

# Flipping the Script on Emergency Care for Children With Medical Complexity

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Children with medical complexity (CMC) are traditionally defined as those who have health conditions that are expected to last at least 12 months and affect multiple body systems or 1 system severely enough that specialty care and hospitalization are necessary.<sup>1</sup> This definition has been refined recently to reflect the necessary multifaceted approach to address increasing prevalence, cost, and challenges of caring for this population in the community and the hospital setting.<sup>2-5</sup> Most of the current literature on CMC focuses specifically on the strengthening of the medical home (and more recently, the medical neighborhood) and highlights the importance of preventing inpatient hospitalization and emergency care.<sup>6</sup> The importance of this work is irrefutable for CMC, but in regard to their emergency needs, we would like to propose a flip in the current script.

## LET US START WITH THE STORY OF...

George, a 6-year-old boy who suffered an anoxic brain injury at birth, is tracheostomy and ventilator dependent, with gastrojeunal feeds, and seizure disorder presents to his local emergency department (ED) at 6:00 PM with increased seizure frequency, rhinorrhea, and cough. His family called the primary care office and spoke to the on-call provider, who understood that care was needed, but the office was closed. The local ED was suggested. At the local ED, a chest radiograph and basic metabolic profile are obtained, and a request is placed for transfer to the local children's hospital where George receives the majority of his care. Studies are not concerning for pneumonia or electrolyte abnormality. He is tolerating all feeds. His home nurse travels home given the expectation of a late-night transfer.

At 11:00 PM, George arrives at the local children's hospital. He is diagnosed with a viral illness, lowering the seizure threshold. Neurology is called and advises a benzodiazepine bridge for increased seizures. The plan is to discharge him from the hospital, but the family has lost home nursing for the night. He is admitted to the pediatric ICU because of respiratory needs and is discharged the following day. A discharge summary is sent to the medical home and arrives 3 days after discharge.

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Dr Pulcini conceptualized and designed the piece and drafted the initial manuscript; Dr Rubin conceptualized the piece; and all authors reviewed and revised the manuscript, approved the final manuscript as submitted, and agreed to be accountable for all aspects of the work.

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The scenario described above is common and accepted as vulnerable patients such as George present to the ED. But we can and should do better in regard to emergency care for George, his family, and the multifaceted team that cares for him daily to the best of their ability.

The first step is to look upstream. Why is this care model common and accepted? We would assert that this is because ED use is often described in current studies to reflect a negative outcome measure, implying that ED visits are a failure of current medical models to address the needs of CMC. Unfortunately, this rhetoric is often carried over to families, which additionally can adversely affect the families' experiences and overall attitudes about emergency care. We would agree that the ED is often not an ideal service location for CMC, but at times, these visits are necessary to comprehensively address the needs of patients such as George. We would argue further that for this particular population and on the basis of emerging definitions and conceptual models, the ED should become part of the medical neighborhood of CMC, deserving significantly more planning, collaboration, and enhanced communication with the ED before an emergency visit.

The second step would be a culture change among ED providers because ~70% of ED visits for CMC occur in a general ED.<sup>7</sup> ED providers, even those with pediatric experience, may not be as comfortable caring for CMC for a variety of reasons, including (but not limited to) inadequate education and/or training, liability, and limited time and reimbursement for care coordination. Therefore, a multifaceted approach is needed, including enhanced communication with pediatricians and pediatric specialists, policy changes to incentivize care of CMC (including care coordination), a stronger educational strategy for all ED providers, and innovative local

models of interdisciplinary care. One such model may involve conceding that most CMC are centralizing to large pediatric health systems with multiple subspecialists in addition to their primary care provider (PCP). This centralization may offer an opportunity to offer a coordinated "emergency care response team" to other EDs throughout the region, with the title and composition of that team being based on local resources and staffing models.

There is currently limited literature on both quality of care of CMC in the pediatric and general ED as well as the reasons why CMC most often visit the ED. We would suspect there is large variation, but by incorporating emergency care into their medical home and/or neighborhood, we can start to focus research on best practices, quality-improvement initiatives, and interventions to optimize emergency care of CMC. Although George's scenario includes the community ED, where most CMC are cared for, the first steps to demonstrate a better care model, which is necessary and feasible, need to occur in the pediatric EDs and/or pediatric centers, where additional partnerships and interventions with community EDs can occur.

### **LET US CLOSE WITH THE SAME VISIT OF GEORGE AFTER FLIPPING THE SCRIPT**

George, a 6-year-old boy who suffered an anoxic brain injury at birth, is tracheostomy and ventilator dependent, with gastrojejunal feeds, and seizure disorder presents to his local ED with increased seizure frequency, rhinorrhea, and cough. His family called the primary care office and spoke to the on-call provider, who understood that care was needed, but the office was closed. The local ED was suggested, and the PCP and family know the local ED staff is aware of the pediatric health system's emergency care response team for CMC in such situations. They place a call to that on-call team and reach

a prespecified patient navigator, who is able draw on the existing care plan in their health system's electronic health record. The local ED therefore has access to the emergency care plan that has been recently updated by George's specialist team, and the PCP and can seek coordinated consultation within the pediatric health system. George's ED team assesses him, notes his vitals are normal, and he most likely has an upper respiratory tract infection and is tolerating feeds. The patient navigator helps facilitate a conversation with the on-call neurologist at their health system while concomitantly calling the medical home provider back to inform them they suspect upper respiratory infection-induced seizures. On the basis of their knowledge of George, the medical home provider agrees, so no studies are performed. The on-call neurologist suggests a benzodiazepine bridge for increased seizures. The first dose is given in the ED, and over the next 2 to 3 hours, he is seizure-free and stable. Family and home nurse are comfortable taking him home, and the care plan is updated regarding the altered seizure management plan. He is discharged with a plan to follow-up with his primary neurologist from home the following day by phone.

As care management solutions mature for CMC, our health systems must adapt to different models that will increase communication and streamline patient-centered care. In this emerging space, there is an opportunity to flip the script on emergency care of CMC and test new models that will help not only us as providers, but more importantly, help George and his family as well.

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#### ABBREVIATIONS

CMC: children with medical complexity

ED: emergency department

PCP: primary care provider

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