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FROM THE EDITOR

Health Care Rich, Resource Poor: Struggling with the National Shortage of Organs in Liver Transplantation

I sat down in the student and resident corner of the conference room and peered up at the screen above my head. There was a long list of patient names and a host of acronyms I'd never seen before. The meeting began as even more people squeezed into the already-packed room. I listened intently as the committee went through the patients one by one, scrolling through what seemed like an endless list. The number of illness manifestations rattled off for each one was so long I'd assumed it was an inpatient list, until I realized that I'd only seen two of the patients on service that week. Then it struck me: this was our center's liver transplant waitlist, and, due to the shortage of organs, only a quarter of the hundreds of hopefuls listed would receive a liver that year.

When we reached the end of the list, the PDF was promptly closed and in its place appeared a photograph of a woman in a wheelchair. The potential new candidate's history was presented by her hepatologist, followed by contributions from each of the staff on the transplant committee. It was like a United Nations of medicine. Everyone from surgery to infectious disease, psychiatry, social work, nutrition, and even a financial advisor who coordinates patients' insurance spoke in turn.

I'd learned earlier in the week about how candidates' rankings on the transplant waitlist were determined by strict criteria, the Model for End-Stage Liver Disease or "MELD" score, which relies solely on three objective laboratory measures to ensure equitable access, minimizing subjectivity or discrimination. However, as the room broke into vigorous debate about candidacy for this clinically and socially complex patient, who came to us after being rejected elsewhere, I realized that access to transplant involves so much more than a simple MELD score—there is an intense decision-making burden on both clinicians and recipients.

This month's issue of the *AMA Journal of Ethics*, titled "Liver Transplant Ethics: From Donation to Allocation," explores some of the ethical challenges that our nation's worsening organ shortage poses for health professionals making clinical decisions, for policymakers working to develop solutions, and for patients and their loved ones.

In this issue, Aaron Ahearn, MD, PhD, <u>reviews</u> a sentinel article by Merion et al. [1] explaining the history, design, and ethical principles underlying past, current, and potential future US allocation systems for ranking patients on the liver waitlist. Although

the multidisciplinary, longitudinal style of waitlist management is common, if not universal, and the whole US uses the MELD-based allocation system, waitlist management and decisions about candidates and organs vary broadly by center [2]. This month's selection of opinions from the AMA *Code of Medical Ethics* also <u>considers</u> ethical topics relating to transplantation.

The road to transplant has many junctures along the way, stops at which transplant teams make decisions critical to a patient's fate; the MELD score just determines the velocity with which the patient travels toward the final destination. The decision about whether to add a patient to the waitlist for organs is the first juncture, after which candidacy is frequently revisited and re-evaluated. There are a number of reasons that a patient could be removed from the waitlist, from alcohol relapse to the committee's clinical judgment that the patient is "too sick to transplant."

In a setting of increasing demand for donor organs, the reason why a patient needs a transplant often comes up in discussions of justice and equity. Alon Neidich, MD, Eitan Neidich, and Irene Kim, MD, <u>discuss</u> whether we should do elective transplantations for pediatric patients with an inherited metabolic disorder. Ajay Singhvi, MD, Alexandra N. Welch, Josh Levitsky, MD, Deepti Singhvi, MD, and Elisa J. Gordon, PhD, MPH, <u>discuss</u> issues of access to transplantation for patients with the most controversial indication: alcoholic liver disease.

The next decision point along the road to transplant occurs at the time of organ offer. A median of five liver offers are made for each candidate on the waitlist over the course of their wait [3]. Each time, the surgical team decides whether to accept or reject the organ based on several factors, including its quality, its suitability for the particular recipient, and the potential that the patient will not only be able to tolerate surgery, but also gain a substantial survival benefit from the procedure (i.e., have a good surgical outcome). These factors are difficult to quantify, yet must be weighed against the risk of the patient dying while waiting for a better liver to come along. Unlike the situation of patients on the kidney transplant waitlist, there is no equivalent to hemodialysis for liver transplant patients. Out of approximately 15,000 patients on the liver waitlist at any given time between 2003 and 2013, approximately 40 percent received a transplant and less than 20 percent succumbed to their disease each year [4].

In their article, Joel T. Adler, MD, MPH, and David A. Axelrod, MD, MBA, <u>discuss</u> additional external influences that can play major roles in transplant centers' decision making. They highlight a Centers for Medicare and Medicaid Services policy that has led to risk aversion among centers seeking to avoid being publicly flagged and audited for outcomes "below expected." Andy A. Tully, MD, Geraldine C. Diaz, DO, and John F. Renz, MD, PhD, <u>comment</u> on the challenges that come up for both clinicians and patients at this point in the road in their case discussion and commentary.

This issue of the AMA Journal of Ethics also includes pieces about current and developing policies that seek to address the organ shortage crisis. In the US, living donor liver donation is relatively rare, at around 5 percent, in contrast to Asian countries, where living donor donation represents more than 90 percent of liver transplants [5]. Thus, we focus this issue's policy articles on deceased donor donation and practical implications of different approaches. Keren Ladin, PhD, MSc, <u>discusses</u> the current state of public opinion and understanding of deceased donor donation and the role of physicians in educating patients about organ donation. This issue also includes the 2015 Conley Essay Contest winning essay, in which Gowri Kabbur considers the ethical merits of using social media to solicit organ donations. Katrina A. Bramstedt, PhD, MA, and Jean-Baptiste Hoang provide an overview of current procurement policies in the US and abroad, as well as techniques and emerging technologies for maximizing the scarce resource. Stuart J. Youngner, MD, comments on a case involving a particular organ donation policy—firstperson consent—in practice. Finally, this issue includes an interview with a prominent leader in the field, Dorry Segev, MD, PhD, who has a successful track record of using his research to change transplantation policies (e.g., HIV-positive donation policy). We discuss current efforts underway to reduce geographic disparities and improve equity in access to transplant by literally redrawing the transplantation map.

This issue includes a range of diverse topics and perspectives contributed by authors from around the globe who are leaders in their respective fields. However, liver transplantation is rich with ethics debates on a multitude of topics, and this issue samples only a fraction. There are still many questions left unanswered and much work to be done. Our goal in this issue is to educate young physicians and trainees on issues that are front-and-center in transplant surgery. I hope it guides readers' understanding about transplantation ethics, enhances their capacity to care well for transplant patients, facilitates their work with transplant teams, and motivates their greater appreciation of the complexity of clinical and ethical decisions being made behind the scenes.

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