

PICU

By Jessica Cheng

Marcus is 6 weeks old when he comes to us in the pediatric intensive care unit. The story we hear is that there was a potential choking event at home. As I'm preparing to go down to the Emergency Department, we get the call that the head CT showed significant bleeding in the space between Marcus' brain and skull, a sign that is highly concerning for non-accidental trauma (NAT), a synonym for abuse.

Marcus experiences continuous seizures that are refractory to anti-epileptic medications and ultimately require him to be placed into a medically induced coma. Over the course of weeks, we wean him off of his pentobarbital drip and extubate him. I successfully trick myself into thinking that when his brown eyes lock on mine, he is seeing me, and that when his fingers grasp mine he is telling me that he's going to be okay.

Matthew is 19 years old. He suffered a hypoxic brain injury when he was a baby and has had a tortuous course to adulthood. He doesn't speak but, rather, produces heartbreaking moans that the layperson is unable to interpret but which his mother swears is replete with distinct meaning in every cadence. Because we cannot understand his moans, we are forced to learn the language of Matthew's body through other means. The rhythm of his heartbeat, the distention of his abdomen, the heat of his body—all serve as proxies to let us know that something is wrong. The trouble is that it is exceedingly difficult to pinpoint exactly what is wrong—Is it pain or infection or withdrawal from the very medicines we are administering to treat his pain and agitation? Or is it some combination of all the above? No one is quite sure. The only thing of which I am sure is that he moans more often than not, and it makes me question whether we are really doing no harm.

Johnnie is 11 years old. He has been here for 32 days now, and no one knows what to do with him. He has a feeding tube in his belly and a breathing tube in his neck. He cannot see and cannot hear. He does not get out of bed. Thankfully, he is stable but he has gathered a veritable litany of fresh diagnoses since being admitted. I make small changes on a daily basis, correcting electrolyte imbalances and tinkering with insulin but not fully comprehending what the plan is in the grand scheme of things. The MRI of his brain shows severe parenchymal loss, most likely due to the unwavering progression of some underlying genetic condition that we have not diagnosed but which diagnosing probably wouldn't do much in the way of helping even if we could. It's not until the end of my first week that I learn that before getting admitted, he was able to walk 20 paces with a walker and attend school daily. The weight of the loss that he and his family have suffered hits me like a ton of bricks. This sensation is immediately followed by a gut punch of shame that I hadn't had the decency to feel that way

previously because I had assumed this was his baseline. As I do my best to explain to his mother that this bedbound state is most likely Johnnie's new normal, I feel useless in the most helpless of ways.

These are the patients that I grapple with, the ones where I see the past, present, and future all jumbled up together. The ones where I wonder "what if...?" but also "HOW?" The ones where I realize that it is the deltas -- the yawning gaps and incremental millimeters between baseline and the new normal that define joy and sorrow. The ones where you hope for a miracle because medicine cannot give you an answer.

These are the patients that teach me what love truly means. That, even if your eyes can't see, and your ears can't hear, and your mouth can't speak, you may yet be able to feel the touch of a warm hand on your face. That, if sung softly and with enough tenderness, the refrain of a nursery rhyme may reach you. That, sometimes the most important and in fact only thing that matters is being there, in the room, sitting in a hard hospital chair.

Jessica Cheng is a pediatric resident at the University of California Davis in Sacramento, California. She is originally from Los Angeles and completed medical school at the University of California San Diego.