UNIVERSITEIT GENT

Equity in cadaveric organ transplantation

13/09/2023 Tbilisi Georgia

Patrick Peeters, M.D.
Dept Nephrology, University Hospital Gent, Belgium

Health equity =

Is the "attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities"

Health Disparities =

a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.

Righteous organ allocation
THEORY

- principes of biomedical ethics : Beauchamp & Childress

* positive contribution	(beneficence)
* do no harm	(nonmaleficence)
* fair	(justice)
* autonomy of the patiënt	(respect for autonomy)

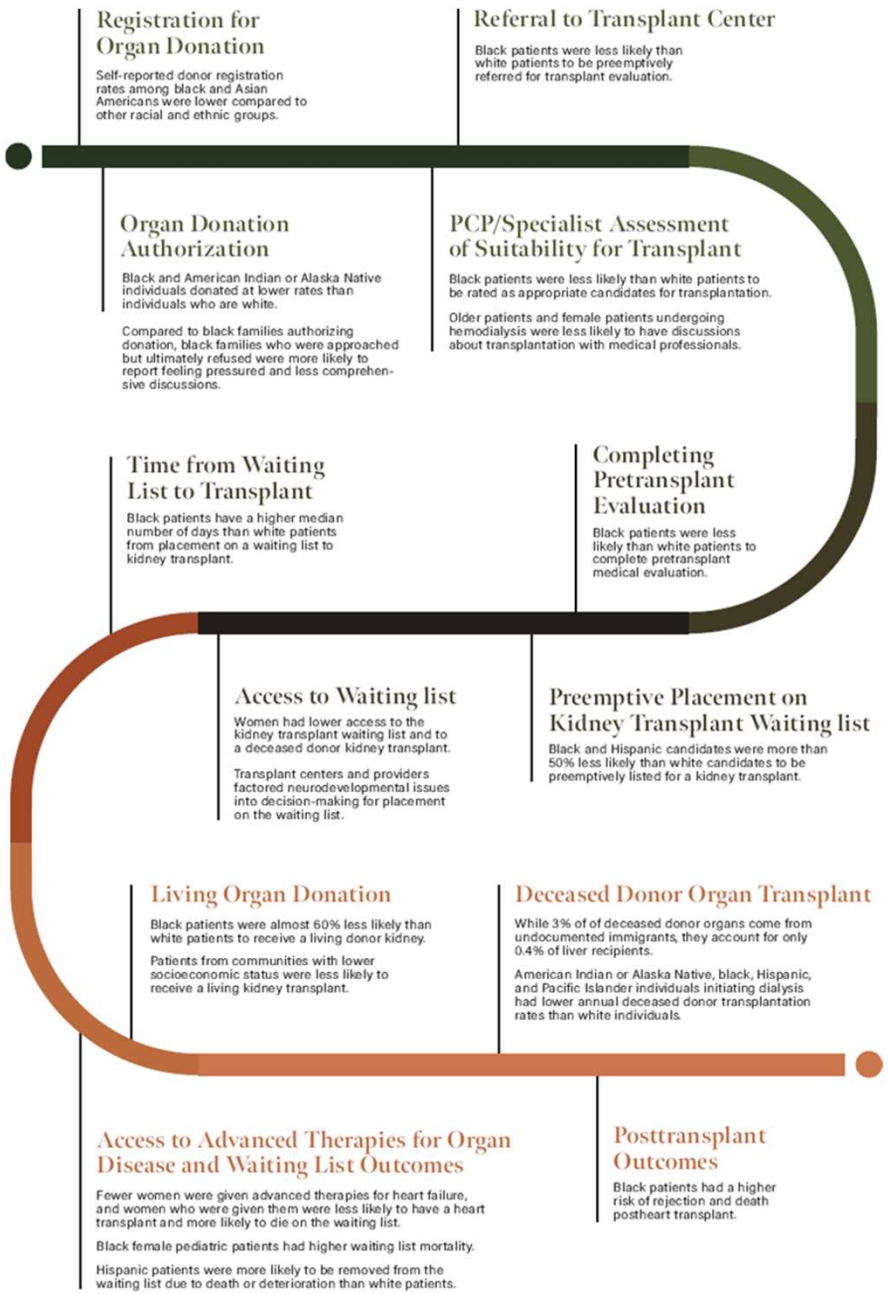
=> in concreto : medical utility, justice } Equity of opportunity

Equitable organ allocation:

maximize patient and graft survival

- minimize deaths while waiting for a transplant
- maximize opportunity for patients with biological or medical disadvantages to receive a transplant
- minimize disparities in chance of organ offer among patients with comparable medical and demographic characteristics
- minimize effects related to geography
- minimize overall transplantation-related costs

=> provide for accountability and public trust



National Academic Press 2022 NAP.edu/10766

Examples

Registration for organ donation	n/a	n/a	Black, Asian American	• Self-reported donor registration rates among black and Asian Americans were lower compared to other racial/ethnic groups (HHS, 2019; p. 25, Table 3).
Organ donation authorization	n/a	n/a	Black, American Indian/Alaska Native	• While deceased organ donation rates have improved over time for individuals who are black or American Indian/Alaska Native, those individuals donated at 69% and 28%, respectively, the rate of individuals who are white (Kernodle et al., 2021). • Black families often experience differences in the donation process. For example, one study found that OPO representatives met with a larger proportion of white families of potential donors (66.1%) than black families (50.8%) (Siminoff et al, 2003).

Examples

Primary care physician/specialist assessment of suitability for transplant[a]	Kidney	Adult	Black	• White patients are more likely than black patients to be rated as appropriate candidates for organ transplantation (20.9% vs. 9.0%) (Epstein et al., 2000).
	Kidney	Adult	Patients over age 65, women	• Older hemodialysis patients are less likely to have had discussions with medical professionals about the potential of transplantation as a treatment option (Salter et al., 2014). • Women undergoing hemodialysis were 1.45 times less likely to have had discussions about transplantation with medical professionals (Salter et al., 2014).
Referral to transplant center[a]	Kidney	Adult	Black	• Black patients have 37% lower odds of being preemptively referred for transplant evaluation than white patients (Gander et al., 2018).

Examples

Preemptive placement on transplant waiting list	Kidney	Adult	Black, Hispanic	• White candidates are more often preemptively listed for kidney transplant vs. black and Hispanic candidates (39.4% vs. 17.5% vs. 18.5%) (Nissaisorakarn et al., 2021).
Access to the waiting list	Kidney	Adult	Women	• Men have greater access to the kidney transplant waiting list compared to women and also have increased access to a deceased donor kidney transplant (Ahearn et al., 2021).
	All organs	Pediatric	Individuals with an intellectual disability	• Transplant centers and providers factor neurodevelopmental issues into their decision-making process for placement on the waiting list in a nontransparent and inconsistent manner. A survey of pediatric transplant program staff found that 71% of heart programs, 30% of kidney programs, and 33% of liver programs would "always" or "usually" consider

Examples

Living organ donation[b]	Kidney	Adult	Black	• There is a lower rate of living kidney donation among the black population (0.4 per 100 patient-years) vs. whites (1.4 per 100 patient-years) (Arriola, February 2021 workshop). • Black patients are almost 60% less likely to receive a living donor kidney (USRDS, 2020).
	Kidney	Adult	Lower socioeconomic status (SES), black	• Transplant recipients in communities with a lower Social Vulnerability Index (SVI)[c] were more likely to receive a living donor kidney transplant than individuals in communities with higher SVI (Killian et al., 2021).
Deceased donor organ transplant	Liver	Adult	Undocumented immigrants	• Approximately 3% of deceased donor organs come from undocumented immigrants (Glazier et al., 2014), while disproportionately fewer undocumented immigrants (0.4 percent) receive liver

Examples

Posttransplant outcomes	Heart	Adult	Black	• Black patients experience a higher risk of rejection and death postheart transplant (Morris et al., 2016).
	Kidney	Pediatric	Uninsured or underinsured	• McEnhill et al. (2016) looked at pediatric outcomes in 289 children (48 undocumented and 241 permanent resident or citizen) and found that early graft survival rates were similar between the two groups, owing in part to insurance access. Of the 24 pediatric patients who reached the age of 21 over the study period (the age at which California state-sponsored transplant funding ends), 19 had stable graft function and access to insurance; the remaining 5 patients were unable to pay for immunosuppressive medication and lost grafts as a result.

Conclusion 4-1:

Although equity in access and allocation has been a proclaimed principle of the organ transplantation system for decades, and appears in federal regulations directing allocation policy, equity has, until recently, been absent as a stated goal or vision in the strategic plans of many organizations working in organ transplantation. While the stated priorities and plans of organizations involved in the transplantation system may now include equity, current policies and practices do not always reflect this commitment to equity.

Conclusion 4-2:

The current organ transplantation system in the United States is demonstrably inequitable. Certain groups of patients (e.g., racial and ethnic minority populations, lower socioeconomic status, female gender, older patients, individuals with intellectual and developmental disabilities, or inheritable diseases such as cystic fibrosis) receive organ transplants at a disproportionately lower rate and in some cases after longer wait times than other patients with comparable need.

Conclusion 4-3:

The absence of U.S. Department of Health and Human Services (HHS) requirements to collect disaggregated data by race and ethnicity, gender/sex, age, and language in organ donation and transplantation research precludes efforts to fully understand inequities in organ transplantation. Data gaps further compound challenges in provider decision making and preclude institutional priority setting for redressing inequities.

Conclusion 4-4:

Coverage of costs for scheduled dialysis for undocumented immigrants with end-stage kidney disease varies by state and results in disparities in the care available to patients. Emergency-only dialysis increases strain on hospital systems, providers, and patients

Conclusion 4-5:

It is well established that inequities arise in access to referrals, evaluation, and the waiting list for organ transplant, yet little is known where along the trajectory in that process disparities are most likely to arise, especially for vulnerable populations. There is a need to expand federal oversight to include the steps involved in identifying patients as needing a transplant before patients are added to the waiting list. Because current oversight begins only when a patient is added to the waiting list, measures and actions to advance equity throughout the system will be hampered until these earlier steps in the patients' process of gaining access to transplantation are addressed as part of the transplantation system and a source for evaluating progress in achieving equity.

Conclusion 4-6:

Based on available information, the committee does not find justifiable reasons for the demonstrable disparities between organ transplant rates for persons who would benefit from organ transplants and the burden of disease in many populations. Disproportionately fewer racial and ethnic minority patients receive organ transplants than are represented on the transplant waiting list. These inequities undermine the trust necessary for the organ transplantation system to function optimally.

Conclusion 4-7:

Evidence-based interventions have been developed to reduce disparities and increase access to transplantation. Nonetheless, such interventions are rarely implemented into practice. Despite the availability of these interventions, dialysis centers, donor hospitals, transplant centers, OPOs, and others have not implemented the interventions to help resolve inequities in access to transplant referral, evaluation, and care

Recommendation: Achieve equity in the U.S. organ transplantation system in the next 5 years.

HHS should be held accountable for achieving equity in the transplantation system in the next 5 years. Within 1 to 2 years, HHS should identify and publish a strategy with specific proposed requirements, regulations, payment structures, and other changes for elimination of disparities. Elements of the strategy should include expanding oversight and data collection, aligning providers with the goal of equity, shared decision making with patients and public education, and elevating voices of those facing disparities.

To Do

Expanding Oversight and Data Collection

- HHS should extend its regulatory oversight of the organ transplantation system beginning, at least, at the time a patient reaches end-stage organ failure and extending beyond 1 year posttransplant.
- HHS should update the OPTN contract to require the collection of disaggregated data by race and ethnicity, gender/sex, age, as well as language and the creation of new measures of inequity in the transplantation system.

Aligning Providers with the Goal of Equity

- The Centers for Medicare & Medicaid Services should adopt payment policies that incentivize all providers—from primary and specialty care of patients with organ failure to referral for transplant, from care while awaiting a transplant to long-term posttransplant care—to improve equity in access to care and outcomes for patients.

Shared Decision Making with Patients and Public Education

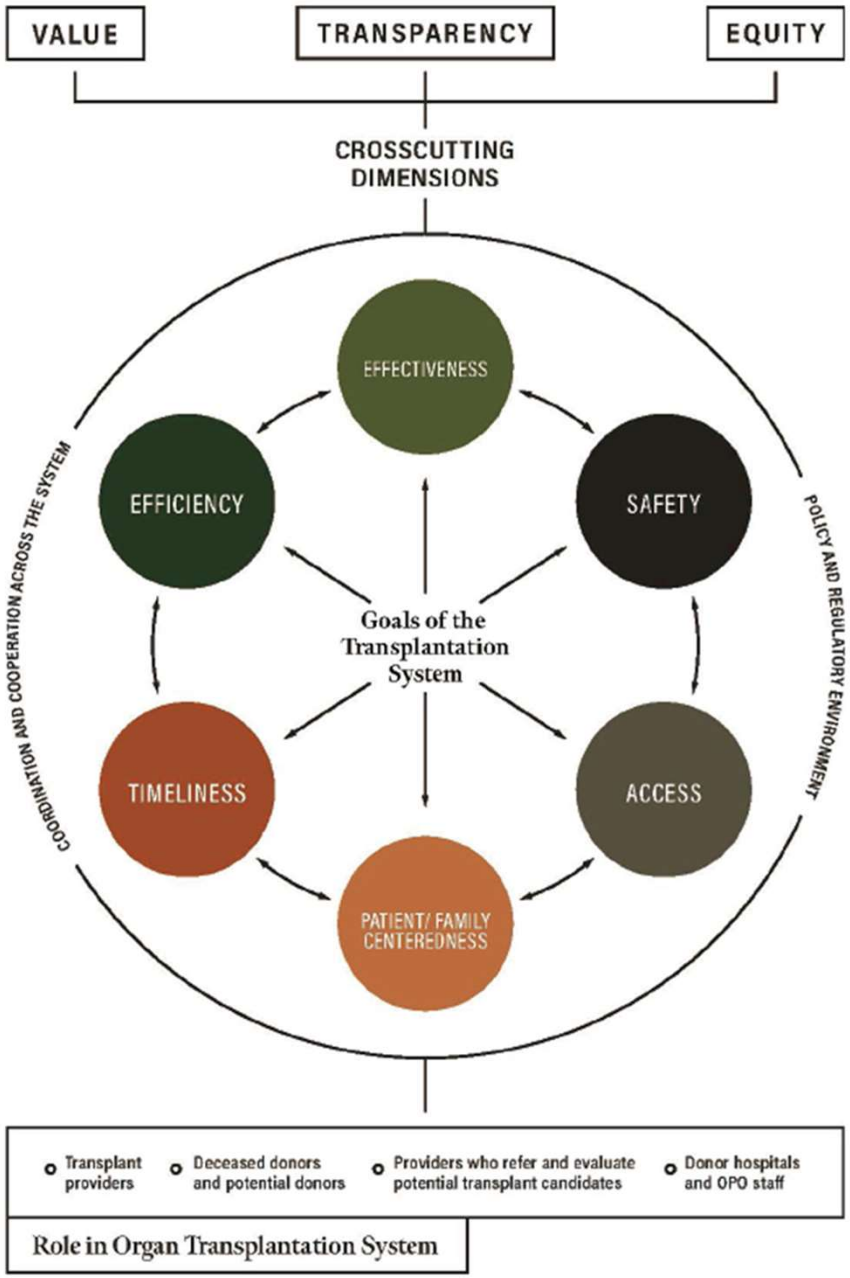
- HHS should develop, implement, and evaluate rigorous approaches for transplant teams to communicate routinely with (1) potential transplant recipients about their status and remaining steps in the process of transplant evaluation; (2) wait-listed candidates about organs offered to them, including information about the benefits, risks, and alternatives to accepting different types of organs to facilitate shared decision making about whether to accept the organ; and (3) wait-listed candidates about the number of organs offered and declined.

To Do

- HHS should develop, implement, and evaluate rigorous approaches for routinely educating the public about the benefits, risks, and alternatives to organ transplantation as a treatment option for end-stage organ disease or for those needing transplantation of tissue or a functional unit.
- HHS should conduct ongoing culturally targeted public education campaigns to convey the need for organ donation to save lives, to eliminate misconceptions about organ donation and transplantation, and to increase the trustworthiness of the transplantation system.

Elevating Voices of Those Facing Disparities

- The OPTN should be required to ensure that all populations facing disparities, including persons with disabilities, are represented in the transplant policy development process.
- HHS should require and support work with OPOs to increase the diversity of their workforce to better meet the needs of donor families.


VALUE
TRANSPARENCY
EQUITY
CROSSCUTTING DIMENSIONS
EFFECTIVENESS
EFFICIENCY
SAFETY
Goals of the Transplantation System
TIMELINESS
ACCESS
PATIENT/ FAMILY CENTEREDNESS
COORDINATION AND COOPERATION ACROSS THE SYSTEM
POLICY AND REGULATORY ENVIRONMENT
Transplant providers
Deceased donors and potential donors
Providers who refer and evaluate potential transplant candidates
Donor hospitals and OPO staff
Role in Organ Transplantation System

Achieving Equity

Areas for Immediate Action

- Diversify the workforce
- Increase public awareness about organ donation & transplantation
- Increase access to living kidney donation
- Remove race from estimated Glomerular Filtration Rate calculations

Research Opportunities

- Patient priorities for organ transplant system
- Improved allocation algorithms to address disparities
- Effect of survival benefit in the kidney allocation system
- Study use of Cystatin C in transplant allocation
- Healthcare delivery science especially in health equity
- Ensure all areas of research enroll and study minority and disadvantaged populations

Dageford et al Transplantation 2023 107,291-296

How Democracy Conquered the World
2012
Democracy

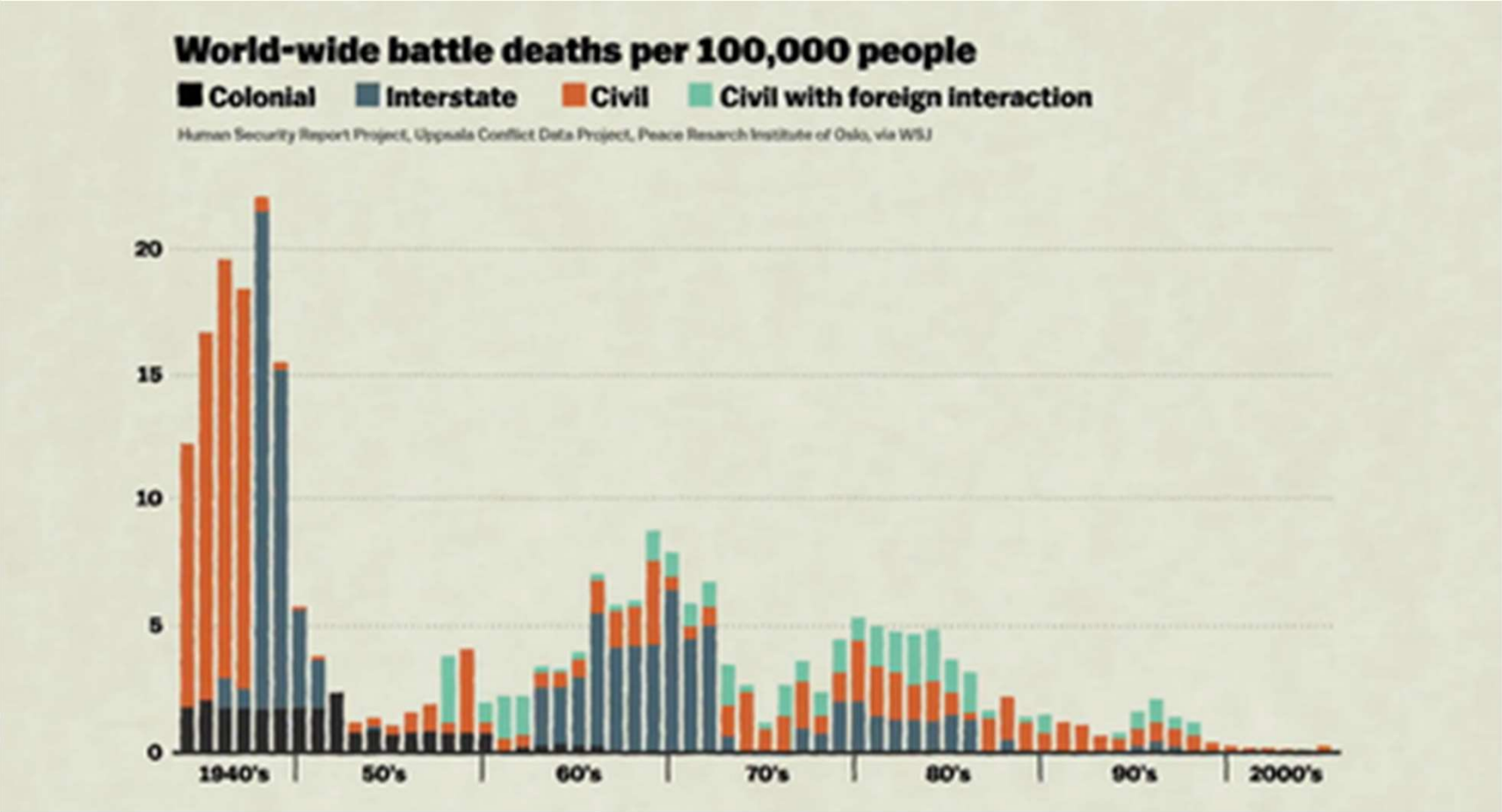
Final message

1/ change is necessary, because inequity is present everywhere

2/ discuss -> reflect -> act

3/ transparency

4/ incorporate equity in every step of the organ allocation decision making process


World-wide battle deaths per 100,000 people
Colonial
Interstate
Civil
Civil with foreign interaction
Human Security Report Project, Uppsala Conflict Data Project, Peace Research Institute of Oslo, via WSJ
20
15
10
5
0
1940's
50's
60's
70's
80's
90's
2000's