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Are geographic differences in transplantation inherently wrong?

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Abstract

Purpose of review—Geographic variation in liver transplantation has been the subject of extensive scrutiny, reflecting concerns that location is unfairly determinative for people needing organ transplantation. Drawing upon a number of established ethical approaches, we examine whether geographic differences in access to livers are inherently unethical.

Recent findings—We posit that the ethical imperative for redistribution largely hinges upon the belief that access to organs is systematically disadvantages certain identifiable groups of patients over others. Yet, our data suggests that regions likely to be net-contributors may suffer from less access to transplantation and other health services, fewer social protections, and greater burden of liver disease. Drawing upon a number of ethical approaches, including: strict egalitarianism, utilitarianism, Maximin, Reciprocity, Sen's Impartial Spectator, and a health equity framework, we demonstrate that the current proposal has significant weaknesses, and may not achieve its goals of improving equity and efficiency.

Summary—Formulating effective policies and programs to ameliorate health inequalities requires an understanding of the interrelated causes of mortality disparities and specific interventions to mitigate these causes. Although our analysis does not indicate how ethically distribute livers, but it suggests that this be done with consideration for population-based health measures.

Keywords

ethical analysis; geographic disparities; social capital; socioeconomic status; transplantation policy; liver transplant; liver allocation

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Conflicts of interest

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INTRODUCTION

Although liver transplantation remains the only life-saving option for patients with end-stage liver disease (ESLD), the organ shortage has intensified, rendering this option unattainable for many. In 2015 12,001 patients were added to the national waiting list, while only 6,798 received a deceased-donor transplant.^{1,2} Access to liver transplantation varies significantly across the United States. Depending on where a patient is listed, the likelihood of receiving a liver transplant within 90-days varies from 18% to 86%.³ The 90-day likelihood of death on the waiting list varies from 14% to 82% for patients with MELD (Model for End-Stage Liver Disease) scores of 38-39 across all donor service areas (DSAs).

Geographic variation in liver transplantation has been the subject of extensive scrutiny, reflecting concerns that location is unfairly determinative for people needing organ transplantation. Consequently, in 2016, the Liver and Intestine Committee of the Organ Procurement and Transplantation Network (OPTN) put forth a redistricting proposal expanding geographic organ sharing to equalize median MELD scores at transplant.⁴ The proposal has been divisive, pitting centers likely to lose organs with those likely to gain organs. Opponents argue that sending livers from areas with greater relative supply and lower median MELD scores to areas with higher median MELD scores unfairly disadvantages local donors and will increase costs associated with organ transport. Proponents argue that local prioritization unjustly advantages some due to arbitrary circumstance, such as being born in or residing in a given state or DSA, and that persons living in areas with longer waiting times deserve redistribution.

The debate about geographic differences begs the question: Are geographic differences in access to livers inherently unethical? We posit that the ethical imperative for redistribution largely hinges upon the belief that access to organs is truly arbitrary, an “accident of geography”, systematically disadvantages certain identifiable groups of patients over others. We examine these beliefs, and drawing from a number of normative approaches, we analyze the moral imperative for broader geographic sharing of livers and implications for fair, equitable, and efficient organ allocation.

a. Differences versus disparities

A health equity framework posits that all people should have a fair opportunity to live a long and healthy life and to receive access to life-saving treatment irrespective of geography, race, ethnicity, sexual orientation, income, and other social conditions. Although numerous definitions for disparities exist, injustice is a key element of all definitions. As an example, the Whitehead-Dahlgren definition, employed by the World Health Organization, defines disparities as systematic “differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust.”⁵ Differences, by contrast, reflect gaps that are not morally laden, such as differing treatment preferences for western versus eastern medicine or differences in hair color or blood type. Determining whether a health difference is considered unfair depends on the degree to which the situation is freely chosen, modifiable, and results in poor health. For example, poor populations may have little choice about living in unsafe and unhealthy environments, whereas differences in injury rates

associated with participation in chosen leisure activities (e.g. skiing) are freely chosen and would not be considered unfair.

Does variation in liver availability constitute a disparity, systematically disadvantaging socially underserved groups, or does it merely constitute a difference? Proponents of redistricting argue that higher median MELD scores of waitlisted patients and long waiting times in some regions reflect a disparity, with patients in these regions unjustly deprived access to life-saving treatments. Yet, others point to greater access to transplantation in these regions and superior survival on the waitlist.⁶

To determine whether geographic differences in liver availability reflect disparities, we must consider what the *residual* difference is, holding constant individual-level characteristics that are unrelated to social justice. To do so, we consider the counterfactual reality: meaning, we imagine how much would change if a person were to live in different region. We may consider a hypothetical patient with ESLD living in New York, California, or Massachusetts (regions with high-demand and low relative supply), and imagine that same patient's circumstances as if she were a resident of South Carolina, Tennessee, or Kansas (areas with high-supply and relatively low demand). In this thought experiment, stipulate that individual-level characteristics (race, ethnicity, gender, age, disease severity) are held constant. However, other contextual factors, such as access to care, quality of care, exposure to environmental risks, likelihood of employment, insurance status, or median income level may differ significantly in the counterfactual life.

In considering this hypothetical, one may note that, in many respects, life in states with more severe liver shortages appears to be preferable from a health and well-being perspective to that of states with higher relative supply. For example, the largest contributors to mortality disparities in the United States are chronic diseases and injuries with established socially-patterned risk factors, including: alcohol and tobacco policies, availability of healthcare, levels of violent crime, rates of vehicular accidents, and obesity.⁷ These risk factors are disproportionately prevalent in regions with high organ supply.⁷ Stronger social protections and public safety laws, healthcare infrastructure, and public funding influence donor-eligible mortality rates and subsequent availability of donors.⁸ Data suggest that states with stronger safety nets may have lower risks of death from traumatic head injuries resulting from vehicular accidents or gunshot wounds, anoxic brain injuries from cardiac arrests, and cerebrovascular accidents.^{9–11,12} In addition, greater access to high-quality health care, especially to transplantation for a larger proportion of ESLD patients, appears to partially explain more people being waitlisted, and therefore higher relative demand for liver transplantation.^{6,13} Indeed, survival among waitlisted patients in areas of greater liver scarcity is higher compared to ESLD patients residing in regions with more limited access to transplantation, potentially reflecting better care.⁶ Higher median incomes, higher rates of health insurance, lower unemployment rates, access to superior Medicaid coverage, and greater access to high-quality care, especially to transplant centers, suggests that the relative liver shortage may be indicative of superior health and longevity. This account suggests that waitlist disparities described in the redistricting proposal may not constitute a disparity, but instead may be a difference. Consequently, policies calling for organ redistribution from high-supply to low-supply regions may exacerbate existing social and health disparities by

redistributing the single benefit (greater organ availability) without redistributing the risks of the donating group (greater risk of violent death, scarcer access to transplantation).

While the tenets of public health and medicine necessitate concern with all determinants of morbidity and mortality, they assign a special moral imperative to rectify disparities over differences, as disparities have been partly caused by unjust social forces. This ethical approach is consistent with policy changes adopted by the UNOS that attempt to rectify disparities over differences, e.g. reducing the importance of HLA-matching to mitigate racial disparities in kidney allocation. Instead of broader sharing of organs, rectifying health disparities could require expanding access to health care, improving transportation, and strengthening financial supports especially to residents in underserved areas.

b. Maximin Principle

Another approach to prioritizing scarce resources is to consider the Maximin rule, which specifies that we select the alternative whose worst outcome leaves the population, specifically the most vulnerable, better off than the worst outcome of all other alternatives. Often cited as part of Rawls' Theory of Justice., it too relies on a thought experiment: in this case the veil of ignorance.¹⁴ Rawls posits that, behind a "veil of ignorance" which blinds us to our particular place in society (class, race, ethnicity, income, etc.), the rational choice would be to protect ourselves from the worst-off scenario by ensuring that all people are provided an adequate share of primary goods guaranteeing equal basic liberties, fair equality of opportunity, and an adequate social minimum for all citizens. In this case, one must question whether redistributing organs would worsen the lot of the most vulnerable.

All things equal, patients awaiting livers in any region are vulnerable and will die without access to transplantation. However, data suggest that waitlisted patients in regions with a more severe shortage experience superior waitlist survival comparatively, and as such, may be considered somewhat better-off.⁶ Moreover, redistributing organs based solely on characteristics of the waiting list may violate liberal egalitarian conceptions of justice. Although Rawls does not explicitly consider health due to a simplifying assumption, the Maximin Principle prioritizes concern for the worst-off and most vulnerable who, due to socially determined causes, may never reach the waiting list.⁶ By numerous standards (described above), the plight of residents from states that would be net organ contributors may unparalleled. If availability of organs reflects a higher likelihood of dying prematurely and less access to life-saving treatments, redistributing organs from these underserved populations may compound their disadvantage. If social determinants result in limited access to preventative care, disproportionate ESLD burden, high levels of poverty and unemployment, inadequate subsidies for health insurance, and less access to health care services, including transplantation, there may be grounds to be concerned with redistributing these organs.

c. Reciprocity

A reciprocity argument, although weaker, but may also apply. It suggests that local claims to local organs are supported by two arguments: First, local claimants endure exposures that place them at a uniquely high risk of becoming organ donors, and this disproportionate risk

justifies proportional benefit. Second, focusing on the waitlist considers only single factor in determining who is worst-off, yet, organ availability should not be considered in isolation because it is a function of many factors, including social determinants of health and divergent health and social policies. Finally, some have noted that prioritizing localities encourages donation and strengthens social norms related to organ donation.^{15,16}

d. Utility (efficiency)

Another consequentialist approach, utilitarianism, suggests that it is best to select the option that will improve efficiency by saving more lives and reducing organ waste. Proponents of the proposal also suggest that ethnic disparities may decrease, although the number of liver transplants for blacks would remain unchanged. Proponents suggest that redistricting would save upwards of 676 lives over 5 years, in addition to saving an estimated \$161 million dollars on Medicare payments for clinical care before, during, and after transplant in the new 8 district model.¹⁷

Yet, controversy of these estimates remains. Ladner and Mehrota raise methodological concerns with the proposal, including uncertainty inherent to the models.¹⁸ Estimates suggest that the proposal may increase costs and risks associated with transporting organs and surgical teams across long distances, and may favor population-dense urban regions over rural impoverished regions.^{19–21} Skeptics cite broader geographic sharing implemented in Region 8 from 2010-2012 which did not significantly reduce mortality but raised costs significantly. Patients served by smaller transplant centers may experience disproportionate cost increases and worse outcomes associated with low volume.¹⁹

Although the utilitarian approach is appealing due to its simplicity (weighing costs against benefits), its application relies upon accurate estimates. Without greater consensus about the costs and benefits, both financial and lives-saved, it is unclear whether a utilitarian would support redistricting.

e. Strict Egalitarianism

A strict egalitarian approach may provide support for a single national list, and thus, for reducing the gap between areas with greater and lesser liver supply. With the argument that all members of society deserve equal access, a strict egalitarian may move to abolish regions entirely and use urgency (MELD) or other criteria to determine priority. While perhaps intuitively appealing, the limitations to this approach are numerous, including feasibility objections. This approach may also result in widening disparities if areas more saturated with transplant centers list more patients (thereby offering preferential treatment due to proximity to a transplant center).

f. Impartial Spectator

Amartya Sen conveys the inherent challenge of distributive justice problems and determining how to proceed justly when there are a plurality of “right” answers and deserving parties.²² Sen observes that many inequalities which cannot be justified, such as differences in health, education, and well-being, favor the wealthier and more powerful. He argues that when attempting fair redistribution, we must consider the imbalance of privilege

as a guiding principle. The privileged have a special obligation to adopt the viewpoint of an “impartial spectator”, assuming the perspective of those whose life chances are severely restricted compared to their own. Those with resources must recognize and respect the interests of the poor and powerless, and with that, the interdependence of people across the country.

Although Sen’s *The Idea of Justice* objects to some of Rawls’ assumptions, he argues in a similar vein (albeit for different reasons) that we ought to be concerned with the most vulnerable. Through this lens, Sen’s approach offers a reasoned justification for questioning the broader geographic sharing as currently proposed because of unintended effects on those already disadvantaged. Those living in regions with fewer social protections may be at higher risk for dying prematurely and as a result, residents of these regions may have access to a greater supply of organs. Consequently, shorter waits for organs may be the only direct benefit of noninterventionist social policies, including: riskier traffic safety laws, higher crime rates, and less access to healthcare. As such, people residing in areas with poor social protections collectively assume disproportionately higher risks than those living in areas with more generous social policies, which may entitle them to greater priority for organs obtained locally. Proposed redistricting based on reducing MELD disparities fails to account for underlying social determinants.¹⁹ Sen cautions us not to equalize access to organs at the expense of a donor class, and not to view those with greater access to organs but less access to transplant centers as less deserving. Instead, he prompts us to consider redistributing health resources, and not organs, as a more fair solution.

CONCLUSION

Fairly balancing considerations for equity and efficiency is a perpetual challenge for the transplant community, and consequently, priorities for organ allocation are ever-evolving based on new data. Drawing upon a number of ethical approaches underscores concerns that redistricting may amplify disparities, not alleviate them. Formulating effective policies and programs to ameliorate health inequalities requires an understanding of the interrelated causes of mortality disparities and specific interventions to mitigate these causes. Although our analysis does not indicate how ethically distribute livers, but it suggests that this be done with consideration for population-based health measures.

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Key points

- Drawing upon a number of ethical approaches underscores concerns that redistricting may amplify disparities, not alleviate them.
- Formulating effective policies and programs to ameliorate health inequalities requires an understanding of the interrelated causes of mortality disparities and specific interventions to mitigate these causes.
- To ethically distribute livers, attention must be paid to population-based health measures