

## Chronic, Complex Care Is...Well, Complex and Chronic

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This month *Pediatrics in Review* starts a section of [review articles focused on chronic, complex care](#). When presented with the idea, editorial board members immediately suggested topics such as “Care of the ventilator-dependent child at home,” “Children and adolescents with Trisomy 13, Trisomy 18,” and “Support of families taking care of children with chronic, complex disease.” Our inaugural article focuses on managing medically complex infants who are discharged to home. Although my initial intention for writing this blog was to comment on this article, I could not ignore three separate somewhat-related thoughts that I just had to share.

Perhaps it was naïve romanticism way back in grade school when I pictured my future self as a pediatrician practicing in a rural countryside, healing some children and supporting families of other children whose diseases had no cure and whose lifespan was unfortunately short. Now, sixty years later, I find myself a residency program director reviewing an intensivist’s email praising two residents who spent many hours during the night figuring how best to manage a medically complicated patient who was emergently admitted to the hospital. The patient, normally cared for by multiple subspecialists at a distant tertiary care institution, was on many, many medications and required nighttime CPAP. The patient and family had been enroute to the tertiary center but the patient’s condition acutely deteriorated and the family chose to divert to our hospital, arriving with no records and no CPAP machine. I tried to imagine the reactions our resident admitting team (and the attending physician) had when first approaching this patient. Not a simple task I am sure, yet the residents ably and nobly assisted the patient, the family and the attending physician. When I was a resident, home care for such a patient was not an option. Now, as more and more complicated patients shift from inpatient to outpatient care and we train our residents for managing these patients with complicated chronic care issues as outpatients, how do we ensure currently practicing pediatric providers are also prepared for these outpatients?

At morning report the other day, the presenting resident spoke about a patient with Duchenne muscular dystrophy. I sat back, expecting a talk about diagnosis and management, but instead, the resident, who

happened to be on the endocrinology service, proceeded to ask the audience under what circumstances this patient could be referred to endocrinology. “Hello,” I said to myself, “when does a genetic disorder of muscle cause an endocrine problem?” As the resident continued his presentation, I sheepishly realized I was assuming a too simple approach to the question. It wasn’t the disease causing an endocrine problem; it was the treatment that was causing the endocrine problem. Administered high dose corticosteroids help increase muscle strength, reduce cardiomyopathy, delay scoliosis, and increase lifespan, but they also cause bone demineralization, delayed puberty, delayed growth, and adrenal insufficiency. In fact, for the patient who was the subject of this morning report, the treatment of his muscular dystrophy was causing new endocrinological problems, which in turn were causing new physical and psychosocial problems that the patient and family were asking for assistance. Rephrasing my earlier question, how do we ensure currently practicing pediatric providers are prepared for outpatients with chronic diseases that have increasing survival rates yet have an increasing number of complications?

Technology can improve our quality of life, but adopting such technology can be hard. Thanks to having multiple ear infections as a child and attending many a hard rock concert as an adolescent, I cannot hear certain frequencies. Denial, pride, and ignorance are reasons why I blamed others for not enunciating well. This past year, with everyone wearing masks and me frequently asking residents to repeat themselves, I finally agreed to having my hearing tested and accepted the need for hearing aids. The difference is remarkable. Before I got the aids, I was unaware I was slowly (insidiously?) growing comfortable with isolating myself from others. My family and colleagues note how more upbeat and engaged I am now, and they can immediately tell when I have forgotten to wear the aids. I fully embrace these technological wonders, but they frequently get entangled with my mask, amplify certain sounds I could do without, and remind me how muffled silence can be enjoyable when I remove the aids before bedtime. While this experience is a poor analogy for what technology-dependent patients may face, I wonder what patients and their families feel about the technology they are dependent on. Do we as practicing pediatric providers understand how patients and families may have difficulties accepting and dealing with technology?

The practice of pediatrics is evolving as more children with complex and chronic diseases live longer. *Pediatrics in Review* hopes our future articles on complicated chronic care issues will help us help these children live longer and—along with their families—have a better quality of life.

- [Case 1: A Medically Complex 10-month-old Boy with Lethargy](#)
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