

The Midnight Toll Booth Operator

I had a wonderful teacher in medical school, who, in an effort to limit the amount of information we had to memorize, taught us the psychiatric personality disorders as cartoons. The stick figure holding up a mirror to look at himself, with perfectly coiffed hair and trophies on display in the background was narcissistic personality disorder. Dependent was a tiny human clinging pleadingly to the shoes of the giant next to her. Schizoid personality disorder featured the head and shoulders of a man encased a box labelled “toll booth.” Next to the booth was an empty road. The moon waxed overhead. In the margins of the picture, I had noted that people with schizoid personality disorder are often “detached loners” who are “happy in isolation” and rarely require treatment as they avoid everyone, including the clinic.

This image of the midnight toll booth operator has lingered in my consciousness. I’ve dreamed of it many times, usually viewing the scene from the outside. In my dream, the operator’s back is to me, and the light from a bare bulb overhead spills down his shoulders and skitters off the pavement around the booth. He is visible to everyone around for miles, vulnerable in a way no other animal would allow. But there is nobody watching except for me, and so he sits and waits, and I know that if someone were to drive by, he would rush them through so he could be alone again. I assume that I fixated on this image because aloneness without loneliness is so foreign to me. Is there joy there? I am so curious about him, which of course is the last thing he would want.

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As a newly minted third-year medical student rotating through the Internal Medicine service, I was assigned to the case of a 52-year-old man. Dave Gutierrez, my resident informed me in an offhand way, likely had schizoid personality disorder. It wasn’t an official diagnosis, and in the context of his medical presentation, which was highly suggestive of pancreatic cancer, his personality quirks were considered unproblematic and therefore insignificant.

As a student my role was to know all the details of his medical care, suggest daily treatment plans that would be evaluated by the supervising doctors, and get to know the patient. This last task was impressed upon us as the way we would be most helpful to the team. The doctors did not have the luxury of time to learn the details of patients’ lives, and we students might be able to discover a tidbit of information that shaped the direction of care. We each fantasized that through our tactful empathy and perceptive questioning we might learn that the patient had in fact been hiding a history of drug use, or taking a supplement that interfered with her medication or neglected to mention a history of leukemia as a child and that we would return lauded as heroes as we cracked the case and saved a life and were given the grand prize of the highest residency recommendation a student has ever received.

So I set about getting to know Dave. I knew from his chart that he was 52 and a veteran and that while he had previously been homeless, for the past few years he had been living alone in a rural area many hours north of San Francisco.

I knocked on his door, waited a breath, and pushed it open.

He was lying on top of the covers of his hospital bed, facing away from me and toward the window at the end of the room. His TV was off, which was unusual as most patients kept it constantly chattering in the background. He rolled to face me and I saw that the whites of his

eyes were tinged with yellow and that a ruddy gold had begun to show in his cheeks above his beard.

“Hi! My name is Kea, I’m the medical student assigned to your case. Would it be okay if I came in and we chatted for a bit?”

“Sure.”

I pulled a chair over to the side of his bed, cringing internally at the sound as it scraped along the floor. I dropped my pen, picked it up again, and finally faced him, notebook in my lap. Was I sitting too close?

“How are you doing today?”

“Fine.”

I tried to smile encouragingly.

“I’m so sorry you’re here in the hospital.”

Silence. I briefly scanned the plastic bags of liquid and tubing connected to him. I recognized saline, but nothing else.

“Just so you know what my role is, I’ll be checking in on you every morning. You can share anything with me that you want your doctors to know, and if you have any questions, I will make sure those get answered.”

He nodded, not looking at me.

“Do you have any questions now?”

“No. I mean, I think I have a pretty good sense of what’s going on.”

I knew that my next question should be to ask him what he meant by “what’s going on,” but I also knew that I likely didn’t have enough medical knowledge to respond appropriately to whatever he came up with. What if this led into questions about cancer medications, or about prognosis, or, God forbid, about death? I made a mental note to google my way through his chart again.

“Is there anyone you want me to update for you while you’re here?”

“No.”

“It doesn’t have to be family; it can be friends or anyone important to you.”

“That’s okay.”

I hoped I hadn’t embarrassed him.

“You must have a way to reach out to folks on your own.” I smiled apologetically.

In answer, he reached across me and lifted his cell phone from the side table. His background was a picture of a chihuahua squinting up at the camera. I noticed as he maneuvered that the 4th and 5th fingers of his left hand did not move with the other three, a symptom that suggested one of the nerves running through his wrist had been severed. I would later learn that the injury was from a suicide attempt and that the resulting hand positioning was incongruously known as the “hand of benediction” because of the similarity to the gesture made by catholic priests when blessing their congregations.

“Who’s that?” I nodded toward the screen.

“My dog. Name’s Cheeba. I got her a few years ago.” His eyes lingered on the image. “She’s a great dog. I drive her to her favorite park every day.” He shot me a glance out of the corner of his eyes. “It’s actually 70 miles from my place.”

Maybe I was getting somewhere.

“Wow, she’s a lucky dog. Who’s taking care of her now?”

“My neighbor. He’s a friend of mine. He’s blind but Cheeba knows him so they’ll be fine.”

“That must be comforting to have someone you know take care of her.”

More silence. I wondered what could be so special about a park or a chihuahua that he would drive 70 miles away for a walk. I tried not to envision the blind friend tripping over the dog when she got underfoot.

“Well okay, I’ll come check on you later. So nice to meet you, Dave. Please let me know if you have any questions.”

He rolled away to face the window again. I dragged the chair back to its corner and retreated from the room.

Over the following week, we settled into an uneasy rhythm. Daily, it seemed, he was yellowing like an old photograph exposed to too much sunlight. His diagnosis of advanced pancreatic cancer was confirmed, and though I learned more about his condition, he never had any questions for me. I don’t remember him ever using my name either, only gesturing when he needed to refer to me. It’s quite possible that he never learned it.

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When I had a quiet afternoon and it was a sunny day, I would take Dave outside. Wheeling him about was always a bit of a challenge, both because we had to bring several IV bags with us that risked tangling, but also because I wasn’t quite strong enough to push him up the sloped path through the hospital parking lot and so always felt on the verge of sending him spinning out toward the trees.

Sometimes we would sit under the red Emergency Room sign and tilt our chins to the sun. In pediatrics I had learned that in some cultures parents bring their newborns into the sun after birth as a natural treatment for jaundice. I wondered if the same trick might help Dave, too.

A building encased in scaffolding stood across the street with construction workers scaling the sides like ants. After only a few months in the hospital, the men looked superhuman in their strength, full of an ease and grace of movement that struck me as foreign. I considered that this might be how I looked to Dave.

Sometimes I pushed Dave a bit further, to the small garden around the back of the hospital. I would lock his wheelchair in place and fetch him scraps of plants, creating a zigzagging map with his chair at the center as I walked back and forth. We rubbed the mint and sage between our fingers and inhaled the scent of green. We marveled at the bounty of strawberries and onions and artichokes that nestled among the thick leaves. I pretended to not know the names of plants so that he could teach me. He told me that at home he liked to make art out of natural materials, which I took to mean that nature was sacred to him in the way it is to me, and so I tried to be comfortable with the silence that still hung thick in the air between us even in the garden.

In too short a time we wheeled back to the alarms and alcohol wipes and needle sticks that were a different kind of healing. I had notes to write. He didn’t want a chaplain.

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The palliative care doctors told us Dave likely had a month to live. It’s easy to identify the palliative care doctors on the wards because they wear plainclothes and because they walk more slowly through the halls than the rest of us. Dying has its own rhythm, I suppose.

I was in his room when they shared the prognosis. There were seven of us standing around the bed; the image of that old Thomas Eakins painting came to mind. When it came time to speak a number aloud, the fellow spoke with less certainty than she had shown just minutes before when sharing the news with me out in the hallway.

“Without treatment, you likely have months to live,” she said.

Months? I thought. You just told me he has weeks.

“How many months?” Dave asked.

“Months that you can count on your fingers.” She held up both her hands, fingers spread wide as if she were offering him a double high five. He looked down at his own hands then, his left hand forever frozen in absolute. I averted my eyes. The machines in the room beeped on.

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The next day after morning rounds, the attending announced that it would be a good challenge for me to lead the conversation with Dave about his two options: chemotherapy, which might prolong his life but would almost certainly cause him to feel sicker, or a full transition to hospice care.

“Do you feel comfortable having the conversation?” the attending asked.

Did I feel comfortable? I could have laughed at the question. I felt so far out of my comfort zone daily that I wasn’t sure I remembered what comfortable felt like anymore. The year so far felt like a twisted improv game where every line I uttered had to start with “yes, and” and never mind that my nerves were jangling and shining and I felt so palpably *afraid* all the time. Afraid of hurting patients who were already hurting, afraid that bearing witness to the deeply intimate secrets of strangers was more voyeurism than solicitude, afraid that I was too soft, too feeling, that I would never make it as a doctor, that I would.

“Sure,” I said. “I’ll give it a try.”

“Tell me what your understanding is thus far.” I was sitting in the now familiar chair in Dave’s room and parroting a phrase I had heard others use with terminally ill patients. Dave looked much the same as yesterday, though perhaps the bags under his eyes had deepened. He cleared his throat.

“The cancer isn’t going to go away.” He spoke as though he were talking about the weather.

“That’s true. And it means you have two possible pathways ahead of you.” I tried to speak slowly and make eye contact, but he had turned his head to look out the window. “One option looks like starting treatment, chemotherapy, which may at most give you an extra few months, but which may give you no time at all.”

“Yeah and it’ll make me feel shitty.” He had already been vomiting daily and returning most of his food trays untouched.

I nodded, even though he wasn’t looking at me. “It’s likely that it would make you feel worse, but we won’t know for sure until we try.”

“And option two.”

“Option two is not doing chemo. That means we are still your doctors, but we focus on making you comfortable, focusing only on treating your symptoms.” Did he understand what I meant? Did I, for that matter? Was dying of cancer ever actually comfortable? I opened my mouth to clarify, but in that moment he turned back to look at me.

“I just want to see my dog.”

I nodded, steeling my face against the feeling in my chest that was so much like heartbreak. But if I could give him nothing else, I would give him my composure.

“Of course,” I said. “I know how important she is to you.”

“Would I get to see her? If I didn’t do the chemo?”

“Yes. You could go home if that’s your priority.”

“That one then.”

“Okay,” I said. “That sounds good.” I immediately regretted my choice of words but thought it better to give him his space than to fumble over my explanation that I knew this was not good, that none of this was good. I stood up to go, and then looked back over my shoulder.

“For what it’s worth,” I said, “all of us on the team were saying we would have made the same decision as you.” Then I walked out. I don’t know if it helped.

As the door shut behind me I looked down the hallways that stretched out in both directions. I thought about the thousands of other providers, perhaps some even in this hospital, who at this very moment were releasing the breath they had been holding and the prayers they had been collecting for the human sitting across from them in an ill-fitting hospital gown. My conversation with Dave had happened before. And it would happen again, and again, and again, sorrow lapping at our shores like waves.

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The medications we were prescribing to prevent Dave’s blood from clotting, a side effect of his cancer, were becoming more complicated by the day. I spent my last two weeks of the rotation calling the hospital pharmacy department, frantically trying to generate a plan that would allow Dave to go home. I learned about the temperature at which anticoagulants need to be stored and the needle sizes that are necessary for patients to self-administer medications that are usually given only through an IV. I worried constantly that I had made false promises to him about going home, that some older, wiser doctor could have explained the situation more clearly and that perhaps he would have chosen chemotherapy instead. Then I remembered the palliative care physician holding up ten fingers to demonstrate months left to live when moments earlier she had said “likely one” to those of us gathered in the hallway. Knowing that the missteps didn’t end after medical school did little to comfort me.

Then, suddenly, my rotation was over. I wrote my last note in Dave’s chart knowing that there would be a new team of physicians taking over his care. I don’t remember saying goodbye to Dave, which tells me the interaction was likely remarkable only for its lack of sentiment, given we had seen one another nearly every day for six weeks. But that too I had come to expect, and so I packed up my workstation and left.

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Two weeks later, when I had switched to the neurology service, I happened to be assigned to see a patient whose room was a few doors down from Dave’s. Dave’s door was ajar, and I could see through the crack that he was facing the window with his TV off as usual.

I thought about going in. I remember walking past his door, then doubling back, before finally walking away, a physical manifestation of the conflict playing out in my mind. He wasn’t my patient anymore, I had things to do, I would only disturb him. How easily the excuses came.

So much of that third year of medical school was an experiment in imagination. Each student pretending to be a medical professional with the same relentless determination that had landed us our place in medical school. We performed confidence and compassion for our patients in front of our audience of attendings until we no longer knew why we cared for the patients the way that we did. We awaited our reviews at the end of each rotation to see whose pretense had triumphed and whose had fallen flat. When we were wearing our hospital issue scrubs, which felt so much like costumes, it became difficult to merge who we were outside of the hospital with who we were inside. Or perhaps these are just more nuanced excuses, and the truth is that in that moment I simply didn't muster the courage to enter Dave's room.

A few days later I got a text message from my attending on the previous service, letting me know that Dave had died. I asked if he ever made it home and she wrote back "Yes, for 4 days before he came back to the hospital. Strong work." My glowing recommendation.

I wonder if I am the only one who thinks about him anymore.

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That day, I stopped at the beach on my commute home. It was a beautiful day and the parking lot was nearly full. I had meant for this to be a spontaneous way to embrace a rare free afternoon, but as soon as I stepped on the sand, I felt something give way inside of me.

I sat in the sand then, only a few yards from the parking lot and watched people play down at the waves. I couldn't name the feeling, exactly, but I knew where this ache in my chest was coming from. I had so desperately wanted to *give* Dave something, to care for him in some meaningful way, but it had been clear from the start that what I wanted to give was not what he needed from me. Instead, I had kept my hands in my lap, fighting the instinct to reach for his hand because if nothing else I was going to respect what few boundaries he had left and I also understood that this was not my tragedy.

But it was also true that I had been there, the partner in this strange and confusing duet that was the doctor-patient relationship, an exchange that sometimes was no more than a stilted conversation between strangers.

I let the tears come, then. I cried for the softness of the sand and for the tenderness of the breeze and for my midnight toll booth operator, who was in so many ways the first patient I ever had.