

OPTN/UNOS Transplant Administrators Committee (TAC)
Meeting Minutes
September 26, 2018
Conference Call

James E. Pittman, Chair
Nancy Metzler, Vice Chair

Introduction

The Transplant Administrators Committee (TAC) met via teleconference on 09/26/2018 to discuss the following agenda items:

1. Guidance on Pediatric Transition & Transfer Public Comment Proposal
2. Pancreas Program Functional Inactivity Public Comment Proposal

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

1. Guidance on Pediatric Transition & Transfer Public Comment Proposal

Summary of discussion:

Many pediatric transplant programs are part of a system that has an adult program. One question was whether the Pediatric Transplantation Committee could look at those programs versus big pediatric hospitals with transplant programs that aren't affiliated and whether any of the patients were coming from out of state, making the follow-up a little bit more difficult. The presenter stated the best data is available for kidney because of volume. Many large programs with majority of patients being in-state residents had higher follow-up rates. Programs with an identified adult provider had higher follow-up rates than those without a linked provider. Subsets of data will be reported in a manuscript.

It is unclear whether or not there are actual data indicating pediatric transition or lack thereof is impacting outcomes or if it is a likely impact. The presenter responded that the data is mostly inferred by additional data beyond the scope of the survey. Additional other data have shown rates of graft loss for pediatric kidney and liver recipients. Rates of adherence are also highest in the adolescent age category, so there is a component of a certain subset of patients, in that anecdotally all centers acknowledge varying degrees of challenge with the transfer process. This is the first attempt of documenting the problem to begin to make recommendations on how to improve it.

One question was whether there was data showing of rates of patients getting transferred to a non-UNOS facility. The presenter stated that center demographics included data on rates of lost to follow-up by types of institution, so that information will be provided to TAC.

One comment was that Pediatric Committee has done a good job identifying the need for more structure around transfers. The guidance document may eventually lead to development of measures of performance. The point was made that an adolescent recipient could be 14 years old, but the transition would not be completed until 18 years old or even as late as 25 years old, so it would be interesting to see data in the 18- to 25-year-olds. The 18- to 25-year-old cohort has similar lost to follow-up rates as the adolescent group. At 10 years after follow-up, they were 4% worse, so a goal would need to be identified.

Many adult centers may get one or two transition patients a year, so if the Guidance Document is making recommendations on accepting adult providers relative to educating staff about

childhood and adolescent psychosocial development, what level of competency would be necessary for that very small population and what age cohort would it be relevant to?

Next steps:

A data summary will be sent back to the TAC for their review. Additional comments can be emailed. Contact information for Pediatric Committee leadership was provided.

2. Pancreas Program Functional Inactivity Public Comment Proposal

Summary of discussion:

One question was whether there was rationale for the 125-mile distance from transplant programs under review. The presenter stated it was assessed how far a recipient was willing to drive and 125 miles is about 2 hours of driving. Originally in-state was only considered due to insurance barriers but it was expanded to include in-state or 125 miles to account for transplant programs within that distance but out-of-state. The Pancreas Committee will make sure all transplant programs have another program geographically within 125 miles.

The data compilation of graft outcomes looks as though the programs were placed together and outcomes aggregated, as opposed to letting individual programs stand on their own and placed in scatter plot. Outcomes might look different if they were evaluated individually. The comment will be taken back to the Committee.

Next steps:

TAC will provide a response for the proposals.

3. Other Significant Items

Upcoming Meetings

- October 3, 2018, in-person meeting in Chicago, IL, 9 am to 3 pm