

Right Brain: Dad's pride

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It was a slow night at the end of a week of slow nights, which felt like a blessing. A blessing you don't want to talk about too loud in case you jinx yourself, but a blessing all the same. I was in the call room starting to consider a nap when my pager went off with the special tone that indicates a stroke code. Patient K, floor 8 West, onset now. I recognized the room number as belonging to the stem cell transplant unit. I took the elevator, congratulating myself on not having gone to bed earlier; it is hard to get on full functioning mode after being woken up suddenly.

The room's door had every kind of isolation sign on display, which always feels somewhat ominous on a hematology floor. I started gowning up while the intern in the primary team briefed me on the story: "He is 32. He is on a medication that can cause intracranial bleeds, defibrotide." Isolation gown open. "We have not seen him tonight, but per his dad he was talking normally earlier in the night and now he is barely saying anything and he is not following commands." Gown wrapped around me and tied. "When was the last time anybody saw him fine?" Right glove on. "11 PM." Left glove on. Pause to look up at the intern.

"Why is he in the hospital?"

"Relapsed ALL."

I will admit that based on the floor we were in, the multiresistant pathogens that my yellow gown and purple gloves portended, and the relatively nonspecific symptoms at a late hour at night, my suspicion for an acute stroke was dwindling. I opened the door resolutely. My first thought upon seeing Mr. K was, "Why is it that they never mention the jaundice?" My neurologist brain had missed the connection between defibrotide and hepatic failure. He was the shade of yellow that comes with a bilirubin over 15 and had his eyes closed and his head bent down, as somebody who is trying to retreat into themselves would do. "Hey, there," I said. He opened his eyes, but he still appeared to be gazing up from a very distant place. "What's your name?" He mouthed an answer but no words came out. "Can you hold this arm up in the air for me?" He did, well enough that I had no doubt that his strength was full despite the violent asterixis that shook his entire body. The same thing happened when I tested the other arm.

"That trembling has been there for a while," offered a voice at the foot of the bed. I turned around to find Dad, a heavyset man in his 60s who appeared much calmer than what I, for some reason, was anticipating. "He did a similar thing the other night. I was here and he started talking out of his mind, but then got better after a couple of hours."

"I heard you saw him acting normally at around 11 tonight? Show me 2 fingers with your left hand, Mr. K."

Tremulous and ashen, 2 fingers came out of his left fist.

"Yes, I was here at 11 and he was fine. I then left for the hotel I'm staying at, and he called me on my cell half an hour ago. He was scared; he did not know where he was. But he had the presence of mind to know I was the one on for tonight."

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“What do you mean? Now smile really big for me, Mr. K.”

Effortful but symmetric grimace.

“My wife and I have been alternating spending the night here. Before we leave for the night we tell him which one of us to call if something happens.” He pointed at the whiteboard next to him, where 2 phone numbers preceded by “Mom” and “Dad” were written in a corner. “He knew to call me and not my wife.” He beamed and looked sideways at Mr. K, so very proud that his son, in the midst of this distorted nightmare, had retained that scrap of common sense.

I stopped going through my NIH Stroke Scale motions and for the first time gave my full attention to the gentleman standing next to me. The meaning of that calm demeanor that had bothered me upon entering the room suddenly sunk in: Dad’s composure was unsettling because it clashed dramatically with the reality of that hospital bed. Because Mr. K, with his multiresistant pathogens, his jaundice, his hands flapping downwards a good 3 inches at a time, and above all, his way of looking at us as if peering from the very center of his being, was dying. And his dad, as the pride in that smile betrayed, did not know or did not want to know.

I allowed myself 5 seconds of looking at this man straight in the eye, of wondering what it must be having your son crumble in front of you a little bit more every day, how on earth you keep entering this room with a straight face. For a moment, I envisioned an alternative reality in which it was not 1 in the morning and I was not a stranger they just met, where, instead of continuing to go down my list of heavily standardized exam maneuvers, I would sit down with dad and discuss, gently but honestly, how we could prepare for what was to come.

And then I turned back around and asked Mr. K to touch his nose with his right pointer finger, because it was indeed 1 in the morning and I was just here for the stroke code.

Common sense tells us that death is an absolute state, defined as “a permanent cessation of all vital functions.” But then we become doctors, and that very clear line separating the living from the departed blurs. We bring people back from cardiac arrests. We transition sick patients to comfort measures knowing that we are committing them to an unavoidable outcome for the greater good. We diagnose them with brain death and have to explain to a grieving family how this is death too, regardless of the green line beeping on the cardiac monitor. Mr. K was very much alive when I saw him, yet in the imaginary spectrum extending from “completely

healthy” to “deceased,” he was not in the same category as the rest of us in his room. He was not, by any means, the most far gone of the patients I have seen, but he stuck with me because of the disconnect between his place in that spectrum and our approach: me, barging in his room and asking him to comply with my seemingly random requests, and Dad, focusing on the small victories instead of on the disheartening big picture.

On the way down to the CT scanner, when Mr. K was out of earshot, the primary resident confided that he had been dodging a transfer to the ICU for several days, because his hematologist was worried that he would be made comfort care as soon as he arrived in the unit. After the head CT showed no bleed and we were all satisfied with encephalopathy as the cause of Mr. K’s decline, I returned to the call room thinking about hope. Of all the human feelings that, as physicians, we have to navigate, hope is one of the most difficult to control. When should we put a limit to it? Is it wrong if we fall prey to hope ourselves, if we too try to delay the inevitable? I could not help wondering how many hours of lucidity Mr. K had left, and if, in the name of hope, we had denied him the opportunity to use them to say goodbye.

I checked his electronic chart a few hours later, as the hospital was waking up around me while the day shift started to come in. By then he had been transferred to the medical ICU. After a small paragraph describing his mental status on transfer, the ICU resident’s note mentioned that when she was leaving the room Mr. K had asked her if she was on her way to talk to the grim reaper. I recalled his sunken eyes and suddenly noticed in them what, trying to focus on his pupillary function, I had not identified during the stroke code: fear. Mr. K was less oblivious to his fate than he appeared, and he was terrified. That is when I understood that Dad’s composure was nothing more than a brilliant performance, not coming from hope as much as it was coming from love. He was just showing me how you keep entering your dying son’s hospital room with a straight face, day after day: by shielding yourself in a determined hope, so that when his demons come to haunt him, he can at least find comfort in his dad’s proud smile.

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