

COMMENTARY

Talking to multi-morbid patients about critical illness: an evolving conversation

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Abstract

Conversations around critical illness outcomes and benefits from intensive care unit (ICU) treatment have begun to shift away from binary discussions on living versus dying. Increasingly, the reality of survival with functional impairment versus survival with a late death is being recognised as relevant to patients. Most ICU admissions are associated with new functional and cognitive disabilities that are significant and long lasting. When discussing outcomes, clinicians rightly focus on patients' wishes and the quality of life (QoL) that they would find acceptable. However, patients' views may encompass differing views on acceptable QoL post-critical illness, not necessarily reflected in standard conversations. Maintaining independence is a greater priority to patients than simple survival. QoL post-critical illness determines judgments on the benefits of ICU support but translating this into clinical practice risks potential conflation of health outcomes and QoL. This article discusses the concept of response shift and the implication for trade-offs between number/length of invasive treatments and change in physical function or death. Conversations need to delineate how health outcomes (e.g. tracheostomy, muscle wasting, etc.) may affect individual outcomes most relevant to the patient and hence impact overall QoL. The research strategy taken to explore decision-making for critically ill patients might benefit from gathering qualitative data, as a complement to quantitative data. Patients, families and doctors are motivated by far wider considerations, and a consultation process should relate to more than the simple likelihood of mortality in a shared decision-making context.

Keywords: conversations, critical illness, decision-making, multi-morbidity, older people, survivorship

Key Points

- Multi-morbid patients are at risk of developing chronic critical illness and ICU admission worsens outcomes.
- Greater relevance of survivorship rather than survival conversations. Quality of life post-critical illness determines judgements on the benefits of ICU support for individual patients.
- Most ICU admissions lead to new functional/cognitive disabilities that are significant and long lasting.
- Data on quality of life with or without ICU admission as a basis for shared decision-making

Death comes to us all; we can only choose how to face it when it comes
—Robert Jordan.

Death has historically been a central part of discussions on critical illness, often in a binary fashion of live/die. We report death as a matter of quality assurance using a standardised mortality ratio (observed/expected mortality accounting for

patient characteristics); we measure death as a primary outcome in our randomised controlled trials and talk about death when we discuss risks of treatment and admission to intensive care units (ICU). Yet in-hospital mortality post-critical illness has fallen considerably in the last decade, with 70% of patients surviving to hospital discharge [1]. Twenty-first century critical care has instead two different outcomes

that require conversations: survival with functional impairment and survival with a late death. The majority of critically ill patients with multi-organ failure lose 2–3% of muscle mass per day and suffer from new cognitive impairments, resulting in significant, long-lasting physical disability affecting their ability to return home or to working lives [2–4]. Talking about outcomes is a two-way conversation, and clinicians need to be willing to calibrate their own opinions on outcomes, before initiating a conversation. The vast majority of clinicians focus on our patients' wishes and the quality of life (QoL) that our patients would find acceptable. However, these views and opinions of patients and their families are increasingly more heterogeneous and therefore influence decision-making on acceptable QoL post-critical illness. One group in particular, those patients with multi-morbidity, are increasingly the focus of such discussions. This article sets out the case that these patients may have a different view on acceptable QoL post-critical illness, which is not necessarily captured in standard conversations.

Outcomes of multi-morbid patients who are critically ill—the view from intensive care

Patients with multi-morbidity who survive critical illness have higher mortality, more time spent in secondary care, reduced health-related QoL and are less likely to return to their own homes [5–8]. Multi-morbidity is likely to be one of the greatest modifiers of functional outcomes in critically ill patients, historically confounding interventional trial results, more so than numerical age [9]. This is likely to a combination of low baseline muscle mass, preceding malnutrition and limited exercise capacity and many of the factors that encompass the clinical frailty syndrome. It is important to recognise that the two states overlap incompletely—not all multi-morbid patients are frail and not all frail patients are multi-morbid [10]. Patients with multi-morbidity are at risk of developing persistent or chronic critical illness, where pre-existing conditions are more predictive of mortality than acute diagnoses, with persistent catabolism a universal feature [11, 12]. These patients have significantly increased in-hospital and early (<6 months) mortality and are unlikely to be discharged home [7]. Frail patients equally have poorer functional outcomes than non-frail patients who suffer a critical illness [13].

Surveys of healthy people reveal that for many, loss of independence, being a burden to family or being admitted to a care facility are considered worse than death [14–16]. The James Lind Alliance lists maintaining independent living as one of the top 10 priorities for patients with multi-morbidity [17].

Leading on from this, an increasingly central precept of modern intensive care is that survival conversations are likely less relevant than survivorship conversations [18]. The QoL that can be achieved post-critical illness is recognised as a major determinant of the assessment of patient benefit

from intensive care support determined on an individual basis [19]. A position statement from the World Health Organisation 'Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity' further informs this view. However the translation of these observations into clinical practice is not straightforward, with potential conflation of health outcome data with QoL.

The response shift phenomena: implications for surrogate decision-making in acute illness

These views do not take into account the phenomena of response shift. This is a change in an individual's values regarding their health, in the way they perceive severity of disability (or their definition of an unacceptable level of health) and/or underestimation of adaptation (i.e. the degree to which a person learns to adjust to a new level of disability and maintain subjective QoL) [20, 21]. Patients with pre-existing stable chronic disease have potentially differing perceptions regarding fates worse than death, focusing less on independence and nursing home admission, but more on physical control of their bodies [22]. While good practice mandates decision-making partnership with patients regarding their own health and wishes, this is not often practical in the context of critical illness. Patients, in the main, present *in extremis* and are not in a position to participate or contribute to this conversation. Decision-making is therefore devolved to the treating intensive care consultant, acting in the best interest of the patient. This decision is informed by conversations with the referring consultant and family members, the latter of whom are often distressed. In this setting clarity of thought may not be easily achieved, and the onus lies on the medical professionals to ask questions related to outcomes of relevance to the patient appropriately. These conversations suffer from being ill informed by health outcome data, which are often conflated with QoL.

Conflation of health outcome data with health status (e.g. QoL)

In health economics health outcomes are differentiated from health status, where the former refers to objective measurable outcomes (e.g. survival rate post-surgery) and the latter refers to the quality of the outcome, which can indexed through subjective and objective measures of experiential health (e.g. QoL) [23, 24]. What we can draw from the findings reviewed here is that those with multi-morbidities have worse outcomes following admission to the ICU, than if they were not admitted to ICU. This implies that their health outcomes and health status (e.g. QoL) are potentially worse if they received the interventions associated with said admission. It is important to highlight that the focus of

conversation between doctor and patient is likely to be embedded within the following trade-off between

- a) Treatment in intensive care, which involved a number of invasive procedures, with the most likely outcomes being either prolonged treatment followed by subsequent significant decrease in physical function and independence, or death.
- b) Treatment with limited invasive treatments (on or off intensive care) with the outcomes being either improvement with minimal support and minimal decrease in physical function or death.

Therefore, it may be that if multi-morbid patients are able to make a trade-off between QoL and survival post-acute illness, they would value QoL over mortality as the most important outcome and for good reason. It is worth noting that simply identifying outcomes which are most important to a patient doesn't automatically dictate an ICU admission, or indeed a treatment limitation, but focuses the decision on its likely results.

However, measured health outcomes and QoL aren't equivalent, although the distinction is frequently unclear to patient and clinician, and thus, they may often be conflated. By defining and keeping them separate, it would clarify whether health outcomes post-ICU admission are being used to make an estimate of QoL in the consultation process.

Given that patients might be critically ill and are impacted by multi-morbidities (in terms of both health status and access to care), they will be sensibly considering how their current situation (e.g. access to family, personal autonomy, current pursuits that they value in their daily activities) and choices impact on their future situation (e.g. access to family, personal autonomy, current pursuits that they value in their daily activities). In conversations regarding survival from critical illness, clinicians need to therefore discuss a full set of ramifications, beyond the simplistic dichotomies of live versus die and own home versus nursing home. Specifically, discussions need to separate out how health outcomes (e.g. muscle wasting, tracheostomies, chronic renal failure) may affect individual outcomes most relevant to the patient and, in turn, therefore the impact on overall QoL.

Future directions

In summary, what is needed to support discussions that would enable appropriate patient-centred trade-offs between potential outcomes is equivalency in data, which measure QoL without ICU admission (paired with survival likelihood with their acute illness) versus QoL after ICU admission (paired with survival likelihood with their acute illness). A parallel discussion is also required regarding the quality of death (with or without ICU admission). Such data are notoriously difficult to produce, although recognised as required by both patients and professional recommendations [25]. In addition, the research strategy taken to explore decision-making in regards to critically ill multi-morbid patients might benefit from more dedicated efforts to gather

qualitative data, as a complement to quantitative data [26]. The reason for this is that current measures could be improved if they were informed by structured interviews to provide a richer profile of outcomes other than observed/expected mortality accounting for patient characteristics. Patients, families and doctors are motivated by far wider considerations, and a consultation process should relate to more than the simple likelihood of mortality as a basis on which decisions are made mutually in a shared decision-making context.

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