Preparing Residents for Children With Complex Medical Needs

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"Patient in room 26 with respiratory distress, saturating 88%. Please assess ASAP." My stomach drops as the message scrolls across my pager. Although the task of assessing acute hypoxemia as an intern makes me nervous, I recognize most of my anxiety centers on doing so in a child with complex medical needs like this patient, Mary.

Mary suffered a perinatal hypoxic event that has led to multiple chronic medical problems, including seizure disorder, intellectual disability, tracheostomy dependence, and gastrostomy tube dependence. She was admitted for altered mental status of unclear cause. With little experience treating hospitalized children with similar medical complexity, her imposing list of comorbidities, medications, and confusing medical equipment have made it challenging for me to care for her as effectively as I would like.

As I enter the room to examine Mary, her thin chest heaves effortfully as saliva pools around her tracheostomy site. Her eyes convey a sense of panic that requires no translation, a fear that I share as I recognize my lack of experience troubleshooting respiratory distress in patients with tracheostomies. I call my senior resident who arrives promptly and provides much-needed clarity: deep suction resolves the hypoxemia without requiring transfer to the PICU.

Reflecting on this encounter later, I found my primary response was one of shame, something I would experience recurrently intern year when encountering challenging clinical scenarios for the first time. More concerning, however, was the fear I felt in responding to Mary's respiratory distress due to my limited experience caring directly for children with complex medical needs.

As I later learned, this sense of fear and discomfort is in fact one shared by many pediatric residents seeking to provide high-quality care for children with medical complexity.[1,2] Issues identified by residents that preclude quality care include lack of care coordination, limited familiarity with the often complex technology many of these patients rely on, patients' significant psychosocial needs, and, most notably, lack of effective training.[2] It is this dearth of training and firsthand experience that can make trainees feel both overwhelmed and anxious when caring for children with complex medical needs.[1–4]

Because children with complex medical needs currently account for one-third of total pediatric health care costs and represent a steadily increasing proportion of hospitalized pediatric patients, the lack of preparation for residents to care for this population should raise concern.[5–7] This has spurred

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innovative responses to reduce hospitalizations, increase caregiver education, optimize transitions between health care settings, and improve provider continuity.[8,9] Yet few measures have been taken at the level of residency education to better equip early-stage pediatric practitioners for future encounters with children with complex medical needs.[1] The lack of organized educational initiatives is particularly problematic considering that residents do desire further exposure to children with complex medical needs to allow for more just and efficacious care.[4] To address the gap in care, we need a commitment to train residents in the care of children with medical complexity, a commitment that might involve 3 potential measures.

First, residency programs could provide more dedicated instruction on children with complex medical needs. For example, programs might include a greater breadth of teaching on the specific epidemiology, underlying causes, clinical manifestations, and treatments of the various conditions that comprise medical complexity currently lacking in medical school curricula. Learning how to address issues with tracheostomies, feeding tubes, and other medical equipment that frequently flummox residents would be an important first step.[2] Offering formal instruction and training before a crisis moment, such as my encounter with Mary, would significantly mitigate trainee anxiety and allow for more thoughtful responses to patients' health needs, both routine and acute. Encouragingly, initial steps have been taken at individual institutions, including the implementation of educational modules and dedicated core curricula focusing on children with medical complexity.[1,10] Still, what is truly necessary is a collective commitment to systematic, evidence-based education on children with complex medical needs across all residency programs.

Second, residency programs could provide a vision of what disability and chronic needs look like not only in sickness but also in health. Unfortunately, the majority of resident experience with patients with complex medical needs currently occurs in the hospital when these patients appear their sickest.[3] Not coincidentally, practitioners underestimate the quality of life of patients with complex needs relative to family member or caregiver assessments.[11] To offer a more well-rounded understanding of this population, programs could broaden the clinical interactions of residents to children with complex medical needs beyond the inpatient setting. Efforts to extend the exposure of residents to children with complex medical needs in the community setting have been favorably received because this allows for enhanced teaching, recognition of the importance of shared decision-making, and understanding of the need for family involvement in patient care.[2–4] Although challenging to incorporate, longitudinal programs that allow practitioners to see patients when both sick and well have also been recognized by trainees as a method to improve care.[2] In addition to these measures, programs might consider organizing presentations from children with complex medical needs and their families to learn more about their everyday lives. In the hospital setting, we should encourage family members to share photographs or videos of their children participating in activities they enjoy. Such measures represent an important step toward garnering a more well-rounded appreciation of children with complex needs that is currently lacking for pediatric house staff.

Third, and most crucially, pediatric residents must seek to identify and address their own prejudices toward people with complex medical needs. Although important conversations in medicine have taken place regarding bias related to race, sexual orientation, and socioeconomic status, less emphasis has been placed on destigmatizing those with disabilities, even as the experience of both disability and medical complexity cuts across all other demographic categories. We must recognize that as new physicians, many of us have been gifted with relative physical health, intellectual aptitude, and independence, characteristics that we may assume to be requisite for flourishing. A society and profession like ours, which highly value these qualities, can struggle to make sense of the lives of those with disabilities and medical complexity who lack similar attributes.[11,12] When we encounter children whose lives involve dependence on others in a way that seems foreign, we initially may feel uncomfortable and falsely assume this to be a deprivation. Given these assumptions and biases, we may find that children with complex medical needs or chronic illnesses challenge our very self-understanding as doctors whose mission is to "fix" and "heal." It is little wonder then that humility has been identified as a key response to improving care for children with complex medical needs.[4] It is difficult to imagine high-quality care that neglects the cultivation of such a skill and virtue.

Although systems-level changes of enhancing emphasis on resident education and providing broader exposure to the experience of medical complexity are important first steps, they will only prove effective when we as practitioners learn that children with complex needs can flourish in their own right and that disability is not synonymous with illness. Only then will patients like Mary receive the empathetic and skilled care they deserve and practitioners caring for them experience fulfillment rather than fear.

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