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Imperfect choices along a transplant journey

Shilpa Raju MPH, Malika Sharma MD MEd

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Shilpa received a diagnosis of Hodgkin lymphoma in 2007, during the final year of her undergraduate studies, at age 21 years. After chemotherapy and radiation, she developed pulmonary fibrosis and was listed for a lung transplant in 2011. Following a double lung transplant a year later, she had several postoperative complications, including primary graft dysfunction, gram-negative sepsis, and an extended intensive care unit (ICU) stay, during which she received mechanical ventilation and extracorporeal membrane oxygenation. She was discharged 2 months after her transplant.

Within a year, Shilpa was readmitted to the ICU with further complications, including post-transplant lymphoproliferative disorder (PTLD), cytomegalovirus viremia, a bowel obstruction, and a major upper gastrointestinal bleed. Her admission was 4 months long. At one point, Shilpa deliberately self-extubated, but given her poor lung function, her physicians considered she needed reintubation, which would have been the fourth intubation in less than 2 months. Shilpa was young, and each of her many health problems was individually manageable but, by that point, she had major concerns about her current and future quality of life, which she had expressed to her clinicians. A spiritual care worker and an inpatient psychiatrist consulted with Shilpa to help the clinical team understand her decision-making around extubation and her resistance to being reintubated. The clinical team and Shilpa's family determined that she was unable to make this decision at the time and, despite her reluctance, she was reintubated. Shilpa's health finally stabilized and she was discharged from hospital 2 months later.

Shilpa now spends time travelling with her husband, eating her way across Toronto with friends and family, and working as an epidemiologist. As a result of long-term use of tacrolimus and treatment with nephrotoxic medications (trimethoprim–sulfamethoxazole) for *Pneumocystis jirovecii* pneumonia, Shilpa developed end-stage renal disease and started nocturnal hemodialysis at home in September 2021. She received a living donor renal transplant from her husband in December 2023.

Shilpa's perspective

A lung transplant saved my life, but the path and decisions along the way were anything but clear. Within months of my transplant, I was back in the ICU with PTLD, and I felt far sicker than in my pre-transplant state. My days were cycles of treatment, reintubations, and transfusions. Confined to a hospital bed, this version of life became unbearable. Many days, I was too sick to acknowledge the loved ones checking on me. However, I felt fortunate that one of my oldest friends was also one of my health care providers — Malika (Figure 1).

Malika Sharma

Figure 1: Shilpa (left) and Malika (right) over the years.

Until then, every treatment choice I had made was singularly geared toward survival. My physicians always framed the discussion around all I stood to gain, listing the potential risks and complications as unlikely inconveniences rather than consequential, new challenges. As those purportedly rare complications accumulated, for the first time since my lymphoma diagnosis 6 years earlier, I questioned whether I was making the right decisions. I had been holding on for dear life, but now began to worry about what that life was going to look like, having been hooked up to machines for months. I decided I was delaying the inevitable, either death or a poor quality of life or both, which meant I needed to let go. I did not want to be reintubated.

At my lowest point, I turned to Malika as someone who would hear me out. I told her that I was done with all of this. As a physician, she knew what the worst case scenario looked like for me, and as my friend, she understood how that would break me. The worst I could imagine was not death, but a life where I could not live freely as myself — not working, travelling, or even just sitting outside.

My family did not want me to give up, and perhaps the doctors did not trust my judgment to make such a pivotal decision, given the state I was in. My memories of this time are hazy, but I recall them trying to make sure I really understood the consequences of not being reintubated. I was not privy to how the decision to reintubate was made, despite my request otherwise, but it happened. Fortunately, I improved after reintubation and developed a renewed will to live.

I was soon extubated, but days later, I was again on the verge of needing a ventilator. I resisted, knowing I did not want to be reintubated, but this time the resistance was because I was fighting for life and for choice. Avoiding the ventilator was no longer a reflection of me accepting death; I had to stay off it to breathe on my own and build the strength to live. My nurse that night understood this and intervened on my behalf, suggesting overnight bilevel positive airway pressure (BiPAP) instead to see if I could avoid another intubation. She cheered me on through the night, counting down the hours to sunrise on my bedside whiteboard. I finally felt some hope, like I had influence over how I was being saved and like it mattered that I was more than merely dead or alive.

I am very grateful for all the medical care I have received; I recognize I might not be here to write any of this otherwise. But patients are often handed imperfect solutions and expected to focus on survival, resigning ourselves to the rest. When I was reintubated, my medical team could not have guaranteed any particular outcome, nor was any outcome certain to be a perfect resolution. It seems to me that, for clinicians, the outcomes of medical care are often binary — life or death. For patients, things are much more nebulous — being alive at all costs is not necessarily what all of us want. Understanding what the patient in front of them values is the only way clinicians can ensure that their decisions are the right ones.

In a world where the impact of each decision can have a domino effect, I have learned to hear what my medical team says and question what that means for me in its entirety, while also appealing to them to see me as more than a patient. That rounded perspective, truly weighing pain against possibility, should underpin the shared decision-making, ultimately influencing the life I will live.

Malika’s (friend and physician) perspective

In 2013, I was an infectious diseases fellow on my transplant rotation when we consulted on Shilpa during her second ICU admission. Shilpa and I had known each other for a decade, considering each other chosen sisters. I asked Shilpa whether I should get someone to substitute for me, but she declined. We both welcomed the opportunity to spend time together. I rounded on Shilpa daily, saving her for last. I would dutifully ask about fevers and gastrointestinal symptoms and then settle in, putting my feet up for a chat. After work, I would take off my stethoscope and cry in the hallway before heading home.

One night, I visited Shilpa in the ICU. She was heading toward reintubation. She had been in the hospital for weeks and was starting to worry that this was what the rest of her life might look like — unable to move, even more restricted than before her transplant. As a physician, reintubation made sense to me. Shilpa was young and her problems were potentially still reversible. As her friend, I wanted her to have agency and control over her own body. I also fundamentally did not want her to die. I had been part of many resuscitation conversations in my years of training — but this was different. Shilpa was not telling me her wishes and concerns as her physician, but as her friend. Despite my own conflicting feelings, I told Shilpa’s mother and sister about Shilpa’s reservations about reintubation, speaking as her friend, not as her physician. Although I was close enough to Shilpa’s family to speak frankly, I did not push — I was not family and I did not want to sow confusion or discord with her family and care providers. If I am honest with myself, I did not think I could bear responsibility for her death if I was the only one advocating strongly against intubation.

I have struggled with that moment for years. I wonder if I failed Shilpa in some way, if I should have pushed more strongly against reintubation. Even though the outcome of reintubation was a good one, I could not have known that at the time. At other times, I suspect that Shilpa was not looking for me to fight her fights — she fights pretty well all on her own, just as she did that first night on BiPAP. Maybe she was looking for me to be a place where she could voice her fears and her anger. A place where she could, just for a moment, put down the heavy weight of optimism, the burden of having to grin and bear it, allowing her to rest before picking that burden up again.

There is an Urdu word — *Sahil* — that means both *shore* and *guide*. Reflecting on my experience during Shilpa’s admission, I realized that in many ways, *sahil* defines clinical work — navigating through choppy waters, ferrying people from riverbank to riverbank. As clinicians, we want the journey to be linear and assured — but water does not flow that way. We cannot contain or avoid uncertainty, only navigate it. As clinicians, the journey is not ours, nor is the raft. The important choices rest in the hands of patients and their loved ones. The best I can do as a physician is bear witness while sharing knowledge and insight to help patients and families navigate the many choices with which they are faced. Shilpa’s desires and choices have taught me a great deal about hope and despair in the face of uncertainty. Despite the horrible things that have happened to her medically, she continues to live, to work. She got married, bought a house, comes over for dinner. She makes space for hope and despair, at times simultaneously, and has taught me to do the same. Shilpa has taught me that, while there is room in the boat for despair, perhaps it is hope that is both shore and guide.

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Affiliations: Patient author (Raju), Toronto, Ont.; Faculty of Medicine (Sharma), University of Toronto; Division of Infectious Diseases (Sharma), Department of Medicine, St. Michael's Hospital, Toronto, Ont.

Correspondence to: Malika Sharma, malika.sharma@utoronto.ca

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