Published in final edited form as:

Pediatr Crit Care Med. 2018 March ; 19(3): 272–273. doi:10.1097/PCC.0000000000001432.

Mortality after Pediatric Critical Illness: Made it Home, Still Vulnerable

Aline B. Maddux, MD, MSCS and Tellen D. Bennett, MD, MS

Pediatric Critical Care, University of Colorado School of Medicine, Children's Hospital Colorado, 13199 E Montview Blvd., Suite 300, Campus Mail F443, Aurora, CO 80045

Keywords

Pediatrics; Intensive Care; Mortality; Recovery of Function; Quality of Life

Hospital mortality after pediatric critical illness or injury has declined, but new morbidity is common among survivors.(1, 2) That morbidity is collectively referred to as post-intensive care syndrome (PICS).(3) Appropriately, pediatric critical care investigators are increasingly focused on understanding PICS in children by studying outcomes such as long-term functional status, health-related quality of life (HRQOL), and health resource use.(4-6)

In many ways, children who survive critical illness are different than their peers of the same age. Unfortunately, those differences include ongoing mortality risk: several groups have reported concerning rates of death among pediatric intensive care unit (ICU) survivors.(6-8) Why do these children die after hospital discharge? That is an important unanswered question. In many cases, the chronic diseases (cancer, cardiac disease, etc.) that cause the critical illnesses that bring the children to our ICUs also likely cause the late deaths.(9) Improving the treatment of the chronic diseases could decrease that mortality. Less understood is the possibility that critical illness and the resulting medical and surgical intensive care children receive (e.g. mechanical ventilation, sedation, ongoing technology dependence) might contribute to mortality risk in both previously healthy and chronically ill children.

Distinguishing between children who die from a chronic disease and those who die from new morbidity is difficult because accurate cause of death information is difficult to obtain. In this issue of *Pediatric Critical Care Medicine*, Kyosti et al began to address this challenge. They report the results of a retrospective cohort study that evaluated long-term mortality and cause of death in children who survived an ICU admission in Finland during 2009-2010.(10) The study cohort of 2,792 children 28 days to 16 years old was primarily identified from a prospectively collected national ICU registry. The research team previously reported hospital events and discharge outcomes for the cohort.(11) For the current study, the authors identified a control group of >1 million children of similar age who did not experience an ICU admission during 2009-2010. In order to obtain information about time, place, and

cause of death, they linked both the ICU cohort and the control group with Finland's national death registry data through 2014.

The study's aims were to compare long-term mortality and causes of death between the ICU cohort and the age-based control group. The ICU cohort experienced relatively low ICU mortality (1.9%). Another 0.5% died within 30 days after discharge, perhaps reflecting family decisions to have their child die at home. An additional 2.4% died during the subsequent 4-6 years (before the end of 2014). Similar to other work using multi-center databases(7, 8), control group mortality during long-term follow-up was much lower (0.1%). In the ICU cohort, neoplasms, metabolic, and neurological diseases caused nearly all (94%) of the deaths that occurred >30 days after discharge. In contrast, injuries and ingestions caused more than half of deaths in the presumably healthy control group. This study's findings are not surprising, but they have not been described well previously. They corroborate other analyses reporting that chronic conditions(1, 4, 5) play a large role in post-PICU mortality. This is also true for adult survivors of critical illness.(12)

Strengths of this study include unusually long follow-up (median 4.9 years in the ICU cohort) and near-complete capture of mortality and cause of death information. As the authors note, the relatively low rates of immigration to and emigration from Finland give the national registry system enviably complete data. Autopsy results informed the cause of death determination for 37% of the ICU cohort and 75% of the control group.

The primary limitation of the study is that the cause of death information was fairly coarse (e.g. "neurological disease"). More granular data might allow hypothesis generation about specific populations that should be targeted to decrease long-term mortality. New and ongoing technology dependence (e.g. shunts after brain injuries, home ventilation after acute respiratory distress syndrome) readily identifies children at risk, but what about more subtly vulnerable children? In adults, ICU-related risk factors such as sedation and immobility contribute to long-term morbidity and mortality, irrespective of underlying condition.(13) Whether or not those potentially modifiable factors contribute to long-term pediatric mortality is unknown. The forthcoming RESTORE-Cog(14) study results should provide badly needed data about the effects of sedation on critically ill children.

Importantly, other factors such as ongoing child development, family structure, socioeconomic status, access to health care, and parental education may influence long-term morbidity and mortality among PICU survivors. A crucial next step to improve long-term outcomes in children who survive critical care is to better define patient, hospitalization, and social characteristics that predict ongoing morbidity and late mortality, both with and without underlying chronic illness. This will allow us to systematically test and target hospital and post-discharge interventions and services for patients and their families. As identified by Kyosti et al., post-PICU care requires that primary care providers have access to the information and resources they need. In addition, optimal post-PICU care should be multidisciplinary and involve rehabilitation and therapy providers, care coordination specialists, and intensivists, among others.(12) Intensivists can contribute a rich and nuanced understanding of PICU course characteristics that might place a child at increased risk of morbidity and mortality.

Overall, this report by Kyosti et al. adds to the available data describing long-term mortality in children who survive critical illness. What can be done going forward? First, the current work underscores the value of information about the causes of patients' deaths. Both retrospective and prospective studies should consider tracking long-term mortality by linking study data to state and national death registries. Second, because each PICU cares for a relatively small number of children, collaboration and data sharing will be necessary to generate sufficiently large datasets to answer important clinical questions.⁽¹⁵⁾ Finally, although labor-intensive to collect, long-term HRQOL and functional status measures are now important outcomes for prospective studies of critically ill and injured children.

Acknowledgments

Copyright form disclosure: Dr. Bennett's institution received funding from the National Institute of Child Health and Human Development, and he received support for article research from the National Institutes of Health.

TB is supported by NICHD K23HD074620

References

1. Namachivayam P, Shann F, Shekerdemian L, et al. Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. *Pediatr Crit Care Med*. 2010; 11(5):549–555. [PubMed: 20124947]
2. Pollack MM, Holubkov R, Funai T, et al. Pediatric intensive care outcomes: development of new morbidities during pediatric critical care. *Pediatr Crit Care Med*. 2014; 15(9):821–827. [PubMed: 25226501]
3. Needham DM, Davidson J, Cohen H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med*. 2012; 40(2):502–509. [PubMed: 21946660]
4. Choong K, Al-Harbi S, Siu K, et al. Functional recovery following critical illness in children: the “wee-cover” pilot study. *Pediatr Crit Care Med*. 2015; 16(4):310–318. [PubMed: 25651047]
5. Pinto NP, Rhinesmith EW, Kim TY, et al. Long-Term Function After Pediatric Critical Illness: Results From the Survivor Outcomes Study. *Pediatr Crit Care Med*. 2017; 18(3):e122–e130. [PubMed: 28107265]
6. Namachivayam SP, Alexander J, Slater A, et al. Five-Year Survival of Children With Chronic Critical Illness in Australia and New Zealand. *Crit Care Med*. 2015; 43(9):1978–1985. [PubMed: 25962079]
7. Czaja AS, Zimmerman JJ, Nathens AB. Readmission and late mortality after pediatric severe sepsis. *Pediatrics*. 2009; 123(3):849–857. [PubMed: 19255013]
8. Hartman ME, Saeed MJ, Bennett T, et al. Readmission and Late Mortality After Critical Illness in Childhood. *Pediatr Crit Care Med*. 2017; 18(3):e112–e121. [PubMed: 28107264]
9. Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980–1997. *Pediatrics*. 2000; 106(1 Pt 2):205–209. [PubMed: 10888693]
10. Kyosti E, L JH, Peltoniemi O, Ohtonen P, Rautiainen P, Kataja J, Ala-Kokko T. Five-year survival and causes of death in children after intensive care - a national registry study. *Pediatric Critical Care Medicine*. 2017 In press.
11. Peltoniemi OM, Rautiainen P, Kataja J, et al. Pediatric Intensive Care in PICUs and Adult ICUs: A 2-Year Cohort Study in Finland. *Pediatr Crit Care Med*. 2016; 17(2):e43–49. [PubMed: 26669639]
12. Herridge MS. 50 Years of Research in ARDS. Long-term Follow-up After ARDS: Insights for Managing Medical Complexity After Critical Illness. *Am J Respir Crit Care Med*. 2017
13. Ely EW. The ABCDEF Bundle: Science and Philosophy of How ICU Liberation Serves Patients and Families. *Crit Care Med*. 2017; 45(2):321–330. [PubMed: 28098628]

14. Watson, RSC. MAQ. [cited 2017 November 13] Sedation Strategy and Cognitive Outcome After Critical Illness in Early Childhood (RESTORE-cog). Available from:<https://clinicaltrials.gov/ct2/show/NCT02225041>
15. Bennett TD, Spaeder MC, Matos RI, et al. Existing data analysis in pediatric critical care research. *Front Pediatr*. 2014; 2:79. [PubMed: 25121079]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript