A Defiant Hope

"Patient refusing dialysis. Please come to the bedside."

She was my first step-down patient from the ICU. She had a complicated hospital course, spanning several months: respiratory failure requiring ECMO, multiple brain hemorrhages, a vent and trach dependence, and acute kidney failure. She was scheduled for dialysis three days a week while awaiting placement in a long-term acute care hospital during the peak of the COVID-19 pandemic. Our job was to keep her medically stable, to keep her alive, until we could transfer her closer to home and her family, as if reducing the physical distance from her loved ones could somehow bridge the divide created by strict no-visitor policies.

I replied to the nurse’s message: “Thanks, on my way,” and rehearsed what I would say.

Maybe she didn’t grasp the importance of dialysis. If you refuse dialysis, you will die.

Maybe it was a gap in education. The dialysis is functioning like your kidneys to remove toxins, excess salt, and fluid from your body.

Maybe dialysis was causing too much suffering. I’m sorry you’re in so much pain. What can we do to make you more comfortable?

But when I said, “Tell me more about why you don’t want dialysis today,” she surprised me.

“I wet the bed this morning.”

I was grateful for the mask and face shield hiding my surprise. She had been anuric for months.

“That’s wonderful news.” I asked about the timing, the amount, the color. I checked the pad underneath her bed and examined her gown. If she had made urine, I could see no evidence of it.

“Have you urinated since?”

She had not. But surely, she said, urinating meant “I no longer need dialysis.” It was a defiant hope that I admired.

I counseled her on how urinating was very reassuring that she was regaining some kidney function. But she still needed some help since her kidneys were not functioning at one hundred percent.

“I wet the bed this morning.”

She still was not convinced.

“Dialysis doesn’t feel good.”

I pressed her to tell me more.

“I feel nauseous.”

We agreed to trial an antiemetic thirty minutes before dialysis and created a plan to check in periodically about her nausea during her treatments.

“The blood is cold.”

We talked about getting her a warm blanket to help. Nevertheless, she remained skeptical about continuing dialysis.

“It’s too long.”

“What if I went with you and kept you company?”

She agreed.

As the primary medical student on her team, I was afforded the luxury of time. The three hours I spent with her in dialysis was not something the rest of her care team could offer any of our patients. I held her hand when the nurses accessed her dialysis catheter. I exchanged her blanket for a warmer one and worked with the nurses to manage her nausea and anxiety. I held her phone upright while she video chatted with her family during treatment.

Throughout the remainder of her hospital stay, we seemed to have the same conversation before every one of her dialysis sessions. She would refuse dialysis, I would be called to her bedside, we’d talk about how to maximize her comfort during treatment, and together, we’d sit for three hours and discuss a wide range of topics, from our favorite recipes to her thoughts on an afterlife.

During her last day at our hospital, she asked me if I thought she was getting better. If I thought she would need to continue dialysis at the long-term facility. If her life would be relegated to a dependence on a machine three times a week that sustained her life but drained the joy of living it.

The only thing I could say for certain was that I didn’t know. That was the last conversation we had.

When I left the hospital that day, I told myself the hopes I held back from her.

I told myself that she was getting better.

That she would regain all her kidney function.

That the dialysis was temporary.

This was the defiant voice of hope she needed to hear, and we both wanted them to be true. My patient showed me the human condition in a mix of suffering and resilience. But more importantly, she encouraged me to remain cautiously and defiantly hopeful in my own life. I realized that as the kidney filters toxins, excess salt, and fluid from our bodies, we must filter out our own biases, the traumas we witness as medical trainees, and an excess of emotions to prevent despair and remain hopeful.

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