

**OPTN Ethics Committee
CAT Rewrite Subcommittee
Meeting Summary
May 20, 2020
Conference Call**

Catherine Vascik, Credentials, Chair

Introduction

The Subcommittee met via Citrix GoTo teleconference on 05/20/2020 to discuss the following agenda items:

1. Recap of 4/15 Meeting and Discussion

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

1. Recap of 4/15 Meeting and Discussion

The Subcommittee reviewed feedback from the April full committee call and discussed what feedback to incorporate.

Summary of discussion:

A UNOS staff member began to review the feedback from the May full committee call. One member commented that most of the feedback appeared outside of the scope of the project.

Organ failure caused by behavior

One member commented that listing specific criteria for this section is outside of the intent of the document, which is intended to be a general reference document. In addition, the member noted that there are a wide variety of behaviors that fall into this topic. Another member commented how challenging it would be to list everything out and rather the subcommittee should focus on covering the topic broadly.

Compliance/Adherence

One member agreed with the feedback that access to medications is an important consideration for this topic but felt that alcohol induced liver failure and adherence contracts were not suitable for the topic. The committee discussed adherence contracts and a member specifically noted that signing an adherence contract would not remove barriers for patients. Another member commented that by limiting the amount of detail included in the section, each center would be able to determine their own threshold for each topic. The workgroup agreed that the paper should address topics more general without so much detail.

Repeat transplant

The workgroup agreed to remove this section as it is a center to center decision.

Alternative therapies

The workgroup agreed to remove this section as it is currently common practice to consider alternative therapies when transplant is not an option.

Intellectual disability

The workgroup had a lengthy discussion regarding the subject of including intellectual disabilities as a new topic. Some members of the group felt that similar to the other sections, this topic should only be covered briefly with a short statement. One member with expertise in this area felt that the topic was too complex to be covered by a brief statement. This member brought up the complexities regarding patients in a persistent vegetative state and those that are classified as covert consciousness and can communicate through technology. The member felt that this distinction is too challenging to explain in this white paper. Another member brought up the possibility of assessing transplant candidacy based on quality of life. A member of UNOS staff mentioned that quantifying quality of life is difficult given the different perspectives of patient's families and medical professionals. The staff member also discussed the history of the ethics committee's analysis of this subject in another white paper which was put on hold after learning about forthcoming guidance from the Office of Civil Rights (OCR).

A member of HRSA suggested that the phrase "intellectual disabilities" can be a lightning rod that may attract controversy and that transplant centers already consider a range of factors with patients including physical, mental and financial issues. One member wondered if this topic would be better addressed in the section on social support. Another member with expertise in this subject matter confirmed that the term "intellectual disabilities" is correct and that most centers consider this factor but may not do so in a consistent manner. The member also noted that in some circumstances preemptive transplant can greatly improve quality of life in the long run even if the patient is not yet on routine dialysis. A member of HRSA noted that this section did not fit under the topic of social support and that it did not currently consider neurological or psychosocial factors. The subcommittee agreed that due to the complex nature of the topic and the impending guidance from OCR, the topic would not be included in the paper.

Financial challenges

One member wondered if patients had been financially impacted by the current pandemic. Another member felt that there were two components to this topic namely paying for medications and paying for the actual transplant. Another member noted that the latter component varies center by center with some insurance companies paying for transplant. Subcommittee members agreed that the medication component should be included, specifically in the adherence section, but the paying for transplant issue should not be included.

Incarceration status

One member noted that their center transplanted incarcerated patients but not every center does. Another member noted that one particular challenge of caring for these patients are the number of people involved. The previous member expressed that these individuals have a right to transplant. One member suggested creating a larger section discussing disadvantaged populations such as the homeless, undocumented and incarcerated which could go under the social support section. Another member felt that this suggestion didn't seem adequate.

The group discussed whether to reconsider the format of the paper but decided that at the moment it was not top priority.

Next steps:

The subcommittee will present an update during the next full committee meeting and continue work on the white paper.

Upcoming Meeting

- May 21, 2020 – Full Committee Meeting