Palliative and Supportive Care

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The harder right

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Essay/Personal Reflection

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"So that's it? You're just going to forget about me?" She spoke softly, her voice trembling. She didn't make eye contact, and I remember feeling grateful for that, as her downward gaze shielded me from her despair.

Her husband didn't speak. He stared coldly at me, unblinking.

We had just informed them that she was no longer a candidate for lung transplantation. She had been listed for almost a year. Over the preceding weeks, her clinical course had shifted. Complications had accumulated, each one manageable in isolation, but together forming a trajectory that transplantation could no longer meaningfully alter. The risks now outweighed the potential benefits, and transplant was no longer in her best interest.

We had spoken before about uncertainty, about thresholds, and about the possibility that circumstances might evolve in ways that would close this door. But in that moment, those earlier conversations were forgotten. To them, delisting was not a recalibration of care – it had a singular meaning: death.

They were not wrong about the stakes. Without transplant, her time would be limited. But they were wrong about what the decision represented. De-listing her was not an act of harm. It was neither giving up nor forgetting. Remaining on the list would have exposed her to an intervention increasingly unlikely to succeed and more likely to prolong suffering. Keeping her listed, however, would have preserved alignment. It would have allowed us to remain united in the pursuit of something. Something that resembled action. Something that masqueraded as hope. And it would have deferred the moment when we were no longer on the same team.

Transplant medicine, like many areas of medicine, sits at the intersection of competing ethical obligations (Varkey 2021; Holm et al. 2022). The first is familiar: to act in the patient's best interests, guided by beneficence and nonmaleficence (Varkey 2021). In this case, transplantation was no longer aligned with that duty. Similar tensions arise across medicine: when an oncologist forgoes further chemotherapy, a surgeon declines to operate, or an intensivist recommends against escalating life-sustaining treatment (Varkey 2021). In each instance, the obligation is not simply to offer what is possible, but to withhold what is unlikely to benefit.

The second obligation is less visible but equally binding: justice (Varkey 2021; Holm et al. 2022). In transplantation, the scarcity of donor organs makes this tangible; every decision to transplant one patient is also a decision not to transplant another. More broadly, clinicians act as stewards of finite resources everyday, balancing the needs of the individual with those of others they may never meet. These principles are embedded in clinical criteria and institutional processes, yet at the bedside they recede, leaving only the patient and the relationship we have built (Leard et al. 2021).

There is a particular kind of distress that comes from causing harm (Kherbache et al. 2022). Moral distress is described as the experience of being unable to act in accordance with one's ethical beliefs (Kherbache et al. 2022). Less attention is paid to the distress that arises when we do act in accordance with those beliefs, but at a profound emotional cost. It is a reminder that the right decision is not always the one that feels right in the moment. And that the work of medicine is not only to make these decisions but to carry them. Delisting a patient, forgoing chemotherapy, declining surgery, or not escalating life-sustaining therapies occupy this space.

For physicians, this creates a dissonance that is difficult to resolve. The decision is grounded in evidence, in collective judgment, and in ethical obligation. Delisting her was the right decision. It also caused pain. Both statements are true.

In the days after that conversation, what lingered was not uncertainty about the decision itself, but the weight of having delivered it. The guilt is subtle but persistent.

At this stage in my career, I carry several of these decisions, each with its own unique burden that I bear each day. The weight is heavy. I sometimes wonder just how many decisions one could possibly carry and at what point does it become too great? Although the patients and their families experience abandonment, what they don't realize is that they stay with us forever. We never leave them, or the decisions, behind. This is the price we pay for choosing the harder right.

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