

2018 AAP and APA Ethics Essay Contest - *Honorable Mention*

Our Rapunzel

Catherina Pinnaro, MD

The intergalactic noise of my hospital-issued phone sung out again. I chugged my large purple water bottle and hoped it was anything except another consult for severe diabetic ketoacidosis, but that is exactly what it was. The Pediatric Intensive Care Unit (PICU) resident calling was very competent at managing these patients, so I wondered why he was contacting me so early in the clinical course. He told me that a 12-year-old patient was comatose. Unarousable. His level of concern was palpable. Her pH was unreadable. I called him back quickly, told him to give mannitol and get her head imaged. I would be there when she was back from computed tomography (CT). My voice shook. I was nervous. I had yet to see someone this ill from diabetes. I hoped I'd given good advice. I'm just a first year fellow. My staff was in clinic. I wished I hadn't chugged that water.

I didn't need to ask for the patient's room number, as the sweet smell of ketones filled the hallway. I was met by her grandmother, mother, step-brother and her caseworker. Her grandmother, who currently had custody, was battling her own serious medical problems and was trying to do her best for the patient. A lot of things went wrong prior to her admission, but after hearing the whole story, I felt that it was just a series of unfortunate events. She had been seen in urgent care, and then spent all day in the school nurse's office. I knew that sorting out the rest of her complicated backstory would be a challenge to deal with when we did education with the family, when she was better, if she ever got better.

Fast forward seven days – she was in a coma and on continuous renal replacement therapy for acute kidney injury. She slowly awoke. And then she did great. She was transferred to the nephrology service and, shortly after, to the endocrine service because her kidneys had completely recovered. She seemed to be the luckiest girl in the world.

A difficult weekend conversation with her grandmother con-firmed our team's suspicions that it would be impossible for her grandmother to safely care for our patient with newly diagnosed diabetes. Her grandmother struggled with fine motor tasks and had limited mobility secondary to a recent stroke. She expressed concerns about being able to call our nurses and draw up and administer insulin. The Department of Health and Human Services agreed with these concerns—our patient would need to go into foster care. This put me at ease, as I was uncomfortable with the idea of this pre-teen being solely responsible for her diabetes care, especially after being in a coma for a week. However, our good intentions cast the spell that trapped Rapunzel in the tower of our children's hospital.

It took two more weeks of this child being hospitalized for me to realize that she had become a prisoner of our institution. She was alone and had been for the majority of her time in the

hospital. She only had pajamas and slippers. She desperately wanted a bra. She wanted to go outside. She had no shoes or coat or anyone to walk with her. By recommending foster placement, I felt we were now actively preventing her from living a normal life—albeit one with diabetes. Had we failed her?

One of the key points we emphasize with patients who are newly diagnosed with type 1 diabetes is that it is not their fault and that they will be able to live happy, successful, “**NORMAL**” lives. I thought about this every day she was in the hospital. I tried to underscore this every time I saw her, but it was so ironic that I can’t imagine it seemed genuine to her. I stopped by before rounds on a Friday and heard Rapunzel singing in the shower. I stayed. We had a long conversation. She revealed that she had a history of depression, but after moving in with her grandmother, she finally felt like she fit in at school and was no longer being bullied. My guilt spilled over—we were preventing her from going to school.

My attending staff and I were wildly conflicted about what to do as it was now Saturday, and we had limited social services resources. We both ultimately knew this couldn’t wait any longer. I went home and contemplated the appropriateness of buying her some necessities. My biggest concern was whether it was right to treat Rapunzel differently than my other patients. In this circumstance, I could see that she needed help. Both I and my attending showed up with clothes and other supplies on Sunday. I felt absolved.

A child life specialist was able to take her outside in her new sneakers and clothes later that day. I stopped by in the afternoon, and she showed me the grass and twigs she picked up on her walk. She was so happy she made it outside that she kept a bit of nature for herself because she wasn’t sure when she would get out again. She hugged me. I held back tears. I went home and reflected on how much we did medically, but how we really could do so much better. Despite (or maybe because of) having a team of over twenty doctors, nurses, physical and occupational therapists, social workers, child life specialists, and music therapists, we did not meet this patient’s basic human needs once she physically recovered.

Once we realized that there was an entire domain of her wellbeing that we weren’t addressing, we still met barriers. There wasn’t even a mechanism for her to get laundry done in the hospital, which was now serving as her home. She wasn’t eligible to go to outpatient appointments since she was still technically admitted. Things that seem so inconsequential compared to being on dialysis in a coma consumed my days as I began to realize the dichotomy of care that can arise when a pediatric patient does not have a constant advocate. Many children’s hospitals have web-sites and signage emphasizing that parents and families are critical members of the care team.¹ But what about patients who are alone? A literature search yielded no studies comparing health or psychosocial outcomes between pediatric patients who consistently had a family member present versus those who did not, but it may be worth studying. As providers, we strive to treat our patients equally, and justly. However, I tried so hard not to treat this patient differently, that I did her a disservice. We must evaluate our motives when veering from the standard, but I now believe there are certain patients and situations that warrant additional attention.

Clinically we did everything right. She is a medical success story. We were beneficent, did no physical harm. However, she was in desperate need for someone to truly care for her, both in and out of the hospital. Her kidneys could not afford another major injury, and she could die if her diabetes was not appropriately managed.

Thus, Rapunzel became a member of a club that I am becoming more familiar with—children who cannot return home because their family is not equipped to care for them medically. As our medical technology continues to advance, there is an increasingly large population of children entering foster care specifically because they have complex medical needs that their families cannot meet. On any given day, there are 428,000 children in foster care in the United States, and nearly half of these children have chronic medical problems and unmet health needs.^{2,3} Approximately one third of licensed foster care providers lack placements because they are reluctant to take on medically complex children, and studies suggest that foster parents feel inadequately prepared to take care of such children.^{2,4} These children deserve a stable and loving environment in which they will be well-cared for, and the healthcare system will unlikely be able to sustain inpatient admissions for all medically complex children no longer requiring inpatient level of care. Medically unnecessary admissions are expensive, and prolonged hospital stays have been associated with decreased quality of life in several chronic pediatric disorders.⁵⁻⁷ Thus, we have an ethical imperative to address this systems issue as the number of children with complex medical problems who need homes will only continue to grow as medical technology continues to advance.

This story eventually has at least a temporary happy ending. After almost a month of trying to identify a foster family willing to learn diabetes cares, Rapunzel was rescued from her tower by a great family. One of her foster mothers has type 1 diabetes herself and felt up to the challenge. We had frequent contact with her foster family in the weeks following her hospital discharge, and medically she has been doing great. Emotionally, I hope so. My colleague reported that Rapunzel has since taken over doing most of her diabetes care supervised, but without assistance, and seems to be thriving. I still think about her often and am grateful she was rescued. I just wonder how many more towers there are out there.

References

1. Advocating for Your Child. (Accessed 6 Apr, 2018,) www.childrenscolorado.org/conditions-and-advice/parenting/parenting-articles/advocating-for-your-child/.
2. Seltzer RR, Henderson CM, Boss RD. Medical foster care: what happens when children with medical complexity cannot be cared for by their families? *Pediatr Res* 2016;79:191-6.
3. Foster Care. (Accessed 6 Apr, 2018,) www.childrensrights.org/newsroom/fact-sheets/foster-care
4. Lauver LS. Parenting foster children with chronic illness and complex medical needs. *J Fam Nurs* 2008;14:74-96.
5. Gaies MG, Watnick CS, Gurney JG, Bove EL, Goldberg CS. Health-related quality of life in patients with congenitally corrected transposition of the great arteries. *J Thorac Cardiovasc Surg* 2011;142:136- 41.
6. Michel F, Baumstarck K, Gosselin A, et al. Health-related quality of life and its determinants in children with a congenital diaphragmatic hernia. *Orphanet J Rare Dis* 2013;8:89.
7. Alonso EM, Martz K, Wang D, et al. Factors predicting health-related quality of life in pediatric liver transplant recipients in the functional outcomes group. *Pediatric Trans-plant* 2013;17:605-11.