

AST T3 Webinar 'Strategies to Improve Recipient Readiness and Reduce Disparities'

Additional Q&A

Speaker: Rachel Patzer, PhD • Emory University

Moderator: Leo Riella, MD, PhD • Harvard Medical School

1. Q: What resources are available for medication costs after pts lose Medicare and do not have a job?

A: At our transplant center, we rely a lot on local social services and advocacy organizations. In Georgia, we are lucky to have a place like Georgia Transplant Foundation, which provides assistance in fundraising pre-transplant, and also assists transplant recipients in returning to work. I would encourage others to check out www.gatransplant.org for more information, as I think that transplant centers and their patient and family advisory boards may be able to provide some of this same assistance if they committed the time.

Additional resources that may be helpful include:

The Medicine Program

www.themedicineprogram.com

A nationwide volunteer program that helps provide prescription assistance to those who do not have an insurance or government program that covers their medicine

Needy Meds

www.needymeds.org - offers listing of drug assistance programs

Other kidney specific resources and organizations that may provide additional guidance include the National Kidney Foundation and the American Association of Kidney Patients:

<https://www.kidney.org/>

<https://www.aakp.org/>

2. Q: Any experience in waiting list intensive education for actual readiness if you have long waiting times in centers?

A: This is definitely a challenge in many of our patient populations, and to my knowledge, there has been little reported on the potential solutions to address this. Some transplant centers re-evaluate patients when they have been waiting for a long period of time, but it's unclear to what extent these patients are re-educated.

3. Q: How much of an impact would changing the requirements for NLDAC have on the pt pop most in need?

A: Currently, the National Living Donor Assistance Program prioritizes financial assistance to people who cannot afford travel and other expenses associated with donating the organ. It is difficult to say the potential impact that changing these requirements – such as expanding the financial assistance program to include funds for patients who most need assistance – would impact inequities in transplant access, but overall I think this would be a tremendously helpful resource for us to provide for our patients.

4. Q: Are there any comparative studies assessing the access equity to transplant between the various solid organ transplants?

A: To my knowledge, there are no studies that have directly examined the disparities and degree of disparities across various organ types.

5. Q: What specific resources can I use to show evidence based data that supports use of a navigator for a transplant center?

A: There are two studies on navigators, including the paper by Sullivan et al (CJASN 2012) that utilized navigators within dialysis facilities and found that patients that had a navigator completed twice as many transplant steps compared to those without a navigator, and a more recent (non-randomized) study by Marlow et al that found that navigators may have increased living donor inquiries. To my knowledge, there are no randomized studies that have been completed showing a transplant center patient navigator was effective in improving access to transplantation.

6. Q: Can you be more specific re patient education, didactic vs interactive. How is interactive education structured?

A: Didactic learning is more traditional, i.e. a lecturer at the front of the room speaking or presenting slides, and interactive education may still involve some didactics (e.g. lectures), but would also encourage two-way communication between a speaker/educator and the patient. This may include stopping often throughout a didactic to check in with patients and ask them if they have questions, or ask for a show of hands in response to a question, or ask patients to share their experiences with their illness, their treatment, etc. It is also helpful to get patient's family members involved in the questions. In our center, we found that the greatest benefit to the interactive education was that those patients and family members that were intimidated to ask questions could still benefit from the responses to questions that other patients and family members offered. We also have found that having multiple people offer different types of educational information (e.g. nurses and coordinators, not just physicians), is helpful to patients.