When Following the Rules Feels Wrong

by Tyler Tate

Sarah leaned toward me, her elbows pressing into the wooden table that separated us. How far apart were our bodies? I hoped six feet—enough to prevent Covid-19 transmission—but it was hard to be certain.

Sarah was the mother of Keaton, my patient, a spunky eleven-year-old who liked hanging out with his cousins and playing the "best video game ever," Fortnite. Today, however, Keaton was not his spunky self. Because today, Keaton was hospitalized for a third recurrence of leukemia with an associated severe pneumonia. Keaton's parents were praying that a third bone marrow transplant would save his life. At the same time, they rightly recognized that Keaton might not survive this latest hospital admission.

I am pediatric palliative care doctor, and I had been consulted to speak with Keaton's parents about their goals of care. As I'd been trained to do during my palliative care fellowship, I started by watching Sarah's body. "The body speaks, Tyler! Learn to listen!" My former attending's words echoed in my head; and in that moment, I didn't have to strain to hear. Sarah's hands clenched in and out of tight fists, and with each clench, the skin around her knuckles turned pink, then white, then pink again. A kaleidoscope of pain.

Sitting across from Sarah, I assumed that her pain was related to Keaton's closeness to death. Yet when I gently asked her, "With all that is happening right now, what is weighing on your heart the heaviest?," Sarah's response surprised me. "Dr. Tate, what is breaking our hearts is that, because of this Covid-19 visitor policy, only one of us parents can be with Keaton at any one time. The only exception is if Keaton is '*dying*.' But by then he won't even recognize us!" Sarah continued. "We've been begging our oncology team *every day* to let us both stay, but no one will *listen*!" Sarah burst into tears. She struggled to whisper, "It feels like your hospital is stealing our son from us. Dr. Tate, what you all are doing is *cruel*."

Oof. This was a kind of anguish I had never witnessed before, and, as I reflected on our conversation throughout the day, I began to feel more and more as if I were participating in something wrong—even evil. I felt complicit in an immoral act but uncertain as to how or why I was complicit. I was just following the rules, aligning myself with our visitation policy. And these rules were designed to save lives. That's a good thing! But then it dawned on me that, in some murky but very real sense, I *was* acting immorally. My uncontested support of a policy that separated a dying child from his parents felt morally incongruent with the responsibilities inherent to my role as Keaton's pediatric palliative care doctor. My whole job was to help families craft good deaths out of terrible circumstances. And now, I was doing just the opposite. I was experiencing moral distress.

The concept of moral distress emerged in the 1980s as a description of what nurses felt when they were prevented from acting in line with their moral values. As Denise Dudzinski explains in a 2016 *Journal of Medical Ethics* article, moral distress can be defined as the angst clinicians experience in response to a "crisis of conscience," a crisis that often leaves them feeling "powerless, threatened, confused or guilty." In a 2013 *Bioethics* article, Carina Fourie points out that this angst can be associated with either "moral constraint"—being prevented from doing what you believe is right for a patient—or "moral uncertainty"—feeling uncertain about what *is* morally right to do for a patient. Moral distress is observed most in intensive care units, when neurologically devastated patients are kept alive against the consensus of intensive care unit staff (usually out of respect for a surrogate decision-maker). However, as my conversation with Sarah helped me begin to see, in the harrowing world of the Covid-19 pandemic, moral distress was proliferating in clinical spaces it had seldomly touched before.

Indeed, after I had examined the literature and spoken with a number of other clinicians, it became clear to me that tethered to the Covid-19 pandemic is another pandemic: one of moral distress. Covid-19 has created an environment in which clinicians are experiencing this distress in numerous and novel ways, due variously to moral constraint and moral uncertainty. For instance, in addition to the angst of enforcing visitation restrictions, clinicians have experienced moral distress when contemplating ventilator triage, worrying about postponing their patients' surgeries, leaving their clinics understaffed while self-quarantining for a potential Covid-19 exposure, forcing high-risk pregnant mothers to come to the clinic without their partners, and feeling torn between an obligation to care for patients and a desire not to work in unsafe conditions with inadequate personal protective equipment.

The day after I met Sarah, I brought up moral distress with the rest of

Keaton's oncology team. The team noted that they were also experiencing this, and that their distress was likely even more intense than mine. Policies like ours are generally crafted by senior hospital administrators, in part to reduce the weight of responsibility on individual practitioners. However, the burden of enforcement inevitably falls on bedside clinicians. And that burden is a beast: as Keaton's oncologist described it, "Each time you round, you find yourself *re*telling them that they cannot both be present with their son. His parents accuse us of 'forcing' them 'to choose comfort care' in order to be together as a family. And honestly, Tyler, it's difficult to disagree!" I found myself unable to disagree, too. What were we doing here?

Of course, what we were trying to do was prevent the spread of Covid-19. Still, it was unclear how our "one-parent" policy would dramatically halt viral spread. After all, Keaton's parents hugged every time they subbed out for "shifts," and they shared food during outdoor dinners with anxious family members. If one parent had Covid-19, both did. But even if the policy did decrease viral transmission, was it worth the anguish it caused the family, the disruption of their rituals for death and dying? Was the possibility of prevention worth the price of pain?

This is the kind of moral tension lying at the heart of moral distress. It is a tension that feels impossible to resolve. And yet, when facing situations like Keaton's, clinicians still must find a way to provide excellent care for patients and maintain some psychological well-being in the process. In response to these challenging realities, I have begun employing two simple strategies when confronted with moral distress; I mention them here in hopes that others may also find them instructive.

First, name the situation. Moral distress arises when all options feel like bad options—where, no matter what we do, we transgress a moral rule. In ethics, we call this type of situation a dilemma. With dilemmas, in a very real sense, all options *are* bad options, and there may be nothing that you can do to change that fact. But, by naming the dilemma for what it is, you acknowledge that the badness is built into the structure of the situation. And by identifying that there is a structural problem causing moral distress, you can seek a structural solution.

Second, support your colleagues. Be quick to forgive, and assume good intent—even when, at first blush, a colleague or superior does something that seems unconscionable. Remember, these are incredibly demanding days to be a clinician. Friendship with coworkers and peers who understand what you are going through and can validate or evaluate your actions in the face of moral uncertainty, while also helping to carry some of the moral burden of care, is crucial. Moral distress cannot be borne alone.

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Sarah's pain continued to haunt me the week after we first met. After several more visits, Keaton's oncology team and I became convinced that the concrete harm done to Keaton and his family outweighed any abstract benefit, and we wrote a letter to the hospital administration detailing our concerns. After reading the letter, our administration reexamined the data, reevaluated their policy, and ultimately decided that allowing two parents to be present for pediatric patients was reasonable and appropriate. Sarah expressed her gratitude, saying she finally felt heard. She and Keaton's father were able to join Keaton in his room. Keaton died two weeks later, with his parents by his side.

Now, several months removed from Keaton's death, I am proud of our collective ability to recognize moral distress and effect a structural change. Although the death of any child is tragic, I am thankful we were able to avoid heaping tragedy on top of tragedy. Caring for Keaton taught me that moral distress can serve as a clarion call, warning us that things are not as they should be. Perhaps, then, the real moral question facing clinicians and health care systems during this pandemic is, when do you accept the things you cannot change, and when do you fight for what you believe in?

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