

Redefining Success in the PICU: New Patient Populations Shift Targets of Care

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Over the last 3 decades, mortality rates of children admitted to PICUs in North America have declined significantly.¹ By this measure alone, PICUs have been extremely successful, offering children the best possibility for survival and recovery after life-threatening trauma and illness. Yet as mortality rates have declined, the PICU patient population has become steadily more complex. A recent analysis of admissions across 54 PICUs in the United States ($n = 52\,791$) revealed that 53% of critically ill children had underlying chronic, complex illnesses.² This finding is supported by a secondary analysis of a national administrative database in the United States that revealed comorbid illness among critically ill children increased from 35% in 1997 to 41% in 2006.³ The emergence of this new population of critically ill children reflects the medical and technological advances of recent decades.¹

What do we mean by children with chronic, complex illness, and how do they impact the provision of critical care? This population has been defined as children with severe antecedent disorders; children with medical complexity, such as neuromuscular conditions and neurologic impairment; children with special health care needs; and children with a chronic comorbid illness, such as cardiovascular disease. What they have in common is a greater risk of PICU admission if they become acutely ill, along with extensive medical needs that continue long after the illness that brings them to the PICU is resolved. They are typically technology dependent, requiring a medical device to maintain body functions necessary to sustain life. Family members act as part- or full-time care providers. Although these children may thrive with home care and community support, others undergo repeated and long-stay PICU admissions with successive health crises and experience a worsening of their health over time. Others have highly sophisticated care needs that may exceed the resources and abilities of their parents to care for them, and may come to live in hospital.

This pattern mirrors the changing epidemiology of pediatric illness as a whole in North America. We are witnessing a dramatic decline in infant and pediatric mortality rates, along with an increase in the prevalence of chronic illness. These changes are evident in hospital admission patterns. Although rates for pediatric hospitalization have dropped for all children over the past several decades, chronic conditions now account for a larger

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portion of admissions and days in hospital.^{4,5} Children with chronic, complex illness are no longer on the periphery of pediatric intensive care.

Reflecting on these changes leads us to ask the following question: How do children who present with critical but nonreversible illness fit into the current culture of critical care?

Although we know a great deal about the experiences of families caring for children with chronic, complex needs beyond the PICU setting, we know very little about what families of these children are experiencing inside the PICU. To date, only 1 qualitative study has explored the needs and experiences of parents of these children ($n = 8$), at Children's Hospital Boston.⁶ The authors argue that these children form a distinct population within the PICU. One father interviewed in this study described himself and other parents of these children as "frequent flyers," highlighting the fact that their needs differ substantially from those of parents new to the PICU, who are unfamiliar with the highly technological nature of critical care. Study findings suggest the acute care model that typifies care delivered in a PICU is a poor fit for these families, and does not provide the support they require to cope with their unique stressors.

Although staff recognize that parents know their child best and provide a level of support that others simply cannot, partnerships with these parents become more difficult to navigate when we consider the unique forms of expertise they have developed. Many parents of children with chronic, complex illness are full-time caretakers, adept at recognizing signs that their child is not well. But they are also proficient with the medical technologies that keep their children alive outside the PICU. This migration of care-taking responsibility from hospital to home constitutes a significant shift in practice that challenges the division

of labor that exists in the PICU, where clinicians adopt the role of the expert care providers, and parents are relieved of that role and transformed into "visitors." It is not clear that clinicians are ready to accommodate parents as technologically sophisticated caregivers inside the PICU.

There is also a potential conflict between the treatment goals of PICU staff and these parents. PICU staff may have a different understanding of what constitutes a successful outcome from PICU treatment. For many, successful treatment might mean returning the child to a state of previous good health. But what happens when the child has an intractable, underlying illness? And who defines "previous good health" when curing the child is not an option? To parents of a child with severe, lifelong health problems who is dependent upon medical technology for survival, successful treatment might mean simply providing the best care possible for their child under the circumstances, with the hope that their child does not deteriorate further. Although PICU staff may recognize distinctions between "rescue" and "cure," they may not acknowledge these distinctions in practice. One result may be communication problems and tensions that can interfere with treatment and recovery.

It is clear that despite the improved health outcomes of critically ill children, PICU care has not become easier. Innovations in pediatric surgery and critical care technologies, along with the changing epidemiology of pediatric disease in the general population, mean that the targets of PICU care and treatment are shifting. In the technology-intensive setting of the PICU where both the treatment goal and the financial imperative is to send children home as soon as possible to resume their lives, what counts as success may need to be redefined in light of the novel health care needs of this complex patient population.

One barrier to such change, according to Graham,⁷ is that medicine is characterized by a "cult of cure" that is antithetical to the needs of children with disabilities and chronic conditions. The critically ill child with an underlying chronic, complex illness challenges a medical rescue culture that has defined PICU treatment to date. We prefer to talk about "cultures of practice" that are shaped by values and goals, and are amenable to change. If we believe that the family-centered care model should prevail, we must make room inside the PICU for the skills and expertise of these parents. How we accommodate this population should be informed by evidence. There is a clear need for research that identifies what constitutes success to these families, along with the challenges faced by staff who care for them. Only by generating this evidence can we change practice and foster a culture of supportive care inside the PICU. Such a culture would, we hope, support the primary mission of rescuing children from critical illness while also making room for the unique needs of this rapidly growing population.

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