

OPTN Covert Factors Subcommittee

Meeting Summary

January 7, 2020

Conference Call

Amy Friedman, MD, Chair

Introduction

The Covert Factors Subcommittee met via Citrix GoToTraining teleconference on 01/07/2020 to discuss the following agenda items:

Covert Factors Impacting Patient Decision Making in Transplantation

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

1. Covert Factors Impacting Patient Decision Making in Transplantation

The Subcommittee discussed an overview of the covert factors project before discussing the project outline and goals.

Summary of Discussion

The Subcommittee Chair highlighted the importance of helping patients understand how to be smart consumers and make the best decisions regarding their healthcare and transplantation opportunities. The Subcommittee Chair clarified that "covert" refers to factors that patients may not know about and may need help to find out about. The concept of this project was to serve the needs of patients so that they have a full picture of the opportunities that exist. The Subcommittee discussed whether the best resource culminating from this Workgroup would be a white paper for communication or another product. The Ethics Committee Chair noted that a white paper may be more focused on transplant programs as an audience, while educational resources may be more focused on patients themselves. The Ethics Committee Chair added that the Ethics Committee often focuses on white papers, but could also do an educational resource. The white paper could also be directed to transplant programs in describing the issues of covert factors affecting patient decisions, and an educational resource could be made available to transplant programs to provide patients.

The Subcommittee discussed reaching out to patient advocacy organizations such as the National Kidney Foundation or American Association of Kidney Patients to get outside perspectives on what factors patients should know about that they currently don't. Transplant programs and UNOS have call centers that patients may utilize – the Subcommittee discussed getting data on how often those call centers are used. The Subcommittee also discussed performing a survey of patients or patient oriented organizations to gather information regarding covert factors that may impact patient decision making with regards to organ transplantation. The Subcommittee also agreed that several stakeholder OPTN committees – the Transplant Coordinator Committee (TCC) and Patient Affairs Committee (PAC) – should be consulted and join the Subcommittee in considering the development of potential resources.

The Subcommittee discussed questions or issues that would be potentially helpful for patients to consider or ask their transplant program prior to transplant. This initial list of questions could be shown to stakeholders or incorporated in a potential survey. The list of potential issues includes:

Transplant center volume: patients on the waiting list, referrals, number of transplants. This information is currently available as part of “program specific reports” through the SRTR website.

- Whether transplant programs follow transplant recipients over the long term or short term
- Financial issues
 - Limited or no insurance
 - Medicaid coverage as it applies to programs in-state or out of state
 - Immunosuppressive drug alternatives, maintenance costs, and generic alternatives
 - Insurance coverage for centers of excellence
- Resources and support for pediatric candidates as they age as adult recipients
- Composition of the transplant team or at least whether the transplant program is at a training hospital

The Subcommittee identified two other potential topics related to non-adherence issues with smoking and double generation skip with younger generations donating to older candidates. These issues may not be included in the list of questions for patient decision making that the Subcommittee is currently working on. A Subcommittee member noted that the questions should be helpful to patients and not provide information without context that could make it more difficult for patients to make decisions. The intent is to aid in decision making, not merely provide more information that adds complexity to decision making with no benefit or no guide for using the information. The Subcommittee also emphasized that they want the resource to be high-level enough to avoid it quickly becoming an irrelevant resource for patients to use. The Subcommittee agreed that the focus of the resource would be transplant candidates, not living donors, because the latter are provided guidance from the OPTN Living Donor Committee.

The Subcommittee identified that resources already available may not be known to the patient community, and access to these resources (such as SRTR reports) could be better promoted. There are also resources for patients understanding the transplant process that were published by HRSA and the OPTN. The Subcommittee is interested in reviewing these documents, adding to its list of questions/issues of covert factors for patients to consider, bringing in stakeholder groups, and potentially creating a survey for patients or stakeholder groups to complete.

Next Steps

UNOS staff will reach out to TCC and PAC staff to identify potential members to join the Subcommittee, and circulate the documents previously drafted for patient support by HRSA and the OPTN.

Upcoming Meetings

- February 4, 2020
- March 3, 2020