



# FOSTER CARE DUE TO MEDICAL COMPLEXITY:

## MY RAPUNZEL

*Catherina Pinnaro*

Pediatric patients who require medical care that is beyond the ability of their family to administer and/or maintain poses numerous ethical questions. Assuming the best interests of the child necessarily compel foster placement, what practical and ethical issues remain? This case presents such a scenario, highlighting several salient issues to consider when contemplating how best to care for these patients. The case analysis looks at both clinician- and systemic-level components to addressing these patients medical and human needs.

### THE CASE

The intergalactic noise of my hospital-issued phone sung out again. I desperately drank some water and hoped it was anything except another consult for severe diabetic ketoacidosis, a serious complication of diabetes that presents with vomiting and dehydration. It evolves to altered mental status and ultimately death if not treated. This would have been the third such consult that day. I'd lost count of how many I'd seen that week, and it was only Wednesday. I couldn't remember the last time I had eaten a meal. Bathroom breaks were luxuries I could not afford.

This should not have been about me, but I was physically and emotionally fatigued. My inner monologue was unable to overcome reality—another diabetic ketoacidosis consult was destiny that afternoon. I put my head down on the table while I waited for the rest of the message. A series of texts appeared from a normally very calm resident, his level of concern palpable from the cadence of this unilateral exchange. "A 12-year-old girl is comatose." Ding. "Her pH is unreadable." Ding. "Blood sugar over 500 mg/dl." Ding. "Call me." Ding. "NOW." Ding.

I called him back quickly, told him to give mannitol and get a CT of her head. I told him I would be there when she was back from the scan. My voice shook as I spoke. I was nervous. I had never taken care of someone this ill from diabetes. I'm just a first-year fellow; I hoped I had given good advice. My staff was in clinic. I was already starting to regret drinking that water.

I didn't need to ask for her room number; the sweet smell of ketones filled the hallway. I was met by her grandmother, mother, step-brother, and her caseworker. I introduced myself to everyone. I tried hard to maintain objectivity and not jump to conclusions while being direct about the serious prognosis—I would also need to obtain information to ensure Rapunzel was not denied critical care leading to such a severe presentation. I have never wanted a "real doctor" to enter the room more so than during this conversation.

I mostly listened, although it was difficult to understand grandma at times due to residual facial weakness she had from a recent stroke. Grandma reported taking Rapunzel to urgent care 3 days prior, where she was discharged with supportive measures for headache and cough. 2 days prior, Rapunzel spent all day in the school nurse's office with similar symptoms. The day prior to admission, she had an episode of vomiting in the afternoon. She had some crackers and 7-UP but continued to feel nauseated. Her mom checked in via phone around 7PM. By midnight, Rapunzel was dizzy and had more rapid breathing—her grandma told me she was planning on bringing her back to the doctor in the morning. She did not want to take Rapunzel that night because she was uncomfortable driving and had already brought her in once without receiving a diagnosis. She then found Rapunzel unresponsive on the bathroom floor at 4AM. That's when she called an ambulance. This seemed a plausible story without red flags—the diagnosis of diabetic ketoacidosis is often delayed, even after seeking medical care. In most instances, I would leave it at that and comfort the family. I was starting to get emotional about this girl, who lay without movement, tethered to insulin and fluids, fighting for her life.

However, the presence of a caseworker and the knowledge that Rapunzel was living with her

grandmother forced me to investigate the situation further. The pit in my stomach was large enough to have its own gravitational pull. The urge to back away was strong. The family could sense I was getting uncomfortable and subtly diverted from my gaze. I tried to reassure them that we were all on the same team and there was no judgement here. I just needed to know what was going on in their family so I could formulate a plan for when she was better, if she ever got better.

**“...PARENTS AND FAMILIES ARE CRITICAL MEMBERS OF THE CARE TEAM.”**

Mom frankly told me that she struggled on and off with alcoholism and was being treated for bipolar disorder. The family had been homeless, and DHS facilitated the temporary living arrangement with grandma. Rapunzel's biological father was not involved, but knew she was in the hospital. The caseworker corroborated this information, adding that mom retained parental rights.

Seven days later, Rapunzel was still in a coma and on continuous renal replacement therapy for acute kidney injury. She slowly awoke, and then she did very well; 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. But was she? I had not seen mom in several days. She stopped answering phone calls. Grandma did the best she could to come and visit, but due to her recent stroke, her mobility was impeded.

It was now time to initiate diabetes education for Rapunzel and her family. But that meant we had to get them here. I already had hesitations about grandma's ability to draw up insulin, check blood sugars, fill and pick up prescriptions for life-sustaining medication, and obtain emergency care. I knew this would not end well and yet at that moment I could not bring myself to say anything. Our patient was happiest when grandma was around. Maybe grandma could do it if given a chance?

**“MAYBE GRANDMA COULD DO IT IF GIVEN A CHANCE?”**

Diabetes education began and our nurses raised concerns almost immediately. My attending switched out, and the incoming staff saw the writing on the wall immediately. The new attending's lack of emotional investment brought a different perspective. She and I discussed conversational approaches, aware that navigating this territory would prove challenging—we had to convey to grandma that she was not failing

Rapunzel, and we had to let Rapunzel know that she was not a burden. We sat down with grandma and asked her how comfortable she felt performing several of the new tasks she would be expected to do prior to discharge. We knew this could possibly backfire, but grandma had insight into her abilities. She was relieved to realize that we understood she could not physically do what we were asking, but understandably she was simultaneously heartbroken. Rapunzel was just angry. They both knew what this meant. We tried to remain factual and express our concern for Rapunzel's well-being, but I couldn't look her in the eye while I did it. We contacted her caseworker with our concerns. She reviewed the case and ultimately agreed—Rapunzel would need to go into foster care. [1]

This should have 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. Her kidneys could not afford another major injury, and she could die if her diabetes was not appropriately managed. However, I knew how hard her life had been, and how happy she was now. 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. Ironically, my good intentions took away normality for this girl and cast a spell that trapped her in the tower of our children's hospital. Medically stable, each day proved a waiting game to see if a foster family could be identified who was willing to learn to administer diabetes care.

It took two more weeks of Rapunzel 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. I started coming in before rounds, trying to find the time and confidence to truly talk to her. She was always pleasant but hard to connect with. I would remark on her drawings, she'd thank me, and that was that. Part of me was selfishly afraid of facing negative emotions appropriately directed at me for my role in her imprisonment. So, I kept it light and got nowhere.

One Friday, I heard Rapunzel singing in the shower. The lyrics were so sad. I waited. It led to our first conversation of substance. She cried then, I cried later. She resented me for communicating my concerns about her grandma's abilities to her caseworker. She

expressed extreme frustration with the uncertainty of her fate. She really wanted to go to her school talent show the next day, which she knew would never happen. 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. She missed her friends. My guilt spilled over—not only did I take her away from her grandma, but I was preventing her from going to school.

I also noticed that after her shower, she put back on her pajamas and slippers. "That's all I have," she said. She desperately wanted a bra. She wanted to go outside. She had no shoes, or coat, or anyone to walk with her. She was all alone here, and I had barely noticed. By recommending foster placement, I was now actively preventing her from living the normal life I promised her a few short days ago.

I brought her clothes and shoes the next day, partly because it was the weekend and I had limited resources to help me, and partly to absolve some of the guilt I felt for not noticing sooner. I needed to start fixing this now. 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 Rapunzel showed me the grass and twigs she picked up on her walk. She was so happy she made it outside that she kept that little bit of nature for herself; she wasn't sure when she would get out again. She hugged me, and I held back tears. I tell myself I could have greatly improved a bad situation had I been brave enough to ask some tough questions and face the answers. Or maybe not completely.

It was actually very challenging to meet Rapunzel's basic human needs once she physically recovered. While there have been improvements in hospital environments for children over time, the environment still poses significant challenges. [2] There was no good mechanism for her to go to school. We were able to get her some assignments, but she was a month behind and we had no way to individualize a lesson plan for her. We couldn't get her to outpatient medical appointments because she was admitted, albeit for no reason other than to identify someone to care for her. Getting her clean clothes was also difficult. Hospital policy indicated that an adult must be present to use the laundry machines on the inpatient units, and the nurses

**“RAPUNZEL  
BECAME A MEMBER  
OF A CLUB THAT  
I AM BECOMING  
MORE FAMILIAR  
WITH—”**

were not allowed to help her. So, the pile of dirty clothes continued to grow. She had no ability to leave and no one to bring her new clothes or take laundry home. I brought her what I could, and sheepishly offered to take dirty clothes to my house to wash them. She declined. I didn't ask again. This was one of her off-limit topics.

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. [3] Many children's hospitals have websites and signage emphasizing that parents and families are critical members of the care team. [4] 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. Even with a team of upward of 20 specialists, including psychology, child life, and music therapy, we could not fulfill the basic functions of family. [3]

### ANALYSIS

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. [5,6] Data showing unmet medical needs of children often endure into foster care led the American Academy of Pediatrics (AAP) to classify children in foster care as a population with special health care needs. [7]

These children deserve a stable and loving environment in which they will be well-cared for. Approximately one third of licensed foster care providers lack placements because they are reluctant to take on those with medical complexity, and studies suggest that foster parents feel inadequately prepared to take care of such children. [3,8] The healthcare system will unlikely be able to sustain inpatient admissions for all medically complex children no longer requiring inpatient level of care, and as shown, it is not ideal to draw on to do so. Medically

unnecessary admissions are expensive, and prolonged hospital stays have been associated with decreased quality of life in several chronic pediatric disorders. [9, 10, 11] Thus, we have an ethical imperative to address this systemic issue as the number of children with complex medical problems who need homes will only continue to grow as medical technology continues to advance. [12,13] Even if advancing technology ultimately affords easier use of medical devices necessary for the care of these children, the initial reluctance of foster families to accept complex children needs to be addressed to overcome this issue.

“—CHILDREN WHO  
CANNOT RETURN HOME  
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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. Rapunzel's kidneys have recovered and her diabetes is under excellent control. Emotionally, she still struggles but her foster moms are providing excellent support. Her biological mom's parental rights have been terminated. I still think

about her often and am grateful she was rescued. I just wonder how many more Rapunzels there are out there.

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THE AUTHOR HAS DISCLOSED NO CONFLICTS  
OF INTEREST

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*Endnotes continued on page 25*

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