OPTN Facilitating Patient Navigation Workgroup
Meeting Summary
March 10, 2020
Conference Call

Amy Friedman, MD, Workgroup Chair

Introduction

The Facilitating Patient Navigation Workgroup met via Citrix GoToMeeting teleconference on 3/10/2020 to discuss the following agenda items:

1. Patient Services Data
2. Communication Data
3. Section Assignments

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

1. Patient Services Data

UNOS Research staff provided an overview of the patient services line and their most common inquiries.

Summary of discussion:

One member thought there was data indicating a specific number of times a specific publication was accessed. A UNOS staff member clarified that the data the member was referring to came from the Communications Department and was regarding the website. The UNOS research staff member explained that the patient services line had received very few calls regarding the publication, *What Every Patient Needs to Know*, considering the number of years this data has been recorded.

Another member asked if this publication was also available in print and if the data captured print access. The UNOS research staff member responded that the print access was not reflected in the data.

Next Steps:

The workgroup will consider this data to inform the direction of the project.

2. Communications Data

A UNOS staff member reviewed the data provided by the Communications Department regarding patients' access to online resources.

Communications

One member noted that the access numbers are startling low and expressed a desire for the workgroup to come up with a different strategy so as to make a greater impact.

One workgroup member commented on their experience as a patient and that they did not have knowledge of the OPTN until after their transplant. They expressed the need for the information to come from the transplant centers. Another member agreed and wondered to what extent the transplant centers inform patients of these resources.

One member commented that their center provides a letter to patient with information about the OPTN and patient resources several time a year but it is unclear if patients read or understand it. Another

member who worked as a transplant surgeon agreed that there may not be robust information being provided to patients through programs. The member suggested creating an innovative approach for patients such as a video on Youtube or something. Another member liked the idea of a video and added that programs could direct their patients there.

One member pointed out that if the workgroup hoped to assist patients by providing information allowing them to choose a transplant program, then the workgroup would want patients to have access to their information before being connected to a program. Another member suggested that transplant programs could post the workgroup's video on their website so as to gain more exposure. The Workgroup leader asked if UNOS or any committees had ever created a video similar to the idea of the workgroup. The UNOS staff member said they would research and get back to the workgroup. The workgroup leader hoped to create a video with a multi-disciplinary group of experts to provide information for patients.

One member commented that UNOS was working on a video for the Thoracic Committee and may have the capabilities to create video for this project.

Next Steps:

UNOS staff will gather information regarding the existence of any patient-oriented videos. The Workgroup will continue creating an outline.

3. Section Assignments

The workgroup reviewed the various researched sections for the guidance document.

Summary of discussion:

What is it transplant program's patient volume for a given organ?

One of the members reported that they found that some of the material provided to patients is so long that it can be a lot for a patient to digest when they have just been informed of the need for transplant. The member suggested maybe breaking the center specific information down to where patients can understand – such as a summary.

Another member asked if the draft section explain why the volume is important? The member noted that it may be meaningful to include an explanation for why this information is important. Another member mentioned that the workgroup should approach giving advice with caution and need to be unbiased.

What resources are available online for patient-specific reports and how can they be accessed?

This questioned was not discussed.

Does the transplant program follow transplant recipients long-term or short-term? If they are monitored short-term, are they followed up by their primary care physician?

This question was not discussed.

Non-compliance/non-adherence information?

A member indicated that all the information in this category is open and accessible to patients. Also that transplant programs are very vigilant about pre-transplantation patient adherence. The member wondered if this document would be a best practices template or more intended to inform patients of resources available to them.

The workgroup leader noted that they did not believe all transplant programs were as proactive towards patients. They cautioned against any type of best practices guidance as it could cross the line into dictating medical practice of programs. The Workgroup leader clarified that the format of the deliverable was not yet determined and that the workgroup seemed interested in pursuing both a white paper and a video directed at patients.

One member spoke in support of creating a white paper as a resource to transplant programs to share with their patients. The member felt that the question of format also applied to how the white paper is written and felt it could have more bulleted succinct information. One member commented that the white paper could be designed in a format easier for navigation so patients could target in on specific sections. Another member commented that how the information is relayed is just as important as what information is relayed because most patients are not used to digesting this type of material.

The workgroup members discussed how to approach the issue of compliance and adherence in regards to patients and to which extent programs share their expectations for compliance without giving patients the ability to game the system. The members also discussed whether patient non-adherence is likely to discourage a transplant program from transplanting that patient or whether programs are more focused on achieving certain metrics regardless of the adherence of a patient.

What financial constraints should the patient be aware of?

One member noted that any statement regarding financial issues would note that it varies greatly from patient to patient based on insurance, geography, support systems, etc. The member explained that it is important that patients know that this can be one of the most expensive surgery and how to ask questions about payers, specifics about transplant costs, non-medical (transportation, lodging), other types of insurance, areas of potential funding, etc.

At what age does a patient "age out" at a transplant program (ex: pediatric patients)? Is there a partnering program that will accept them?

This section has not been assigned to a member yet, but it was suggested to add it into the transplant composition section.

What about the team of the transplant program should the patient know about?

A member indicated that there is a great outline in OPTN bylaws that gives information about the training of transplant program members. The member discussed questions patients may have about training, noting that a training program may have more updated training/technology, etc. but other transplant centers might also be great because senior surgeons might do most of the procedures. Patients may wonder if programs have trainees doing the procedures or if senior surgeons are in the room.

Insurance identification for centers for excellence – how much do patients know?

Another member shared their research regarding centers for excellence. The member shared that each center should be transparent about their designation. It is unclear how insurance companies rank the centers and some insurance companies only allow procedures at these centers. In some cases, the approval for procedures can be over-ruled by a case manager at some centers. The workgroup leader noted that this is a thorny subject as some transplant programs can really suffer from these designations.

What is the transplant program's general policy about accepting candidates based on certain characteristics/behaviors?

The workgroup did not have time to discuss this section and will lead with it on the next call.

Lastly, a member raised the issue of transparency regarding organ discard information per center. The workgroup leader agreed that it should be addressed in the paper. Another member noted that the term "discard" had very negative connotations particularly for donors and patients and suggested finding an alternative term.

Next Steps:

Workgroup members will review the outline and the workgroup leader will work on a document laying out the audience and pedagogical goals.

Upcoming Meeting

- TBD

Attendance

- **Workgroup Members**
    - Amy Friedman
    - Randee Bloom
    - Andrew Flescher
    - Elisa Gordon
    - Stephanie Little
    - Colleen Reed
    - James Sharrock
- **HRSA Representatives**
    - Jim Bowman
    - Marilyn Levi
- **UNOS Staff**
    - Kiana Stewart
    - Robert Hunter
    - Joann White
    - Betsy Gans