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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
relative is often also asked to act as a decision maker and to
represent the patient when considering the various therapeu-
tic 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 HROQL
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 HROQL in populations with greater
disease severity [7]. Scales and coworkers [7] suggested
that predictions of poor ICU outcome may be exaggerated if
proxies underestimate HROQL. 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
HROQL. 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 HROQL.

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 de-
perception of HROQL [9]. This could either be because
patients become accustomed to their illness or chronic
disease, or because their expectations about their HROQL
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 HROQL 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 HROQL 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 HROQL 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 develop-
ment 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 HROQL 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 HROQL
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 intellec-
tual content. AIPS 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
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to the design and the interpretation of the data, and revised
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conceived of the study, contributed to the interpretation of
the data, and revised the manuscript for important
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