OPTN Patient Affairs Committee
Meeting Summary
October 15, 2024
Teleconference

Molly McCarthy, Chair
Lorrinda Gray-Davis, Vice Chair

Introduction

The Patient Affairs Committee met via WebEx teleconference on October 15, 2024, to discuss the following agenda items:

1. OPTN Expeditious Task Force Update
2. Introduction: Meet. Dr. Earnest Davis, SRTR
3. HRSA Request: Committee Input Regarding Social Determinants of Health Relevant to Policy Monitoring and Evaluation
4. Patient Awareness of Listing Status (PALS) Subcommittee Update
5. Public Forum

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

1. OPTN Expeditious Task Force Update

> **Update only. No decisions were made**

The Committee received an update on OPTN Expeditious Task Force activities from a member of both the task force and the OPTN Kidney Transplantation Committee.

Summary of Presentation:

The Expeditious Task Force was charged by the OPTN Board of Directors with findings ways to improve organ non-use. Currently, some of the group's projects are at a pause as HRSA is developing new budgetary guidelines and work permissions. The group's initiatives remain improving organ utilization and decreasing non-use. Several key factors were identified here to meet these initiatives.

The presenter noted that improving efficiency is important to reducing non-use. OPOs need to get "hard to place" organs to the right centers and the right patients who will accept them more quickly. He noted that, for kidneys, non-use is often the result of allocation taking too long. By the time a center is located that will accept the kidneys, so much time on ice (cold ischemic time) has accrued, that interest begins to wane.

Education was also noted as a crucial factor here for both patients and clinicians. He suggested that clinicians need to understand that kidneys deemed unusable ten years ago are now being used successfully, getting people off dialysis. He referred to the importance of time in trying to get patients off dialysis and the waitlist, suggesting that perfect not be the enemy of good if it takes away the opportunity for transplant altogether and results in death.

In preparing to talk with this Committee, he noted multiple conversations with colleagues and this Committee's visiting Board members. The presenter was particularly committed to making education

more patient facing in this area. Tools to assist in this education were discussed, including predictive analytics. For predictive analytics, the user can look at an organ offer for a patient and the graphic will show when that patient will be expected to be the number one primary potential recipient on the match list for an organ offer of a given KDPI. It also shows the patient's survival expectancy over time. He suggested that there should be another curve in this graphic that shows how long the patient can expect to wait for a similar or better organ than the current offer and what their life expectancy looks like if they accept the kidney offer at hand. The presenter noted that statistically speaking he believes that this information should be available to both the clinician and the kidney transplant candidate, allowing them to be more in the driver's seat when it comes to organ acceptance. The presenter recognized the challenge for clinicians as humans. They are well intentioned, but bring their own expectations, wants and prejudices on organ acceptance when considering offers for their patients. When considering kidney offers for his patients, he is putting them in his shoes and judging for them. He acknowledged that the candidate may look at the world completely differently than the clinician does. Patients are called with an organ offer and the pros and cons of the donor organ are shared. While the patient always has the final say, there are still nuances and details that the clinician may take for granted because they do this every day. The patient has had a few meetings in the clinic, is talking to friends at dialysis, and then receives an offer in the middle of the night and has to think quickly. Having a predicting analytics tool that is patient facing was seen as bringing great benefit to this situation.

The presenter acknowledged that not all patients are device or tech savvy, or even have access to these resources. For this reason, it was suggested that rather than focusing on the tool in real time with the offer, it would be beneficial to share these graphs as part of the evaluation process. This would help patients better understand what to expect and what they can expect if they accept organs of varying KDPI scores. He recognized the importance of how this information is shared, noting that simplicity is needed for clear interpretation. Having patients more educated and involved in this decision-making process was noted as paramount, as this decision impacts the rest of their lives.

Summary of Discussion:

The Chair thanked the presenter for sharing this update and his thoughts. Committee members recognized that every center manages things a little differently. The fear and emotions of learning that a transplant is needed and having to navigate the system were recognized as challenging on top of often not feeling well. A member asked if there is an opportunity to build an intelligent system that allows for patient voice and a choice at the table, managing this based upon the weary wisdom of those who have navigated the system and enjoyed post-transplant success.

The presenter recognized competing concerns as clinicians think about how to make this patient-facing. Two different patients and two quite different people. One may be tech savvy, highly educated, and "tough as nails." The other may be battling depression or even had suicidal ideation and have no tech or computer skills. These two patients must be approached very differently. The tech solution itself also must be scalable. If it becomes too tailored to an individual or too complex, it will be challenging to implement and may never work well. Having something on paper rather than the computer as an education model works because then everyone can be presented with the information as they come to the transplant center for evaluation. It is easily accessible by everyone and must be easy to interpret to be successful.

Seeing an oncologist for the first time was referenced, where the first question is always, "doc, how long do I have?" That is not a question that comes up in nephrology or transplant nephrology clinics, but it is something that is very much a concern. The presenter noted that a gentle way to fully inform patients that they are living on the clock and there are options available to them that will get them off the clock sooner. This must be done in such a way that it does not create depression but rather gives a sense of

hope and aggressiveness to the patient. This is where the educational tools to understand the clock and how to navigate the path to transplant are key. The presenter noted that the education tools are well within the community's power to develop but recognized that some clinicians are better than others at delivering nuanced messaging. This is where clinician education is important. In addition to having these conversations with patients, it was also noted as important to share data on turndowns- here are the organs that you declined last week. Of this group X number were transplanted and recipient(s) are doing well. This is not meant to shame clinicians, but rather to educate them to recognize missed opportunities. This could be applied to patients as well. The presenter suggested that patients who are not yet on dialysis or just starting it are more apt to hold out for "the perfect" kidney. After a few years on dialysis, the risk tolerance level changes and patients want to be done with dialysis. That is where the predictive analytics information will be especially helpful in understanding the clock, the life expectancy and impact of accepting a kidney sooner rather than later.

A Committee member asked if this education would be applicable to pediatric patients as well, noting the understanding that pediatric organs are generally low KDPI and have less wear and tear than adult organs. The Expeditious Task Force's efforts have been almost wholly applied to adult transplant to date, as this is where the most lost opportunity resides. There has been no community concern to date that usable organs for children are not being utilized. If this were to become the case, the community would most certainly rally around this concern.

A concern that candidates do not understand the process and the urgency, seeing dialysis as a bridge to transplant was noted by a Committee member. The member shared stories of friends who declined offers because they were feeling good. Th presenter noted that he believes that organ non-use would be much less if clinicians and patients knew what potential many of these organs presented. He shared an example of a recent donor where his center transplanted both kidneys successfully despite a donor's history of diabetes, smoking, hypertension. The facts were shared with his potential recipients, noting that delayed graft function was anticipated with the transplant of these organs. Over half of his patients on the match run declined the offer. He recognized that patients sitting at the top of the waitlist are getting offers regularly and have some flexibility to wait for their "perfect" organ, but those who are sitting at 400-500 on the list are not going to receive one of these low KDPI kidney offers for years. He shared that he struggles when these individuals decline offers, wondering when they will get another opportunity like that but recognizing that this is not a conversation that he can have with a patient in the moment. He would never want to talk someone into something with which they are not comfortable. The presenter suggested that these are the conversations that should be had in the months and years beforehand, when you are educating people on what they should expect and want over time.

The Chair thanked the presenter for his time and sharing. A number of members had continued questions and comments, but time constraints did not allow for further discussion. The presenter is happy to return to talk with the Committee.

Next Steps:

Due to the number of hands raised as the presenter was exiting the call, he will be invited to return and continue this discussion with the Committee at a later date.

2. **Introduction: Dr. Earnest Davis, SRTR**

> **Introduction. No decisions were made.**

Dr. Earnest Davis introduced himself as a transplant recipient, former OPTN Board member, and his new role as Senior Staff of r Patient & Family Affairs at the SRTR. He will serve as the new primary SRTR liaison to the Committee.

Committee members welcomed Dr. Davis to the Committee.

3. **HRSA Request: Committee Input Regarding Social Determinants of Health Relevant to Policy Monitoring and Evaluation**

> **The Committee will submit feedback on this topic to OPTN Contractor Staff for inclusion with feedback from other relevant committees.**

The Committee was asked to consider an overview of social determinants of health and share their thoughts on how this might best be incorporated into policy monitoring and evaluation.

Summary of Presentation:

Social determinants of health (SDOH) are the conditions in the environment where people live, work and age that affect a wide range of quality-of-life and health outcomes. Domains and elements can differ across SDOH frameworks, but there are five primary focus areas:

- Economic Stability
    - Poverty
    - Employment
    - Food insecurity
    - Housing instability
- Education
    - High school graduation
    - Enrollment in higher education
    - Language and literacy
    - Early childhood education and development
- Health and Health Care
    - Access to health care
    - Access to primary care
    - Health literacy
    - Insurance status
- Neighborhood and Built Environment
    - Access to healthy food
    - Quality of housing
    - Crime and violence
    - Environmental conditions
- Social and Community Context
    - Social cohesion
    - Civic participation
    - Discrimination
    - Incarceration

The success of patient education is dependent on health literacy. It is challenging as there is often a lot of medical jargon. It is important to make sure that patients are educated enough to be able to make decisions that are in their best interest. Patient facing materials must be presented in a manner that is understandable to them.

SDOH data is important because we know that groups with varying SDOH experience different health outcomes. The OPTN does not currently collect extensive SDOH data. More data is needed to better understand the connections between SDOH and health outcomes in organ transplantation. This SDOH data could also be utilized in committee data requests and monitoring reports.

The goals for this SDOH project include:

- Assessing which public sources provide data most relevant and available for linking to OPTN data for the purposes of policy monitoring
- Integrating public sources of SDOH data into policy monitoring to support OPTN committee efforts to assess equity in the system

OPTN Contractor staff are working on behalf of HRSA to identify 6-7 public data sources that can be matched at the zip code level. Input is being requested from this Committee as well as the OPTN Minority Affairs and Data Advisory Committees with a goal of providing recommendations for committee and HRSA review by December 31, 2024.

The Committee was asked to consider which SDOH sets would be most relevant to them as patients and what access to transplant as well as post-transplant outcomes will look like. Understanding income or poverty level and socioeconomic disadvantages within a zip code was offered as a valuable element to understand here.

OPTN Contractor staff walked through several data sets as examples to the Committee before seeking their thoughts and feedback.

Summary of Discussion:

A Committee member shared that she deals with the minority business development agency and small business administration along with the Department of Commerce. She frequently uses the HUBZone (Historically Underutilized Businesses)[1] because it tracks by zip code and has the breakdown of qualified census tracks, non-metropolitan counties, and redesignation areas, as well as areas that have been in a disaster zone on the past. It also captures information qualified native American land and governor designated areas (as the governor may at their state a lot differently than the federal government related to rural communities).

The Committee asked who this information is trying to identify: pre-transplant candidates, post-transplant recipients? OPTN Contractor staff shared that the OPTN currently collects information on patients who are on the waitlist. Understanding those patients in the pre-evaluation phase will be extremely valuable to understand barriers to listing and transplant.

A member noted the importance of transportation availability as critical to access to transplant. Without a car or access to public transportation, a candidate may not be able to get to the hospital for evaluation or treatment. This was suggested as a high issue on the list. Access to healthcare locally was also noted as a challenge. Living in a rural community could mean that individuals may have to travel great distances to receive the care they need. An individual may have health insurance but no transplant center near them and no means to travel to one.

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[1] https://www.sba.gov/federal-contracting/contracting-assistance-programs/hubzone-program Accessed 10/30/2024

Language was also noted as a missing element in the focus areas outlined at the start of the presentation. Committee members agreed that this is an important focus that should be near the top of the list to successfully navigate the transplant journey using a second language.

Inadequate caregiver support was noted as a barrier to transplant listing. OPTN Contractor staff recognized this concern but noted that this is not data that can be collected at the zip code level.

A Committee member asked what the application of this effort will be. Will it be shared with the public to communicate the rate of death, rate of transplant, rate of active versus inactive status for different socioeconomic groups by zip code? OPTN Contractor staff noted that this information will be available to OPTN committees on request as they are developing and monitoring policies. The primary focus here will be understanding factors associated with access to organ transplant, considering health equity through not only clinical variables but also socioeconomic variables. Many questions can be considered through the lens of SDOH once this data is collected.

Next Steps:

Committee members will revisit the materials related to this topic and submit their feedback via email for inclusion alongside feedback from the Minority Affairs and Data Advisory Committees.

4. **Patient Awareness of Listing Status (PALS) Subcommittee Update**

> **No decisions were made.**

This topic was not covered due to time constraints.

5. **Public Forum**

No public forum items were submitted for discussion.

Upcoming Meetings
- November 19, 2024
- December 17, 2024
- January 21, 2025
- February 18, 2025
- March 18, 2025
- April 15, 2025
- May 20, 2025
- June 17, 2025

Attendance

- **Committee Members**
  - Molly McCarthy
  - Lorrinda Gray-Davis
  - Patrice Ball
  - Michael Brown
  - Elizabeth DeVivo
  - Tonya Gomez
  - Calvin Henry
  - Karlett Parra
  - Andreas Price
  - Cathy Ramage
  - Cody Reynolds
  - Michael Slipowitz
  - John Sperzel
  - Steven Weitzen
  - Justin Wilkerson
- **HRSA Representatives**
  - Mesmin Germain
  - Robert Johnson
- **SRTR Staff**
  - Katherine Audette
  - Earnest Davis
- **UNOS Staff**
  - Shandie Covington
  - Desiree Tenenbaum
  - Kaitlin Swanner
  - Kimberly Uccellini
  - Tatenda Mupfudze
- **Invited Speakers**
  - Jason Rolls