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Tools for revealing uncomfortable truths? Measuring child-centred health-related quality of life after paediatric intensive care

Received: 5 May 2015
Accepted: 6 May 2015
Published online: 3 June 2015
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The benefits of paediatric intensive care units (PICU) are self-evident. Mortality rates for critically children have declined dramatically [1]. The greatest gains are occurring in higher-risk groups in whom the appropriateness of critical care was previously questioned. For example, those with malignancies [2] fare better and require a more optimistic approach than hitherto thought [3].

In this edition of *Intensive Care Medicine*, Dr. Aspesberro et al. [4] further this point: that mortality per se has ceased to be a meaningful outcome measure for the majority of paediatric intensive care admissions. Their response is to attempt to identify more meaningful outcome measures from the health-related quality of life (HRQL) literature published between 1980 and 2015 in the context of paediatric critical care.

The review is timely, important and uncomfortable. Timely, because there is a growing appreciation that the

provision of paediatric intensive care is associated with increased morbidity [5]. Why? Perhaps at least in part because there has been a shift in PICU casemix from 'acute' to 'acute on chronic' critical illness. A recent study from the USA identified that 53 % of critically ill children had pre-existing chronic complex illnesses [6]. This change has many implications. One major implication is that the HRQL outcomes that might be hoped for many of our patients are becoming more distinct from those of previously healthy children [7].

This subject is important, because paediatric intensive care is costly: for the child, their family and society. Equally, the association of increased morbidity with improved mortality should make intensivists uncomfortable, as now we enter an era where the outcomes shift from the "hard" objective, binary 'life or death' outcome to the more "fuzzy" concept of HRQL.

The World Health Organisation (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [8].

Ironically, this definition will render most of us unhealthy most of the time as the emphasis is on "complete" well-being. Moreover, the WHO definition of health does not do justice to resilience and the capacity to adapt and function well with chronic disease or disability. This understanding prompted a group of international health experts to reframe health as the ability to adapt and self-manage [9]. Adaptation and resilience are vital attributes to successfully navigate through childhood, and self-management is increasingly relevant to children as they grow older. Thus, the concept of "health" requires a more operational framework, as well as meticulous measurement, in order to better advance our clinical practice to meet these new outcome goals.

Other high-risk paediatric medical specialties have previously confronted this same challenge of evolving a more empirical basis by which to assess the potential

Fig. 1 Percentage of children with the same or better health status post PICU by pre-existent health status. In 1982 those with severe disability had worse outcome than those who were previously normal, in 2005/6 there was no difference in health status change between the groups. Data from [1]

benefit of a therapy. Paediatric oncology has evolved beyond solely assessing mortality to now include also the quality of life for survivors of childhood cancer [10]. Follow-up programs that assess neuro-developmental and complex conditions are now routine in neonatology. However, relatively few paediatric critical care follow-up programs exist and prospective studies describing well-being after PICU stay are scarce [11].

Which patients can benefit from paediatric intensive care might be seen in absolute or relative terms. The three decades of Melbourne data [1] show that over time the group with pre-existent health needs stands to benefit more than previously healthy children if one defines a “good outcome” as functional status equal to, or better than, prior to admission (Fig. 1). Being able to assess benefit systematically requires more sophisticated tools, however, than are available from historical comparisons.

In this issue of *Intensive Care Medicine*, Aspesberro and colleagues review the use of HRQL in paediatric critical care [4]. This focused review identified 78 papers that fulfilled the selection criteria. From this review of the literature it is now apparent that many HRQL tools are far from ideal in the paediatric critical care setting. Although they perform well in terms of validity, interpretability and mode of administration, arguably their usefulness is limited because they are arduous to respond to, are not well adapted to the critical care setting or are insensitive to change over time. The authors, however, do identify four HRQL tools that represent the best available to start the iterative process of measuring and assessing paediatric critical care-related HRQL. These tools are the PedsQL™ 4.0, CHQ-PF28 (both from the USA), KIDSCREEN-27 (international) and KINDL (Germany).

There are several reasons to create an empirical evidence base for outcome after PICU. While the paediatric

critical care community likely accepts that mortality has ceased to be the only pertinent outcome measure to describe health benefit in critically ill children, we have been slow to shift our focus to morbidity or HRQL. The reasons for this may be in part because of unfamiliarity with measurement tools, difficulties in assessing baseline functioning and anticipated development. Could it also be that our scientific model has been anchored too long in a culture that prefers *p* values above the narrative of qualitative research?

Further, as health care workers, we are now also doing our job in the epoch of emotive discussions on social media and a high value placed on parental autonomy [12].

Finally, from a rather different perspective, outcome measures might also inform us when we face decisions in times of scarcity. Outcome measures such as HRQL may open the door to the development of more transparent admission triage criteria in resource-limited environments [13].

Paediatric intensive care is transitioning from a specialty that deals with acute illness to one that is part of the multidisciplinary team that looks after children with chronic illness. Aspesberro and colleagues provide an important advance for the field with this review of HRQL tools that will better allow us to measure and analyse a broader range of important outcomes of paediatric critical care.

This review joins two recent systematic reviews on measurement tools for post intensive care admission functional physical [14] and psychosocial health status in adults [15]. All three rightly call for a standardized way in which we evaluate recovery and outcome after intensive care admission.

Conflicts of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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