Caring for Long-Stay Critically Ill Children and Infants Refers Back to the Fundamentals of Patient- and Family-Centered Care*

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The goal of intensive care is to restore health in the shortest possible time. In some cases, patients do not recover as expected and present with complications resulting in extended length of stay in the PICU. The number of long-stay patients (LSPs) in the PICU increases because of advances in technology and improved treatment. However, LSPs are reported to have less-positive outcomes when compared with non-LSPs, with increased morbidity and lower health-related quality of life (1, 2). Those with life-threatening chronic conditions are particularly at risk of repeated hospital stay with length of stay during the terminal stage varying between 75 days (interquartile range [IQR], 28–132 d) and 99 days (IQR, 51–146 d) (3). These long hospitalizations have a major impact on cost, resources, and patients and families.

Health professionals in PICUs and neonatal ICUs need to be specifically trained to care for critically ill patients and families. Patient- and family-centered care (PFCC) is one of the key elements for nurses to be competent in caring for children and families in PICUs (4). Nurses are expected to promote compassionate and therapeutic care and individualized emotional and psychologic support to very sick patients and their families (4). Families being considered as full partners in care (5), effective communication with patients and families and within the team is essential. It allows for evaluation of patient and family needs, establishment of shared decision making, setting realistic goals, and provision of appropriate support (6).

The study in this issue of Pediatric Critical Care Medicine by Geoghegan et al (7) reports on the challenges of caring for LSPs in the PICUs and cardiac and neonatal ICUs of a teaching referral hospital for children in the United Kingdom. Their results show that health professionals, especially nurses, report moral distress, burnout, difficulties with family relationship, and a lack of sense of accomplishment and skill development when caring for LSPs. Although these results are somewhat astounding when one relates to the standards of PFCC and caring as the essence of nursing, they cannot be ignored.

Psychologic health of nurses and other health professionals is paramount to the delivery of safe quality care. Moral distress, meaning in patient care, and hope are predictors of burnout (8). In the study by Geoghegan et al (7), the focus is on health professionals. During the interview conducted, deeper understanding of the reasons behind the negative emotional responses would have been interesting and added values to the study. Participants expressed their expectation of patient recovery, with no reference to palliative and supportive care. Is it because they did not feel comfortable talking about these difficult issues? Or is it because they have unrealistic expectations of patient recovery? Both questions refer to communication skills and reliance on specialized palliative care team (9). Discussion of what would mean futile life-prolonging treatment for parents with health professionals is paramount and should be based on all key PFCC principles (9, 10).

Results of the study by Geoghegan et al (7), namely, the views of health professionals, should be compared with those of families. This comparison would allow deeper understanding and contrasting of the impact of long stay on families and health professionals. Indeed, competing values between nurses and families and poor staff understanding of family needs have been described as major barriers to provide adequate care to families (11, 12).

Geoghegan et al (7) propose peer support groups to allow staff to share experiences and express negative feelings. When this approach has demonstrated benefits, it does not provide a framework to include patients and families. Communication between health professionals and patients and families is the essential ingredient of PFCC. The best mode(s) of communication has yet to be determined (13), but without a PFCC approach, care tailored to the individualized need of the patient and the family will never be provided.

REFERENCES


Outcomes After Pediatric Critical Illness: Important to Be Accurate*

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When a child is admitted to an ICU, the first thought of healthcare professionals and families is usually what is going to happen to this child? Will she/he recover? Will there be any long-term problems? One of the most important issues for clinicians researching the outcome of children after intensive care is the reason the outcome is wanted. Are we interested in knowing our ICU performance? Do we wish to use it for providing information to parents or children about their future or do we wish to compare our performance with other units, or to use the data for resource allocation, or maybe to determine effectiveness of certain therapies. All these different uses of outcome data are important, but ultimately, it should be about being able to talk to families (or children) at the bedside and determine a possible course of action in a given clinical situation. Knowing what a child’s outcome after ICU is central to modern pediatric intensive care practice. As pediatricians, we are always interested in children growing up and so long-term outcome is very important to us (1–3). Increasing interest in this area has occurred with the decrease in mortality for children. The proportion of children who died in a PICU fell from 11% in 1982 to 4.8% in 2006 (4), and recent report from major intensive care registries reports mortality rates between 2% and 3% (5, 6).

A review of intensive care literature on long-term outcomes highlights wide variations in outcome assessment: different patient cohorts from general ICU patients or targeted populations (congenital heart disease, septic shock, brain injury, emergency vs elective admissions etc.) (7–9) from single-centre to multicentre reports (10), types of outcomes assessed (mortality, functional outcome, quality of life, health-related quality of life [HRQL], and complex neuropsychological and neurodevelopmental), timing of outcome assessment (ranging from 3 months to up to 10 years), method of assessment (face to face, letter, and telephone), and finally the instrument used to assess outcome (too many to mention). Along with these variations, the proportion of children who actually have an outcome assessment performed varies from less than 50% to as high as 95%. There are currently no agreed guidelines or recommendations for performance or reporting of outcomes in critically ill children, and many major intensive care societies in the United States, United Kingdom (11), Australia, and New Zealand (5) are yet to include long-term outcomes as part of their registry data acquisition and reporting.

In this issue of Pediatric Critical Care Medicine, Aspesberro et al (12) report a cohort of 367 children admitted to the ICU over 18 months from January 2012 to June 2013. This cohort constituted 16% (367 of 2,299) of patients admitted to the ICU during that period. More than 50% of patients (n = 1,188) could not be contacted (because of unavailability of research staff or care giver not present for consent). Of the remaining 1,111 who were approached, a combination of exclusion criteria and refusal of consent resulted in a final total of 367 children reported in the study. The authors report the responsiveness and construct validity of the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales and Infant Scales

*See also p. e272.

Key Words: children; intensive care; outcome; quality of life

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