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THE INFLUENCE OF DEMOGRAPHIC, SOCIAL, AND ECONOMIC FACTORS ON REFERRAL FOR HEART FAILURE SERVICES

Catherine Elaine Kelty, Ph.D.

Western Michigan University, 2022

Patients with end-stage advanced heart failure must go through an extensive evaluation process before being selected for either heart transplantation or left ventricular assist device (LVAD). This evaluation not only assesses a patient's medical need for advanced heart failure treatments but also includes an assessment of psychosocial and economic factors that may affect a patient's success post-treatment. While it is important to allocate scarce resources, such as donated organs, to the patients who will benefit the most, there is also a need for equity in the allocation of and access to healthcare services. This raises the question of whether patients who are diagnosed with heart failure ever have the opportunity to be evaluated for advanced heart failure services in the first place, due to gatekeeping events that may prevent patients from being referred to or have an appointment with a specialist.

The independent variables age, sex, marital status race/ethnicity, preferred language, smoking status, and insurance status were compared between patients referred and not referred, who had a clinic visit and did not have a clinic visit, and who received treatment and did not receive treatment. Patients who were younger (HR 0.934, 95% CI 0.925, 0.943), males (HR 2.216, 95% CI 1.544, 3.181), married (HR 0.665, 95% CI 0.488, 0.905), or non-smokers (HR 0.549, 95% CI 0.389, 0.776) were more likely to be referred to a specialist. Married patients (p=0.024) and nonsmokers (p=0.039) were more likely to have a clinic visit and younger age was

shown to contribute as well (HR 0.981, 95% CI 0.966, 0.995). Younger age (B coefficient = -0.21; HR 0.980 [95% CI 0.961, 0.998]), White race (p=0.042), Hispanic/Latino ethnicity (B coefficient = 1.504; HR 4.501 [95% CI 1.574, 12.875]), and both public (B coefficient = -0.758; HR 0.468 [95% CI 0.270, 0.813]) and private insurance (p=0.027) were significantly influencing whether patients received a heart transplant. Hispanic ethnicity was also associated with receiving an LVAD (HR 33.833, 95% CI 3.207, 356.968). Advanced age, Hispanic ethnicity, and smoking were associated with one-year mortality after heart failure diagnosis.

This study confirmed that disparities in access exist before patients are ever evaluated for advanced heart failure therapies. The gatekeeping events preventing patients from referral are multifactorial and based on historical injustices and structural barriers outside of the scope of healthcare. Recommendations for improving equity in access include improved heart failure guidelines for referral, cultural bias training for healthcare professionals, and government-led initiatives to provide universal financing for transplantation.

THE INFLUENCE OF DEMOGRAPHIC, SOCIAL, AND ECONOMIC FACTORS ON REFERRAL FOR HEART FAILURE SERVICES

by

Catherine Elaine Kelty

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Catherine Elaine Kelty

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CHAPTER I

INTRODUCTION

Significance of the Research

Despite medical advances, there is no cure for AHF (AHF). Patients with AHF are in such an advanced disease state that they cannot be managed by conventional medical treatments such as medication or surgery. For these patients, cardiac transplantation is the best available intervention. The next best treatment is the left ventricular assist device (LVAD), which is a surgically implantable, mechanical pump that provides circulatory support, either while the patient waits for a transplant or long-term support if the patient is ineligible for transplant.[1] Heart transplantation provides the best outcomes, with 91% one-year survival and LVAD providing 82% one-year survival.[2] Candidates for both cardiac transplantation and LVAD must undergo an extensive selection process before becoming eligible for either treatment. Organs are a scare resource with inherent restrictions on their availability and access. Both transplantation and LVAD implantation require extensive lifelong medical management, making patient selection a crucial step toward determining appropriate candidacy.

There are national policies to dictate the allocation practices of donor organs, but transplant programs are responsible for selecting patients that are in medical need and are likely to have a successful transplant. The autonomy of each transplant program allows for variability in how patients are selected to be candidates for transplantation, and it is not until they are candidates that the national policies are applicable. The United Network for Organ Sharing (UNOS) and the Organ Procurement and Transplantation Network (OPTN) are responsible for developing the policies for organ procurement and allocation in the United States. UNOS is a private, non-profit organization based in Richmond, Virginia that is under contract with the United States Department of Health and Human Services (DHHS). UNOS serves as the OPTN and manages all organ transplantations in the United States.

An allocation system is necessary due to the scarcity of donor organs. Factors such as distance from the donor hospital, blood type, and the medical need of the candidate play a role in how donor hearts are allocated.[3] The National Organ Transplant Act (NOTA), a federal law passed in 1984, requires that the allocation system for donor organs must account for both efficiency and equity.[4] Equity is important so that there is justice in allocation, and efficiency allows for increased survival and number of recipients.[3] However, there are no regulations insisting on equitable allocation as part of the selection process at the transplant hospital.

Eligibility for AHF treatments such as transplant and LVAD involve an extensive selection process. Organizations under contract with the U.S. government such as the United Network of Organ Sharing (UNOS) or the Organ Procurement and Transplantation Network (OPTN) have no regulations or requirements for the institutional selection procedures, and it is up to each transplant program to develop their own guidelines. Therefore, even though the allocation system put in place by UNOS and OPTN is uniform and considers justice and medical utility, each transplant center develops their own criteria for candidacy of both transplantation and LVAD implantation.

The International Society of Heart and Lung Transplantation (ISHLT), Academy of Psychosomatic Medicine, American Society of Transplantation, International Consortium of Circulatory Assist Clinicians, and the Society for Transplant Social Workers collaborated to produce a guidance document for individual transplant programs which outlines recommendations for the psychosocial assessment of transplant or LVAD candidate.[5] This included guidance for such factors as social support, cognitive impairment, substance use, and substance abuse. Notably, OPTN policies state that allocation should not be dependent on financial status,[6] but eligibility based on ability to pay is left to the individual transplant programs to determine. The financial evaluation is in fact a part of the evaluation process for transplant and LVAD at transplant programs across the country. According to a national survey, 48% of heart transplant programs require proof of appropriate insurance coverage before evaluation for transplant and 84% require coverage before listing.[7] Recent research has shown that patients with Medicare or Medicaid were less likely to be eligible for a transplant when compared to privately insured patients.[8]

This leads to the question if there are gatekeeping events keeping patients from seeing an AHF specialist in the first place, despite clinical eligibility. There is currently a deficit in the literature investigating referrals to heart failure services, and the research that does exist is focused on the clinical aspects of referral.[9,10] Understanding physician decision-making during the clinical evaluation is difficult, as decisions are based on clinical, social, and personal characteristics.[11] The inherent restrictions witnessed in the evaluation process for advanced therapies therefore lead us to investigate whether there are disparities in access to services *before* a patient receives an advanced therapy evaluation, and whether the disparities are caused by social or economic factors.

This study builds on previous, unpublished[12] research by the author, which investigated the demographic, psychosocial, and socioeconomic factors affecting eligibility for AHF interventions such as heart transplant and LVAD and whether these treatments were received. That research found that public insurance and social support were significant factors in the selection process. The proposed study takes a step back, asking whether or not the access to heart failure treatments exists only at the level of advanced therapies or if patients are determined to be unsuitable earlier in their disease trajectory.

This study provides evidence regarding potential issues with access and eligibility for AHF services because the patients not referred for heart failure services have not been investigated before. Limited research has been done on referrals because the data related to physician-decision making is not readily available and required detailed chart review.[11] This research assesses whether there are points of access before the patient has a chance to go through the transplant and LVAD evaluation process. The study was conducted at one Midwest hospital system with a transplant program that serves 13 counties.[13] Even a single center study such as this may have far-reaching implications, as patients and providers strike for justice in access to healthcare services. Ultimately, this research has the potential to produce practice changes that may reduce disparities in referral.

Statement of Purpose

The aim of this research was to understand the extent to which disparities in referral influence utilization of AHF services. To do this, the progression of heart failure care at one Midwest hospital system with a transplant and LVAD program was examined. The study identified demographic, social and economic factors that differed between patients referred for and able to receive AHF services, and those that were not referred or did not receive services. Patients with social determinants of health are hypothesized to be less likely to be referred for and receive AHF services. Findings from this research may provide information to increase use of AHF therapies in vulnerable populations.

Research Questions

The following questions will be asked:

1.) Do patients who were diagnosed with heart failure and referred for AHF services differ from patients diagnosed with heart failure and were not referred with regards to demographic, social, and economic factors?

2.) Do patients who were referred for AHF services and had a clinic visit with an AHF specialist differ from patients referred but did not have a clinic visit with regards to demographic, social, and economic factors?

3.) Do patients who had a clinic visit and received AHF treatment (transplant and LVAD) differ from patients who had a clinic visit and did not receive AHF treatment?

4.) Does the length of time from diagnosis to referral, diagnosis to clinic visit, diagnosis to treatment, and/or diagnosis to death differ based on demographic, social, and economic variables?

Definition of Terms

1. *Advanced heart failure (AHF):* An advanced subset of heart failure with severe, persistent symptoms despite medical management.[14]
2. *Advanced therapy:* A heart transplant or mechanical circulatory support, such as an LVAD, for treatment of heart failure.[15]
3. *Heart failure:* A complex clinical syndrome resulting in impaired ventricular filling or ejection of blood.[14]

4. *Heart transplant:* The surgical removal of a diseased heart and replacement with a healthy heart from a deceased donor in an effort to increase lifespan and improve quality of life.[16]
5. *Left ventricular assist device (LVAD):* A type of mechanical circulatory support used to treat patients with AHF, consisting of a mechanical pump that provides circulatory support.[1]

Chapter Summary

Patients with AHF are in an advanced disease state with limited medical options, and a heart transplantation or LVAD are the best available treatment option. There is an extensive evaluation process for the selection of heart transplant and LVAD candidates due to the scarcity of donor organs and lifelong medical management required for either therapy. It is unknown what barriers exist that prevent patients with heart failure from undergoing an evaluation with an AHF specialist. Whether demographic, social, and economic factors affect referral to the AHF clinic and patient visits with an AHF specialist in one Midwest hospital system will be investigated.

CHAPTER II

REVIEW OF LITERATURE

Due to the selection process for AHF services, lifesaving treatments will not be provided to everyone in medical need. While selection of the most appropriate candidates for services is imperative for success, a patient's demographic, social, and economic characteristics play a role in eligibility resulting in inequitable distribution of services. This section examines the trajectory from heart failure diagnosis through the referral process and ultimately eligibility for advanced services. Understanding the criteria that prevent patients from receiving AHF services after a referral is essential in investigating whether these same barriers exist before a patient receives a referral for AHF services.

Heart Failure

The American College of Cardiology Foundation and the American Heart Association define heart failure as "a complex clinical syndrome that results from any structural or functional impairment of ventricular filling or ejection of blood."[14] Heart failure often involves pericardium, myocardium, endocardium, or great vessels disorders, but most patients have impaired left ventricular myocardial function.[17] As of 2019, an estimated 6.2 million Americans over the age of 20 years old had heart failure.[18] Risk factors for heart failure include hypertension, diabetes mellitus, metabolic syndrome, and atherosclerotic disease.[14]

Some patients with heart failure are in such an advanced disease state that they cannot be managed by medication or standard surgery. For those patients, the best available treatment is a heart transplantation, with the next best option being an LVAD. Both treatments require lifelong medical management. A heart transplant is the surgical removal of the diseased heart and replacement with a healthy heart from a deceased donor.[16] A heart transplant recipient must take immunosuppressants for the rest of their life so that their body does not reject the new heart. An LVAD is a surgically implanted device that supports heart function and the flow of blood out of the heart.[1] The LVAD consists of the pump placed inside the body, tubes that carry blood from the heart to blood vessels, a power source for the pump, and an electronic controller for the pump. The pump is connected to the external controller by a driveline that passes through the skin from the inside to the outside of the patient's body.[1] The device must be connected to a power source at all times, therefore the patient must either carry a battery pack or plug the device directly into a wall outlet. Daily dressing changes at the driveline exit site in the abdomen are required to reduce the risk of infection and may require the assistance of a caretaker. Many LVAD recipients take anticlotting medications due to the increased risk for blood clots when blood is in contact with the device.[1]

LVADs may be utilized as bridge-to-transplant (BTT), meaning the patient is implanted with an LVAD while they wait for a donor heart to become available. As more patients have been stabilized and supported by LVADs as BTT, the number of heart transplant candidates has increased as well.[19] LVADs may also be used as destination therapy (DT), in which an LVAD is used in heart failure patients that may be ineligible for a heart transplant. Further, some heart transplant candidates may not be eligible to be supported by an LVAD due to their specific anatomy or nature of their heart failure.

Referral for Advanced Heart Failure Services

In recent years, the gatekeeping model has become more prominent in the United States health care system.[20] In this model, a primary care practitioner must refer a patient before they may have an appointment with a specialist. This system is meant to avoid unnecessary, costly, and invasive procedures[21] in addition to providing preventive, routine care and total coordination of an individual's health care needs.[20] However, some insurance policies, such as a preferred provider organization (PPO) plan, may allow patients to go directly to a cardiologist without a referral.[11]

For patients with heart failure, they are often first seen by their primary care physician, and it is there that they may be first diagnosed with heart failure. Many patients with heart failure present to their healthcare provider with decreased exercise tolerance, symptoms of fluid retention, or the patient may have no cardiac symptoms and cardiac dysfunction may be noticed as an incidental finding.[17] The physician must assess disease severity and request appropriate testing. Based on those results, the patient may then receive a referral to a cardiologist and potentially a second referral to a heart failure cardiologist. Referral to the heart failure clinic is indicated based on clinical deterioration despite optimal care, including medications such as angiotensin-converting enzyme inhibitor, angiotensin receptor blocker, beta-blocker, aldosterone antagonist, hydralazine, and/or isosorbide dinitrate, or an implantable cardioverter defibrillator or resynchronization therapy.[9] Markers for referral include the commonly used New York Heart Association functional classifications of III or IV, intolerance to heart failure medication, hypotension, anemia, decreased renal function, and/or recurrent heart failure hospitalizations.[10] At the heart failure clinic, the patient may finally receive an evaluation by a surgeon specializing in heart transplant or LVAD services.[22]

When a patient meets the criteria for an evaluation with an AHF specialist, it is up to the primary care physician or cardiologist to make that referral. Even if the patient has a known contraindications to AHF therapies, such as active malignant disease or noncompliance, the patient should still be referred to see a heart failure specialist who will conduct their own evaluation.[9] Ideally, the patient is medically stable as the time of the long, complex evaluation process but, at times, this evaluation is conducted in an urgent and accelerated manner. A patient-specific risk-benefit analysis should be performed and include patient preferences, center-specific protocols, and consideration for post-transplant or post-LVAD outcomes.[9]

While bias may be introduced at any step in the specialist referral process, a specific area of concern is when patients may not be referred at all and why that situation may occur. Current research has focused on the heart failure specialist while limited research has been done on the patient’s initial presentation to their primary care physician with heart failure symptoms. The main reason patients are not referred to heart failure specialists is likely due to insufficient understanding of the disease by primary care clinicians and lack of clear guidelines to identify appropriate patients.[23] The primary care physician and/or cardiologist must believe that certain tests or procedures are warranted for patient evaluation. Referral or non-referral may be based on something as simple as the relationship that exists between the referring physician and the specialist,[11,24] and concerns have been made that clinician bias could negatively affect the patient-clinician relationship.[25]

Clinician Decision-Making

The primary care physician or cardiologist has an important role in the clinical care a patient with heart failure may receive. While it is expected that clinical decision-making is based on evidence-based practices, a number of non-clinical factors may influence clinical decisions.[24] Referral bias is the non-referral of certain populations, i.e., the uninsured, for evaluation by a specialist, or a hospital or institution not accepting certain populations of patients.[26] The term *bias* may be defined as the negative evaluation of the members of one group compared to another.[27] In most cases, bias in healthcare is implicit, meaning the clinician is unconsciously and unintentionally biased against members of a particular social group. Just as biases exist in all areas of society, implicit bias may influence clinical decision-making and ultimately promote disparities in health care.[27]

According to the Institute of Medicine, three factors caused by providers might be involved in promoting healthcare disparities based on race/ethnicity: bias or prejudice against minorities, increased clinician uncertainty during interactions with minority patients, and provider-held stereotypes about the health or behavior of minorities.[25] Research suggests that physician bias can impact decision-making and promote health care disparities. Quantitative[24] and qualitative[28] research has demonstrated that clinical decisions are not only made by medical information and that patient race/ethnicity play a factor. When black and white patients present to the emergency room with similar levels of pain, black patients are less likely to receive analgesia.[29] Between black and white patients with similar severity of depressive symptoms, black patients were less likely to be prescribed antidepressant medication.[30] Black and Hispanic patients were less likely than white patients to receive care in a physician's office or outpatient setting, while hospital and emergency room care were the same in all groups.[31] In a qualitative study assessing clinician's views toward racial disparities in health care, one physician stated that racial/ethnic minority patients were less likely to be adherent to taking their medications and therefore she was less likely to refer her patients to specialists.[32] This is in agreement with the idea that if patients show mistrust, have poor compliance, or refuse treatment, they may not receive more specialized services.[25] This may become a circular response to one another's attitudes, but undeniably the provider is in the more powerful position and should be looked at for targeted interventions.[25]

Socioeconomic factors also play a role in physician decision-making. Clinicians may order fewer tests or choose a different medication strategy based on economic status and insurance coverage.[24] Care may even be delayed care due to an assumed financial burden on the part of the provider.[24] In a cohort of women over 50 years old, those with lower educational attainment and household income were less likely to receive a physician recommendation for mammography.[33] Unfortunately, these adjustments in patient care may result in lower quality services compared to patients with more flexible schedules and the means to pay for their care and transportation. Patients with no insurance tend to have cancer diagnosed when it is at a later stage.[34] Patients with private insurance receive better primary care, in terms of first contact, longitudinality, comprehensiveness, and coordination, compared to the publicly insured; and the publicly insured received better care than the uninsured.[35] In a focus group setting, black patients have voiced concerns about discrimination and preferential treatment based on financial status and insurance coverage.[36] It is unknown how many people in need of a heart transplant are excluded due lack of referral of uninsured patients.[26]

Other areas of implicit bias include gender, age, and patients that are obese.[37] Females with similar symptoms and health history as men were less likely to be diagnosed with COPD.[38] Age has an effect on treatment decisions, as older patients have been less likely to be referred for diagnostic procedures[39] or prescribed beta-blockers after myocardial infarctions[40] when compared to younger patients. Clinicians specializing in obesity who took the Implicit Associations Test were found to associate obese patients with negative stereotypes such as being lazy, stupid, or worthless.[41]

Additionally, the intersection of any of the above factors can have an effect on access to healthcare. Race is likely a surrogate for other patient factors which affect access to healthcare services and patient outcomes.[42,43] Socially vulnerable groups often face a "chain of events" that lead to poor outcomes, which can include limitations with education, transportation, health literacy, social support and results in reduced access to healthcare, poor compliance, diet, or lifestyle choices.[44]

Limited English language fluency may also influence access to health care services, as well as trust in the medical system, the cultural competence of physicians, and the lack of representation in clinical trials.[45] The intersection between race and socioeconomic factors is revealed when looking at rates of insured individuals stratified by race. According to the United States Census Bureau report from 2020, people of Hispanic origin had the highest uninsured rate at 18.3%.[46] The uninsured rate for black, Asian, and non-Hispanic white individuals was 10.4%, 5.9%, and 5.4%, respectively.[46] The higher rates of uninsured individuals in non-white racial and ethnic groups is an important contributor to limited access to healthcare services in these populations. As for public insurance coverage, individuals in the black racial group had the highest rate at 41.4%, with 35.9% of people of Hispanic origin, 33.8 of non-Hispanic whites, and 27.0 of Asian individuals with public insurance.[46] The highest rate of private insurance was in non-Hispanic whites individuals (73.9%), followed by Asians (72.4%), blacks (54.6%), and people of Hispanic origin (49.9%).[46] As illustrated above, differences in insurance type and coverage can have an effect on access to services in addition to outcomes, although other unseen factors are also likely at play.

Conditions of social inequality function as fundamental causes of disease. For instance, an analysis of tax records from 2001-2014 revealed that higher income was associated with a longer life.[47] The gap in life expectancy in the United States was 14.6 years between the richest 1% and poorest 1% of men and 10.1 years between the richest 1% and poorest 1% of women.[47] The complex factors contribute to unfavorable outcomes in non-white racial and ethnic groups. Heart failure patients belonging to non-white racial and ethnic groups tend to have greater morbidity and mortality.[45] Higher rates of comorbidities such as hypertension, diabetes, chronic kidney disease, and obesity in black heart failure patients compared to white heart failure patients have been noted in the literature.[48]

Patient involvement is an essential part of the clinical decision-making process.[24] In qualitative studies, clinicians have shared through interviews that improved patient-clinician relationships occur when clinicians are willing to understand a patient's culture, can comminute using the patient's language, and works with the patient toward treatment goals.[28] The extent to which health care disparities affect the utilization of technologies is the crux of the proposed research.

Patient Decision-Making

Access to healthcare services and utilization of services are not interchangeable terms.[49] Patients may decline healthcare services for personal, cultural, religious, or socioeconomic reasons. Socially reinforced roles may influence patient decision-making in terms of choosing to undergo a medical treatment.

Research has demonstrated that women turn down medical treatments more often than men, for example, women who were eligible for heart transplantation were more likely to refuse transplantation than men despite recommendation that it was the best therapeutic option.[50] A potential reason for this refusal is the ubiquitous role women play when it comes to reproductive labor. Women are more likely to take on the childcare, cooking, and cleaning responsibilities of a household than men.[51] Advanced heart failure therapies such as transplantation and LVAD are life-changing with regards to follow-up care, lifestyle changes, and lifelong medications, which may not be feasible for women more than men due to reproductive labor.

Socioeconomic factors also play a role in patient decision-making. Patients who refused heart transplantation were more likely to have insurance coverage through Medicaid, Veterans Affairs, or workers' compensation compared to patients who had commercial insurance, health maintenance organization, or Blue Cross/Blue Shield insurance that did not refuse.[50] The financial burden may be too much for some patients to choose the best therapeutic option, with patients in economic hardship choosing comfort care over life-extending measures.[52] Further, if employed patients miss work due to their heart failure symptoms, they may lose their eligibility for insurance coverage and therefore may not be able to get the healthcare they require.[26]

Regional differences in the availability of primary care are an important aspect of patient access. Of particular importance to this research is the ability to have continuity of care, from a primary care physician to a cardiologist, to an AHF specialist. This continuity varies regionally and is essential in obtaining an appointment with a specialist.[11] Lack of a primary care physician affects likelihood of referral, since the evaluation and referral process requires follow-up visits and an ongoing discussion of symptoms with the provider. Therefore, lack of an appropriate provider or specialist is one's area could be problematic, especially for those with transportation limitations or scheduling hurdles with work and childcare.[11]

Patient trust in the healthcare system also affects decision-making. This is particularly true for black patients. Some are afraid, whether conscious or not, that white medical providers will subject them to experimentation.[11] The fear stems from events such as the Tuskegee syphilis study[53] and still exists today. Focus groups have revealed that black patients have concerns about potential experimentation in medical settings.[36] Other qualitative research has suggested that racial and ethnic minority patients have lower levels of trust in the health care system, spiritual beliefs that guide decision-making, and fear of procedures.[28] In addition to the Tuskegee atrocity, mass incarceration, immigration raids, and police killings have all contributed to peripheral trauma for minority populations and may impact trust in the medical system.[54]

As mentioned above, race is inextricably intertwined with class and gender. In seriously ill patients, non-white patients were more likely than white patients to suffer from a loss of their family savings that white patients.[52] Race shapes social encounters as well as educational and economic opportunities in ways that affect emotional, mental, and physical health.[43] Black patients in focus groups have stated that they want their physician to trust them regarding what they feel about their health.[36] The Kaiser Family Foundation reported that as of 2019, nonelderly adults of American Indian and Alaskan Native, Hispanic, Native Hawaiian and Other Pacific Islander, and black racial and ethnic groups were less likely to have health insurance compared to the white nonelderly population.[55]

Perceptions of illness severity may impact decision-making, and vary with culture, race, or ethnicity. In a community telephone survey, non-white respondents and those with lower socioeconomic status were less likely to know symptoms of a heart attack.[56] Therefore, patients of racial and ethnic minority may delay seeking medical care due to lack of recognition of coronary artery disease symptoms.[11]

The patient's comprehension of the risks and benefits to certain treatments also play a role in decision-making. Acceptability of risk may vary for patients, in addition to views about quality of life and future life expectancy. Some patients may refuse treatment to preserve their current quality of life, even if that goes against the medically optimal treatment.[24]

The refusal, or unaffordability, of treatment may ultimately be detrimental when a patient is too sick to receive appropriate care. For example, since women who saw a primary care physician were more likely to undergo mammography for cancer screening,[57] those women who did not see a primary care and therefor did not receive a cancer screening may one day be ineligible for AHF services should they get cancer.

Advanced Heart Failure Services

Patients who have been referred for a visit with an AHF specialist must face a complex evaluation process with restrictions on the availability of life-saving services. The process outlined in this section illustrates the complexity of care and hurdles every patient with heart failure must face.

Donor organs are a limited resource and there is a national allocation system in place to guide the distribution of organs to suitable candidates. The United Network for Organ Sharing (UNOS) is a private, non-profit organization under contract with the federal government and administers the Organ Procurement and Transplantation Network (OPTN). The National Organ Procurement Act (NOTA) was passed in 1984 and mandated the creation of an OPTN to manage the allocation of all donor organs in the United States. All organ procurement organizations and transplant centers must be OPTN members. Patients in need of a donor organ must be added to the OPTN national waitlist in order to be eligible to receive a donor organ.[6] According to NOTA, the national allocation system must be both efficient and equitable.[4]

Transplant centers are responsible for selecting patients to place on the transplant waiting list. Before a patient is deemed to be an eligible candidate for a donor organ, the patient must undergo an extensive evaluation process at their transplant center. Since both heart transplant and LVAD recipients require lifelong medical adherence and pharmacological care, there is a selection process to determine candidacy for either intervention. Medical, surgical, psychosocial, and financial eligibility must be determined in order to become a candidate for heart transplant or LVAD. Eligibility decisions are based on medical need but are also based on selecting patients who are likely to have a successful transplantation without a high risk for mortality or adverse events. The psychosocial evaluation is an important step in determining candidacy due to the major lifestyle changes patients of either advanced therapy must undergo. The assessment is necessary to determine whether there are concerns with medical adherence, social support, mental health, substance use/abuse, and cognition which may inhibit a patient's success post-intervention. The assessment also identifies patient risk factors that may be modified in an effort to improve patient outcomes before the patients is eligible for transplant or LVAD.[58]

Each transplant center determines their own criteria for the transplant waitlist. Many organizations recommend psychosocial evaluations for transplant eligibility there are no regulations dictating the candidate selection process at each transplant center. OPTN bylaws state that transplant centers are required to employ trained professionals to conduct the psychosocial evaluations of potential candidates[59] The Centers for Medicare and Medicaid Services (CMS) advise that a psychosocial evaluation of potential transplant recipient occurs when possible.[60] A consensus paper from groups such as the International Society for Heart and Lung Transplantation (ISHLT), Academy of Psychosomatic Medicine (APM), American Society of Transplantation (AST), International Consortium of Circulatory Assist Clinicians (ICCAC), and the Society for Transplant Social Workers (STSW) has provided some guidance on patient selection, naming adherence, mental health history, and substance use history as risk factors for poor outcomes for heart transplant or LVAD recipients.[5] The recommendations for the psychosocial evaluation are based on the need to assess for risk factors that may predict post-transplantation and post-LVAD implantation outcomes; obtain information related to a patient's decision-making capacity regarding transplant or LVAD implant; obtain information about personal, social, and environmental characteristics that could reduce the impact of how their psychosocial risk factors affect post-transplantation and post-implantation outcomes; and specific MCS-related evaluations related to a patient's ability to operate the equipment.[5] The guidance document also suggests that the transplant and LVAD care teams should provide tools and interventions to high-risk patients in an effort to improve outcomes, but implementing and improving likelihood of candidacy of underserved populations is up to the care team at each institution.

While there are no regulations outlining the psychosocial evaluation requirements, CMS requires that transplant programs track and report their institutional outcomes which are then taken into account by CMS when determining conditions of hospital participation.[60] As Boyum et al. pointed out, herein lies an incentive for transplant centers to select low-risk patients for transplantation in order to maintain CMS coverage for their transplant program.[61]

Social Support

The ISHLT/APM/AST/ICCAC/STSW guidance document states that lack of social support is a contraindication to heart transplantation and MCS implantation.[5] Social support is considered a requirement to improve the likelihood of patient adherence to their complex medical needs. In this context, social support means that the patient has available, stable, and capable individuals to provide support for their medical care and emotional needs.[5] Social support has a particular importance for VAD patients who must adjust to a new way of life with the implanted device. The available research on social support highlights this concern. In a prospective study of heart, liver, and lung transplant candidates, lack of pretransplant social support was a predictors of post-transplant nonadherence.[62] This study also demonstrated that lack of a partner, such as a spouse or living with a stable significant other, was a predictor of graft loss between six and twelve months.[62] Not only the presence of a caregiver but the relationship of the caregiver has an effect on survival, as shown in two studies.[63,64] Mollberg et al. demonstrated that lung transplant recipients with spousal caregivers had increased rates of survival compared to patients with a sibling or adult child as a caretaker.[63] Similarly, an analysis of heart transplant recipients revealed improved 1-year and 5-year survival in married patients compared to patients with children and/or grandchildren.[64]

In a 2016 survey of thoracic transplant professionals, 85% of respondents felt that patients with higher socioeconomic status were more likely to have adequate social support compared to patients with a lower socioeconomic status, and 93% of respondents considered adequate social support to be a fair requirement.[65] These findings shed light on the inequity of the transplant evaluation process, as the current system reduces the likelihood of those with social and economic disadvantages becoming eligible for heart transplant or LVAD.

Economic Factors

The use of insurance coverage as a requirement for transplantation and LVAD has been controversial, and many transplant professionals believe it should not be used to determine eligibility.[26,66] Even though the World Health Organization states in their Guiding Principles on Human Cell, Tissue and Organ Transplantation that organ allocation should not be based on financial circumstances,[67] few patients that are underinsured or without insurance receive a transplant[7] or even undergo an evaluation.[26] Specifically, public insurance has shown to be associated with reduced access to advanced therapies. A single center review of advanced therapy evaluations indicated that patients with Medicare or Medicaid were less likely to be eligible for a transplant when compared to privately insured patients.[8] An analysis of the nationwide inpatient sample demonstrated the private insured to have the highest rate of utilization amongst LVAD recipients.[68] One reason for reduced eligibility is that many public insurance plans only offer partial coverage and multiple Medicare coverage plans are required for eligibility at many programs.[69,70]

Less favorable outcomes among the publicly insured are well documented in the literature. A single center chart review showed that Medicaid insurance was associated with increased risk of one-year mortality in patients ineligible for AHF therapies.[8] In two separate analyses of the UNOS database, Medicare and Medicaid insurance were shown to be predictors of mortality in heart transplant recipients.[71,72] An analysis of the Scientific Registry of Transplant Recipients of heart, liver, lung, and renal recipients demonstrated that patients with Medicaid insurance had significantly lower rates of survival compared to the privately insured.[73] Patients with public insurance, and patients who transitioned from private to public insurance, have been demonstrated to have increased rates of mortality on year after heart transplantation.[74] Waitlist mortality is also worse amongst BTT LVAD patients with Medicaid coverage compared to those with private insurance.[75] Poor outcomes in patients of lower socioeconomic status may be the result of limitations in the financing of healthcare services in the United States.[5,76] Previous investigators have noted that access to follow-up care and coverage of immunosuppressive medications may contribute to higher mortality rates in the publicly insured.[71] Medicare requires a 20% copayment for immunosuppressive medications which may not be feasible in the long-term for some patients.[77] Barriers to access likely cause delays in treatment, and publicly insured patients with AHF may be evaluated for advanced therapies in a more advanced disease state compared to the privately insured. Such delays could have a direct effect on the success of transplantation or LVAD implantation.

Other socioeconomic factors have been shown to affect outcomes in patients with a heart transplant or LVAD. In an analysis of the UNOS data, Allen et al showed that a college education decreased the risk of mortality by 11% compared to patients without a college education,[71] and Wayda et al demonstrated a college education reduced mortality by 18% in a separate analysis of the UNOS data.[72] Another analysis of UNOS data showed that among heart transplant candidates, those who lived in counties with higher concentrations of household incomes greater than $75,000 had a lower risk of mortality compared to candidates living in counties with high concentrations of income below the Federal poverty line.[78] Yet another study analyzed patients from the UNOS registry, but this time calculated the Agency for Healthcare Research and Quality socioeconomic index, and found that patients within the lowest socioeconomic index quartile had an earlier and increased risk of post-transplant mortality compared to patients in each of the other quartiles.[79] In a study which assessed the self-reported financial status of patients with heart failure, those with lower financial status were more likely to experience a cardiac event in comparison to patients with a higher financial status.[80] Another study utilizing census-based socioeconomic indicators demonstrated an inverse association between cardiovascular disease mortality and education, income, and occupation amongst patients in the National Longitudinal Mortality Study.[81] Among middle-aged, healthy study participants with higher than average socioeconomic status, those that were unemployed were more likely to have a cardiovascular event.[82] While employment status has been used as a predictor of poor health and mortality, it is possible that those with poor health are more likely to become unemployed.[83] Lower household income has also been shown to be associated with rejection for heart transplant candidacy.[50]

Due to the insufficient coverage for heart and transplantation and LVAD implantation by the country's healthcare system, some have argued that the financial burden and hardships placed on recipients and caregivers may be too much for some patients and should be avoided.[66] The ethical consequences of such a decision must be considered. Denying organs based on financial eligibility has moral implications, as it is unjust that the uninsured can donate organs but may be unable to receive an organ if they are in need of a transplant.[26,84] A survey of transplant professionals from 2013 revealed that only 6% of transplant programs participate in fundraising efforts for patients with insufficient resources.[7] However, it is likely that socioeconomic status, specifically public insurance, is a surrogate for other personal and environmental characteristics that affect a patient's disease trajectory and outcomes.

Substance Abuse

Substance abuse is another contraindication for transplant and LVAD implantation due to concerns with patient compliance with the medical regimen resulting in poor patient outcomes. Substance use has been shown to be associated with non-compliance and adverse outcomes in heart transplant recipients.[85] For substance use such as tobacco, alcohol, and marijuana, each transplant program develops their own criteria for the risk associated with eligibility, while illicit drugs are absolute contraindications. Transplant programs often require a period of sobriety before candidacy for advanced therapies in order to reduce the likelihood of relapse in the post-transplant period.

Previous research has shown that substance use and abuse is associated with poor outcomes in heart failure patients. A single center, retrospective review found that smoking was associated with an increased risk of one-year mortality among LVAD recipients who were smokers at the time of admission for LVAD implant.[86] An analysis of the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) registry revealed that 1,941 (12.6%) of 15,403 LVAD recipients had substance abuse (either alcohol abuse or drug use) listed as a psychosocial risk factor.[87] Both alcohol abuse and drug use were associated with device-related infection and hospital readmission, while only drug use was associated with device thrombosis and only alcohol use was associated with gastrointestinal bleeding.[87]

Due to differing attitudes and regional differences in legality, marijuana use may or may not be prohibitory to eligibility by transplant centers. In some states, laws have been passed to protect patients bring denied a transplant based on medical marijuana use,[88] but opinions regarding marijuana use and eligibility vary widely in the transplant community with some believing there is not enough research available to understand the risks involved.[89] Of transplant professionals surveyed in 2015, 64.4% felt that legal marijuana use should be allowed in transplant candidates, but 65.7% of respondents considered marijuana to be physically harmful.[90] A 2016 survey of the American Society of Transplantation members revealed that most (72%) respondents were concerned about the association between fungal complications and marijuana use, although less than half of those respondents reported observing fungal infections that they considered attributable to marijuana use.[91] Other possible adverse effects of marijuana use that are of concern include drug-drug interactions, pulmonary disease, cardiovascular disease, renal disease, gastrointestinal disease, addiction, and neuropsychiatric disease, although there is limited clinical data available on how marijuana use affects outcomes in organ transplantation.[92]

Variability between transplant program in the philosophical approach to substance use eligibility for advanced therapies is problematic. Such variability creates disparities in access to an inherently limited resource and therefore calls for a universal standard defining substance abuse, expectations of abstinence, testing standards, and action plans for patients have been made.[89] It has been speculated that patients with a history of substance use and/or abuse may not be viewed as favorably as patients with other behaviors such as sedentary lifestyle, morbid obesity, poor dietary choices, non-adherence, and altered mental status.[92] Improving candidacy of patients who have a substance use or abuse history is important, as these patients are able to contribute to the organ donor pool but may be unable to receive a transplant if medically needed. Uniform practices for assessment and treatment of patients with substance use which prevents them from advanced therapy eligibility could improve equity for such patients across all transplant programs.

Depression and Mental Illness

Uncontrolled psychiatric conditions that affect medical adherence are a contraindication to heart transplantation and LVAD implantation.[5] Therefore, the psychosocial assessment is important for understanding a patient’s mental health history as well as previous and current treatments. Understanding risk factors is essential for offering appropriate treatments to potential candidates who are medically eligible for AHF treatments.

The available evidence on research examining patients with AHF patients and mental health diagnoses show less than ideal outcomes.[93–95] Previous research has shown depression to be associated with poor health outcomes post-transplantation, with a prospective study revealing patients with depression and social isolation at the time of listing had lower post-transplant survival compared to patients without depression and social isolation at time of listing.[93] A single center analysis of psychosocial risk factors demonstrate that current depression disorder and history of a suicide attempt were predictors of shorter survival time in heart transplant recipeints.[94] In a meta-analysis, Dew et al. found a 65% increase in mortality risk among patients with diagnosed depression.[95]

However, not all heart transplant recipients with depression have poor outcomes. In a single center retrospective review, Delibasic et al. found that patients with depression had similar survival rates, number of organ rejections, and compliance with outpatient appoints compared to patients without depression.[96] The patients with depression had a higher number of hospitalizations post-transplant as well as a higher number of admissions due to infection. Another single center study showed no difference in survival, time to first hospitalization, and rejection rates between patients diagnosed with depression and those without depression.[97] All patients with depression were treated with antidepressant medications or psychotherapy before or within of year of transplantation. Transplant recipients at the Veterans Health Administration (VHA) who had severe mental illness did not have increased mortality or post-transplant complications compared to patients with other mental illness or without mental illness.[98] The mental health services offered at the VHA may contribute to the post-transplant outcomes.

Further, in their review of the effect of affective and psychotic disorders on transplant eligibility, Cahn-Fuller and Parent[99] describe published reports of patients with psychotic disorders including schizophrenia who have had successful transplants.[100–102] As Cahn-Fuller and Parent summarized, the positive outcomes were likely due to the extensive, individualized psychiatric care that these patients received. Further, differences in candidate selection criteria and the heterogenous psychiatric population make comparisons between practices at different transplant programs difficult. Therefore, generalizations about psychiatric illness and success after transplantation cannot be made.

While there is not enough research to confirm transplantation is appropriate in patients with psychiatric disorders, there is not enough evidence to prohibit patients from AHF therapies based on psychiatric conditions. As stated by Cahn-Fuller and Parent, post-transplant outcomes are likely the result of multiple factors in addition to psychiatric illness, including inadequate social support and medical noncompliance, and selection processes that exclude psychiatric patients are unjust.[99] The authors of that review suggested that the assessment of noncompliance is more important than presence of psychiatric illness and call for future research identifying risk factors of noncompliance. The variability in outcomes post-transplant demonstrate the need for interventions early in the heart failure disease trajectory.

Cognitive behavior therapy (CBT) interventions showed promising results in a prospective randomized controlled study including patients who had a heart failure diagnosis, a current major depressive episode, and a depressed score on the Beck Depression Inventory.[103] Patients were randomized into groups that received CBT or usual care, and those in the CBT arm had lower score for depression at six months, in addition to improved scores for anxiety, heart failure-related quality of life, mental health-related quality of life, fatigue, and social functioning.[103] These findings emphasize that psychiatric diagnosis alone should not be prohibitive to transplantation, and interventions should be offered to those who may be eligible but require additional support.

Gender-Related Factors

Of the over 6.2 million Americans with heart failure, over half are women.[18] Research has demonstrated that heart disease manifests differently based on sex, with different symptoms, including more complex and multifactorial signs in women than in men.[104] Complex factors are involved, but one reason is that the presence of estrogen acts as a protective factor against heart disease.[105] Current research indicates that in general, women with heart failure have better survival than men with heart failure.[45] Men are more likely to experience a cardiovascular-related cause of death than women.[106,107]

At the advent of LVAD use, women were rarely enrolled in clinical trials because early versions of LVADs were too large for many female bodies.[22,108,109] LVAD recipients tend to be younger and male compared to heart failure patients without an LVAD.[68] A review of the UNOS database found that while LVAD use in women has increased over the years, the rate of LVAD at listing remains significantly less in females (4.3% in 2008 and 18.9% in 2017) compared to males (5.0% in 2008 and 29.9% in 2017) ($p<0.001$).[110] LVAD use in males may be reflected by the conventional use of LVADs in men due to larger body size, despite the decrease in LVAD size over the years.[22,68] The available data suggests that there is no difference in survival rate after LVAD implantation between men and women,[111,112] but women had greater risk of first neurological event,[112] longer length of stay, and higher incidence of right-heart failure, renal, and respiratory dysfunction.[111] The differences in adverse events may be due to the fact that women are referred for AHF therapies when their heart failure is at a more advanced disease state.[109]

Women receive heart transplants less frequently than men, with 28.4% of the available hearts going to women and 71.6% going to men in 2017.[2] Heart transplantation in women has increased over the years, with women accounting for 19.7% of the total heart transplantations occurring in the years 1992-2000 and 23.7% in the years 2006-2011.[113] However, women are more likely than men to refuse a heart transplant after they were determined eligible candidates.[50] These findings suggested that patient choice, rather than physician bias, was the reason behind fewer women receiving heart transplants.

Influence of Race and Ethnicity

The federal government has classified race into 5 categories (American Indian or Alaska Native, Asian, black or African America, Native Hawaiian or Other Pacific Islander, and white) and ethnicity is divided into two categories (Hispanic or Latino, or not Hispanic or Latino).[114] While heart failure affects all populations, limited research is available on non-white populations. Non-white races and ethnic groups are underrepresented in clinical trials, making it difficult to understand the applicability of many research studies to non-White populations. An analysis of the nationwide inpatient sample database revealed that while the majority of LVAD recipients were white (78.5%), the rate of utilization was highest in Black patients (1.04%), compared to 0.89% in White patients.[68] However, available data shows the Black and White patients have similar outcomes after LVAD implantation.[115] White patients are more likely to be candidates for heart transplantation than non-White patients.[50] Interestingly, prospective research investigating the development of cardiovascular disease showed that Black patients were more likely to develop heart failure before the age of 50 compared to White patients.[48] While Black heart failure patients had more episodes of rejection and more hospitalizations compared to White patients, however there was no difference in mortality after heart transplantation between the two racial categories.[116]

Patients in the Hispanic ethnic group are the most affected by risk factors for heart failure, such as diabetes, being overweight or obese, atherogenic dyslipidemia, metabolic syndrome and insulin , and poorly controlled hypertension.[117] Compared to non-Hispanic whites, Hispanics have been shown to have higher rates of hospitalization and readmissions but rates of in-hospital and short-term mortality were lower.[117] The increase in hospitalizations may be the result of limited access to preventive care due to Hispanics having high rates of uninsured individuals. Language barriers may also contribute to reduced access to preventative care. A report from the Pew Research Center stated that 11% of Hispanics in the U.S. over the age of 5 (over 5.5 million individuals) did not speak English proficiently as of 2013.[118]

As discussed above, lack of trust in the medical system is another reason for the differences in access and outcomes between racial and ethnic groups. Black persons have been subjected to exploitation within the medical system, a notable example being the Tuskegee syphilis study.[53] It is therefore expected that there would be mistrust in the medical system. This mistrust has likely contributed to less black organ donors as the health care system is not viewed as equitable.[119]

Age

The lifetime risk for heart failure is high in older adults, at 20-45% for individuals 45 to 95 years old.[18] A number of age-related changes in the physiological cardiac characteristics may contribute to the increased risk of heart failure as we age, including decreased numbers and function of cardiac muscle cells, impaired regenerative functions, buildup of amyloid protein in the heart, and increased risk of hypertension.[45]

The management of heart failure in older patients is different from that in younger patients. Older adults have an increased number of comorbidities which can complicate management of their heart failure.[45] Older adults are not often treated with transplant or LVAD, and some institutions have upper age limits for transplant eligibility. Seventy years old has been the historical cut-off, but as care has improved, more patients ≥70 years old have been transplanted with good outcomes.[120] The decision between aggressive treatment for heart failure or maximizing quality of life is a decision for the individual patient. Like the other groups mentioned above, older adults are less represented in clinical trials, therefore making evidence-based practices less applicable to this group.

Age is a key factor predicting mortality in heart failure patients, likely due to increasing numbers of noncardiac comorbidities.[45] An analysis of nation-wide heart failure hospitals revealed the youngest (less than 25 years old) and oldest (over 64 years old) patients had the greatest rates of in-hospital mortality.[121] Older LVAD recipients have higher risks of complications and mortality, however older heart transplant recipients had similar rates of survival as younger recipients.[122]

Structural Barriers

A multitude of factors affect any person’s access to healthcare services, although certain barriers are considered the result of systemic biases that have existed for hundreds of years. Scientists as far back as the 1600s have contributed to the myth of White male superiority, with the publication of the first scientific article on racial classifications and has continued over the centuries.[25] The Atlantic slave trade, together with European colonization and Eurocentrism, were global events that has seemingly limitless repercussions on racial, class, and economic disparities to the present day.[123] In the American English colonies, the health system was formed on an inherently biased structure based on race and class.[25] The hierarchy against non-White persons, immigrants, and women in the scientific and medical arenas persisted into the 20th century with those populations being excluded or marginalized by the healthcare systems. The move toward desegregation in healthcare culminated with the Civil Rights Act of 1964[124] but this did not end discrimination. Racial, ethnic, gender, and class-based biases and inequities have prevented minorities from accumulating wealth, inhibited access to care, and created gaps in health status and outcomes. These divides have been promoted by limitations in government funding for Medicare and Medicaid.

Unraveling healthcare discrimination from the disproportionate poverty levels[125] and uninsured rates[46] in racial and ethnic minorities is difficult if not impossible. Income rates as of 2019 for Black households was 60% of that of White households, and Hispanic households had an income rate 74% of that of White households.[125] As stated in the 2008 documentary, Unnatural Causes, wealth equals health.[126] The two are inextricably linked in the United States, with income affecting access to housing, neighborhoods, employment, transportation, childcare, schools, and hospitals. The disparities will be passed to the next generation, with even wider income inequality and less opportunity for mobility in future generations, a phenomenon called The Great Gatsby Curve.[127] While accounting for systemic inequality is outside of the scope of this research, it is important to keep in mind the factors influencing the current inequities in access to healthcare services.

Ethics

In the United States, organ allocation is based on algorithms determined by UNOS policy-making practices.[128] The allocation algorithms take into account efficiency and equity, which are required for organ distribution by Federal law.[4] These two terms are equivalent to the ethical principles of utility and justice.[84] When it comes to organ allocation, utility is commonly thought of as medical benefit and refers to allocation practices that maximize the benefit to patient as well as the whole community while also reducing harms.[129] Therefore in this case, utility combines the principles of beneficence and nonmaleficence. OPTN considers the principle of justice, defined as the fair distribution of benefits and burdens, to be equally important to the principle of utility in organ allocation.[129] While donated organs should be allocated to maximize overall good, ethicists such as Robert M. Veatch and Lainie F. Ross argue that when it comes to scarce resource allocation, justice has moral authority over utility.[84] According to Veatch and Ross, just and morally correct distribution follows a pattern of equal access. A notable interpretation of the principle of justice has been made by John Rawls,[130] whose egalitarian view of justice allows for a redistribution of goods to maximize the potential advantage for the most disadvantaged persons. This view avoids making distributive decisions based on arbitrary characteristics, such as social or economic advantage, accident of birth, or natural talents.[131] The equitable, or just, distribution of goods to promote the maximum advantage for the worst-off persons is distinct from the equal distribution of goods. Therefore, equitable distribution requires that we account for the principle of justice.

Since equity in allocation is agreed upon for the distribution of both transplant and LVAD AHF services, the current research theorizes that the concept of justice should be just as important in the distribution of healthcare services before a patient is ever evaluated for AHF therapies. The UNOS and OPTN policies, which are required to be efficient and equitable, only apply to patients that are determined to be eligible for transplantation. However, if a patient never has the opportunity to be evaluated by an AHF specialist, or even be referred for an appointment, inequity in allocation is already present before allocation ever occurs. Therefore, in order to improve disparities in the health, the practices leading up to heart transplant candidacy must also be equitable.

The structural barriers described above contribute to the disadvantage of certain populations, such as those lacking financial resources, and promote inequity in allocation. The strong association between race and poverty described above perpetuates the withholding of transplants from disadvantaged populations.[132] The current practices reveal that justice is not weighed equally in the current policies and practices promoted by UNOS and OPTN.

Another area of ethical concern is the variability in eligibility rules and evaluation practices between providers and institutions which may create inconsistent and inequitable organ allocation. There is limited information on how psychosocial evaluations vary between transplant programs, and what is available is from the early 1990s.[133,134] Unfortunately, that data is likely outdated due to being is approximately 30 years old. While it is presumed institutions are abiding by the guidelines issued by ISHLT and other organizations, there is no overarching requirement in place. Cahn-Fuller and Parent have questioned the extent to which transplant programs follow the recommendations from ISHLT and other professional associations.[99]

Disparity in treatment due to variations in rules is problematic, especially for the allocation of scarce resources. One negative impact from this variability in practices is that it encourages patients with sufficient resources to be evaluated for advanced therapy at more than one transplant center. Such “shopping” [89] for transplant programs creates disparities in access to donated organs. Further, the principle of justice is abandoned as these practices create an unfair advantage for patients with a higher socioeconomic status. Therefore, calls have been made for a standard set of selection criteria to avoid such variation.[99]

Reciprocity of the donor pool is an important area to consider when examining the evaluation practices leading up to the allocation of donated organs. Various groups, including psychiatric patients[99] and the uninsured,[26] contribute to the donor pool but may not be eligible should they ever medically require one. Asking a population to contribute to the donor pool when they would be considered ineligible violates the principle of justice.[26] These populations deserve access to organs when in need and there is a moral obligation to fairly consider these populations if they are in need of an organ. Donated organs are a public resource, and altruistic organ donors expect that organs will be distributed equitably.[26]

While inequities exist throughout the healthcare system, the need for a just assessment of heart failure patients at each step in the evaluation process is amplified when looking through the lens of organ scarcity. The proposed research argues that since practices surrounding the distribution of donor hearts must be just, so should the evaluations process of patients who one day may need the services of an AHF team. Judgments about a patient's social worth should be avoided.[99]

Summary

For some patients with AHF, the only medical option is a life-saving heart transplant or LVAD. A patient with AHF must go through an extensive evaluation process in order to be determined eligible for such advanced therapies. Demographic, social, and economic factors all play a role in that determination process. When these factors play a role in the eligibility for AHF therapies, healthcare resources are not distributed equitably. While some of the factors playing a role in eligibility have been researched, there are likely unseen factors beyond the scope of this research that also contribute and have not been properly captured and analyzed. Understanding whether certain factors affect a patient's ability to receive services earlier in their disease trajectory, just after they display heart failure symptoms and receive a diagnosis, is the basis of the proposed research.

CHAPTER III

METHODOLOGY

Approach

This is a retrospective chart review of electronic medical records (EMR) available at a large, Midwest hospital system over a four-year period. This study investigated how demographic, social, and economic factors influence the referral of patients for advanced heart failure services and whether those factors affect if patients are seen in the heart failure clinic. The study also assessed if those factors affect the length of time between diagnosis and referral, clinic visit, treatment, and/or death.

Study Population

Adult patients from one large, Midwest hospital system who were diagnosed with heart failure by a provider in the inpatient or outpatient setting, were eligible for this retrospective chart review. Patients were identified by the presence of heart failure diagnosis codes from the 10th edition of the International Classification of Diseases (ICD-10) in the hospital system's EMR. Patients with ICD-10 codes for heart failure (I42.8 [Other cardiomyopathies], I50.20 [Unspecified systolic heart failure], I50.22 [Chronic systolic heart failure], I50.23 [Acute on chronic systolic heart failure], I50.33 [Acute on chronic diastolic heart failure], I50.42 [Chronic combined systolic and diastolic heart failure], and I50.43 [Acute on chronic combined systolic and diastolic heart failure]) between the dates of November 1, 2017 through December 31, 2021 were included in the study. This time frame was chosen to align with the switch of EMR to Epic[135] at our hospital system in November 2017, and the end date aligns with the approximate date of IRB approval. Patient identifiers were not collected except for dates of service.

Therefore, this study received a waiver of patient consent as well as a HIPAA waiver due to the non-human subjects determination by the Spectrum Health Institutional Review Board (#2022-034) and the Western Michigan University Institutional Review Board (#2022-096).

Study Design

Demographic, social, and economic data was retrieved by retrospective chart review. To comply with Spectrum Health research guidelines, data was pulled from the EMR by a specified Spectrum Health Office of Research employee, called the honest broker. “Honest broker” is a term used by the Office for Human Research Protections, within the U.S. Department of Health and Human Services, and is defined as a neutral intermediary person or system that collects patient information, replaces the identifiers with a code, and then releases only coded information to the researcher.[136] The Spectrum Health honest broker has specific access to the institutional data warehouse, containing all patient medical record data from the EMR software, Epic. The honest broker fulfilled the data acquisition from this retrospective review by retrieving the requested data from the data warehouse, removing all identifiers except dates of service, and saving in password-protected Microsoft Excel files. The Microsoft Excel files were shared with the investigator who completed the data cleaning and statistical analysis.

The independent variables selected for this study were based on the above literature review and specific research questions. Social history and social determinants of health information (such as employment status, number of children, years of education, highest education level, alcohol use, drug use, financial resource strain, food insecurity, lack of transportation [medical or non-medical], physical activity, stress, social connections, depression, and housing stability) collected from patients either at their primary care office or in the inpatient setting should be entered into the EMR; however according to preliminary data queries by an honest broker, the data for these fields is rarely entered. Smoking status was the only variable from the social determinants of health documentation that was sufficiently available to include in this study.

Independent variables collected from the Demographic section of the EMR include age, sex, race, preferred language, and marital status. As stated above, smoking status was collected from the social history and social determinants of health sections of the EMR. Type of insurance was obtained from the EMR documentation. The above variables were captured at the time of heart failure diagnosis. The categories of some variables had to be combined due to small sample sizes and to reduce the risk of identification. For the variable, marital status, the categories married and significant other were combined into one group, and the categories divorced, legally separated, single, widowed were combined into one "unmarried" group, and patients with unknown marital status were marked as missing. The category, "Other", in the race/ethnicity variable, included such categories as American Indian, Alaskan Native, Asian Indian, Asian or Pacific Islander, Asian not Hispanic, Chinese, Filipino, Japanese, Multiracial, native Hawaiian, and Other. The "patient refused/unreported" patients were marked as missing. Preferred language was categorized into English and non-English language. The category, current smoker, included patients recorded as current cigarette, cigar, and/or pipe smokers in the EMR, while non-smokers included both never-smokers and former smokers. Public insurance included both Medicare and Medicaid.

The dependent variables, referral AHF specialist, clinic visit with AHF specialist, heart transplantation, LVAD implantation, 1 year mortality, and in-house mortality (post heart transplant or LVAD) were obtained by electronic abstraction by the honest broker. Dates of diagnosis, referral, first clinic visit, heart transplantation, and LVAD implantation required for the survival analysis were all be electronically abstracted from the EMR.

Analytical Framework

A total of 24,258 patients diagnosed with heart failure from one Midwest hospital system were included in this research. Independent variables include age, sex, race, preferred language, marital status, smoking status, and insurance type. Dependent variables include referral to advanced heart failure services, clinic visit with advanced heart failure specialist, treatment by either heart transplantation or LVAD, and mortality (1-year mortality post-diagnosis; 1-year mortality post-treatment; or mortality during hospital stay of heart transplant or LVAD implantation). For all analyses, values of $p \leq 0.05$ were considered statistically significant for all tests. The ANOVA, Chi Square, and Cox proportional hazards analyses were conducted in SPSS and the Logistic Regression was performed in R for SPSS.[137]

The following research questions will be investigated by statistical analysis: 1.) Do patients who were diagnosed with heart failure and referred for AHF services differ from patients diagnosed with heart failure and were not referred with regards to demographic, social, and economic factors; 2.) Do patients who were referred and had a clinic visit with an AHF specialist differ from patients referred but did not have a clinic visit with regards to demographic, social, and economic factors; 3.) Do patients who had a clinic visit and received AHF treatment (transplant and LVAD) differ from patients who had a clinic visit and did not receive AHF treatment? and 4.) Does the length of time from diagnosis to referral, diagnosis to clinic visit, diagnosis to treatment, and/or diagnosis to death differ based on demographic, social, and economic variables?

Statistical Analysis Plan

1.) Research Question One
    a. Independent Variable(s)
        i. Patients who were referred visit will be compared to the patients who did were not referred based on age, sex, race, preferred language, marital status, smoking status, and insurance type
    b. Dependent Variable
        i. Referral to advanced heart failure clinic

ANOVA will be used for the continuous variable, age

Chi Squared test will be used for categorical variables: sex, race, preferred language, marital status, smoking status, and insurance type

2.) Research Question Two:
    a. Independent Variable(s)
        i. Patients who had a clinic visit will be compared to the patients who did not have a clinic visit based on age, sex, race, preferred language, marital status, smoking status, and insurance type
    b. Dependent Variables
        i. Clinic visit with advanced heart failure specialist

ANOVA will be used for the continuous variable, age

Chi squared test will be used for categorical variables: sex, race, preferred language, marital status, smoking status, and insurance type

3.) Research Question Three:
    a. Independent Variable(s)

        i. Patients who received advanced heart failure treatment (transplant and LVAD) will be compared to the patients who did not receive treatment based on age, sex, race, preferred language, marital status, smoking status, and insurance type

    b. Dependent Variables

        i. Advanced heart failure treatment (either heart transplant or LVAD)

        ii. Heart transplantation only

        iii. LVAD implantation only

    ANOVA will be used for the continuous variable, age

    Chi squared test will be used for categorical variables: sex, race, preferred language, marital status, smoking status, and insurance type

4.) Research Question Four:

    a. Time to event analysis: A Cox proportional hazards model will be used for the time to event analysis. Hazard ratios with 95% confidence intervals will be reported.

        i. Independent variables:

            1. A sensitivity analysis[138] will be included in Research Question 4. The sensitivity analysis (as follows) will reveal if there are hidden suppressor variables that did not show up as significant in Research Questions 1-3 or if there is no or little influence on the conclusions of Research Questions 1-3, which would provide more robust conclusions.

            a. First, only the independent variables that were found to be significant in Research Question 1, 2, and 3 will be examined evaluated by Cox proportional hazards model.
            b. Next, all independent variables (age, sex, race, preferred language, marital status, smoking status, and insurance type) will be assessed in a Cox proportional hazards model.
    ii. Dependent variables
        1. Survival analysis will be used to evaluate:
            a. time from diagnosis to referral
            b. time from diagnosis to clinic visit
            c. time from diagnosis to advanced heart failure treatment

b. Mortality
    i. Independent Variables
        1. A sensitivity analysis will be done similarly as described in Research Question 4. First, only the independent variables that were found to be significant in Research Question 1, 2, and 3 will be examined by Logistic Regression
        2. Next, all independent variables ((age, sex, race, preferred language, marital status, smoking status, and insurance type) will be assessed by Logistic regression.

a. Death within one year post heart failure diagnosis (yes/no)
b. Death before discharge from heart transplant or LVAD implant hospital stay (yes/no)
c. Death within 1 year of heart transplant or LVAD implant (yes/no)

CHAPTER IV

RESULTS

There were 24,258 patients diagnosed with heart failure included in the analysis (Figure 1). The mean age was 71.47 and ages ranged from 18 to 106 years old (Table 1). Patients were mostly male (58.7%), married (51.5%), White (88.1%), had preferred language listed as English (98.6%), and had public insurance coverage (81.2%). Of the 7,238 patients with smoking data available, 1982 (8.2%) were current smokers at the time of diagnosis. Of the patients diagnosed with heart failure, 617 (2.5%) had a date of referral to see a heart failure specialist documented in the EMR.

Referral

A total of 617 patients received an AHF referral. Research question 1 compared the independent variables between the referral group and non-referral group (Table 2). The ANOVA analysis revealed that patients referred to an advanced heart failure specialist were younger than patients who were not referred (mean age 57.84 vs 71.83, $p<0.001$). Over twice as many men were referred, with 3.2% of the men and 1.5% of the women with heart failure having a referral ($p<0.001$). Married patients were more likely to be referred than the unmarried patients (2.9% vs. 2.1% respectively, $p<0.001$). Race was significantly associated with referral ($p<0.001$), with White (2.3%) and Hispanic/Latino patients (2.4%) showing less referrals than Black patients (4.3%) or patients in Other racial categories (4.8%). There was no difference in referral based on preferred language ($p<0.828$) or smoking status ($p=0.057$). Insurance category was associated with referral ($p<0.001$), with the most referred category being the publicly insured, followed by

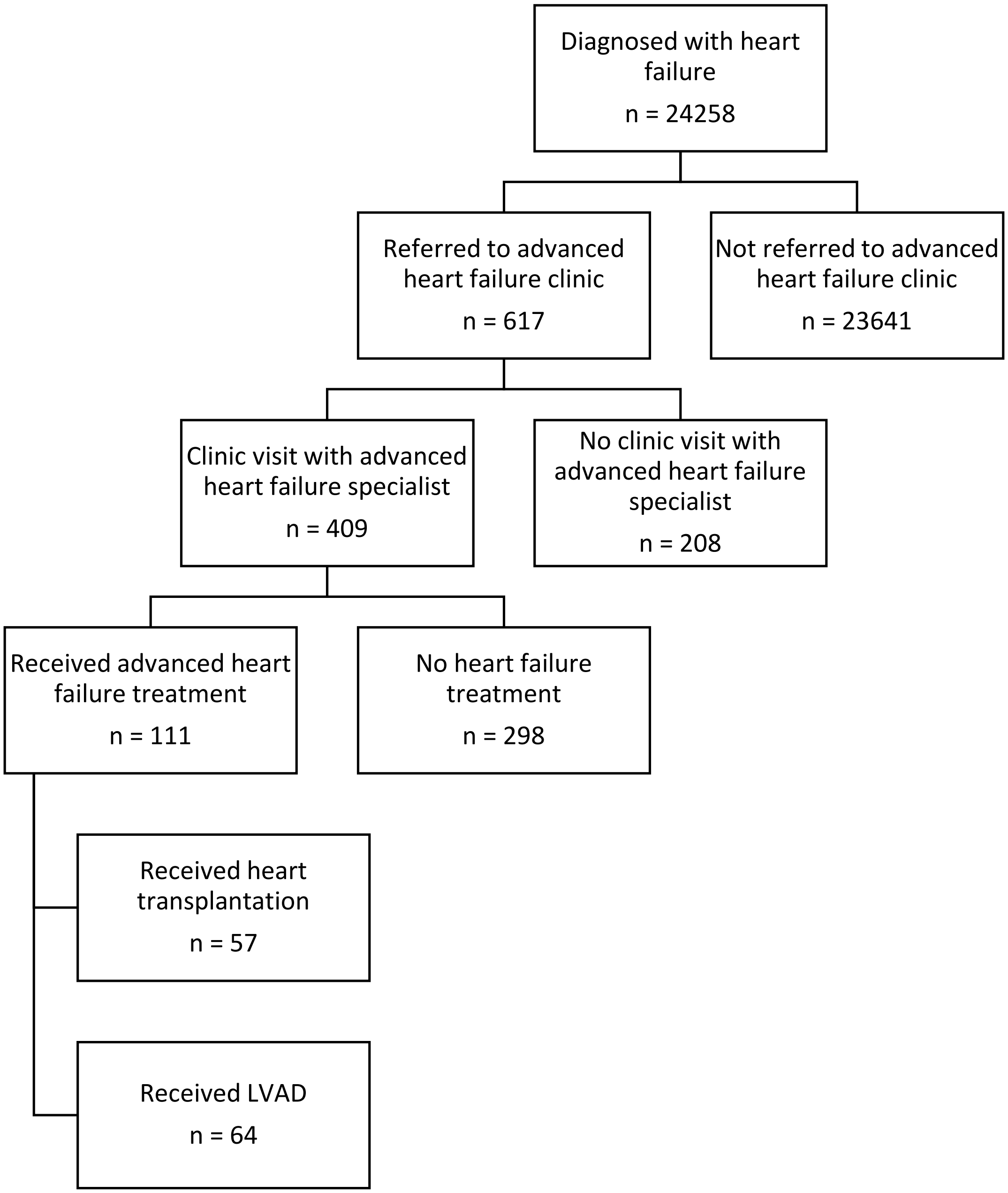

Figure 1. Flowchart of patients diagnosed with heart failure

privately insured, then self-pay (Table 2). Since zero of the 7 patients in the Other insurance category were referred, this category was removed from the analysis.

Table 1. Summary of baseline characteristics for all patients diagnosed with heart failure

Variable	**Category**	**Mean ± Std dev. or N (%)**
Age (years)		71.47 ± 14.244 Min – Max 18 - 106
Sex	Female	10019 (41.3)
	Male	14239 (58.7)
Marital Status	Divorced	2962 (12.2)
	Married	12483 (51.5)
	Other/Unknown	289 (1.2)
	Single	3386 (14.0)
	Widowed	5138 (21.2)
Race/ethnicity	Black or African American	1573 (6.5)
	Hispanic/Latino	546 (2.3)
	Other	400 (1.6)
	Patient refused/not reported	379 (1.6)
	White or Caucasian, not Hispanic	21360 (88.1)
Preferred Language	English	23925 (98.6)
	Other/Unknown	333 (1.4)
Current smoker	Yes	1982 (8.2)
	No	5256 (21.7)
	Unknown	17020 (70.2)
Insurance	Other	7 (0.001)
	Private	3977 (16.4)
	Public	19703 (81.2)
	Self-pay	571 (2.4)

A Cox proportional hazards model (Research question 4a) compared the interval from diagnosis to referral for the variables that were significant in the ANOVA and Chi square analyses above. The overall model showed significance; at least one independent variable was predictive of referral (Table 3). Age showed a B coefficient of -0.62 and Exp(B) of 0.940, meaning each year a person ages, there is 6% less likelihood of them being referred for treatment (95%CI [0.934, 0.946]). The model revealed men were over 200% as likely as women to be referred (B coefficient = 0.772; HR 2.165 [95% CI 1.746, 2.686]). Unmarried patients were less than half as likely to be referred (B coefficient = -0.451; HR 0.637 [0.523, 0.776]) and the

Table 2. Patients referred to an advanced heart failure specialist compared to patients not referred

Variable	**Category**	**Referred** Mean ± Std. Dev. or N (%)	**Not referred** Mean ± Std. Dev. or N (%)	**p value**
Age		57.84 ± 12.448	71.83 ± 14.113	< 0.001
Sex	Female	155 (1.5)	9864 (98.5)	< 0.001
	Male	462 (3.2)	13777 (96.8)	
Marital Status	Married/Significant other	367 (2.9)	12116 (97.1)	< 0.001
	Divorced/Legally Separated/Single/Widowed	236 (2.1)	97.9 (23366)	
Race/ethnicity	Black or African American	67 (4.3)	1506 (95.7)	< 0.001
	Hispanic/Latino	13 (2.4)	533 (97.6)	
	Other	19 (4.8)	381 (95.3)	
	White or Caucasian, not Hispanic	496 (2.3)	20864 (97.7)	
Preferred Language	English	608 (2.5)	23317 (97.5)	0.828
	Spanish	4 (2.2)	175 (97.8)	
	Other/Unknown	5 (3.2)	149 (96.8)	
Current smoker	Yes	56 (2.8)	1926 (97.2)	0.057
	No	197 (3.7)	5059 (96.3)	
Insurance	Private	164 (4.1)	3813 (95.9)	< 0.001
	Public	437 (2.2)	19266 (97.8)	
	Self-pay	16 (2.8)	555 (97.2)	

publicly insured were nearly 30% more likely to be referred than the privately insured (B coefficient = 0.261; HR 1.298 [95% CI 1.038, 1.623]).

In the sensitivity analysis including all independent variables, the overall model was once again significant. In this model, younger age (B coefficient = -0.68; HR 0.934 [95% CI 0.925, 0.943]), male sex (B coefficient = 0.796; HR 2.216 [95% CI 1.544, 3.181]), and married status ([Reference variable Unmarried] B coefficient = -.408; HR 0.665 [95%CI 0.488, 0.905]) were contributing to referral. This model additionally revealed that current smokers were half as likely (B coefficient = -0.599; HR 0.549 [95% CI 0.389, 0.776]) to be referred (Table 3).

Table 3. Time from diagnoses to referral assessed by Cox proportional hazards model

Variable Name	**B**	**SE**	**P value**	**Exp (B)**	**95% CI Lower**	**95% CI Upper**
Cox regression including variables significant in ANOVA and Chi square analyses						
Overall Omnibus Tests of Model Coefficients	Chi square score 559.651		<.001			
Age	-.062	.003	<.001	.940	.934	.946
Sex (Male)	.772	.110	<.001	2.165	1.746	2.686
Marital Status (Unmarried)	-.451	.100	<.001	.637	.523	.776
Race (White)			.360			
Race (Black/African American)	.045	.149	.763	1.046	.781	1.401
Race (Hispanic/Latino)	-.556	.322	.084	.574	.305	1.078
Race (Other)	.043	.266	.870	1.044	.620	1.760
Insurance Status (Private)			.073			
Insurance Status (Public)	.261	.114	.022	1.298	1.038	1.623
Insurance Status (Self-Pay)	.179	.283	.528	1.196	.686	2.084
Cox regression sensitivity analysis including all independent variables						
Overall Omnibus Tests of Model Coefficients	Chi square score 222.488		<.001			
Age	-.068	.005	<.001	.934	.925	.943
Sex (Male)	.796	.184	<.001	2.216	1.544	3.181
Marital Status (Unmarried)	-.408	.158	.010	.665	.488	.905
Race (White)			.386			
Race (Black/African American)	.048	.240	.841	1.049	.655	1.681
Race (Hispanic/Latino)	-.930	.720	.196	.395	.096	1.618
Race (Other)	.386	.359	.282	1.471	.728	2.970
Preferred Language (English)	.467	1.037	.653	1.594	.209	12.174
Smoking Status (Current)	-.599	.176	<.001	.549	.389	.776
Insurance Status (Private)			.081			
Insurance Status (Public)	.312	.191	.103	1.366	.939	1.985
Insurance Status (Self-Pay)	-.852	.727	.241	.427	.103	1.774

Clinic Visit with Advanced Heart Failure Specialist

As assessed in Research Question 2, 409 of the referred patients had a clinic visit with an advanced heart failure specialist. A Chi Square test demonstrated that 70.3% of married patients had a clinic visit with an advanced heart failure specialist while 61.4% of unmarried patients had a clinic visit (p=0.024, Table 4). Smoking was also associated with having a clinic visit, with a higher proportion of non-smokers being seen by a specialist (70.0%) compared to the proportion of smokers (55.4%, p=0.39). Age, sex, race/ethnicity preferred language, and insurance status were not associated with having a clinic visit (Table 4).

Table 4. Patients with a clinic visit compared to patients without a clinic visit

Variable	**Category**	**Clinic visit** Mean ± Std. Dev. or N (%)	**No clinic visit** Mean ± Std. Dev. or N (%)	**p value**
Age		57.49 ± 12.591	58.52 ± 12.163	0.332
Sex	Female	104 (67.1)	51 (32.9)	0.806
	Male	305 (66.0)	157 (34.0)	
Marital Status	Married	258 (70.3)	109 (29.7)	0.024
	Divorced/Legally Separated/Single/Widowed	145 (61.4)	91 (38.6)	
Race/ethnicity	Black or African American	44 (65.7)	23 (34.3)	0.091
	Hispanic/Latino	10 (76.9)	3 (23.1)	
	Other	8 (42.1)	11 (57.9)	
	White or Caucasian, not Hispanic	340 (68.5)	156 (31.5)	
Preferred Language	English	403 (66.3)	205 (33.7)	0.981
	Other/Unknown	6 (66.7)	3 (33.3)	
Current smoker	Yes	31 (55.4)	25 (44.6)	0.039
	No	138 (70.0)	59 (30.0)	
Insurance	Private	107 (65.2)	57 (34.8)	0.338
	Public	294 (67.3)	143 (32.7)	
	Self-pay	8 (50.0)	8 (50.0)	

A Cox proportional hazards model (Research Question 4a) assessed time from diagnosis to clinic visit for the variables which were significant in the above Chi Square analysis assessing patients receiving a clinic visit versus those who did not. Marital status (B coefficient -0.179; HR 0.836 [95% CI 0.597, 1.172]) and smoking status (B coefficient = -0.272; HR 0.762 [95% CI 0.506, 1.146]) showed no association with clinic visit (Table 5). When all independent variables were included in the sensitivity analysis, the overall model did not show significance (Table 5). However, younger age was shown to contribute to patients receiving a clinic visit (B coefficient = -0.20; HR 0.981 [95% CI 0.966, 0.995]). The hazard ratio of 0.981 predicts that with each year of age, there is a 2% less chance of having a clinic visit.

Advanced Heart Failure Therapies

For Research Question 3, patients that had a clinic visit were evaluated for whether or not they received advanced heart failure therapies such as heart transplantation of LVAD. When the treatment category was combined with both heart transplant and LVAD recipients (n = 111), the ANOVA and Chi square analyses showed no difference in any of the independent variables between who received a treatment and who did not receive a treatment (not shown). The Cox proportional hazards model assessing time from diagnosis to either treatment included all independent variables as none were significant in the ANOVA and Chi square analysis above. The overall model showed significance and at least one independent variable was predictive of treatment. Age and Hispanic/Latino ethnicity both contributed to patients receiving a heart failure treatment, with each year of age decreasing likelihood of treatment by 4% (B coefficient = -0.041; HR 0.960 [95% CI 0.929, 0.991]) and Hispanic/Latino patients were more likely to receive treatment that White patients (B coefficient = 2.161; HR 8.682 [1.475, 51.09]) (Table 6).

Table 5. Time from diagnosis to clinic visit assessed by Cox proportional hazards model

Variable Name	**B**	**SE**	**P value**	**Exp (B)**	**95% CI Lower**	**95% CI Upper**
Cox regression including variables significant in ANOVA and Chi square analyses						
Overall Omnibus Tests of Model Coefficients	Chi square score 2.674		.263			
Marital Status (Unmarried)	-.179	.172	.298	.836	.597	1.172
Smoking Status (Current)	-.272	.208	.192	.762	.506	1.146
Cox regression sensitivity analysis including all independent variables						
Overall Omnibus Tests of Model Coefficients	Chi square score 16.559		.085			
Age	-.020	.008	.010	.981	.966	.995
Sex (Male)	.256	.220	.244	1.292	.839	1.988
Marital Status (Unmarried)	-.185	.189	.328	.831	.573	1.204
Race (White)			.173			
Race (Black/African American)	-.455	.283	.108	.634	.364	1.105
Race (Hispanic/Latino)	.944	.788	.231	2.571	.548	12.057
Race (Other)	-.421	.486	.386	.656	.253	1.701
Preferred Language (English)	.684	1.134	.546	1.982	.215	18.305
Smoking Status (Current)	-.268	.213	.208	.765	.504	1.161
Insurance Status (Private)			.259			
Insurance Status (Public)	.165	.230	.474	1.179	.751	1.851
Insurance Status (Self-Pay)	.997	.615	.105	2.710	.811	9.051

When assessing heart transplant alone (n = 57), ANOVA demonstrated age was significantly associated with receiving a heart transplant, with a mean age of those receiving a heart of 53.06 and those not receiving an organ of 58.31 (p=0.002, Table 7). A higher proportion of females (23.1%) than males (13.1%) received heart transplants (p=0.016). Privately insured patients were more likely to receive a heart transplant, with a proportion of 23.4% receiving a

Table 6. Time from diagnosis to AHF treatment assessed by Cox proportional hazards model

Variable Name	**B**	**SE**	**P value**	**Exp (B)**	**95% CI Lower**	**95% CI Upper**
Cox regression sensitivity analysis including all independent variables						
Overall Omnibus Tests of Model Coefficients	Chi square score 19.581		0.033			
Age	-.041	.016	.012	.960	.929	.991
Sex (Male)	.538	.523	.303	1.712	.615	4.771
Marital Status (Unmarried)	-.004	.355	.990	.996	.497	1.996
Race (White)			.109			
Race (Black/African American)	-.308	.759	.685	.735	.166	3.255
Race (Hispanic/Latino)	2.161	.904	.017	8.682	1.475	51.090
Race (Other)	-.075	.999	.941	.928	.131	6.572
Preferred Language (English)	2.038	1.339	.128	7.675	.556	105.939
Smoking Status (Current)	-.306	.427	.474	.737	.319	1.700
Insurance Status (Private)			.425			
Insurance Status (Public)	-.571	.437	.191	.565	.240	1.329
Insurance Status (Self-Pay)	-11.987	520.808	.982	.000	.000	.

heart, while 13.3% of the publicly insured and no self-pay heart recipients (p=0.023).

Time from diagnosis to transplant alone was also assessed, and the Cox proportional hazards model was significant with at least one predictor of referral (Table 8). Age (B coefficient = -0.21; HR 0.980 [95% CI 0.961, 0.998]), White race (p=0.042), Hispanic/Latino ethnicity (B coefficient = 1.504; HR 4.501 [95% CI 1.574, 12.875]), and both public (B coefficient = -0.758; HR 0.468 [95% CI 0.270, 0.813]) and private insurance (p=0.027) were significantly influencing the outcome heart transplantation. For the heart transplantation sensitivity analysis assessing all independent variables in the Cox proportional hazards model, the model was once again

Table 7. Patients who received heart transplantation compared to patients without transplantation

Variable	**Category**	**Heart transplant** Mean ± Std. Dev. or N (%)	**No heart transplant** Mean ± Std. Dev. or N (%)	**p value**
Age		53.06 ± 13.140	58.31 ± 12.33	0.002
Sex	Female	24 (23.1)	80 (76.9)	0.016
	Male	40 (13.1)	265 (86.9)	
Marital Status	Married	43 (16.7)	215 (83.3)	0.446
	Divorced/Legally Separated/Single/Widowed	20 (13.8)	125 (86.2)	
Race/ethnicity	Black or African American	5 (11.4)	39 (88.6)	0.048
	Hispanic/Latino	4 (40.0)	6 (60.0)	
	Other	3 (37.5)	5 (62.5)	
	White or Caucasian, not Hispanic	52 (15.3)	288 (84.7)	
Preferred Language	English	66 (16.3)	340 (83.7)	0.978
	Other/Unknown	1 (16.7)	5 (83.3)	
Current cigarette smoker	Yes	2 (6.5)	29 (93.5)	0.229
	No	20 (14.5)	118 (85.5)	
Insurance	Private	25 (23.4)	82 (76.6)	0.023
	Public	39 (13.3)	255 (86.7)	
	Self-pay	0 (0)	8 (100)	

significant but only age (B coefficient = -0.058; HR 0.943 [95% CI 0.902, 0.987]), White race (p=0.011), and Hispanic/Latino ethnicity (B coefficient = 2.459; HR 11.698 [95% CI 2.191, 62.471]) were significant predictors in the model (Table 8).

When the same factors were assessed for influencing treatment with an LVAD (n=64), no variables were shown to be significantly associated with receiving or not receiving an LVAD in the ANOVA or Chi Square analyses (Table 9). In the Cox proportional hazards model assessing the outcome time to LVAD, the overall model was not significant but White race (p=0.023),

Table 8. Time from diagnoses to heart transplantation assessed by Cox proportional hazards model

Variable Name	**B**	**SE**	**P value**	**Exp (B)**	**95% CI Lower**	**95% CI Upper**
Cox regression including variables significant in ANOVA and Chi square analyses						
Overall Omnibus Tests of Model Coefficients	Chi square score 42.970		<0.001			
Age	-.021	.010	.034	.980	.961	.998
Sex (Male)	-.384	.274	.160	.681	.398	1.164
Race (White)			.042			
Race (Black/African American)	.069	.484	.886	1.072	.415	2.769
Race (Hispanic/Latino)	1.504	.536	.005	4.501	1.574	12.875
Race (Other)	.528	.647	.415	1.695	.476	6.030
Insurance Status (Private)			.027			
Insurance Status (Public)	-.758	.282	.007	.468	.270	.813
Insurance Status (Self-Pay)	-11.042	250.646	.965	.000	.000	3.586E+208
Cox regression sensitivity analysis including all independent variables						
Overall Omnibus Tests of Model Coefficients	Chi square score 28.476		.002			
Age	-.058	.023	.011	.943	.902	.987
Sex (Male)	-.233	.576	.686	.792	.256	2.451
Marital Status (Unmarried)	-.551	.543	.310	.576	.199	1.671
Race (White)			.022			
Race (Black/African American)	-.619	1.087	.569	.539	.064	4.533
Race (Hispanic/Latino)	2.459	.855	.004	11.698	2.191	62.471
Race (Other)	-1.184	1.313	.367	.306	.023	4.015
Preferred Language (English)	.211	1.219	.863	1.235	.113	13.477
Smoking Status (Current)	-1.474	.816	.071	.229	.046	1.134
Insurance Status (Private)			.831			
Insurance Status (Public)	-.333	.547	.543	.717	.245	2.096
Insurance Status (Self-Pay)	-11.666	552.491	.983	.000	.000	.

Table 9. Patients who received a LVAD compared to patients who did not receive LVAD

Variable	Category	**LVAD** Mean ± Std. Dev. or N (%)	**No LVAD** Mean ± Std. Dev. or N (%)	p value
Age		58.12 ± 12.591	57.39 ± 12.777	0.683
Sex	Female	9 (8.7)	95 (91.3)	0.072
	Male	48 (15.7)	257 (84.3)	
Marital Status	Married	37 (14.3)	221 (85.7)	0.730
	Divorced/Legally Separated/Single/Widowed	19 (13.1)	126 (86.9)	
Race/ethnicity	Black or African American	2 (4.5)	42 (95.5)	0.222
	Hispanic/Latino	9 (90.0)	1 (10.0)	
	Other	2 (25.0)	6 (75.0)	
	White or Caucasian, not Hispanic	50 (14.7)	290 (85.3)	
Preferred Language	English	57 (14.1)	346 (85.9)	0.321
	Other/Unknown	0 (0)	6 (100)	
Current smoker	Yes	6 (19.4)	25 (80.6)	0.363
	No	18 (13.0)	120 (87.0)	
Insurance	Private	14 (13.1)	93 (86.9)	0.947
	Public	42 (14.3)	252 (85.7)	
	Self-pay	1 (1.3)	7 (8.7)	

LVAD, left ventricular assist device

Hispanic/Latino ethnicity (B coefficient = 3.521; HR 33.833 [95% CI 3.207, 356.968]), and public insurance (B Coefficient = -1.396; HR 0.248 [95% CI 0.077, 0.792]) affected the likelihood of receiving a LVAD (Table 10).

Mortality

In Research Question 4b, Logistic regression analysis was performed to assess 1-year mortality from the date of diagnosis. In the initial regression model using only variables significant in the above ANOVA and Chi square analyses, increasing age and Hispanic/Latino ethnicity were associated with death within 1 year of heart failure diagnosis (Table 11). A second

Table 10. Time from diagnosis to LVAD implantation assessed by Cox proportional hazards model

Variable Name	**B**	**SE**	**P value**	**Exp (B)**	**95% CI Lower**	**95% CI Upper**
Cox regression sensitivity analysis including all independent variables						
Overall Omnibus Tests of Model Coefficients	Chi square score 14.641		.146			
Age	-.029	.023	.213	.972	.929	1.017
Sex (Male)	2.473	1.438	.085	11.862	.709	198.496
Marital Status (Unmarried)	.520	.490	.289	1.681	.644	4.392
Race (White)			.023			
Race (Black/African American)	-.069	1.071	.949	.934	.115	7.613
Race (Hispanic/Latino)	3.521	1.202	.003	33.833	3.207	356.968
Race (Other)	1.441	1.430	.313	4.227	.257	69.646
Preferred Language (English)	16.662	488.662	.973	17221536.689	.000	.
Smoking Status (Current)	.524	.540	.332	1.689	.586	4.864
Insurance Status (Private)			.063			
Insurance Status (Public)	-1.396	.593	.019	.248	.077	.792
Insurance Status (Self-Pay)	-14.828	3166.835	.996	.000	.000	.

LVAD, left ventricular assist device

logistic regression model including all independent variables from this study revealed that current smoking was an additional predictor of 1-year mortality (Table 11). Death within hospital stay for transplant and LVAD recipients, as well as mortality within one year of receiving each treatment were also assessed, and no independent variables showed significance in any of those models (not shown).

Table 11. Factors affecting 1-year mortality from date of diagnosis assessed by logistic regression

Variable Name	**Estimate**	**SE**	**Z value**	**P value**
Logistic regression including variables significant in ANOVA and Chi square analyses				
(Intercept)	-14.1	138.0	-.102	0.919
Age	0.053	0.003	18.75	<0.001
Sex (Male)	0.019	0.066	0.294	0.768
Marital Status (Unmarried)	0.118	0.062	1.890	0.058
Race (White)	-0.443	0.296	-1.499	0.134
Race (Black/African American)	-0.576	0.323	-1.786	0.074
Race (Hispanic/Latino)	-1.034	0.407	-2.540	0.011
Race (Other)	-0.494	0.387	-1.276	0.202
Insurance Status (Private)	9.50	138.0	0.069	0.945
Insurance Status (Public)	9.27	138.0	0.067	0.946
Insurance Status (Self-Pay)	10.25	138.0	0.074	0.941
Logistic regression sensitivity analysis including all independent variables				
(Intercept)	-14.36	136.6	-0.105	0.916
Age	0.055	0.003	19.03	<0.001
Sex (Male)	0.019	0.066	0.284	0.776
Marital Status (Unmarried)	0.095	0.063	1.520	0.128
Race (White)	-0.438	0.296	-1.480	0.139
Race (Black/African American)	-0.580	0.323	-1.795	0.072
Race (Hispanic/Latino)	-0.921	0.417	-2.203	0.028
Race (Other)	-0.421	0.394	-1.071	0.284
Preferred Language (English)	-0.389	0.384	-1.014	0.310
Smoking Status (Current)	0.254	0.071	3.591	<0.001
Insurance Status (Private)	9.53	136.6	0.070	0.944
Insurance Status (Public)	9.31	136.6	0.068	0.946
Insurance Status (Self-Pay)	10.27	136.6	0.075	0.940

CHAPTER V

DISCUSSION

Patients diagnosed with heart failure face similar barriers as the patients who go through the extensive evaluation process for AHF therapies. This research investigated potential demographic, social, and economic factors that affect referral to an AHF specialist, whether patients have a clinic visit, and whether they ultimately receive treatment. The results of this investigation as described below emphasize the obstacles patients face with regards to continuity of care and access to healthcare services.

Referrals for AHF Services

Patients with a heart failure diagnosis were more likely to be referred to a heart failure specialist is they were younger, male, or married (Table 2). While there may be age constraints on the eligibility for a heart transplant, the age restrictions have become less strict over the year with more patients over the age of 70 being transplanted.[139,140] The leadership council of the professional society, American College of Cardiology, has noted that lack of clear guidance for cardiologists and internal medicine physicians on which patients to refer for AHF services has led to delays in referral, often to the point candidacy is no for heart transplantation or LVAD is longer possible.[66] Age in itself is not a contraindication for either treatment, however increasing age is a predictor of mortality post-heart transplantation.[140] In LVAD recipients over the age of 70, similar 2-year survival and quality of life to younger recipients have been shown.[141] Furthermore, other medical, pharmacological, and palliative options should be assessed by an AHF specialist. Previous research has also demonstrated lack of referral for cardiac services for older patients, although the authors note than it is unknown how many patients of advanced age decline invasive testing and procedures.[39] Knowing a person's age alone cannot determine whether or not a patient may benefit from advanced heart failure services and researchers have voiced opinions that even if a patient may be presumed to not benefit from a heart transplant or LVAD, they still deserve a minimum of one expert assessment by a heart failure specialist.[10] This reinforces the ethical claim that equity is needed in referral for AHF services and that younger patients are not selected for in the referral process.

Men were twice as likely to be referred compared to women as shown in both the Chi Square (Table 2) and Cox proportional hazards model (Table 3). The difference in clinical presentation of heart failure in men and women[104] might be thought to contribute to this disparity, however, the percentage of men (58.7%) diagnosed with heart failure was not twice that of women (41.3%) in the overall cohort (Table 1). A well-cited study from 1999 found that even after adjustment for symptoms, clinical characteristics, and disease assigned by the physician, men were more likely to be referred for cardiac catheterization than women.[142] The authors of that study concluded that implicit physician bias was involved in recommendations for chest pain, which in turn affects differences in treatment of cardiovascular disease by sex. Similar factors could be at play in the current study, although the current research did not assess decision-making at the physician level and therefore cannot draw similar conclusions as done in the previous study. Bias could be introduced at one of many steps in the referral process, including recognition of initial symptoms by the provider, when making recommendations, the degree of communication, and the referrer's perception about the patient's suitability for advanced interventions.[11] to name a few, and each step warrants future investigation. Unbiased decision-making is an expectation of the American healthcare system and discrimination based on sex or gender violates the just allocation of healthcare services.

According to the Chi square analysis, more referrals occurred for patients in the Black and Other racial/ethnic groups (Table 2), but race did not show significance in either Cox proportional hazards model (Table 3). More referrals in the Black and Other racial/ethnicity categories is an interesting finding because much of literature on various conditions reports inadequate referral and treatment for non-White patients[29–32,142] A possible theory explaining these findings is the conscious dedication of clinicians to improve their implicit bias. There are many calls in the literature explaining the need for training requirements to help reduce clinician implicit bias.[143] One of the main solutions, however, is to diversify the provider pool which should be considered a national priority.[144]

Patients with public insurance at the time of diagnosis had more referrals, as shown in the Chi Square analysis (Table 2) and was confirmed by the Cox proportional hazards analysis (Table 3). Since inclusion in this study required a diagnosis of heart failure, the patients that never received such a diagnosis were not captured. There are many reasons why a patient who has heart failure may never see a clinician to receive a diagnosis, with lack of appropriate insurance coverage being one main reason. The uninsured have a more difficult time getting the medical care they need, with uninsured persons being less likely to see a clinician after an unintentional injury or presence of a new chronic condition.[145] Health insurance has been shown to not only improve mortality, but also improve self-rated health and reduce likelihood of depression, acting as a gateway to medical care.[146] Improving chronic conditions such as hypertension, diabetes, and metabolic syndrome, which are risk factors for heart failure, is important in reducing disparities in access to AHF services.[14] With over 28 million (8.6%) of Americans recorded as uninsured in the recent Census data,[46] the preventable health challenges a large portion of our population faces is a major national crisis.

Clinic Visit with AHF Specialist

Once patients had a referral, they were more likely to have a visit with an AHF specialist if they were married. Previous research has found that married patients had more outpatient visits[147] and other research has demonstrated that increased continuity of care reduces hospitalizations.[148] Patients that are married or have a significant other may have the benefit of "marriage protection," which is the idea that married people are healthier, especially men, because of the physical and emotional support a spouse provides.[147,149] Single and divorced persons, especially men, have been shown to have negative effects on health,[150] and the "bereavement effect" similarly affects widowed patients.[149,151] While increased clinic visits by married patients may have to do with increased medical adherence in this group, AHF programs should be mindful of processes that could be implemented to improve likelihood of follow through in single patients once a referral is made, which would improve equity of services based on marital status.

Patients that had a clinic visit were also more likely to be nonsmokers, despite no association above between smoking status and referral. Patients that smoke have been shown to have more outpatient visits than non-smokers,[152] but the distinction between primary care visits and specialist visits has not been made. Our study suggests that while a patient that smokes may be seen in an initial visit in which their heart failure was diagnosed, they may not follow through with an appointment with a specialist. Previous research has demonstrated that current smokers are more likely to have incomes below the national poverty level and less likely to have health insurance than former smokers and non-smokers,[152] which would have a direct effect on healthcare utilization. With a number of intersectional characteristics at play, efforts to improve equity in access to healthcare services is essential to reduce the disparities in follow through with outpatient care.

AHF Treatment

The analysis demonstrated that more stringent criteria are used for heart transplantation eligibility compared to LVAD. When both treatments were combined, the ANOVA and Chi square analyses showed no association with any of the independent variables on whether or not patients received treatment. However, the Cox proportional hazards sensitivity analyses revealed that younger age, White race, and Hispanic ethnicity were associated with treatment. Further analysis revealed that younger age was also associated with whether patents received a heart transplant (Table 8), but not with whether patients received a LVAD (Table 10). As mentioned above, the general guidance is that heart transplant candidates be 70 years of age or less,[120] although guidelines for LVAD management do not mention an upper cutoff for age.[153] The most advanced age receiving a transplant was 70 in the current analysis, and 75 was the highest age for LVAD recipients. Adamson et al. has reported ages of LVAD recipients up to 87 years.[141]

White race and Hispanic ethnicity were associated with receiving any AHF treatment as shown in the Cox proportional hazards models. Further, while no other independent variables showed an effect on receiving an LVAD, the sensitivity analysis once again revealed that White and Hispanic/Latino patients were more likely to receive an LVAD compared to the Black and Other racial category patients (Table 10). Previous research has established that White patients have greater access to healthcare services than other racial and ethnic groups.[50,142] While Hispanic patients have been noted in the literature to have more cardiovascular risk factors and decreased access to healthcare,[154] the current research showing disparities in treatment suggests

Hispanic patients may be more likely than Black patients or those in Other racial categories to follow through with recommended procedures. This finding may intersect with increased levels of familism and allocentrism in the Hispanic community, which in itself has the potential for positive health implications.[155] In an unpublished study, the authors demonstrated that social support is associated with selection for AHF therapies.[12] Though Hispanic patients were not shown in the current study to have more referrals or more AHF clinic visits than other racial groups, their increased likelihood of treatment may be related to their social support structure. Conversely, the results could be interpreted to illustrate lack of treatment recommendations for patients in the Black and Other racial categories. Reduced access to healthcare services has been repeatedly noted in the literature with regards to Black patients.[57,142,156]

Additionally, there are many points in the disease trajectory that patients may make decisions that affect their treatment, either intentionally decision-making or unknowingly. For example, patients with cardiac symptoms may not recognize their symptoms[56] and either avoid or delay care. There may be cultural or spiritual reasons a patient may not choose to see a provider or follow through with planned procedures.[28] Or if a patient does see a provider, patients may not trust or accept the assessment or recommendations they are given by a physician.[11] Any perceptions of discrimination would impact a patient's decision-making and trust in the medical system, ultimately affecting continuity of care.

It must be noted that race is a social construct and not a biological construct. Members of any racial or ethnic categorization have a wide range of varying socioeconomic and structural barriers present. Even epidemiologists question racial/ethnic categorization of individuals and the utility of the categories relating to public health endeavors.[43] Further, the link between race and systemic and structural racism is undeniable,[157] leading to unequal clinical treatment as explored in this study.

The Chi square showed a higher proportion of females received heart transplants in this study compared to males, even though the number of females transplanted was lower than that of males (Table 7). This finding was not significant in the subsequent Cox proportional hazards models and is inconsistent with what is reported in the literature, as more males receive heart transplants than females on the national level.[2,140]

The privately insured were also more likely to receive a heart transplant according to the Chi Square results, and both private and public insurance showed significance in the Cox proportional hazards model that included age, sex, race, and insurance status with private insurance having a positive effect on transplantation and public insurance having a negative effect; however, insurance status did not show significance in the sensitivity analysis (Table 8). The insurance requirement for transplantation has been well-documented in the literature[7,8,26] and support the current findings. The sensitivity analysis, however, implies that other variables in the model, such as age and race, had more of an effect on receiving a transplant than type of insurance.

Mortality

One-year mortality after heart failure diagnosis was associated with increased age and Hispanic/Latino ethnicity (Table 11), but neither variable was significant in the logistic regressions assessing 1-year survival post-transplant and post-LVAD. Therefore, the older patients that were dying within one year of diagnosis were those that did not receive AHF therapies. Older patients are more likely to have other comorbidities which would affect mortality. However, this study suggests patients that lack of referral and eligibility for advanced heart failure services affects patient mortality in the advanced age group.

The higher mortality rates of Hispanic/Latino patients in the whole cohort but not in the treatment groups likewise suggests that lack of referral and visit with an AHF specialist contributes mortality. It is also possible that patients may turn down services once eligible, due to cultural or spiritual beliefs that impact decision-making.[28]

The sensitivity analysis also revealed that smoking was associated with 1-year mortality post-heart failure diagnosis. Smoking is a leading cause of preventable disease, with over 480,000 deaths attributable to smoking per year, and contributes to cardiovascular disease through various mechanisms.[158] It was surprising that smoking did not show as a significant predictor for AHF treatment, and even more surprising was the two patients recorded as current smokers who received heart transplants. This was likely an artifact of using baseline data; even though the patients were smokers at the time of diagnosis, they likely stopped by the time they were selected for transplant candidacy.

Limitations and Future Research

The current study investigated the demographic, social, and economic variables available through the electronic data pulls at one hospital system. While additional variables would make the study more robust, they were not available for most patients. Therefore, this research provides a limited view of the factors influencing the referral and care trajectory in heart failure patients. Further, this research does not take into account medical factors that may contribute to differences in referral and treatment. For example, some providers may not refer patients to specialists due to presence of certain comorbidities. The factors affecting referral outside of the independent variables examined in this study were not evaluated. Future research should include looking at the medical reasons that contribute to lack of referral. Also, this research does not take into account changes in insurance coverage over the course of the patient's heart failure disease trajectory, or for changes in any of the other independent variables. All non-English languages were categorized together due to limitations with sample size. Preferred language did not influence referral, clinic visit, treatment, or mortality in any of the analyses above, which may be an artifact of this grouping.

Future research on referrals data should also include multicenter data from various geographic locations. Guidelines for referral and treatment vary across AHF programs, so differences between institutions would be interesting to understand.

Epidemiological research inherently makes claims about social differences, such as race, gender, and class. The literature review attempts to delve into some of these wrongful claims but is not comprehensive in doing so. Additionally, the current research did not examine the difference between race and gender, due to the insufficient availability of information beyond "male" and "female" in the dataset. When data is available, accounting for gender is important in understanding additional barriers affecting access to AHF services. Researchers should be mindful of their use of labels as they can exacerbate social inequalities.[43]

Notably, this research does not take into account the many structural barriers in place affecting referral, both before and after a heart failure diagnosis is made. Access to a provider to make the initial heart failure diagnosis often requires insurance coverage as well as the work flexibility, feasibility with geographic proximity, assistance with any caregiving responsibilities, and transportation to visit a provider. Without insurance or a means to pay for healthcare, patients may avoid having doctors' visits and therefore are never captured in medical datasets.

This is in part due to employment-based insurance coverage in the United States, which contributes to the disparities in health between patients with more or less means as patients may choose not to pay for health insurance or healthcare entirely due to the prohibitive costs. These structural barriers are outside the scope of this investigation.

Interdisciplinary Research

AHF services require interdisciplinary collaboration between clinical and non-clinical professionals from varying fields. The trajectory from heart failure diagnosis to treatment is complex and unique for each patient. Patients diagnosed with heart failure may meet with professionals in upwards of 10 different disciplines. Therefore, the findings of this investigation are of interest to a multidisciplinary audience and have implications for changes at the level of transplant programs, hospital systems, state government, and federal government entities.

This research synthesized the clinical, ethical, and political aspects of AHF treatment as well as access to healthcare services as whole. The allocation of donor organs is a complex process, rich with moral underpinnings and medical requirements. Therefore, any investigation involving transplant practices requires an ethical perspective. The allocation system is based on policies which are influenced both by clinical outcomes and justice in distribution. The same approach should be considered for all healthcare services, as justice is needed to increase equity in care at the primary care and outpatient level.

Recommendations

Clinical and Health System Recommendations

Tools and guidance are needed in order for primary care physicians and cardiologists to appropriately refer patients to an AHF specialist. An electronic algorithm within the EMR to alert physicians in a timely manner when certain criteria are met has been developed,[159] however, the exact criteria needs further development. In the system reported by Evans et al, a patient aged 80 years old or older would not elicit a prompt in the system for AHF referral.[159] Additional research is needed to identify evidence-based guidelines for referral. Timely referral is an important consideration when developing future guidelines.

Cultural training to improve implicit bias in clinicians is an important component of improving equity in access to AHF services. Including such training as part of the medical school curriculum and as continuing education for practicing clinicians is essential to improve access and health outcomes. Many publications have recommended cultural competency training to improve patient-provider relations.[11,25,27,28,37,154,160]

Health systems should be aware of systems in place that may incentivize clinicians to promote disparities in access.[25] Clinician should be rewarded for their invaluable effort and expertise but doing so at the detriment of vulnerable populations must be avoided and practices that reduce barriers should be rewarded. Further, diversifying the workforce of health professionals will have vast benefits on healthcare equity.

Policy Recommendations

Insurance coverage through Medicaid should be available to all patients in need of organ transplantation in the United States. Medicare currently requires a 20% copay for heart transplantation.[161] Universal insurance coverage would certainly improve equity in transplantation, and it is interesting to consider the effects on organ donation that might occur if the government provided this service to the nation. State and federal representatives should be assessing areas of inequity in healthcare delivery and looking for available funds to help with solutions. This should also include healthcare coverage that encourages outpatient visits and continuity of care, which would improve access to care as well as health outcomes.

As mentioned above, CMS requires transplant programs to report institutional outcomes through UNOS in order to monitor performance and maintain CMS coverage. This practice may encourage programs to select low-risk patients. A recommendation would be for CMS and UNOS performance algorithms to account for equity in transplantation, thus encouraging transplant centers to identify patients from a more diverse set of criteria. Wadhwani et al. suggests that transplant centers should be financially incentivized to choose candidates with limited financial resources, and this should continue through the life of the transplant.[132]

Addressing income inequality is another area that should be of national priority. As the richest and poorest members of our society become farther and farther apart, so will increase the disparities in both access to healthcare and the health of our nation. From a productivity level, the health of our citizens is of upmost importance, which is important in the context of the ethical principle, utility. The application of justice in the distribution of healthcare to improve the health of our citizens is also advantageous since good health across all populations is essential for the functioning of society.[162] We, as a society, have a moral duty to reduce health disparities since the principle, respect for all persons, is not met when there are such drastic inequalities in health. Further, the presence of health disparities perpetuates the historical injustices of disenfranchised populations.[163]

Conclusions

This research was a first of its kind investigation examining a large cohort of heart failure patients and the factors that affect referral, clinic visits, and treatments. Current registries do not record patients that are never evaluated or eligible for AHF therapies, which was the population of interest in the current study. The study included a total of 24,258 patients diagnosed with heart failure at a single hospital system. Patients that were referred were more likely to be young, male, married, Black race, and have public insurance. Patients who had a clinic visit with an AHF specialist were more likely to be young, married, and non-smokers. Patients receiving advanced heart failure treatments were more likely to be White race or Hispanic ethnicity, and specifically heart transplant recipients were also younger and had private insurance. Hispanic patients and smokers had increased risk of 1-year mortality. These findings show differences in selection at each step in the care trajectory of heart failure patients as well as injustices in access to healthcare services. Future research should investigate additional factors influencing referral as well as compare multi-center data. Diversifying the healthcare workforce is an important step in reducing the health disparities in our country.

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