OPTN Pediatric Transplantation Committee
Meeting Summary
April 19, 2023
Conference Call

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

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met via Citrix GoToMeeting teleconference, on 04/19/23 to discuss the following agenda items:

1. Welcome
2. Presentation on Scientific Registry of Transplant Recipients (SRTR) Pediatric Metrics
3. Working Session: Monitoring Report Reference Documents

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

1. Welcome

Staff and Committee leadership welcomed the Committee members.

2. Presentation on Scientific Registry of Transplant Recipients (SRTR) Pediatric Metrics

SRTR staff provided an overview of the pediatric metrics for the SRTR's annual data report (ADR).

Presentation Summary:

- General overview of annual report
    - What data are presented
    - How data are reported – for example, age is reported but how is it presented in terms of the age categories. Similar with the etiology of diseases and how they can be categorized for pediatrics
- Purpose
    - Align for UNOS monitoring requests
    - Seek input on ensuring optimal pediatric data presentation in the ADR

SRTR staff provided an overview of the annual data report on the SRTR website. The report is categorized by organ type and within each organ type there is an adult and pediatric section. Each section includes the following sections:

- Waiting list
- Transplant
- Immunosuppression
- Outcomes

The information provided within each section includes:

Waitlist

- Number added to the waitlist per year

- Total number on waitlist
- Demographics on waitlist by age/sex/race, etiology of disease, waiting time, blood type, calculated panel reactive antibody (cPRA), medical urgency, ventricular assist device (VAD) status and life support (heart), geography, and miles to transplant center
- Three-year outcomes for waitlist candidates (still on waitlist, deceased donor, living donor, died, removed from list)
- Transplant rates (age, race, cPRA, geography, and urgency)
- Pretransplant mortality (age, race, geography, urgency status)

Transplant

- Number of transplants per year
- Patient characteristics (age/sex/race, etiology of disease, height (lung), waiting time, insurance, blood type, cPRA, dialysis time, geography, and miles to transplant center)
- Transplant type (deceased, living, donation after brain death, donation after circulatory death, whole liver, partial liver, split liver)
- Human leukocyte antigen (HLA) mismatches
- Kidney Donor Profile Index (KDPI) (kidney)
- Urgency status (liver and heart/lung)
- ABOi
- Multi-organ
- Re-transplant
- Donor and recipient Epstein Barr virus (EBV) and cytomegalovirus (CMV) serostatus
- Number of centers performing peds and adults vs peds only

Immunosuppression

- Induction – yes/no
- Maintenance – 30 days post-transplant

Outcomes

- Delayed graft failure (Kidney)
- Estimated glomerular filtration rate (eGFR) (Kidney)
- Acute rejection
- Graft survival
- Patient survival
- Post transplant lymphoproliferative disorder (PTLD)

SRTR staff explained how the data is currently reported and showed an example of a demographic table from the report. This table showed changes over time from 2011 to 2021, including the age categories used by the SRTR. An example of pediatric diagnoses for kidney was shown and it was noted that 47% of diagnoses were "other/unknown." SRTR staff noted that it is a problem and a potential issue for the Committee to address. SRTR staff noted that the only new category was insurance captured as private, Medicare, Medicaid, or other/unknown. SRTR showed an example of data from each organ type.

Summary of Discussion:

A member asked if subcategories of diagnoses could be added and offered to provide a list to SRTR staff. The Chair noted that the Committee has previously discussed the diagnoses. SRTR staff noted the key to the annual data report is to keep it updated. She added that the purpose of this effort is to ensure the monitoring requests and follow up data aligns with how the SRTR is reporting data.

A member commented about the difference between heart patients less than 1 year of age and those less than five kilograms and how the risk of transplant translates into success. The Chair added that the categories need to identify high risk patients, however it can be challenging to analyze due to the smaller population of patients. She added that each organ type is potentially different for the smaller size patients. SRTR staff asked if the numbers should describe patient demographics (e.g., less than 5 kilograms) in addition to the pre-transplant mortality. She added that the data should describe the high-risk groups so there is an opportunity to make improvements.

A member noted that, for heart, the Committee could look at the Pediatric Heart Transplant Society Database and what is used for diagnoses to see if there are any differences to reconcile.

A member asked if there was a way to look at the mortality for the retransplanted population. SRTR noted that currently graft survival is not captured for that population of recipients as well as pediatric multi-organ transplants. These additions could be part of an initiative to update the reports. The Chair asked if there is any information about multi-organ transplants in the annual report. SRTR staff noted there are numbers for each of the organ types but no descriptors about the outcomes and noted the small numbers. The SRTR is currently discussing the option to include a chapter on multi-organ transplants.

SRTR staff noted that liver-intestine is included in the report and specifies intestine-alone transplants versus intestines included with the liver. He noted the challenge of identifying split versus partial livers and what that actually means. For example, the types of grafts such as whole liver, living splits, and deceased splits and how it would be beneficial to be able to identify them. A member asked if SRTR has ever audited the data on split livers to know how reliable it is. SRTR staff responded that they have looked at identifying splits as those livers that get transplanted into two individuals. He added that it might not be clear because if an organ gets split for the left lateral segment and the right lobe is transplanted is a different graft than a complete partial liver transplant. The challenge is that any split is now used for any technical variance so it might impact the reliability of the data.

A member commented that it might be useful to identify how many livers are going to two recipients instead of one to analyze donor utilization rates. Another member noted that it could also be tracked by using the donor identification (ID) number if there are two livers transplanted with the same donor ID. SRTR staff added that it might be useful to know how many times a liver is split and the right lobe is not used.

A member asked about the monitoring for the new ABO incompatible policy and whether it is tracking age and ABO incompatible or just ABO incompatible "yes or no." SRTR staff noted that currently it is collected as yes or no for ABO incompatibility. Staff reviewed the monitoring plan and provided the following information:

- Current monitoring for heart ABOi includes: The count and percent of pediatric heart candidates willing to accept an ABOi organ by age group and medical urgency status
- The count and percent of pediatric ABOi heart transplants by age group, medical urgency status, and blood type
- Anti-A and Anti-B titer at listing and at transplant for pediatric heart candidates by age group

Staff noted that the annual data report has been uploaded to SharePoint.

The Committee had no further comments or questions.

3. **Working Session: Monitoring Report Reference Documents**

Staff provided some background information and explained the purpose of this effort:

- All implemented policy projects are evaluated through OPTN monitoring reports, although the metrics being reported are not standardized.
- UNOS research team develops outcome metrics in conjunction with sponsoring committees for each project.
- There may be more helpful or additional metrics for evaluating the impact of policies on pediatric candidates that are not currently included on monitoring reports

Staff noted that the goal is to create an internal reference document for UNOS Research staff to determine which metrics to include on monitoring reports moving forward. This effort is in conjunction with a larger effort by the Policy Oversight Committee and Research department to make policy evaluation metrics more accessible.

Staff noted that the reference document is still a draft and will be updated based on feedback from the Committee members. Additionally, Staff noted that language revisions and formatting will be updated as the document gets finalized before the end of May 2023.

The Chair noted that the document, along with the link to the SRTR ADR, will be distributed to members following the call.

Summary of Discussion:

Staff noted that the general reference information section would apply to all organs and dual/multi-organ combinations as well as the general development of a monitoring report.

A member suggested clarifying if normothermic regional perfusion (NRP) was part of the donation after circulatory death (DCD) donor process. She also added that some of the information should also be collected by the SRTR.

A member commented that, for kidneys, the mortality rate is small for pediatric candidates on the waiting list due to dialysis. However, she added that it is important to show why pediatric candidates need to be transplanted sooner. She recommended that if someone is listed, the transplant center can report how many hospitalizations the pediatric patient had while on the waiting list. This could provide more information about co-morbidities for pediatric candidates waiting for a kidney transplant instead of death. SRTR staff acknowledged that pediatric kidney pre-transplant mortality is low and the only way to describe burden of disease in pediatric kidney patients is duration of dialysis and waiting time.

Another member questioned the data burden of reporting additional information. SRTR staff noted that based on previous discussions the data burden is significant. The Chair acknowledged that it is also outside the scope of this effort to add new data collection. However, if something is already collected, such as growth failure for kidney, that needs to be analyzed in a different way that is something for the Committee to consider.

A member noted that if a patient changes their status on the waiting list, such as priority for lung, it has something to do with their morbidity and questioned whether that is tracked over time. For example, if a patient is on high flow oxygen and then requires bilevel positive airway pressure (BiPAP), it is a sign of deterioration. SRTR staff noted that the information would be captured both at listing and at transplant. The Chair noted that the waitlist records should include changes in status from listing to removal so it could be analyzed.

A member noted that during previous breakout group discussions there were an unusual number of Status 7 patients, however there was no information about how long or for what reason. Another member noted that if a patient's status changes to a Status 7 the transplant center needs to report the

reason. The Chair noted that the monitoring reports typically show the status at listing or removal which doesn't provide information about what happens in between those dates.

A member asked about cold ischemia time being reported as less than 12 hours, more than 12 hours, or more than 24 hours. She suggested breaking that down further to better analyze the geographical areas and how difficult logistically it is to get an organ to the recipient because it does influence the long-term outcomes.

A member clarified that current data collection should be used; it just might be grouped in a different way. Staff noted that the feedback will be provided to UNOS Research staff for additional feedback and to ensure the document will be helpful when developing monitoring reports for policy changes.

A member suggested that how a patient is doing in school (e.g., delayed, missing school) might be a better marker than mortality. The Chair noted that functional status and academic level are collected, but it can be variable in how transplant centers report the data. For example, oncologists are trained to determine the Karnofsky score which is "a standard way of measuring the ability of cancer patients to perform ordinary tasks."[1] She added that for transplant patients it's derived more subjectively from information in the patient's chart, so it is hard to know the accuracy of those but it might be interesting to evaluate. A member noted that since the pandemic a lot of kids are homeschooled, therefore it is difficult to determine their true academic level. The Chair suggested that Research staff show the Committee what those categories currently look like.

A member noted that the Lansky score is more for pediatrics and the Karnofsky score for adults.[2] He added that there are overlaps between the two and neither one is being requested for lung patients. He added that his transplant center summarizes what patients can do in a less granular fashion.

Staff noted that the Committee can create a list of metrics that are not currently collected by the OPTN that could be used for a future data collection project.

Next Steps:

Staff will send the updated documents to the Committee for review prior to the next meeting.

Upcoming Meeting

- May 17, 2023 (Teleconference)

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[1] https://www.cancer.gov/publications/dictionaries/cancer-terms/def/karnofsky-performance-status
[2] https://www.mdcalc.com/calc/3176/lansky-play-performance-scale-pediatric-functional-status

Attendance

- **Committee Members**
  - Emily Perito
  - Evelyn Hsu
  - Abigail Martin
  - Caitlin Peterson
  - Caitlin Shearer
  - Jain Namrata
  - Geoffrey Kurland
  - Gonzalo Wallis
  - Jennifer Lau
  - Meelie Debroy
  - Reem Raafat
- **HRSA Representatives**
  - Jim Bowman
- **SRTR Staff**
  - Jodi Smith
- **UNOS Staff**
  - Kieran McMahon
  - Betsy Gans
  - Dzhuliyana Handarova
  - Robert Hunter
  - Susan Tlusty
- **Other Attendees**
  - Daniel Ranch
  - JoAnn Morey
  - Simon Horslen
  - Katrina Fields
  - Shelley Mason