

MEDICINE AND SOCIETY

Epistemic Authority and Trust in Shared Decision Making About Organ Transplantation

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Abstract

Patient epistemic authority acknowledges respect for a patient's knowledge claims, an important manifestation of patient autonomy that facilitates shared decision making in medicine. Given the scarcity of deceased donor organs, transplantation programs state that patient promises of compliance cannot be taken at face value and exclude candidates deemed untrustworthy. This article argues that transplant programs frequently lack the data to make this utilitarian calculation accurately, with the result that, in practice, the psychosocial evaluation of potential transplant candidates is discriminatory and unfair. Historically excluded candidates, such as patients suffering from alcohol use, have turned out to benefit highly from transplantation. Transplant programs should tend to trust patients when they claim to be good potential organ stewards, thereby respecting patient autonomy, advancing justice, and saving more lives.

Epistemic Authority Is Foundational

Epistemic authority is granted when an agent is trusted and his or her knowledge claims are respected by outside parties.¹ Health care usually prioritizes the physician's epistemic authority. The physician is a highly trained expert making a medical assessment of the patient, and the patient's willingness to consider the physician's assessment is a critical component of any patient-physician interaction. Presumably, the patient visits the physician because he or she values the clinician's expertise—that is, the physician's epistemic authority.

Respect for patient autonomy is another key pillar of the patient-physician relationship in Western clinical medical ethics. In the shared decision-making framework, physicians offer expertise and judgment, and patients bring their own values and preferences to the collaborative decision-making process. We assert that respecting patient autonomy calls for the physician to grant the patient a degree of epistemic authority regarding claims of self-knowledge. To build a strong patient-physician relationship, the physician must consider the patient reliable and trustworthy until proven otherwise. For example, if a physician believes a patient has not been adherent to a treatment, the physician might conclude that the patient has “failed” a treatment. Trusting the patient calls for

the physician to first ask, “Why did this treatment fail the patient?,” not, “Why did the patient fail the treatment?” If the physician does not trust the patient, the patient-physician relationship devalues patient autonomy and becomes more paternalistic.

We consider the role of patient **epistemic authority** when a patient is evaluated by the organ transplant team prior to being placed on the waiting list. During this paternalistic process, the reliability claims of potential candidates are repeatedly challenged on utilitarian grounds during an intense psychosocial evaluation.^{2,3} Transplant providers believe this high level of scrutiny is justified to select good organ “stewards” to make best use of scarce deceased donor organs and save the most lives. We argue that current organ transplantation system incentives encourage unwarranted bias against many patients with psychosocial risk factors and paradoxically lead to organ allocation decisions that do not maximize utility. We conclude that distrust of patient epistemic authority reduces patient autonomy, vitiates utilitarian outcomes, and leads to injustice.

Utilitarian Frameworks in Transplant Ethics

Hundreds of thousands of patients have end-stage organ failure in the United States and are potential candidates for transplantation. Heart failure kills more than 300 000 Americans a year,⁴ and approximately 750 000 patients are on hemodialysis for end-stage kidney disease.⁵ Currently, a fortunate 124 000 or so patients are on the transplant waiting list,⁶ which has not been shortened despite an increase in the donor supply from the opioid epidemic.

Two major federal regulatory actions shape the **organ allocation policy** landscape and define its primarily utilitarian ethical framework. First, the Centers for Medicare and Medicaid Services imposes strict posttransplant graft and patient survival benchmarks that transplant programs must meet to remain in operation.⁷ Centers are frequently penalized or shut down due to these requirements; more than 20 lost Medicare funding and most of these were shut down; an additional 40 were placed in a probational status during the last 10 years alone.⁸ Second, federal rules for organ allocation policy calls for wait-listed candidates to meet standardized minimum listing criteria and be ranked “in order of decreasing medical urgency.”⁹ Synthesizing the high posttransplant survival benchmarks with the prioritization of medically urgent candidates, the effective ethical framework is primarily utilitarian, ie, focused on maximizing the medical benefit of each transplant. Equitable access is also a consideration (eg, increased priority for highly immunologically sensitized patients with few potential compatible donors), but it is secondary to utility. Finally, federal organ allocation rules intend to minimize **geographic disparities**,⁹ but these mandates are largely ignored in current organ-specific allocation policies or their implementation.^{10,11,12,13} More complete multiprinciple ethical frameworks for allocation have been proposed that explicitly incorporate conceptions of equal access and justice (eg, allocating organs to younger people so that they can live a complete life).^{14,15,16} However, in the current policy framework, these considerations are secondary to ensuring that each organ transplant results in a tangible, sustained medical benefit for the recipient.

Reliability in Candidate Selection Processes

Candidates for transplantation undergo a rigorous evaluation by transplant programs. Programs have standardized **candidate selection criteria** that are intended to exclude candidates at higher risk of postoperative mortality or complications. Candidacy restrictions are distinct from and in addition to strict contraindications to transplantation. For example, lung transplantation is contraindicated in patients with

left-ventricular failure, as it would worsen their condition due to lack of lymphatic drainage in the transplanted lungs.¹⁷ In contrast, lung transplantation is not strictly contraindicated in patients with chronic kidney disease.¹⁷ However, renal dysfunction is associated with significantly worse outcomes posttransplantation,¹⁸ and thus the strict posttransplant survival benchmarks might incentivize programs to exclude these patients from transplantation.

These candidacy criteria extend beyond objective medical comorbidities. Strict adherence to antirejection medication is necessary for a complication-free and low-risk posttransplant course. Therefore, programs impose nonmedical psychosocial candidacy criteria based on detailed psychiatric and social evaluation by a mental health professional.^{2,3} A potential organ transplant candidate must convince the transplant team that he or she has adequate social support and the ability to adhere to treatment to meet whatever threshold has been set by the transplant team. Psychosocial requirements for organ transplant candidacy directly challenge patient epistemic authority regarding claims of reliability and organ stewardship, decidedly shifting the balance of decision making towards the transplant providers. Transplant programs are unilaterally empowered to tell candidates, “We don’t trust that you will be reliable posttransplantation,” and to cut off access to the waiting list.

Sources of Bias

Relying on a utilitarian notion of medical benefit of transplantation implies that a precise utilitarian calculation of benefit is possible. The most common metric employed in organ transplantation is survival benefit, defined as the improvement in survival expected from transplantation compared to remaining in a state of end-organ failure.^{19,20,21,22,23} In the utilitarian framework, in order for a psychosocial requirement for transplantation to be justified, it must have a clear relation to net survival benefit.

However, the evaluation of psychosocial factors is compromised due to the underlying biases of the transplantation team. Multiple studies have revealed evidence of systematic bias on the basis of race in accessing transplantation. Among “very healthy” patients with isolated single organ failure and no medical comorbidities, non-Hispanic white patients have substantially higher rates of renal transplantation than minority groups.²⁴ When liver allocation relied on subjective inputs from transplant providers, a significant disparity in transplantation rates existed between African-American and white candidates that completely resolved with the implementation of the objective Model for End-stage Liver Disease (MELD) score.²⁵ Moreover, African-American patients are less likely to be given information about kidney transplantation at dialysis centers and more likely to be found “psychologically unfit” for transplantation.²⁶

The best available tool for systematic assessment of psychosocial factors, the Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT),² can predict social support system failure and episodes of acute organ rejection.²⁷ However, the SIPAT was tested and validated in a predominantly white and well-educated patient population; although recently translated into Spanish,²⁸ its performance in diverse patient populations is unknown. Importantly, the SIPAT has not reliably predicted posttransplant survival in any patient population.²⁷ Without proper design, prediction models can exacerbate disparities driven by biases present in the data, depending on how those inaccurate models are used.²⁹ The evidence we have discussed suggests that psychosocial risk cannot be accurately assessed based on clinicians’ judgment and

existing screening tools. Biases lead to inaccurate utility calculations and injustice from unacceptable discrimination.

In addition, existing *de facto* systems for predicting the benefit from transplantation do not accurately account for the utility benefit of transplanting patients with increased psychosocial risk. Candidates with higher psychosocial risks are often the sickest and have very high expected mortality without transplantation.³⁰ This group thus has a large expected benefit from transplantation, despite the increased risk the psychosocial factors pose in the posttransplant period, as was demonstrated when transplant centers in France broke with an arbitrary “6-month abstinence” rule and began performing early liver transplantation for active drinkers with severe acute alcoholic hepatitis.³⁰ Recipients experienced a 6-month absolute survival benefit of over 50%; in contrast, the average US liver transplant recipient has no significant absolute survival benefit at 6 months. Low rates of recidivism posttransplantation were observed, and the limited posttransplant drinking that did occur was not substantial enough to mitigate the long-term survival benefit.³¹ Clearly, any utilitarian calculation would support broadening liver allocation to active drinkers based on these data.

Roles of Financial Incentives

The paternalism that transplant programs display with respect to patient epistemic authority may be driven by reasons without a solid ethical justification. While the federal rules are clear on medical urgency being prioritized, candidacy criteria are poorly designed to achieve this goal. Transplant programs are incredibly lucrative. A heart or lung transplant bills for over \$1 million,³² so program shutdown for poor posttransplant outcomes leads to enormous economic losses for providers and hospitals. Recent media reports have illustrated that programs will go to tremendous lengths to prevent recipient deaths within a year.⁸ With large incentives to keep the transplant program busy and minimize postoperative costs, transplant programs are driven to select candidates with the highest expected posttransplant 1-year survival, regardless of the absolute survival benefit from transplantation for the patient. These incentives lead to gaming of waiting list rankings,^{33,34,35} with the result that they likely contribute to overly restrictive social criteria for transplantation as well. Because higher medical urgency is correlated with increased survival benefit,²³ centers cherry-picking healthy patients to maximize posttransplant 1-year survival are prioritizing profit over the utilitarian intent of the transplant system rules.

Conclusion

To be clear, we are not arguing for transplant teams to completely ignore psychosocial factors and write their patients blank epistemic checks. The current utilitarian ethical framework for organ transplantation certainly allows for withholding transplantation from candidates with obvious and insurmountable social limitations that would make benefit from transplant unlikely. The basic major transplantation society guidelines are reasonable in recommending abstinence from alcohol and illicit drugs, adherence to medication, absence of uncontrolled psychiatric disease, and presence of a strong social support system.^{17,36}

However, both utilitarianism and justice demand that organ transplant providers rely on patient epistemic authority for reliability claims fundamental to candidacy. In the absence of clear unbiased data suggesting otherwise, transplant programs should trust patient claims regarding social support networks and commitment to adherence. When disqualification based on social factors is pursued, best use of organs demands that the

threshold be high and supported by rigorous empirical evidence of low transplant effectiveness. If transplant programs want to save the most lives, they should learn to trust their patients and engage in true shared decision making.

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