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# American Medical Association Journal of Ethics

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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, [reviews](#) 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 [considers](#) 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, [discuss](#) 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, [discuss](#) 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, [discuss](#) 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, [comment](#) 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, [discusses](#) 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—first-person 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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## ETHICS CASE

### Should Physicians Attempt to Persuade a Patient to Accept a Compromised Organ for Transplant?

Commentary by Andy A. Tully, MD, Geraldine C. Diaz, DO, and John F. Renz, MD, PhD

While in an administrative meeting, Dr. Calvin, chief of transplant surgery at a major academic hospital in California, receives a phone call from a regional organ procurement organization. A liver has become available for the hospital's sickest patient, Mr. Lawrence, who was recently admitted with severe complications from advanced alcoholic liver disease and encephalopathy. Knowing how severe Mr. Lawrence's condition has suddenly become, Dr. Calvin excitedly breaks away from his meeting to page other attending physicians on the transplant service and review the donor information.

They find that the available liver is not without concern: it comes from an older donor with multiple comorbidities, including obesity with a degree of fatty liver, and, most importantly, the patient passed away from cardiac failure, which results in considerable hypoxemia and free-radical damage. The risk of graft failure is significant enough for the center to classify the organ as an "extended criteria donation (ECD)." Nevertheless, the team is confident and enthusiastic about the potential for transplantation, having had extensive experience successfully transplanting similar organs. So, the team rushes upstairs to the patient's room to relay the news about an available liver.

"Mr. Lawrence!" Dr. Calvin exclaims, "We're going to save your life today! An organ has become available!"

Waking from a foggy state, exhausted, exasperated, and fearful, Mr. Lawrence tries to process everything the team is telling him about the organ and the prospective transplant surgery. "So you're saying you want to give me a damaged liver?"

His daughter, who had been sitting in a chair on the side of her father's bed, stands up to take in what is being said. "Maybe we should just wait until a better one comes along," she suggests.

Dr. Calvin reminds them that they've discussed ECD organs before, and all the risk factors in their previous conversations are present in this one. He then explains the list of

additional risk factors present and what they mean, eventually concluding that this is a calculated risk, but one they have to take.

Mr. Lawrence says, “Doc, I don’t understand what you are saying,” while squinting at the dense text on the consent form they just handed him with a pen, “but I trust you and want to do whatever you tell me. I’m just so overwhelmed and tired. I don’t have the energy to get through something like this now—I’m so exhausted. All I want to do is cry.”

The team listens patiently and intently, and Dr. Calvin tells Mr. Lawrence sternly but compassionately, “Mr. Lawrence, there is no better time to do this than now. Without this liver, you will die. This organ is a blessing.”

His daughter says to Mr. Lawrence, “Well, I understand what the doctors are saying. There’s no way to really know what the outcome with this organ will be, or whether a better organ will come along in time. But I’m not the one who has to go through surgery, Dad. You do. And no one can make this decision for you.”

Mr. Lawrence requests more time to think about the decision.

“Mr. Lawrence,” another caregiver speaks up, “The longer we wait, the worse the organ quality gets. If you don’t take this liver right now, it’s gone.”

### **Commentary**

Mr. Lawrence, his daughter, and Dr. Calvin have to decide how best to respond to an indecisive patient. We can imagine a few weeks ago in clinic, when Mr. Lawrence had energy and willpower to brave surgery and to attempt to regain his life. At that time, he was clear-minded and committed during clinic discussions about organs, telling Dr. Calvin that, for him, any new liver was worth the risk. Now, after several weeks in the medical intensive care unit, Mr. Lawrence is demoralized by watching hospital roommates’ conditions deteriorate, poor sleep, and endless consultant visitations. His health has diminished from liver failure and advanced encephalopathy, and now he thinks differently than he did during his clinic visits. Now a potentially lifesaving organ is available for transplant and Mr. Lawrence expresses ambivalence. How ought the team led by Dr. Calvin to reconcile this patient’s past and present attitudes and expressions while trying to facilitate best possible outcomes? Should Dr. Calvin and the team try to persuade Mr. Lawrence to accept this particular organ and undergo surgery?

### **How Ought Physicians to Help Patients Decide?**

As in many [medical-ethical deliberations](#), principles of nonmaleficence, justice, respect for autonomy, and beneficence can be helpful in considering how to respond to a patient’s indecisiveness [1]. Nonmaleficence tends to endorse a course of nonintervention. As Mr. Lawrence and his daughter are well aware, he might have a long,



painful, and complicated postoperative course that no one can predict. Neither is it known whether he will have the physiologic reserve to tolerate and recover from the operation. The risks and potential harms of surgery can only be avoided by not performing surgery. Even if Mr. Lawrence's course of surgery and recovery goes well, surgery will give him postoperative pain that he might not be willing to endure at this time. One might object that surgery is not subject to a principle of strict *primum non nocere*—the dictum to first do no harm—since the very act of incision requires that harm precede therapy. But, in this case, because the surgery carries significant potential for harm and Mr. Lawrence's capacity for tolerating even predictable surgical harm is unknown, the principle of nonmaleficence can be applied to support his refusal of the liver [2].

Justice is given extra consideration in transplantation, and justice prompts Dr. Calvin to try to persuade Mr. Lawrence to accept the extended criteria donation liver. Society has made special provision for organs such as this to be matched with recipients like Mr. Lawrence. Many experts have weighed the level of individual benefit these organs provide against the overall benefit of decreasing waitlist times [3, 4], and, if Mr. Lawrence fits the qualifying criteria, then in the eyes of society he has a right to that organ. Granted, there is ample evidence that the quality of the organ to which he has access will vary depending on the region in which he lives, but this is a variable beyond the scope of Dr. Calvin's influence [5]. There are limits to indecision, too, as an organ must typically be accepted within one hour of offer. If Mr. Lawrence continues to delay, the organ will be offered to the next recipient. Thus, Dr. Calvin has an obligation to press Mr. Lawrence to consent or refuse.

How to respect autonomy is particularly unclear in the case of the indecisive patient. Each patient has authority to consent or refuse, provided he or she has the capacity to comprehend and make decisions. At this point, there is no clear evidence that Mr. Lawrence lacks capacity, but it seems pathophysiology is influencing his exhaustion and indecision. It could be argued that his encephalopathy will only advance without transplant and that, interestingly, further delay of his decision could actually diminish his autonomy. Without a decision, his declining physiological status will effectively make his decision for him. After all, at an earlier time, when he was not so exhausted, and was perhaps more autonomous, Mr. Lawrence appeared to have understood the risks and benefits and chose transplant. On the other hand, his acute state should not be brushed aside. Neither should the quality of the liver. That is, if Mr. Lawrence's prior enthusiasm about the transplant was based on the assumption of an uncompromised liver, how ought this variable to be considered here? One factor to consider is that Mr. Lawrence's risk of waitlist mortality tracks his physiological decline; this risk of mortality could be mitigated by his accepting a compromised organ.

Mr. Lawrence might have been changed by his hospital experience, and his beliefs about how a transplant would work in his life might now be more pessimistic. For a man who will have to adhere to a lifelong regimen of checkups, medications, and lifestyle changes, the whole success of the transplant endeavor depends both on his genuine autonomous support and on the quality of the organ he receives. So, the team might be justified in not pushing him harder toward accepting transplant. Another important source of ethical complexity in how we regard Mr. Lawrence's autonomy is that it's not clear whether the source of his hesitation is the quality of the liver, the stress of surgery, or looming challenges of recovering from surgery.

Beneficence requires physicians to guide and advise patients, especially those who have trouble making critical decisions in urgent situations that could affect others. Applying the principle of beneficence seems to support Dr. Calvin's advocacy for Mr. Lawrence to receive a liver transplant; he has probably witnessed hundreds of patients' similar illness experiences—physical deterioration, emotional distress, and psychological doubt followed by surgery, frustrating postoperative experiences, and extended duration of life. Dr. Calvin has good reasons to reassure Mr. Lawrence that what he is experiencing and thinking now could pass with time and that ultimately he will likely be glad he received a new liver. Dr. Calvin is obligated to provide a realistic assessment of risks of transplantation surgery with this specific liver as part of informed consent. If Mr. Lawrence accepts those risks, his consent expresses his trust in Dr. Calvin's team.

However, leaning too heavily on beneficence can be problematic, too. Dr. Calvin is not omniscient, and his outcomes cannot be 100 percent positive. Dr. Calvin has an interest in seeing his patients transplanted and does everything in his power to keep his waitlists moving. If Dr. Calvin is sufficiently self-aware that his self-interest does not present a conflict of interest, applying the principle of beneficence suggests that trying to persuade Mr. Lawrence to receive the transplant is ethically permissible.

The classic Greek paradox story of the Ship of Theseus prompts us to ask, *As the boards of the ship are repaired or replaced over time and over the entirety of the hull, is it still Theseus's ship?* In Mr. Lawrence's case, as we apply ethical principles of autonomy, beneficence, nonmaleficence, and justice, how ought we best to express respect and support for Mr. Lawrence? We refer to these principles as if they are immutable, timeless, and not subject to case-specific variables. As such, many might choose to apply these principles as we have here. But these principles can suggest different courses of action based on when we apply them and whose perspective is used to apply them. In this scenario, it seems prudent to rely on beneficence as one important product of the physician-patient relationship. By virtue of their long-term relationships with the patient, Mr. Lawrence's daughter and Dr. Calvin can work with him to help him through doubt and indecisiveness. In doing so, they respect his past and present and aim toward the best possible future consistent with his best autonomous self.

### **How Ought Physicians to Guide Patients' Perceptions of Risk?**

Another way of looking at this case is that Mr. Lawrence's indecision results from two fundamental errors committed by the transplant team that, unfortunately, are very difficult to remedy. First is allowing a misperception of extended donor criteria (EDC) liver allografts [6] and second is a loss of process and orientation of the patient as his health deteriorates.

Let us begin with the misperception of EDC. If one remembers that "donors are people and people are donors," then one should conceive of the donor pool as a continuum ranging from organs with a high probability of success through allografts with a high probability of failure. In addition to the probability of allograft physiologic failure is the risk of disease transmission that occurs throughout the donor spectrum, even from donors thought to have little disease transmission potential.

The US donor population is not necessarily always healthy, so limitations to organ donation favor causes of ischemic encephalopathy that are often associated with high-risk behaviors. This point must be stressed early in the candidate's educational process, as once allografts are stigmatized, it introduces uncertainty for the candidate about whether to wait for a better organ. This decision has been widely studied [7], and the optimal outcome has always been to utilize an allograft deemed appropriate, from a clinical point of view, by the transplant surgeon [8].

Allocation calculators have been developed to begin estimating risk of organ failure [9]; however, these calculators have been derived from a recipient database that does not integrate multiple factors associated with poor organ function [10]. Hence, further refinement of these calculators is stalled until the development of a national *donor* database. Ideally, discussions regarding allocation, the US donor pool, and organ acceptance criteria should occur *prior* to listing so that the listing process reflects acceptance of the inherent risks of donation.

This leads to the second critical error by the transplant team: not providing continuing education during the candidate's progress towards transplantation. Initial discussions as to the appropriateness of allografts and the composition of the US donor pool require continual review within the context of the candidate's physiology. As our patient deteriorates, his or her need for a lifesaving transplant increases. The need for increased access to allografts should be met through [expansion of donor selection criteria](#) (i.e., higher tolerance for allograft failure). The interplay between access and risk requires constant reinforcement by the clinician to prepare the candidate for an impending organ offer and to emphasize their need for immediate transplantation. Made correctly, organ offers can be welcomed by the candidate, regardless of the donor's background, and may be overwhelmingly accepted following a discussion of the risks with the transplant

surgeon. Ultimately, transparency, education, and reinforcement form a foundation of trust between the transplant team and candidate.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

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# American Medical Association Journal of Ethics

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## ETHICS CASE

### How to Communicate Clearly about Brain Death and First-Person Consent to Donate

Commentary by Stuart J. Youngner, MD

Michael is a healthy 21-year-old man who is brought by ambulance to an emergency department after a motor vehicle accident. His family is devastated when he falls into a coma, is put on a ventilator, and, three days later, is declared brain-dead by two physicians. Dr. Allen, the attending trauma physician on service in the intensive care unit that week, explains to Michael's parents the unlikelihood of his recovering and initiates a discussion about whether and for how long the family would like to continue life-sustaining care. Michael's parents are distraught over the idea of stopping it. His mother says, "How can you even suggest discontinuing care? His heart is still beating, he still has life energy inside of him, and you want us to kill him?"

Later that afternoon, a nurse taking care of Michael, Rhana, learns that he had registered to be an organ donor on the state's donor registry and lets Dr. Allen know. She asks whether he would like her to inform the local organ bank so it can send an organ procurement representative to speak with the family, as is expected of hospitals when a patient has either died or is in critical condition *and* is a potential organ donor [1]. Rhana and Dr. Allen know that such involvement of organ procurement organizations (OPOs) is standard practice in the US, in order to ensure that all potential donors' families are eventually approached by someone trained to speak to them in a thoughtful manner. However, although OPOs must be notified, organ procurement coordinators may not directly speak with families until death is declared. Although Dr. Allen could follow the regulations strictly and contact the local OPO, he thanks Rhana but says that he will revisit the issue in the next day or so after the family has had more time to process what's happening to Michael.

After several days with no change in Michael's reflexes or vital signs, Dr. Allen again brings up the issue of continuing life-sustaining care, this time to a slightly more amenable, and extended, family. He also tells the family that Michael has listed himself as an organ donor on the state's registry. The family is shocked by this news and questions Dr. Allen about the procedures by which organs are actually taken from a donor. Some family members respond with agitation when they learn the answers: Michael would be left on a ventilator until being taken to surgery for organ retrieval and would die after the organs are removed from his body and the ventilator is turned off. Michael's father is the first to speak. "Wait. We had no idea that the retrieval procedures

would interfere with Michael's dying process so much. That's not what we've envisioned for him. We're not comfortable with that."

Afterward, Rhana asks Dr. Allen whether she should still call the organ bank. He explains that the state's first-person consent law—as established in Illinois, for example, in 2006—prohibits one's next of kin from overriding a documented decision to donate [2]. Every state in the country has such a law [3]. Rhana asks, "Can the patient's family override Michael's decision if he would have declined to be an organ donor?" He nods and starts to emphasize the extent of the organ shortage crisis, but she says, "I don't understand. How can respect for patients' autonomy apply only if they made the 'right' decision according to the state and the OPO? Especially in a case like this one, when the state's and the OPO's priorities are really different from the family's?"

### **Commentary**

This case raises two major classes of ethical issues. First, it prompts us to wonder about organ donation under a first-person consent law and about the ethical relevance of states' support for a legal climate that seeks to increase the numbers of available organs without considering consequences for patients' death processes. The Illinois law, for example, mandates that a patient's wish to donate, as expressed in a state registry, *must* trump any family wishes to the contrary [2]. Second, it prompts our consideration of ethically relevant consequences—including confusion among Michael's family members—of Dr. Allen's poor communication about brain death.

### **Confusion**

Dr. Allen is compassionate and probably wise to give the family a limited time to come to terms emotionally with Michael's situation, but his communication causes problems that are ethically relevant. For example, he gives the family a mixed message that could both confuse them and make them feel guilty. When he says that Michael will "die after the organs are taken," Dr. Allen seems to be giving and taking away hope at the same time by presenting the idea that Michael is simultaneously not yet dead and already dead. Michael's family might wonder, "Is he dead or isn't he?"

Michael has been pronounced dead by neurological criteria after a motor vehicle accident. In all states, such a determination meets legal criteria of death [4]. Michael is legally dead. Yet, Dr. Allen, the attending trauma surgeon, tells a devastated family about the "unlikelihood" of Michael recovering as a prelude to a discussion about withdrawing supportive care. The fact is that Michael's recovery is not unlikely; it is impossible. His prognosis is as certain as any in medicine [5]. The law in every state gives as the clinical criteria for declaring the death of a person that he or she has suffered either: (1) irreversible loss of cardiopulmonary function or (2) irreversible loss of all brain function. There is widespread agreement that any clinical criterion of death must have a sound conceptual definition that supports it [6]. A definition of death must answer the

question, which function of the human being is so critical that, without it, a person would be dead (not irreversibly dying but actually dead)? In 1981, James Bernat and his colleagues offered the first definition supporting brain death as the cessation of the functioning of the organism as a whole. By “functioning of the organism as a whole” they meant:

the spontaneous and innate activities carried out by the integration of all or most subsystems (for example, neuroendocrine control), and at least limited response to the environment (for example, limited response to light and sound) [7].

Bernat’s formulation has been largely refuted by scholars [8, 9] and even a Presidential Commission [10]. For example, integration of subsystems is not irreversibly lost in brain death because, after the initial shock, other centers in the body take over integrative functions like temperature and blood pressure [11]. Although they will never wake up or breathe again, some brain-dead patients have been maintained at home without full intensive care for months and even years [11]. Furthermore, all integrative functions—for example, neuroendocrine control—remain but are simply not measured [12]. Brain death has largely been accepted because the diagnosis, even with the limitations described above, adequately predicts a dismal and irreversible prognosis. It is what some have called a legal fiction [8] that serves organ transplant policy well. In other words, for all intents and purposes, [brain-dead patients are dead enough](#) to donate their organs [13].

What might Dr. Allen have said to make things better? When brain death was declared, he should have told the family clearly that Michael was dead according to state law. If, for example, Michael’s family members had commented that Michael had signs of life, Dr. Allen could have empathized with them but pointed out that those signs indicated that his body was being maintained alive, but that Michael was gone, dead. He should have told them that, unlike other types of brain-damaged patients who do wake up rarely, brain death is a completely reliable diagnosis and no one has recovered from it, ever. When he brings up the possibility of donating organs, he should explain that the declaration of death is now, before organs are removed. Michael will be legally dead before organs are removed. The appearance of life has understandable emotional impact, but it is not legally or clinically determinative of death. Furthermore, it is reasonable to give the family members time to come to grips with their “cognitive dissonance” [14].

Dr. Allen should not engage Michael’s family members in a discussion of philosophical debates regarding the conceptual validity of brain death unless they bring it up and ask to him do so. (Perhaps Dr. Allen is not very familiar with these debates since they almost never, in my experience at least, occur in clinical settings.) What seems to interest



families and health professionals most is that, while a patient's diagnosis is often reliable, the prognosis is typically bleak and the law in every state says that the patient is dead.

Such confusing communications about the medical and ontological status of brain-dead patients seem to occur frequently. In my experience, it is not uncommon for health professionals and news media to refer to a patient as brain-dead but then go on to say that the patient died when the ventilator was turned off. Poor communication about brain-dead patients probably reflects underlying [confusion and ambivalence](#) about brain death that has been documented in studies [15, 16]. And no wonder. Brain-dead patients are phenomenologically very different from most dead patients—they are pink and warm with beating hearts. They digest food, produce excrement and, after a period of time, stabilize and require much less intensive care to prevent cardiovascular collapse [11, 17]. Brain-dead patients have “incubated” living fetuses for weeks or months until they can survive *ex utero* [18]. There has also been considerable scholarship [questioning the fundamental philosophical and clinical coherence of the brain death concept](#) itself, making matters even more complicated [8].

### **Are First-Person Consent Laws Ethical?**

There is little doubt that we need more organs for transplantation. There are more than 100,000 people on the United Network for Organ Sharing (UNOS) waiting list and many die every day waiting for an organ [19]. When an organ is available, transplantation has become standard care for end-stage organ failure. The American public clearly favors organ transplantation and organ donation; in the 2012 National Survey of Organ Donation Behaviors and Attitudes, 94.9 percent of adult respondents supported or strongly supported donation [20]. Yet organs are scarce, in part, perhaps, because of the confusion surrounding brain death.

Many attempts have been made over the years to increase the pool of organs but with insufficient success. A recent effort successfully pushed by the transplant community is the adoption of first-person [consent laws](#) in every state [21]. These laws require that, if a person has registered to be a donor at an official online registry or the department of motor vehicles, her or his wish must be honored even over the objection of immediate family members [21]. When the transplant community advocated for these laws, it justified them by extolling the principle of individual autonomy that it knew is highly valued in our society [22].

However, at least in the author's state, Ohio, the online registry offers no opportunity to register a refusal to be a donor. Ohio's driver's license only allows a person to self-identify as a donor. The card is silent about a wish *not* to donate. I leave it to readers to research their own state policies, since possession of a state driver's license is often required to access the registration website. One point of ethical relevance that should be

considered is that a state's lack of process by which to register a person's wish not to donate assumes that the donation's interference with the patient's death process is irrelevant. At the very least, this assumption should be deliberated upon, considered, and recognized in clinical encounters and cases such as Michael's.

In any event, by not allowing a registered refusal, the law allows organ procurement agencies to approach families of dead persons who might not have wanted to be donors. If the families authorize donation, it will take place. Thus, the policy only supports autonomy when it serves the interest of providing more organs. This is not in itself wrong if you believe getting more organs trumps a consistent commitment to autonomy.

### **Conclusion**

Brain death is a relatively new clinical concept and diagnosis that many believe was adopted in large part to increase the availability of organs [8, 23]. Its conceptual, clinical, and experiential inconsistencies are not without consequences. It fosters a kind of cognitive dissonance that hinders the ability of health professionals to communicate, and of families to understand, what is really at stake.

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# American Medical Association Journal of Ethics

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## CONLEY ETHICS ESSAY CONTEST WINNER

### Can Social Media Help Increase the Organ Supply While Avoiding Exploitation and Trafficking?

Gowri Kabbur

The combined ethics committee of the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) issued a 2015 [white paper](#) explaining the ethical principles that should guide *allocation* of human organs. The white paper does not mention *procurement* of organs, other than to say that selling organs is prohibited. Must procurement of organs also adhere to certain ethical principles? If so, which principles and why? In view of your argument, is use of social media to solicit organ donation ethical?

#### Response

The need for more organ donation in the United States is an ongoing struggle for the transplant community. According to the US Department of Health and Human Services (HHS), approximately 22 people die daily awaiting an organ transplant [1]. As of October 2015, an estimated total of 122,440 people nationwide were on organ waiting lists, a roughly fivefold increase from 1991 [1]. Unfortunately, the number of organ transplants performed in 2014 remained stagnant at around 29,532, which is less than a twofold increase over a 23-year period [1]. Recent social media campaigns, described below, have focused on increasing online organ registry enrollment rates, an alternative to registering citizens through states' driver's licensure processes. The United States currently uses an "opt-in" system for organ donation, requiring "concrete action" from citizens to declare their intentions to donate [2]. An alternative option in the US is "mandated choice"; for example, in 2006, Illinois passed a first-person consent law, according to which citizens are required to indicate legally binding organ donation preferences when registering or renewing their driver's licenses [2]. In contrast, some European countries such as Spain, Belgium, and Austria use an "[opt-out](#)" system [2] in which consent to donate is presumed [3]. This presumed consent model generally applies to all organs; a model is termed "soft" if family views are taken into account or "hard" if only the patient's wishes are honored [3]. A 2006 study that followed the organ donation rates of 22 "presumed consent" countries over a 10-year period found that, after correcting for other determinants impacting donation, "cadaveric donation rates [were] 25-30% higher on average in presumed consent countries" [4]. This study suggests that increased organ donation rates are due to legislative changes, but the impact of social media and ethical constraints of presumed consent laws are not discussed. The influence of social media on our daily lives cannot be denied, however,

and the current technology-driven social and cultural landscape gives rise to numerous ethical issues in transplant medicine, which are discussed here.

### **Current Guiding Principles for Organ Allocation**

In the summer of 2015, the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) released a white paper outlining some ethical principles that can guide organ allocation [5]. In the paper, practical utilitarian considerations, such as the need to maximize quality-adjusted life years (QALYs) and to minimize harms such as morbidities, complications, and mortality, are balanced with attention to justice. According to the report, "Factors to be considered in the application of the principle of justice are: 1) medical urgency; 2) likelihood of finding a suitable organ in the future; 3) waiting list time; 4) first versus repeat transplants; 5) age; and 6) geographical fairness" [5]. UNOS also emphasizes that the organization "has long opposed donations directed to a social group (based on race, religion, gender, or sexual orientation)" [5]. Patient autonomy is given less weight in conflict resolution, since the authors do not consider this principle often to be in disagreement with utility and justice [5].

### **Ethical Considerations about Organ Procurement**

Although the OPTN/UNOS paper unequivocally states that an autonomous decision to sell organs for profit is unethical [5], not much is said on the topic of organ procurement, which is just as ethically significant as deciding where organs will go. Because organ procurement interferes with patients' death processes and bodily integrity, it must be deliberated upon from an ethical point of view, just as we deliberate upon organ allocation. For organ donation and procurement, respect for patients' autonomy becomes the foremost ethical principle, to be carefully balanced with justice and equality. Utility seems to be less important to consider in procurement than in allocation, since the need for organ donors is the driving force behind procurement. In addition to these ethical principles, I propose that confidentiality should also be considered in deliberations about ethical procurement of organs. In the following paragraphs, I will explore the application of these ethical principles to organ procurement, focusing in particular on how social media in moderation can be a strong tool for increasing organ donation and spreading awareness about organ procurement practices.

### **Autonomy: Is Social Media a Help or a Hindrance?**

A goal of the transplant community is to increase organ donation as much as possible, preferably through mass media campaigns [6]. If more people are registered as organ donors before life-threatening events, it might be easier for medical teams to discuss organ procurement with shocked or grieving family members. A patient's prior indication of donation preferences could help medical care teams, including a patient's family members, fulfill the wishes of the deceased patient. The decision to donate rests solely with the individual and requires informed consent, which is what some national

initiatives, such as the HHS Organ Donation Breakthrough Collaborative, strive to facilitate [6]. In this respect, social media could influence organ procurement by giving patients a nonlegal and generally accessible platform to use to express their wishes.

In 2012, Facebook announced that its 150 million users now had the option to indicate their organ donor statuses on their “Timelines” and share that life event with their extended friend networks [6]. Upon selecting their status as an organ donor, users are given a link to their state organ registry (if possible) to officially sign up. Researchers found that on the first day of the new initiative, approximately 13,054 users (who upgraded to the Timeline feature) updated their organ donor profile, representing a 21.1-fold increase in online donor registrations from the baseline rate [6]. Although it slowly diminished over the next 12 days, the substantial increase in registrations from baseline was termed “the Facebook effect” by Cameron et al. [6]. In contrast, state driver’s license signatories’ registration rates (control data for comparison from four states) remained relatively unchanged from baseline during the same period [6]. This study showed the powerful, immediate impact of social media on donor registration rates, especially on a social platform where the effect of one update can multiply across a vast social networking tree.

The organ donor profile on Facebook also has worldwide implications. In countries without registries, a Facebook profile might be the only document specifying an individual’s intentions [6]. Some critics who contend that media campaigns such as these lack transparency and act as propaganda fail to understand that these organizations’ goals are to educate the public and provide individuals ready access to information so they can make better informed decisions; the platform happens to be social networking sites [7, 8]. Profile updates can prove useful in advanced care planning, by helping care teams learn something about patients’ wishes.

### **Coercion and Organ Trafficking**

As evidenced above, social media has been shown to be a powerful tool to spread awareness and motivate action. However, social media also has the power to enable illegal and unethical practices in the realm of organ procurement, specifically organ trafficking. With organs being in such short supply in the United States, desperate people in need of a transplant turn to international black markets as a source of organs and transplant surgery [9]. Anthropologist Nancy Scheper-Hughes, founder of Organs Watch, an organization dedicated to tracking kidney suppliers worldwide, highlights the risks “transplant tourists” are willing to take to “purchase a stranger’s kidney” [9] and the vulnerable states of kidney sellers. She calls organ trafficking “international organized crime” involving patients, sellers, travel agents, brokers, lab technicians, “outlaw surgeons,” and more, defying laws and professional codes of ethics [9].

The sale of human organs is deemed unethical by UNOS [5] and illegal by the National Organ Transplant Act of 1984 [10], directly violating the principles of justice and, in some instances, respect for autonomy. Organ donation is often thought to be an [altruistic](#) act, carried out after [voluntary](#), informed consent [7]. The decision to sell an organ, however, might be colored by coercion, blackmail, or financial need, calling into question free decision making. For example, a desperate family could coerce and be willing to pay an individual for an organ, knowing that the donor could be poor. [The sale of human organs](#) could establish a free market system that unjustly allocates human organs to the highest bidder, widening health care disparities and violating the principle of justice [5].

A startling example of such coercion and violation of human rights is an organ procurement strategy used in China. A Chinese national law in 1984 legalized organ harvesting from executed Chinese prisoners for transplantation, with “consent” obtained seven days prior to execution after sentencing by a court of law [11]. Aside from the probable coercion occurring during the consent process, the use of vulnerable prisoners as organ farms is morally reprehensible, since members of this population lack many basic rights and the power to refuse without ramifications. A 2006 investigation by David Matas and David Kilgour [12] revealed an “on-demand organ harvesting system” [13] at the Falun Gong prison, allowing Chinese physicians to advertise a two-week waiting period for organ transplantation. This shortened wait time, compounded with social media access, has made China a frequent destination for transplant tourism [14].

This example underscores that, ethically and clinically, how we procure organs is just as important as how we allocate them. A person’s autonomy should not be violated for free market trade, especially if the commodity is traded without consent and at high risk to the person’s well-being. It is of utmost importance to respect the sanctity of autonomy and avoid coercive behaviors in gaining consent.

### **Maintaining Justice with Living Donors**

Although the majority of organ donations come from deceased donors, a growing number of people have opted to become living donors of certain organs and tissues, such as liver, kidneys, bone marrow, and skin. According to HHS, single kidney donations are the most frequent living organ donations [15]. Although the decision to become a living donor might be completely autonomous and altruistic in intent, the donation must abide by certain ethical principles—namely, justice—that in practice can be undermined. The Uniform Anatomical Gift Act of 1968, for example, allows families of the deceased to bypass the UNOS waiting list and direct organ donation to specific individuals [16]. This well-intentioned act inadvertently condoned public solicitation of organs outside the UNOS waiting list. As a result, websites for donor-patient matching such as [MatchingDonors.com](#) [17] have gained popularity.



These websites allow living donors to be paired with people looking for transplants through patient and donor profile webpages that permit pictures and personal biographies. This profile page set-up allows for “shopping” of potential recipients by donors, which puts the process in danger of becoming a “beauty contest” or a popularity contest that favors those with the best personal story, appealing background, or good looks [18]. This process of donor-patient matching violates the UNOS guidelines [5] and the principle of justice, which condemns discrimination by sex, race, sexual orientation, or religion. Additionally, this process of matching invites donors to establish stipulations for an organ, an unethical practice that impinges on the supposed altruistic nature of the donation. For example, one donor on MatchingDonors required the recipient not to be associated with a “killing” vocation, such as hunting or fishing [18]. In light of this phenomenon, it can be said that organ procurement should occur without stipulations and should be altruistic, without ulterior motives. In this instance, social media can act as an unfair arbiter of organ procurement by introducing popularity and social bias into the decision-making process about organ donation.

### **Confidentiality in the Social Sphere**

Social platforms are increasingly used by people seeking organs who attempt to solicit public empathy through personal human-interest stories, but sometimes patient confidentiality is put at risk. In one particular example published in *Science and Engineering Ethics*, a patient and his family were done a disservice by a social media violation of confidentiality [19]. After being involved in a terrible motor vehicle accident, an 18-year old woman experienced significant trauma, resulting in brain death. Before the family could be approached about the patient’s brain death and options for organ donation, news of the event spread via social networking sites and local media stations, prompting the patient’s friends and school to push for her organs to be donated. Unfortunately, due to this information breach, this woman’s family did not find out about her state from the hospital medical team. This case exemplifies social media exploitation of a tragic story and its use as a platform for organ donation. Social media should never influence the decision making of the medical team and family members at such a crucial time, and patient confidentiality should be upheld.

### **Concluding Thoughts**

In the course of discussion, we have established that organ procurement should be held to similar ethical standards as organ allocation, specifically with regard to respect for persons and justice. Autonomous, altruistic decision making can be aided by social media campaigns to raise awareness. But out of respect for justice and equality, organ donation via websites like MatchingDonors.com should be blinded and done independently of a patient’s background or demographics. Also, organ procurement in the setting of end-of-life care should be respected and protected from social media influences that could sway medical decision making. The power of social media should not be underestimated when it comes to coercion, illegal sales, public shaming, and peer pressure. The younger

generations thrive on social media; however, careful use of the Internet is essential to protect patient autonomy, confidentiality, and justice—a challenge that the future generation of technologically adept medical professionals should be prepared to handle. The US organ transplantation system must evolve with the times and use social media to increase organ supply and ensure an ethical and sustainable future for transplantation.

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# American Medical Association Journal of Ethics

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## THE CODE SAYS

### The AMA *Code of Medical Ethics*' Opinions Relevant to Organ Transplantation and Procurement

Bette-Jane Crigger, PhD

Organ procurement and transplantation involve ethically complex considerations across a variety of scenarios. Ethically sound practice in transplantation medicine requires, first and foremost, that both donors and recipients be carefully evaluated for suitability. Also central to all transplantation scenarios is ensuring that the rights and well-being of both donors and recipients are protected, that decisions to donate organs and tissues are well informed and voluntary, and that possible conflicts of interest are minimized. On the transplantation side, organs and tissues must be equitably distributed among patients on the basis of medical need.

Several opinions in the AMA *Code of Medical Ethics* address these fundamental requirements.

- [E-2.03 Allocation of Limited Medical Resources](#)
- [E-2.15 Transplantation of Organs from Living Donors](#)
- [E-2.152 Solicitation of the Public for Directed Donation of Organs for Transplantation](#)
- [E-2.155 Presumed Consent and Mandated Choice for Organs from Deceased Donors](#)
- [E-2.157 Organ Donation After Cardiac Death](#)
- [E-2.16 Organ Transplantation Guidelines](#)

#### Appropriately Selecting Donors and Recipients

Opinions E-2.15 [1], E-2.152 [2], and E-2.157 [3] all specify that prospective donors and transplant recipients must undergo appropriate clinical and psychosocial evaluation.

#### Informed, Voluntary Decisions

Opinions E-2.16 [4], E-2.15, and E-2.157 seek to facilitate deliberation by distinguishing among the different contexts in which decisions involving organ or tissue donations need to be made.

*Living donation.* Opinion E-2.15 states that [living donors](#) must provide separate consent to donate and to undergo surgery to retrieve the donated organ or tissue. A robust consent process is essential for living donation, in which donors undergo the harms of surgery with no prospect of physical benefit. In these situations, it is important to ensure that donors have not been [unduly influenced](#), a consideration that may carry special weight under the (very limited) circumstances in which [a minor may donate](#) an organ or

tissues. The opinion further identifies special considerations that should be addressed in consent for living donation because the donor's right to withdraw from donation carries distinct implications for others, particularly in situations involving multiple donation-transplantation cycles. Scenarios that involve multiple donors and recipients can also raise unique privacy challenges.

*Cadaveric donation.* In cadaveric donation, opinion E-2.16 requires that death be determined by a physician other than the prospective transplant recipient's physician. Providing guidance for organ donation specifically in the context of cardiac death, opinion E-2.157 requires that decisions to forgo or withdraw life-sustaining treatment be made independently of any decision to donate an organ or tissue. In addition, separate consent must be obtained to use interventions before cardiac death specifically to preserve organs and tissues with the goal of improving the opportunity for successful transplant.

*Alternatives to the opt-in model of advance consent.* [Models of "presumed consent" and "mandated choice"](#) about whether to donate organs after death are intended to increase the supply of cadaveric organs available for transplant. As opinion E-2.155 [5] notes, each model raises special issues about the voluntariness of informed consent. Ethically appropriate presumed consent by deceased donors requires three things: that individuals be made aware that it is presumed they wish to donate organs, that it be easy to document and honor [refusals to donate](#), and that physicians verify that a donor's family is unaware of any objection (on the part of the deceased patient) to donating. Mandated choice models of recruiting donors require an individual to declare her or his preferences regarding organ donation when performing a state-regulated task, such as obtaining or renewing a driver's license. Mandated choice models are ethically appropriate only when an individual has sufficient information to make a meaningful and informed decision. Mandated choice models also require that physicians be able to verify one's documented consent to donate, for example, on the back of one's driver's license.

### **Conflict of Interest**

Concerns about voluntariness of consent to donate organs or tissues accompany concerns about possible conflicts of interest, especially among health care professionals. Opinion E-2.157 requires that end-of-life care for cardiac donors and organ retrieval are executed by independent medical teams. Similarly, opinion E-2.15 states that, in cases of living donation, both donors and recipients have independent advocate teams exclusively dedicated to their medical best interests and overall well-being.

### **Equitable Distribution of Donated Organs and Tissues**

The *Code of Medical Ethics* also provides guidance about ethically appropriate [distribution of organs and tissues](#) in opinion E-2.03 [6], which holds that organs and tissues should be allocated among potential recipients solely on the basis of medical need. Ethically acceptable criteria include "likelihood of benefit, urgency of need, change in quality of

life,” and “duration of benefit.” Supplementary criteria to distinguish among candidates who meet the foregoing criteria are, first, avoiding death or extremely poor outcomes and, second, anticipated “change in quality of life.” Under no circumstances should organs or tissues be allocated on the basis of nonmedical criteria, such as age, social worth, ability to pay, or the role of [patients’ lifestyle and behavior](#) in contributing to their illnesses.

[Public solicitation of organs](#) for directed donations—those made to a particular recipient—raises concerns about fairness in the distribution of organs for transplantation. Opinion E-2.152 holds that directed donation is ethically acceptable if it results in a net gain of organs in the pool without unreasonably disadvantaging other patients on a waiting list for a particular organ. This opinion prohibits payment to donors beyond reimbursement for travel, lodging, lost wages, and the medical care associated with donation.

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## IN THE LITERATURE

### **Ethical Dilemmas in Liver Transplant Organ Allocation: Is it Time for a New Mathematical Model?**

Aaron Ahearn, MD, PhD

**Merion RM, Sharma P, Mathur AK, Schaubel DE. Evidence-Based Development of Liver Allocation: A Review. *Transpl Int.* 2011;24(10):965-972.**

Liver transplantation has rapidly progressed from an experimental procedure to a lifesaving operation for patients with end-stage liver disease. This success, however, has been challenged by an ever-worsening shortage of donor organs [1, 2]. Mismatch between supply and demand continues to challenge the transplant community as we struggle to develop a system that fairly rations the limited liver allografts available, saves a maximum number of lives, and balances the needs of populations with those of individual patients.

“Evidence-based Development of Liver Allocation: A Review” describes the history of liver allocation in the US [3]. It nicely frames the progress the transplant community has made by adopting increasingly accurate mathematical models to guide organ allocation and accurately documents the failures of both the previous and current systems of liver allograft allocation. The article then discusses what the goals of an optimal allocation system should be and proposes a new mathematical model to try to achieve them. Given [the consequences of suboptimal allocation](#), an equitable model that offers significant improvement in survival for transplant patients must be seriously considered.

### **The History of Organ Allocation in the US: How We Got to the MELD Scoring System**

As Merion et al. explain, in its clinical infancy the field of liver transplant used an *ad hoc* system to allocate organs. However, in 1984 the National Organ Transplant Act formalized a system of organ allocation in the US [4]. This original system was based on patients’ wait times but also prioritized patients based on their hospitalization status (outpatient, inpatient, intensive care, or surgical emergency). This fledgling attempt to prioritize patients based on their medical acuity was relatively unsuccessful because hospitalization status was not always an accurate reflection of the patient’s medical necessity and was subject to “subtle and sometimes overt manipulation by transplant providers” [5]. Essentially, transplant professionals were escalating the level of care pretransplant patients were receiving in order to exaggerate their patients’ illness acuity and move their patients “up” the waitlist.



To rectify these deficits, the transplant community turned to mathematical models that try to predict the three-month mortality rates of end-stage liver disease patients, assuming those patients do not receive a transplant. The first model adopted was the Child-Turcotte-Pugh scoring system, which assigns points based on patients' albumin, bilirubin, international normalized ratio (INR)—one measure of blood coagulation—and the presence or absence of ascites and hepatic encephalopathy [4]. This system was in place from 1996 to 1999 and then was replaced by a system based on Model of End-Stage Liver Disease (MELD) scoring. MELD is based solely on the patients' bilirubin levels, INR, and creatinine levels [6]. Both systems moved away from wait time as the primary factor in allocation and instead focused on getting livers to the sickest patients on the waitlist, allocating based on medical urgency. This approach maximizes the number of lives saved by transplanting the patients who are most likely to die otherwise.

Merion et al. also describe the success of MELD-based allocation. Since 2002, the US transplant community has utilized the MELD-based allocation system to prioritize transplant candidates with the highest mortality risk on the waitlist. Minor modifications to the system have been made to correct for patients whose mortality risk is not linked to MELD score (i.e., patients receive additional MELD points for the presence of hepatocellular carcinoma) [7]. In general, the MELD-based allocation system is believed to be widely successful in that it has reduced waitlist mortality without significant changes in posttransplant survival [8]. These benefits are likely because the MELD score is a mathematically accurate predictor of waitlist mortality and therefore can successfully allocate organs based on medical urgency. However, MELD scoring also has practical advantages over previous systems in that the lab values used to calculate MELD scores are objective, quantifiable, and verifiable. This objectivity has mostly eliminated the transplant clinician's abilities to exaggerate a patient's disease severity in order to move "up" the patient's place on the transplant list.

### **Ethical and Clinical Merits and Drawbacks of MELD Scoring**

After reviewing the history of liver allocation in the US, Merion et al. challenge the concept that we should continue to allocate based on medical acuity. They describe three approaches to organ allocation: (1) a utility-based approach that allocates livers to patients with the best survival after transplant, (2) an urgency-based approach (including our current MELD-based system) that allocates livers to the patients with the highest pretransplant mortality, and (3) a [total survival benefit approach](#), which takes into account a patient's mortality both pre- and posttransplant. Merion et al. fault the utility-based approach because, while transplanted patients would do well, their waitlist mortality would be unacceptable. But they also fault urgency-based allocation systems because these systems dictate transplanting the sickest patients on the waitlist even if these patients' predicted postoperative outcomes are inferior to those of other patients on the waiting list. Thus, they propose that an ideal allocation policy would maximize

survival time gained at the population level for each liver transplant by accounting for the risks of death both before and after transplant.

Merion et al. then endorse their group's model of "predicted transplant survival benefit," which they reported on in Schaubel et al. [9] as an alternative allocation system. This complicated mathematical model uses the survival data from prior patients who were listed for and underwent liver transplant to predict prospective patients' pre- and posttransplant survival rates based on numerous patient variables. Using computer simulation, they predict 2,000 life-years could be saved over five years if this model were used in place of the existing MELD-based allocation system. Although this number of life-years cannot be easily disregarded, this change would be a major shift in the ethics of organ allocation and would have practical drawbacks as well.

The authors' argument that a model should maximize total life-years for all end-stage liver disease patients is based on utilitarian ideals of getting the most benefit from any given organ for our collective patients. However, to adapt utilitarian ideals too strictly risks overshadowing other ethical principles that have also influentially shaped modern medicine. A cornerstone of modern medical practice is physicians' obligations not only to populations, but also to individual patients. Thus, physicians must balance the goal of maximizing good with our obligation to provide patients just access to care. One potential adverse consequence of switching from an urgency-based to a total-survival-based model of allocation is that it could risk abandoning the sickest patients. A major driver of adopting an urgency-based system was the extremely high mortality of high-MELD end-stage liver disease (ESLD) patients (the three-month mortality of a patient with a MELD score of 40 is over 90 percent) unless they were provided access to transplant [10]. However, patients with high MELD scores also tend to have higher morbidity and mortality after transplant because they are so sick. In a total survival benefit model, these patients would be less likely to receive a liver because their posttransplant outcomes are predicted to be inferior. The ethical principle of justice requires us to question a system in which a significant group of potential transplant recipients would not have an opportunity to undergo a potentially lifesaving procedure.

A "predicted transplant survival benefit" model might also have unintended practical consequences if implemented for organ allocation. The benefit of more accurate mathematical models is only one part of what must be learned from the history of liver allocation. As I described above, a merit of the MELD-based system is its objectivity. In contrast, the survival-benefit-based allocation system includes subjective variables, such as patient diagnosis and hospitalization status [9]. The previous "status" allocation scheme was misguided because it created an incentive for clinicians to hospitalize patients for subjective indications in order to subversively influence the allocation system [4]. However, even the model's included variable "diagnosis" is a subjective and therefore corruptible value. For example, is a diabetic, overweight 58-year-old man with

steatohepatitis who drank three to four alcoholic beverages per week a case of alcoholic or nonalcoholic liver disease? If the response to this question resulted in a higher or lower “posttransplant survival benefit,” then it would determine this patient’s waitlist status. If this system were adopted, professionals could have an incentive to assign the patient’s diagnosis such that it would maximize allocation points rather than express a clinical judgment. This is just as problematic, from an ethical perspective, as exaggerating a patient’s illness acuity to move that patient “up” a waitlist. Incentives like these are clinically and ethically suspect because they can influence the allocation system, the quality of care provided to patients, and our ability to accurately study disease processes in the future.

Another practical consideration of changing to a model based on total survival is the potential effect on surgeons’ use of lower-quality liver allografts, also known as extended criteria organs. As the organ shortage has worsened, transplant surgeons have continued to expand the pool of eligible donors in order to meet the growing demand. This has led to the use of “expanded criteria donor allografts,” which are organs that can be successfully used for transplant but carry a higher risk of postoperative complications than organs from standard donors. In areas of relative organ scarcity, the risk of accepting an organ of marginal quality is low when compared to the risk of mortality of remaining on the waitlist. The use of these organs is also dependent on the clinical skillset and experience of the various centers in the regions. As centers gain more experience with extended criteria organs they become better at dealing with the complications that arise and therefore more comfortable using them. Every day, transplant surgeons across the country make their best decisions about uses of organs of various quality for their patients. Often centers will decline marginal livers for patients at the top of the list but be willing to accept them for patients further down. This is in some part due to clinical judgment, as some surgeons believe patients with lower MELD scores might be better able to tolerate complications that are more likely to occur with extended criteria grafts. Surgeons might also target marginal organs that are not wanted at other centers for patients whose clinical conditions make their mortality risk on the waitlist disproportionate to their lower MELD score. A model that incorporates potential outcomes should eliminate this kind of *ad hoc* decision making. In theory, the mathematical model should dictate optimal allocation for any given organ. But what’s optimal for society (i.e., the maximum survival benefit from a marginal liver) might not be what’s best for the patient (who could be better off waiting for a better liver). Will surgeons continue to be allowed to selectively allocate these organs to patients of their choice? If surgeons have difficulty bringing marginal livers to patients who they feel are appropriate matches, the net result could be fewer transplants.

Finally, another weakness of the predicted transplant survival benefit model is that it is based on the past results of liver transplants in the US. Because the MELD formula is a reflection of the patient’s liver disease, it remains an accurate predictor of mortality for

end-stage liver disease patients without transplant even as improvements are made in the clinical care of pre-transplant patients. On the other hand, the predicted transplant survival benefit model is dependent on the predicted pre- and posttransplant outcomes of past patients, which might not reflect clinical improvements in the field. A simple example would be the outcomes for patients with hepatitis C. If the model is based on the history of transplant in the US, patients with hepatitis C would be predicted to have posttransplant outcomes inferior to those of patients with other diagnoses. This is because recurrent hepatitis C was a serious problem that reduced the survival of patients after transplant. However, the advent of new therapies for hepatitis C seems to have completely changed the risks of this disease. Early reports suggest excellent results from hepatitis C treatment both before and after transplant [11]. No one knows what the long-term outcomes will be for hepatitis C transplant patients in the current era, because no patients have been treated for more than five years. Therefore, the predicted transplant survival benefit model will unfairly disadvantage these patients; their predicted outcomes will presumably be inferior to their actual outcomes.

### **Influences of Policy on Patients**

In conclusion, Merion et al. recap the history of liver allograft allocation in the US and nicely articulate some of the failures of the previous systems. They also draw attention to the fact that our policies must take into account the outcomes of both posttransplant patients and patients on the waitlist. As a group of professionals we must continue to evaluate our practices to improve our outcomes. However, organ allocation is a multifaceted decision process that involves ethics, clinical judgment, and local factors that surgeons routinely confront. Although adoption of a “better” mathematical model could increase our society’s number of “predicted life years,” it could also result in a plethora of unintended consequences. The more complicated an allocation system becomes, the more difficult it will be for surgeons to adapt to their local situations and optimize their results.

On the other hand, understanding a policy’s effects on the outcomes of patients both before and after transplant is extremely important. Policies that address outcomes only before or after transplant often have perverse effects on the overall survival benefit of patients with ESLD. For instance, there is a growing body of evidence that Centers for Medicare and Medicaid Services guidelines [12], which were implemented to improve postoperative liver transplant outcomes, might have resulted in the removal of more sick pre-transplant patients from the waitlist [13]. Thus, although transplant surgery outcomes improved, the overall survival of patients with end-stage liver disease might not have. Merion et al. drive home the point that our policies should target improved survival for the entire population of patients with liver disease, both before and after liver transplant. Even if we do not adopt their model, it is crucial to keep their goal in mind as we continue to refine our systems of organ allocation and transplant care.

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## POLICY FORUM

### Regulations' Impact on Donor and Recipient Selection for Liver Transplantation: How Should Outcomes be Measured and MELD Exception Scores be Considered?

Joel T. Adler, MD, MPH, and David A. Axelrod, MD, MBA

#### Introduction

The allocation of donated livers to patients waiting for transplantation is a classic example of a medical ethical conflict, rooted in the challenge of balancing urgency and utility in a limited resource setting. Current allocation policy, which determines the order in which waitlisted patients are offered an available liver, is based on the Model for End-Stage Liver Disease (MELD) score, a validated measure, based on patients' objectively verifiable lab values, of the likelihood of death without transplant. By prioritizing a patient with the highest MELD score, the system is [explicitly designed](#) to reduce the likelihood of patients' dying while waiting for a liver, rather than choosing those patients who are likely to have the best posttransplant survival [1]. It is possible to compare organ allocation to similarly resource-limited clinical challenges, such as triage during a mass trauma, the protocols of which dictate that those patients with the highest chance of long-term survival are given top priority [2]. Transplantation differs from trauma care in key ways, however, notably in the extended time to make allocation decisions among waitlisted patients, our limited ability to predict long-term outcomes after transplant, and the variable quality of donor organs, which are seen as gifts that oblige stewardship. Consequently, the United Network for Organ Sharing (UNOS) has implemented a liver transplant allocation policy that seeks to reduce the risk of dying immediately rather than attempting to predict future survival after transplant [3, 4].

In marked contrast to allocation policy, transplant programs are evaluated principally on posttransplant liver graft and patient survival. Thus, despite a system that prioritizes transplant for the sickest patients on the waiting list, centers are required to maintain posttransplant graft survival rates that are generally greater than 90 percent at one year [5]. We explore here how these well-intentioned but conflicting policy decisions result in unanticipated challenges in transplant care by describing the current system of regulating center performance and its impact on both patient selection and liver graft selection.

### **The Transplant Environment under the Medicare Conditions of Participation**

In the United States, federal law requires that transplant center outcomes are universally tracked and publicly reported, serving as a prime example of transparency in health care delivery. Solid organ transplantation practice has been regulated by the federal government under the National Organ Transplant Act (NOTA) since 1984 [6]; however, the regulatory landscape dramatically changed in 2007 when new Conditions of Participation (CoPs) were issued by the Centers for Medicare and Medicaid Services (CMS) [7, 8]. Under the new rules, minimum risk-adjusted posttransplant graft and patient survival rates are required for Medicare certification and reimbursement. CMS promulgated these rules for transplant center certification in the name of advancing patient safety and improving transplant outcomes [7, 8]. However, since implementation of the CoPs, some experts have questioned whether these rules have improved outcomes or simply resulted in restricted access for higher-risk patients and reduced innovation [9-12].

The current CoP requirements are based on risk-adjusted one-year graft and patient survival outcomes in patients transplanted over a 2.5-year period, as reported by the Scientific Registry of Transplant Recipients (SRTR) [8]. Outcomes are based on data reported by transplant programs and validated through comparison with the National Social Security Death Master File. Data are risk-adjusted using donor and recipient characteristics (e.g., age, race, cause of liver failure, cause of donor death) to account for differences in patients and donors. Unfortunately, risk adjustment methods remain imperfect and many important factors (e.g., cardiovascular disease) are poorly captured in risk-adjusted outcomes. Centers are flagged for poor performance when all three of the following criteria are met for either death or graft failure one year after transplant: (1) the ratio of observed outcomes to risk-adjusted outcomes (standardized mortality ratio) is greater than 1.5; (2) observed outcomes minus expected outcomes ("excess") is greater than 3; and (3) the difference between observed and expected outcomes is statistically significant (one-sided  $p$ -value < 0.05). There are appeals processes in place should centers be sanctioned for poor performance (referred to as "mitigating circumstances"); however, many of these appeals have been unsuccessful and the centers still receive significant sanctions that result in costly process improvement agreements [10, 13]. Furthermore, although the CoPs have been established through federal regulation, commercial insurers tend to use similar data to qualify programs for Centers of Excellence status and determine network eligibility [14]. Both directly and indirectly, the regulatory environment heavily influences transplantation practice and outcomes.

By design, the CoP outcomes standards are designed to identify centers in which graft loss or patient death significantly exceeds risk-adjusted expected values. CMS officials point to empirical evidence that the CoP standards have improved posttransplant outcomes [7]. Although there is no published data on the effect of the CoP standards on



liver transplantation, the data on kidney transplantation is illustrative: in an initial review of 15 kidney transplant centers that entered systems improvement agreements as a result of CoP citations, the standard mortality ratio for one-year post-transplant survival decreased from 2.05 to 1.17 over a two-year period [10]. CMS argues that these data demonstrate that CoPs have led to improved post-transplant survival for patients undergoing kidney transplantation at those centers [10]. As another added benefit, hospitals were required to increase the amount of resources available to transplant centers as a requirement to remain in the Medicare program [8]. However, there is also clear evidence that failure to meet the publicly reported outcome standards can have a devastating impact on transplant programs [9, 15]. Not surprisingly, when centers receive low performance evaluations, they perform fewer transplants and reduce the size of their waitlists for both kidney [12] and liver [16] transplantation. Centers cited for poor outcomes often see dramatic reductions in referrals [17], resulting in fewer new listings for transplant and substantial losses of clinical volume and hospital revenue.

### **Impact of CMS Regulations on Donor and Recipient Selection**

It is important to recognize that the CoP criteria are contingent on only two metrics: one-year post-transplant patient survival and one-year graft survival [18, 19]. These metrics do not capture outcomes over patients' entire episodes of care, which extend from the onset of advanced organ failure to death with or without a transplant. The CoPs do not evaluate the center rates of transplantation, impose no penalties for higher-than-expected waitlist mortality, or consider low acceptance rates of riskier donors or recipients. Because the CoPs do not incorporate measures of pretransplant outcomes (e.g., waitlist mortality), they have created a dilemma for transplant centers: *Should a transplant center become risk-averse and perform fewer, lower-risk transplants with likely better early posttransplant outcomes or should the center be more aggressive and perform potentially riskier transplants by using marginal organs to provide a greater population-level benefit but face a higher risk of sanctions under the CoPs?*

The CoPs have also directly undermined the efforts of UNOS to increase utilization of all deceased organ donors. To improve posttransplant outcomes, many centers choose to decline offers for marginal donor organs [17, 20], including livers with moderate-to-severe steatosis ("fatty liver"), which have a higher rate of early dysfunction, or livers donated following cardiac death (DCD), which have increased rates of biliary complications. Aggressive centers that seek opportunities to expand the organ supply by using these marginal, lower-quality organs are potentially at greater regulatory risk. These programs can be cited for minimal decreases in posttransplant survival, despite the benefit resulting from substantial increases in the overall rate of transplant. Some of these more aggressive centers have been able to successfully convince CMS that they qualify for "mitigating circumstances" and should not be subject to regulatory penalties. However, doing so requires substantial and costly investments and is not always

successful [15]. Accordingly, the rate at which these “marginal” organs are declined appears to be increasing since the CoPs were announced [21].

Because the impact of poor performance evaluations is so drastic, potentially affecting not only certification and reimbursement but also referrals, many transplant centers are altering their patient selection criteria to reduce risk of a negative evaluation [20]. Because race, ethnicity, and [socioeconomic status](#) are known risk factors for poorer liver transplant outcomes, but are inadequately accounted for in the risk-adjusted outcome models [22], [already-disadvantaged](#) groups are disproportionately affected by transplant centers that are less willing to engage in “riskier” transplants. Despite inclusion of risk adjustment in the CoP assessment of transplant outcomes, centers are *de facto* incentivized to avoid listing patients [perceived as having a high risk of early graft failure or mortality](#). These incentives are relevant from an ethics perspective because they can disproportionately affect patients who are also commonly disadvantaged: patients who are older or have advanced comorbid conditions, have a higher body mass index, or are of low socioeconomic status.

The impact of the CoPs on donor and recipient selection appears to be mitigated, in part, by the competitiveness of the local transplant environment. The first geographic unit for liver allocation is the donor service area (DSA). It has been useful to conceptualize DSAs as 58 individual markets or transplant “micromarkets.” These DSA “micromarkets” vary considerably in a number of factors such as the size of the waiting list, the number of transplant centers, and the “market share” controlled by each [23]. “Market share” within a DSA matters, as DSAs with one dominant center and three smaller centers are less competitive than those with four centers each possessing a relatively equal market share [23]. Listing practices vary widely among DSAs as a consequence of different practice environments [24]. More competitive DSAs, in which a greater number of transplant centers compete for the care of transplant patients, tend to transplant patients who are sicker. These centers also tend to accept riskier (lower-quality) organs [23]. In other words, in competitive environments, the need for patients drives centers to aggressively pursue available organs to retain volume despite concerns about posttransplant outcomes.

Currently, there are efforts to promote broader sharing of liver allografts among micromarkets, which may have the effect of increasing *de facto* competition and encouraging more aggressive listing and organ utilization practices [23, 25]. By combining DSAs of differing levels of competition into larger organ allocation regions, these policies effectively make every allocation region in the country “more competitive.” In turn, this may encourage more aggressive listing and organ utilization practices, reducing the cherry-picking of donors and recipients that can lead to systemic disadvantages for certain patients [25-27].

### **Measuring Outcomes: Limitations and Innovations**

Despite nearly two decades of public reporting, metrics used to assess transplant center outcomes are significantly limited by several key factors, including sample sizes and the lack of detailed clinical data. An individual transplant center's annual volume of procedures performed can range from 1 to 200, providing insufficient statistical power to detect statistically significant differences between observed and expected outcomes in many centers [5]. The SRTR addresses this issue by basing observed and expected one-year survival rates on center data aggregated over 2.5-year cohorts. Despite frequent data collection, the prolonged analytic period results in substantial delay in recognizing changes in center performance, with reported outcomes that may appear worse than expected outcomes despite meaningful process improvement during the 2.5-year period. Finally, key factors including the patient's cardiac status and the degree of steatosis in the liver allograft are not captured in national data.

Several potential solutions to these limitations have been proposed. For example, cumulative sum (CUSUM) charts intended for real-time assessment of program-specific clinical outcomes are available on a confidential basis to transplant centers but have not been used for regulatory review [27]. CUSUM charts provide more responsive, real-time data. However, these methods are designed for process improvement, not regulation; they have high sensitivity and relatively low specificity when identifying poorly performing centers, and this limits enthusiasm for broadening their use.

In an effort to respond to concern about the reliability of the older metrics used to assess performance, the SRTR recently introduced new performance assessment tools using Bayesian methods [11, 28]. These methods adjust the precision of the outcomes assessment according to the size of the program and national data, to provide a more reliable estimate of performance. Of concern, it appears that more centers will be identified as poor performers under the Bayesian system [11, 28]. This methodology has yet to be adopted by CMS under the CoPs; however, the data are publically reported and are available for patients and other payers. In theory, the Bayesian methods provide a more robust assessment of performance; unfortunately, in practice, the results are more difficult to interpret and the current choice of signaling thresholds is likely to exacerbate the issues of risk aversion and organ discard. Furthermore, the new or proposed models remain limited by the same lack of key clinical variables data for risk adjustment as the current models.

Finally, there also is little agreement on methods to measure outcomes starting from initial diagnosis, because not all potential organ transplant recipients are referred, evaluated, or listed. End-stage organ disease is a population-based problem with a long continuum of care, from the onset of early organ disease, through progression of disease while on the waiting list, and, finally, to posttransplant care for those fortunate enough to receive a transplant. There is clear evidence that many patients who are reasonable

candidates for transplant are never evaluated or listed [29-31]. Currently, transplant centers are not rewarded for increasing access to transplant services or for effectively managing the health of patients on their waiting lists. This clearly fails to incentivize centers to promote the health of their waitlisted patients, let alone the population of patients with end-stage organ failure in their regions. Not only would measuring the quality of care for end-stage organ disease along the entire continuum be a worthwhile endeavor, it could refocus attention from survival of transplanted patients to reducing mortality from liver disease overall.

### **Impact of MELD Exception Scores on Recipient Selection under the CoPs**

Under the current allocation system, a substantial number of liver transplant candidates move up the waitlist after their MELD scores are recalculated incorporating “exception points” designed to address the MELD score’s weaknesses in measuring effects on mortality risk of diseases such as hepatocellular carcinoma (HCC). Exception points are awarded independently of the patient’s actual MELD score, and the use of these mechanisms varies widely across the country [32]. The current systems have been shown to overestimate the risk of death from HCC, leading to relative overtransplantation of these patients at the expense of patients without malignancies [33]. The population of patients with HCC also tends to be better insured and of higher socioeconomic status [34], which exacerbates the existing economic disparities in access. HCC patients may, in fact, be transplanted too quickly, and posttransplant survival appears to be improved by waiting longer for a liver and selecting patients with less aggressive disease and lower chance of recurrence [35]. Thus, strategies like “ablate and wait” (i.e., radiofrequency ablation as a bridge to transplant to remain within acceptable listing criteria) may prove prudent prior to subjecting patients with aggressive cancers to a major procedure and the need for immunosuppression.

Unfortunately, current quality measures do not reward centers for making such appropriate clinical decisions. The CoPs compound these issues, as centers are strongly incentivized to identify and transplant patients with HCC who, in general, are healthier at the time of transplant and have excellent early patient and graft survival despite the potential for disease recurrence.

### **Conclusions**

Transplantation is a heavily regulated and scrutinized field that has witnessed remarkable improvements in outcomes over the past 20 years. Although much of this improvement is the result of innovation in surgical techniques and immunosuppression, a significant component of continued improvement can justly be attributed to transplant centers’ public reporting of outcomes and their desire to achieve excellent outcomes. Transplantation thus has been a leader in transparency by publishing center-specific outcomes and providing national data that centers can use to identify opportunities for self-improvement.

However, using measured outcomes for punitive purposes may have resulted in significant unintended consequences. Transplant professionals will, by necessity, adapt practice to minimize the risk of regulatory citation and loss of transplant volume [36]. This self-protective strategy will contribute to lower transplant rates (typically among higher-risk candidates) and greater organ discard (of low-quality organs) unless transplanting higher-risk patients and acceptance of marginal organs are properly accounted for in CoP criteria that incorporate robust risk-adjustment methodology.

The goal is not to eliminate measurements, but rather to incentivize improvement of meaningful outcomes. One solution to encourage innovation could be to exempt recipients participating in funded IRB-approved trials from a center's reported outcomes. To prevent abuse of this system, a limit on the number of exempt transplants would need to be defined and outcomes would require extra review and regular reporting. To date, the CoPs have not been adapted to support innovation though this type of proposal. Without such a system, programs face strong disincentives for generating novel approaches to the most difficult problem facing transplant clinicians: the need to expand the supply of available organs. Similarly, by choosing appropriate measures to define the CoPs in the future, including a focus on pretransplant outcomes, transplant regulations may actually encourage acceptance of marginal organs and transplantation of higher-risk patients. With the right metrics and appropriate risk adjustment, transplantation will continue to lead in public reporting and transparency, which honors the gift of life given by thousands of donors annually. Without changes, however, we will exacerbate risk aversion in donor and recipient selection and lose an opportunity to provide access to lifesaving procedures.

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### **Disclosure**

Dr. Axelrod is an owner of XynManagement, a private corporation that provides quality monitoring and improvement software to transplant programs.

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**POLICY FORUM**

**Technology- and Policy-Based Strategies for Increasing Supply of Deceased Donor Livers**

Katrina A. Bramstedt, PhD, MA, and Jean-Baptiste Hoang

Currently, liver transplantation remains the only effective treatment for end-stage liver disease [1], and living and deceased donor graft (the organ) survival rates are nearly equivalent (82.5 percent and 82.0 percent at 1 year post-transplant; 72.2 percent and 71.9 percent at 3 years after transplant; 65.9 percent and 65.1 percent at 5 years after transplant) [2]. According to the Organ Procurement and Transplantation Network, there have been at least 15,000 patients awaiting liver transplant at the start of each year since 2011 [2-5]. The size of the waitlist fluctuates during the year as patients are added or removed (because they received transplants or died), but when patients are listed at more than one hospital, the patient is counted only once [3]. In the United States, between 2006 and 2012, approximately 6,391 liver transplants occurred each year, indicating a consistent shortfall of organs [3]. Living liver donation is a risky elective surgical procedure [6]; thus the ethically optimal way forward is *not* increasing the number of living donations to facilitate more transplants but increasing the number of deceased donor livers available for transplantation.

Attempts to increase the deceased donor pool encounter the intersecting clinical problems of an aging donor population with ever-increasing rates of diabetes and steatosis (fatty liver) [7] that contribute to high discard rates (i.e., grafts rejected by transplant teams because of poor quality). Specifically, in 2010, the utilization rate of deceased donor livers in the United States was 78 percent; however, this rate is expected to decline to 44 percent by 2030 [7]. The best approaches to increasing the deceased donor liver pool will likely entail a combination of technology and policy strategies (see table 1 and table 2).

**Technological Strategies**

As shown in table 1, the technological approaches to expanding the deceased donor liver pool comprise three categories: surgical techniques, medical devices, and organ procurement and selection methods.

**Table 1.** Technological approaches to expanding the deceased donor liver pool

| Technology Type    | Examples                    |
|--------------------|-----------------------------|
| Surgical technique | Split liver transplantation |

|                                     |  |
|-------------------------------------|--|
|                                     | Reuse of auxiliary livers                                |
| Surgical technique + medical device | Liver regeneration with three-way sharing <sup>a</sup>   |
| Medical device                      | <i>Ex vivo</i> perfusion                                 |
| Procurement/organ selection         | HIV-positive livers                                      |
|                                     | Donation after controlled circulatory death (DCD) livers |
|                                     | Extended criteria livers                                 |

<sup>a</sup>Currently experimental.

*Split liver transplantation (SLT).* In the US, it has been estimated that 20 percent of donor livers are suitable for SLT [8], and thus wider use of this technique could significantly impact the rate of liver transplantation. SLT involves dividing a deceased donor liver into two portions for transplantation. Most commonly, a child is the recipient of the left lateral segment (Couinaud segments II and III), while an adult receives a right extended graft (Couinaud segments I, IV-VIII). Less commonly, the donor liver is divided for two adult recipients (right graft, Couinaud segments V-VIII; left graft, Couinaud segments I-IV). In both scenarios, SLT is technically challenging due to complex biliary anatomy, and high-quality livers are generally selected for optimized outcomes [9]. (Importantly, SLT remains the key source of transplants for children [10]; thus skilled teams are an ethical necessity.) According to Lauterio et al. [9], the outcomes of SLT that involve the left lateral segment graft and right extended graft are “equivalent” to those of whole liver transplant when these surgeries are performed by experienced teams. When the liver is split for two adult recipients, one- and five-year graft and patient survival rates are roughly 20 percent lower than for whole liver transplants [9]. SLT has been in clinical use since 1988 [11], but, due to the challenging nature of the procedure and need for high-quality grafts at baseline, SLT is rare, representing only about 6 percent of all liver transplants in Europe and Oceania [9] and 1 percent of US liver transplants [8].

*Reuse of auxiliary livers.* It is estimated that 10 percent of liver transplants are due to acute hepatic failure [9]. Auxiliary liver grafts (from both living and deceased donors) are liver segments implanted adjacent to the native liver as a form of *in vivo* bridging therapy while the native liver recovers from acute failure. Leiden University Medical Centre (Netherlands) has been successful at reusing auxiliary liver grafts after they have regenerated in their original recipient and are no longer needed due to recovery of native hepatic function [9]. If widespread reuse of these grafts were feasible, it could impact the number of recipients who could be helped. Feasibility for reuse will depend on matters such as the observed success of *in vivo* graft regeneration, the structural integrity of the graft following removal, and the absence of chronic rejection, which would cause deterioration in the graft.

*Liver regeneration with three-way sharing.* A technology that has the potential to vastly expand the pool of deceased donor livers is *ex vivo* liver regeneration with graft sharing.

Specifically, researchers at the Wyss Translational Center Zurich are developing a method of splitting a whole donor liver into three segments, followed by *ex vivo* regeneration of each segment into full liver grafts for transplant into three patients [13]. The Wyss group also proposes to use this same technology for liver disease patients to grow their own grafts for transplant by way of resection of a healthy portion of the patient's liver, followed by *ex-vivo* regeneration of that segment into a graft suitable for transplant back into the patient (at which time the remaining diseased native liver would be removed). As this work is in the early stages, there are many unknowns, such as what criteria define a pristine liver for three-way splitting or optimal *ex-vivo* regrowth [14]. Furthermore, while potentially promising, this technology raises ethical concerns when the donor graft originates from a living person with end-stage liver disease: the live donor will be exposed to more risks, because this technique requires two surgical procedures (explant and replantation) rather than the customary primary transplant, and it is unknown whether the technology will be affordable, which may raise questions about justice and access [14].

*Ex vivo perfusion (EVP).* EVP could enable the use of organs that would otherwise be discarded or be of elevated risk due to "marginal quality" (i.e., grafts from older donors, fatty livers, DCD livers). It is a leap beyond routine cold, static liver storage before transplant. In general, EVP involves perfusion of donor livers with either normothermic or subnormothermic solution after procurement (prior to transplantation) with the aim of nourishing the liver while also flushing out toxins and cytokines. The technology is still relatively new, and teams are using various temperatures and perfusion solutions to determine which have the best protective effects [15]. Guarrera et al. [16] report fewer biliary complications and significantly shorter hospitalizations for patients receiving EVP extended criteria livers than for patients receiving static cold storage extended criteria (see discussion below) livers. Machine and solution costs are potentially challenging, but EVP could result in overall savings if it led to fewer livers being discarded and improvements in patient and graft outcomes with marginal grafts. If EVP becomes standard practice, all organ procurement organizations could incorporate the technology by transferring the associated costs into the organ acquisition fee. Transplant teams should specifically discuss EVP in their consent process, just as they do extended criteria organs.

*HIV-positive livers for HIV-positive recipients.* It is estimated that the US could provide approximately 250 HIV-positive donor livers annually for HIV-positive patients [17], thus increasing the number of organs available overall. Three-year patient and graft survival for HIV-positive recipients of HIV-positive livers is roughly the same as that for HIV-negative recipients receiving HIV-negative livers [18]. A problem, however, is that many HIV-positive liver grafts are also positive for hepatitis C antibodies and thus only suitable for patients who are also infected with hepatitis C. This latter group of patients has worse outcomes after transplant than those not co-infected with hepatitis C [18],

making decisions about burdens and benefits complex for hepatology teams. As the opportunities for treating HIV and hepatitis C co-infection improve, the transplant opportunities for this population should be further enhanced [19].

*DCD livers.* Livers procured after controlled circulatory death (donation after circulatory death—DCD) have evidenced poor outcomes due to problems with nonanastomotic biliary strictures, bile leaks, hepatic artery stenosis, and graft failure [20-22]. Contributing factors include advanced donor age and lengthy cold ischemic time. But these livers could be successfully used if evidence for EVP’s effectiveness is compiled [15] or if *antemortem* interventions are used. The latter are ethical as long as they provide clinical benefit (improved organ viability), have a low chance of patient harm, and are consented to by the patient or family.

*Extended criteria livers.* The term “extended criteria liver” is a broad category for livers that are not “pristine.” In general, these are livers from older donors (age 55 or older); grafts with increased ischemic exposure, hepatitis C virus, and hepatitis B core antibodies; and steatotic grafts. Because there is no standard definition for the “extended criteria liver,” the conceptualization can creep wider to include variables such as length of hospitalization of the donor and donor weight. With knowledge of the rising rate of discarded organs [7], it is critical to develop an understanding of how “extended criteria” variables impact graft and patient outcomes in order to create options for donation that are clinically and ethically sound. By using “extended criteria,” the discard rate can potentially fall and the rate of transplantation rise.

**Policy Options**

As shown in table 2, the policy options for expanding the deceased donor liver pool can be categorized into three areas: referrals, consent, and incentives. Referrals are hospital-driven activities; consent is focused on individuals or families, depending on the procedure; and incentives involve both financial and nonfinancial rewards for donation.

**Table 2.** Policy options for expanding the deceased donor liver pool

| Policy type       | Examples                     |
|-------------------|------------------------------|
| Referral policies | Routine referral legislation |
| Consent policies  | First-person authorization   |
|                   | Presumed consent             |
|                   | Mandated choice              |
| Incentives        | Reciprocal altruism          |
|                   | Noncurrency incentives       |
|                   | Currency incentives          |

*Routine referral legislation (RRL).* RRL is fundamental to organ donation practice in the US [23]. With RRL, hospitals are required to notify their regional organ procurement

agencies of all deaths and impending deaths, regardless of cause of death or patient age (as examples) so that trained procurement personnel, rather than hospitalist physicians, make the clinical judgments regarding the suitability of potential donor organs. Clinician fatigue or personal biases are ethically inappropriate reasons for failing to make donor referrals [24]. If these practices were implemented worldwide, it would result in the elimination of missed opportunities for potential donation.

Various [policy models](#) governing donors' consent to donate have also been used to try to increase the deceased donor pool.

*First-person authorization (FPA).* The US uses [FPA policy](#) as a method of increasing the number of deceased donors. FPA means that those who register to be organ donors via a registry or advance directive/living will are voicing their voluntary, autonomous wish to donate, and therefore no additional consents or permissions are needed from the next of kin [25]. Furthermore, family members are not permitted to veto or cancel their relative's donation registration [25, 26]. Not only does FPA save time in a time-sensitive specialty such as transplant, but families are not burdened with donation decision making when they are emotionally stressed by the death or impending death of their loved one [26]. However, many countries, including Australia and the UK [26], do not use FPA because they believe family should be the ultimate decision makers regarding organ donation even when adults have formally registered their wish to donate [21]. From an ethics perspective, it is important to honor the values and wishes of those registered as donors. Families who are upset by the donation decision of their loved ones can receive counseling and emotional support from specially trained staff within organ procurement organizations and hospital pastoral care programs.

*Presumed consent (PC).* PC is used in some countries, particularly in Europe, to increase the number of available organs. PC means that adults are assumed to have consented to organ donation when they die, unless, while alive, they register themselves as opting out of organ donation. In the "hard" PC model (practiced in Austria, for example [27]), there is no further approach to next of kin regarding people's preferences in the matter and donation proceeds for those who have died and have not opted out. The "soft" PC model (practiced in Spain, for example [27]) requires next-of-kin consent for all donations, even for those patients who did not opt out. We express ethical concern about the "hard" PC model's not accounting for those who might not want to be donors but have not yet opted out or have not been able to due to lack of computer or transport access. It would seem that home visits could be made to facilitate opt-out registration in these situations, although this service could be expensive to support if there was a large volume of home visit requests.

*Mandated choice (MC).* The MC model forces adults to make and register a choice about organ donation at the same time they are engaging other civil processes (e.g., seeking a

vehicle driver's license, registering to vote, filing a tax return). It has been argued by the American Medical Association that MC would be ethical only if the choice was made with informed consent and the consent documentation verified [28]. In our view, this is not ethically necessary, as FPA does not require informed consent [25, 26] yet has been the gold standard in the US for many years [25].

Other potential ways to increase the pool of donors are to reward those who donate and to remove financial barriers that impede donation. The following sections discuss [these concepts](#).

*Reciprocal altruism (RA).* Altruism is generally accepted as a fundamental source of motivation for organ donors that can be used to frame policy. The foundational principle of RA is higher priority on transplant waiting lists for those who have previously donated or registered to be an organ donor in the future [29]. Israel [30, 31] has an RA donation policy, and there is a nongovernmental RA donation organization in the US [32]. Legally and ethically, RA programs are not considered a form of remuneration but rather motivators to encourage people to register as donors [29]. Whether the registrant or family member receives priority for transplantation, it is the prioritization that is the reward for registration. Overall, RA is an ethically permissible approach that embraces the willingness to both give and receive an organ, rather than to be a free rider. Also, organ donor registration is an altruistic activity.

*Government-sanctioned noncurrency incentives (NCI).* NCIs focus on conveying gratitude without any exchange of money (real or virtual, such as tax credits). According to Section 23 of Israeli transplant law [31], living donors receive a certificate of recognition and an exemption from entrance charges to national parks and nature reserves. In the US, living organ donors and family members of deceased donors can receive a bronze Stephanie Tubbs-Jones Congressional Gift of Life Medal [33]. Because NCIs honor the altruism of organ donation they are ethically permissible, but the motivators described are not likely to be strong enough to trigger future organ donations, partly because they are not widely promoted as being available.

*Currency incentives.* Currency-based incentives can take various forms. Payments for organs are illegal in the US [34]. Additionally, we view such incentives as ethically problematic, because the direct involvement of money (other than reimbursement of donor costs, below) commodifies the human body and creates vulnerability to exploitation. Iran provides a stipend to living kidney donors (approximately \$400) and one year of free medical insurance [35]. Controversially, the Iranian government permits the exchange of money between organ recipients and their donor candidates (even providing a "private space" where these negotiations can take place) [36]. There is no limit to the fees proposed by the donor candidate, but if the rate rises too high for the recipient's budget, the Iranian Patients' Kidney Foundation [36] will provide new

potential donors for consideration. Israel pays the cost of transport and burial (inside or outside of Israel) for those who are organ donors [31]. Because it is a reimbursement of costs related to donor death, not a payment for organ donation, this incentive can be viewed as ethically permissible.

Furthermore, we argue that removing financial barriers (disincentives) to donation is important and should be ethically encouraged. When such barriers are in place, living donation can be financially burdensome, which is ethically unacceptable in the setting of a lifesaving altruistic gift [37]. In the US, several states provide tax deductions up to \$10,000 for travel, lodging, and lost wages related to the living donation process [38]. Also, the US Health Resources and Services Administration provides grants up to \$6,000 for reimbursement of travel, accommodation, meals, and incidental expenses incurred by the donor and a support person during the donor candidate assessment, hospitalization, and clinical follow-up [37].

### Conclusion

The ethically optimal way to achieve more transplants is to implement a combination of technological and policy strategies. FPA and RRL policies are ethically and legally proven and should be implemented worldwide. Continuing efforts to prove the efficacy of *ex vivo* perfusion and liver regeneration with three-way sharing should continue, as these approaches have great potential to expand the deceased donor liver pool. Additionally, technologies that optimize donor registration (i.e., accessible, user-friendly, informative, streamlined processes) and donor referrals [39], as well as continued community education efforts to [raise organ donation awareness](#), should be encouraged.

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## POLICY FORUM

### Elective Transplantation for MMA Patients: How Ought Patients' Needs for Organs to be Prioritized when Transplantation Is Not their Only Available Treatment?

Alon B. Neidich, MD, and Eitan Neidich

Methylmalonic acidaemia (MMA) is an autosomal recessive inborn error of metabolism that presents in infancy with episodes of metabolic acidosis (i.e., buildup of methylmalonic acid and other harmful substances in the blood) that can lead to intellectual disability, chronic kidney disease, and, in some cases without treatment, coma and death. Long-term symptom management requires a protein-restrictive diet, but patients can still suffer from recurrent metabolic crises, chronic renal disease, and neurologic disorders [1]. Despite advances in research and improved understanding of the disease process, long-term management remains a burden for patients and families, and at significant cost [2].

Recently, liver transplantation has become an alternative treatment for MMA. For example, liver transplantation (LT) and combined liver-kidney transplantation (LKT) have been demonstrated to improve patients' quality of life, with benefits including increased energy, decreased hospitalizations, and the ability to attend school [3]. While LT or LKT decreases levels of methylmalonic acid in the blood, it is still unclear whether early LT improves long-term neurologic outcomes for patients [3]. It is hypothesized that, in MMA, methylmalonic acid is produced *de novo* in the central nervous system, contributing to poor outcomes in spite of dietary restrictions and transplantation [4].

Determining the relative benefits of dietary management and transplantation for MMA is a complex judgment that requires weighing at least four well-known principles of medical ethics: autonomy, beneficence, nonmaleficence, and justice. Expressing beneficence for an MMA patient requires both dietary management and consideration of the potential benefits of transplantation. Nonmaleficence in the context of MMA care requires minimizing risks of harm to the patient, so discussion of long-term neurological outcomes following transplantation and risks associated with the procedure and long-term immunosuppression is critical. Expressing respect for an MMA patient's autonomy means preserving that patient's right to make health care decisions and also clarifying that a request for transplantation might not be honored. This is because, given organ scarcity, the principle of autonomy must be weighed against the principle of justice; clinicians and health care organizations must consider the interests of communities, not

just the interests of individual patients, when assessing criteria for organ allocation. One concept that can help us think more deeply about justice is utility.

For diseases other than MMA, such as [alcoholic liver disease](#) and [hepatocellular carcinoma](#), there are clinical scenarios in which no viable alternative treatment beyond liver transplantation exists [5]. An ethical question related to justice in these cases is whether quality of life should be part of our definition of utility. If we assume that increased longevity has more ethical value than increased quality of life, a utilitarian perspective would not prioritize transplants for patients with MMA. An additional point to consider in this analysis is that the number of patients diagnosed with MMA could increase in the future. If newborn screening becomes more widespread, additional patients will likely be diagnosed with MMA, and if they are all eligible for liver transplants, this would place additional demands upon the scarce resource of deceased donor organs. So, the burden of providing transplants for all patients with MMA in the future is a factor the transplant community must consider in crafting new allocation policy.

Since it is up to individual clinicians to decide whether to list a particular patient for an organ, it is imperative that the transplant community engages clinicians, patients, and the public to develop clear policies regarding the use of deceased donor organs for transplantation. Furthermore, a robust public discussion is required to determine which values inform our conception of utility and whether patients with MMA should be prioritized lower or higher on the deceased donor organ waitlist than those patients for whom there is no therapeutic alternative to transplantation.

Transplantation considerations for patients with MMA should incorporate utility and also values such as clinical efficacy, equity, and respect for patient autonomy. Further research is needed to determine long-term benefits, risks, and rates of success of transplantation in patients with MMA. As the future of treatment for patients with MMA continues to evolve, the transplant community must continue to deliberate upon the ethical principles, including utility, which drive allocation policy for patients with MMA.

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## MEDICINE AND SOCIETY

### Organ Donation as a Collective Action Problem: Ethical Considerations and Implications for Practice

Keren Ladin, PhD, MSc

The organ shortage is one of the most pressing concerns facing the transplantation community, and the gap between supply and demand continues to widen [1]. An average of 22 people die daily in the United States awaiting lifesaving organs of all types [2]. Public policy initiatives have long aimed to increase organ donor designation, most recently through the use of educational campaigns, broadening the criteria for acceptable organs, and social network campaigns [3-6]. Yet, in 2013, the percentage of adult US residents designated as donors was less than half (48 percent) [7].

Guidance for reframing our approach to organ donation can be found in the writings of economist Mancur Olson, whose seminal work *The Logic of Collective Action* was first published in 1965 [8]. Olson conjectured that collective action is unlikely to occur in response to shared interests when they contradict individuals' immediate self-interest:

If the members of a large group rationally seek to maximize their personal welfare, they will *not* act to advance their common or group objectives unless there is coercion to force them to do so, or unless some separate incentive, distinct from the achievement of the common or group interest, is offered to the members of the group individually on the condition that they help bear the costs or burdens involved in the achievement of the group objectives.... These points hold true even when there is unanimous agreement in a group about the common good and the methods of achieving it [9].

Under these circumstances, the problem of "free ridership" arises, with some individuals either consuming a disproportionate share of a common resource or contributing less than their fair share to the common pool [8]. Collective action problems involve activities that are vital to a community and its residents but in which individual participation [conflicts with self-interest](#). Organ donation fits this definition because, although the benefit to community is significant, individual incentives to participate are low and free ridership is high, in that organ recipients are not required to have been registered donors. Disincentives to register include discomfort with making a donation decision, lack of motivation to register, concerns about burial, and repugnance associated with death and organ procurement [10, 11]. Assuming that we all have some unknown

risk of needing an organ, having the largest possible reservoir of organs could benefit everyone by reducing preventable deaths, and a smaller pool increases the likelihood that those waiting for organs will die.

In the United States, the ability of physicians to treat patients facing organ failure is largely dependent on public willingness to supply treatment—that is, to donate organs. This reliance on [voluntarism](#) raises the following questions: What obligations arise for physicians and other stewards of public health in addressing a problem, such as organ shortages, that could affect anyone? And [what types of interventions are ethically justified](#) to increase the pool of available organs and minimize preventable deaths? To address these questions, I first examine public support for organ donation and then the moral imperative for action at the individual, clinical level, and at the systemic, public health level.

### **Is There Public Support for Organ Donation?**

Findings from the *2012 National Survey of Organ Donation Attitudes and Behaviors* demonstrate that an overwhelming proportion of US adult respondents in a nationally representative telephone survey support or strongly support organ donation (94.9 percent), as they did in surveys conducted in 2005 (92.9 percent) and 1993 (93.5 percent) [12]. Strong support for donation was significantly higher among whites and Native Americans than among those with African-American and “other” backgrounds and was significantly lower among those age 66 and older than among younger respondents. Non-Hispanics were significantly more likely than Hispanics to strongly support donation. Socioeconomic gradients were also evident; strong support for donation was significantly lower among persons with a high school education level or less than those with more education.

The proportion of registered donors is increasing but not in comparison to the overwhelming support for donation. From 2005 to 2012, the percentage of US adult survey respondents designated as organ donors on their driver’s license increased from 51.3 percent to 60.1 percent [12]. By 2012, 52.2 percent of adult respondents over age 65 were designated organ donors on their driver’s licenses; that number was just 26.3 percent in 2005 [12]. Among respondents not designated as organ donors, 36.8 percent said they had reservations about donation and 59.2 percent said they were open to considering donation [12]. The large gap between support for and commitment to donation suggests a need for strategies to encourage people to make a decision. Collective action offers one approach to increase accountability and personal responsibility associated with organ donation that could benefit the community.

### **Are Physicians Morally Obligated to Discuss Organ Donation with Patients?**

In light of social support for organ donation, what role does the medical community have in promoting education about donation? Physicians can have [a key role](#) in facilitating

education and discussion with patients regarding donation, both because of their professional ethical obligations to facilitate informed decision making and because they are well situated to have conversations about advance directives. Family physicians in particular are well positioned to overcome some of challenges unique to collective action problems [13]. First, they have established relationships of trust with patients cultivated during multiple discussions, often over the course of many years. Second, family physicians tend to see a range of age groups, including adults over 65, who comprise the smallest share of adult deceased donors but could likely donate at significantly higher rates [14, 15]. Third, family physicians have successfully promoted decision making regarding advance directives and organ donation through conversations with patients [16]. Finally, a new Centers for Medicare and Medicaid Services (CMS) policy will reimburse physicians for end-of-life discussions beginning in January 2016 [17]. Although annual visits present key opportunities for engaging patients in discussions about their preferences for end-of-life care, facilitating discussions about organ donation can be done by physicians in various specialties and settings.

Physicians are not only well positioned to effectively increase organ donation, they are also ethically obliged to encourage patients to consider it, according to the principles of beneficence and justice, in particular [18]. Because any patient's future need for an organ is unknown, it is in all patients' best interests to have access to the largest supply of organs possible. Relying on this conception of the principle of beneficence, physicians are morally obliged to discuss organ donation with their patients in an effort to increase the supply of organs available to them in the future should the need arise. Beyond their responsibility to individual patients and families, physicians have an additional obligation to promote justice: in this case, a chance at lifesaving treatment for all persons in need. In the context of collective action problems, this often corresponds to a duty to encourage prosocial behavior. Because of their role in promoting health, physicians are ethically obligated to encourage organ donation, rather than remaining value-neutral—both for their patients' possible future best interest and for the best interest of society [19].

### **Considerations for Patient Autonomy**

How can the principles of justice and beneficence, which require that the physician encourage organ donation, be balanced with the principle of autonomy, which requires that patients decide about treatments in accordance with their preferences and values? Ezekiel Emanuel and Linda Emanuel consider four models of patient-physician decision making: paternalistic, informative, interpretive, and deliberative [20]. Although the paternalistic approach (in which the physician recommends the treatment he or she considers optimal) does not offer enough control to patients, the informative model limits the physician's role to that of technical expert conveying only facts, leaving little scope for physicians' values. In the interpretative model, physician-patient interactions are meant to clarify patients' values and preferences and help patients identify



treatments that best align with their values. By contrast, the deliberative model casts the physician in the role of clarifying health-related values associated with available treatments and suggesting why certain values are worthier. Emanuel and Emanuel, who consider several models and advocate for the deliberative model as superior, note that, in this last model, “the conception of patient autonomy is moral self-development; the patient is empowered not simply to follow unexamined preferences or examined values, but to consider, through dialogue, alternative health-related values, their worthiness, and implications for treatment” [21].

Indeed, such a deliberative approach would require physicians to engage patients in discussion about organ donation and encourage them strongly to consider the moral values associated with donation. A deliberative approach has been recently taken in pediatric practices that require patients without medical exemptions to be vaccinated. In addition, new guidelines from the American Academy of Pediatrics advocate more stringent criteria for prescribing antibiotics for treatment of acute otitis media, in part to reduce antibiotic resistance [22].

### **Are Public Health Authorities Morally Obligated to Intervene?**

What types of broader interventions are justified to increase the pool of organs?

Historically, public health authorities have had a broad mandate and power to enforce, through policing powers when necessary, public participation in ensuring the safety and health of the public—especially to overcome collective action problems that relate specifically to the nature and scope of the role of the state. Illustrative examples include: *Jacobson v. Massachusetts* (1905) [23], in which the United States Supreme Court upheld the authority of states to enforce compulsory vaccination laws (despite the potential harms to individuals); state- or court-mandated directly observed therapy for treatment of tuberculosis [24]; and the recent instance in which a nurse who had been in contact with Ebola patients in West Africa was quarantined against her will upon her return to the United States [25]. In these cases, the state intervened to force action where inaction (and free riding) might have constituted a threat to public health. Given the levels of intervention taken by public health authorities to reduce preventable morbidity or mortality from infectious disease, perhaps similar interventions are warranted to achieve higher organ donation rates. Although mandating organ donation has generally been seen as an overreach of state authority, possible interventions to bolster social capital—a network of social connections that gives rise to norms of reciprocity—include presumed consent (or “opt-out” policies), the provision of minimal incentives for donor registration, and encouraging physicians to discuss organ donation with patients and families.

Social capital has been shown to mitigate collective action problems of free ridership by reinforcing norms supporting prosocial behavior [26, 27]. Social capital can be used to [encourage prosocial behavior](#), and, in the case of the organ supply, could be used to

increase donation. Other countries, such as Israel, have begun to promote donation by giving priority to registered donors in organ allocation [28]. The United States has long granted living donors priority on waiting lists, which expresses support for the ethical value of reciprocity [29]. A recent study of more than three million registered drivers in Massachusetts found that community-level sociodemographic and social capital variables, as measured by levels of racial segregation and violent crime, explain more than half of the variation in organ donor status in Massachusetts [26]. This study demonstrated that, beyond living in a neighborhood with low social capital, even living *on the border of* a neighborhood with low social capital was independently associated with lower levels of organ donor designation, even after controlling for residents' own neighborhood characteristics. This suggests that "raising" social capital could lead to higher levels of organ donation.

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## SECOND THOUGHTS

### Ethical Considerations of Transplantation and Living Donation for Patients with Alcoholic Liver Diseases

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Given organ shortages and social and cultural concerns about alcohol use, transplantation for patients with alcoholic liver disease (ALD) remains controversial. Ethical concerns pertain to equity and utility in the allocation of scarce resources and [social stigmatization](#) of patients with a disease that is thought to be self-inflicted [1-5]. Moreover, patients with ALD have been subjected to additional protocols in [the evaluation for transplant candidacy](#) that are unique to ALD and can influence one's waitlist status for liver transplantation (LT).

#### Background

In 2010, alcohol-related cirrhosis was responsible for 493,000 deaths worldwide (1 percent of all deaths) [6]. In the US, ALD is the second most common indication for LT, behind chronic hepatitis C infection [6, 7]. Before the National Institute of Health Consensus Conference on Liver Transplantation in 1983, LT was rarely performed in patients with ALD [8]. After multiple studies found that patients with ALD undergoing LT had favorable outcomes and low relapse rates [9, 10], transplant centers began performing LT on patients with ALD, but not without imposing conditions on recipients. These strong recommendations include a six-month abstinence rule, enrollment in a structured program to prevent alcohol relapse, and ensuring good psychosocial support prior to and after transplant [11].

In 1991, based on studies demonstrating benefits of transplant in ALD patients, the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) identified ALD as one of the seven conditions for which it approved payment for LT [12]. Despite the controversy surrounding donation of organs to patients with perceived self-inflicted injury or illness and the concern about relapse of alcoholism, public opinion has gradually become less negative and more favorable towards LT for ALD patients [13]. This shift in public opinion might have contributed to an increase in the number of these transplants performed, with 1,088 LT transplants for ALD in 2013, compared to 901 in 2003 [14].

Many who oppose LT for ALD argue that graft survival rates—i.e., rates of the transplant functioning well enough to preclude the need for another organ—are lower in ALD

patients than in patients with other liver diseases and attribute that to relapses of alcoholism [15]. Yet studies have shown that, for ALD patients overall, the five-year graft survival rate is 72 percent with a five-year relapse rate of 20–50 percent [16, 17], which is comparable to the five-year average graft survival rate (59 percent) for all LT recipients [18]. However, the most up-to-date deceased and living donor graft survival rate data, from 2007, show that graft survival for ALD patients at five years posttransplant is lower than that for patients with cholestatic disease, but higher than for patients with hepatitis C and other diseases [19]. Despite the increase in LT for patients with ALD over the past decades, they still experience a large unmet need for LT. As of November 2015, 64 percent of patients with ALD were on the waitlist for LT more than 1 year, compared to 52 percent of patients with nonalcoholic fatty liver disease, and many were dying of comorbidities secondary to their liver disease as they waited [20].

This paper delineates some of the ethical concerns that commonly arise when transplant professionals evaluate patients with ALD for LT and highlights how sociocultural values and assumptions inform those professionals' considerations.

### **Sociocultural Values and Assumptions**

*Stigma and personal responsibility for health.* Transplantation for patients with ALD has generated widespread debate among the general public, health care professionals, patients, living donors, and family members [4]. A commonly expressed concern pertains to a patient's personal responsibility for his or her own health [5]. Specifically, opponents argue that, in ALD, liver damage is self-induced—alcoholism leading to end-stage liver disease was due to a patient's voluntary actions—and, accordingly, providing a deceased donor LT to patients with ALD means taking a scarce resource away from patients who are purportedly "more deserving." As one ethicist posits, "what justifies giving them lower priority for a liver transplant is that they are not only causally but also morally responsible for liver failure" [21].

This kind of advocacy of personal responsibility for health [22] relies on a punitive conception of "giving people what they deserve." By focusing on personal responsibility for health among alcoholics, transplant clinicians and ethicists subject patients with ALD to a different level of scrutiny than other patients with liver disease, utilizing dissimilar definitions of justice in granting access to the waitlist. It appears that this viewpoint espouses a notion of justice for patients with ALD that means maximizing graft survival by imposing abstinence periods intended to reduce recidivism, while justice for all other liver patients means helping patients who have the greatest medical need, as assessed by their MELD score. In delaying access to transplantation among patients with ALD regardless of their medical need, transplant clinicians and ethicists allow the MELD score to become overshadowed by the patient's personal behavior. This inequality expresses condemnation of alcohol consumption and a belief that engaging in socially disparaged behavior makes one less deserving of treatment.

Equity in access to transplantation is an ethical requirement [3]. Using different definitions of justice for, or standards of evaluating, the same patient population (liver patients) is unethical. Treating all liver patients the same way would eliminate the possibility that some patients gain quicker access to transplantation than others because of a trait, such as demographics, experiences, or behaviors. A commitment to equity demands that “the only reason to give alcoholic patients lower priority for transplantation is if subgroups of alcoholics can be shown to have unacceptably poor transplant prognoses” [23].

The ideology of personal responsibility for health is used to argue that LT would be better suited to patients with diseases that are not behavior-associated, such as primary biliary cirrhosis and primary sclerosing cholangitis. Yet many diseases for which LT is readily recommended could also be considered self-inflicted. For example, one could argue that patients with diseases such as nonalcoholic steatohepatitis (NASH) chose to consume excess calories, which leads to metabolic syndrome and NASH cirrhosis. However, less controversy surrounds access of patients with NASH to transplant. Moreover, mounting evidence of a genetic basis for alcoholism [22, 24] suggests that a belief in absolute personal responsibility for ALD might be unfounded.

As a disease, alcoholism requires careful medical treatment, as does any other disease. Clinicians’ focusing on disease causality in treatment decisions violates the principle of beneficence; clinicians have a duty to treat all patients regardless of the cause of the health problem. Decisions not to provide LT based on the presumption that *all* LT recipients with ALD will fare worse than those without ALD unfairly discriminate against ALD patients, as occurred in a study using hypothetical descriptions of kidney transplant candidates [25]. Clinician decision making based on predicting patients’ behaviors undermines patient autonomy by failing to respect particular patients’ individuality and expressions of free choice.

*Public opinion.* Public opinion polls have traditionally reported negative support for LT for patients with ALD. According to a 1991 public opinion survey in Oregon, citizens prioritized LT for nonalcoholics over patients with alcoholism [26]. Studies in the UK (1998) and in Hong Kong (2006) similarly found that public support for LT was higher for naturally occurring diseases rather than for behavior-associated liver diseases such as ALD [26-29].

The transplant community is also concerned that people will be less willing to donate if organs are allocated to patients with ALD or others perceived as “undeserving.” The perception that the public was reluctant to donate is supported by the paucity of LTs for ALD in the 1980s and early 1990s [12]. On the other hand, a recent survey of 503 participants reported that the majority were “at least neutral” (81.5 percent) toward early transplantation for patients with ALD [13]. Thus, public opinion appears to be

shifting toward lending greater support for treatment to all people, regardless of their historically stigmatized disease. Further research should investigate whether and when knowledge of transplantation in patients with ALD impacts people's decisions to donate.

### **The Questionable Value of Abstinence Plans**

Transplant centers have traditionally adhered to a 1997 guideline established in the Consensus Conference on Liver Transplantation, recommending that patients with ALD undergoing evaluation for LT must abstain from alcohol for at least six-months before being waitlisted [30]. The abstinence period is presumed to enable patients to resolve their addictions and reduce the likelihood of relapse and subsequent graft failure. Among patients with recent alcohol consumption or acute alcoholic hepatitis, the abstinence period might enable spontaneous recovery and obviate the need for LT, as well as reduce the risk of alcohol relapse if LT remains unnecessary. Evidence supporting the six-month abstinence period is poor, however; the introduction of the abstinence period emerged from three poorly controlled studies [31-33], and subsequent data failed to show that it affects survival after LT [34]. One study reports that the length of sobriety from alcohol is an insufficient predictor of relapse risk in most patients, and that the optimal abstinence period remains unclear [35]. Moreover, the definition of relapse is inconsistent across studies, ranging from occasional drinking to regressing to alcoholic states [30].

The six-month abstinence rule is also ethically suspect for faster and life-threatening alcohol-induced liver diseases, such as alcoholic hepatitis [30]. The treatment of severe alcoholic hepatitis (defined as a Maddrey's discriminant function of more than 32) will entail initiation of steroids in the absence of signs or symptoms of infection. If patients do not respond to steroids, mortality rates at 28 days are exceedingly high, 40-50 percent, and there are limited medical therapeutic options [36]. Given these high mortality rates, early LT for patients with alcoholic hepatitis is a medically promising option. In a study of steroid nonresponders with severe alcoholic hepatitis, the six-month survival rate was 77 percent with early LT and only 23 percent without LT [37]. In the 26 LT recipients, zero relapses occurred within the first six months, and three relapses occurred more than two years after transplant. No patients suffered from graft failure.

Although insurance companies mandate a six-month period of pretransplant abstinence, few transplant programs require LT recipients to attend substance abuse programs. A study of substance abuse treatment found, however, that relapse rates did not differ among 118 recipients who did or did not receive substance abuse treatment before LT [38]. On the other hand, LT recipients who received substance abuse treatment before *and after* LT had significantly lower relapse rates (16 percent) than those who received no substance abuse treatment (41 percent) or substance treatment only before LT (45



percent). Accordingly, substance abuse treatment after transplant appears to be more clinically beneficial than pre-LT treatment.

In addition to failing to uphold the principle of beneficence, imposing the abstinence period can contradict the principle of nonmaleficence because the ancillary time patients are required to wait before being listed for an LT can exacerbate their disease and thereby cause harm. Moreover, the utilization of the abstinence period discriminates against a patient group based on a class of diseases [30], which violates conceptions of health care justice. Thus, we should provide, but not limit, waitlist access because substance abuse treatment prior to LT and maintained afterward can help prevent relapse. Without solid evidence to support the use of abstinence periods, many support its elimination [30, 39].

### **Live Donor Liver Transplantation**

Many of the aforementioned ethical concerns can be mitigated by considering the option of adult-to-adult living donor liver transplantation (ALDLT), a form of directed donation from one adult to another, for patients with ALD. ALDLT overcomes the commonly held reservation that patients would take a deceased donor organ from another on the waitlist. Indeed, ALDLT upholds ethical values: it supports equity in patients' access to LT (justice), might improve recipient outcomes (beneficence), and increases the number of organs available for LT, a strategic priority of the OPTN/UNOS.

However, ALDLT raises additional ethical issues [40]. Live liver donors undergo considerable risks to themselves, including a 40 percent chance of a medical complication (e.g., infection, hernia, death) or a psychological complication (e.g., anxiety, feeling inadequately prepared for postoperative pain, suicide) [41, 42], but receive no direct medical benefit to themselves [43]. Potential donors must make a decision about donation with little long-term donor outcomes data [41]. These circumstances differ substantially from those of potential living kidney donors, who face a 3 to 6 percent chance of a major perioperative complication [44] and a 0.03 percent chance of death [45] and have comparatively more information about donors' long-term outcomes, as living kidney donation has been performed for more than 60 years [46]. Furthermore, when the potential LT recipient has alcoholic hepatitis, there is limited time to treat, and potential live liver donors might feel pressured to avoid regret or other consequences of refusing. A core element of informed consent is that individuals make treatment decisions voluntarily, without undue pressure on their decision making. However, some potential living donors feel that they have no choice but to donate in order to save the life of their loved one or fulfill culturally valued family obligations [42].

Besides time constraints, the informed consent process itself remains questionable [42, 47] because many potential live liver donors have little understanding of the transplant candidate's liver disease and therefore the likelihood of benefits to recipients gained

from the transplant and of donors' risks. A living person's decision to donate differs ethically from the allocation of deceased-donor organs; one thing that deserves particular attention is the likelihood of risks and benefits to the donor. Accordingly, informing potential live liver donors about the patient's diagnosis of alcoholic cirrhosis, the date of his or her last drink, and the posttransplant substance abuse treatment plan might help them evaluate the likelihood of benefits of LT to the recipient. Greater information might better enable potential live liver donors to weigh whether the risks and potential benefits to recipients of transplantation are worth undertaking in relation to the risks and potential benefits to themselves. In sum, although it might be unjust for transplant centers to consider how a person's liver became diseased in transplant candidacy and allocation decisions, potential living donors should still be told about the candidate's condition to make an informed donation decision.

In sum, despite that we've argued that it's unjust to consider how a person's liver became diseased in allocation and donation decisions and despite that we've clarified that the relationship between abstinence and relapse rates are dubious, we still acknowledge that living persons deserve something that dead donors don't: opportunities to consider what we might call a kind of the "return" on her or his altruistic "investment" in a recipient.

While ALDLT can be justified on the basis of respect for the donor's autonomy and presumed psychological benefit, it is unclear whether these risks should be undertaken in a given case. Regardless of the cause of the patient's liver disease, transplant centers must still determine whether live liver donors should be allowed to undertake the risks of donation. Studies document that individual patients, donors, and transplant centers tolerate different levels of donor risk [48, 49]. Unlike living kidney donation, ALDLT is relatively new (it has been performed in the US since 1998) [50], and relatively few transplant centers perform it because gaining the necessary surgical experience to reach acceptable donor and recipient outcomes requires a large patient volume. Because live donor complication rates remain high [41], the transplant field has not reached consensus about the appropriateness of ALDLT.

### **Conclusion**

As stewards of transplantable organs, transplant centers have a responsibility to ensure that potential recipients are evaluated carefully without the influence of stigma, and that organs are provided to eligible patients. LT for patients with ALD has traditionally been called into question given social and cultural norms and attitudes about personal responsibility for health. Transplant teams should be mindful of assumptions potentially informing their patient evaluations. Decisions about ALD should be based on the most up-to-date empirical data. Given recent evidence calling into question the value of abstinence periods and public opinion increasingly supporting LT for ALD [13], transplant

centers should consider revising protocols to reflect more equitable and beneficial practices for evaluating this patient population for LT.

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## Suggested Readings and Resources

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