

VIEWPOINT

VOICES IN CARDIOLOGY

Breaking Barriers



Advancing the Mission of The Equity in Heart Transplant Project

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ABSTRACT

The Equity in Heart Transplant Project, Inc (TEHTP), a 501(c)(3) public charity founded in 2022, addresses financial and social barriers impeding access to heart transplantation for patients with end-stage heart failure in the United States. Rooted in the World Health Organization's declaration on health as a fundamental right, TEHTP champions equitable care. Financial impediments disproportionately affect minority populations, perpetuating disparities in heart transplant outcomes. Since its inception in 2022, TEHTP has successfully supported 31 patients. Looking ahead, TEHTP aims to influence health policies surrounding insurance coverage through advocacy efforts and expand assistance to posttransplant care. Past accomplishments and future goals exemplify the organization's commitment to eradicating systemic barriers and ensuring that poverty does not become a death sentence for transplant patients. (J Am Coll Cardiol Case Rep 2024;29:102354) © 2024 The Authors. Published by Elsevier on behalf of the American College of Cardiology Foundation. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Established as a 501(c)(3) public charity in 2022, The Equity in Heart Transplant Project, Inc. (TEHTP) is dedicated to providing financial support to patients with end-stage heart failure (HF) who face financial and social barriers to being listed for a heart transplantation in the United States. This paper aims to detail the inception, achievements, and future directions of TEHTP in bringing equitable care to patients suffering from end-stage HF.

THE FUNDAMENTAL RIGHT TO HEALTH

The preamble to the constitution of the World Health Organization in 1946 asserts that “The enjoyment of

the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic, or social condition.”¹ This statement encapsulates the guiding principles on which TEHTP was founded. The organization is committed to addressing financial and social barriers, as well as any unmet needs not covered by health insurance, faced by patients with end-stage HF being evaluated for heart transplantation. The financial and social barriers faced by patients with HF seeking heart transplantation are discussed in the following sections.

FINANCIAL AND SOCIAL BARRIERS TO TRANSPLANT

The journey to heart transplantation is fraught with systemic inequities, posing significant barriers for many patients. A primary obstacle for these patients relates to issues of underinsurance and uninsurance, which serve as significant bottlenecks contributing to disparities in heart transplantation.² Authorization by an insurance provider and financial capability are prerequisites for heart transplantation listing.³ This issue is particularly pronounced, considering that approximately 43% of heart transplant patients rely

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**ABBREVIATIONS
AND ACRONYMS****ACA** = Affordable Care Act**HF** = heart failure**TEHTP** = The Equity in Heart
Transplant Project

on public insurance, among whom 30% are Medicaid beneficiaries.² However, the requirement of adequate insurance coverage for heart transplantation listing aims to allocate organs to individuals with the highest likelihood of successful outcomes and the greatest ability to fulfill complex posttransplant care. Although this criterion intends to promote transplant success, it presents a practical barrier, rendering patients of lower socioeconomic status and those grappling with social determinants of health obstacles practically unable to access heart transplantation in the United States. This is where TEHTP's vision lies—to help patients in need of heart transplantation but who are unable to obtain one purely because of financial barriers.

A pivotal change in health care policy occurred in 2014 with the introduction of the Affordable Care Act (ACA), substantially increasing insurance coverage, especially for racial and ethnic minorities with lower socioeconomic status.² In participating Medicaid expansion states, there were significant increases in heart transplant listings for Black patients, although similar trends were not observed among Hispanic or Caucasian patients.² Although effective, challenges persist due to the ACA's controversial nature, leaving 10 states unenrolled and creating a coverage gap for individuals with incomes between 100% and 138% of the Federal Poverty Level.

Patients lacking adequate insurance coverage often present with advanced symptoms, necessitating hospitalization because of lack of access to routine outpatient care. Moreover, racial and ethnic minorities have historically had the highest rates of uninsurance.² Many patients have difficulty navigating the health care system and the marketplace to obtain insurance or require asset reallocation to be eligible for Medicaid. Lack of insurance is intricately tied to social determinants of health including housing, transportation, education, and health literacy, all of which can impact HF outcomes. These factors may partly explain why Black and Hispanic patients receive significantly fewer heart transplants relative to their burden of HF compared with White patients.⁴

Medical crowdfunding has become an increasingly common practice, as certain posttransplant costs are not covered by insurance but can still be significant.⁵ Certain programs may require patients to have independent funds in cases of underinsurance to ensure adequate compliance with posttransplant follow-up care. Unfortunately, prior studies have shown that among the most successful medical crowdfunding campaigns, the beneficiaries tend to be male and

White, with racial and ethnic minorities having less success in raising funds.⁶

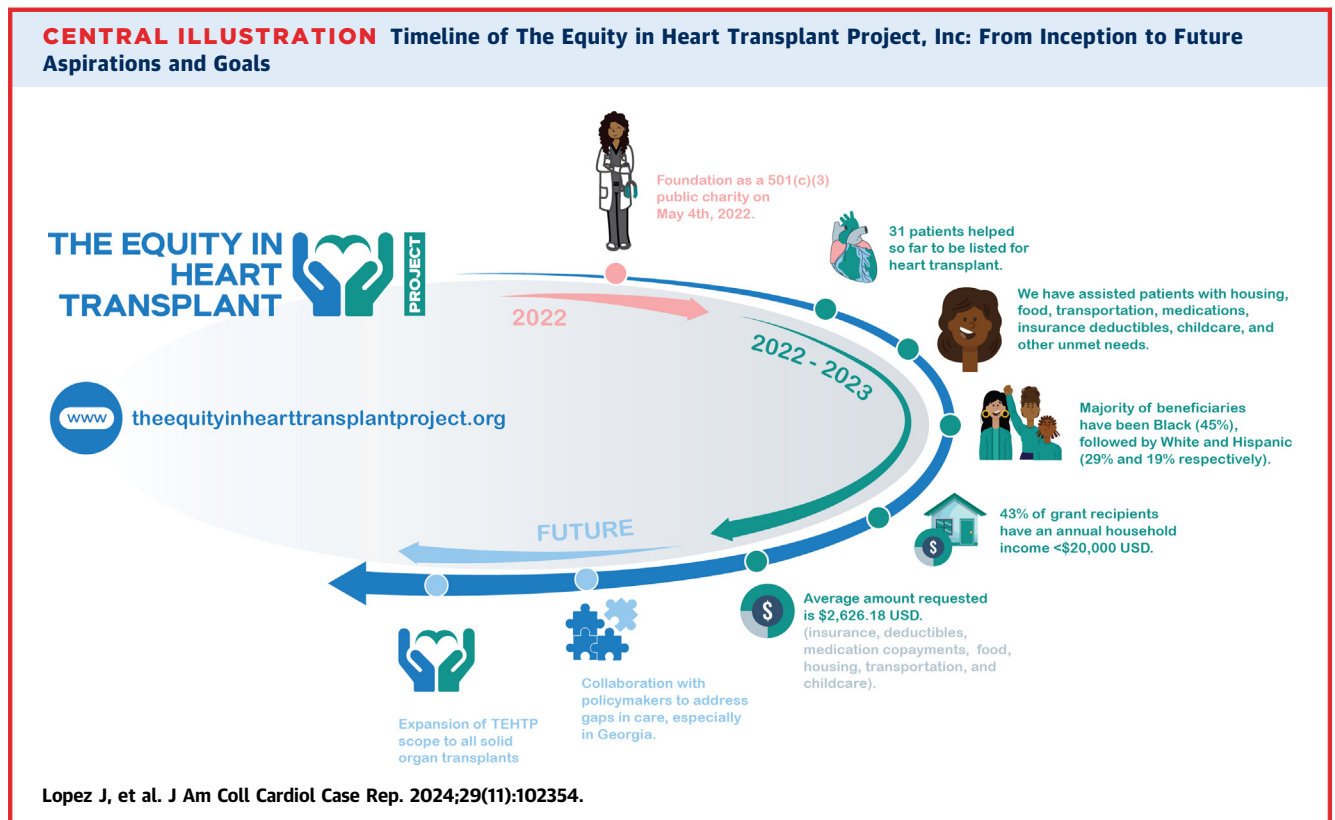
In addition, heart transplant centers are frequently located in large, high-volume urban areas, posing significant challenges for patients residing in rural regions. A study focusing on lung transplantation found that recipients lived an average of 70 miles away from the transplant center.⁷ Given that heart transplant recipients need frequent follow-up care, the distance imposes substantial costs related to relocation, lodging, and travel, which can disproportionately affect disadvantaged populations.

THE GENESIS OF TEHTP

Moved by these inequities in heart transplantation, TEHTP was born in June of 2022. The organization's unwavering mission is to assist patients in need of a lifesaving heart transplant. TEHTP devised a system to try to ensure fairness and justice in every endeavor the organization undertakes. The process involves the patient's transplant team filling out a form after exhausting all institutional avenues to raise the required funds. A detailed budget outlining fund allocation for the patient's transplant journey is required, and approval is subject to a majority vote by members of the board of directors. Applicants are rarely turned down, provided the request is within the scope of the mission, which is to help patients get listed for a heart transplant. Applications for assistance can be submitted on the TEHTP website⁸ where additional information about the organization is also available. An overview of TEHTP, highlighting its origins, key accomplishments, and future goals, is provided in the [Central Illustration](#).

ACHIEVEMENTS

Since September of 2022, when TEHTP began accepting applications for assistance, the organization has helped 31 patients get listed for a heart transplant. In alignment with previous knowledge of disparities in end-stage HF, most beneficiaries have been Black patients (45%, n = 14), closely followed by White and Hispanic patients (29%, n = 9 and 19%, n = 6). Approximately 43% of grant recipients have an annual household income <\$20,000 USD, and 37% have an annual household income <\$40,000 USD. The average amount requested by patients is \$2,626.18 USD, and the granted amounts have ranged from \$1,500 to \$8,000 USD. Grant requests encompass essential needs such as insurance deductibles, medication copayments, food, housing, transportation to the transplant center, and childcare.



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Typically, these funds are for a limited period of time until a patient can return to work or appointments become less frequent, for example. TEHTP's success owes much to the dedication of its donors, board members, and ambassadors. The organization has effectively orchestrated multiple fundraisers attesting to the collective effort invested in achieving its mission. These interventions have played a pivotal role in enabling more marginalized patients to be listed for heart transplantation.

It is worth noting that only 13% of those assisted were women (4 of 31 total patients). Although women are a key target demographic for the organization, the referral process primarily relies on inpatient members of the patient's care team. The observed low assistance rate for women may reflect systemic inequities in the heart transplantation listing process, given that TEHTP has not denied any applications for patient assistance to date. This observation is likely reflective of a complex issue, encompassing disparities not only in transplant listing but also in implicit biases.

FUTURE DIRECTIONS OF TEHTP

TEHTP recognizes that financial assistance addresses immediate needs but does not eradicate the root

causes of inequities in access to heart transplantation. Despite ethical principles mandating organ allocation based on medical necessity and improvements to insurance access through the ACA,⁹ poverty poses a significant barrier for heart transplantation as insurance premiums, deductibles, and out-of-pocket costs may be unaffordable for these patients who otherwise have no medical contraindications to transplantation. Even with coverage, if certain insurance policies do not adequately cover heart transplantation, including pretransplant evaluation, surgery, and posttransplant care, this can lead to financial barriers for individuals with lower socioeconomic status, creating disparities in access. TEHTP's primary long-term objective for the future is to influence and reform health policies, striving to make heart transplantation accessible to all patients. Although we have focused this work on financial hurdles in transplantation, it is important to acknowledge that additional hurdles concerning medical comorbidities and psychosocial factors, including substance use, are critical barriers in the transplant process.

Most patients (32.3%, n = 10) assisted by TEHTP have been from Georgia. This is in part because Georgia Medicaid does not cover heart

transplantations in adults 21 years of age and older. TEHTP aims to collaborate with policymakers in the future to shape legislation and policies that address these gaps in care and barriers to transplantation.

Although pretransplant evaluation and organ transplantation are both costly and have a tremendous impact on patients, posttransplant care is another vulnerable time for transplant patients and their families, as they balance their medical expenses and living expenses. One of the future goals of the TEHTP is to provide posttransplant assistance to patients in need. Although the primary focus of this organization is to provide financial assistance to heart transplant patients, the financial burden of other solid organ transplants has been well-documented. TEHTP envisions expanding its outreach and scope to provide financial assistance for various solid organ transplants and to offer potential posttransplant support as the organization grows. Last, as the organization widens its social impact on transplant care, in collaboration with transplant centers, a future goal would be to create transplant access centers that address social determinants of health in order to address and minimize the systemic barriers faced by patients during evaluation for organ transplantation. Ultimately, any patients who are eligible for organ transplantation should not be denied the chance of a second life because of financial, social, and economic barriers to transplantation.

In conclusion, TEHTP stands as a beacon of hope, actively dismantling financial and social barriers to heart transplant access. Rooted in principles of

equitable care, TEHTP's impactful interventions have already helped 31 patients become listed for transplantation, emphasizing the impact of financial assistance. However, it is imperative that the organization's efforts work alongside concerted grassroots efforts to improve public policy and advocacy, ensuring that the root causes of these inequities are addressed.

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Dr DeFilippis is a member of the Board of Directors of The Equity in Heart Transplant Project, Inc. Drs Lopez, Latif, and Makuvire are ambassadors at The Equity in Heart Transplant Project, Inc. All authors have reported that they have no relationships relevant to the contents of this paper to disclose.

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