



April 2018 | A periodic e-bulletin to share results of organ donation and transplantation projects funded by the Division of Transplantation.

Bridging Barriers to Living Kidney Donation Education

This is the second in a two-part series featuring the results of Division of Transplantation grant projects focused on living kidney donation education.

Access to in-home education and culturally appropriate information improves knowledge



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Patients of low socioeconomic status are less likely than those living above the poverty line to receive kidney transplants. Hispanic/Latino patients are also less likely than other individuals to receive kidney transplants, even though they are disproportionately more affected by end-stage renal disease. Two HRSA-funded grant projects found that offering at-home living donor kidney transplant (LDKT) education and tailoring information to address specific cultural concerns improved transplant understanding among these two groups.

Strategies that work:

- Educating patients in their homes
- Providing education content gradually, over time
- Using culturally appropriate language and media



Gradual home-based intervention increases informed decision-making

Education interventions at dialysis centers have been shown to be effective at increasing patients' understanding of and willingness to explore a living donor transplant. However, dialysis and transplant center staff may not have the time or educational resources to provide information gradually.

From 2014 to 2016, **David Geffen School of Medicine at UCLA** and **Missouri Kidney Foundation** adapted Explore Transplant, a living donation curriculum used in dialysis centers, to be used at home by patients living at or below 250% of the federal poverty line. The Explore Transplant@Home program included 20-minute videos, brochures, fact sheets, and postcards, which were gradually given to participants in two at-home groups over eight months. Participants also received text messages with facts, recommendations, and quiz questions about living donation. Participants in one group also received four 20-minute coaching calls with a health educator.

Results of the study showed that the Explore Transplant@Home interventions were more effective at increasing patients' knowledge about transplant than education in dialysis centers that were not using the Explore Transplant program. **More than 90% of patients in both at-home groups said they could make an informed decision about getting an LDKT.**

"Dialysis centers and transplant centers are great places to reach patients, but they may not provide enough time to help patients who are less educated about living donation as a treatment choice," says principal investigator Amy D. Waterman, PhD. "Reaching patients directly helps spread the information out over time and can be done cost-effectively."

Researchers are starting a second trial that will adapt the program for stage 4 chronic kidney disease and Spanish-speaking patients.

Culturally appropriate website informs and resonates with Hispanics

In another grant project that addressed barriers to LDKT education, researchers created a bilingual website called Informaté: Living Kidney Donation for Hispanics/Latinos (Informaté Acerca de la Donación de Riñón en Vida, informaté.org). The English/Spanish site includes sections called "Immigrant Issues" and "Cultural Beliefs & Myths" as well as quizzes and telenovela-style videos.

Between 2013 and 2015, **Northwestern University Feinberg School of Medicine** and the **National Kidney Foundation of Illinois** added the website to the routine education that patients received in two transplant centers in Illinois and California.

After taking a pretest assessing their knowledge of kidney transplant, participants viewed different sections of the website for 30 minutes. Three weeks later, their **knowledge scores increased by 22.6%**. More than **92% of participants said that they planned to return to Informaté in the future** and **89.6% agreed that they would recommend the website** to other Hispanics/Latinos.

After the project concluded, researchers promoted the website throughout the Chicago area with targeted Facebook ads and traditional print and radio ads in English and Spanish. The mass media campaign brought more than 1,200 new visitors per month, nearly doubling the number of new visitors from a one-month period before the campaign.

“People are often unaware of living donation as an option unless someone in their family has kidney disease,” says principal investigator Elisa Gordon, PhD, MPH. “A website is a great resource because it’s available any time people need it, for free, in the privacy of their own homes, and they don’t need to go to a doctor to learn about the option of living kidney donation.”

Learn more about these projects using the resources below.

Want to know more?

Improving Low-Income ESRD Patients’ Transplant Knowledge: A Case Management Trial

Principal Investigator: Amy D. Waterman, awaterman@mednet.ucla.edu, 424-372-7278

McSorley A, Gonzalez C, Peipert JD, Norris KC, Goalby CJ, Peace LJ, Lutz PA, Waterman AD. Dialysis Providers’ Perceptions of Transplant Barriers for Minority and Low-Income Patients Along Levels of the Socio-Ecological Model. Poster presentation at National Kidney Foundation Spring Clinical Meeting. 2017 April, Boston, MA.

Waterman AD, McSorley AM, Peipert JD, Goalby CJ, Peace LJ, Lutz PA, Thein JL. Explore Transplant at Home: A Randomized Control Trial of an Educational Intervention to Increase Transplant Knowledge for Black and White Socioeconomically Disadvantaged Dialysis Patients. *BMC Nephrology*. 2015. Vol. 16, No. 150.

Waterman AD, Morgievlch M, Cohen DJ, Butt Z, Chekkera HA, Lindower C, Hayes RE, et al. Donor Kidney Transplantation: Improving Education Outside of Transplant Centers about Live Donor Transplantation—Recommendations from a

Consensus Conference. *Clinical Journal of the American Society of Nephrology*. 2015. Vol. 10, No. 9: 1659-1669.

Waterman AD, Peipert JD, McSorley AM, Goalby CJ, Peace LJ. At-Home Transplant Education Increases Black and Low-Income Dialysis Patients’ Transplant Knowledge, Attitudes, Informed Decision-Making, and Pursuit: An Explore Transplant @ Home Randomized Controlled Trial. Oral Presentation at American Transplant Congress. 2017 May, Chicago, IL.

Evaluation of a Culturally Competent Website on Living Kidney Donation for Hispanics

Principal Investigator: Elisa Gordon, Northwestern University Feinberg School of Medicine, egordon@northwestern.edu, 312-503-5563

Gordon EJ, Chaput J, Black A. Google Analytics of a Pilot Mass and Social Media Campaign Targeting Hispanics about Living Kidney Donation. *Journal of Internet Interventions*. 2016. Vol. 6: 40-49.

Gordon EJ, Feinglass J, Carney P, Ramirez D, Olivero M, O'Connor K, MacLean J, Brucker JB, Caicedo JC. An Interactive, Bilingual, Culturally Targeted Website about Living Kidney Donation and Transplantation for Hispanics: Development and Formative Evaluation. *JMIR Research Protocols*. 2015. Vol 4., No. 20: e42.

Gordon EJ, Feinglass J, Carney P, Vera K, Olivero M, Black A, O'Connor K, MacLean J, Caicedo JC. A Website Intervention to Increase Knowledge about Living Kidney Donation and Transplantation among Hispanic/Latino Dialysis Patients. *Progress in Transplantation*. 2016. Vol. 26, No. 1: 82-91.

Gordon EJ, Feinglass J, Carney P, Vera K, Olivero M, Black A, O'Connor K, MacLean J, Nichols S, Sageshima J, Preczewski L, Caicedo JC. A Culturally Targeted Website for Hispanics/Latinos about Living Kidney Donation and Transplantation: A Randomized Controlled Trial of Increased Knowledge. *Transplantation*. 2016. Vol. 100, No. 5: 1149-60.

Gordon EJ, Mullee J, Ramirez D, MacLean J, Olivero M, Feinglass J, O'Connor, K, Carney P, Caicedo JC. U.S. Hispanic/Latino Concerns about Living Kidney Donation: A Focus Group Study. *Progress in Transplantation*. 2014. Vol. 24, No. 2: 152-162.



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