Children's Hospital of Philadelphia PolicyLab

Improving Emergency Care for Children with Complex Conditions

Population Health Sciences

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Only about 1% of children in the U.S. are considered medically complex, but when you work in a busy Children's Hospital Emergency Department (ED) in a large urban area, the prevalence seems much higher. We see a range of children with complex conditions, such as severe asthma coupled with significant eczema, metabolic disorders, and illnesses requiring a ventilator or other life-sustaining equipment. In our anecdotal experience, these children have a much more difficult time navigating through a complex system when an emergency occurs, and some studies suggest that they are at higher risk of adverse medication events. To understand the experiences of these children and their families when they seek care in an ED, our team interviewed 20 parents and 16 pediatric emergency physicians.

Our goal was to learn from parents of children with medical complexity who were admitted to the hospital through the ED, as well as from the pediatric emergency physicians who cared for them. Families and physicians identified limited time, complex communication (particularly with the patient's primary provider/specialist), and electronic medical record issues as particular challenges in emergency care of children with medical complexity.

For example, one parent recounted being "in the ER for five and a half hours basically just re-telling the same thing." Similarly, another said, "[w]e keep having to tell the story over and over again and the medicines over and over again, even if they are in the computer…there should be some kind of knowledge of who he is—to prime them for what they're experiencing and not necessarily rely on us to regurgitate everything, considering his vast history here."

Providers also pointed to the extended time needed when caring for children with medical complexity. "It just takes a lot longer to try to do a comprehensive medical interview of the family, one provider said, while another noted, "caring for medically complex kids requires more time, more attention to detail...sometimes the problem isn't quite as clear-cut."

We found that parents and providers alike described their experiences in the ED in challenging terms. Parents used language like "anxious," "nervous," and "frustrated," and providers said the visits were "stressful" and could be "anxiety-causing."

Our study yielded important suggestions about how to address these issues and improve care. From the parents:

- “Just to listen to the parents a little more…if we need something or if we ask if you can do something, then we know what's best for her.”
- “It's almost like I want to hand them a card with bullet points where I don't have to explain it anymore.”

And suggestions from the providers:

- “We can make their medical history transparent and easily accessible and especially their current medications…that would save a lot of time.”
- “I think for some of these complex kids, we don't always have an attending to attending discussion…I think some of them really warrant that level of consideration.”
- “A letter that kind of accompanies them to the ED to say, this is what could go wrong and this is what you could do.”

We are now considering how to respond to what we heard. We have great opportunity to provide support for the caregivers and providers, while also making changes across an institution, health system, and beyond. For example, families of children with medical complexity could have a well-prepared and readily accessible emergency plan that provides essential shared information. Other strategies could include streamlining care in the ED through improved communication, adjusting staffing models to accommodate a higher number of patients with complex needs, or engaging other staff in the ED to assist with their care. Of course, reimbursement models for such services would need to be explored and likely modified for these ideas to take shape.

Our study is one of the first to show that providers and patients appear to be on the same page, identifying the need for strategies that improve the emergency care experiences of children with medical complexity.

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