

EDITORIAL

Equity in Heart Transplant Allocation: Intended Progress Up the Hill or an Impossibility?

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It's the past we step into and how we repair it. —Amanda Gorman, National Youth Poet Laureate, The Hill We Climb

It always seems impossible until it is done. —Nelson Mandela

Racial and ethnic inequities in heart failure (HF) are long-standing and pervasive, ranging from disparate access to preventative and therapeutic treatments to unequal outcomes.¹ Disparities are defined as racial and ethnic differences in the quality of health care, attributable to the operation of health-care systems and recognized or unrecognized bias or discrimination.² Black and Hispanic adults are disproportionately impacted by higher HF incidence and prevalence as well as poorer reported health status.³ Black adults have the highest rates of HF hospitalization, readmission, and 5-year mortality risk after incident HF diagnosis.¹ Black and Hispanic adults are less likely to receive care by a cardiologist when admitted for HF and are less likely to be referred for advanced HF therapies.^{4,5} Premature HF-related deaths in young and middle-aged Black individuals are increasing, widening a troubling HF mortality disparity antithetical to the myriad of advancements in modern HF therapy.^{1,6}

Heart transplantation (HT) is the most effective treatment of end-stage HF, as it improves quality of life and survival, but it is also the scarcest of HF therapies. Increasing HF prevalence has been coupled with an ≈34% increase in HT demand over the past decade.⁷ The US HT allocation, as addressed by policy iterations of 1988, 1998, and 2005, was intended to prioritize candidates with the highest acuity illness and longest accrued wait times within prespecified geographic regions.⁸ These policies had a positive impact on the evolving HT landscape, but also unintended consequences, with disparate waiting list mortality among certain groups and concerns for inadequate organ sharing, particularly in densely populated urban areas.⁸ The ceiling effect of a 3-tiered allocation system (defining urgency for transplantation) restricted in its ability to distinguish acuity, limited status exceptions, and the unique considerations of a growing population of patients with left ventricular assist devices prompted the directive to readdress HT allocation policy in 2012, and again more recently in 2018. The latest version changed the allocation system into 6 tiers and extended the geographical area (to a radius of 500 nautical miles) for which patients with the highest urgency could match with a donor.

The primary directive of the US governing body for transplants, United Network for Organ Sharing, is the Final Rule: equitable allocation of organs. However, inequitable HT allocation and disparate HT outcomes in Black and indigenous people of color have been

See Article by Chouairi et al.

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observed across allocation policy iterations of the past 35 years. Despite increased HF burden in Black and indigenous people of color, overall HT rates for Black and Hispanic candidates have declined from 82 to 69.2 and from 90.2 to 80 per 100 waiting list years, respectively, since 2008.⁷ The gap between HT rates and HF mortality rates is the greatest for Black patients compared with other races.⁹ Black patients with left ventricular assist devices awaiting HT are less likely to achieve transplantation, more likely to be delisted, and more likely to die after transplant.¹⁰ Five-year post-transplant survival is lowest in Black recipients; however, more equitable survival outcomes are possible with multidisciplinary team care.^{11,12}

In this issue of the *Journal of the American Heart Association (JAHA)*, Chouairi et al used the United Network for Organ Sharing registry to determine contemporary HT outcomes and trends among 32 353 HT candidates self-identified as Black, Hispanic, and White patients from 2011 to 2020.¹³ In their secondary analysis, the study team offered new insights on transplant listing and outcomes associated with the October 2018 allocation policy change. The article highlights several key take-aways in HT allocation. First, over the 10 years studied, this analysis echoes the observation that Black candidates, in comparison to White candidates, are significantly less likely to be transplanted once listed, and more likely to die once transplanted. This is juxtaposed to significantly younger age at listing and lower waiting list mortality in Black candidates in comparison to White candidates in this analysis. Hispanic candidates were noted to have similar rates of transplantation, and Asian American candidates had higher rates of transplantation, in comparison to White candidates.

Second, the proportions of self-identified Black and Hispanic patients listed as candidates for HT have increased since 2011 (from 21.7% to 28.2% and from 7.7% to 9.0%, respectively), and the proportion of Black candidates transplanted increased from 20.8% to 27.3%. This, however, does not account for increased HF prevalence in Black and Hispanic patients, as noted by the authors.¹⁴ Previous studies have noted HT listing increased by one third overall between 2008 and 2018,⁷ which may be related to increased survival to time of listing with left ventricular assist devices. In addition, HT listings increased by 30% following implementation of the Affordable Care Act in 2014 among Black patients residing in states that adopted the Affordable Care Act policy.¹⁵ Medicaid coverage gains were highest for Black and indigenous people of color aged <64 years, as uninsured rates for Hispanic adults, Black adults, and American Indian adults decreased from 32.6% to 19.1%, from 19.9% to 10.7%, and from 32.0% to 22.0%, respectively, between 2010 and 2016.¹⁶ Uninsured rates in Asian and White adults

also decreased, from 16.7% to 7.1% and from 13.1% to 7.1%, respectively, over the same interval.¹⁶ Limited sociodemographic data at the time of listing included in this analysis demonstrate higher proportions of public insurance in Black and Hispanic candidates, in comparison to White candidates, who are listed predominantly with private insurance. Fewer than 15% of all listed candidates of any demographic group were noted to be working for income. Availability of public health insurance has had considerable impact in expanding HT access, particularly in financially underresourced, minoritized communities.^{15,17}

Third, the study team found an increased likelihood of transplantation among all racial/ethnic groups after the change in the allocation system; however, Black candidates were still significantly less likely to be transplanted after allocation amendments, despite similar acuity and listed status. Likelihood of transplantation among Hispanic and White candidates was similar after the 2018 policy changes. Previous studies have observed fluctuation in HT rates in the decade preceding the 2018 allocation change, reaching a nadir in 2014 to 2015.⁷ Since 2015, transplant rates increased, although less robustly for Black and Hispanic candidates.⁷

This study also highlights additional implications of the 2018 allocation policy change, including a 3-fold increase in use of intra-aortic balloon pumps across all groups, halving of waiting list times, and increased median ischemic time and distance traveled with the change in radius access for higher status listings. This study contributes to the literature by providing timely feedback of the impact of the 2018 policy change over its first 20 months of implementation.

INTENDED PROGRESS IN TRANSPLANT EQUITY OR AN IMPOSSIBILITY

The directive of the United Network for Organ Sharing Final Rule is clear: create policies for the equitable allocation of organs. A certain truth is that policy can powerfully impact change, but the challenge is crafting a policy to have the intended impact. The intended goal of the 2018 allocation policy, in part, was to reduce waiting list times of higher-acuity patients. Across racial and ethnic groups, waiting list times reduced by nearly 50%, and the overall likelihood of transplant increased. However, 3 times as many patients were waiting on temporary mechanical support. Heart recipients had longer ischemic time related to receiving donations from further distances. *Did the patients change?* Is this the intended goal, or reflective of the familiar, inherent tension between high acuity status (defined by therapeutics) and conflicting incentives for programs and providers as advocates?¹⁸

Furthermore, has there been *progress* toward equity in HT allocation? It is well recognized over decades that Black and Hispanic patients are less likely to be referred for HT. Black patient race has been shown to influence clinical decision making among HF providers, often concluding that Black patients are less suitable for HT.^{4,19} Given increased HF prevalence among Black and indigenous people of color, increased proportions of Black and Hispanic patients gaining access to the waiting list may, in itself, *be* progress. Despite the allocation policy change, however, Black candidates are still less likely to be transplanted. The undeniable question remains, *why?* Once transplanted, Black candidates are more likely to die, *why?* Sensitization and human leukocyte antigen mismatching, although more prevalent in Black candidates, does not sufficiently explain either of these continuously observed disparities.²⁰ An attributable biologic difference or propensity has not been discovered that explains increased incidence, prevalence, and mortality, lower likelihood of transplantation, or poorer posttransplant survival in Black patients with HF. These insidious disparities must be the fervent focus of well-resourced investigation. Systemic racism and implicit bias are inherent to the “groundwater” or structure of US health care, but demolishing complacency with this fact is a tangible and actionable pursuit.²¹

Equity in HT allocation will require deliberate intention. Erosion of gatekeepers to HT referral and targeted interventions to improve listing and outcomes are needed. As HT is a life-saving, but expensive endeavor, individuals without insurance are unable to be considered. Expansion of insurance coverage must be a primary consideration in improving equitable access to transplantation in diverse communities. Previous calls for reform in financial considerations of HT are decisively still warranted. Adequacy of posttransplant insurance must be paired with these reforms. Reconsideration of end-stage HF as a condition warranting Medicare coverage regardless of age may be central to equitable access.

Clinician and programmatic bias and racism must be addressed systematically in consideration of advanced therapies, but also in upstream decisions for referral to a cardiologist or HF provider. Recognizing that each transplant program develops its own culture and aptitude for patient selection, objectivity, transparency, and earnest assessments of recognized or unrecognized bias in HT committee considerations for listing and waiting list removal is imperative. These assessments should be standardized, obtained across programs, and independently ascertained. Implicit bias training, education in shared decision making, and directly confronting systems of bias will aid the physician and advanced practice provider workforce in navigating considerations for diverse populations.

Including diverse communities in the development of allocation policy, particularly patients, is a practice that must be amplified and safeguarded. Social and structural determinants of health must be considered and targeted for evidenced-based interventions to improve posttransplant outcomes. Multidisciplinary and patient-centered care have been proven to improve posttransplant outcomes and must be reinforced.¹² Prevention of end-stage HF with equitable risk factor reduction and use of guideline-directed HF therapies remains a priority. These endeavors are only possible with authentic stakeholder engagement to build a foundation for HF equity interventions.¹

The current era of HT has been made possible only by the tireless pursuit of women and men and who were persistent to see it to fruition. There was a time when HT was all but given up on, but perseverance attained. Disparity and inequity are not an acceptable legacy; the toll in human life is too costly a wage. It is the “hill we climb,” seemingly impossible, until equity is achieved.

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