Published in final edited form as:

Crit Care Med. 2015 September ; 43(9): 2035–2036. doi:10.1097/CCM.0000000000001100.

It seems like the resuscitation happened ages ago—chronic critical illness in children: Digging in for the long haul:

“Therefore in medicine we ought to know the causes of sickness and health.” Avicenna

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Keywords

pediatric critical care; outcomes; morbidity; mortality; duration; long-stay

Many of us in critical care entered the specialty with an affinity for acute resuscitation. However, as Namachivayam, et al in this issue of the journal,¹ and other groups have pointed out, a growing part of our duty is to care for children who require prolonged stays to achieve PICU discharge. Accordingly, the Society for Critical Care Medicine defines chronic critical illness as a prolonged need for mechanical ventilation, whether in an ICU or not, in which the patient is not back to his or her prior functioning and remains at increased risk of mortality (<http://www.myicucare.org/Adult-Support/Pages/Chronic-Critical-Illness.aspx>). Research has shown that this group of patients requires special attention, as they consume a sizeable amount of resources and frequently have poor long-term health outcomes after PICU discharge.^{1,2}

Pollack, et al, first described “long stay” patients (those with a PICU length of stay > 95% [12 days]) as encompassing 7% of PICU admissions at a single center.² They were younger, sicker, and having more chronic disease versus shorter stay patients and consumed more than 50% of ICU resources. Expanding to a 32 site US study, they found that long stay patients accounted for between 2% and 8% of PICU admissions and occupied between 15% and 58% of PICU bed days.³ Predictors of long stay included age <12 months, previous ICU or emergency admission, no need for CPR before admission, admission from another ICU, chronic care requirements, diagnosed with either acquired cardiac disease, pneumonia, and other respiratory disorders, having never been discharged from the hospital, need for ventilatory support or an intracranial catheter, and a Pediatric Risk of Mortality III score between 10 and 33. Echoing the notion that children with chronic illness often had lengthy PICU stays, another multicenter study in the US found that moderate and severe baseline

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Dr. Kochanek disclosed that he does not have any potential conflicts of interest.

deficits for both the POPC and PCPC score predicted children who would have a prolonged length of PICU stay.⁴

In this multicenter (n=8) study of PICUs in Australia and New Zealand by Namachivayam, et al,⁵ children with chronic critical illness were defined as those requiring ≥ 28 PICU days. Although accounting for only 1.3% of PICU admissions, these children's longer lengths of stay amounted to 24% of PICU bed-days. Children had a mean duration of mechanical ventilation of over 3 weeks, and length of PICU stay of 40 days and hospital stay of 75 days. Further stressing the singularity of the “long stay” cohort, mortality was 6 times higher than overall PICU mortality, and remained flat over the 2 study epochs (2000-2005 and 2006-2011). Subsequently, another 129 (15%) of children who survived to PICU discharge died within the 5 year follow-up period. Although site differences were not reported in this paper, one of the study's centers previously published a 20-year retrospective analysis of long-stay patients, finding that PICU bed days had rocketed from 8-21% over the study period, highlighting an important trend.¹

The most frequent primary diagnosis in the early epoch was sepsis but cardiac/respiratory arrest led the second epoch, increasing from 12% to 20%. Children with single ventricle physiology (5-9%) and acute renal failure (7-14%) doubled. The reason for these changes were not explored, but likely represent technological advances and corresponding culture change by clinicians and/or caregivers over time towards pursuing survival, risking an increase in more children surviving with short or long-term disability.⁶⁻⁸ Notably, the proportion of children who required extracorporeal membrane oxygenation was not reported in the current study, but comprised a substantial 24% of study patients in the 20 year single center analysis.¹

As we become more adept at survival, there is a natural push to know longer term clinical outcomes in children, although this is rarely regularly performed outside of the neonatal and congenital heart disease populations or research.^{9,10} Although this current paper did not investigate outcomes beyond survival, health-related quality of life outcomes were obtained in the related single center study. They found that quality of life was poor or very poor in 71% of children at 4 years median follow up.¹ Quality of life studies have shown significant disparities between parent and child report, and may also be different from a clinician's point of view.¹¹ Understanding which if any of these disability outcomes are important to patients and families is key in identifying strategies to prevent or improve them and to assist in accurately informing families when making difficult care decisions.^{12,13}

The authors and families involved in this remarkable registry are to be commended, with outcomes obtained for 95% of children. Trends in ICU case-mix and outcomes over time are useful for future planning and quality of care assessment. Important limitations of the database include its reliability on charge codes and inclusion of only primary diagnosis as many children (and very likely those with “long stay”) have complex, simultaneous medical issues. Also, there is a vital need to account for what elements led to longer lengths of stay in order to examine strategies to shorten a child's PICU experience. Extended time in the ICU puts children at increased risk for cognitive deficits, skin breakdown, hospital acquired infections, venous thrombosis, and physical decline, among other problems. The database

does not account for site differences in admission criteria and cultural and clinical practices or how they may change over time. Elements of the social determinants of health, which have substantial impact on health outcomes of children, were not reported here. Similarly differences in rehabilitation strategies both in the PICU and on discharge were not characterized. Finally, the authors did not report resource use or cost estimates, which may have added impact on future policy.

Children with chronic critical illness, as highlighted by this work, are at high risk of poor outcomes despite substantial resource use and require skills by the critical care physician beyond resuscitation and stabilization. These are almost certainly very special skills that even the most skilled pediatric intensivists are far from mastering. Learning how to best care for these children, including the prevention of debilitation and morbidity and optimizing outcomes important to patients and families most notably quality of life should be a priority for future research and likely a specific facet of trainee education.

Acknowledgments

Dr. Fink received support for article research from the National Institutes of Health (NIH). Her institution received grant support from PCORI and the NIH.

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