Intersectionality and Transplant Disparities: Opportunities for Improvement

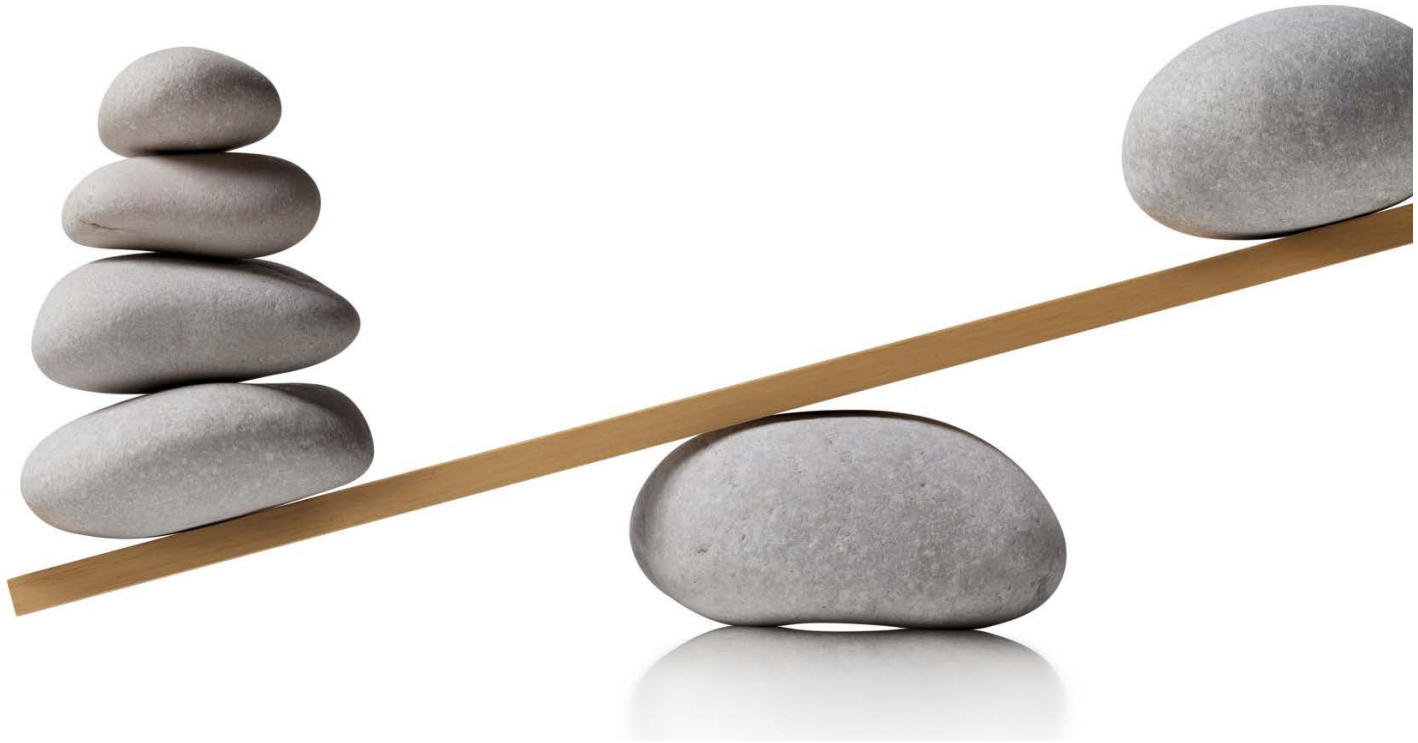
Keren Ladin, PhD, MSc

Associate Professor

Departments of Occupational Therapy and Community Health

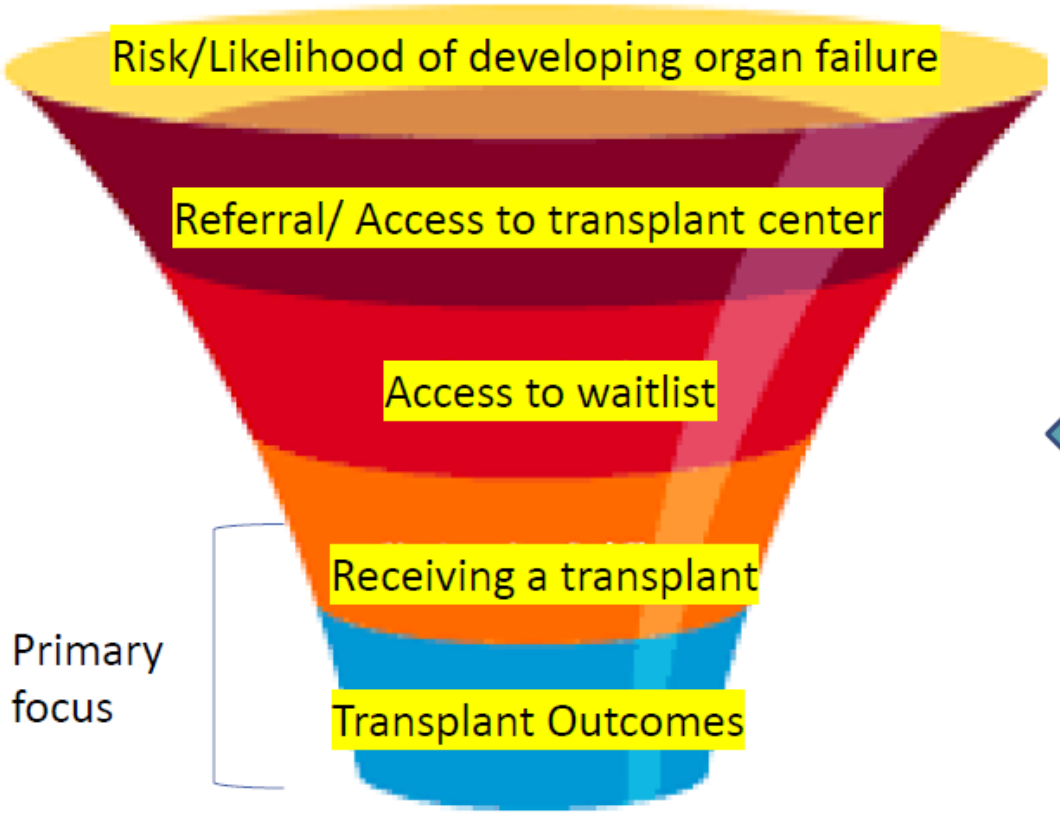
Tufts University

Ethical Redesign in Organ Transplantation



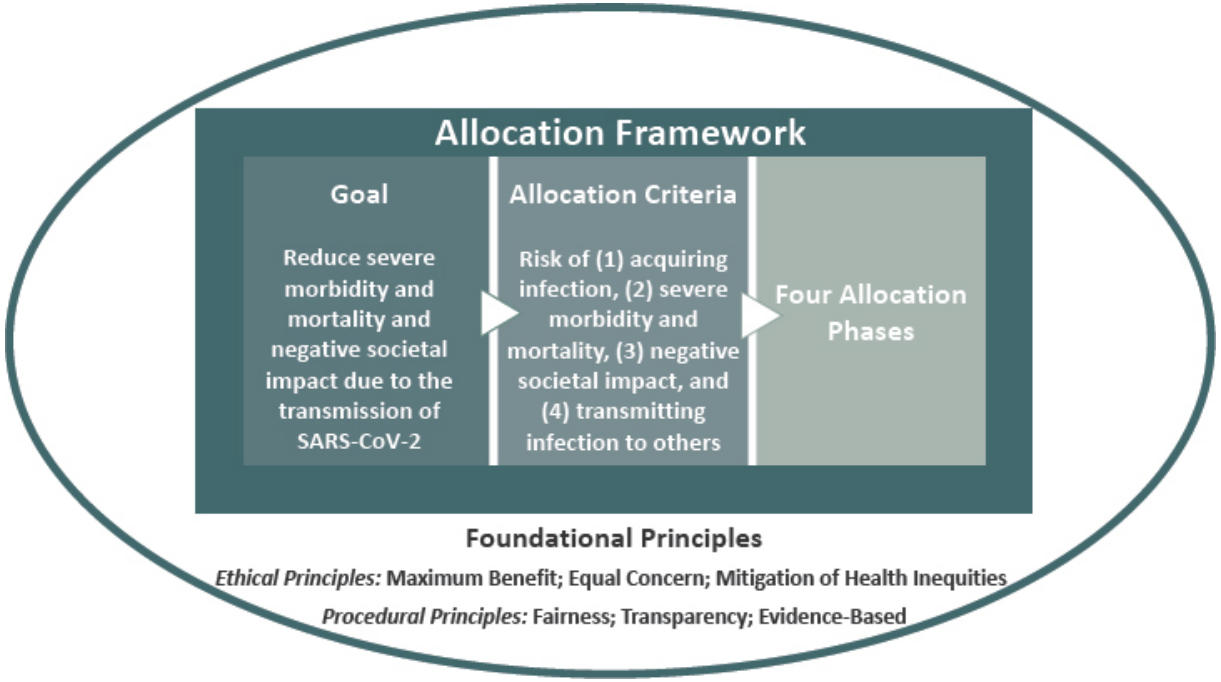
- Ethical principles guiding organ allocation include balancing utility, justice (equity), and respect for persons (autonomy)
- "Every system is perfectly designed to achieve exactly the results it gets.“ Donald Berwick, MD, MPP
- Disparities in transplantation persist, begging the question:
- **How should the transplant system be redesigned to achieve a different, more equitable, outcome?**

Disparities Along the Clinical Continuum: Organ Failure to Transplantation

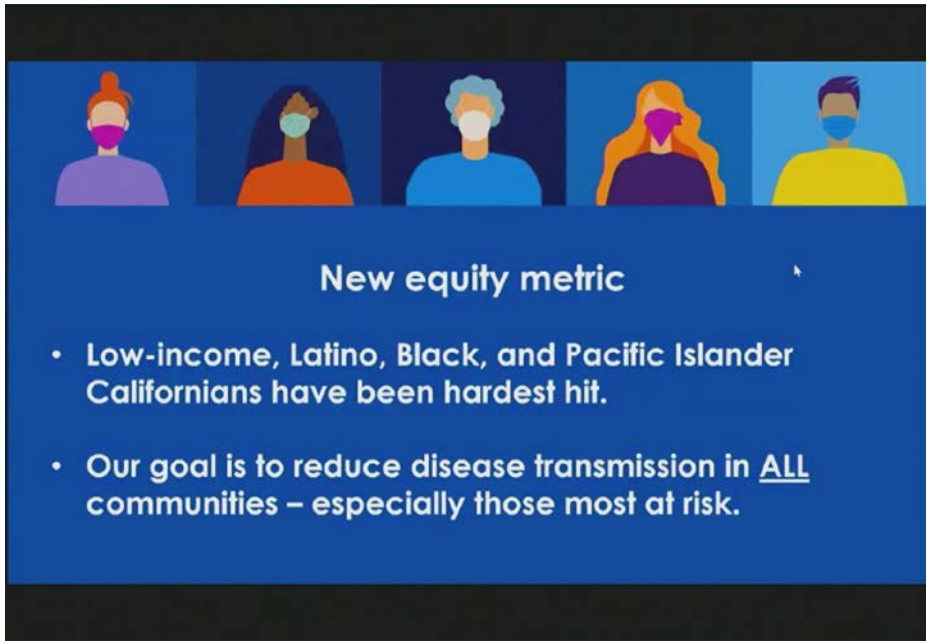


- Race
- Ethnicity
- Socioeconomic Status
- Age
- Gender
- **Geography**
- Language
- Disability
- Citizenship
- **Social Support**

Equity Requires Purposeful Reframing in Allocation of Scarce Resources: Example from COVID-19 Vaccination



National Academies of Sciences, Engineering, and Medicine. 2020. *Framework for Equitable Allocation of COVID-19 Vaccine*. Washington, DC: The National Academies Press. https://doi.org/10.17226/25917.



CA COVID-19 Effort: https://covid19.ca.gov/equity/

Rationale For Reliance on Subjective Criteria

Need to improve efficiency (minimize bad outcomes)

Expertise

Risk Aversion

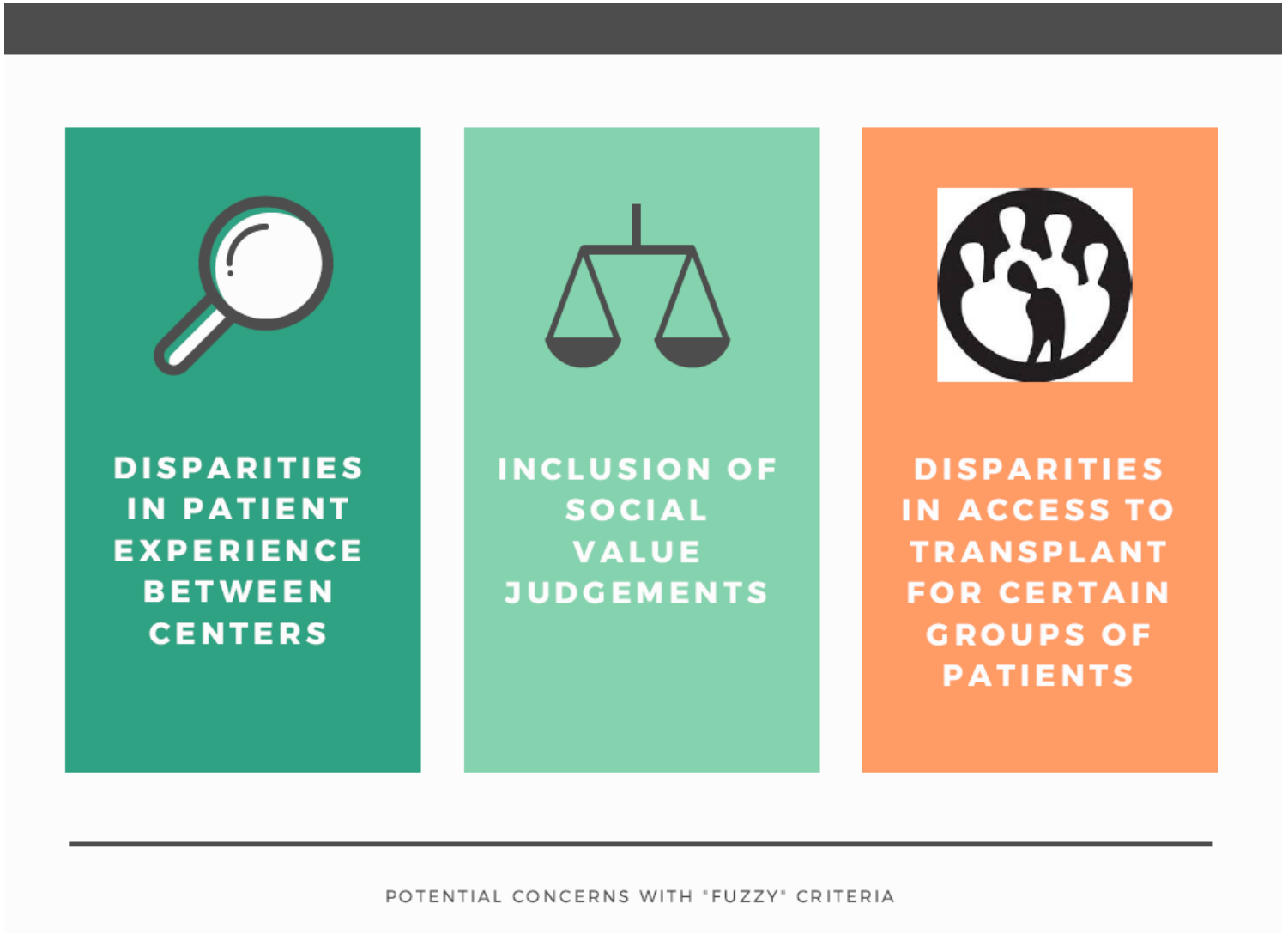
What Does the Ideal Candidate Look Like?

Subjective Criteria: Psychosocial Factors

- Patient motivation
- Adherence
- Potentially injurious behavior
- Disability
- Social Support
- Socioeconomic status

Heuristic: Simplified cognitive strategy, used to save time and improved efficiency, allowing decision-maker to make acceptable deductions

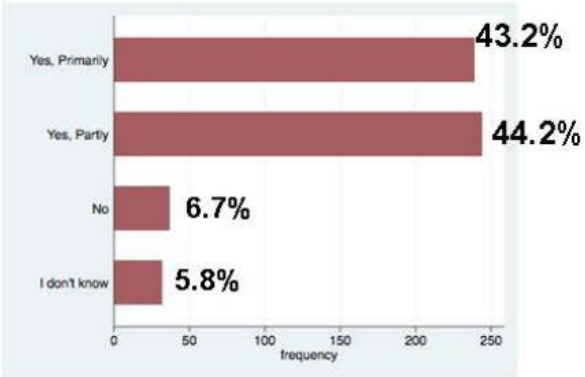
Ethical Concerns with Using Subjective Criteria



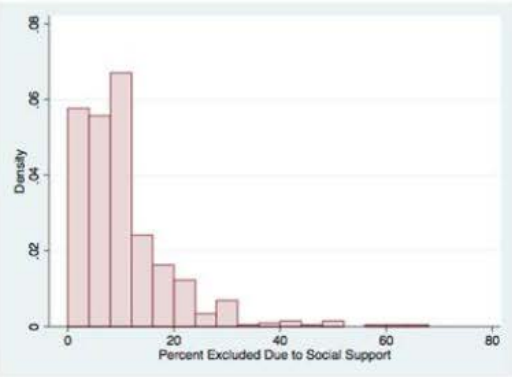
Social Support: Key Factor in Transplant Decision-Making

Social Support Matters

- Has lack of social support ever prevented a patient from being waitlisted at your center?

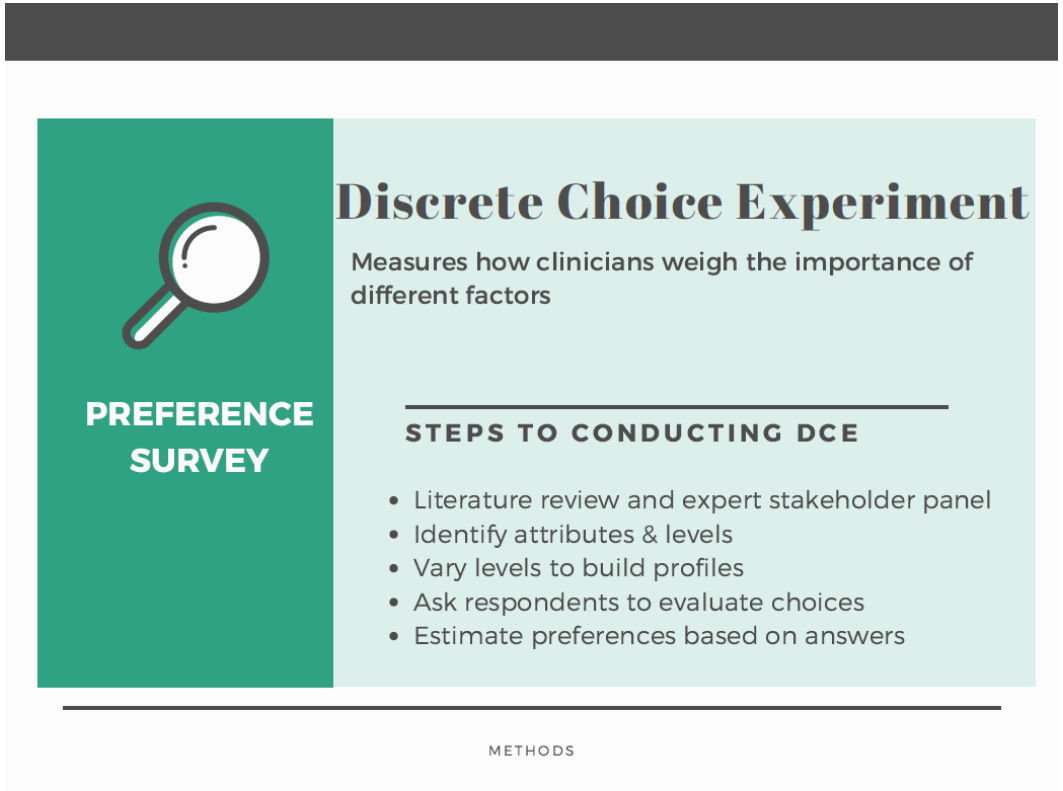


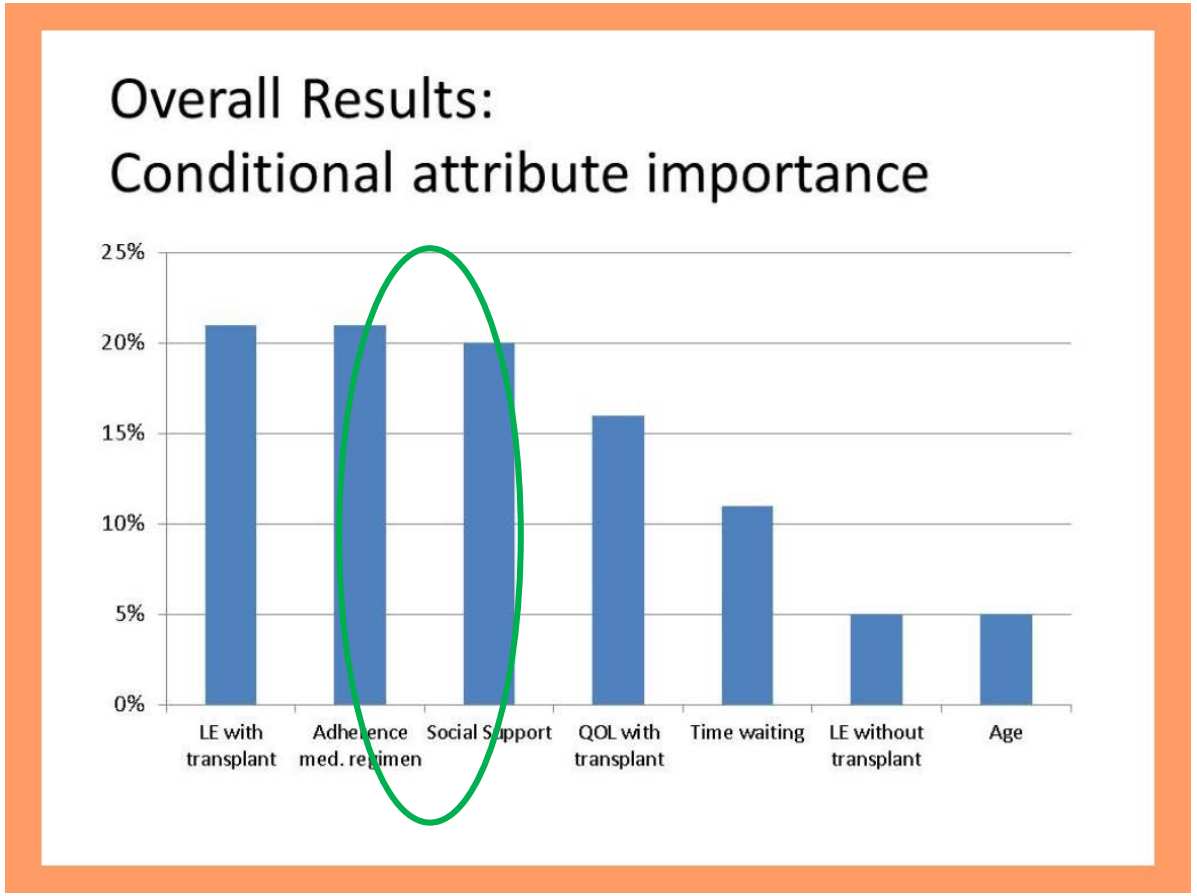
- Over the past year, approximately what percentage of patients at your center were not listed for transplantation due to inadequate social support?



Obs	Mean	Std. Dev.	Range
507	9.95%	9.21	0-66

Social Support: Key Factor in Transplant Decision-Making





Ladin K, Emerson J, Butt Z*, et al* How important is social support in determining patients' suitability for transplantation? Results from a National Survey of Transplant Clinicians. *Journal of Medical Ethics* 2018;**44:**666-674.

Disparities in Access to Transplantation: Accidents of Geography, or Consequences of Poor Social Policy?

- 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.

Considerations for Geographical Equity

- 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.

- While broader geographic sharing and removal of hard boundaries reduces arbitrariness, it also impedes local prioritization which may be ethically important.

- In other words, risk of premature death, risk of organ failure, access to health care, and access to transplantation, are not evenly distributed within the United States. By redistributing only organs, and not considering the cause of premature death or access to transplantation within these communities, we may be harming an already structurally underserved group.

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[1], 0.42[2], 0.27[1], 0.24[3]	1.37[2]	0.85[3], 1.64[2], 1.23[2], 0.86[2], 1.64[2], 2.0[2], 0.46[1]
Waitlist mortality by program (rate per 100 person-years)	0.1[1], 0.21[1], 0.23[2], 0.11[3]	0.51[2]	0.34[3], 0.16[3], 0.13[3], 0.19[3], 0.13[1], 0.33[3], 0.16[3]
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. 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.

[1]Lower than expected.

[2]Higher than expected.

[3]Not different than expected.

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[1]	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.[1]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/.

Equity Requires Purposeful Reframing in Transplantation

- **Data**: National data for all ‘funnel’ stages
- **Equity Metrics:** Development and publication of equity metrics
- **Subjective Criteria:** Reduced use and reliance on subjective, poorly defined criteria
- **Consideration of potential harms (and benefits) to worst-off:** Consideration of local priority in organ allocation