

OPTN Ethics Committee – General Considerations in Assessment for Transplant Candidacy (CAT)

Rewrite Subcommittee

Meeting Minutes

January 15, 2020

Teleconference

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Introduction

The OPTN Ethics Committee CAT Rewrite Subcommittee (the Subcommittee) met via Citrix GoToMeeting teleconference on January 15, 2020 to discuss the following agenda items:

1. Recap of 12/18 Meeting
2. Discussion: CAT Outline (current and new criteria ideas)
3. Next Steps

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

1. Recap of 12/18 Meeting

The Subcommittee Co-Chair provided an overview of the discussion from the December 18, 2019 meeting.

Summary of discussion:

During the December 18, 2019 meeting, the Subcommittee reviewed the current CAT white paper and provided feedback on the sections. Some feedback from the initial review of the CAT are as follows:

- **Preamble** – The Subcommittee determined that this section needs to be rewritten. There should be more clarity on the intent of the document.
- **Compliance/Adherence Section** – The Subcommittee recommended to retain this section. The term “adherence” is believed to be the more appropriate term to use as compliance has a negative connotation. There needs to be clarification/delineation between the two terms.
- **Repeat Transplantation Section** – The Subcommittee recommended to retain this section, but should be revised to provide more detail and clarity. There was discussion on whether pediatrics should be specified in this section (pediatric candidates may need a second or third transplant during their lifetime). The Subcommittee determined that this section should be more generalized and not limited to pediatric patients.
- **Alternative Therapies section** – The Subcommittee recommended the removal of this section. Other means of therapy is looked into to hold off on transplantation.

Additionally, the Subcommittee discussed potential new criteria to be considered in adding to the CAT white paper. Topics included intellectual disability, financial challenges, and current incarceration status.

A member asked about considering a patient's legal status (documented vs. non-documented). UNOS staff clarified that topics can be suggested such as intellectual disability and immigration status. The

Subcommittee would then need to define the context and rationale for including these topics into the white paper.

The Subcommittee decided to review the current CAT white paper to discuss in further detail. The Subcommittee's discussion were as follows:

Preamble

A member stated that during the last meeting, there was discussion on psychosocial evaluations and whether or not this should be included. The Subcommittee Co-Chair stated that psychosocial considerations are an important part of a patient's evaluation and suggested keeping this in the preamble.

A member agreed that psychosocial evaluations should be included in the Preamble and suggested that a piece should be added regarding what extent people are using psychosocial evaluations for listing/developing treatment plans around those evaluations. There was no opposition voiced by the Subcommittee to this suggestion.

The Subcommittee Co-Chair also suggested an expansion on each criteria listed to provide more detail to the content of the white paper. A member recommended removing the discussion about alternative therapies.

Life Expectancy

The Subcommittee Co-Chair stated that life expectancy would rely heavily on the adherence of the patient.

A member stated that life expectancy in the context of this white paper is more about whether the organ will outlive the patient.

The Subcommittee Co-Chair suggested further elaboration to this section. It was suggested that there be some discussion on the age of the patient and addressing age discrimination. The Subcommittee was asked their thoughts on being more descriptive in this section to address this. An example was provided of transplanting a 70 year old with no co-morbidities over a 50 year old with chronic obstructive pulmonary disease (COPD).

A member stated that for the context of this white paper, the section is fine as written and no further clarification is needed.

A HRSA representative stated that in the U.S., there is concern about advanced age transplant candidates being discriminated against due to their age. The question was posed to the Subcommittee on whether this specific topic was something that would want to be considered and discussed.

Another HRSA representative commented that the topic of age would be outside of the purview of this white paper as it is the understanding that this white paper is more about considerations for candidates to be placed on the waitlist.

Organ Failure Caused by Behavior

A member asked if non-adherence factors should be included in this section or if it would be better suited in the Compliance/Adherence section of the paper.

The Subcommittee Co-Chair stated that this is addressed in the Compliance/Adherence section of the paper.

No additional comments were made on this section.

Compliance/Adherence

A member stated that adherence is difficult to define and track from a transplant program's perspective. For kidney patients, it is somewhat easy to track dialysis adherence, but what criteria would be used for other organs?

The Subcommittee Co-Chair agreed and added that adherence is a subjective topic. Subcommittee members were asked how this topic could be broken down to make it beneficial to patients and transplant programs.

A member stated that compliance should not be measured and that adherence is more appropriate in addressing.

Another member stated that patient self-reporting adherence should be taken into consideration as it pertains to non-adherence. Rather than using the term "compliance", "non-adherence" may be the better term to use.

A member stated that non-adherence could occur for a variety of reasons; one patient may choose to be non-adherent whereas another patient is unable to adhere based on resources. There are many layers to this particular topic.

Another member stated that if a patient has any of these barriers it would still be something to consider when listing a patient. Programs should recognize the barriers patients face prior to listing and come up with solutions to overcome those barriers. It may be helpful to suggest checklists to encourage programs to identify the adherence barriers.

Repeat Transplantation

A HRSA representative asked the Subcommittee their thoughts on the intent of this section.

The Subcommittee Co-Chair stated asked if this section pertains to non-adherence. This section needs to be expanded on to clarify the intent of this topic.

A member suggested keeping this section so that people know this was considered by the Subcommittee. The focus could be on the psychological fortitude of the patient who would need a re-transplant.

A HRSA representative suggested that this topic be added to the Adherence section of the white paper to talk about re-transplantation. Factors outside of the patient's control should not be discussed.

Alternative Therapies

The Subcommittee Co-Chair stated that every programs considers alternative therapies before moving towards transplantation. The Subcommittee were asked if they would be in favor of removing this section.

There was no opposition to this suggestion.

Next steps:

The Subcommittee will be sent a summary of the meeting's discussion and will provide any additional feedback.

2. Next Steps

The Subcommittee discussed next steps of the CAT Rewrite project.

Summary of discussion:

The Subcommittee's discussion from the last two meetings will be summarized and the project outline will be updated to a project form that will be sent to the OPTN Policy Oversight Committee (POC) for their review and consideration.

The Subcommittee will review a summary of the meetings and provide any additional feedback. Members were encouraged to include any suggestions for new criteria that should be considered to include in the white paper. Those topics would be discussed during the next meeting in further detail.

There were no additional comments. The meeting was adjourned.

Upcoming Meeting

- February 19, 2020