



Expanding Living Donor Transplantation Through Improved Education



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Hello, From The Tower Building!

→
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Talk Objectives

- Introduce my research team & approach.
- Assess why deceased and living donor transplants aren't always occurring.
- Evaluate the effectiveness of Explore Transplant education on helping dialysis providers become motivated to educate their own patients about transplant and on their patients' living donation rates.
- Discuss how improved transplant education may help more African-American patients learn more about transplant & receive living donor transplants.
- Discuss the possibilities for an Center of Transplant Education and Living Donation.

Background

- Social/Health Psychologist
- Faculty Member at Washington Univ. School of Medicine, Health Services Research Division
- Quality Manager, Barnes-Jewish Transplant Center
- Founder of Explore Transplant, a Nonprofit Corporation

Mission: "to increase informed transplant decision-making to promote the highest possible quality-of-life for patients and improve access to transplant education in underserved communities."



Research as an Academic Ladder



- A Rigorous Climb
- What I Produce
- Others are competing
- One Way (Up) to Success
- One Leader
- Precarious
- Fixed



Research as a Jungle Gym



- Climbing as Play
- What We Produce
- Others are Collaborative
- Multiple paths to success
- Move in many directions
- Stable
- Creative

-Sheryl Sandberg, *Lean In*



My Jungle Gym

Grant Funding	<ul style="list-style-type: none">■ NIH, NIDDK■ HRSA■ OneLegacy Foundation
Research Team	<ul style="list-style-type: none">■ Christina Goalby, MSW■ Crystal Kynard-Amerson, MPH■ Anna-Michelle McSorley, BA■ John (Devin) Peipert, MA■ Riya Rajan, BA■ Jessica Thein, BA
Advisory Board	Representatives of ESRD Networks, UNOS, Dialysis, Transplant Centers, and OPOs, Kidney Patients & Living Donors

Research Collaborators, So Far

Research Collaborators	<ul style="list-style-type: none">■ Mark Robbins, PhD & Andrea Paiva, PhD <i>University of Rhode Island</i>■ Alan Leichtman, MD <i>University of Michigan</i>■ Francis Weng, MD, MSCE <i>St. Barnabas Transplant Center</i>■ Timothy McBride, PhD <i>Washington University School of Medicine</i>■ Osama Gaber, MD <i>Methodist Houston Transplant Center</i>■ Keith Norris, MD, PhD, Jeffrey Veale, MD, Eric Treat, MD <i>David Geffen School of Medicine, UCLA</i>
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Why Transplant, Anyway?

- Best of humanity, best of healthcare.
- We can intervene to reduce or solve this healthcare problem – “the need for organs for transplant.”
- Allows the work of a Social Psychologist to improve health and sustain lives.

Research Mission

- To develop, assess the effectiveness of, and nationally disseminate patient and provider education that improves informed transplant and living donation decision-making, care, and outcomes.
- To reduce racial disparities in access to transplant and living donation.
- To increase living donation rates.

...To solve the shortage of donated organs!

Dialysis & Kidney Transplant

Dialysis Population:

- 594,000 patients with kidney failure¹
- 415,000 (70%) on dialysis¹
- 96,000 candidates on the transplant waiting list²

Dialysis Patients of color are less likely:

- To be referred for transplant evaluation³
- To receive deceased or living donor transplants⁴

**So, are dialysis patients
who are not pursuing transplant uninterested
or unaware of the option?**

¹USRDS (2012) Atlas; ²OPTN data as of 05/10/2013; ³Alexander & Sehgal (1998) *JAMA* 280(13):1148-1152.
⁴Epstein, et al. (2000) *N Engl J Med* 343(21):1537-1544

Road to Transplant Requires:

- Learn about transplant as an option
- Call to begin evaluation
- Mail medical packet
- Attend transplant appointments
- Get listed for transplant
- Complete yearly re-evaluation
- Find a matching kidney
- Receive a deceased or living donor transplant



Road to Transplant

- ▶ Learn about transplant as an option
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Transplant Study: 2004-2010

At Barnes-Jewish Transplant Center, we surveyed 695 White and Black patients at the start of transplant evaluation and tracked their final transplant outcomes years later.

- 27% received a deceased donor kidney transplant (DDKT)
- 18% received a living donor kidney transplant (LDKT).
- Fewer Black patients received a LDKT compared with Whites (9% vs. 22%, $p < .001$)

We measured less- and more-modifiable variables to determine what predicted successful completion of evaluation and LDKT.

¹Waterman, et al. *Clin J Am Soc Nephrol*; Mar 21 2013.



Transplant Study: 2004-2010

At the beginning of evaluation, patients who:

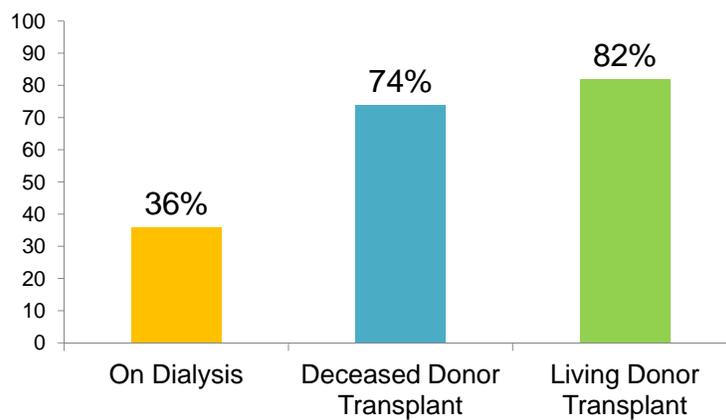
- had received better education from community nephrologists/in dialysis centers
- were more knowledgeable about transplant
- were more motivated to pursue DDKT and LDKT

...were 2 to 3 times more likely to complete transplant evaluation successfully and receive LDKTs six years later.

¹Waterman, et al. *Clin J Am Soc Nephrol*; Mar 21 2013.



5-Year Life Expectancy: Dialysis vs. Transplant



USRDS Annual Report 2012



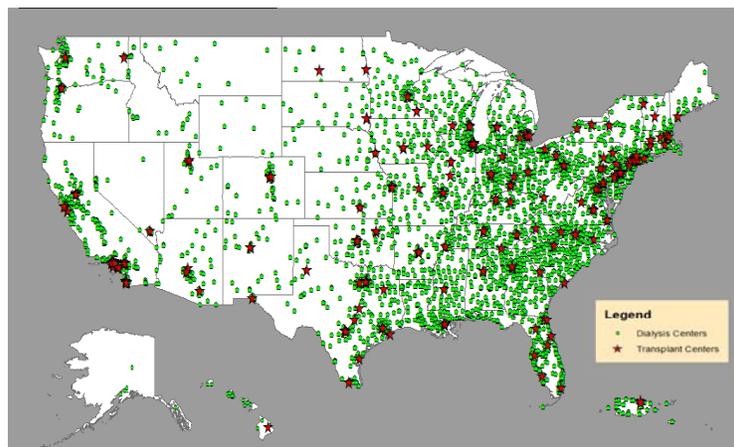
CMS Conditions for Coverage for Dialysis Facilities

US Dialysis Centers must:

- Provide evidence of transplant education (V458, V554)
- Track patients' transplant referrals and their status on wait list (V561)
- Communicate with transplant facilities regarding patient status annually and when there is a change in transplant status (V561)



6000 Dialysis and 250 Transplant Centers



What Transplant Education is Happening?

Surveyed 1544 dialysis providers from 1035 dialysis centers to learn:

- Attitudes about educating about transplant
- Transplant knowledge levels
- Transplant educational practices



Transplant Education Attitudes

55%

Were **dissatisfied** with currently available transplant education materials

53%

Were **not confident** in their ability to be a transplant educator

27%

Perceived communication between dialysis and transplant centers to be **poor**



Poor Dialysis Provider Knowledge About Transplant

	% Correct of 16 Questions (N=1544)
A living donor kidney lasts 15-20 years, on average.	19%
Dialysis is equivalent to the work of 10-15% of one functioning kidney.	23%
Living donors have a risk of high blood pressure after donating.	27%
90% of transplanted kidneys function for at least 1 year.	41%
Transplant Knowledge	42%

Transplant Education Practices in Dialysis Centers

	Providers engaging in this practice: (N=1544)
Orally recommend patients learn more about transplant themselves	72%
Orally recommend being evaluated for transplant	69%
Refer patients to an external transplant educational program	44%
Distribute transplant center phone numbers	37%
Detailed discussion about advantages/risks of DDKT	21%
Detailed discussion about advantages/risks of LDKT	21%

How Can We Help Dialysis Providers Better Educate about Transplant?



Partnerships with 8 ESRD Networks overseeing care of 150,000 Patients

**The National
FORUM of
ESRD NETWORKS**
Improving Care Through Collaboration



Network #15
InterMountain ESRD Network, Inc.

The Renal Network, Inc.
ESRD Networks 4, 9 & 10

End Stage Renal Disease
Network of New England




Western Pacific Renal Network, LLC



National Quality Improvement Initiative

Conduct Dialysis Provider Trainings to better prepare dialysis providers to educate their own patients about transplant.



During the Training

Peer-to-peer discussions about:

- Barriers to transplant education in dialysis centers
- What transplant education approaches might help



During the Training

Videos, exercises, and training demonstrating how to use Explore Transplant education with patients



During the Training

Expert Panel discussing:

- Being a Kidney Recipient or Living Donor
- Risks/benefits, out-of-pocket costs associated with transplant, living donation



After Completing This Training

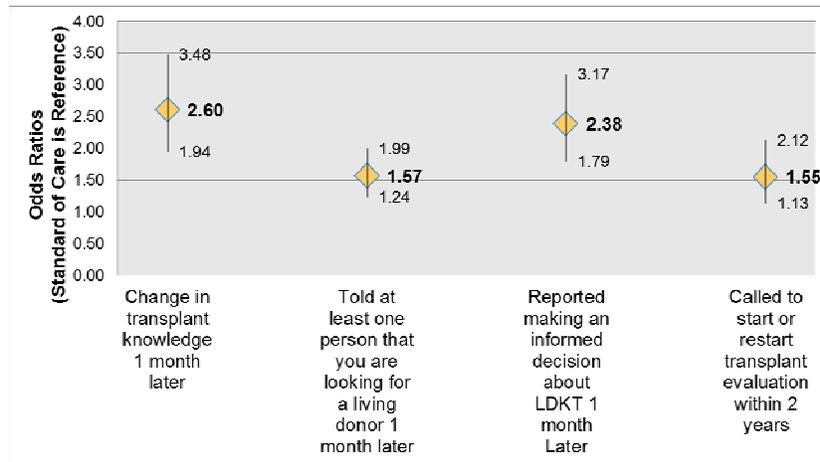


What is Explore Transplant?

- Comprehensive education program that **helps kidney patients make informed transplant decisions**
 - Video, print resources with patient and donor stories
 - Discussion of risks/benefits of transplant and living donation
- Individually-tailored conversations based on what is important to patient
- Educational materials for dialysis patients, family members & living donors



cRCT: Impact of Explore Transplant



†All statistical tests accounted for dialysis center clustering.

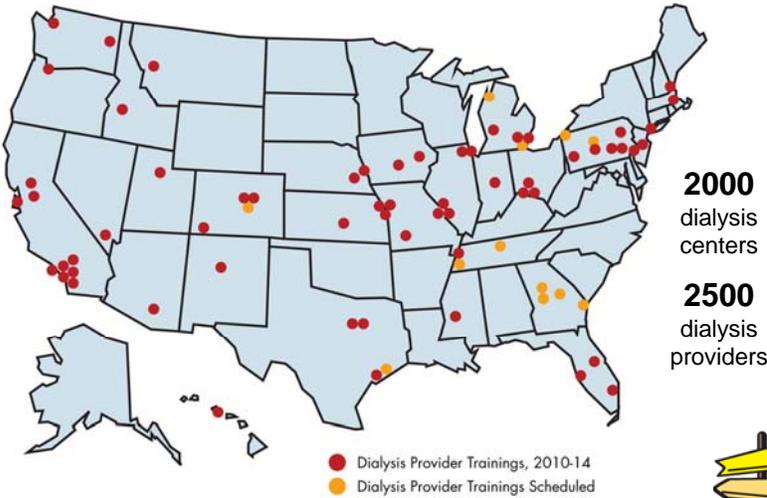
Goal: Train an Army of Dialysis Providers as Transplant Educators



Goal: Generate Transplant & Living Donation Discussion Within Families



65 Explore Transplant Trainings to Date



Regional and National Transplant Education Data

2009-
2011

11 Trainings with Heartland Kidney Network
257 providers trained, 199 dialysis centers
(73% RR)
Six-month provider & two-year center follow-up complete

2011-
2013

32 Trainings sponsored by multiple Networks and organizations
1544 providers trained, 1035 dialysis centers
Follow-up ongoing

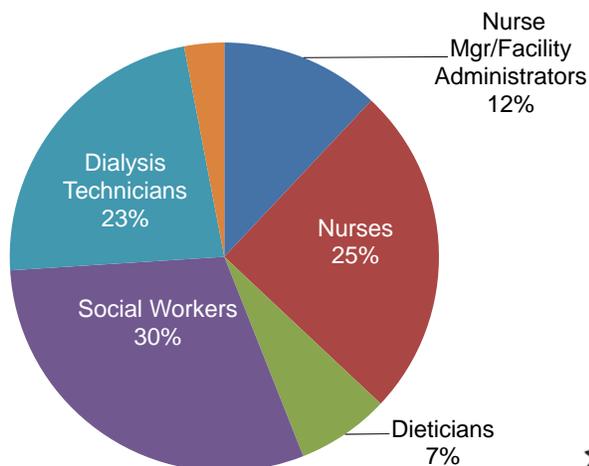


Outcomes Assessed

- Post-training (national data)
 - Changes in providers' transplant knowledge & confidence educating
 - Transplant Education Action Plans
- Six months later (regional data)
 - Number of education packets disseminated
 - Actual transplant education practices
- Two years later (regional data)
 - LDKT rates at dialysis center level



Who Attended Trainings?



N=1544

Transplant Attitude Change

	Before Training (% Agree)	After Training (% Agree)
I am sufficiently knowledgeable about transplant that I could answer most patients' questions.*	46%	82%
I am confident in my ability as a transplant educator.	41%	77%
The transplant education materials available at my dialysis center are excellent.*	39%	69%

*p<.001; N=1544

Transplant Knowledge Change

	Before Training (% Correct)	After Training (% Correct)
A living donor kidney lasts 15-20 years, on average.*	19%	86%
Dialysis is equivalent to the work of 10-15% of one functioning kidney.*	23%	82%
Living donors have a risk of high blood pressure after donating.*	27%	87%
90% of transplanted kidneys function for at least 1 year.*	41%	92%
Overall Knowledge*	42%	92%

*p<.001, N=1544

Explore Transplant Action Plans

	Already done or planning to do (N=1544)	Completed six months later (N=601)
<i>After the training, do you plan to:</i>		
Determine which patients are on the waiting list?	88%	85%
Determine which patients are transplant candidates?	87%	75%
Hang Explore Transplant posters in your dialysis center waiting room?	86%	54%
Share Explore Transplant materials and videos with your dialysis team?	85%	44%

N=1544

Post-Training Planned & Actual Education Actions

	% planned to do within 1-6 months (N=1544)	Took action 6 months later (N=601)
Educate at least 1 patient using <i>Explore Transplant</i>	84%	34%
Educate at least 5 patients...	75%	25%



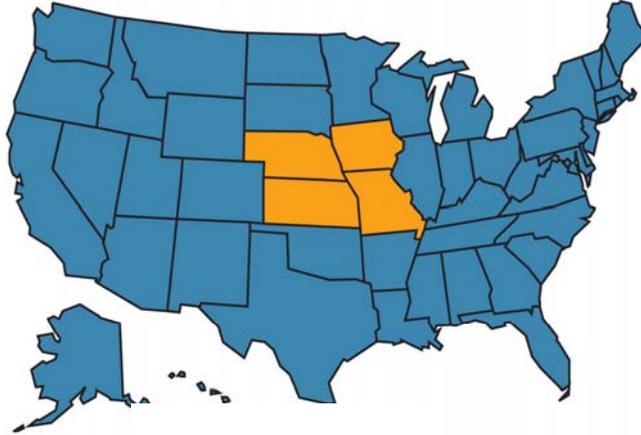
Explore Transplant Education Packets Disseminated

English	Spanish	Total
10,698	3,635	14,333



N=1544

The Heartland Kidney Network



The Heartland Kidney Network (ESRD Network 12) oversees quality of care for 14,000 patients in 274 centers



Explore Transplant In Action

Marianne used Explore Transplant, and in the first six months:

Patients who...	of 14 dialysis patients educated
Are currently being evaluated	5
Identified donors and approved for transplant	2
Received a living donor transplant	2
Were evaluated, medically ruled out	1
Total Patients Who Initiated Transplant Evaluation	10



Predictors of Having ≥ 1 Living Donor Transplant in 2010 & 2011

Dialysis Center Level Data	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Provider reported educating ≥ 5 patients using ET (yes/no)	1.37 (1.03, 1.81) [*]	1.32 (1.01, 1.74) [*]
Center located in urban area (yes/no)	1.65 (1.33, 2.04) ^{**}	1.63 (1.32, 2.02) ^{**}
For-profit center (vs. non-profit)	0.88 (0.70, 1.11)	-
Proportion of Patients Age > 65: $\geq 50\%$	0.77 (0.62, 0.95) [*]	-
Proportion of Black Patients: $\geq 50\%$	0.87 (0.66, 1.15)	-
Proportion of Female Patients: $\geq 50\%$	0.91 (0.70, 1.18)	-

^{*}p<0.05, ^{**}p<0.001

Next Steps within Dialysis Centers

- Conduct secondary data analyses to understand predictors of dialysis centers having increased transplant rates using Explore Transplant nationally
- Explore transplant education failures and what else is needed (e.g., transplant outreach + Explore Transplant)
- Expand and replicate Explore Transplant research and education program for the Spanish-speaking Latino community



Patient Education by Phone/Mail: A Health Insurance Education Model

- Use of Explore Transplant varied by dialysis center educator.
- Health Insurance Companies conduct phone/mail interventions to patients with specific ICD-9 codes directly, often using a case manager
- Determine best transplant education practices for use by health insurance companies



Conducting an RCT of “Explore Transplant at Home”

- Compared to receiving only transplant education within the dialysis center, 675 White and African-American dialysis patients meeting specific lower income criteria will receive:
 - “Explore Transplant at Home.” Guided video program, sequential print mailings, and texting reminders over 8-months (Lower cost)
 - Case-manager facilitated education + “Explore Transplant at Home” program (Higher cost)
- Outcomes: Transplant knowledge change & plan to take different transplant steps



Road to Transplant: At Transplant Center

- Learn about transplant as an option
- Call to begin evaluation
- Mail medical packet
- ▶ Attend transplant appointments
- ▶ Get listed for transplant
- ▶ Complete yearly re-evaluation
- ▶ Find a matching kidney
- ▶ Receive a deceased or living donor transplant



National Racial Disparities in Transplant

- African Americans are 3.4 times more likely to have kidney failure than Whites¹
- Despite this:
 - In 2013, African-Americans received only 25% of all kidney transplants and 13% of all living donor transplants²
 - A 2012 study found that there was a disparity in attainment of living donor transplants between African-Americans and non-African-Americans ***in every transplant center in the U.S.***³

¹USRDS, 2013; ²OPTN, 2/7/2014; ³Hall et al., 2012



Racial Disparities in Transplant at UCLA

- In 2013, at UCLA:
 - 1453 patients presented for evaluation
 - 265 total kidney transplants, 110 living donor transplants
 - African-Americans received 11% of all transplants ($n=30$)¹
 - African-Americans only received 4.5% of living donor transplants ($n=5$)¹

¹OPTN, 2/7/2014



Educational Trial Targeted to Reduce This Disparity

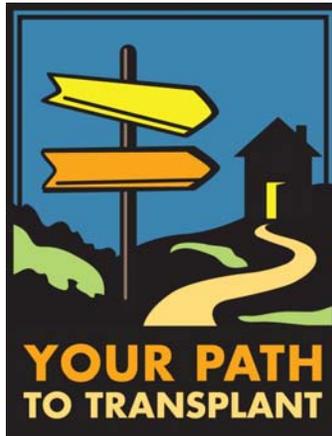


- Individually-Tailored Education & Coaching for patients pursuing transplant

¹OPTN, 2/7/2014



Two-Year Development of a Transplant Expert System



What is an Expert System?

- An expert system is a computerized database of transplant information; thousands of responses to what patients could know, think, and believe about transplant
- Based on answers to survey questions:
 - A patient can receive individually-tailored feedback.
 - The patient and her provider can focus on what information is most important to learn or do today.
 - Over time, new data can be compared with old data to see how this patient is changing and to make new recommendations.



Uniqueness of Expert Systems

- Recognizes there is a decision process that happens in stages
- Tailored to the needs of all patients, not just those ready for action
- Targets different variables at each stage
- Can produce 2-3 times more impact than programs focused on the “prepared.”



R01 Grant Aims

Compared to standard-of-care transplant education, to determine whether African-American and White patients receiving *Your Path to Transplant*:

- Have greater living donation readiness
- Have greater knowledge
- Are taking more living donation action steps
- Complete transplant medical evaluation
- Receive living donor transplants



Method & Measurement Plan

- 930 White and African-American patients presenting for transplant, followed for 18 months
- Telephone assessments of demographic, clinical, attitudinal, and knowledge variables before evaluation, during, 4 and 8 months later
- 18 months later, medical record review to learn final transplant outcomes



You have told us where you are today...

Dear James:

Every kidney patient must decide whether to wait for a kidney from someone who has died or find a living donor. When making important health decisions, only you know what is right for you. You recently completed a telephone survey about your thinking regarding kidney transplant. This report summarizes your answers and provides information that may be helpful for you.

YOUR PATH TO TRANSPLANT

Your Thoughts about Deceased Donation:

You've told us that you are considering taking actions in the next 6 months to get a deceased donor transplant.

Maybe you are still thinking, "Could a transplant really help me?" Patients who get transplants often say that their lives return to normal—that they have more freedom, energy, and are able to do the things they love. Is there something important to you that you are not able to do now?

Anna's Story

Anna was used to her dialysis routine but felt it would be nice to have more energy and be able to visit her grandchildren more often. Since she was on dialysis one day, Roger, her friend stopped by to visit. Roger had been on dialysis for three years, but she hadn't seen him since he had gotten a kidney transplant a few months ago. Roger talked about how much he was traveling—seeing Terry, he hadn't seen in years.

Anna asked her doctor about transplant and started thinking about this as an option. Although she was nervous about the tests and going into the city, she continued to talk to her social worker about the option of transplant. Her social worker told her to ask lots of questions and to talk to her so they could figure out if transplant was right for her.

Here is something Anna learned from her transplant coordinator:

Dialysis only does 10-15% of the work of a functioning kidney, whereas a kidney transplant can do 50-80% of the work of two functioning kidneys.

Did You Know...?

Some patients start transplant evaluation so they can learn more and ask experts questions. If they learn that transplant isn't right for them, they can stop pursuing it. Getting evaluated for transplant could help you learn more.

Thank you for taking time to answer our survey about your thoughts on kidney transplant. As you may already know, someone who has died, a deceased donor, is a family member or a friend. Some people allow their friends to donate their kidneys to them. Some people decide to wait for a deceased donor transplant. Whatever you decide, this education can help you think more about your choices.

When it comes to your health, you are the expert. Some people decide to wait for a kidney transplant. Others allow their friends to donate their kidneys to them. Some people decide to wait for a deceased donor transplant. Whatever you decide, this education can help you think more about your choices.

Many people have found it helpful to talk to someone who has had a kidney transplant. We recommend that you talk to the people who care about you, your doctor, or a social worker about your thoughts on kidney transplant.

Dear Donor: Transplant Step

Your next step is to find a list of people who might be a living donor for you next. There are some suggestions: People who are interested in helping, friends, and people from church. It's possible that someone else might be interested in you or the other way around. If you are interested in being a living donor, please contact your social worker.

Living Donor: Transplant Step

Your next step is to find a list of people who might be a living donor for you next. There are some suggestions: People who are interested in helping, friends, and people from church. It's possible that someone else might be interested in you or the other way around. If you are interested in being a living donor, please contact your social worker.



Coaching is Critical

Guided Coaching based on Feedback Report:

- Addresses key transplant and living donation knowledge gaps
- Discusses benefits of getting a transplant and pursuing living donation
- Promotes taking small actions to complete evaluation successfully and pursue living donation
- Celebrates small successes with patient
- Compares current behavior to past behavior to describe how patient has changed on key dimensions

Focus on Transplant Derailers

Is there anything in your life that could prevent you from successfully completing transplant evaluation?

- Financial instability
- Insufficient childcare coverage
- No access to transportation
- Safety in neighborhood
- Needing more social support than what is available
- Having other stressful events occurring at the same time as evaluation

If Your Path to Transplant works...

The Expert System could be delivered:

- Online
- At a transplant center while patients wait (e.g. laptop, tablet)
- Via telephone by transplant staff
- Through printed mailed reports to supplement transplant care



Next Steps in Transplant Centers

- Understand the impact of transplant derailers and develop interventions to overcome them
- Develop new mHealth (phone) interventions
 - Video/Print/Web resources in multiple languages
 - Secure texting initiatives
 - Phone applications for patient and providers
- Develop education to ensure informed decision-making and motivate recipients and donors to participate in chains



The Status Quo in Education

- Due to the need for living donors, educational initiatives will launch, but they may not truly increase informed decision-making or be maximally effective.
- Individual researchers will explore the effectiveness of different educational approaches, as funding permits.
 - Some educational strategies will work but it will take a long time to know what those are.
- Many healthcare providers will not be having the most effective conversations to increase living donation.
- More patients will die while we all learn, especially minorities.



What Else is Possible?

A Center for Transplant Education and Living Donation at UCLA

“A Transplant Education Think Tank”



Center Two-Fold Mission

- *To develop, assess the effectiveness of, and make available state-of-the-art patient, living donor, and provider education about transplantation.*
- *To improve informed transplant and living donation decision-making so that the rates of transplant and living donation nationally are increased.*



Center for Transplant Education and Living Donation

- Accelerate education development and research on transplant education for all racial/ethnic groups
- Study emerging trends: donor chains, social media, online resources
- Design and test state-of-the-art transplant education resources, including mhealth resources, for patients/living donors
- Conduct secondary data analysis on educational trends in dialysis centers
- Explore transplant policy and economic ramifications of transplant disparities & education gaps.
- Disseminate best practices and education nationally.
- Train providers how to discuss living donation.



Opportunities

- Become a friend of the Center!
- Provide coaching on the direction of the Center and how it could fit into established research collaborations most successfully.
- Expand or source your research inside of the Center in some way, strengthening ability to obtain grants.
- Help the Center focus in new areas: medication adherence, measurement development, cultural issues affecting health, spirituality, & mhealth design.
- Involve your graduate students, MDs, and PhDs in work happening within Center.



What This Will Make Possible

- Reduce racial disparities in access to transplant education and transplant
- Ensure informed patient decision-making
- Increase transplant referrals
- Increase living donor transplant rates
- Improve transplant care
- Help more patients live longer with an improved quality-of-life
- Help more families benefit from having these patients living and contributing fully



Thank You...

...for all you do to help patients!

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R01 Study Design

Study Design

