OPTN Ethics Committee
Facilitating Patient Navigation Workgroup
Meeting Summary
July 7, 2020
Conference Call

Amy Friedman, Chair
Andrew Flescher, Vice Chair

Introduction

The Facilitating Patient Navigation Workgroup (Workgroup) met via Citrix GoToTraining teleconference on 07/07/2020 to discuss the following agenda items:

1. Project Proposal Review & Internal Feedback
2. Workgroup Discussion

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

1. Project Proposal Review & Internal Feedback

UNOS staff gave an overview of the project review process and the Workgroup reviewed the internal feedback of the proposal.

Summary of discussion:

The Vice Chair shared that the Workgroup's project ideas were reviewed by internal OPTN staff. Staff provided feedback that the Workgroup consider whether the target audience for the project are designated OPTN members, namely transplant programs, organ procurement organizations (OPOs), and histocompatibility labs. Additionally, the audience should be tailored to the focus of the Ethics Committee, for example most projects geared towards patients are addressed by the Patient Affairs Committee. The Vice Chair noted that the scope of the Ethics Committee (Committee) is typically to provide ethical analysis of principles rather than develop educational materials.

The Vice Chair summarized that the intent of the proposed project is to ensure that the information shared with transplant candidates is transparent in a way that they are able to make an informed decision about where they receive care. This project would address the principles of equity, safety, utility, and social justice. The Vice Chair noted that the new proposed Workgroup product will be an analysis in the form of a white paper.

UNOS staff shared that the Workgroup Chair incorporated the feedback into a revised project summary. The project's core principles remain the same but the product and audience have been adjusted to better align with the Committee's charge of providing ethical analysis.

A member commented that they were familiar with two brochures targeted at patients created by the Patient Affairs Committee and wondered whether the workgroup should have a product which was similarly directed at patients as an educational material. The Vice Chair commented that there is a distinction between determining what the patient ought to have available to them and how to best make it available. An example of what the Committee could focus on is a patient's right to know which surgeon will be operating on them. Building patient materials is not the purview of the Ethics Committee specifically. The member commented that the Patient Affairs Committee's role differs from the Ethics Committee's role which is to look at issues from a higher level as opposed to a deliverable to patients.

UNOS staff shared that the various committees may have different approaches to the same project subject matter. This varies by the expertise, charge, and lens of each of the committees. The Ethics Committee's focus is to provide analysis to issues from an equity, justice, or utility standpoint. Although the proposed project is still centered around patients, it will take a different format than a deliverable created by the Patient Affairs Committee. An Ethics Committee deliverable would take the form of an analytical white paper for transplant programs that discusses their potential duties or responsibilities to ensuring transparency with their patients on specific criteria determined by the Committee. A member commented that these parameters makes the project more straightforward.

2. Workgroup Discussion

The Workgroup discussed criteria to address in their project proposal.

Summary of discussion:

The Vice Chair suggested identifying examples in which more transparency between patient and transplant program would be beneficial and then linking those suggestions to principles as a starting point. Transparency, for example, has been identified as a matter of social justice. There may be populations that have a harder time understanding the information readily available. For example, on the basis of equity, certain information should be discussed by a transplant coordinator. There could be rationale explaining why, what, and when information is revealed to the candidate. The Vice Chair questioned if the way information is currently shared is adequately balancing paternalism and autonomy in an appropriate manner. He defined paternalism as protecting the patient from information that will bewilder them and autonomy as ensuring they are able to make informed choices. This balance should be considered prior to determining how the patient is receiving the information.

A member suggested including the topic of the exclusion of the patient from the decisions of the transplant program when declining organs. A patient may choose to accept a more marginal organ if given the opportunity. This is an example of a loss of autonomy.

A member suggested looking into how everyday people endeavor to utilize the Scientific Registry of Transplant Recipient (SRTR) data. They questioned whether every transplant candidate and candidate family are able to use this data in a meaningful way specifically when considering the aggressiveness of a hospital or the efficacy of transplants at the one-year marker during the time they are choosing a hospital. The ability to use this data may be a factor in how patients choose certain centers. The member gave an example of the Medicare star rating system which simplifies data to assist in the selection of a nursing home.

The Vice Chair asked the member which principle this relates to. The member responded that it could be related to equity and safety. They shared that this could be considered under the principle of equity by way of ensuring that people are equally informed when making a choice of which hospital to use and safety because the patient may need to know which hospital can accept more challenging cases. A member shared a personal experience about how this affected them when seeking a transplant. They said that they were not accepted to a waitlist at the first center they went to and ended up being transplanted at the second due to the aggressiveness of the center.

A member commented that the level of scrutiny and consensus among a transplant program's staff regarding the psychosocial criteria required to be eligible for transplant has a lot of variability program to program. There may be miscommunication around how the psychosocial evaluation is completed and perceived. Additionally, it is important for the patient to be aware of how their responses affect their eligibility and the hospital's decision-making. Several different components including the process, the questions asked, the interviewer, how the answers are perceived, as well as the weight given to the psychosocial evaluation are all highly variable between programs. The Vice Chair asked if the member was concerned about any discrimination on the basis of what may be revealed during the psychosocial evaluation. The member said they were concerned and added that patients are not given enough information about why they are asked to meet with a social worker and how it may factor into the care they receive. For some patients that reveal a history of alcohol consumption, substance abuse disorder, suicidal ideation, incarceration, or other factors, their evaluation may be longer and they may not be aware of why. The patient should be given a clear overview of the value of the process, the questions they will be asked, why it is important to truthful, and describe the way the information they provide will be used in order to increase and adhere to the value of transparency.

A member agreed and added that contraindications should also be examined. These can include being uninsured or having a history of depression. Programs can vary on these determinations as well.

A member commented that issues regarding acceptance of insurance should be discussed as well as how this affects patients particularly those who are limited in other ways such as geographically. If these patients are privately insured, their options may be limited to their insurer's obligations.

The Vice Chair asked for clarity around the idea of how patients use SRTR data. He wanted to know that the intent is not to determine how SRTR data should interpreted but that transplant hospitals should provide a mechanism that helps the patient interpret the data.

A member commented that it would be challenging to interpret the SRTR data as a lay person. They agree that there is an opportunity for this data to be explained to assist in understanding.

A member commented that this information is important to share during the evaluation process. They gave an example of two hospitals in which one may be able to provide a transplant faster but with a slightly greater chance of graft failure. The member described that at the one hospital, they would share that their methods are best and the patient will be transplanted faster while the other hospital would also say their methods are best, the wait may be longer, but the outcomes will be better. The Vice Chair asked if there are principles that underlie how much and what should be disclosed to the patient. The member asked if there are principles in clinical transplantation that are used by everyone. They asked if members all share the goal of increasing transplantation or if their goal is to increase patient longevity. Their individual principles may be guided by personal philosophies or morals.

The Vice Chair commented that the workgroup Chair is very interested in patient autonomy and providing as much transparency as possible. A member agreed that they strongly believe in informed consent however there is no uniform way of reviewing data and that patients may interpret what they are told differently. Patients often rely on the hospital to provide a framework to understand the data they have access to. The Vice Chair asked what the Workgroup's focus should be regarding the SRTR data. A member suggested having hospitals as a group consider how to build a framework to help answer patients' questions about the data. They suggested analyzing what data helps patients choose a center as well as what the data means to patients who are unable to choose. A member commented that the majority of the population are not able to choose their center. A member responded that these patients may still be empowered by understanding the data and have a more positive outcome. A member emphasized that the way the information is delivered is complex. The Vice Chair commented that the Workgroup should focus on the why, what, and when and trust the how to others.

UNOS staff presented ideas previously discussed by the workgroup. A member commented that the support system the transplant recipient has post-transplant is critical and asked the group to discuss how support systems are evaluated prior to transplantation. A member commented that candidates may overlook what is required for support when they first start their journey as a transplant candidate. The member commented that patients without the proper support system may be denied so transparency is very important. The Vice Chair agreed. He shared that his hospital strives to be as upfront with the patient about any red flags they perceive, such as if the patient has a pattern of missing dialysis appointments. He suggested that the ethics could be evaluated regarding if a transplant hospital should feel a burden to disclose their rationale as it occurs to them. The Workgroup could write on this topic.

UNOS staff commented that the group sounds like they are in agreement to continue with writing a white paper discussing information provided to patients for the audience of transplant hospitals. A member suggested that the Workgroup read other white papers written by the Ethics Committee so there’s a better understanding of the final product.

Next steps:

UNOS staff shared that a next step will be to report out to the workgroup Chair about the criteria the Workgroup would like to explore. At the next meeting, the Workgroup will review more items gathered in a brainstorming session and determine how these items fit under each ethical principle. The proposal will later move on to the Policy Oversight Committee to gain approval.

Upcoming Meeting

- July 16th - Full Committee Meeting