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Outcome after pediatric intensive care unit discharge

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The evaluation of the outcome of children treated in intensive care units (ICUs) has altered substantially over the last 25 years. The increasing availability and capacity of mechanical and artificial organ support systems and the resultant low mortality rates in most pediatric intensive care units (PICUs) have meant that survival after admission to ICU is no longer the only outcome of interest. Thus, increasingly functional outcome and quality of life are seen as very important. The physical and intellectual capacity of a child to perform tasks and be an independent functioning individual (functional outcome) is different to the health-related quality of life (HRQoL), which evaluates the individual's social emotional health and well-being, as well as mobility and other functional capacity indicators. What is the outcome of children after discharge from a PICU? This seems to be a very simple question; but, unfortunately, it has a very complex answer, with many subtle issues that require consideration.[1]

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In this edition of the journal, Cunha et al.[2] examine the HRQoL of children who survived after intensive care. A total of 1,495 children were admitted during the study period, and 517 over 6 years of age were eligible for the study; among these, 320 had an admission evaluation and 252 had a second evaluation, by phone, at 6 months after admission from the ICU. Severe disability was present in 36% of the children before admission, with some improvement in 60% of the cases 6 months later. Overall, 21% had their HRQoL unchanged, 40% improved, and 38% worsened. The change in HRQoL was in part dependant on diagnosis, since cardiorespiratory and musculoskeletal patients tended to improve, whilst children with trauma and acute sepsis/shock tended to worsen. This was a well-conceived study that has tried to deal with the complex issues associated with outcome assessment and also presented an interesting and detailed analysis. The authors have used a recognized and standardized outcome assessment tool developed in Canada and have evaluated pre-ICU status, which is one of the single biggest influences on patient outcome. They have tried very hard (up to five attempts) to contact families and achieved a good second interview rate of 79%. The follow-up period was 6 months, a short time after ICU, when neurological recovery may not be complete; however, the outcome is relevant to treatment protocols and hospital and health system performances. One of the key findings (similar to those from other studies) was that individual patients can vary greatly; thus, this type of data is useful for resource planning and health program evaluation rather than for individual patient prognostication.

When a unit wishes to determine the outcome after ICU for its patients, it must start by deciding whether to assess outcome in terms of survival, functional outcome or quality of life. Many tools exist for this purpose, but the current best general tools for children include the Pediatric Overall Performance Category,[2] the Pediatric Cerebral Performance Category,[3] and the Functional Status Scale for functional assessment,[4] and the Health Utilities Index Mark 3[5] for

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quality of life assessment. In one study[6] in which both assessments were performed after a median of 3.5 years (range 2.3-6 years), there were small but real differences: 10% had an unfavorable functional outcome and 16% had an unfavorable quality of life.

The unit also needs to decide what patient group is of interest for follow-up: is it all patients in the PICU or a specific diagnostic group? Specific diagnostic groups (e.g., trauma, immune-suppressed, cardiac) or specific outcome interests (neurodevelopmental) often require targeted outcome tests such as the Stanford-Binet test, the Bayley test, the Vineland Adaptive Behavior Scale or the Adaptive Behavior Assessment System II. Most of these outcome tests are not age independent; therefore, the age of assessment of the patient is vital, which often requires the use of different tools or versions of the same tool. Will the tool be simple and allow its application over the phone or will we need to examine the patient in front of us? This clearly impacts on practical ability to perform larger and more detailed studies, because a phone call is much cheaper and easier than the family returning to hospital for detailed assessment. Many of these tools require subjective opinion, especially telephone interviews. Whose perspective will we assume is accurate? Older children and adolescents may view their situation differently to their parents. Will interviewers speak to older children, or only to their parents? How long after discharge will we assess outcome, considering that it will change over time?

In one study that evaluated neurological outcome 1 and 5 years after discharge from the ICU after brain injury,[7] functional outcome at the 5-year follow-up showed that 53% of children had good or moderate function, whilst 47% were severely disabled, vegetative or dead. Moreover, 17 of the 40 survivors had changed outcome between 1 year and 5 years after discharge: 12 had improved, three had worsened and two had died. Small differences were also noted between quality of life outcome and functional outcomes. These outcomes could be predicted by short-latency somatosensory evoked potentials.[7] This is of interest in view of recent opinions about outcome prediction and about whether mortality or morbidity (function/quality of life) should be used in outcome assessment.[8] The length of time after discharge from the ICU also affects the follow-up rate, in that the longer the time after discharge, the fewer patients will attend/respond.[9] This is of vital significance, because low follow-up rates may lead to uncertain information due to very wide confidence intervals surrounding the mean or median value.[10]

The outcome of any individual child depends very much on many different factors, including individual patient factors such as diagnosis, pre-existing health problems, severity of illness, lead time bias, standards within the ICU and another factors such as available treatments, social/cultural attitudes towards complex patients and complex treatments, attitudes towards prolonged care and withdrawal of care, and overall hospital and state health care system. These factors are all subject to subtle or dramatic change over time; therefore, results from a single unit can change dramatically.[9] In reviewing one unit's experience over three decades, Namachivayan et al. showed that, although the mortality rate fell from 11 to 4.8%, the proportion of survivors with moderate or severe disability rose from 8 to 18%. Additionally, readmission rate increased from 11 to 31% and the percentage of children with no pre-existing abnormality on admission fell from 79 to 64%. Moreover, in this study, there were major changes in the number of children with trauma, congenital heart disease or requiring admission after surgery. One of the most fundamental and powerful determinants of long-term outcome is the pre-admission health state.[11] In children who were normal before ICU admission, 69-82% recovered to normal after ICU discharge,[9] whilst 92-100% of children with severe disability before ICU admission died or remained severely disabled. All these factors become even more important when a unit wishes to compare their results to those from other units in different countries. We tend to assume that all ICUs and systems of delivery of health care are similar; however, this is not true.[12]

It is very important, when performing outcome studies, to be clear as to why this study is being performed. If we seek information to advise parents of general or "group" prognosis, then general information is appropriate and useful. If we want to use this information for outcome prediction about an individual patient, then specific and accurate information is required, with a high degree of confidence and certainty, which requires rigorous and exact data that are relevant to that patient and his/her diagnosis. If the information is being used to assess treatment outcome or to optimize resource allocation, then a balance between accuracy of data and proximity to treatment is vital. The UK extracorporeal membrane oxygenation (ECMO) trial[13] is a very good example of this: a randomized controlled trial of ECMO showed an initial improved survival, which continued at subsequent follow-up evaluations at 1,3 and 7 years; however, changes in neurological performance also occurred. As longer term follow-up is being performed, interesting data emerge, but the relevance to modern clinical treatment protocols diminishes. Conventional treatment (as offered in the control arm of the study) has changed outcome as has the implementation of ECMO technology. Thus, timing of follow-up has important implications for the utility of the information.

Outcome assessment is of considerable interest to parents, intensive care staff, and health administrators. Its evaluation demands substantial thought about what information is required. Cunha et al.[2] provide useful information about the HRQoL of children older than 6 years of age, both before and 6 months after ICU admission.

Patient diagnosis and pre-existing abnormality appear to be key factors in determining outcome; these outcome studies are vital in the modern era of multiple organ support technology in contributing knowledge to evaluate the outcome of PICU patients.

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