OPTN Minority Affairs Committee
Meeting Summary
February 27, 2023
Houston, Texas

Paulo Martins, MD, Ph.D., Chair
Alejandro Diez, MD, Vice Chair

Introduction

The OPTN Minority Affairs Committee (the Committee) met in Houston, Texas, on 02/27/2023 to discuss the following agenda items:

1. eGFR Implementation Update
2. Social Determinants of Health Data Request Results
3. OPTN Policy Development Process
4. KDPI Literature Review
5. 2009 vs. 2022 KDPI Research
6. Impacts of Removing Race from the Calculation of the Kidney Donor Profile Index
7. Public Comment Presentations
8. New Project Brainstorm

The following is a summary of the Committee's discussions.

1. eGFR Implementation Update

The Committee heard an implementation update on Modify Waiting time for Candidates Affected by Race-Inclusive eGFR Calculations.

Summary of discussion:

A member shared that their program population is 77% African American. They found that the verbiage on sample candidate notifications was above most patients' education and reading level. Therefore, their staff had to modify the candidate notifications to make them more accessible. This member added that finding supporting lab documentation has also been challenging.

A member stated that the pre-registration patient evaluation process is out of the scope of the Organ Procurement and Transplantation Network (OPTN). They continued that there has been ongoing criticism of transplant access issues, including pre-registration practices. The member stated that this issue is currently out of the United Network for Organ Sharing (UNOS) scope. Members discussed that the goal of the eGFR waiting time modification policy is not to give an advantage to candidates listed as African American or Black but to remove the disadvantage from this specific population. A member asked if the Committee has heard any questions from patients regarding self-reported race, such as individuals that may be listed as Black-Hispanic. Staff explained that the reason for sending notifications to all candidates is so that if a candidate is misidentified in the OPTN Computer System, they can come forward and have their race corrected.

A member emphasized that much of the work done pertaining to this project was done for the first time by UNOS, such as creating sample candidate notifications. Another member noted that it might be helpful to understand where else eGFR is involved in the evaluation process and where it could have an

additional impact on candidates. Another member asked how programs have successfully navigated obtaining patient data from outside their institution, such as communicating with referring nephrologists. A member replied that educating patients to advocate for themselves to obtain lab documentation is important.

2. Social Determinants of Health Data Request Results

The Committee heard a presentation on the Social Determinants of Health (SDOH) Characteristics of Kidney Candidates Ever Waiting in 2020.

Data summary:

Kidney Candidates by Estimated Income

- The majority of registrations had an estimated annual income of $30,000 to $120,000.
- 33.02% of registrations had an estimated income of $50,000+ -$80,000, and 24.34% of registrations had an estimated annual income of $80,000 - $120,000.

Kidney Candidates by Access to Banking Services

- The majority of candidates were likely banked (53.09%), but a substantial percent were likely unbanked (26.7%)

Kidney Candidates by History of Derogatory Record

- About half of the cohort (49.72%) had a history of derogatory records.

Kidney Candidates by the Number of Address Changes in the Last 60 Months

- The majority of kidney candidates moved 0 times in the last 60 months (55.44%).
- 9.68% moved three or more times in the last 60 months.

Kidney Candidates by Education

- A plurality of candidates (36.98%) had a high school education or GED as their highest level of educational attainment.

Kidney Candidates by Distance to Listing Center

- The median distance to listing center was 26.79 miles.

Kidney Candidates by Primary Care Profession Shortage Area

- The majority of candidates (88.12%) lived in a partial county primary care shortage area.

Kidney Candidates by Neighborhood Crime Index

- The median neighborhood crime index was 92.

Kidney Candidates by Median Neighborhood Property Value

- The median of the median neighborhood property value was $183,177.50.

Kidney Candidates by Voter Registration Record

- Less than half of the candidates (42.56%) had a voter registration record.

Kidney Candidates by the County Index of Nonwhite/White Residential Segregation

- The median nonwhite/white residential segregation was 36.23

Kidney Candidates by County Violent Crime Rate

- The median violent crime rate was 395.31 per 100,000 people.

Summary of discussion:

A member asked if the research team looked at data on candidates who live in urban areas versus candidates in rural areas to compare access to care and referrals. The presenter replied that that information was not looked at for this specific data request. When looking at distance, the member also asked if the research team looked at distance in a straight line or actual driving distance. They continued, explaining that someone living in a rural area may not have a straight drive to point A to point B. The presenter responded that they looked at a linear distance from point A to point B; however, they will review the analysis to confirm that answer. Another member suggested collecting more granular data on a regional or state level.

A member expressed that this data is essential with organ allocation shifting to continuous distribution, as there may be concerns that it would change the ability of certain patients access to transplants. A member asked if there were opportunities to collect data from previous years. The presenter replied that the cohort they are trying to obtain now is from 2022. As of now, there has not been a discussion about collecting data from previous years.

Another member asked if the research team looked at how many individuals traveled across state lines. The presenter replied that information was not collected in this study. However, it would be helpful to understand where patients travel from when looking at multiple listed patients. A member commented that as a lung doctor, it is not always clear where patients are traveling from. They suggested collecting data on the density of nephrologists in a particular county and the location of dialysis centers.

3. OPTN Policy Development Process

The Committee heard an overview of the policy development process and discussed the problem analysis phase of the Committee's next project.

Summary of discussion:

A member asked about the difference between the kidney donor profile index (KDPI) and the kidney donor relative index (KDRI). A member explained that KDRI is a relative risk scale and KDPI is a translation of that risk to a percentage. Higher KDPIs are lower-quality kidneys, whereas lower KDPIs indicate better-quality kidneys. The original intent of KDPI was to establish a system to classify good, better, and best in terms of kidneys and try to match organs and recipients as best as possible. Kidneys from African Americans have a 20% higher risk of graft failure than non-African Americans, representing about 15% of all organ donors.

Next steps:

The Committee will continue its work on KDPI.

4. KDPI Literature Review

The Committee provided feedback on KDPI literature.

Summary of discussion:

Donor Race has no Role in Predicting Allograft and Patient Survival Among Kidney Transplant Recipients

A member commented that this literature looked at how much would the actual performance of the KDPI change if race was removed, and the researchers found that it didn't change significantly. However, other factors in the KDRI model were strengthened when the race factor was removed. Race

should not be used as a biological proxy. A member noted that it's important to consider the timeframe of graft failure. The original paper discussed the risk of graft failure after five years but was not mentioned in this literature. Therefore, when considering the average life expectancy for a patient that may be a diabetic and on dialysis, it's vital to keep in mind the timeframe.

Effect of Replacing Race with Apolipoprotein L1 Genotype in Calculation of Kidney Donor Risk Index

A member noted that this literature is going away from subjective criteria to more objective biological criteria. This paper is all about genetics and provides insight into how to think about allocation. Another member stated that with the APO1L1 genotype, only 20% who have this variant would develop kidney problems, and 80% who have the genetic mutation variation will not be considered increased risk. Not everyone who has this mutation will develop kidney failure disease.

5. 2009 vs. 2022 KDPI Research

The Committee heard a presentation on KDPI research.

Summary of discussion:

A member asked if adding the APOL1 coefficient to the new KDPI equation is possible or if it is better to zero out the race coefficient. The presenter replied that the Apollo study examines this question; however, it may not be a good solution to substitute race for APOL1. Another member asked, in the 2009 KDPI research paper, there was no rationale for why the race variable was absorbed, can this be further explained? The presenter replied that more thought should have been put into this; however, race was not seen as a detrimental factor when variables were being considered.

Another member asked if there was a way to quantify the organs discarded due to KDPI. Staff replied that information on non-utilization rates by KDPI could be looked at; however, information specifying why the organ was turned down may not be available. Another member pointed out that it would be interesting to understand how many kidneys are not recovered because of KDPI and what percentage of kidneys could be recovered and transplanted that are not recovered. A member asked if there were any other highly correlated parameters or values that may have been excluded from the model, along with race or any other instances of co-linearity in the newer model that was looked at. The presenter replied no, nothing that stood out.

6. Impacts of Removing Race from the Calculation of the Kidney Donor Profile Index

The Committee heard a presentation on the impacts of removing race from the kidney donor profile index calculation from the Scientific Registry of Transplant Recipients (SRTR).

Summary of discussion:

A member asked if eliminating the race coefficient would increase the overall of kidneys available or only kidneys from African Americans. The presenter replied that as long as KDPIs greater than 85 are being discarded, it probably will not increase the number of available kidneys very much. Another member asked if the presenter could provide thoughts on zeroing out the race coefficient. The presenter replied that there was an analysis done on zeroing out the coefficient rather than removing it entirely and found that although there was better parity of KDPI 85 and greater, the interpretation was relatively similar.

7. Public Comment Presentations

The Committee heard public comment presentations on *Ethical Evaluation on Multiple Listing* and *Update on Continuous Distribution of Livers and Intestines*.

Summary of discussion:

Ethical Evaluation on Multiple Listing

A member asked if the presenter could define "exceptionally difficult to match." The presenter replied that exceptionally difficult to match would include kidney patients with a very high calculated panel reactive antibody (CPRA) or patients that will be limited in the number of offers that might match them.

Another member noted that only a small segment of the cohort seems to travel a large distance to a second center. The member indicated that if an individual lives in New York, Boston, or Philadelphia, where there may be different options for transplant centers, it might be easier to go to multiple centers. Additionally, socioeconomic differences may not play a more significant role when compared to an individual who lives in more of a rural setting and may not have as many options. The member then asked if the Committee looked at individuals that multi-list broken down by city and state. The presenter replied that most patients who are multiple listed are either within driving distance or 250 nautical miles of the center.

A member explained that centers have different behaviors in terms of risk tolerance. For example, one transplant center that is more aggressive may transplant a candidate, while another center that is not as aggressive may not transplant that same candidate. A member asked how the Ethics Committee plans to educate candidates on this concept. The presenter agreed that it is essential for candidates to understand that much of the benefit of multiple listing might not be related to geography but to center practices such as aggressiveness with offer and acceptance. However, the Ethics Committee acknowledges that educating patients on many factors early in the process is complex.

A member noted that from a pediatrics perspective, less than half of pediatric centers in the U.S. perform more than five living donors a year. Therefore, it's vital for every child to have the ability to list geographically in different places. The member asked if there was data on if insurance companies cover multi-listing. The presenter replied that at the Region 5 meeting, there were discussions about this topic, as there was similar feedback. They continued that the pediatric population will be looked at more specifically. There are no clear answers to questions regarding insurance, but creating an equitable environment has been challenging. The member also asked how centers can collaborate to help other children. The presenter stated that collaboration among centers is encouraged to support all patients.

Another member noted that centers should educate their patients and encourage them to list at multiple centers, which will help provide more patient options. A member stated that there might be unintended consequences. For example, suppose a patient is limited in the number of centers they can be evaluated at. In that case, there's also a decrease in the competitiveness of centers to evaluate faster and have better outcomes. If there is no competition, centers are not incentivized to perform better.

Update on Continuous Distribution of Livers and Intestines

A member asked, under the attribute patient access, for a prior living donor, if someone who donated a liver organ is weighed the same as someone who has donated a kidney weighed the same. The presenter replied that the Committee is still discussing this specific attribute.

Next steps:

The Committee will submit feedback on the two public comment proposals.

8. New Project Brainstorm

The Committee brainstormed new projects.

Summary of discussion:

KDPI Project

The Committee discussed the different types of options to approach the KDPI project. The Chair explained that the three options would include zeroing out the race coefficient in the existing KDPI equation, refitting the analysis that excludes the race variable, or adding an APOL1 gene.

A member asked for further clarification on zeroing out the race coefficient in the existing KDPI equation. A member clarified that in the KDPI presentation, the Committee heard earlier, the presenter explained that in one study, the coefficient was changed to zero in the analysis, as opposed to another study, which excluded the race variable from the equation. A member asked about the difference between zeroing out the race coefficient and refitting the KDPI equation. The member replied that by zeroing out the race coefficient, there's no confounding for the other variables in the equation as opposed to refitting the model, which includes confounding. Both approaches were analyzed but resulted in minimal differences. The member favored refitting the equation.

Staff noted an ongoing discussion of the removal of hepatitis C. in KDPI. If the Committee addresses a race in KDPI, the community might express that Hepatitis C should be addressed simultaneously. Staff also highlighted that if the Committee believes this needs to be addressed, this could be done by establishing a workgroup.

A member expressed concerns that refitting the KDPI equation would involve keeping the same model and removing what is no longer necessary. The member favored eliminating race from the equation instead of removing multiple variables. The process can become complex when considering removing race and other variables simultaneously. Staff emphasized that being clear about the project's goals is essential, which will help define the scope.

A member stated that in their experience, there are disproportionately more African Americans impacted by hepatitis C. The member inquired about the ratio of hepatitis C. positive donors nationally and, among this group, how many are African American. Additionally, the member asked if there was data on kidney discards greater than 85 that were African American and how many of this specific population would have been less than 85 if race was not included.

A member noted that high KDPI kidneys have a higher discard rate. If there are a lot of discarded kidneys and 20% of them would be below 85% if race were not included, in theory, these kidneys could have been placed more aggressively with more aggressive centers that wouldn't decline them based on high KDPI. Another member noted that a KDPI article was written in 2009 and revised in 2019 and inquired if the KDPI formula is the same formula used today and suggested that the equation be refitted to data periodically. Refitting an equation is not uncommon, especially in heart transplantation. The Society of Thoracic Surgeons (STS) risk calculator calculates the risk mortality from a heart operation that is continuously adjusted yearly.

A member explained that KDPI is derived from KDRI, which then a system assigns weights to different variables. Then it's compared to the cohort from the year before; however, the weight allotted to each variable remains the same. The member replied that the race variable may be excluded from the

equation. A member replied that once the race variable is removed, the equation must be refitted to the latest data set. A member agreed that the Committee should remove one variable at a time. For example, prioritizing removing race from KDPI, the removing another variable, such as hep. C from KDPI.

New project ideas

A member suggested brainstorming about initiatives for other organs that affect minorities—for example, assessing disparities as a pediatric patient transition to an adult program. A member expressed that looking at essential topics for each organ would be interesting. For example, MELD and PELD are important topics in liver, like eGFR and KDPI are important topics when discussing kidneys. Therefore, it would be interesting to look at the importance of each specific organ and the factors that overlap with all the organs. A member replied that social support is one of the most critical topics that overlap with all the organs. Social support is a difficult topic because sometimes there is biased about social support based on other cultural backgrounds. Another member explained that the Committee should collaborate with some of the bigger societies because research has been published on social support.

The chair suggested revisiting a previous project, which included calculating the poverty line by collecting the range of income and household size. Another member suggested looking at the population density and how it affects access to care, which would be a good project because it impacts all organ groups. Another member explained that a potential project could consist of looking at nonbinary individuals who do not list a specific sex when having their eGFR calculated; this may result in inequity in the nonbinary community who have kidney disease.

Upcoming Meeting

- April 17, 2023 @1pm ET

Attendance

- **Committee Members**
  - Paulo Martins
  - Alejandro Diez
  - Amaka Eneanya
  - Ayana Andrews-Joseph
  - Christiana Gjelaj
  - Christine Hwang
  - Manuel Rodriguez-Davalos
  - Reynold Lopez-Soler
  - Steven Averhart
  - Tatia P Jackson
  - Wayne Tsuang
  - Reynold Lopez-Solar
  - Jason Narverud
  - Niviann Blondet
  - April Stempien-Otero
- **HRSA Representatives**
  - Shelley Tims Grant
  - Lauren Darensbourg
  - Medmin Germain
- **SRTR Staff**
  - Bryn Thompson
  - Monica Colvin
  - Grace Lyden
  - Jonathan Miller
- **UNOS Staff**
  - Kelley Poff
  - Tamika Watkins
  - Lauren Mauk
  - Jesse Howell
  - Amber Fritz
  - Cole Fox
  - Kieran McMahon
  - Laura Schmitt
  - Morgan Jupe
  - Sarah Booker
  - Stryker-Ann Vosteen
  - David Roberts
- **Other Attendees**
  - Douglas Schaubel
  - Morgan Reid
  - Panduranga Rao
  - Rachel Meyer
  - Sylvia Rosas
  - Sena Wilson-Sheehan
  - Vanessa Pucciarelli