need closure to all of it, because I need to be able to move on, get rid of these feelings, get some answers.”

*Appearance*

Some physical changes altered one’s appearance, which was sometimes distressing. As one survivor said:

“…there’s been no physical side since this has happened but Tom (her husband) wanted to cuddle and I didn’t, I kept pushing him away all the time. And I said to Susan (her nurse), it’s because I felt that this (meaning the stoma) was horrendous and ugly and she was saying no, you know, just cuddle… And she said, Tom obviously doesn’t think that that’s ugly and horrendous but when it’s on you, I mean I don’t look in the mirror. If I see meself in the mirror, I just think that (stoma) is the most hideous thing I’ve ever seen.”.

Some of these changes were transient whereas others like scars and stomas might be more permanent.

*Clothing*

For some survivors, their physical status had an impact on the clothes they could wear. Many found that the clothes they had worn before their illness were no longer suitable. For example, one of them, because of a large prolapsed stoma, could not wear any of her clothes:

“...for weeks I stayed in pyjamas because it was more comfortable for me but then I wanted to get dressed and I wanted to go out, so we just had to change all my clothes. I’ve got a wardrobe full of clothes upstairs that I just can’t wear…All that has been hard to cope with. I found that really hard with my clothes and everything, I found that hard.”

*Place of residence*

Some participants could not return to their homes if they were without support or had homes that were unsuitable for anyone with any kind of physical limitation. For example, one participant who had had bilateral amputations had to move with her family because the layout of her home was too challenging:

”…it’s an old Victorian terraced so it’s got seven steps going into the house that I can’t get around, up to it, I actually need a lift to go up and Social Services won’t pay for that so they moved us….a goal, for me, is to be able to walk up the steps, not normally, but to be able to manage to be able to do that, then to try and live in my house because it’s my house, you know. I made it the way that I wanted it, but as I say the way the structure of it, it’s not practical….”

*Finances*

Some participants who were unable to go back to work due to their physical limitations spoke about the loss of income and the worry this caused. In some cases, their financial worries were compounded by the loss of a second income as their carers also needed to quit their jobs and/or their outgoings increased.

This was in contrast to participants with emotional/psychological and cognitive limitations; they either went back to work despite their limitations or they did not speak of financial concerns even when they did not return to work:

“…work’s hard. I had to go back after six months ‘cause of financial reasons and I really wasn’t in a state to go back. Um, I struggle at work because, um, I can’t remember things…”

Content mapping between the generic measures and the conceptual framework for HRQL

The extent to which the SF-36 and EQ-5D captured the three health status domains and the nine areas of impact on QoL that survivors reported in the interviews is summarised in Table 3.

*Content mapping between the SF-36 and the conceptual framework for HRQL*

*Domains of health status*

Physical status and emotional/psychological status were, at least, partially captured by the SF-36. In comparison, cognitive status was poorly covered, if at all.

Physical status was addressed by Sections 1, 7, 9 and 11. Sections 1 and 11 (general health perceptions) tended to capture physical status consistently, because all study participants appeared to consider physical status part of the term ‘health’. Sections 7 and 9 (bodily pain; vitality and mental health) covered pain and (physical) fatigue, which were important to at least some survivors. Section 9 was especially relevant because fatigue was common among participants and could be very pronounced and long lasting.

Where emotional/psychological status was concerned, Section 9 (vitality and mental health) covered anxiety, depression and (mental) fatigue, all of which were prominent experiences for many participants. In addition, in survivors whose interpretation of ‘health’ included their emotional/psychological status, Sections 1 and 11 also provided an overview. However, the questionnaire did not specifically ask about several significant emotional/psychological changes reported by many participants, such as nightmares and intrusive memories. This, together with the fact that Sections 1 and 11 inconsistently provided an overview of individual survivors’ emotional/psychological status, meant that the SF-36’s coverage of survivors’ emotional/psychological status was likely to be incomplete.

With respect to capturing cognitive status, the SF-36 did not have any specific questions on memory, concentration, language or the ability to carry out complex mental tasks such as problem solving – problem areas frequently spoken about by several of the participants. In addition, although Sections 1 and 11 (general health perceptions) may capture cognitive status in survivors who included this in their interpretation of the term ‘health’, this was not the case for all survivors.

The poor coverage of cognitive status was evident to some participants who identified this as a gap during the ‘questerview’. One commented,”…concentrating for me has been a problem. And they (the questions in the SF-36) didn’t ask about concentrating.” Three other participants also noted that cognitive changes were not captured in the SF-36.

*Areas of impact of health status*

Most areas were not well captured by the SF-36. It managed to capture some of the mutual effects that aspects of survivors’ health status exert on one another. Physical consequences were most consistently captured, emotional/psychological consequences less so and cognitive consequences, the least.

In addition, Sections 3, 4, 5, 6, 8 and 10 (physical functioning; role-physical; role-emotional; social functioning; and bodily pain) covered the effects of survivors’ physical and emotional/psychological statuses on their activities and behavior, albeit incompletely. These sections, however, did not ask about all the activities and behaviour listed by participants as being affected. For instance, some participants were so weak, when they were first discharged, that gripping a pen or opening a plastic food container was a struggle but such activities were not covered. Other poorly covered categories of activities and behaviour were using transport, sleep/rest, communication with others and sexual activity. Moreover, these sections only asked about restrictions in activities and behaviour whereas some participants indicated that increases in certain activities and behaviour could occur. For example, many participants slept a lot more due to fatigue and one participant became obsessed with cleaning herself and her surroundings because of her worries about falling ill again.

Besides such gaps, the SF-36 lacked questions specifically aimed at capturing the effects of survivors’ cognitive status. There were also no direct questions on the effects of survivors’ health status in terms of: perception of, interpretation of, and responses to life; personality; appearance; physical zone of comfort and/or activity; clothing; interactions and relationships; place of residence; or finances.

*Content mapping between the EQ-5D and the conceptual framework*

*Domains of health status*

Like the SF-36, the EQ-5D directly captured both physical and emotional/psychological statuses to some extent but not cognitive status.

Physical status was captured, at least to an extent, by Question 4. It asked about pain/discomfort, which was of relevance to some survivors. In addition, the visual analogue scale asking survivors to rate their own health seemed to consistently provide an overview of survivors’ physical status, as participants tended to interpret ‘health state’ as referring to their physical status.

Emotional/psychological status was partially addressed by Question 5 (anxiety/depression). Further, an overview of emotional/psychological status may have been reflected in the visual analogue scale (health state rating) for those survivors whose interpretation of the term ‘health state’ included their emotional/psychological status. However, the EQ-5D did not explicitly ask about any changes other than anxiety and depression.

In terms of cognitive status, none of the questions in the EQ-5D specifically addressed cognitive function. Moreover, the visual analogue scale (health state rating) would only capture survivors’ cognitive status if they interpreted ‘health state’ as including this domain.

The gaps in the EQ-5D’s coverage were corroborated by the ‘questerview’ data. One participant highlighted lack of libido as an important issue that was not addressed:

“…the only question on mental issues are anxiety and depression, it could be expanded a little bit really…There’s nothing wrong with the questions that are being asked, I just think that there should be more…Emotions change and you know, loss of libido, that can be a massive issue…I’ve got no libido, you know, and it’s like you know your sex life is over and you’re not even 50…”.

He also listed low self-confidence as another important emotional/psychological issue to assess. With respect to the lack of direct cognitive assessment, three participants affirmed this and elaborated on how the EQ-5D did not adequately capture their cognitive status.

*Areas of impact of health status*

Questions 4 (pain/discomfort), 5 (anxiety/depression) and visual analogue scale (health state rating) of the EQ-5D consistently covered some of the effects that physical status, emotional/psychological status and cognitive status exert on one another. Physical consequences were best captured, followed by emotional/psychological and then cognitive consequences.

In addition, the impact of survivors’ physical status on activities and behaviour tended to be consistently covered by Questions 1-3 (mobility; self-care; and usual activities). This was because physical status was generally interpreted by participants as part of their ‘health state’. Nonetheless, the assessed activities and behaviour did not include all those activities and behaviour identified by survivors as being affected by their physical status. Participants spoke about many more activities under the headings of ‘mobility’ and ‘self-care’ than just ‘walking’ and ‘washing and dressing’, respectively. One participant highlighted this by asserting that transfer activities (such as moving from bed to chair) should be evaluated:

”…I know that they obviously have to be short but I mean it could be extended in this…like mobility, yes I’ve got no problems walking about but then, transferring, how do you do…”.

In addition, although ‘usual activities’ were so broadly defined that they could contain all activities that could not be readily classified under ‘mobility’ and ‘self-care’, participants did not interpret it that way. Two of them listed the absence of evaluation of sleep/rest, communication with others and sexual activity as omissions in the questionnaire. Ultimately, the exact (groups of) activities and behaviour not captured depended on how survivors interpreted the term ‘usual activities’, which differed from participant to participant. Furthermore, the questionnaire only assessed limitations in activities and behaviour resulting from survivors’ physical status when there could be increases in certain activities and behaviour among survivors.

Other than not addressing all possible effects within the sub-domains it consistently captured, the EQ-5D also did not always capture the impact of emotional/psychological status and cognitive status on activities and behaviour, as some survivors did not interpret these aspects of health status as part of their ‘health state’. Moreover, even when it did capture these sub-domains, it still failed to fully cover them, for the same reasons that the EQ-5D did not completely capture the effects of physical status on activities and behaviour. Finally, the EQ-5D did not address the effects of survivors’ health status on their: perception of, interpretation of, and responses to life; personality; appearance; physical zone of comfort and/or activity; clothing; interactions and relationships; place of residence; or finances.

**Discussion**Main findings

This is the first study to have systematically sought the views of survivors of adult, general critical care and used their views of HRQL to construct a conceptual framework. Such an exercise is complex because, while survivors of critical illness share the common experience of coming extremely close to death as they survive a life-threatening illness, they can differ from one another in many ways. Some of these differences include: health status before their illness; the specific event or disease triggering the illness; their reactions to the illness and; their capacity to recover. Moreover, an episode of critical illness was clearly life-changing for most of the study participants; many of whom had a lot to say about the changes that had occurred/were occurring in their lives after their illness. This is reflected in the fact that the interview time for the 25 participants totaled close to 40 hours, with one participant talking for five hours (combined - on two separate occasions).

Therefore, it is an analytical and presentational challenge to accurately represent the viewpoint of these survivors (a diverse group of individuals who have been through a similar experience) without the representation getting overly unwieldy. As HRQL is a patient-centred outcome and survivors are unable to make a clear distinction between disease-specific processes and those related to having being in critical care, the study findings mirror this phenomenon. However, during the analysis, to ensure that the representation did not become overly complex, the data were scrutinised to look for broader themes that would encompass the more specific issues. For instance, while a stoma was not present in every survivor, the clothing issues it caused was seen in a number of other survivors, albeit for other reasons such as profound weight loss which was not uncommon among survivors.

After constructing the framework, we used it to demonstrate that the current generic HRQL measures recommended by experts for use with these patients (19) have substantial gaps in their coverage of important aspects of HRQL in this population (details of the gaps are summarised in Table 3). Both measures fail to capture survivors’ emotional/psychological and cognitive statuses completely. In addition, both measures only evaluate a small part of the impact of survivors’ health status on their lives. Besides some of the mutual effects exerted by various aspects of survivors’ health status on one another, and some of the effects in relation to activities and behaviours, the rest of the consequences incurred by survivors’ health status were either inconsistently captured or not captured at all. Many of these consequences, such as the changes in appearance, the problems with clothing and the changes in survivors’ place of residence, were of significant importance to study participants, and thus, they need to be covered by the measures used if survivors’ HRQL was to be accurately captured. Such gaps are not surprising and are in keeping with the findings of similar work in other fields of healthcare that investigated the use of generic measures in specific conditions (32).

Relationships to published studies

There have been several studies that focus on the health consequences that befall particular subsets of survivors (33-35) and on specific consequences of critical illness (16, 36-52), but most of these and other studies (53-67) reporting on the impact of surviving critical illness on HRQL have not been based on what constitutes HRQL from the perspective of the survivors themselves.

While there have been two studies that attempted to obtain survivors’ perspectives on the important influences on their HRQL through qualitative interviews (68, 69), neither study reported survivors’ views in great depth. Both studies highlighted, in broad terms, the changes that occurred in survivors, including the impact that these changes had had on their lives, but provided scant details. For example, when Hall-Smith et al. described survivors’ physical status after critical illness, only weakness and fatigue were mentioned specifically (69). All other physical changes were classified under ‘ongoing physical problems related to critical illness’ with no further elaboration (69). Moreover, both studies used convenience, rather than true purposive sampling and provided no indication as to whether data saturation was reached. Therefore, there is no way of ascertaining whether everything that would have affected survivors’ HRQL was identified. Also, in the study conducted by Brooks (68), there was a strong possibility that survivors’ views had been influenced by a draft HRQL questionnaire that was administered to them before their interview. As this questionnaire had been developed top-down from a literature review and professional opinion, it was unclear how much of the subsequent qualitative interview data truly represented survivors’ own views.

In terms of research investigating (some of) the psychometric properties of the SF-36 and EQ-5D in the critical care population, the experts (in critical care) who have recommended these measures by consensus have acknowledged that the evidence supporting this consensus was limited and recognised the need for further research (19).

Strengths and limitations

This is the first study, that we are aware of, to conceptualise HRQL from the viewpoint of critical care survivors and use the resultant conceptual framework to assess the extent to which generic measures commonly used in this population capture their HRQL. To help increase the robustness of the findings, purposive maximum variation sampling, interviewing until the point of ‘data saturation’, minimal prompting and steering, strategies to encourage open and in-depth sharing of participants’ perspectives, and triangulation of methods between semi-structured interviews and ‘questerviews’ were all used.

The study had one limitation. Participants were limited to white British people admitted as emergencies (no survivors from minority ethnic groups could be successfully recruited at the two centres used for the study - in the time available), so the findings may not be generalisable to other types of adult, general critical care patients. However, the secondary analysis of previous interviews that was used to develop the preliminary conceptual framework did include some survivors of other ethnic groups, such as British African and British Caribbean, so these findings may extend to ethnic groups other than just the white British population.

**Conclusions**

The study increases our understanding of how critical care survivors view their HRQL. It also demonstrates that the two generic HRQL measures most commonly used in research with adult, general critical care survivors have a number of significant gaps in their coverage. Therefore, there is a strong case for the development of a critical care-specific HRQL instrument (possibly to be used in conjunction with an existing generic measure if comparison with HRQL in other areas of health care is required) to better capture survivors’ HRQL. A new instrument needs to cover survivors’ emotional and cognitive statuses (alongside their physical status) and to consider the effects of survivors’ health status on their: perception of, interpretation of, and responses to life; personality; appearance; physical zone of comfort and/or activity; clothing; interactions and relationships; place of residence; and finances. This would ensure that we do not underestimate the burden of disability borne by these survivors, such that more comprehensive assistance could be offered to them.

**Key messages**

* The patient-based conceptual framework has two distinct aspects: survivors’ health status; and the impact of their health status on QoL. Health status has three domains: physical; emotional/psychological; and cognitive. Each domain has an impact of various areas of survivors’ lives and the impacts can be collated into nine categories: activities and behaviour; physical zone of comfort and/or activity; interactions and relationships; perception of, interpretation of, and responses to life; personality; appearance; clothing; place of residence; and finances.
* The two generic HRQL measures recommended for use with survivors of adult, general critical care – the SF-36 and EQ-5D - have substantial gaps in their coverage of the areas identified as of importance to patients, especially in relation to cognitive status and its subsequent impact.
* A critical care-specific HRQL measure is needed that covers all the areas of relevance to survivors.

**Abbreviations**

HRQL, Health related quality of life  
QoL, Quality of life

**Competing interests**

The authors declare that they have no competing interests.

**Authors’ contributions**

All authors were involved in the conception and design of this study. WL interviewed the participants and analysed the data with help from NM. WL drafted the paper initially; NB, KR and NM helped with redrafting.

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**Appendix A**

**Interview Guide**

*Administration: Face-to face in a private place of the participant’s choosing (most likely to be their home)*

*(Obtain written informed consent from participant just before formally starting the interview. This includes going through the information sheet with the participant and giving them the opportunity to ask questions)*

**Introduction**

We have just gone through the purpose of the study as well as what will be involved in this interview.

Do you have any more questions about what we are about to do before we start?

Please remember that you are free to take a break at any point during this interview, just let me know when you need to take a break. Also, if there is a particular question you do not wish to answer, let me know.

Are you happy to start?

(*Notify the participant that the tape has been switched on and is recording)*

**Topic Guide**

1. How are you feeling today?

*Cover the activities which have been affected including participant’s ability to look after themselves and run their lives[[1]](#footnote-1)1*

*Cover aspects of life affected by admission to critical care[[2]](#footnote-2)2*

1. Can you tell me a bit more about your health before the admission to critical care?

*Cover information about chronic health conditions and previous limitations*

1. Before moving on to asking you to fill in the questionnaire, I would like to collect some personal information about you, is that alright with you?

*Cover the following details:*  *age, marital status, number of children, housing (including details of who is living in the same household), employment, reason for admission to critical care, length of stay in critical care, length of hospital stay and length of time since hospital discharge.*

I would like to ask you to fill in a questionnaire at this point. This questionnaire is used very frequently to measure the health and quality of life of critical care survivors. I am very interested to know what you think of the questionnaire. Do you want to take a break or do you want to continue? If you feel that you are getting tired, we can either take a break or I can come back another day.

Please answer all the questions in this questionnaire. If you have problems answering any of the questions, please make a note beside them. After you have completed the questionnaire, we will discuss these problems. I would also like to hear your thoughts and views of the questionnaire.

Do you have any questions for me before we start?

**Questions for “questerview[[3]](#footnote-3)3” component of interview**

1. Are there any questions you find difficult to answer? Why?

*Cover how participants produce their answers, with particular emphasis on retrieval from memory and subsequent judgements and decisions about response categories.*

1. What do you think about this questionnaire? Do you think that it accurately reflects how you think about your health and quality of life?

*Cover the dimensions which constitute their HRQoL.*

*Cover how participants quantify the different dimensions of their HRQoL.*

1. Does the questionnaire cover everything which is important and relevant to you?

*Cover any dimensions which are relevant to participants but are not covered in the questionnaire.*

Thank you very much for taking the time to participate in this interview.

Do you have any further questions for me?

*(Notify participant that the tape recording has now been switched off and is no longer recording. Explain to participant that the tape recording will be transcribed to provide a written record for analysis. Inform participant that the study is likely to be completed by late 2009 and that the results are available upon request from the contact listed on the information sheet)*

**Appendix B**

**Table A: Abbreviated Questions from the SF-36**

|  |  |
| --- | --- |
| **Question** | **Abbreviated Content** |
| 1 | Is your health: excellent, very good, good, fair, poor |
| 2 | How health is now compared to 1 year ago |
| 3a  3b  3c  3d  3e  3f  3g  3h  3i  3j | Vigorous activities, such as running, lifting heavy objects or participating in strenuous sports  Moderate activities, such as moving a table, pushing a vacuum, bowling or playing golf  Lifting or carrying groceries  Climbing several flights of stairs  Climbing one flight of stairs  Bending, kneeling, or stooping  Walking more than a mile  Walking several hundred yards  Walking one hundred yards  Bathing or dressing oneself |
| 4a  4b  4c  4d | Cut down the amount of time spent on work or other activities because of physical health  Accomplished less than you would like because of physical health  Limited in kind of work or other activities because of physical health  Had difficulty performing work or other activities (e.g. it took extra effort) because of physical health |
| 5a  5b  5c | Cut down amount of time spend on work or other activities because of emotional problems  Accomplished less than you would like because of emotional problems  Did work or other activities less carefully than usual because of emotional problems |
| 6 | Extent health problems interfered with normal social activities |
| 7 | Intensity of bodily pain |
| 8 | Extent pain interfered with normal work |
| 9a  9b  9c  9d  9e  9f  9g  9h  9i | Feel full of life  Been very nervous  Felt so down in the dumps that nothing could cheer you up  Felt calm and peaceful  Have a lot of energy  Felt downhearted and depressed  Feel worn out  Been happy  Feel tired |
| 10 | Frequency health problems interfered with social activities |
| 11a  11b  11c  11d | Seem to get sick a little easier than other people  As healthy as anybody I know  Expect my health to get worse  Health is excellent |

Adapted with permission fromWare, J.E, Jr., Kosinski, M., Bjorner, J.B., Turner-Bowker, D.M., Gandek, B., & Maruish, M.E. (2007). *User’s Manual for the SF- 36v2® Health Survey* (2nd ed.).Lincoln, RI: QualityMetric Incorporated. Optum’s Table *Abbreviated Item Content for the SF-36v2® Health Survey Health Domain Scale*, Table 2.1, page 15.

(For the complete version of the SF-36v2 Health Survey, please refer to <http://www.qualitymetric.com/demos/TP_Launch.aspx?SID=100>.)

**Appendix C**

# Health Questionnaire

# *English version for the UK*

# *(validated for Ireland)*

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**

I have no problems in walking about ❑

I have some problems in walking about ❑

I am confined to bed ❑

**Self-Care**

I have no problems with self-care ❑

I have some problems washing or dressing myself ❑

I am unable to wash or dress myself ❑

**Usual Activities** (*e.g. work, study, housework, family or*

*leisure activities)*

I have no problems with performing my usual activities ❑

I have some problems with performing my usual activities ❑

I am unable to perform my usual activities ❑

**Pain/Discomfort**

I have no pain or discomfort ❑

I have moderate pain or discomfort ❑

I have extreme pain or discomfort ❑

**Anxiety/Depression**

I am not anxious or depressed ❑

I am moderately anxious or depressed ❑

I am extremely anxious or depressed ❑

9 0

8 0

7 0

6 0

5 0

4 0

3 0

2 0

1 0

100

Worst

imaginable

health state

0

Best

imaginable

health state

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own**

**health state**

**today**

1. 1 Activities which may have been affected are listed on Page 1 of the appendix. [↑](#footnote-ref-1)
2. 2 The possible dimensions participants may bring up are listed in Page 2 of the appendix. [↑](#footnote-ref-2)
3. 3 A form of cognitive debriefing in which a HRQoL measure currently recommended for this patient group (that is either the SF-36 or the EQ-5D) will serve as a focus point to trigger narratives and generate data relating to individuals’ perceptions and definitions of HRQoL and its measurement, as well as providing insight into how well each measure ‘works’ with this patient group. [↑](#footnote-ref-3)