

OPTN Vascular Composite Allograft Committee
Vascular Composite Allograft – Living Donor Data Collection Workgroup
Meeting Summary
March 16, 2020
Conference Call

Linda Cendales, Chair, MD

Introduction

The Vascular Composite Allograft (VCA) – Living Donor (LD) Data Collection Workgroup of the OPTN Vascular Composite Allograft Committee met via Citrix GoTo teleconference on 03/16/2020 to discuss the following agenda items:

1. Review of Living Donor Registration (LDR)/Living Donor Follow-up (LDF) Purpose
2. Currently Collected VCA LD Data
3. Relevant Literature on Uterus Transplantations Outcomes and Possible Complications

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

1. Review of LDR/LDF Purpose

UNOS staff reviewed the discussion from the previous Workgroup call held on 03/09/2020, noting that members had questions about the LDR and LDF during this call. UNOS staff reviewed background information on these forms and their purpose, which is to capture information pre- and post-transplant to ensure living donor safety and to allow for meaningful analysis on the effects of living donation.

Summary of discussion:

Workgroup members did not have any questions.

2. Currently Collected VCA LD Data

UNOS staff noted that on the previous call, Workgroup members had questions about data currently collected for living VCA donors. UNOS staff explained that the current VCA LDF is not mandatory and the information that is collected on VCA living donors is relatively minimal as it is focused on demographic information. The VCA LDF requests more detailed information, but it is also not mandatory. Specific complications are not documented on these forms.

Summary of discussion:

Workgroup members did not have any questions.

3. Relevant Literature on Uterus Transplantations Outcomes and Possible Complications

UNOS staff reviewed key findings from two journal articles on outcomes of uterus transplantations and possible complications. The lead authors on the papers were Azaan Ramani (“DUETS (Dallas UtErus Transplant Study): Complete report of 6-month and initial 2-year outcomes following open donor hysterectomy,” 2019, *Clinical Transplantation*) and Liza Johannesson (“DUETS (Dallas UtErus Transplant Study): Early Outcomes and Complications of Robot-Assisted Hysterectomy for Living Uterus Donors,” provided ahead of print). The Ramani paper reported the 6 month post-operative outcomes of 13 open donor hysterectomies, and also reviewed complications identified in other literature. UNOS staff invited

Workgroup members to share their thoughts on elements from the literature that should be included on the LDR and LDF.

Summary of discussion:

A member advised the group to collect an extensive amount of detail collected around bladder, urinary, and ureteral complications, as these are complications that are unique to uterus transplants and have not been observed previously in kidney or liver donors.

The Workgroup discussed the importance of collecting information about sexual dysfunction. A member said that while this information is historically hard to capture, it is important for living donors and to differentiate menopause and sexual pain from the organ procurement process. The member was not sure if there are good metrics for this currently or if the Workgroup would need to device metrics for this. Potential data elements include physical pain with intercourse or sexual activity, and menopausal factors resulting from removal of the ovaries. The member noted that it is important to collect this data to share while counseling prospective donors about what they can anticipate experiencing after the procedure. Another member noted that programs within the United States have not been eager to remove ovaries from donors so as not to make these patients menopausal. The Workgroup agreed that if ovaries are being removed as part of a living uterus donation, then it is important to collect this data, particularly because creating menopause has major implications for overall health and cardiovascular morbidity over time, as well as quality of life.

A member also suggested collecting information about the surgical approach (e.g. open, robotic, or hybrid).

Next steps:

The Workgroup will reconvene on 03/30/2020 to continue discussing uterus-specific data elements to add to the LDR and LDF.

Upcoming Meetings

- March 30, 2020
- April 13, 2020
- May 4, 2020