OPTN Pediatric Committee
Meeting Summary
December 13, 2023
Conference Call

Emily Perito, MD, Chair
Rachel Engen, MD, Vice Chair

Introduction

The OPTN Pediatrics Committee ("Committee") met via WebEx teleconference on 12/13/2023 to discuss the following agenda items:

1. Expeditious Task Force Update
2. Pediatric Loss to Follow Up
3. Discussion

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

1. Expeditious Task Force Update

The Committee received an update from the Expeditious Task Force

Presentation summary:

The task force aims to address three areas for increase efficiency:

- Growth of deceased donor transplants
- Utilization of organs
- Efficient decision making

The scope of the task force includes:

- Examining data
- Reviewing best practices
- Run trials
- Share information with OPTN Committees

The task force is not a policy-making committee. It will provide recommendations for policy opportunities to the appropriate committees.

Summary of discussion:

The Vice-Chair inquired if Committee members were familiar with any of the task force members. They felt that pediatric representation was an important perspective to consider in all the task force's aims. Members shared some connections, with one noting a pediatric cardiologist on the task force's roster.

The Vice-Chair asked the Committee if there were specific questions they wanted to be brought to the task force. A member requested information regarding best practices around deceased donor kidney recovery and pump use.

A member asked if there would be quality measurements reviewed in conjunction with the total number of organs transplanted to ensure that the outcomes of patients are not being impacted, as well as more

medically complex organs being used. The Chair replied that the task force has an outstanding ask for committees to provide recommendations on quality measures to help evaluate the progress of the task force's goals. However, they agreed that there should be quality guardrails in place around post-transplant survival, especially regarding pediatric patients.

The Vice-Chair requested that the utilization data for kidneys, stratified by kidney donor profile index (KDPI), be shared with the OPTN committees to better understand non-utilization trends. They clarified to a member that one goal of the task force is to address the low utilization rate of medically complex but viable organs.

A member highlighted their experience with a national transplant hospital forum in which participants will share cases of either organs that retrospectively likely could have been used or where medically complex organs were used. They felt that the shared learning model had potential to greatly improve their practices and approaches to medically complex organ usage. A second member agreed and highlighted the potential for improved tools within the OPTN Donor Data and Management System.

It was suggested that a quality improvement effort for the OPTN could be to create a forum for programs to share information with other programs on offer review and acceptance practices.

A member wondered if there was any consideration of incentivizing programs to take more medically complex organs to improve transplant rates. The Vice-Chair stated they would pass that question along to the task force. The Chair agreed this was a crucially important question, especially when considering program size, patient population, and a program's ability to manage medically complex organs.

Next steps:

Staff will share the Committee's questions with the task force.

2. Pediatric Loss to Follow Up

The Committee heard a presentation on the rate of pediatric patients who are lost to follow up post-transplant. This was presented by a guest speaker from the Membership and Professional Standards Committee (MPSC).

Presentation summary:

- The transplant recipient follow-up (TRF) form is required to be submitted 90 days after the 6 month and annual anniversary of the transplant date until recipient death or graft failure.
- Approximately 12% of pediatric kidney transplant recipients ages 0-17 transferred to non-OPTN member programs within 5 years post-transplant between the years 2000 and 2010.
    - This percentage increased to approximately 19% for ages 18-25.
- Loss to follow up occurred in approximately 50% of kidney recipients who transferred institutions.
    - This peaked at 20% for 20 year old recipients.
- Approximately 17% of pediatric liver transplant recipients were lost to follow up between the years 1990 and 2018.
- There is no standard definition of "Loss to follow up"

Summary of discussion:

The presenter requested feedback on data collection opportunities to inform potential policy updates surrounding loss to follow up. Furthermore, are there specific challenges relating to pediatric loss to follow up that should be considered separately from the whole transplant population.

A member suggested the collection of insurance information to determine if changes in insurance status impacts loss to follow up.

The Vice-Chair highlighted the importance of this data collection, noting that when analyzing continuous distribution for pediatric kidneys, a limitation of their analysis was the high rate of loss to follow up.

A member requested the drop-down option for "transfer to a non-OPTN center" return to the TRF.

A member shared their experience creating and running a transition clinic for recipients aged 12-21. They noted that this improved treatment compliance rates as well as lowered loss to follow-up rates. They suggested analyzing how many programs had a similar clinic. It was also proposed to create a requirement to report recipient 5-year graft survival rate. The Chair clarified that there was still a requirement to report recipient status annually after the required 3-year check in. However, if a recipient transfers to a non-OPTN program, the TRF cannot be sent to that program, likely reducing the likelihood of its completion. The presenter contributed that, in some cases, it is geographically difficult for a recipient to travel to their transplant program to receive this follow-up.

It was also suggested to have more granular data collection surrounding loss to follow-up, which could provide context for how this issue should be addressed. Additionally, the OPTN should consider innovative ways to follow patients such that the burden is not entirely on the transplant program to maintain follow-up. A suggestion was made for a patient portal for recipients to self-report their status. The Vice-Chair noted that a limitation in that approach is that accessing the TRF form requires OPTN Computer System access.

A member felt that the key issue to address would be facilitating the completion of the form, rather than re-including a drop-down option that details where the recipient has gone. The issue at stake is how complete is the data, rather than how descriptive it is.

Next steps:

Staff will share the list of the Committee's recommendations with the MPSC.

Upcoming Meeting

- January 16, 2023

Attendance

- **Committee Members**
  - Emily Perito
  - Rachel Engen
  - Daniel Ranch
  - Aaorn Wightman
  - Geoff Kurland
  - Neha Bansal
  - Carol Wittlieb-Weber
  - Gonzalo Wallis
  - Reem Raafat
  - Sonya Kirmani
  - Caitlin Peterson
  - Dan Carratturo
  - Katrina Fields
  - JoAnn Morey
  - Ryan Fischer
  - Joe Brownlee
  - Namrata Jain
  - Melissa McQueen
  - Simon Horslen
- **HRSA Representatives**
  - Marilyn Levi
  - Jim Bowman
- **SRTR Staff**
  - Avery Cook
  - Jodi Smith
- **UNOS Staff**
  - Alex Carmack
  - Julia Foutz
  - Kieran McMahon
  - Betsy Gans
  - Kaitlin Swanner
- **Other Attendees**
  - Roshan George