ENGINEERING EQUITY INTO LIVER TRANSPLANTATION:
AN APPROACH TO FAIR ARTIFICIAL INTELLIGENCE-BASED
CLINICAL DECISION SUPPORT

by
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A dissertation submitted to Johns Hopkins University in conformity with the requirements
for the degree of Doctor of Philosophy

Baltimore, Maryland
April 2022

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ABSTRACT

Liver transplantation (LT) is the only cure for patients with cirrhosis. In the US, 4.5 million adults are living with liver disease,¹ and annual deaths from cirrhosis in the US increased 65% from 1999 to 2016. To receive a LT, patients proceed through an arduous process. LT centers assess each patient’s appropriateness for transplant, culminating in a decision whether to place them on a waitlist for an organ. Health disparities have been demonstrated across the continuum of LT.² Warren et al. showed 81% of US transplant center waitlists under-represent Black patients and 62% under-represent Hispanic or Latino patients. Interventions that can address racial and ethnic disparities in LT listing can more broadly impact equity for those in need of LT. Since the decision for listing and evaluation process are complex, decision support may be a viable intervention to improve objectivity and reduce biased decision-making.

First, we leveraged a large cohort of referred LT patients to assess the association between neighborhood SES and access to the LT waitlist (Chapter 2). We found patients from neighborhoods with low SES had higher risk of not being listed, not initiating evaluation, and dying prior to evaluation compared to patients from neighborhoods with high SES after controlling for individual-level factors. When stratified by race and ethnicity, we also found heterogeneous effects for underrepresented populations compared to Non-Hispanic White patients.

Then, in a multi-center study, we used semi-structured interviews and ethnographic observations to ascertain transplant team perceptions about mechanisms for racial and ethnic disparities in LT listing (Chapter 3). We found participant perceptions about mechanisms for racial and ethnic listing disparities were related to external factors (e.g.,
structural racism, subjective national guidelines, national quality metrics) and internal factors (e.g., implicit bias, lack of resources, and minimal data collection or center-level feedback about disparities).

Lastly, we utilized semi-structured interviews as part of a human-centered design for fair AI-CDS (Chapter 4). We described 6 themes described by participants about fair AI-CDS for LT evaluation decision-making, 6 themes emerged: (1) need to know who made the AI-CDS and their motivations; (2) desire to understand how the AI-CDS was developed; (3) opinion that AI-CDS could mitigate emotions and biases by being objective; (4) AI-CDS as a new member of the transplant team, not a replacement; (5) want AI-CDS to help with identification of patient resource needs; and (6) the patient’s role in AI-CDS should be considered.

By addressing equity further upstream, we can more effectively improve outcomes for minority populations. This work is a call for action for the national collection of pre-listing data. By not prioritizing data collection to understand disparities, we are perpetuating inequity. These results will be used by hepatologists, transplant surgeons, and policy makers to address LT disparities in listing, so all patients have the opportunity to benefit from the life-saving gift of organ donation.

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ACKNOWLEDGEMENTS

This work was supported by a training grant from the National Institute of Diabetes and Digestive and Kidney Diseases (T32DK007632) and the Pearl M. Stetler Foundation Award. The contents of this dissertation are solely the responsibility of the author and do not necessarily represent the official views of the JHMI or the NIH.

This work would not have been possible without the support of the following:

Scott Levin – Thank you for welcoming me into your lab and giving me an inside look at how to improve medicine through data science.

Dorry Segev – Thank you for your dedication to creating physician-scientists capable to make a difference. This all would not have been possible without your mentorship and encouragement.

James Hamilton – Thank you for showing by example how to be both a dedicated clinician and researcher. You’re one of the reasons I am becoming a Hepatologist.

Lorraine Dean – Thank you for all that you do to educate students about social epidemiology. Your class was defining for not only my future research career but also in making me a better physician for my patients.

Craig Hendrix – Thank you for your constant support and optimism throughout all of this.

Roland Thorpe – I will always be grateful for you introducing me to the world of social epidemiology. Thank you.


Center for Data Science in Emergency Medicine – Especially Diego Martinez, Jeremiah Hinson, Eili Klein, Aria Smith, Cam Morgan, and Matt Toerper.

Graduate Training Program in Clinical Investigation (GTPCI) Colleagues and SPH Faculty - Especially John Jackson, Amber Kernodle, Michelle Ogunwole, Bill Werbel, Jennine Weller, and Eunice Yang.

GTPCI Staff/Faculty – Thank you for your dedication to maintaining a program for clinicians to pursue doctoral training.

Malone Center/Whiting School of Engineering Faculty & (Current/Prior) Students - Especially Ayse Gurses, Harold Lehmann, Ilya Shpitser and Dan Malinsky.

Finally, I dedicate this dissertation to my family. Mom and dad, thank you for many years of dedicated and steadfast support. Lauren, I am endlessly appreciative of your patience encouragement throughout this wild adventure. You’ve been my rock to make this all happen.

- Aly
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Chapter 1. Introduction

Liver transplantation (LT) is the only cure for patients with cirrhosis. In the US, 4.5 million adults are living with liver disease.\(^1\) Morbidity from cirrhosis is complicated by a stochastic crescendo of disease severity,\(^4\) which can lead to hospitalizations from cirrhosis complications such as gastrointestinal hemorrhage, ascites, cancer, and hepatic encephalopathy.\(^5\)\(^–\)\(^7\) Annual deaths from cirrhosis in the US increased 65% from 1999 to 2016; deaths from hepatocellular carcinoma doubled.\(^8\) Unfortunately, LT is the only option to combat the significant morbidity and mortality, and to receive a LT, patients proceed through an arduous process. LT centers assess each patient’s appropriateness for transplant, culminating in a decision whether to place them on a waitlist for an organ. If listed, patients are prioritized for transplant based on disease severity.

Health disparities have been demonstrated across the continuum of LT.\(^2\) Prior research has demonstrated racial and ethnic disparities in post-listing LT outcomes, such as death on the waitlist and receiving a transplant.\(^2\)\(^9\)\(^–\)\(^21\) Moreover, health disparities exist in gaining access to the waitlist.\(^3\)\(^9\)\(^,\)\(^14\)\(^,\)\(^19\)\(^,\)\(^22\)\(^–\)\(^30\) Warren et al. showed 81% of US transplant center waitlists under-represent Black patients and 62% under-represent Hispanic or Latino patients. This national finding is consistent with prior studies showing that patients that are Black or lack commercial insurance are less likely to be listed for LT.\(^28\)\(^–\)\(^30\) Fortunately, the introduction of the Model for End Stage Liver Disease (MELD) score improved racial disparities in organ allocation for those on the waitlist.\(^31\)

Information about people that need LT but are not listed is not widely available. While we can see breakdown based on race for all transplant center waitlists, we do not know the
denominator. Specifically, the breakdown of those not listed by race/ethnicity is not known. Without national data about who is not being listed, we do not know the true measure of racial and ethnic disparities in listing. For example, we can ascertain that a transplant center has a waitlist composed of 20% Black candidates. However, the knowledge that 20% of referred patients were Black leads to different inference about disparities than if 50% of referred patients were Black. Transplant centers have robust measures for post-listing outcomes due to a readily available national registry data collected after a patient is listed. As an example of exploring the pre-listing landscape with national data, Paul et al. combined national registry data with the dialysis data from the US Renal Data System to study patients referred for kidney transplant and their waitlisting rate. They defined this metric as the ratio of patients waitlisted at a center relative to the person-years referred for evaluation at that center. While this study captured center level waitlisting practices with a large sample size, this approach is not easily translated to liver because there is not a national cirrhosis registry pre-listing. Mathur et al. attempted to address this issue in patients referred for LT by defining the “liver-waitlisting-ratio”. Using the national liver registry and National Center for Health Statistics data for demographic, waitlist, and mortality data, they were able to advance our knowledge about racial disparities in LT listing but were limited by assumptions about the denominator representing patients that should have been listed based on death data as opposed to those truly referred and evaluated. Due to this paucity of data, mechanisms for the disparities waitlists have been difficult to elucidate.

Despite the lack of national data pre-listing, single center efforts have been made to investigate risk factors for not being listed. In a single center, retrospective study, Kemmer et al. looked specifically at patients deemed ineligible for transplant and found
39% of Black patients were not listed due to psychosocial concerns, compared to only 17% of White patients. This was an important study for determining the substantial weight of the psychosocial evaluation. This study was not able to determine the mechanism for the difference between groups due to implicit bias. Jesse et al. demonstrated in a large single center study that Black patients have 26% lower odds of being listed for LT compared to White patients, despite adjusting for medical and socioeconomic factors. These findings provided critical insight about the presence of other mechanisms such as racism or implicit bias. They also delineated risk factors for not being listed: alcohol-induced hepatitis, unmarried marital status, more than 1 insurance, inadequate insurance, and low household income. These studies describe the racial disparities stemming from complex structures at and between the patient, community, provider, and transplant center levels. Notably, Hispanic or Latino populations were not included in the above studies.

LT evaluation involves a thorough gathering of objective clinical information and multi-disciplinary transplant team discussion about listing. The evaluation process and listing decision can be permeated with subjectivity in the data gathering, clinical observations, and psychosocial assessments. The psychosocial assessment is largely related to “fundamental causes”. Fundamental causes are social conditions, such as racism, socioeconomic status, and social support, that provide access to resources that prevent the development of disease. Later, these concepts became more commonly referred to as social-behavioral determinants of health (SDOH). SDOH are defined by the World Health Organization as “conditions in which people are born, grow, work and age” that affect health outcomes. More specifically, SDOH are socioeconomic position (education, employment status, income, wealth, insurance), social environment (social support or social service access), socio-demographic (age, sex, racism), socio-cognitive
(health literacy, self-efficacy), and behavioral indicators (drug use, food systems). Additionally, due to complex and non-linear causal links, social epidemiology literature also calls for thinking “across” rather than “within” levels and considering “risk regulators” (e.g., neighborhood/community conditions) that impact behaviors and disease in a probabilistic manner. SDOH have been identified as important for health equity in LT. The American Association of the Study of Liver Diseases guidelines for LT evaluation and listing clearly outline contraindications, which are both objective and subjective. The highly subjective and SDOH-related contraindications are the critical parts of the psychosocial evaluation: 1) ongoing alcohol/substance abuse, 2) persistent non-compliance with care, 3) lack of adequate social support system.

Interventions that can address racial and ethnic disparities in LT listing can more broadly impact equity for those in need of LT. Since the decision for listing and evaluation process are complex, decision support may be a viable intervention to improve objectivity and reduce biased decision-making. As discussed, LT evaluation involves a thorough collection of granular data on individuals available in the electronic health record (EHR). Artificial intelligence-based clinical decision support (AI-CDS) tools have been used increasingly in medicine. These analytical techniques can manage the interdependencies in the multi-level, non-parametric EHR data. Through the ethical design, deployment, and evaluation of AI-CDS, there may be potential for mitigating biases and incorporating equity in model performance, resource allocation, and patient outcomes.

This dissertation focuses on assessing health equity in liver transplant evaluation and the potential for fair AI-CDS. In Chapter 2, we identify mechanisms and potential solutions for racial and ethnic disparities in listing for LT using a systems engineering
framework. In Chapter 3, we define user perceptions and recommendations related to fair AI-CDS for liver transplant evaluation. In Chapter 4, we measure the association between neighborhood socioeconomic status and listing for LT. This comprehensive assessment of mechanisms of racial and ethnic disparities in access to LT listing and potential AI-CDS interventions will inform future research, policies, and innovations to improve patient care.
Chapter 2. Association of Neighborhood Socioeconomic Status and Access to Liver Transplantation

ABSTRACT

Although health disparities are revealed throughout most aspects of liver transplantation, the role and distribution of neighborhood-level factors on the evaluation process are not well understood. Building on literature demonstrating an impact of structural racism from neighborhood-related measures on health outcomes in other fields, our aim was to evaluate the relationship between patient neighborhood and access to liver transplantation. In this retrospective cohort study, we linked electronic health record data with the Area Deprivation Index (ADI). The ADI is a validated construct utilizing 17 neighborhood-based measures (e.g., employment, income, education) from the American Community survey to rank census block groups across the country by percentile (1: least disadvantaged or high socioeconomic status [SES], 100: most disadvantaged or low SES). Our study included adults ≥18 years-old who were referred to our transplant center for initial liver transplant evaluation from 8/1/2016-12/31/2019. For our primary exposure of neighborhood SES, we dichotomized ADI at the median for our sample (33 percentile). We compared cohorts using \( \chi^2 \) test or Fisher’s exact test for categorical variables and Kruskal-Wallis test for continuous variables. The primary outcome was not being listed for transplant. We used modified Poisson regression for the three outcomes of non-listing (model 1), not starting evaluation (model 2), and death prior to evaluation (model 3). We then adjusted for age and sex. We tested for effect measure modification by race and ethnicity. For 1,377 referred patients, there was no difference in age (low SES median 56 vs high SES 55; p=0.4) or females (41.4% vs
41.2%; p=0.97) between those in low and high SES neighborhoods. Compared to those living in neighborhoods with high SES, patients living in low SES neighborhoods had a lower proportion of patients that were Non-Hispanic White (66.8% in high neighborhood SES vs 58.8% in low neighborhood SES; p<0.001) and patients that had primary indication for LT of alcohol-related liver disease (29.6% vs 19.4%; p<0.001). Conversely, the proportions of patients that were Non-Hispanic Black (11.1% vs 23.3%), had Medicaid insurance (22.7% vs 25%), had hepatocellular carcinoma (9% vs 12.1%), had HCV (6.9% vs 11.1%), and had non-alcohol hepatic steatosis (8% vs 10.4%) was higher in the group from low SES neighborhoods. Patients from neighborhoods with low SES had higher risk of not being listed (adjusted risk ratio [aRR] 1.14; 95% confidence interval [CI] 1.05-1.2; p<0.001), not initiating evaluation (aRR 1.20; 95%CI 1.01-1.4; p=0.03) and dying prior to evaluation (aRR 1.55; 95%CI 1.09-2.2; p=0.03) compared to patients from neighborhoods with high SES after controlling for individual-level factors. When stratified by race and ethnicity, White patients from low SES neighborhoods were not at an increased risk of not being listed compared to White patients from high SES neighborhoods (aRR 1.06; 95%CI 0.96-1.17; p=0.25). However, patients from underrepresented populations living in low SES neighborhoods were at 31% increased risk of not being listed compared to patients from underrepresented populations living in high SES neighborhoods (aRR 1.31; 95%CI 1.12-1.5; p<0.001). The association of neighborhood SES and not being listed was modified by race and ethnicity (adjusted interaction term p-value=0.02). In summary, our findings suggest that interventions addressing neighborhood deprivation may not only benefit patients from neighborhoods of low SES but may help address racial and ethnic disparities. Further research is needed to elucidate the relationships between neighborhood deprivation and other social determinants of health.
INTRODUCTION

Since liver transplantation (LT) is a life-saving treatment for patients with cirrhosis or liver cancer, assessing and addressing the differential in access to LT based on race/ethnicity is critical to health equity. Specifically, racial and ethnic disparities exist in patient listed for LT.\textsuperscript{3,29,30,44} Mechanisms for the relationship between race and ethnicity and LT listing are complex and not fully understood, but structural racism and social determinants of health (SDOH) likely are related.\textsuperscript{29,30,45} Due to the significant patient time and resources involved in being evaluated for LT as well as the post-transplant responsibilities of close follow-up care and medication compliance, psychosocial factors play a role in LT evaluation for listing. Recently, awareness about systemic concerns has increased, so neighborhood-level deprivation has been increasingly studied for several areas of healthcare.\textsuperscript{46–50} While prior studies have identified important risk factors for not being listed based on individual factors,\textsuperscript{30} the effect of neighborhood exposures has not been rigorously assessed. For example, when evaluating two people referred for LT, the patient from a highly disadvantaged neighborhood may not have access to accurate information about liver disease or have increased exposure to substance abuse. Conversely, the patient from a low disadvantaged neighborhood may have a robust social support network and access to resources.

When considering neighborhood deprivation, one must consider the historic role of structural racism, particularly the history of redlining.\textsuperscript{51} Briefly, redlining played a major role in housing segregation in many major cities in the United States through classifying areas of predominantly non-White people as “high risk” for defaulting on mortgages.\textsuperscript{51,52} Based on race and ethnicity, people were funneled to certain areas through monetary and social (dis)incentives. Areas predominantly consisting of minority populations were
lacked resources to thrive. Although time has passed, the negative impacts, such as wealth-building, segregation, and health are still present.\textsuperscript{52,53} The generational and perpetual effects of this historic structural racism on housing, education, employment opportunities, and city infrastructure in these neighborhoods may lead to difficulty being approved for listing from a psychosocial perspective. For example, their social support, likely also in these neighborhoods, are less likely to have flexibility with their employment to get off work or have transportation means to help with getting to appointments. Another example is limited access to internet, so inability to comply with telemedicine visits.

To understand the implications of exposure to neighborhoods with low SES, we analyzed the association between neighborhood SES and access to LT. We hypothesized that patients from neighborhoods with low SES were less likely to be listed for LT. Additionally, given the known racial and ethnic disparities in neighborhood SES, we examined the effect measure modification by race and ethnicity.

**METHODS**

**Study population**

In this cohort study, we included adults \( \geq 18 \) years-old who had an initial referral to an urban transplant center for LT evaluation from 8/1/2016-12/31/2019. We followed for outcomes from the time of referral to the end of follow up on 12/31/2020. Exclusion criteria were those missing a neighborhood SES (see ADI section below) and had prior LT. Based on Organ Procurement and Transplantation Network data, the transplant center from 2016-2019 had an average of 185 adult candidate waitlist additions/year (15.8% Non-Hispanic Black, 3.9% Hispanic or Latino). The study was approved by IRB (#00240083).
Individual-level data

We extracted patient-level data from the electronic health record (EHR). Patient demographics and general information collected included age, sex, race, ethnicity, insurance type, interpreter use, and address. Race and ethnicity can be entered into the EHR by clinicians and staff and is determined based on inputter interpretation or asking the patient. The options in the EHR for race are “White or Caucasian”, “Black or African American”, “Asian”, “American Indian or Alaska Native”, “Other Pacific Islander”, “Other”, “Choose not to Disclose”, “Unable to obtain”, and “Unknown”. “Other” may be entered if the specific race is not one of the options or if multi-racial. The EHR options for ethnicity are “Not Hispanic or Latino”, “Hispanic or Latino”, “Choose not to Disclose”, “Unable to obtain”, or “Unknown”. The choice of language for reporting scientific research related to race and ethnicity is important but not standardized. For transparency and aligned with Hollinger’s ethnoracial pentagon,54 we will outline the precise mapping from EHR data for the race and ethnicity terms used henceforth. The 5 monoracial categories will be: (1) “Hispanic or Latino” (“Hispanic or Latino” ethnicity regardless of race), (2) “Non-Hispanic Black” (“Black or African American” and not “Hispanic or Latino” ethnicity), (3) “Non-Hispanic White” (“White or Caucasian” and not “Hispanic or Latino” ethnicity), (4) “Indigenous Peoples” of America (“American Indian or Alaska Native”), (5) “Asian” (“Asian” or “Other Pacific Islander”). “Non-Hispanic Other” was used for patients listed as “Other” for race and not “Hispanic or Latino” ethnicity. Patient-level clinical data included indication for LT and Model for End-Stage Liver Disease-Sodium (MELD-Na) at time of referral.

Neighborhood SES
Neighborhood SES was determined based on the Area Deprivation Index (ADI).\textsuperscript{47} The ADI is a validated construct utilizing 17 neighborhood-based measures from the American Community Survey to rank census block groups across the United States by percentile (1: least disadvantaged or high neighborhood SES, 100: most disadvantaged or low neighborhood SES) (Figure 2.1). These measures are related to employment, income, education, and housing quality. The ADI data was downloaded from the 2018 v3.0 publicly available dataset. The ADI was linked to EHR patient-level data through the census block group of the patient’s address at time of the initial committee meeting. For those that did not have a committee meeting, ADI was linked to the census block group for the address at the time of referral. A third-party system, Alteryx, which incorporates a TomTom GIS database and a USPS Coding Accuracy Support System, was used to assign census block groups to patient addresses. ADI was dichotomized at the median (ADI: 33 percentile). ADIs are missing when: (1) block group has low population or housing, (2) block group has high group quarters, and (3) block group does not have an ADI due to missing variables from the American Community Survey. The missingness for ADI was 4.2% and these patients were excluded.

**Outcome measures**

The primary outcome was not being listed. Patients that did not have a committee meeting were considered not listed. Patients with initial committee decisions of “declined” or “needs representation” were considered not listed. Secondary outcomes were evaluation initiation and death prior to evaluation initiation. We collected these outcome measures from the EHR. For higher probability of accuracy, the date of death was collected from both the EHR and from the Vital Statistics Maryland Department of Health (MDOH; certain data were provided by the Vital Statistics Administration, Maryland Department of Health, Baltimore, Maryland. The Department of Health
disclaims responsibility for any analyses, interpretations or conclusions). For discrepancies between the EHR and MDOH death date, the MDOH death date was considered accurate.

**Analysis**

We reported the descriptive statistics with respect to frequency (percentage) and median (interquartile range [IQR]). We assessed differences between patients with low and high neighborhood SES using χ² test for categorical variables (Fisher’s Exact test for small numbers) and Kruskal-Wallis test for continuous variables. We tested the association between neighborhood SES and LT evaluation outcomes with modified Poisson regression. The three models were for unadjusted and adjusted outcomes of non-listing (model 1), not starting evaluation (model 2), and death prior to evaluation (model 3). We tested for effect measure modification by race and ethnicity where we compared those that were White (Non-Hispanic White) to those that were from underrepresented populations (Hispanic or Latino, Non-Hispanic Black, Asian, Indigenous Peoples of America, Other pacific Islander, Other). A p-value < .05 was considered statistically significant. All analyses were performed using R (4.1).

**RESULTS**

**Patient demographics**

There were 1,377 patients included in the study population (Table 2.1). The median age was 56 years (IQR 48-63), and most were males (58.7%), Non-Hispanic White (62.7%), and had private insurance (42.3%). Of the 1,377 patients, 665 (48.3%) were in the high neighborhood SES group. There were 274 (41.2%) females in the group of patients living in neighborhoods with high SES and 295 (41.4%) of the patients in neighborhoods with low SES (p=0.4). There were no differences in age at referral and interpreter
preference between patients in neighborhoods with low or high SES (Table 2.1). While the proportion of Non-Hispanic White patients from neighborhoods of high SES is higher than neighborhoods with low SES (66.8% vs 58.8%), the proportion of Non-Hispanic Black patients in neighborhoods with high SES is less than in neighborhoods with low SES (11.1% vs 23.3%; p < 0.001) (Table 2.1). The proportion of Hispanic or Latino patients was higher in the group from neighborhoods with high SES compared to low SES (5.9 vs 4.5; p < 0.001). Patients from neighborhoods with low SES were more likely to have Medicaid insurance compared to those from neighborhoods with high SES (25.0% vs 22.7%; p < 0.001).

**Baseline liver disease**

Of the 1,377 patients referred for LT, 335 (24.3%) had primary liver disease indication for transplant of ARLD, which was the most common. Compared to patients from neighborhoods with high SES, those from neighborhoods with low SES were more likely to have primary liver disease necessitating transplant from HCC (9.0% vs 12.1%), HCV (6.9% vs 11.1%), and NASH (8.0% vs 10.4%) (p <0.001) (Table 2.1). Conversely, ARLD was more likely to be the indication for LT in patients from neighborhoods with high SES compared to low SES (29.6% vs 19.4%; p<0.001). There was no significant difference in MELD-Na between patients in neighborhoods with low or high SES (16 in low SES vs 17; p=0.3) (Table 2.1).

**Liver transplant evaluation outcomes**

We found that patients from neighborhoods with low SES had a 13% increased risk of not being listed compared to those from neighborhoods of high SES (risk ratio [RR] 1.13; 95% confidence interval [CI] 1.05-1.2; p=0.001) (Table 2.2). This risk increased to 14% after adjusting for age and sex and this was statistically significant (adjusted risk ratio
[aRR] 1.14; 95%CI 1.05-1.2; p<0.001). Patients from neighborhoods with low SES had an 18% increased risk of not initiating evaluation compared to those from neighborhoods of high SES, but this was not statistically significant (RR 1.18; 95%CI 0.999-1.40; p=0.053). This risk increased to 20% after adjusting for age and sex and this was statistically significant (aRR 1.20; 95%CI 1.01-1.4; p=0.03). Patients from neighborhoods with low SES had a 56% increased risk of dying prior to evaluation compared to those from neighborhoods of high SES (RR 1.56; 95%CI 1.10-2.2; p=0.01). After adjusting for age and sex, patients from neighborhoods with low SES had a 55% increased risk of dying prior to initiating evaluation compared to those from neighborhoods of high SES (aRR 1.55; 95%CI 1.09-2.2; p=0.01) (Table 2.2).

After stratifying by race and ethnicity, 130 patients were excluded from the effect measure modification analysis due to unknown race and ethnicity. When stratified by race and ethnicity, Non-Hispanic White patients from low SES neighborhoods were not at an increased risk of not being listed compared to Non-Hispanic White patients from high SES neighborhoods (aRR 1.06; 95%CI 0.96-1.17; p=0.25) (Table 2.3). However, patients from underrepresented populations living in low SES neighborhoods were at 31% increased risk of not being listed compared to patients from underrepresented populations living in high SES neighborhoods (aRR 1.31; 95%CI 1.12-1.5; p<0.001). The association of neighborhood SES and not being listed was modified by race and ethnicity (adjusted interaction term p-value=0.02).

**DISCUSSION**

**Study conclusions**

In this retrospective cohort study of patients referred for LT, the proportion of patients that were Non-Hispanic Black, had Medicaid insurance, had hepatocellular carcinoma,
had hepatitis C virus, and had non-alcoholic steatohepatitis was higher for people from neighborhoods with low SES compared with those from neighborhoods with high SES. Notably, ARLD was the most common indication for LT and was more likely in patients from neighborhoods with high SES compared to low SES. Patients from neighborhoods with low SES had higher risk of not being listed, not initiating evaluation, and dying prior to initiating evaluation compared to patients from neighborhoods with high SES after controlling for individual-level factors. When stratified by race and ethnicity, there were heterogenous effects for patients from underrepresented populations and Non-Hispanic White patients.

Our finding that patients from neighborhoods with low SES had higher risk of not being listed is critical to understanding the mechanisms of racial and ethnic disparities in listing. Minority populations are disproportionately distributed across neighborhoods of low and high SES, which is consistent with our observation that Non-Hispanic Black patients comprise a larger proportion of those from neighborhoods with low SES. Future work to allocate resources to address these neighborhood-level disparities could mitigate racial disparities in LT access if carried out ethically. The use of ADI to identify areas of need and address inequity has been an approach considered in other areas of public health.

Our findings build on prior work about patient-level psychosocial factors and listing. For example, patient-level SES has been related to not being listed, specifically that Medicaid was associated with not being listed for psychosocial reasons. We demonstrated an increased risk to not be listed for patients from neighborhoods with low SES. In addition to SES, a survey of 584 transplant providers by Ladin et al. reported social support is the second most important factor in listing decisions. This subjective
measure may be associated with neighborhood SES because social support may frequently come from those that live in the patient’s neighborhood. Our study is consistent with prior work demonstrating an association between neighborhood and post-listing LT outcomes.\textsuperscript{57,60,61} Future research should continue to investigate mechanisms of the association between neighborhood SES and outcomes during LT evaluation, such as death, not starting evaluation, and not being listed.

\textbf{Study limitations}

This study has some limitations. This was a single center study with sample size and sample population that limit generalizability. Future work with other transplant centers is needed to further elucidate the relationships between neighborhood SES, race and ethnicity, and access to LT. Retrospective data collected from an EHR may contain errors as it is inputted for clinical purposes, which could lead to misclassification bias. For example, date of death may not be entered if there were no interactions with the patient. However, data input regarding transplant is highly regulated through audits and national guidelines, so there is less risk of error for this specific patient population. Additionally, to mitigate misclassification of death, we collected date of death both from the EHR and from the state Department of Health. A second limitation is a lack of accounting for unmeasured confounding, such as historical experiences with racism or childhood SES. Regarding the exposure of interest, ADI, our cohort’s median ADI was skewed towards neighborhoods of higher SES. ADI, among other measures, is only an approximation of “neighborhoods” or “communities” and may not accurately represent each individual patient's perceived neighborhood. Importantly, we were able to link our patients through census block groups. Census block groups are the most accurate representations of neighborhoods,\textsuperscript{62} as compared to zip codes or zip+4, which can also be used in other measures of neighborhood level deprivation.\textsuperscript{63} Despite these limitations,
this is the first study to our knowledge to evaluate an association between neighborhood deprivation and LT evaluation outcomes.

**Conclusion**

In summary, our findings suggest that interventions addressing neighborhood deprivation may not only benefit patients from neighborhoods of low SES but may help address racial and ethnic disparities. Further research is needed to elucidate the relationships between neighborhood deprivation and other social determinants of health.
Figure 2.1 Map of Maryland with national area deprivation index. Map of Maryland from Neighborhood Atlas.\textsuperscript{64,65} Arrow shows location of transplant center.
### Table 2.1 Characteristics of patients referred for liver transplantation categorized by neighborhood socioeconomic status

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Overall (N = 1377)</th>
<th>Neighborhood SES*</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>High (N = 665)</td>
<td>Low (N = 712)</td>
</tr>
<tr>
<td>Referral Age, median (IQR)</td>
<td>56 (48-63)</td>
<td>55 (47-63)</td>
<td>56 (49-62)</td>
</tr>
<tr>
<td>Female</td>
<td>569 (41.3)</td>
<td>274 (41.2)</td>
<td>295 (41.4)</td>
</tr>
<tr>
<td>Race &amp; Ethnicity**</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>863 (62.7)</td>
<td>444 (66.8)</td>
<td>419 (58.8)</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>240 (17.4)</td>
<td>74 (11.1)</td>
<td>166 (23.3)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>71 (5.2)</td>
<td>39 (5.9)</td>
<td>32 (4.5)</td>
</tr>
<tr>
<td>Asian</td>
<td>46 (3.3)</td>
<td>35 (5.3)</td>
<td>11 (1.5)</td>
</tr>
<tr>
<td>Indigenous Peoples</td>
<td>6 (0.4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Non-Hispanic Other</td>
<td>21 (1.5)</td>
<td>14 (2.1)</td>
<td>7 (1.0)</td>
</tr>
<tr>
<td>Unknown</td>
<td>130 (9.4)</td>
<td>54 (8.1)</td>
<td>76 (10.7)</td>
</tr>
<tr>
<td>Interpreter Preference</td>
<td></td>
<td></td>
<td>0.3</td>
</tr>
<tr>
<td>No</td>
<td>1319 (95.8)</td>
<td>635 (95.5)</td>
<td>684 (96.1)</td>
</tr>
<tr>
<td>Yes</td>
<td>50 (3.6)</td>
<td>28 (4.2)</td>
<td>22 (3.1)</td>
</tr>
<tr>
<td>Unknown</td>
<td>8 (0.6)</td>
<td>2 (0.3)</td>
<td>6 (0.8)</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Private</td>
<td>583 (42.3)</td>
<td>342 (51.4)</td>
<td>241 (33.8)</td>
</tr>
<tr>
<td>Medicare</td>
<td>329 (23.9)</td>
<td>151 (22.7)</td>
<td>178 (25.0)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>268 (19.5)</td>
<td>90 (13.5)</td>
<td>178 (25.0)</td>
</tr>
<tr>
<td>Other</td>
<td>88 (6.4)</td>
<td>45 (6.8)</td>
<td>43 (6.0)</td>
</tr>
<tr>
<td>Unknown</td>
<td>109 (7.9)</td>
<td>37 (5.6)</td>
<td>72 (10.1)</td>
</tr>
<tr>
<td>Primary Disease</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>ARLD</td>
<td>335 (24.3)</td>
<td>197 (29.6)</td>
<td>138 (19.4)</td>
</tr>
<tr>
<td>HCC</td>
<td>146 (10.6)</td>
<td>60 (9.0)</td>
<td>86 (12.1)</td>
</tr>
<tr>
<td>HCV</td>
<td>125 (9.1)</td>
<td>46 (6.9)</td>
<td>79 (11.1)</td>
</tr>
<tr>
<td>NASH</td>
<td>127 (9.2)</td>
<td>53 (8.0)</td>
<td>74 (10.4)</td>
</tr>
<tr>
<td>Other</td>
<td>183 (13.3)</td>
<td>112 (16.8)</td>
<td>71 (10.0)</td>
</tr>
<tr>
<td>Unknown</td>
<td>461 (33.5)</td>
<td>197 (29.6)</td>
<td>264 (37.1)</td>
</tr>
<tr>
<td>MELD-Na, median (IQR)</td>
<td>16 (10-25)</td>
<td>17 (10-25)</td>
<td>16 (10-23)</td>
</tr>
</tbody>
</table>

Data presented as count (%) except when noted otherwise. χ² test for categorical variables (Fisher’s Exact test for small numbers) and Kruskal-Wallis test for continuous variables.

*Neighborhood SES: Defined by the Area Deprivation Index national percentile with a cut off at the median.

**For race & ethnicities where a cell was <5, the neighborhood SES was not displayed due to identification concerns. “Other” is based on input into the electronic health record of “Other” (not specified race because not an option or multi-racial)

***Meld-Na unknown: 20.4% overall, 17.7% for high Neighborhood SES, 22.9% for low neighborhood SES

Abbreviations: ARLD, Alcohol-Related Liver Disease; HCC, Hepatocellular Carcinoma; IQR, Interquartile Range; MELD-Na, Model End Stage Liver Disease-Sodium; NASH, Non-alcoholic Steatohepatitis; SES, Socioeconomic status
Table 2.2. The association between low neighborhood socioeconomic status and outcomes related to liver transplantation.

<table>
<thead>
<tr>
<th>M</th>
<th>Outcome</th>
<th>Outcome, n(%)</th>
<th>Outcome, n(%)</th>
<th>RR</th>
<th>95% CI</th>
<th>p-value</th>
<th>aRR</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not listed</td>
<td>419 (63.0)</td>
<td>507 (71.2)</td>
<td>1.1</td>
<td>1.05-1.22</td>
<td>&lt;0.001</td>
<td>1.1</td>
<td>1.05-1.22</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2</td>
<td>No evaluation</td>
<td>174 (26.2)</td>
<td>220 (30.9)</td>
<td>1.1</td>
<td>0.999-1.40</td>
<td>0.053</td>
<td>1.2</td>
<td>1.01-1.42</td>
<td>0.03</td>
</tr>
<tr>
<td>3</td>
<td>Died pre-eval</td>
<td>46 (6.9)</td>
<td>77 (10.8)</td>
<td>1.5</td>
<td>1.10-2.22</td>
<td>0.01</td>
<td>1.5</td>
<td>1.09-2.2</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Neighborhood SES: Defined by the Area Deprivation Index national percentile binarized at the median.

Adjusted Risk Ratio for age at time of referral and sex

Abbreviations: aRR, Adjusted risk ratio; M, Model; Pre-eval, pre-evaluation; RR, Risk Ratio; SES, Socioeconomic status.
Table 2.3 Association between Neighborhood Socioeconomic status and listing for liver transplantation stratified by race & ethnicity.

<table>
<thead>
<tr>
<th>Race &amp; Ethnicity**</th>
<th>White</th>
<th>Underrepresented Populations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RR (95% CI)</td>
<td>RR (95% CI)</td>
</tr>
<tr>
<td>Neighborhood SES*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>Ref</td>
<td>Ref</td>
</tr>
<tr>
<td>Low</td>
<td>1.06 (0.96-1.17)</td>
<td>1.31 (1.12-1.5)</td>
</tr>
</tbody>
</table>

*Neighborhood SES: Area Deprivation Index national percentile binarized at the median.
**White: Non-Hispanic White; Underrepresented Populations: Hispanic or Latino, Black, Asian, Indigenous Peoples of America, Other Pacific Islander, Other (entered as “Other” in health record if race not an option or multi-racial)

RRs are adjusted for age and sex. Adjusted Interaction term p-value: 0.02

Abbreviations: RR, risk ratio; SES, socioeconomic status
Chapter 3. Multi-center study of racial and ethnic inequities in liver transplant evaluation: understanding mechanisms & identifying solutions

**ABSTRACT**

Racial and ethnic disparities persist in access to the liver transplant (LT) waitlist. Given the complex nature of LT candidate evaluation, a systems engineering approach may provide insights. In this multi-center, qualitative study, we used SEIPS 2.0, a human factors-based model for health care quality and safety, to create a conceptual framework specific to equity in LT evaluation. From 12/2020-7/2021, we performed ethnographic observations (patient-provider appointments, committee meetings) and semi-structured interviews (N=54 interviews, 49 observation hours). Participants were LT team members from 2 centers (coordinators, providers, social workers, dieticians, pharmacists, leadership). Participant perceptions about listing disparities described external factors (e.g., structural racism, subjective national guidelines, national quality metrics) that permeate the LT evaluation process. Mechanisms identified included minimal transplant team diversity, implicit bias, interpersonal racism. A lack of resources, such as social workers, transportation assistance, non-English speaking materials, and time to be adaptable (e.g., more education for patients with health literacy concerns), was a common theme. Due to minimal data collection or center feedback about disparities, participants felt uncomfortable with and unable to adapt to unwanted outcomes, which perpetuates disparities. We proposed transplant center-level solutions to modifiable barriers that could help patients navigate, reduce disparities, and improve access to care.
INTRODUCTION

Liver transplantation (LT) is the only cure for advanced liver disease, yet racial and ethnic disparities, known to exist for decades, continue to impede access to care.² To receive a LT, patients proceed through a lengthy, sometimes opaque, process (Figure 3.1). LT centers assess each patient’s appropriateness for transplant, culminating in a decision to list or not to list for LT. If listed, patients are prioritized based on disease severity; some will later be de-listed for a variety of reasons, such as death or being too sick to survive transplant. Health disparities exist related to access to the waitlist (Figure 3.1, Step 5),³¹,²⁹,³⁰,⁴⁴ which have negative downstream effects. For example, when waitlist race/ethnicity distributions from 109 US transplant center waitlists were compared with their donor service area, Black patients were under-represented on 81% of the waitlists, and Hispanic or Latino patients were under-presented on 62%.³ Tackling upstream LT listing barriers can improve access to LT downstream. Systematic and plausibly avoidable differences in LT listing adversely affecting socially disadvantaged groups⁶⁶ stem, at least in part, from social determinants of health (SDOH, e.g., income, employment, education, insurance) and structural racism.⁶⁷–⁷⁰ Structural racism can be defined as the result of laws, rules, and practices sanctioned by the government and institutions and embedded in the economic system and societal norms.⁷¹ LT evaluation may also be susceptible to structural racism, and these effects may be augmented due to its clinical, logistic, and/or ethical intricacies.

Understanding mechanisms to LT listing disparities has been difficult due to a paucity of data and the complex evaluation process. Most of the transplant community’s knowledge about the burden related to health disparities comes from kidney transplantation⁷²–⁷⁶ largely because data on patients on hemodialysis are in a national database. Therefore, pre-transplant data from LT evaluation is not nationally available. Per hepatology society
guidelines, a standard workup involves a battery of bloodwork, imaging, and evaluations with several UNOS defined providers: a hepatologist, surgeon, clinical social worker, and dietician. The evaluation can range from a day to months based on the severity of disease, and certain co-morbidities may necessitate additional testing. Throughout the evaluation, the patient, caregivers, and providers intermittently engage in-person and with various technologies (e.g. Electronic Health Record [EHR]) for communication of information. Importantly, LT listing involves a transplant committee decision, which is complex due to: (1) a nationally regulated multi-disciplinary team, (2) ethics of balancing donor organ stewardship with helping those in need of a LT, and (3) the diverse patient population.

Given the complexity of the LT evaluation process and mechanisms of disparities in listing, a systems engineering approach, specifically rooted in human factors engineering (HFE), may be useful. HFE principles systematically define the components and interactions of complex sociotechnical work systems, highlighting opportunities for improving patient care. For example, training providers to understand their biases is critical, but only one approach to addressing the larger work system. The Systems Engineering Initiative for Patient Safety (SEIPS) model has been used to assess complex work systems in other areas of medicine. The main domains of the SEIPS 2.0 model are: (1) the external environment, (2) work system (people, tasks, tools/technology, internal environment), (3) process, (4) outcomes, and (5) adaptation. This framework applied to LT evaluation may provide a clarifying and systematic view of pathways leading to disparities in listing.

To characterize transplant team perceptions and attitudes about potential mechanisms within the LT evaluation process leading to racial and ethnic disparities in listing, we
performed a comprehensive multi-center, multi-method (i.e., ethnographic observations, semi-structured interviews) qualitative study using an HFE approach. Qualitative methods studies are useful for providing rich, in-depth knowledge on a nuanced topic.\textsuperscript{87,88} This study aimed to develop a conceptual framework specific to equity in LT listing through developing an understanding of the work of the transplant team during evaluation and possible mechanisms for inequity in listing. These insights could inform potential transplant center-focused solutions for improving access to the waitlist.

**METHODS**

2.1 Research Design

We conducted a qualitative study with ethnographic observations and semi-structured interviews.\textsuperscript{89} Ethnographic observations included: (1) patient-provider interactions during candidacy assessments and (2) transplant committee meetings. The semi-structured interviews assessed provider descriptions and perceptions of the evaluation process and disparities.\textsuperscript{89}

2.2 Setting

We conducted a multi-center study at the two transplant centers from December 2020 through July 2021. We chose the centers for the high transplant volume\textsuperscript{90} and proximity of 2 centers serving a diverse patient population,\textsuperscript{91} Baltimore, MD. In 2019, each center had between: 79-98 adult deceased donor LT, (6-14\% on Medicaid per OPTN as of 3/4/22), 15-18.5\% Black patients on the waitlist, and 3.8-4\% Hispanic or Latino patients on the waitlist.\textsuperscript{92}

2.3 Sample population and recruitment
We used purposeful sampling to identify LT team experts: pre-/post-transplant coordinators and providers, social workers, dieticians, pharmacists, and leaders. We recruited via e-mail. We consented participants for observations and interviews if they met inclusion criteria of being a LT team member during the study period. We performed observations consecutively until saturation achieved within each provider type for patient-provider encounters and center for committee meetings.93

2.4 Data collection methods

Ethnographic observations conducted by non-transplant team members and qualitatively trained investigators (ATS, CNS, VSJ) included: (1) individual patient-provider appointments and (2) committee meetings. Direct observers recorded field notes on interactions among people, tasks, and technology, particularly for aspects related equity. We observed information gathering and discussions for decision-making. Observers created memos based on field notes. Each observation was 30-60 minutes.

We developed a semi-structured interview guide informed by HFE literature,86,94–102 including, the SEIPS 2.0 model.86 The SEIPS model domains are: (1) External environment, (2) Work system, (3) Process, (4) Outcomes, and (5) Adaptation. “Work system” domain has 4 components that complete the “Process”: people, tasks, tools/technology, and internal environment; “Work system” characteristics and interactions impact the quality of the “Process” and “Outcomes”. “Adaptation” domain has feedback loops between “Outcomes,” “Process,” and “Work system.” We pilot tested and iteratively refined the interview guide with clinicians, qualitative researchers, social epidemiologists, and human factors engineers to test question interpretation and understanding. Interviews included open-ended questions related to outlining the evaluation process, individual tasks, team decision-making, and mechanisms for racial
and ethnic listing disparities (Figure 3.2). We asked participant demographics (transplant experience, gender, race, ethnicity). One researcher (ATS, physician researcher with training in HFE and health equity) conducted all semi-structured interviews. Interviews were 1 hour, audio-video recorded, transcribed verbatim, and de-identified. The Consolidated criteria for Reporting Qualitative Research (COREQ) guidelines\textsuperscript{103} were used for this Johns Hopkins University Institutional Review Board approved study (#00242367). Participants completed informed consent.

2.5 Analysis

The research team analyzed the observational field notes and interview transcripts using thematic analysis with inductive and deductive analysis.\textsuperscript{104,105} The ethnographic observational memos were used to inform the codebook development and provide context for the interviews. First, investigators (ATS, CNS) used inductive coding to descriptively categorize participants’ responses to develop themes (e.g., “implicit bias,” “education,” “transportation”). The investigators coded initial interviews together to develop themes with retroactive revisions. When thematic saturation was reached (i.e., no new themes emerged), we finalized the code book. Investigators independently coded the interviews using qualitative NVivo software (QSR, Version 10) and reconciled discrepancies in coding through consensus.\textsuperscript{106} Then, using data matrices, the themes and corresponding text were categorized into higher-order domains based on the SEIPS model.\textsuperscript{86} The categorizations were determined through consensus by the investigators (ATS, CNS), and they used the data matrix to create a SEIPS-based conceptual framework adaptation. The conceptual framework then received feedback and approval by the team (clinicians, health equity researchers, qualitative researchers, and a systems engineer). The themes informed the conceptual framework by providing LT and health equity specific applications of the pre-existing SEIPS components.
RESULTS

3.1 Participant characteristics

Of the 104 transplant team members contacted (response rate: 71.8%, 74/103), 68 were consented for observation and/or semi-structured interviews (6 unavailable/not interested on follow-up). We conducted ethnographic observations of (1) individual patient-provider appointments (N=52; 27.5 hours) and (2) committee meetings (N=32; 21.5 hours). The 54 semi-structured interviews averaged 58.2 minutes. Participants had a median (IQR) of 8.5 (IQR 4, 14) years of LT experience, and 18.5% (10) of participants had leadership/administration roles (Table 3.1)

3.2 Conceptual framework for mechanisms of racial and ethnic disparities in liver transplant listing

Participant descriptions of the LT evaluation process were organized into a conceptual framework using the SEIPS model domains (Figure 3.3). Components of the Work system for LT evaluation are: (1) transplant center/local health system; (2) people (e.g., patients, caregivers, providers), (3) tasks of patient/caregiver and providers; and (4) tools/technology (Table 3.2). The LT process starts with receiving the referral, includes the work-up and committee meeting, and ends with informing the patient of the decision (Figure 3.3). Observed and participant identified outcomes potentially susceptible to racial and ethnic disparities are listing decision, incomplete evaluation, and delay in evaluation as important. Some participants also described feeling “uncomfortable” or “struggling with” decisions that could lead to listing disparities. The following sections summarize conceptual framework elements and describe how the process may function differently for minority populations, which can lead to differential outcomes.
3.3 External environment

Two themes emerged from participants linking structural racism from the external environment to additional external environment factors closely related to LT patient evaluation (Figure 3.3). The first theme was structural racism propagated through subjective listing guidelines. Many participants explained the psychosocial criteria in the national transplant society’s LT candidacy guidelines are subjective, and vulnerable populations “struggle to meet” them (see Process: Work-up section) due to “systemic issues ingrained for so long and in every aspect of society” (Table 3.3). The second theme was structural racism contributes to issues with insurance policies and national transplant metrics. Participants outlined structural racism operates through SDOH (e.g., education, employment, geography, citizenship) to transplant center barriers with insurance policies because the patient is not insured or under-insured (e.g., no transportation assistance benefit or limited covered transplant centers). Participants explained differential access to insurance for minority populations is important because they cannot afford post-LT medications, and risk graft rejection. Additionally, participants explained the viability of a transplant program relies on successful national metrics which do not incorporate equity, so being “aggressive patient advocates” for patients with less resources could lead to lower scores on quality metrics.

3.4. Process: Work-up phase

3.4.1 Transplant center & local health system in the Work-up phase

During Work-up phase of LT evaluation, participants identified two themes related to how the Transplant Center/Local Health System component of the Work System may lead to inequitable outcomes: Limited social worker resources and Limited resources for non-English-speaking patients. Many participants described that more social workers and resources would allow for necessary time and assistance with certain patients, such
as those with transportation barriers (Table 3.3). Additionally, participants outlined the importance of non-English-speaking patients having readily available consent forms, letters, and questionnaires.

3.4.2 People in the Work-up phase

Participants identified 3 Work-up-related themes regarding People in the Work system that, through SDOH, play a role in racial and ethnic listing disparities: (1) Patient socioeconomic status, (2) Patient health literacy, and (3) Patient’s geography and access to transportation. Participants explained how the effects of structural racism, such as differences in income and access to jobs and education, impact their access to resources for transplantation (Table 3.3). Participants described education was linked to health literacy, and health literacy was critical to understanding how to complete the work-up and utilize the tools given to them by the providers. Also, due to the high volume of visits during work-up and post-transplantation, providers found transportation and geography are barriers (e.g., access to car, affording gas/parking, and distance from the center). Paralleling these patient themes, participants also explained the effects of these SDOH for caregivers (Table 3.3). Specifically, participants recognized minority populations have support systems that are “barely surviving” and may be unable to provide financial support or to demonstrate social support (e.g., leave work to be at the patient’s appointments/hospital bedside). Participants explained patients with encephalopathy or frailty benefit from having a caregiver with good health literacy and no transportation/geographic barriers, but some may be limited due to SDOH as described above.

3.4.3 Tasks of patient, caregiver(s), and providers in the Work-up phase
Participants described 3 themes in the Work-up phase related to tasks that may be on the pathway to listing disparities: (1) *Variable patient engagement in the complex process*, (2) *Barriers to building trust in the patient-provider relationship*, (3) *Adaptability required by providers during assessments and education of patients*. Participants reflected on patients/families feeling overwhelmed by the many tasks expected of them (Table 3.2). To overcome this task burden, some participants emphasized the importance of patient engagement. In our observations, conversations with and about patients from minority populations involved SDOH related to difficulties demonstrating patient engagement (Table 3.3). Secondly, participants described a lack of diversity in providers may lead to patients feeling the providers cannot relate to them. Participants noted that provider diversity is especially important for those where there is “some distrust in the system” due to personal interactions or historical events related to race and the health system. Lastly, participants described providers gather information from the patient to “understand their insight into their disease” and educate about transplant. Observations demonstrated that patients from minority populations, due to SDOH, may need more time to describe their insight or understand educational information, but providers were not always able to adapt their communication or delivery.

### 3.4.4 Tools & technology in the Work-up phase

Two themes related to the Work system component Tools and technology in the Work-up phase were: *Reliance on information propagated through the EHR* and *Limited access to technology inhibits communication*. From participant interviews and observations, the transplant team uses EHR documentation by other providers (including outside records), and that information may include inaccuracies, inconsistencies, or implicit biases (Table 3.3). Additionally, participants explained limited access to
technology, such as virtual interpreters and cell phones, are barriers for equitable evaluation.

3.5. Process: Committee Meeting Phase

3.5.1 People in Committee Meeting Phase

Participants identified the 2 themes of Transplant team diversity and Role of social worker in psychosocial assessment as potential mechanism for racially/ethnically based differentials in listing. Participants described a homogeneous transplant team lacks “multiple voices at the table of different perspectives,” which could lead to inequitable listing decisions (Table 3.3). Additionally, while many participants expressed the social worker opinion is “probably the most prized, and most valued, because they're the professional expert on the matter,” some explained other provider opinions (e.g., surgeon, hepatologist) are sometimes prioritized. Congruent with this, we observed that the social worker’s psychosocial evaluation was sometimes less influential on the final decision when another provider knew the patient for a longer time.

3.5.2 Tasks of Providers in the Committee Meeting Phase

The 2 themes about Tasks in the Committee meeting phase that may result in listing disparities were Subjectivity and inconsistency in decision-making and Implicit bias and personally mediated racism in decision making. Participants reflected that sometimes emotionally based discussions related to the patient’s likeability or “who’s advocating for the patient” can lead to deviation from objective and consistent decision-making (Table 3.3). We observed tangential discussions and side comments (e.g., “He’s a good guy.”) reflecting this subjectivity. The closely related theme, Implicit Bias & Personally Mediated Racism in decision-making stemmed from participants noting that providers may not know their own implicit biases, which may impact committee meeting discussions.
Participants outlined that biases may lead to personally mediated racism (defined as differential actions towards others based on race/ethnicity)\textsuperscript{107} where the transplant team may raise concerns about substance abuse or follow-up in minority patients and not be as supportive towards their candidacy. Some described LT evaluation as an “unforgiving system,” and minority populations sometimes may “work harder to prove to the whole team” that they meet the psychosocial requirements.

3.6 Adaptation
The 3 themes about Adaptation related to listing disparities were (1) Limited review or awareness of transplant center outcomes related to equity, (2) Team member feedback, and (3) Transplant center role/ability to address disparities. Since most participants identified general morbidity and mortality conference as the only form of review of outcomes, some were not aware of mechanisms of racial and ethnic disparities (Table 3.3). Another opportunity for adaptation in the process that participants described was team member feedback. We observed instances in committee meeting where team members spoke up about someone’s potentially biased statements. However, participants also described a hierarchy and lack of structured feedback which may inhibit constructive criticism. Finally, while some participants felt the transplant center’s role in addressing listing inequities was unclear due to overshadowing pre-existing issues (e.g., referral patterns, structural racism), others felt it was the transplant centers duty to “do better…and see where patients get lost in this process.” Table 3.4 is a summarizing table of the themes across the conceptual framework.

DISCUSSION

4.1 Study Conclusions
In this multi-center qualitative study, transplant team members shared their perceptions of the LT evaluation, uncovering mechanisms that may generate racial and ethnic disparities in LT listing. Transplant team members perceived decisions about listing were largely influenced by external factors (e.g., structural racism, subjective guidelines, and national quality metrics) that permeate the LT evaluation process (work-up and committee meeting phases) through various components of the work system, such as the transplant center/local health system, people (patients, caregivers, providers), tasks, and tools. Mechanisms included implicit bias or interpersonal racism at the time of decisions and structural barriers related to limited transplant center resources or lack of diversity in the transplant team. Further, since the data related to inequitable outcomes were not specifically collected or reported back to the team, adaptation to address unwanted outcomes was limited, perpetuating disparities.

Volk et al. described the decision-making behind the evaluation process in a multi-center qualitative study. We have expanded upon this understanding to provide a framework which centers can use to assess disparities at their center. By developing interventions that target the transplant center and modifiable patient-level barriers along the LT evaluation process, we can redesign work systems and processes to reduce disparities and improve care (Table 3.5). This perspective shifts from patient-level barriers (e.g., inadequate health literacy of patient) to systems-level approaches (e.g., transplant center having appropriate patient education materials) to understanding the issues and creating solutions. For example, labeling a patient with the risk factor of non-English-speaking puts the burden on the patient to overcome inequities. How can we support patient-centered care and re-align transplant center metrics of success to include promoting equity? Transplant centers balance national quality metrics (waitlist survival, access to transplant, and post-transplant survival) with wanting to help patients that may
have a higher risk profile from psychosocial barriers. Transplant center level solutions (Table 3.5) could be incentivized through expanding quality metrics about equity. Since tackling all these solutions at once would be difficult, they should be prioritized by each transplant center based on their patients and institutional environment concerns. The goal of health equity involves a customizable approach to tools and programs based on needs.

Participants identified a controversy among transplant team perspectives regarding the role or ability of the transplant center to alleviate inequities in LT listing. Some argue that the principal mechanisms to barriers in access to the waitlist are outside the transplant center’s control. They may seem insurmountable (e.g., structural racism) or be pre-referral, such as late diagnosis/treatment or inequitable referral patterns. While it is true that transplant centers themselves may be ill equipped to directly change society at large, it may be possible to design healthcare delivery in such a way that it helps patients respond and navigate the SDOH-related barriers. We utilized the SEIPS model from human factors engineering to assess mechanisms for disparities because it includes aspects from the social-ecological model; this is a common model used by the Centers for Disease Control and Prevention and the National Institutes of Health to understand health equity. The SEIPS model incorporates the various levels from the social-ecological model (e.g., patient, family, health system, society) as parts of the work system and external environment. Additionally, the SEIPS model situates these components within a process with outcomes, and feedback loops. Thus, we were able to organize participant perceptions within our LT specific SEIPS conceptual framework and identify feasible strategies for the transplant center to play an active role in prioritizing and confronting inequities.
These findings highlight the potential problems with the psychosocial-related contraindications to LT in the current transplant society guidelines,\textsuperscript{33} which are: (1) ongoing alcohol or illicit substance abuse, (2) persistent non-compliance, (3) lack of adequate social support. First, the definition of “ongoing” substance use and post-transplant outcomes is currently under debate.\textsuperscript{115} Second, compliance is difficult to assess because it is not uniformly defined and “persistent” is vague. Thirdly, “adequate” social support is not clearly defined and may negatively impact listing rates.\textsuperscript{116} These non-specific criteria give opportunity for implicit bias and subjectivity to pervade the decision-making. As seen in our findings, social support that is non-traditional (e.g., not a spouse/parent) or working to afford medical bills may not be viewed by the team as adequate and compliance may be questioned. By standardizing assessments locally with more precise definitions for these subjective contraindications and applying these similarly across all races/ethnicities, we may decrease the number of patients excluded from LT.

### 4.2 Study limitations

While qualitative studies have limited generalizability, this study has good transferability, which is the qualitative research equivalent to generalizability.\textsuperscript{117} Prior work has demonstrated similarity in LT evaluation and decision-making between multiple centers,\textsuperscript{34} so our large size, high response rate, and the multi-center component should allow for transplant centers/providers to relate to at least some of the mechanisms and solutions for listing disparities. Importantly, this study was only with transplant team providers, not patients, so these findings may not match patient-reported experiences. While the literature evaluating Black patients undergoing kidney transplant evaluation demonstrated some similar findings, such as patients having medical mistrust, wanting
transplant center support, and valuing education about the process, patients interviews added insights about the importance of provider attitudes and an understanding of certain provider roles.\textsuperscript{118,119} Qualitative research including LT patient experience during evaluation is needed. While some participants may be biased in their recollection of events, our parallel ethnographic observations allowed us to see inconsistencies between what was described and actuality. The juxtaposition of these methods homed in on a single step of the LT process, evaluation, provided a rich understanding of the nuances and perspectives in all aspects of the process.\textsuperscript{89} Without having such an in-depth understanding, solutions developed may have unintended negative consequences.\textsuperscript{120}

4.3 Conclusion

In summary, the mechanisms for racial and ethnic disparities in LT listing are rooted in both external factors, as well as the internal process composed of complex tasks undertaken by patients, caregivers, providers, and the transplant center. Participants identified barriers at the patient level (e.g., health literacy, transportation, and social support limitations) and transplant center level (e.g., transplant team diversity, resources for non-English speaking patients) that can be prioritized by transplant centers to tackle disparities. We have demonstrated use of the SEIPS 2.0 model to tease apart problematic aspects of a process that may exacerbate disparities downstream, and other fields with complex work systems for treatment decisions (e.g., oncology) may find this applicable. This work is a call for transplant centers, national societies, and policy makers to shift from a lens of equality (same resources for all) to equity (tailored, patient-centered resources) for our diverse population of LT patients.
We appreciate Haneefa Saleem’s assistance in the early qualitative research guidance.

This work was supported by grant number K23DK115908 (Garonzik-Wang) from the National Institute of Diabetes and Digestive and Kidney Diseases; by grant number K24AI144954 (Segev) from the National Institute of Allergy and Infectious Diseases (NIAID); by grant number K01HL145320 (Jackson) from the National Heart Lung and Blood Institute; and by grant K01HS024600 (Purnell) from the Agency for Healthcare Research and Quality. This work was also supported by the Stetler Foundation (Strauss). The funders had no role in the preparation, review, or approval of the manuscript or the decision to submit for publication. This work was supported in part by Health Resources and Services Administration contract HHSH250-2019-00001C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.
FIGURES

Figure 3.1 Simplified steps of the liver transplant process from healthy to receiving a liver transplantation.
Figure 3.2 Semi-structured interview questions for providers about the liver transplant evaluation process and potential mechanisms for racial and ethnic disparities in listing.

**Sample Open-Ended Questions for Interviews**

1. I’d like to start by hearing about you. Please tell me briefly about your role on the liver transplant team.

2. Can you talk me through the liver transplant evaluation process from your perspective from time of referral to the decision of whether or not to list them for transplant? [Draw map and check with participant periodically]

3. When and how do you obtain information about a patient that is undergoing liver transplant evaluation?

4. What information do you use to determine if someone is a good transplant candidate?

5. Who is most at risk for not being a good candidate for listing and why? What puts certain people more at risk for not being listed for transplant?

6. What do you think about the teamwork to evaluate patients for liver transplant?

7. Think of a tough case related to psychosocial factors where the team had trouble making a decision and it involved a lot of discussion. Can you explain the case including the cues that helped the team make the decision?

8. How do you feel psychosocial factors are considered by the team?
Figure 3.3 Conceptual framework of a systems engineering approach to racial and ethnic disparities in listing for liver transplantation.

*Adapted from SEIPS 2.0 model. Elements were identified from semi-structured interviews and ethnographic observations at two transplant centers.
### Table 3.1 Characteristics of participants from two transplant centers that completed semi-structured interviews about the liver transplant evaluation process and potential mechanisms for listing disparities.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Summary N=54</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Participant, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Leadership(^1)</td>
<td>10 (18.5)</td>
</tr>
<tr>
<td>APP</td>
<td>4 (7.4)</td>
</tr>
<tr>
<td>Coordinator(^2)</td>
<td>13 (24.1)</td>
</tr>
<tr>
<td>Dietician/Financial/Pharmacist</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td>Physician(^3)</td>
<td>22 (40.7)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>6 (11.1)</td>
</tr>
<tr>
<td>Women, n (%)</td>
<td>40 (74.1)</td>
</tr>
<tr>
<td><strong>Self-Reported Race/Ethnicity, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>39 (72.2)</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>7 (13.0)</td>
</tr>
<tr>
<td>Other(^4)</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td><strong>Experience, years, median (IQR)</strong></td>
<td></td>
</tr>
<tr>
<td>Any Transplant</td>
<td>9.5 (5, 14.8)</td>
</tr>
<tr>
<td>Liver Transplant</td>
<td>8.5 (4, 14)</td>
</tr>
</tbody>
</table>

Center 1: N=33, Center 2: N=21

1 Not mutually exclusive to other types. Administrative/leadership roles
2 Coordinator includes pre-transplant and post-transplant
3 Physician includes hepatologist, surgeon, anesthesiologist, psychiatrist
4 Other: Hispanic or Latino, Asian, and Multi-racial combined due to small numbers

Abbreviations: Advanced Practice Provider (APP), Interquartile Range (IQR)
Table 3.2 Participant defined elements of each Work system component from a conceptual framework of a systems engineering approach to racial and ethnic disparities in listing for liver transplantation

<table>
<thead>
<tr>
<th>Work System Component</th>
<th>Participant Defined Elements from Liver Transplant Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplant Center &amp; Local Health System</td>
<td>• Transplant Center culture, structure, policies, processes, volume&lt;br&gt;• Local Health System culture, structure, policies, processes</td>
</tr>
<tr>
<td>People</td>
<td>• Patient&lt;br&gt;• Caregiver(s)/Support System&lt;br&gt;• Transplant Coordinators&lt;br&gt;• Hepatologist, Surgeon, APPs&lt;br&gt;• Social Worker&lt;br&gt;• Dietician&lt;br&gt;• Pharmacist&lt;br&gt;• Consultants</td>
</tr>
<tr>
<td>Tasks of Patients, Caregiver(s), &amp; Providers</td>
<td><strong>Patient/Caregiver(s):</strong>&lt;br&gt;• Coordinating, communicating, and interacting with social support/caregiver(s) and the transplant team&lt;br&gt;• Building bi-directional trust with provider&lt;br&gt;• Learning about liver transplantation&lt;br&gt;• Completing lab work, imaging, procedures, and appointments&lt;br&gt;&lt;br&gt;<strong>Providers:</strong>&lt;br&gt;• Coordinating, communicating, and interacting with the patient and their social support/caregiver(s)&lt;br&gt;• Building bi-directional trust with patient&lt;br&gt;• Data collection about patient (including outside records)&lt;br&gt;• Documentation&lt;br&gt;• Formulating personal impression of patient for candidacy&lt;br&gt;• Balancing wanting to help with not wasting limited organs&lt;br&gt;• Team decision-making&lt;br&gt;&lt;br&gt;Tools &amp; Technology</td>
</tr>
</tbody>
</table>

The conceptual framework was adapted from the Systems Engineering Initiative for Patient Safety (SEIPS) 2.0 model. Elements were identified through ethnographic observations and semi-structured interviews at two urban transplant centers. APP: Advanced Practice Provider; EHR: electronic health record; SIPAT: Stanford Integrated Psychosocial Assessment for Transplant.
Table 3.3 Representative quotations organized based on a conceptual framework of a systems engineering approach to racial and ethnic disparities in listing for liver transplantation.

<table>
<thead>
<tr>
<th>THEME</th>
<th>REPRESENTATIVE QUOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EXTERNAL ENVIRONMENT</strong></td>
<td></td>
</tr>
<tr>
<td>Structural racism propagated through subjective listing guidelines</td>
<td>“It's [structural racism] been ingrained for so long and in every aspect of society it pervades everything. As much as we try and do an objective psychosocial, in quotes [uses hand quotes], assessment of a patient, the psychosocial metrics that we use, persons of color minority groups fall short of those metrics because of generations of racism…We can try and claim to be objective about things like ‘well, we're just looking at what resources they have,’ and you can't argue that that's not important post-transplant. You need resources to succeed post-transplant. So you can try and hide behind the guise that that's just being objective.” (#0601, Physician).</td>
</tr>
<tr>
<td></td>
<td>“Part of the reason that there are disadvantages due to their race is structural racism…Some aspects of our transplant evaluation are subjective that transplant candidates of different racial backgrounds will struggle to meet and check off those boxes…specifically African American individuals, they struggled to get evaluated and they struggle to get listed.” (#060. Physician)</td>
</tr>
<tr>
<td></td>
<td>“There's many communities of color…They have no opportunity for education. They have no opportunity for jobs. They have no opportunity for even fresh groceries…that has played a major role in the ability of communities of color to get to transplant in the city.” (#0406, Physician)</td>
</tr>
<tr>
<td>Structural racism contributes to issues with insurance policies and national transplant metrics</td>
<td>“Because of education, because of lack of employment, and that will explain why they're not insured. That will set them up for the failure to be listed because they don't have insurance, or at least delay the process of being listed…If you don't have insurance to have a liver transplant, it requires a lot of resources, liver transplant is almost half a million dollars…it is the structural setup that may predispose some people to have disparity…Why do we not have universal healthcare?” (#0309, Coordinator)</td>
</tr>
<tr>
<td></td>
<td>“They [unauthorized immigrants] may be the best people in the world. They may have great jobs, but if they can't get insurance, and they can't afford the medication, we can't transplant them because they won't be able to take care of the organ.” (#0107, Physician)</td>
</tr>
<tr>
<td></td>
<td>“We want physicians that are aggressive patient advocates. Wouldn't want it any other way, couldn't imagine being emotionally neutral towards a person who has come to you, put their lives in your hands, and said ‘You’re my doctor. You'll take care of me.’ So that's fine. But there's another agenda in play for those at the selection committee meeting and that's that our program has to be successful and viable.” (#0902, Physician)</td>
</tr>
<tr>
<td><strong>PROCESS: WORK-UP PHASE</strong></td>
<td></td>
</tr>
<tr>
<td>Transplant Center &amp; Local Health System</td>
<td>“Psychosocial evaluation support are definitely some of the areas where I think we need more help-more FTE's. I think our social workers are fantastic. There's just not enough of them. That is probably one of the biggest challenges for our patients. And if we don't have enough resources for them, sometimes we have to question—are they unsuccessful because we didn't have enough resources for them?” (#0407, Dietician/Financial/Pharmacist)</td>
</tr>
<tr>
<td>Topic</td>
<td>Quote</td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Limited resources for non-English-speaking patients</td>
<td>&quot;Our consents sometimes aren't translated to Spanish, and we have a lot of Spanish speaking patients or living donor questionnaire. I don't know of any living donor questionnaire that's in any other language but English. So I do think that even with an interpreter, the barrier definitely doesn't go away.&quot; (#0300, Coordinator)</td>
</tr>
<tr>
<td></td>
<td>&quot;We have letters that we can send to patients that are in Spanish. We don't have anything in any other language...A goal of mine is to increase the number of Spanish letters that we have available to us to send to patients at any point of their time before transplant whether it's evaluation, like 'Hey, we haven't heard from you. Here's what you need to do. The orders are in enclosed.'&quot; (#0602, Coordinator)</td>
</tr>
<tr>
<td>People</td>
<td>&quot;So then there's a financial obligation that what happens when you're off of work for six to eight weeks at least after transplant, maybe even longer depending on how you're doing. They may not be able to afford to do that...especially if they're the breadwinner of the family...They might not have any health insurance because of the type of work that they do.&quot; (#0205, Social Worker)</td>
</tr>
<tr>
<td>Patient socioeconomic status</td>
<td>&quot;Socioeconomic disparities that cluster around people who are not white that impact their ability to access resources and attend to the issues that surround transplantation in the operative and post-operative period, which lead to significant obstacles and make the transplant unsuccessful. So, it may be that there are difficulties for these populations in coming to clinic frequently or having the understanding of aggressively seeking care when it might be more challenging to do so or to understand the reasons to do so.&quot; (#070, Social Worker)</td>
</tr>
<tr>
<td>Patient health literacy</td>
<td>&quot;I do feel as though we should be more understanding that they may just need more of an assistance, more help to even have the information. If you don't have that knowledge or you don't come from a background where that knowledge is available to you, it's all going to be a learning stepping-stone (#0106, Dietician/Financial/Pharmacist).&quot;</td>
</tr>
<tr>
<td>Patient's geography and access to transportation</td>
<td>&quot;Can they afford gas and transportation to get to Baltimore...We transplant people as far as Garrett County. You know it's a hardship. A lot of them are elderly or older folks, so they don't have the extra funds to drive the two and a half hours here and pay to park or spend the night. So that's a big hardship on them as well.&quot; (#0402, Coordinator)</td>
</tr>
<tr>
<td>Support system/caregiver(s) socioeconomic status</td>
<td>&quot;I do find it troublesome when we talk about transplanting someone who might live six, seven hours away from [hospital] because that makes it very difficult to take care of them post-transplant. So, that's a geographical bias.&quot; (#0406, Physician)</td>
</tr>
<tr>
<td></td>
<td>&quot;A barrier is transportation and making it to appointments...but we don't have resources to assist with that.&quot; (#0103, Social Worker)</td>
</tr>
<tr>
<td></td>
<td>&quot;Who they identify as primary support I get their name and number and see if the primary support is working full time and if they're able to take leave...A lot of people in the city, they don't have that [support]. The parents are barely surviving parents...so they're not going to be a part of their transplant process.&quot; (#0103, Social Worker)</td>
</tr>
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</table>

"The husband has never been in the hospital to visit with her. Always working, working, working behind the wheel in his truck. I understand."
He wants to keep the insurance up and running. And if he doesn't work full time, they might just take that insurance away from him.” (#0405, Physician)

### Support system/caregiver(s) health literacy

“Some patients are encephalopathic...having a person like a caregiver, a designated person who is health literate for them when they can't be for themselves.” (#0605, Coordinator)

“If a family member or support person is asked, 'Are you willing? Are you going to be available to help them as they recuperate with getting to the labs, getting to clinic?' They're going to say yes because they don't want to feel like they're hindering a person's life if they say no...They may think that's something they can do, but when they're actually faced with the reality of everything it involves, it may be too much for them.” (#01000, Coordinator)

### Support system/caregiver's access to transportation

“I've had patients who I need them to get a cath, and they're like 'well I don't have anybody to take me because everyone I know works.' So they would need that person to take off work to drive them there.” (#0300, Coordinator)

“A lot of folks don't drive or don't have a car and so if they don't have that reliable caretaker who can actually bring them places and bring them to lab work and bring them to physical therapy and things like that. It's not just somebody in the home to help them with their medications and their meals. It's somebody who can actually get through the process successfully.” (#0502, Advanced Practice Provider)

### Tasks of Patient, Caregiver(s), and Providers

#### Variable patient engagement in the complex process

“They [patients] are overwhelmed, and there's so many appointments. Because after you have your evaluation, then you're getting all this medical testing done, all this blood work done. You're just trying to tick those things off your list.” (#0204, Social Worker)

“One of the things I also talked to them [patients] in clinic about is: I don't want them coming in here thinking that they're in the center, and there's a circle of people around them, and that's their team, and they just have to do whatever the people around them told them to do. I told them that they need to view themselves as part of a circle, and they are an equal team member. So, I have responsibility to them. They have a responsibility to me, and to the hepatologist, and to whoever else is part of the team.” (#0506, Coordinator)

[In our observations, conversations with and about patients from minority populations involved SDOH related to difficulties demonstrating patient engagement.]

#### Barriers to building trust in the patient-provider relationship

“There needs to be a little bit more diversity...if I was a patient, I wouldn’t think that they would know how to relate to what I'm going through, or what I've been through, to really look at me as a person first.” (#0509, Dietician/Financial/Pharmacist)

“You also have a patient population coming in who can be slightly apprehensive of the process and used to sometimes being jerked around. And so it makes for some distrust in the system and just trying to get through that can be very challenging.” (#0607, Physician)

“Our role as coordinators and social workers is: Let me educate you on why this is important.” (#0506, Coordinator)

#### Adaptability required by providers during assessments and education of patients

“As I'm interviewing a patient, it's important for me to understand their insight into their disease, and whether or not they've continued to drink, despite being told they had alcoholic liver disease, or despite developing decompensated cirrhosis. So sort of having a timeline of how things have gone. At least having some clue allows me to sort of gauge the patient.” (#0307, Physician)
Observations demonstrated that patients from minority populations, due to SDOH, may need more time to describe their insight or understand educational information, but providers were not always able to adapt their communication or delivery.

**Tools & Technology**

**Reliance on information propagated through EHR**

“There’s documentation in the chart for the past year or so that patient has been told multiple times that she needs to stop drinking.” (#0405, Physician) [We observed these descriptions were not always accurate.]

“Other people gathered and their interpretation of the information that they gathered. Same outside of our system, information that's been put into [EHR] by other providers, maybe looking at the patient through a different lens.” (#0204, Social Worker)

**Limited access to technology inhibits communication**

“We do have the iPad translators here which worked really well to help translate what we're saying and medical terminology to their language. However, sometimes the iPads aren't always in the patient's room...so you do have the resources, it's just sometimes I've seen it's limited.” (#0303, Dietician/Financial/Pharmacist)

“Unless someone comes with a cell phone, and availability to reach us, then it's going to be very challenging.” (#0503, Physician)

**PROCESS: COMMITTEE MEETING PHASE**

**People**

**Transplant team diversity**

“We all advocate for people who remind us of ourselves, and there’s just not a lot of African American faces in the transplant community.” (#0607, Physician)

“The representation at the table for the decisions is made by a group that is not only white men, so that is a step…It is beneficial to our team to have multiple voices at the table of different perspectives.” (#0902, Physician)

**Role of social worker in psychosocial assessment**

“A lot of times some of the physicians give a lot of the psychosocial stuff or maybe that should just be left to the social worker who did the full psychosocial evaluation before it kind of gets little pieces of it sprinkled here and there--before the social worker kind of gives their input” (#0304, Coordinator)

“I think it's pretty good because usually the social workers present their objective assessment of the patients, leave out all those sort of subjective minor details. So things that matter the most to getting listed for liver transplant are, whether there's social support, whether there's a post-op care plan, whether if--especially in like substance use disorder cases--whether they've remained sober, whether they've enrolled in treatment programs and those are all sort of yes or no questions that can be answered.” (#050, Physician)

[We observed that the social worker’s psychosocial evaluation was sometimes less influential on the final decision when another provider knew the patient for a longer time.]

**Tasks of Providers**
| Subjectivity and inconsistency in decision-making | “I do think sometimes things get emotional and non-objective and kind of get lost, and you can see that the biggest variation is in social approval.” (#0803, Physician)  
“Social work will say ‘not a good candidate.’ But then you get back to the surgeons, and they’ll be like, ‘Oh, but this lady has two small children at home. We need to save her for her children.’ And I don’t know if that’s what we should be basing our decisions off.” (#0801, Dietician/Financial/Pharmacist)  
“If you are conveying information that's very subjective about a patient you have to be careful about the way you say it to not kind of skew people's thinking about the patient.” (#0304, Coordinator) |
| Implicit bias & Personally mediated racism in decision-making | “It's complicated and the reasons why these disparities exist and access for minority populations or populations that are Latino or African American community to transplant are complicated is definitely on the one hand probably racism or stereotyping that occurs by providers and judgments based on skin color or population classification that occurs.” (#070, Social Worker)  
“African American patient compared to a Caucasian patient--I do sort of observe a pattern, in which there's more of a barrier to overcome. They almost have to work harder to prove to the whole team that they're going to be able to take on this responsibility, and that they have the appropriate support in order to do that. I feel like we're maybe less strict in our evaluation for certain groups, for people that seem like they have it together.” (#0802, Physician)  
“We can do a little bit better before saying that some people are just not a good candidate, or they're just not going to follow up, or they're just going to go back to using whatever they were using before…I do want to be my patients advocates regardless of their race or color or gender.” (#050, Physician)  
“We have a very unforgiving system for people without privilege and people with privilege have second, third, fourth, fifth chances. People without privilege, you don't even sometimes get a chance. That's my definition of privilege, people that get endless second chances” (#0105, Physician). |
| ADAPTATION | Limited review or awareness of transplant center outcomes related to equity | “I don't really see that [listing disparities]. I feel like we're very fair at who we list and transplant. It's really about their medical and social aspects. There's a lot of Caucasian people that also have a lot of psychosocial issues, so we, I think, treat them very equally.” (#080, Coordinator)  
“I don't think it affects it at all. I don't even know what the patient looks like. We don't ask what their race is.” (#0808, Dietician/Financial/Pharmacist) |
| Team member feedback | “I think that the teamwork can be sort of a semi-dysfunctional family. We've known each other for years...so we're very okay to speak up our minds.” (#0503, Physician)  
“I wouldn't say that it's [feedback] in any structured way. I would say that if somebody had feedback to give it would be that person being brave enough to say it. And I wouldn't even know who to direct that to, at what forum to express that.” (#0602, Coordinator) |
| Transplant center role/ability to address disparities | “There's a different, there's a definite kind of weeding out process I feel that happens even before transplant [team] gets involved” (#0100, Physician) |
"It's [listing disparity] so multifactor. Every answer is going to be too naive. It's so systemic. Just trying to solve it as a very center-based level is not even enough. It's also center dependent and what is your goal as a transplant center...to help everybody...it would be a nice thought, but I'm not sure we have everything in place to actually do it.” (#040, Physician)

"I don't know the answer, but I think that we need to do better...and see where patients get lost in this process and how we can make it smoother, make it more objective." (#060, Physician)

The conceptual framework was adapted from the Systems Engineering Initiative for Patient Safety (SEIPS) 2.0 model. Themes were identified through semi-structured interviews and ethnographic observations [noted italicized and in brackets] at two urban transplant centers. EHR: Electronic health record; SDOH: Social determinants of health
### Table 3.4 Summary table of themes organized based on the conceptual framework specific to equity in liver transplant evaluation from ethnographic observations and semi-structured interviews with transplant team members

<table>
<thead>
<tr>
<th>EXTERNAL ENVIRONMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Structural racism propagated through subjective listing guidelines</td>
</tr>
<tr>
<td>• Structural racism contributes to issues with insurance policies and national transplant metrics</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PROCESS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Transplant Center &amp; Local Health System</strong></td>
</tr>
<tr>
<td>• Limited social worker resources (W)</td>
</tr>
<tr>
<td>• Limited resources for non-English-speaking patients (W)</td>
</tr>
<tr>
<td><strong>People</strong></td>
</tr>
<tr>
<td>• Patient socioeconomic status (W)</td>
</tr>
<tr>
<td>• Patient health literacy (W)</td>
</tr>
<tr>
<td>• Patient’s geography and access to transportation (W)</td>
</tr>
<tr>
<td>• Support system/caregiver(s) socioeconomic status (W)</td>
</tr>
<tr>
<td>• Support system/caregiver(s) health literacy (W)</td>
</tr>
<tr>
<td>• Support system/caregiver’s access to transportation (W)</td>
</tr>
<tr>
<td>• Transplant team diversity (C)</td>
</tr>
<tr>
<td>• Role of social worker in psychosocial assessment (C)</td>
</tr>
</tbody>
</table>

**Tasks of Patient, Caregiver(s), and Providers**

- Variable patient engagement in the complex process (W)
- Barriers to building trust in the patient-provider relationship (W)
- Adaptability required by providers during assessments and education of patients (W)
- Subjectivity and inconsistency in decision-making (C)
- Implicit bias & personally mediated racism in decision-making (C)

**Tools & Technology**

- Reliance on information propagated through electronic health record (W)
- Limited access to technology inhibits communication (W)

<table>
<thead>
<tr>
<th>ADAPTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Limited review or awareness of transplant center outcomes related to equity</td>
</tr>
<tr>
<td>• Team member feedback</td>
</tr>
<tr>
<td>• Transplant center role/ability to address disparities</td>
</tr>
</tbody>
</table>

W: Work-up Phase of Process  
C: Committee meeting Phase of Process
Table 3.5 Modifiable barriers in liver transplant evaluation at the patient and transplant center level and potential transplant center solutions that may mitigate racial and ethnic disparities in listing.

<table>
<thead>
<tr>
<th>MODIFIABLE BARRIER</th>
<th>POTENTIAL TRANSPLANT CENTER SOLUTION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TRANSPLANT CENTER LEVEL BARRIERS</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Lack of feedback to transplant team about disparities and variable transplant team awareness of inequities | • Setting transplant center goals on equity  
• Re-engineering team didactics and conversations to incorporate growing team understanding about health equity  
• Data-driven feedback/reports about outcomes to the transplant team |
| Providers feeling overwhelmed by deep-rooted mechanisms of disparities | • Partner with community health initiatives, mental health providers, and substance rehabilitation centers  
• Collaborate with public health experts and community-based participatory research experts  
• Engage in health policy changes and quality metric definitions as a transplant center and leaders  
• Resource-sharing with other groups in health system (e.g., oncology) |
| Subjective and inconsistent decision-making                   | • Data-driven, objective decision support tools and processes  
• Create/update and actively use easily understood protocols to increase standardization and transparency in decisions  
• Instead of declining based on subjective factors, question how to approach objectively as a team  
• Ensure team understands extensive and valuable prior training by Social Workers and their role is clear in determining psychosocial aspects of evaluation  
• Standardize patient assessments (e.g., patient insight of disease) and patient education so all providers meet the patient where they are. |
| Implicit bias & personally mediated racism                    | • Implicit bias training for individual team members  
• Team-based implicit bias training  
• Building team culture and cohesion where acknowledging implicit bias is accepted and encouraged |
| Unavailable or under-utilized social work resources            | • Hire more social workers  
• Gather, organize, support more social work resources  
• Transparency of resources available and whom they are available for  
• Reports back to team about how resources are being used across all populations |
| **PATIENT LEVEL BARRIERS WITH TRANSPLANT CENTER SOLUTIONS**  |                                     |
| Low Health literacy                                           | • Tools to assess and identify health literacy concerns, so they can be understood and addressed  
• Tailored patient education materials  
• Group educational sessions (patients, caregivers/social support) |
| Limited transportation                                         | • Transportation vouchers  
• Proactively (early and often) engage patient with Ride Assistance Programs  
• Telemedicine when feasible to reduce burden  
• Increase racial and ethnic diversity of transplant team through recruitment and retention |
| Non-English-speaking                                           | • Have non-English speaking transplant team members (particularly coordinator, social worker)  
• Translated materials (e.g., letters, consents) |
<table>
<thead>
<tr>
<th>Concerns about patient's social Support/Caregiver(s)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• More mobile translation tools and interpreters readily available</td>
<td>• Create tools to assess social support, so patient, social support and team can better understand gaps in knowledge and resources.</td>
</tr>
<tr>
<td></td>
<td>• Create tools to educate social support/caregivers about the transplant process and post-op responsibilities</td>
</tr>
</tbody>
</table>
Chapter 4. Fair artificial intelligence-based clinical decision support

**ABSTRACT**

Despite growing evidence that artificial intelligence-based clinical decision support (AI-CDS) tools can leverage large-scale data to provide helpful diagnostic and prognostic information, providers have valid adoption hesitancies. In this multi-center study, we provided a case study demonstrating the benefits of utilizing an evidence-based framework within a human-centered design approach to understand perspectives of users about a fair AI-CDS tool specific to their domain. We performed thematic coding with inductive analysis of semi-structured interviews with liver transplant providers (hepatologists, surgeons, coordinators, social workers, nurse practitioners, administrators, dieticians, and pharmacists) from two urban transplant centers. Interviews elicited information on the transplant evaluation workflow and perceptions about AI-CDS. Two coders independently analyzed the interviews and reconciled differences in coding by consensus until thematic saturation was achieved. Related to user perceptions about fair AI-CDS for LT evaluation decision-making, 6 themes emerged: (1) need to know who made the AI-CDS and their motivations; (2) desire to understand how the AI-CDS was developed; (3) opinion that AI-CDS could mitigate emotions and biases by being objective; (4) AI-CDS as a new member of the transplant team, not a replacement; (5) want AI-CDS to help with identification of patient resource needs; and (6) the patient's role in AI-CDS should be considered. Overall, future users of AI-CDS were cautiously optimistic about the potential for fair AI-CDS to improve outcomes for patients.
INTRODUCTION

Since artificial intelligence (AI) is being increasingly used in medicine, incorporating considerations about health equity in the design, deployment, and evaluation of AI-based clinical decision support (AI-CDS) systems is critical. AI uses large amounts of data to create relationships and make predictions that can facilitate decisions in clinical practice, and AI can use many types of data from images to words. The National Academy of Medicine encourages domain specific considerations of AI use. AI-CDS for different clinical applications requires careful tailoring, so multi-disciplinary teams creating or implementing AI-CDS will need guidance on considerations for their specific domain application. Understanding concerns of users, such as clinicians, and engaging users at an early stage in AI-CDS development through human-centered design may alleviate fears and lead to better implementation and adoption downstream.

AI adoption has been controversial due to concerns about fairness. Algorithms learn from data about under-represented populations that may have experienced structural or personally mediated racism. Those experiences may manifest in the data through differences in healthcare utilization, variations in diagnostics, or implicit biases in documentation. Therefore, these groups are at risk for inaccurate predictions or misallocation of resources. This concept of data perpetuating inequity has been demonstrated outside of medicine in hiring and criminal justice. Algorithm design, biases in data, and interactions of model predictions with clinicians may exacerbate health disparities, but distributive justice can be incorporated into model design, deployment, and evaluation to proactively improve health equity.

We aimed to use a case study to demonstrate the benefits of utilizing an evidence-based framework within a human-centered design approach to understand perspectives of
users about a fair AI-CDS tool specific to their domain. The case study is AI-CDS for liver transplantation (LT). AI has been increasingly used in LT generally to facilitate decision making. The decision on whether to list someone for liver transplant is complex and involves considerations about a patient’s medical, surgical, and psychosocial appropriateness for transplant. An impetus for AI-CDS could be to predict success of transplant, but understanding user needs and insights for AI-CDS, such as definitions of success would be helpful to design. By understanding user perceptions about potential concerns and benefits of AI related to fairness, stakeholders (e.g., clinicians, developers, policymakers) will be better equipped to design and utilize these types of tools.

**METHODS**

**Research Design & Setting**

As part of our larger qualitative study related to racial and ethnic disparities in LT listing, this study is focused on the careful considerations about AI in this setting. We conducted a multi-center study at the two transplant centers from December 2020 through July 2021. In 2019, each center had between: 79-98 deceased donor LT, 15-18.5% Black patients on the waitlist, and 3.8-4% Hispanic or Latino patients on the waitlist. We conducted semi-structured interviews with transplant team members and assessed their perceptions of AI generally and specifically for LT evaluation.

**Sample population and recruitment**

We used purposeful sampling to identify LT team experts: pre-/post-transplant coordinators and providers, social workers, dieticians, pharmacists, and leaders. We recruited via e-mail. We consented participants if they met inclusion criteria of being a LT team member during the study period.
Data collection methods

We developed an evidence-based framework for engaging users in the design phase of a fair AI-CDS (Figure 4.1).\textsuperscript{122,131,132} The framework incorporated meeting the participants where they were regarding their setting (e.g., prior experience, attitudes about AI, workflow). Also, the framework included considerations about expected attributes of AI (e.g., standards about transparency and explainability, data used, interface), potential impact (e.g., who, what decision, outcomes), and the patient. Based on this framework, we developed, pilot tested, and iteratively refined an interview guide with clinicians, qualitative researchers, social epidemiologists, and human factors engineers. Interviews included open-ended questions (Italic text in Figure 4.1). We asked participant demographics (transplant experience, gender, race, ethnicity). One researcher (ATS, physician researcher with training in HFE and health equity) conducted all semi-structured interviews. Interviews were audio-video recorded, transcribed verbatim, and de-identified. We followed Consolidated criteria for Reporting Qualitative Research (COREQ) guidelines.\textsuperscript{103} The study was approved by the Johns Hopkins University Institutional Review Board (#00242367).

Analysis

Investigators (ATS, CNS) used inductive coding to develop thematic categories from the participant responses. The investigators coded initial interviews together with retroactive revisions to the codebook. When thematic saturation was reached (i.e., no new themes emerged), the investigators finalized the code book. Investigators independently coded the interviews using qualitative NVivo software (QSR, Version 10) and reconciled discrepancies in coding through consensus.\textsuperscript{106} Next, the investigators independently used constant comparison, first within codes and then across codes, to develop thematic
statements and write summaries for each thematic statement. Thematic statements and summaries were finalized through consensus.

**RESULTS**

**Participant Characteristics**

Participants were described previously (Table 3.1). Most participants described experience using basic examples of CDS, such as the model for end stage liver disease and Milan criteria. Only a few had any experience with AI-CDS. Despite limited experience, most were open or optimistic about using AI-CDS for LT evaluation.

**Understanding the workflow**

*Workflow Overview*

The participants created LT evaluation process maps that provided a complete understanding of the workflow. A generalized example is shown in Figure 4.2. The two over-arching phases are work-up and committee meeting. Throughout the process, there are steps that involve gathering information from outside sources, such as other hospitalizations, outpatient clinics, or labs. Several different types of providers are involved throughout the process, such as navigators or coordinators, hepatologists, surgeons, financial advocates, and consultants. These various transplant team members have several steps that involve communication of information.

*Workflow Steps*

Within the work-up phase, the process starts when the referral is received by the transplant center. If the patient has a history of hepatocellular carcinoma, they will first be evaluated at tumor board for contraindications to proceeding to evaluation for LT. They will then be screened for any other contraindications to proceeding with evaluation. If
there are any uncertainties, the patient may be seen in the hepatology or surgery clinics.

Prior to being scheduled for evaluation clinic, the patient is reviewed by the financial team for insurance coverage for transplant evaluation. Once the patient is scheduled for evaluation clinic, the patient and the transplant team prepare for clinic. The transplant team (e.g., hepatologist, surgeon, social worker, dietician, pharmacist) evaluate the patient's LT candidacy. The team communicates about the work-up, concerns, and impressions while collecting more data. Sometimes additional consultations with anesthesia, cardiology, or psychiatry are needed. Once the necessary information has been gathered, the team is informed that the patient will be reviewed at committee meeting. The patient’s case is prepared, and materials are distributed to the team. The patient is reviewed by the transplant team at committee meeting and the decision is made to accept, decline, or defer the patient.

**Themes related to user perceptions for the development and assessment of fair AI-CDS**

Based on the semi-structured interviews, 6 themes emerged: (1) need to know who made the AI-CDS and their motivations; (2) desire to understand how the AI-CDS was developed; (3) opinion that AI-CDS could mitigate emotions and biases by being objective; (4) AI-CDS as a new member of the transplant team, not a replacement; (5) want AI-CDS to help with identification of patient resource needs; and (6) the patient’s role in AI-CDS should be considered.

*Need to know who made the AI-CDS and their motivations*

When discussing how the use of a tool can impact health disparities, participants wanted to know who made the tool and about their motivations (Table 4.1). Motivations such as improving patient care were highly valued compared to AI-CDS created by entities.
purely by profit. For example, if the tool was made by academic or government institutions, then participants were more comfortable that there would not be conflicts of interest due to profit-related motivations or unethical goals. Some participants wanted to play an active part of the development of the tool early on or be part of the validation, so they could build trust in the fairness of the AI-CDS.

Desire to understand how the AI-CDS was developed
Participants were concerned about what and how data would be incorporated in the AI-CDS related to fairness (Table 4.1). Participants want the developer of the tool to be forthcoming and clearly explain how they developed and validated that the tool would be fair to all patients. Some had concerns about data integrity were discussed: inputted incorrectly, difficult to read by the computer, or inaccurate (e.g., outdated). For example, the state of a patient’s sobriety can change over time and impact patient decisions. Some participants brought up that a tool may consider data which perpetuates structural racism, such as particular types of substance abuse. While most participants wanted to actively understand how the tool works to build trust, some admittedly know they cannot comprehend every aspect of an algorithm. However, they want to, at the minimum, have a general understanding. Most commonly, participants noted they would want to be presented with data about the output of an algorithm that shows it is not biased based on race, gender, or other demographics. For example, they mentioned that the tool should be validated externally also on diverse populations and continued re-evaluation of the fairness of the tool after implementation.

A tension point of transplant team member responses was identified regarding what data the AI-CDS tool should consider. Some participants thought that the tool should only consider objective data, like medical test results, because it would be easier for the
computer to consider. As the tool would not be able to appropriately consider subjective data, such as the psychosocial evaluation. Others thought the data should also include subjective data and help make recommendations for the psychosocial components of evaluation. There were varying opinions about whether the tool should include race as a factor. Some participants thought that excluding factors like race, ethnicity, gender, and other demographics would make the tool fairer.

*Opinion that AI-CDS could mitigate emotions and biases by being objective*

Many participants felt AI-CDS could mitigate current decision-making that was highly subjective and potentially led to inequities in who gets listed (Table 4.1). They described the AI-CDS as having the advantage that it only looked at data without the personal aspect of knowing the patient. Nearly all participants commented on the objectivity that AI-CDS could bring to liver transplant evaluation and eliminate the emotional or biased aspects. For example, some participants felt this would be particularly useful for the psychosocial evaluation because the sensitive nature made it most at risk for varying interpretations. Additionally, due to the objectivity of AI-CDS using purely data points, they felt AI-CDS may facilitate more consistent decision-making across all patient populations. They viewed the AI-CDS as performing the same algorithm for every patient as opposed to inconsistently applied logic of humans.

*AI-CDS as a new member of the transplant team, not replacement*

When compared to AI-based decision-making, participants described human intelligence-based decision-making as a double-edged sword, particularly related to equity (Table 4.1). On one hand as described above, human intelligence-based decisions are frequently flawed, even if unintentionally, by subjectivity and emotions. Conversely, humans can incorporate hard-to-quantify and intangible information into
their decision-making. Participants were concerned AI-CDS would not capture nuances, such as a special circumstances, patient resilience, or motivation. As an example from one participant, someone may be categorized as non-compliant but there’s a difference between someone that missed an appointment because (1) they don’t like dialysis versus (2) they could not afford or secure transportation. For this reason, participants want to use AI-CDS as a guide or starting point, not as the final decision that replaces their human-based intelligence. They would want to be able to override as needed. Some thought this was particularly important if the AI-CDS was indicating not to transplant someone. Participants described needing to verify themselves that the tool generally aligns with their clinical assessment based on evidence and clinical experience.

*Want AI-CDS to help with identification of patient resource needs*

Some participants described that AI-CDS could not simply determine which patients are too high risk to transplant, as this approach may lead to further inequity. Instead, they described an AI-CDS that inform transplant teams which patients needed resources to have a successful transplant experience (Table 4.1). Participants said the tool could help transplant teams understand each patient’s modifiable risks to assist the team and the patient in mitigating those risks pre- and post-transplant. For example, a participant described knowing the specific domain the patient may struggle in will guide planning to offset those impending barriers.

*The patient’s role in AI-CDS should be considered*

Overall, participants were conscious and aware of the importance for patients benefiting from the use of AI-CDS. Participants had varied views on the patient role with developing and using AI-CDS for this purpose. Some participants thought patients
should have no direct interaction with the tool and had concerns about patients altering data to improve their candidacy (Table 4.1). Others thought patients should enter data themselves and see the output of the tool, as an educational tool for patients about what the team is considering. Some participants thought that patients should be consulted in the creation of the tool to give feedback. The majority of participants agreed that the main role for the patient was to provide honest and accurate information. Additionally, some participants felt that if the team were to use an AI-CDS tool, then patients should be informed about its use. Participants identified that patients from minority populations have been shown to have higher level of distrust in medicine, so transparency is important for building trust. Participants noted that a patient’s role with the tool is dependent on their health literacy and their ability to interact with the tool, so this should be considered.

**DISCUSSION**

**Study Conclusions**

In this multi-center study, we provided a case study demonstrating the benefits of utilizing an evidence-based framework within a human-centered design approach to understand perspectives of users about a fair AI-CDS tool specific to their domain. Related to user perceptions about fair AI-CDS for LT evaluation decision-making, 6 themes emerged: (1) need to know who made the AI-CDS and their motivations; (2) desire to understand how the AI-CDS was developed; (3) opinion that AI-CDS could mitigate emotions and biases by being objective; (4) AI-CDS as a new member of the transplant team, not a replacement; (5) want AI-CDS to help with identification of patient resource needs; and (6) the patient’s role in AI-CDS should be considered. Overall, future users of AI-CDS were cautiously optimistic about the potential for fair AI-CDS to improve outcomes for patients.
While the perceptions are specific to this case study domain of LT evaluation, we used them to identify potentially generalizable recommendations for fair AI-CDS (Table 4.2). These recommendations can be considered from 3 perspectives. First, the perspective of the provider or potential user can consider these best practices as a guide for gauging the fairness of AI-CDS. Second, the perspective of the developer can consider these best practices when designing, developing, and implementing fair AI-CDS. Lastly, the perspective of providers that are also involved in the design, development, and implementation of fair AI-CDS. As AI becomes more pervasive, providers are increasingly involved in its development. This case study serves as an example of the benefits of this type of human-centered design approach that specifically incorporates users. For example, since participants identified the need to know who made the AI-CDS, a recommendation is for developers to provide information about its lead developers, their affiliations, and motivations. Additionally, users should assess AI-CDS for this information (Table 4.2).

Our participants identified that the responsible use of AI-CDS includes an understanding by the user that people created the data and algorithms. Additionally, regardless of the design, the user has a responsibility, which includes the equitable use of the AI-CDS. The tool may give outputs or recommendations that a provider or a group of providers will use to enhance their decisions. Aligned with this concept, this study demonstrated participants want to work alongside AI-CDS. They described AI-CDS more similar to adding a new transplant team member, as opposed to replacing their roles as decision-makers. They value building trust in AI-CDS through demonstration of its transparency and explainability, which can be paralleled to human-to-human trust building also through clearly and honestly communicating thought processes. They
voiced concern about the data not capturing all aspects, and a human component being necessary to cross-check the fairness of the AI-CDS output. While our findings are consistent with the literature about providers valuing the revolutionary potential of AI more than they fear being replaced, others have found providers with less AI understanding are more concerned about being replaced. Since setting and background AI exposure may influence user attitudes and adoption, understanding user perceptions of the human-machine interaction is key for AI-CDS design and implementation.

In this study, participants described fair AI-CDS would help with identification of patient resource needs. This theme describes an interesting application of precision medicine to shift from equality to equity. Precision medicine is concept of defining subgroups of patients and targeting therapy for them to improve outcomes. Although this concept is typically applied to recognizing genomic patterns, our findings about using AI-CDS to recognize SDOH patterns and target resources is in parallel with other literature using big data from observational datasets. Using our case study as an example, status quo is an equality-based approach to LT, where decisions are made for treatment based on the same set of resources provided to all patients. Our findings suggest that users want to harness the power of AI-CDS to more equitably allocate resources.

Our findings that patients should play a role in the use of AI-CDS is consistent with literature about patient considerations being important for building trust about AI. Some participants felt the patients should provide feedback in the development of the tool. While this involvement would add insights to the tool and potentially in adoption later, the timing of patient feedback depends largely on the clinical application. Importantly, this case study was for an AI-CDS designed purely for use by clinicians and
was early in the design phase, so patient feedback would be difficult. Future work about incorporating patients into the fair design of AI-CDS would be helpful for patient-facing tools or assessment in the deployment phase (e.g., ease of provider explaining tool output to patients).

In qualitative research, the goal of transferability is the parallel concept to generalizability in quantitative studies. The goal of qualitative work is to be context-specific, so researchers can examine a domain more deeply. Yet the idea that research should be relevant for many cases and not just one case still matters, which is transferability’s role. These findings may be transferable to other contexts, particularly given the large sample size, adequate response rate, and dual-center perspectives. The context for this study was specific to liver transplantation and users were within academic settings. Due to the rapidly evolving landscape of transplantation and research environment, these characteristics may make the users more open to AI-CDS. This may be similar to other transplant centers, even other organs. AI-CDS being designed for users outside these settings may have different perspectives. While organ transplantation, particularly evaluation for listing, has ethically charged aspects that may require closer attention to fairness in AI-CDS, other relatable areas could be oncology treatment or life-saving decisions in resource-limited settings (e.g., monoclonal antibody use). Indeed, since all clinical decisions affect patients from various backgrounds, the framework proposed here was kept broad so it could be considered widely and still be applicable.

**Study Limitations**

This study should be considered with its limitations. The providers interviewed for this study had limited experience with AI-CDS, so this may have biased their responses. However, while AI is increasingly abundant in medicine, the areas that have less
exposure may have similar perceptions as these participants. Additionally, the recommendations are limited by this case study application and should be expanded upon based on additional insights from other domains. This study was with transplant team members and not patients, so the results do not include the patient perspective. Since the goal of this study was to understand the perceptions of the users of the tool, which are transplant team members, patient perspectives should be performed in future work. Follow-up work including patient comprehension about AI-CDS and provider communication about the outputs would provide additional complementary knowledge.

Conclusion

In summary, this multi-center study exemplifies the potential for the use of an evidence-based framework within a human-centered design approach to understand perspectives of users about a fair AI-CDS tool specific to their domain. Overall, providers are cautiously optimistic for AI-CDS if developed ethically, transparently, and in collaboration with clinical experts. Our findings can be harnessed not only by developers, but also by users, administration, and policy-makers that may be involved in developing, deploying, and evaluating these tools. In addition to using our findings to monitor for improper AI-CDS use, these findings importantly call for AI-CDS to be developed specifically for the purposes of addressing racial and ethnic disparities.
Figure 4.1 Framework for human centered design of fair artificial intelligence-based clinical decision support.
Figure 4.2 Example of a process map for liver transplant evaluation.
Table 4.1. Representative quotes from semi-structured interviews with transplant team members for themes related to user perceptions of fair artificial intelligence-based clinical decision support tools

<table>
<thead>
<tr>
<th>THEME</th>
<th>REPRESENTATIVE QUOTES*</th>
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<tbody>
<tr>
<td>Need to know who made the AI-CDS and their motivations</td>
<td>“Who is making the tool or publishing the tool. What their motives are?...Is it a private company? Is it a consortium? A university? Who is developing this tool?...If it’s non-profit or academic-based or highly regulated, like UNOS or OPTN, that would make it more trustworthy in my eyes.” (#41, Physician)</td>
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<tr>
<td></td>
<td>“Assessing who made the tool or who is with them and also understanding the motives behind creating the tool, I think would be important.” (#94, Coordinator)</td>
</tr>
<tr>
<td>Desire to understand how the AI-CDS was developed</td>
<td>“A tool by definition meets that standard [fairness] right...if gender or race or class or any of those things don't have anything to do with what the tool is asking for, then I think that the tool by nature is not discriminatory.” (#28, APP)</td>
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<td>“Having someone who was involved in developing it walk through the steps of how they developed it. What decisions were made into picking which algorithms. That would be the best delivery of it--from someone who actually developed it.” (#61, Physician)</td>
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<td></td>
<td>“Transparency is understanding the tool, understanding how the calculations occurs and feel comfortable with it...You don't necessarily have to understand every aspect of how the model works. You have to have a general—[it] cannot be explained that easily, but it's transparent to me because I kind of get the gist of how it’s developed.” (#17, Physician)</td>
</tr>
<tr>
<td>Opinion that AI-CDS could mitigate emotions and biases by being objective</td>
<td>“We're human, so I think that we have emotion, and we sometimes can allow emotions to play into our clinical decision making, and that can be a good thing, or it can be a bad thing. And sometimes I think taking that emotion or that personal experience, out of it, would occasionally potentially be a good thing...maybe it'll be better to allow a machine to make clinical decisions on patients because it takes the emotion out of it...a tool wouldn't care if you were rich or if you are poor, and a tool wouldn't care if you were black or if you were white.” (#28, APP)</td>
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<td>“I am in support of it, I always love more data and more information, and I would like to have more information to help us make an objective decision...I could see being used for the social assessment, social behavioral assessment of the patient cause I, that's the part of the assessment that I worry is the most subjective. And as most at risk for being interpreted differently depending on who does the evaluation.” (#6, Physician)</td>
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<td></td>
<td>“The benefit of it is it would be consistent for every patient...I think we tend to base our opinions off of past, similar cases. So if you had more objective data, we would I think be less inclined to do that.” (#94, Coordinator)</td>
</tr>
<tr>
<td><strong>AI-CDS as a new member of the transplant team, not a replacement</strong></td>
<td>“At the end of the day, we're still dealing with a human being that has a unique set of life circumstances, and I don't know that artificial intelligence can fully capture or appreciate some of those.” (#82, Physician)</td>
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<td>&quot;It gives you a baseline. That's about it. I think those tools are great for baseline that I can put all this into some type of calculation...You have the baseline to be able to build on. That's about it. I don't think you should [be] concrete—if you have this, this is it.” (#18, Social worker)</td>
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<td></td>
<td>“As long as there's an opportunity for, I guess real time intelligence to kind of step in. I think every patient has a different story, a different circumstance. But if it were to help lead them [transplant team] in the right direction—if it would help us to not have a bad outcome. I would welcome that. (#90, Coordinator)</td>
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<tr>
<td><strong>Want AI-CDS to help with identification of patient resource needs</strong></td>
<td>“If there was a tool developed that could help us make our clinical decisions as far as what patients...we need to provide some other support, either pre- or post-transplant. That would help us better prepare to follow them. That would be helpful.” (#100, Coordinator)</td>
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<td></td>
<td>“I know up front that they're [the patient] going to be so much riskier in this domain, so maybe up front we can put planning into place to kind of help offset the impending horrible outcomes that we think might be coming.” (#6, Physician)</td>
</tr>
<tr>
<td><strong>The patient’s role in AI-CDS should be considered</strong></td>
<td>“Viewing things from the patient perspective and getting their input would be important creating a tool like this. Just because again, we're just viewing things from our perspective, and we may not be viewing things from the patient perspective.” (#23, Physician)</td>
</tr>
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<td></td>
<td>“Probably not directly, but I guess the information that they provide. So answers to questions and things like that would be involved. I don't know if they would necessarily be involved in the tool.” (#14, Dietician/Finance/Pharmacist)</td>
</tr>
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<td></td>
<td>“How you explain what you did to the actual person that matters the most, which is your patient, and how you came up with the decision. That's absolutely paramount. There's enough mistrust in medicine in certain groups. And even overall, so I do think as transparent as you can be and being able to explain what you're doing is important to me.” (#83, Physician)</td>
</tr>
</tbody>
</table>

**Abbreviations:** Artificial intelligence-based clinical decision support (AI-CDS); Advanced Practice Provider (APP)
**Table 4.2. Recommendations for assessing and developing fair artificial intelligence-based clinical decision support tools**

<table>
<thead>
<tr>
<th>User Perceptions for Fair AI-CDS</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Need to know who made the AI-CDS and their motivations</strong></td>
<td>• Tool should have easily accessible section for background information • Information on lead developers and their affiliations • Information on funding sources for tool development • Information on motivation to create tool and its purpose</td>
</tr>
<tr>
<td><strong>Desire to understand how the AI-CDS development considered fairness</strong></td>
<td>• Tool should define how inputted data was collected • Tool should provide background information about each inputted data element (e.g., timing, accuracy, missingness reason for inclusion) • Tool should have demographic information and other relevant background about the population used to train the model • If data relevant to SDOH were not included, details should be provided for why these were excluded.</td>
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<tr>
<td><strong>Opinion that AI-CDS could mitigate emotions and biases by being objective</strong></td>
<td>• Design and develop AI-CDS for decisions prone to subjective and emotional bias • Incorporated objective data into AI-CDS that is not already biased • When inputted data is known to be subjective, transparently identifying this</td>
</tr>
<tr>
<td><strong>AI-CDS as a new member of the transplant team, not a replacement</strong></td>
<td>• AI-CDS should report model performance and details (e.g., ROC curve, precision, recall, accuracy) to build trust and demonstrate transparency • Identification of limitations to predictions, particularly clarifying where human-interpretation may be necessary</td>
</tr>
<tr>
<td><strong>Want AI-CDS to help with identification of patient resource needs</strong></td>
<td>• Output and use of the output is focused on addressing health equity as opposed to rationale for worsening health equity • Provides guidance for next steps</td>
</tr>
<tr>
<td><strong>The patient’s role in AI-CDS should be considered</strong></td>
<td>• Provides information regarding how to explain the tool to a lay person with varying health literacy • Information on patient involvement in development of tool</td>
</tr>
</tbody>
</table>

Abbreviations: (AI-CDS) Artificial intelligence-clinical decision support; (ROC) Receiver operator curve; (SDOH) Social determinants of health
Chapter 5. Conclusion

In this dissertation, we have examined racial and ethnic disparities in LT listing. We leveraged a large cohort of referred LT patients to assess the association between neighborhood SES and access to the LT waitlist. Then, in a multi-center study, we used semi-structured interviews and ethnographic observations to ascertain transplant team perceptions about mechanisms for racial and ethnic disparities in LT listing. Lastly, we utilized semi-structured interviews as part of a human-centered design for fair AI-CDS.

First, we found patients from neighborhoods with low SES had higher risk of not being listed (adjusted risk ratio [aRR] 1.14; 95% confidence interval [CI] 1.05-1.2; p<0.001), not initiating evaluation (aRR 1.20; 95%CI 1.01-1.4; p=0.03) and dying prior to evaluation (aRR 1.55; 95%CI 1.09-2.2; p=0.03) compared to patients from neighborhoods with high SES after controlling for individual-level factors. When stratified by race and ethnicity, White patients from low SES neighborhoods were not at an increased risk of not being listed compared to White patients from high SES neighborhoods (aRR 1.06; 95%CI 0.96-1.17; p=0.25). However, patients from underrepresented populations living in low SES neighborhoods were at 31% increased risk of not being listed compared to patients form underrepresented populations living in high SES neighborhoods (aRR 1.31; 95%CI 1.12-1.5; p<0.001). The association of neighborhood SES and not being listed was modified by race and ethnicity (adjusted interaction term p-value=0.02).

Then, we found that participant perceptions about listing disparities described external factors (e.g., structural racism, subjective national guidelines, national quality metrics) affecting patient experience in the LT evaluation process. They identified mechanisms
were minimal transplant team diversity, implicit bias, interpersonal racism. Also, a lack of resources, such as social workers, transportation assistance, non-English speaking materials, and time to be adaptable (e.g., more education for patients with health literacy concerns), was a common theme. Due to minimal data collection or center feedback about disparities, participants felt uncomfortable with and unable to adapt to unwanted outcomes, which perpetuates disparities. We proposed transplant center-level solutions to modifiable barriers that could help patients navigate, reduce disparities, and improve access to care.

Finally, we described 6 themes described by participants about fair AI-CDS for LT evaluation decision-making, 6 themes emerged: (1) need to know who made the AI-CDS and their motivations; (2) desire to understand how the AI-CDS was developed; (3) opinion that AI-CDS could mitigate emotions and biases by being objective; (4) AI-CDS as a new member of the transplant team, not a replacement; (5) want AI-CDS to help with identification of patient resource needs; and (6) the patient’s role in AI-CDS should be considered. Generally, users of AI-CDS were cautiously optimistic about the potential for fair AI-CDS for LT evaluation.

This work challenges the status quo that patients have well defined, fixed, and absolute barriers to transplant that are outside the transplant center’s control. Through combining the fields of systems engineering and social epidemiology, we have uniquely assessed the highly ethically and emotionally charged clinical domain of transplantation at the individual patient level and the built environment level. Simultaneously, we have provided next steps for the field to address health equity. For this dissertation, the underpinnings of social epidemiology served as the foundation when leveraging qualitative research methods and a large dataset for quantitative analysis. As
a result of the overarching findings from this dissertation within the context of the literature, we constructed a parsimonious causal directed acyclic graph (DAG) (Figure 5.1). DAGs are graphical representations of hypothesized causal relationships depicted with nodes and arrows to facilitate scientific communication of concepts.\textsuperscript{143–146} To depict a focus of racism, as opposed to the singular socially constructed variable of race, we have carefully considered proximal and distal potential causes for racial and ethnic disparities in LT listing.\textsuperscript{147} This DAG can function as the foundation for future research that is grounded in subject matter expert perceptions, data, and the literature.

Moving forward, next steps should be pursued to develop fair AI-CDS for LT evaluation that align with our recommendations. Importantly, our findings identified the need to better understand the funneling effect occurring prior to referral. By addressing equity further upstream, we can more effectively improve outcomes for minority populations. This work is a call for action for the national collection of pre-listing data. By not prioritizing data collection to understand disparities, we are perpetuating inequity by omission. These results will be used by hepatologists, transplant surgeons, and policy makers to address LT disparities in listing, so all patients have the opportunity to benefit from the life-saving gift of organ donation.
FIGURES

Figure 5.1 Causal directed acyclic graph of liver transplant evaluation and access to the waitlist.
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2021-pres Member, Trainee and Early Career Committee (AGA)

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#90088546
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Dr. Aly Strauss was born in New Brunswick, NJ and raised in Medford, NJ. She completed her undergraduate studies in Economics at Emory University and matriculated to medical school in Tampa Florida at the University of South Florida. During that time, she pursued a dual MD-MIE (Master of Industrial Engineering). She continued at the University of South Florida for Internal Medicine residency where she also served as Chief Resident. She then started Gastroenterology fellowship at Johns Hopkins University, where she was on the T32 from the NIH on the clinical researcher track. During fellowship, she pursued a PhD through the Graduate Training Program in Clinical Investigation at the Bloomberg School of Public Health. After graduating Gastroenterology fellowship, Aly is now completing PhD work and Transplant Hepatology fellowship before starting at Johns Hopkins Hospital as an Assistant Professor in Hepatology. While in Baltimore, Aly has enjoyed living on the water and learning how to sail on the Chesapeake Bay. Aly, her wife, and their dog, Covi (pandemic puppy) love exploring local farms to enjoy the picturesque scenery and to taste-test freshly made ice cream from Maryland creameries.