Helplessness

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"We've failed you. I'm sorry."

So said my attending physician to a patient. This apology validated the feeling of helplessness that had gripped me for the previous few days. This sense of guilt and failure was foreign to me. In my encounters with hundreds of patients, medicine had been able to cure or at least provide comfort at the end of life. This had given me comfort and the confidence that I could make a difference; it confirmed what we learned in medical school about the impact of simply being present for our patients. Yet now, I could not get over my feeling of wanting nothing else but for this patient to be able to lie comfortably.

For the past few days, my attending, myself and many nurses had been attempting to manage the young woman's pain from a large pelvic tumour. We had exhausted nearly all adjunct analgesics, and there were substantial contraindications to interventional anesthesia. We were hesitant to completely sedate her because she required transfer to a hospital several hours away for definitive management of her tumour in a few days. Opioid titration was difficult because of occasional signs of opioid toxicity.

As I looked around her dimly lit room, I could not help but notice stuffed animals atop medical supplies on a bedside table. It was a poignant reminder of how young she was, which was sometimes easy to forget when we discussed serious topics such as her grim prognosis. She should have been playing with her toddler and spending time bonding with her newborn infant. Instead, she had spent the last 4 months in hospital, and the last few weeks completely bed bound.

Moving from the foot of the bed, my attending knelt to meet her eyes.

"I promise that we have been doing and will continue to do our best to manage this under the circumstances."

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He held her hand as he tried to convey this. Her quivering jaw made it clear that our best had not been good enough. Clutching her diseased hip, she tearfully responded, "I'm losing hope that you will be able to help me."

I braced myself for the negative emotions that I thought were going to surface in me, but they never came. Unlike other times when patients expressed their distrust, I did not become defensive. Perhaps it was because she was justified in losing trust in us, or because I knew that she wasn't saying it to insult or hurt; it was simply what she was feeling. My attending physician and I took some time afterwards to debrief about this emotionally charged encounter. What my attending saw as an admission of his failure, I saw as an example of vulnerability and humility, a reflection of genuine care for his patients.

I checked in on our patient at least once every hour throughout the day to monitor her response to escalating doses of opioids. Part of me wanted to see her often to make sure we were doing the best we could to help her. But there was also a part of me that struggled every time I saw her. Her face was unrecognizable from the effects of long-term treatment with steroids. Her head was rendered smooth from chemotherapy. Her muscles had withered from inactivity and weakness. She cried, pleaded and begged for any relief. Any progress we thought we made by increasing her medications lasted mere minutes before her pain resurged.

Her begging was draining. I found it incredibly difficult to emotionally engage with other patients during those days. I couldn't help but compare others' pain and suffering to hers, but none came close to what I felt she was going through. I had to constantly remind myself to be present while listening to other patients, because my mind was easily distracted. Was her pain better? Was her breathing normal? Had she regained the function of her bowels? When I spoke to peers, I found myself repeatedly bringing up my struggles in caring for her as a means of decompression.

I wasn't the only one struggling in caring for her. While reviewing other patients, I could tell that my attending physician also had a hard time not thinking about her case. It brought up conflicting feelings of comfort and concern. I had a feeling of solidarity: someone else knew what I was going through. Yet seeing someone who I respected in distress was upsetting.

Feelings of guilt were also pervasive. I felt guilty for longing for relief that would come when she was transferred. This conflicted with the idea that I should feel rewarded when caring for patients. I felt guilty when the nurses praised me for being so caring even though I couldn't do anything for her.

At the time, all these feelings melded together into a sense of uneasiness. Teasing them out took time. It required deliberately setting aside time to process, and having my feelings explored and normalized by my attending physician. It took self-reflecting by writing this narrative.

Aside from the medicine, I learned a lot caring for her. I learned how it felt to be helpless in the face of someone pleading for help. How the emotional baggage from one interaction can colour other professional and personal relationships. I learned how much relief and validation I felt by being able to relay my distress to those who cared about me.

After two days, we were finally able to escalate to a medication dose that provided some relief, a reprieve for both her and me. She was at the forefront of my mind even after she was transferred; I was waiting for news about her progress from her medical oncologist. I knew she had yet to undergo what would have been a grueling and morbid surgery and possibly more chemotherapy and radiation. But I took comfort in knowing that we had at least provided her with some pain relief and that all our effort and struggle was not in vain.

She never made it to surgery. It was found that her disease was far too advanced. She was transferred back to us several weeks later for consideration of palliative chemotherapy. Although her situation was grim, I felt less distressed than before. Perhaps it was because I had already taken the time to resolve my feelings around her care, or because I held on to the fact that at least she was comfortable, that we had helped.

Medicine has advanced so much over the years yet is still limited in its ability to cure or heal. What happens if I see these limitations often? Do I become accustomed to them and help others to navigate through the process of helplessness and distress? Do I eventually burn out?

This narrative was written from my perspective, and I acknowledge that my distress is incomparable to this patient's suffering. Trying to understand a patient's illness story takes time, a scarce resource in the current medical landscape, but I hope that effort produces empathy and resilience in the face of distress.

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This article has been peer reviewed.

This is a true story. The attending physician and the patient have given their consent for this story to be told.