

Commentary

Conceptual issues specifically related to health-related quality of life in critically ill patients

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Abstract

During recent years increasing attention has been given to the quality of survival in critical care. Health-related quality of life (HRQOL) is an important issue both for patients and their families. Furthermore, admission to the intensive care unit can have adverse psychological effects in critically ill patients. Recent studies conducted in critically ill patients have measured HRQOL. However, usually absent from such reports are evaluations of conceptual issues, addressing factors such as why HRQOL should be measured in critically ill patients, how to define and standardize domains of HRQOL, whether proxies can provide useful information about HRQOL in critically ill patients, whether response shift occurs in critically ill patients, and whether post-traumatic stress disorder (PTSD) occurs in critically ill patients. Some studies reported moderate agreement between patients and their proxies, although lower levels of agreement may be reported for psychosocial or physical functioning. Response shift (adaptation and change in perception) appears to be an important phenomenon and likely to be present, but it is seldom measured when estimating HRQOL in critically ill patients. Furthermore, vigilance for symptoms of PTSD and early interventions to prevent PTSD are needed.

Introduction

Traditionally, assessment of critical care has focused largely on survival. However, during recent years attention has increasingly been paid to the quality of that survival - an important issue for patients and their families [1]. Patients recovering from critical illness may exhibit impaired functional status, with associated reduced health-related quality of life (HRQOL). Recent studies conducted in critically ill patients have measured HRQOL, but an evaluation of conceptual issues is usually missing from such reports [2]. Here we discuss specifically these conceptual issues.

Why measure health-related quality of life in critically ill patients?

Development of intensive care unit (ICU) technology has grown rapidly during the past few years, enabling ICU staff to sustain and restore the lives of critically ill patients who otherwise would have died. In the past, survival alone was enough to justify any intervention, but the current climate of budgetary constraint and the high costs of many interventions have made ICU staff increasingly aware of the importance of HRQOL measurement [3]. An important issue is how ICU patients feel and function. This information seems essential for making decisions at the bedside, but it is also important in the evaluation of the efficacy and efficiency of ICU interventions [4]. HRQOL investigation in critically ill patients can help to address these issues of long-term prognosis [4].

Definition and domains of health-related quality of life in critically ill patients

In HRQOL studies in general, as well as those specifically in critically ill patients, there is a lack of a clear framework for defining and describing HRQOL. Measuring HRQOL is in essence evaluating the health status of individuals, both mental and physical, together with their own sense of well being [5]. The World Health Organization defines health not only as the absence of infirmity and disease, but also as a state of physical, mental and social well being [6]. By using this definition we can define HRQOL.

Can proxies provide useful information on HRQOL in critically ill patients?

It is rarely possible to assess the effects of critical illness or ICU treatment on HRQOL because the patient's condition on admission prohibits completion of a questionnaire. A close

HRQOL = health-related quality of life; ICU = intensive care unit; PTSD = post-traumatic stress disorder.

relative is often also asked to act as a decision maker and to represent the patient when considering the various therapeutic options [7]. Completing a HRQOL questionnaire on behalf of someone else requires the proxy to put himself or herself in another person's shoes, to imagine what it feels like to be the patient. The literature concerning agreement between patients and their relatives in terms of HRQOL assessment before ICU admission is not very conclusive. We and others have validated the use of proxies and found good agreement between proxy and patient [8]. The use of proxies appears sensible, because the critical illness itself may influence the patient's recollection of their pre-admission health status. However, concerns have been raised about proxy estimations of HRQOL in populations with greater disease severity [7]. Scales and coworkers [7] suggested that predictions of poor ICU outcome may be exaggerated if proxies underestimate HRQOL. However, in contrast to the above-mentioned studies, those investigators interviewed patients 3 months after ICU discharge and their proxies at study entry. The analysis shows that it is entirely possible for survivors of critical illness to overestimate their pre-admission HRQOL. Nevertheless, although relatives may not be fully able to express the patients' perception of well being, their estimation of functional ability may sometimes be the only way to determine baseline HRQOL.

Response shift in critically ill patients

Patients become accustomed to their illness. An important mechanism in this adaptive process is termed 'response shift'. Response shift is the change in internal standards of values and conceptualization, and consequently in perception of HRQOL [9]. This could either be because patients become accustomed to their illness or chronic disease, or because their expectations about their HRQOL have changed. Several studies have suggested that patients make significant response shifts during treatment, such as patients with cancer [10] and those receiving pancreas-kidney transplants [11]. To our knowledge, no studies have been performed to investigate response shift in critically ill patients. The important issue is whether we can measure response shift in critically ill patients. Response shift is important not only in longitudinal observations of HRQOL but also in medical decision making. To measure response shift, some investigators used the then-test. The then-test is a technique that aims to measure change in reference values by comparison of a retrospective baseline measurement with a conventional baseline measurement [10]. In the then-test, which is conducted at follow up, patients are asked to provide a renewed judgement about their HRQOL at the time of the conventional baseline measurement. If the then-test is completed with a concurrent follow-up measurement, it is assumed that the same reference value is used for both assessments. Comparing the then-test with a follow-up measurement has been proposed to be a method for assessing change in HRQOL over time, which is not confounded by change in reference values [10].

Post-traumatic stress disorder in critically ill patients

Memory of traumatic experiences may lead to the development of psychological problems, such as post-traumatic stress disorder (PTSD), which can be triggered by traumatic events (such as critical illness) and may last for years after the event. Characteristic symptoms include re-experiencing the events through nightmares or flashbacks, avoidance of the stimuli associated with the event and hyperarousal symptoms [12]. Cuthbertson and coworkers [13] found not only a high incidence of PTSD symptoms in general critical care patients 3 months after discharge, but also that the presence of these symptoms correlated with younger age and longer time on the ventilator. The authors highlighted a way to identify patients with symptoms of PTSD and raised the possibility of scoring patients at risk before discharging them home, assessing their recovery environment and ensuring that patients are assessed at the critical care follow-up clinic. Schelling and colleagues [14] found that PTSD occurred more frequently in acute lung injury survivors than in hospital control individuals and United Nations soldiers. Post-traumatic stress was associated with impaired HRQOL and was highly correlated with patients' recollections of traumatic events in the ICU. However, a study conducted by Jones and coworkers [15] revealed that, although delusional memories of ICU were associated with symptoms of PTSD, factual memories appeared to be protective. This study suggests that factual memories may allow ICU survivors to reject delusional memories, which are thereby diminished, sparing the patient from PTSD symptoms.

Conclusions

Knowledge of conceptual issues pertaining to HRQOL measurement in critically ill patients appears to be essential for measuring the long-term impact of critical illness and intensive care treatment.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

JGMH interpreted the data and drafted the article. HFvS conceived of the study, contributed to the interpretation of the data and revised the manuscript for important intellectual content. AJPS contributed to the interpretation of the data and revised the manuscript for important intellectual content. JHR conceived of the study, contributed to its design and the interpretation of the data, and revised the manuscript for important intellectual content. JB contributed to the design and the interpretation of the data, and revised the manuscript for important intellectual content. PES conceived of the study, contributed to the interpretation of the data, and revised the manuscript for important intellectual content. All authors contributed substantially to the manuscript, and all authors approved the final version submitted for publication.

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