

## Personal Viewpoint

# Geographic Disparities in Liver Availability: Accidents of Geography, or Consequences of Poor Social Policy?

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**Recently, a redistricting proposal intended to equalize Model for End-stage Liver Disease score at transplant recommended expanding liver sharing to mitigate geographic variation in liver transplantation. Yet, it is unclear whether variation in liver availability is arbitrary and a disparity requiring rectification or reflects differences in access to care. We evaluate the proposal's claim that organ supply is an "accident of geography" by examining the relationship between local organ supply and the uneven landscape of social determinants and policies that contribute to differential death rates across the United States. We show that higher mortality leading to greater availability of organs may in part result from disproportionate risks incurred at the local level. Disparities in public safety laws, health care infrastructure, and public funding may influence the risk of death and subsequent availability of deceased donors. These risk factors are disproportionately prevalent in regions with high organ supply. Policies calling for organ redistribution from high-supply to low-supply regions may exacerbate existing social and health inequalities by redistributing the single benefit (greater organ availability) of greater exposure to environmental and contextual risks (e.g. violent death, healthcare scarcity). Variation in liver availability may not be an "accident of geography" but rather a byproduct of disadvantage.**

**Abbreviations:** CDC, Centers for Disease Control and Prevention; ESLD, end-stage liver disease; MELD, Model for End-Stage Liver Disease; OPTN, Organ Procurement and Transplantation Network; UNOS, United Network for Organ Sharing

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## Introduction

Federal guidelines stipulate that "allocation of scarce organs will be based on common medical criteria, not accidents of geography"(1), yet access to liver transplantation varies across the United States (2). Depending on listing location, patients with MELD (Model for End-stage Liver Disease) scores of 38–39 have a 90-day likelihood of liver transplantation or death that varies from 18% to 86% and from 14% to 82%, respectively (3). In 2015, median MELD score at transplantation varied by as much as 12 points (35 vs 23) across the 52 donor service area (DSAs), equivalent to a 60% difference in the estimated risk of 3-month mortality without a liver transplant (4).

In 2016, the OPTN (Organ Procurement and Transplantation Network)/UNOS (United Network for Organ Sharing) sought public comment about a highly controversial redistricting proposal to expand geographic sharing and equalize median MELD at transplantation (4). Opponents contend that sending livers away from areas with greater supply and lower median MELD unfairly disadvantages local recipients and will increase logistical complexity and costs associated with organ procurement and transport (5). Some raise methodological concerns, including uncertainty inherent to the models (6). They say that for several diseases, such as liver cancer, the points added to MELD scores based on laboratory tests are determinative of transplantation, not the MELD score itself. Others predict increased cost associated with broader transporting both organs and transplant teams (7). Proponents argue that patients are equally entitled to organs, regardless of geography (2). They assert that local prioritization unjustly advantages some due to arbitrary circumstance, like being born in or residing in a given region. They estimate 50 fewer waitlist deaths per year and significant cost savings for the health care system.

We consider whether residents of high-supply states have special claims to local organs, stemming from disproportionate exposure to risks associated with more donor-eligible deaths. Using a comparative approach, we observe the potential relationship between local organ supply and the uneven landscape of health care, social determinants, and social policies in three states, central to the debate and illustrative of the potential winners and

losers. We consider the ethical implications of organ redistribution, the merit of local claims, and whether redistribution exacerbates existing disparities.

## Case Comparison

In Massachusetts, 762 liver transplant candidates are waitlisted (with 55% waiting for <1 year), compared with 53 in South Carolina (with 36% waiting for >1 year) and 533 in Florida (with 40% waiting for <1 year) (8) (Table S1). Characteristic of states likely to benefit, Massachusetts candidates have a higher MELD score at transplantation, longer time to transplantation, lower transplantation rate, but lower waitlist mortality rate compared with South Carolina and Florida (Table 1). Although the impact for all states is uncertain, most models show organs flowing out of states like South Carolina, Tennessee, and Florida and toward states like Massachusetts, New York, and California.

Our comparative analysis assesses the relationship between factors likely to influence the organ supply, as well as factors likely linked to demand or transplantation. Although organ allocation and distribution policies can address only issues related to transplant candidates and cannot rectify broader social inequities, transplantation

policies do not function in a vacuum. Therefore, the effect of new policies on already disadvantaged populations should not be neglected. The long tradition of transplant policy has been to examine the effect of new organ allocation and distribution policies on vulnerable populations, including by race, geography, and age, among other factors. As such, we examine potential implications of redistricting for underserved populations.

### **Does redistricting harm persons bearing a disproportionate risk of becoming donors?**

Local exposures predispose some populations to a greater risk of preventable death, potentially resulting in greater organ supply. In 2015, stroke (30.4%), blunt/vehicular injury (20.4%), cardiovascular events (18.2%), drug use (9.3%), and gunshot wounds (8.4%) were the most common causes of death among organ donors (9). Many of these are socially and geographically patterned. Between 14% and 43% of these deaths are considered preventable, although rates vary widely by state (Table 2) (9,10). Vehicular safety and gun laws, and access to emergency medical services, can influence preventable death and, in turn, the organ supply.

Speed limits and helmet laws may partly account for the gap in accidental deaths. Massachusetts mandates that all motorcyclists wear helmets, whereas Florida and

**Table 1:** Liver transplant candidate and waitlist characteristics by state

	Massachusetts	South Carolina	Florida
Median MELD score at transplantation (CY2014)	31.0–33.1	23–25	25–28.6
Percentage of adults undergoing transplantation within 5 years of listing since 2009	37.3–45.4	73.7–81.8	65.5–81.8
Time to transplantation by program for candidates listed between January 1, 2010, and June 30, 2015, 25th percentile (months to transplantation) (national 2.4 months)	11.0, 5.2, 9.8, 3.3	0.9	0.7, 1.2, 0.4, 1.4, 1.0, 0.6, 3.1
Transplantation rate by program (rate per 100 person-years)	0.28 <sup>1</sup> , 0.42 <sup>2</sup> , 0.27 <sup>1</sup> , 0.24 <sup>3</sup>	1.37 <sup>2</sup>	0.85 <sup>3</sup> , 1.64 <sup>2</sup> , 1.23 <sup>2</sup> , 0.86 <sup>2</sup> , 1.64 <sup>2</sup> , 2.0 <sup>2</sup> , 0.46 <sup>1</sup>
Waitlist mortality by program (rate per 100 person-years)	0.1 <sup>1</sup> , 0.21 <sup>1</sup> , 0.23 <sup>2</sup> , 0.11 <sup>3</sup>	0.51 <sup>2</sup>	0.34 <sup>3</sup> , 0.16 <sup>3</sup> , 0.13 <sup>3</sup> , 0.19 <sup>3</sup> , 0.13 <sup>1</sup> , 0.33 <sup>3</sup> , 0.16 <sup>3</sup>
Ratio of ESLD deaths to waitlist deaths	9	33	31

Data for median MELD at transplantation and percent of adults undergoing transplant within 5 years of listing from Kim WR, Lake JR, Smith JM, et al. Liver. Am J Transplant 2016;16(S2): 69–98.

Data for time to transplant by program, transplant rate, and waitlist mortality obtained from the Scientific Registry of Transplant Recipients Transplant Program reports for liver transplantation, release date June 16, 2016. Accessed December 1, 2016, at [www.srtr.org](http://www.srtr.org). There are four liver transplant programs in Massachusetts, one in South Carolina, and seven in Florida.

Data for waitlist time from OPTN data reports, state data, organ by waiting time. <https://optn.transplant.hrsa.gov/data/view-data-reports/state-data/#>. Accessed: October 31, 2016.

Data for ratio of ESLD deaths to waitlist deaths adapted from Goldberg DS. Redistricting: Do we have the correct metrics of allocation and distribution? Atlanta, GA: Emory University Medical Center; October 2016; according to OPTN/UNOS data as of June 3, 2016, and Centers for Disease Control and Prevention (CDC) cause-of-death data from [wonder.cdc.org](http://wonder.cdc.org).

<sup>1</sup>Lower than expected.

<sup>2</sup>Higher than expected.

<sup>3</sup>Not different than expected.

**Table 2:** Estimated preventable deaths from the top five leading causes of death by state (2014)

State	Cause of death				
	Heart disease	Cancer	Stroke	Chronic lower respiratory disease	Accidents
Massachusetts	59	732	−62 (0)	100	775
South Carolina	5742	1641	524	823	1090
Florida	4000	3240	782	1837	3046

Source: García et al (11).

South Carolina mandate helmets only for riders under age 21 years (Table 3) (11–13). A recent study using data from 1991 through 2014 found that repeal of statewide motorcycle helmet laws was associated with a nearly 20% increase in the local supply of transplantable organs from donors killed in motor vehicle accidents (14,15). In 2014, the vehicular death rate in Massachusetts was 4.9 per 100 000 residents, compared with 12.5 and 17.1 deaths per 100 000 residents in Florida and South Carolina, respectively, a fourfold difference (Table 3) (16). Since 1994, approximately 16% of all organ donations came from motor vehicle accidents, with rates significantly higher in Florida and South Carolina than in Massachusetts.

Gun-related fatalities and violent crimes are lower in Massachusetts compared with Florida and South Carolina (29). The firearm death rate per 100 000 population is 3.2 in Massachusetts, 11.5 in Florida, and 15.5 in South Carolina, nearly a fivefold difference (30). South Carolina and Florida have the 11th and 23rd highest rate of gun-related deaths per capita, respectively, while Massachusetts has the second lowest. South Carolina and Florida do not require firearm licenses or weapon registration, whereas Massachusetts requires firearm owners to be licensed (30,32) and bans assault weapons and large-capacity ammunition magazines (35).

Access to emergency medical services can reduce preventable deaths from the most common causes of deaths among organ donors. Survival after stroke is improved by prompt referral to a designated stroke center (36). Massachusetts has 1.02 stroke centers per 100 000 population, South Carolina has only 0.37, and Florida has 0.60 (Table 3) (18,19). Nationally, South Carolina has the seventh highest death rate from stroke, Florida has the ninth lowest, and Massachusetts has the third lowest (37). In 2014, Florida had 782 preventable deaths from stroke; South Carolina had 524, while Massachusetts had none (Table 2). Similarly, survival after trauma is correlated with access to Level 1 trauma centers, and distribution of trauma centers and trauma deaths mirrors those of stroke in these states (Table 3) (20–22,31,38). Quality of care is also disparate across these states, with Massachusetts ranking first in the nation according to the Commonwealth Fund's Scorecard on State Health System Performance for access and

affordability, while South Carolina and Florida rank 41st and 40th, respectively. (26).

Less-stringent vehicular and gun safety laws and lack of access to health care may increase the risk of preventable death. Massachusetts has fewer eligible donors per 1 million population than South Carolina or Florida (Table 3) (39). Thus, disproportionate risk and poor social protections may yield a single benefit: more transplantable organs. Consequently, redistributing organs violates the principle of reciprocity, whereby disproportionate risk merits reciprocal priority to benefit.

#### ***Does redistricting disadvantage the most vulnerable?***

Redistributing organs away from states with candidates with lower MELD scores may disadvantage vulnerable and underserved populations. Compared with states likely to gain organs, states likely to lose organs have patients who have shorter life expectancies, are poorer, and have less publicly funded health care and have more patients with end-stage liver disease (ESLD) who are not waitlisted.

Life expectancy at birth ranges from 80 years in Massachusetts to 77 years in South Carolina, representing the extremes of predicted lifespans in the United States (26). Teenagers die at over twice the rate in South Carolina as in Massachusetts (33). Rates of smoking, preventable death, and obesity also affect people's ability to lead long and healthy lives and vary significantly across the states, with Massachusetts consistently ranking near the top of the healthiest states in America, while Florida and South Carolina rank near the bottom (Table 3) (10,17,33,34,40).

Economic indicators are similarly disparate. While Massachusetts has the sixth highest median household income in the United States, Florida and South Carolina rank 39th and 42nd, respectively (Table 3) (24). South Carolina and Florida have 1.5 times more families below the federal poverty line than does Massachusetts (Table 3) (24).

Health spending per capita varies from \$9,278 in Massachusetts to \$6,323 in South Carolina and \$7,156 in Florida (25). Neither Florida nor South Carolina expanded Medicaid following the Affordable Care Act, leaving many

**Table 3:** Selected statistics for case comparison between Massachusetts, South Carolina, and Florida

	Massachusetts	South Carolina	Florida
Health care saturation			
Commonwealth Fund Scorecard on State Health System Performance: Access and Affordability rank out of 50 states (2015) (17)	#1	#41	#40
Number of designated primary stroke centers (18,19)	69	18	121
Number of Level 1 trauma centers (20–22)	11	4	9
Number of Level 2 trauma centers (20–22)	2	4	15
Number of adult liver transplant centers (23)	7	1	7
Population (2014 census)	6 794 422	4 896 146	20 271 272
Stroke centers per 100 000 population	1.02	0.37	0.6
Trauma centers per 100 000 population	0.19	0.16	0.12
Transplant centers per 100 000 population	0.09	0.02	0.03
Socioeconomic factors			
Percent of households under poverty line (2014) (24)	11.6%	17.9%	16.5%
Median household income (2014) (24)	\$69 160 ± \$957	\$47 463 ± \$507	\$45 238 ± \$329
Health spending per capita (2014) (25)	\$9278	\$6323	\$7156
Life expectancy at birth (years) (2014) (26)	80.5	77	79.4
Medicaid expansion? (2016) (27)	Yes	No	No
Medicaid eligibility for parents of children (percent of federal poverty line) (2016) (27)	133%	62%	30%
Legislation and social policies			
Helmet requirement for motorcyclists? (2016) (11–13)	Yes for all	Only under age 21	Only under age 21
State-mandated rural interstate speed limit (2016) (28)	65 mph	70 mph	70 mph
Motor vehicle fatalities per 100 000 population (2014) (16)	4.9	17.1	12.5
Motor vehicle fatalities per 100 million vehicle miles driven (2014) (16)	0.57	1.65	1.24
Violent crime rates per 100 000 population (2013) (29)	413.4	508.5	470.4
Firearm deaths per 100 000 (2014) (30)	3.2	15.5	11.5
Traumatic death rate per 100 000 (2004–2010) (31)	11.1	25.5	20.3
Rate of teen deaths (15,16,29,30,32) per 100 000 teenagers (2014) (33)	29	62	50
Percentage of adults (18+) who smoke (2014–2015) (34)	14.0% ± 1.0%	19.7% ± 1.1%	15.8% ± 1.1%
Donor potential			
Eligible donors per 1 million <sup>1</sup>	20.9	35.3	36.6

Sources: Scientific Registry for Transplant Recipients, CDC Wonder, US Census Bureau, The Commonwealth Fund, Massachusetts Department of Public Health, The Joint Commission, American College of Surgeons, Scientific Registry of Transplant Recipients, The Kaiser Family Foundation, US Department of Health and Human Services, DMV.org, The Governor's Highway Safety Association, the Highway Loss Data Institute, the Federal Bureau of Investigation, and CDC.<sup>1</sup>Eligible donors per 1 million calculated based on data from the Association of Organ Procurement Organization. Reported eligible deaths and recovered deceased donors 2008 to 2016. Accessed December 1, 2016, at <http://www.aopo.org/related-links-data-on-donation-and-transplantation/>.

low-income adults uninsured (41). States with generous Medicaid programs, like Massachusetts, provide transportation and home-based support services often needed to meet transplant eligibility. Without this, poorer, rural residents of Florida and South Carolina often face insurmountable barriers to referral and listing for transplantation.

Prevalence of ESKD, and thereby need for liver transplantation, is also geographically patterned. By focusing on median MELD score among waitlisted patients, the proposal neglects ESKD patients in high-supply regions who are never listed due to lack of access or inability to afford transplantation (42). ESKD death rates among people aged 20–74 is higher in South Carolina (23.0–25.9 per 100 000 population) compared with Massachusetts (15.6–16.9) and Florida (20.0–22.9) (Figure S1). Furthermore, the ratio

of ESKD deaths to waitlist deaths is lowest in Massachusetts (9) compared with South Carolina (17) and Florida (26) (Table 1). Differences between waitlist and population-based measures disadvantage patients with chronic liver failure, who experience greater benefit from liver transplantation and are more likely to die on the waitlist than are patients with hepatocellular carcinoma, who have a lower risk of dying on the waitlist and experience less survival benefit but are waitlisted at dramatically higher rates. Moving livers from areas of poor social circumstance may undermine efforts to improve the overall care of patients with liver disease in these areas.

Massachusetts's residents generally live longer, healthier lives and enjoy numerous advantages in access to transplantation. Redistributing organs to areas with

greater resources may entrench deeply rooted disparities, funneling resources away from underserved communities.

### ***Does redistricting favor saturated medical areas, masking population health disparities?***

Redistributing organs based on MELD score also favors areas with more liver transplant centers. High density of liver transplant centers has been associated with more listings, greater demand for liver transplantation, greater competition for organs, and higher MELD score at transplantation (43). Massachusetts has triple the number of transplant centers per 100 000 population compared with Florida and South Carolina (Table 3), potentially reflecting an unmet need in these states (23). While greater access to transplant centers improves equity within states, it also increases the average waiting time for patients. Waitlisted patients in Massachusetts also have lower mortality rates compared with waitlisted patients in South Carolina (Table 3), perhaps owing to greater access to quality medical care. Redistributing organs away from regions with fewer transplant centers may further distort the gap in health care availability by weakening of centers serving disproportionately rural and low socioeconomic status communities, limiting the ability of underserved populations to find local care (5). Additionally, due to the strict regulatory environment, high-risk donors and candidates are often referred to larger centers that, because of higher volumes, can assume more risk without the same impact on center performance measures. This may already advantage some regions and centers over others. Small centers, particularly those providing care to patients of lower socioeconomic status and rural populations, may export marginal organs to avoid potential ramifications for accreditation. Future policies should consider including rapid allocation of marginal organs to high-use centers to improve efficiency while protecting the rights of local populations.

Disparities in social determinants contribute to differential risk of liver failure, and thus demand for transplantation, a factor somewhat obscured by focusing exclusively on waitlisted patients. For example, in 2014, the prevalence of diabetes among adults was 8.8% in Massachusetts, compared with 9.4% and 10.7% in Florida and South Carolina, respectively (44). Similarly, in Massachusetts the obesity rate of 23.3% was eclipsed by Florida (26.2%) and South Carolina (32.1%) (40). Prevalence of hepatitis B followed the same trend, while the prevalence of hepatitis C was highest in Massachusetts (3.4 per 100 000 in 2014) among the three states (45). Taken together, these factors suggest greater need for liver transplantation in some states likely to lose access to livers.

### ***Is variation in liver availability an “accident of geography”?***

A health equity framework posits that all people should have fair opportunity to live long and healthy lives and

access lifesaving treatment regardless of geography or other social conditions. Disparities are considered systematic differences in health outcomes that are unnecessary, avoidable, and unfair or unjust (46), while differences are gaps that are not morally laden. While all determinants of morbidity and mortality necessitate concern, rectifying disparities over differences is of special moral importance as disparities have been partly caused by unjust social forces. This ethical approach is consistent with policy changes previously adopted by UNOS, including concern for racial disparities when reducing the relative importance of HLA matching for kidney allocation. In other words, reforming health and transplant policy should aim to correct for disparities in transplantation and health that are primarily linked to injustice (e.g. expanding access to underserved populations, reducing barriers for populations with limited resources) over differences occurring randomly (e.g. by blood type).

Our analysis further demonstrates how local policies can directly affect both organ availability and access to transplantation. Our analysis provides a clear example of liver availability being lower in states with superior health and longevity, yet access to transplantation in these areas is much higher. Stronger social protections, public safety laws, and health care infrastructure may reduce preventable deaths, limiting organ supply; therefore, populations with more health care and social protections may experience an organ shortage relative to those exposed to riskier environments (47). Concurrently, greater access to transplant centers may increase waitlisting, thereby heightening demand for liver transplantation. Waitlisted patients in areas of greater liver scarcity also experience superior waitlist survival compared with patients in regions with limited transplant access, potentially reflecting better care. Taken together, the geographic differences considered in the proposal do not constitute disparities.

Local organ supply is determined by local exposures, further strengthening the ethical imperative for local priority. Residents enduring exposures placing them at uniquely high risk of becoming organ donors should be entitled to reciprocal benefit. At times, this may benefit states like South Carolina and Florida, though this may not always remain true. An important limitation of the current proposal for liver sharing stems from the assumption that current patterns of organ supply are fixed. Yet, as the devastating effects of the opioid epidemic indicate, local organ supply is sensitive to changes in mortality patterns, which to some degree may self-correct for regional variation in MELD score at transplantation (Figure S2). For example, since 2010, there has been a nearly 900% increase in donations across New England (Figure S3). In 2016, more than 27% of donations in New England were from people who died after a drug overdose. Nationally, that rate decreased to 12% during that same time period. As the highly localized effects of the opioid epidemic demonstrate, those most at risk who are

disproportionately harmed should be entitled to the only silver lining of this tragedy—namely, greater access to donated organs.

Redistributing organs based solely on waitlist characteristics may also violate the Maximin principle, which prioritizes concern for the worst-off, who, due to socially determinants, may never reach the waitlist. By numerous standards, the plight of residents from states that would be net organ contributors is unparalleled. 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.

### Coping With Unsatisfying Resolutions to Distributive Justice Problems

This case illustrates the challenges of distributive justice problems and of proceeding justly when a plurality of “right” answers and deserving parties exist (48). Throughout *The Idea of Justice*, Amartya Sen argues that, when attempting fair redistribution, we must consider the imbalance of privilege as a guiding principle, comparing the fairness and impact of particular policies on all members of society. The privileged must adopt the viewpoint of an “impartial spectator” assuming the perspective of those whose life chances are severely restricted compared to their own, especially the poor and oppressed. Although transplantation cannot rectify health inequities *in totum*, reforms in transplant policy should not exacerbate or ignore the existing landscape.

Sen’s approach provides justification for questioning the redistricting proposal because of its unintended effects on the disadvantaged. As our analysis illustrates, living in regions with fewer social protections may be associated with more donor-eligible deaths and 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 health care. 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 score disparities fails to account for these legitimate claims and relies too heavily on the assumption that organ availability is random, overlooking the impact of underlying social determinants (5).

Therefore, by redistributing a single advantage (i.e. available organs) without redistributing any of the disadvantages (e.g. preventable death), existing disparities may be

exacerbated. While the proposed policy may improve aggregate efficiency by preventing some waitlist deaths, it may do so at the expense of vulnerable, identifiable populations, thereby favoring too heavily efficiency over equity. Variation in liver availability may not be an “accident of geography” but rather a byproduct of disadvantage.

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## Supporting Information

Additional Supporting Information may be found in the online version of this article.

**Table S1:** Waitlist characteristics.

**Figure S1:** Age-adjusted death rates from chronic liver disease, viral hepatitis, and hepatocellular carcinoma (2010–2014).\*

**Figure S2:** Opioid deaths in the United States in 2015.

**Figure S3:** Trends reflecting percentage of organ donated by donors that experienced overdose in the United States and New England, 2010–2015.