



July 2021 | A periodic e-bulletin to share results of organ donation and transplantation projects funded by the Division of Transplantation.

Educational Program Helps Patients Learn about Chronic Kidney Disease and Treatment

Additional materials outside of the doctor's office increased knowledge about chronic kidney disease and living donor kidney transplantation.



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Chronic kidney disease (CKD) affects one in seven Americans, according to the Centers for Disease Control and Prevention. However, education about CKD and kidney transplantation is inconsistent, with some patients receiving information about dialysis and treatment options only after their kidneys fail. A grant study, funded by the Health Resources and Services Administration's Division of Transplantation, focused on how to improve education about CKD and help patients in CKD Stages 3–5 understand treatment options for end-stage kidney

failure earlier with an emphasis on living donor kidney transplantation (LDKT).

The University of California Los Angeles (UCLA) and Kaiser Permanente Southern California (KPSC) explored how knowledgeable CKD Stage 3-5 patients were about kidney disease and LDKT. Researchers also examined whether there were any disparities across races, ethnicities, and primary languages spoken. KPSC's healthcare system provided a pool of 900 patients in various stages of CKD to study.

"What I found shocking was that a lot of CKD patients didn't understand their own disease very well, let alone their treatment options for kidney failure," said Dr. Amy Waterman, Director of the Transplant Research and Education Center at UCLA. "You could have kidney problems for years where your kidneys are working, but they're not fully optimal. All of those patients in those

early stages of having kidney problems could be learning about how they can prevent their kidneys from failing and planning what treatments are best for them if their kidneys failed.”

Waterman found that CKD patients in earlier stages, socioeconomically disadvantaged patients, and Spanish-speaking patients were less knowledgeable about CKD and transplant compared to other patients. Overall, patients lacked knowledge about the benefits of LDKT over remaining on dialysis and had concerns about risking a living donor’s health, their own surgical pain, and the possibility of the transplant failing.

Strategies that work:

- **Start early.** Patients with CKD should begin learning about kidney failure and their treatment options as early as Stage 3.
- **Break the information up** into digestible chunks to improve patients’ ability to remember and understand what they have learned.
- **Involve their families.** Informed family members can better help care for patients with CKD, and they could be viable living kidney donors.



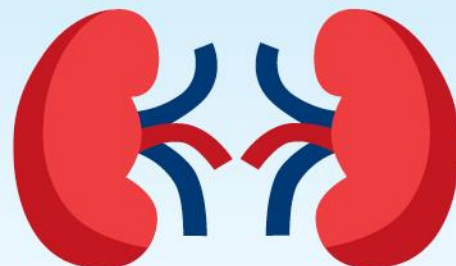
Explore Transplant@Home

UCLA and KPSC compared KPSC’s standard of care education about CKD and treatment to additional education via the Explore Transplant@Home (ET@Home) program. Standard of care education has patients discuss CKD with their providers and take a 1-to-2-hour course on kidney transplants, including how to get on the transplant waiting list. ET@Home educates patients from the comfort of their homes with four modules delivered via video, print, and text messages over six months. ET@Home explores CKD, including: 1) becoming a kidney recipient or involving a living donor; 2) the risks and benefits of each; and, 3) making a decision about the best treatment option.

The study found that patients who completed ET@Home were twice as likely than patients who received the standard of care to make informed decisions about pursuing LDKT, and they showed increased understanding of CKD symptoms and transplant options.

ExploreTransplant@Home has been used to:

- Educate **end-stage renal disease patients** about LDKT
- Provide at-home LDKT education for **Hispanic/Latino patients** post-appointment



“Patients really love small chunks of educational content presented over time,” said Waterman, pointing to ET@Home features like educational postcards and texts with clickable links that reinforce what patients learn in the videos.

To build on the success of ET@Home, Waterman and the KPSC team are: 1) exploring increased access to culturally competent transplant education in multiple languages; 2) pairing appropriate content to a patient’s CKD stage instead of giving the full spectrum at once; and, 3) increasing system-wide follow-up as CKD progresses to help patients make more informed choices about transplants.

“We have a healthcare challenge here for equal access, where we need to help people understand kidney disease in the same way they understand diabetes and high blood pressure,” Waterman said. “I want to do better by the American people who have kidney problems, and that’s all about preparation, information, systematized support, and referral. That can lead to more patients pursuing early transplantation, especially living donation. We’re going to try to make that happen.”

Want to know more?

Explore Transplant
www.exploretransplant.org

Dr. Amy Waterman @ ExploreTransplant.org
<https://exploretransplant.org/about-us/who-we-are/amy-waterman-phd/>

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<https://doi.org/10.1177/1526924820913520>

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