Expanding Living Donor Transplantation Through Improved Education

Amy D. Waterman, PhD
Associate Professor of Medicine in Residence
Nephrology

Hello, From The Tower Building!

12th Flr, Suite 1223
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 a 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 Sandburg, Lean In
### My Jungle Gym

<table>
<thead>
<tr>
<th>Grant Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIH, NIDDK</td>
</tr>
<tr>
<td>HRSA</td>
</tr>
<tr>
<td>OneLegacy Foundation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christina Goalby, MSW</td>
</tr>
<tr>
<td>Crystal Kynard-Amerson, MPH</td>
</tr>
<tr>
<td>Anna-Michelle McSorley, BA</td>
</tr>
<tr>
<td>John (Devin) Peipert, MA</td>
</tr>
<tr>
<td>Riya Rajan, BA</td>
</tr>
<tr>
<td>Jessica Thein, BA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advisory Board</th>
</tr>
</thead>
<tbody>
<tr>
<td>Representatives of ESRD Networks, UNOS, Dialysis, Transplant Centers, and OPOs, Kidney Patients &amp; Living Donors</td>
</tr>
</tbody>
</table>

### Research Collaborators, So Far

<table>
<thead>
<tr>
<th>Research Collaborators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mark Robbins, PhD &amp; Andrea Paiva, PhD</td>
</tr>
<tr>
<td>University of Rhode Island</td>
</tr>
<tr>
<td>Alan Leichtman, MD</td>
</tr>
<tr>
<td>University of Michigan</td>
</tr>
<tr>
<td>Francis Weng, MD, MSCE</td>
</tr>
<tr>
<td>St. Barnabas Transplant Center</td>
</tr>
<tr>
<td>Timothy McBride, PhD</td>
</tr>
<tr>
<td>Washington University School of Medicine</td>
</tr>
<tr>
<td>Osama Gaber, MD</td>
</tr>
<tr>
<td>Methodist Houston Transplant Center</td>
</tr>
<tr>
<td>Keith Norris, MD, PhD, Jeffrey Veale, MD, Eric Treat, MD</td>
</tr>
<tr>
<td>David Geffen School of Medicine, UCLA</td>
</tr>
</tbody>
</table>
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 failure\(^1\)
- 415,000 (70%) on dialysis\(^1\)
- 96,000 candidates on the transplant waiting list\(^2\)

Dialysis Patients of color are less likely:
- To be referred for transplant evaluation\(^3\)
- To receive deceased or living donor transplants\(^4\)

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


---

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
- 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

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.

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.


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

<table>
<thead>
<tr>
<th>Question</th>
<th>Correct Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>A living donor kidney lasts 15-20 years, on average.</td>
<td>19%</td>
</tr>
<tr>
<td>Dialysis is equivalent to the work of 10-15% of one functioning kidney.</td>
<td>23%</td>
</tr>
<tr>
<td>Living donors have a risk of high blood pressure after donating.</td>
<td>27%</td>
</tr>
<tr>
<td>90% of transplanted kidneys function for at least 1 year.</td>
<td>41%</td>
</tr>
<tr>
<td><strong>Transplant Knowledge</strong></td>
<td><strong>42%</strong></td>
</tr>
</tbody>
</table>

Transplant Education Practices in Dialysis Centers

<table>
<thead>
<tr>
<th>Practice</th>
<th>Providers engaging in this practice: (N=1544)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orally recommend patients learn more about transplant themselves</td>
<td>72%</td>
</tr>
<tr>
<td>Orally recommend being evaluated for transplant</td>
<td>69%</td>
</tr>
<tr>
<td>Refer patients to an external transplant educational program</td>
<td>44%</td>
</tr>
<tr>
<td>Distribute transplant center phone numbers</td>
<td>37%</td>
</tr>
<tr>
<td>Detailed discussion about advantages/risks of DDKT</td>
<td>21%</td>
</tr>
<tr>
<td>Detailed discussion about advantages/risks of LDKT</td>
<td>21%</td>
</tr>
</tbody>
</table>
How Can We Help Dialysis Providers Better Educate about Transplant?

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

2000 dialysis centers
2500 dialysis providers

- Dialysis Provider Trainings, 2010-14
- Dialysis Provider Trainings Scheduled
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?

- Nurse Mgr/Facility Administrators: 12%
- Nurses: 25%
- Social Workers: 30%
- Dialysis Technicians: 23%
- Dieticians: 7%

N=1544

Transplant Attitude Change

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

*p<.001; N=1544
**Transplant Knowledge Change**

| 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**

After the training, do you plan to:

<table>
<thead>
<tr>
<th></th>
<th>Already done (N=1544)</th>
<th>Completed six months later (N=601)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Determine which patients are on the waiting list?</td>
<td>88%</td>
<td>85%</td>
</tr>
<tr>
<td>Determine which patients are transplant candidates?</td>
<td>87%</td>
<td>75%</td>
</tr>
<tr>
<td>Hang Explore Transplant posters in your dialysis center waiting room?</td>
<td>86%</td>
<td>54%</td>
</tr>
<tr>
<td>Share Explore Transplant materials and videos with your dialysis team?</td>
<td>85%</td>
<td>44%</td>
</tr>
</tbody>
</table>

N=1544
Post-Training Planned & Actual Education Actions

<table>
<thead>
<tr>
<th>Activity</th>
<th>% planned to do within 1-6 months (N=1544)</th>
<th>Took action 6 months later (N=601)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate at least 1 patient using <em>Explore Transplant</em></td>
<td>84%</td>
<td>34%</td>
</tr>
<tr>
<td>Educate at least 5 patients…</td>
<td>75%</td>
<td>25%</td>
</tr>
</tbody>
</table>

Explore Transplant Education Packets Disseminated

<table>
<thead>
<tr>
<th>Language</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>10,698</td>
</tr>
<tr>
<td>Spanish</td>
<td>3,635</td>
</tr>
<tr>
<td>Total</td>
<td>14,333</td>
</tr>
</tbody>
</table>
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:

<table>
<thead>
<tr>
<th>Patients who...</th>
<th>of 14 dialysis patients educated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are currently being evaluated</td>
<td>5</td>
</tr>
<tr>
<td>Identified donors and approved for transplant</td>
<td>2</td>
</tr>
<tr>
<td>Received a living donor transplant</td>
<td>2</td>
</tr>
<tr>
<td>Were evaluated, medically ruled out</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Patients Who Initiated Transplant Evaluation</strong></td>
<td><strong>10</strong></td>
</tr>
</tbody>
</table>
Predictors of Having ≥ 1 Living Donor Transplant in 2010 & 2011

<table>
<thead>
<tr>
<th>Dialysis Center Level Data</th>
<th>Unadjusted OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider reported educating &gt; 5 patients using ET (yes/no)</td>
<td>1.37 (1.03, 1.81)*</td>
<td>1.32 (1.01, 1.74)</td>
</tr>
<tr>
<td>Center located in urban area (yes/no)</td>
<td>1.65 (1.33, 2.04)**</td>
<td>1.63 (1.32, 2.02)**</td>
</tr>
<tr>
<td>For-profit center (vs. non-profit)</td>
<td>0.88 (0.70, 1.11)</td>
<td>-</td>
</tr>
<tr>
<td>Proportion of Patients Age &gt; 65: ≥ 50%</td>
<td>0.77 (0.62, 0.95)*</td>
<td>-</td>
</tr>
<tr>
<td>Proportion of Black Patients: ≥ 50%</td>
<td>0.87 (0.66, 1.15)</td>
<td>-</td>
</tr>
<tr>
<td>Proportion of Female Patients: ≥ 50%</td>
<td>0.91 (0.70, 1.18)</td>
<td>-</td>
</tr>
</tbody>
</table>

*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 Whites\(^1\)
- Despite this:
  - In 2013, African-Americans received only 25% of all kidney transplants and \(13\%\) of all living donor transplants\(^2\)
  - 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.\(^3\)

\(^1\)USRDS, 2013; \(^2\)OPTN, 2/7/2014; \(^3\)Hall 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)\(^1\)

\(^1\)OPTN, 2/7/2014

Educational Trial Targeted to Reduce This Disparity

- Individually-Tailored Education & Coaching for patients pursuing transplant

\(^1\)OPTN, 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…
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!

Amy D. Waterman, PhD
awaterman@mednet.ucla.edu
(314) 322-3880

www.exploretransplant.org

References
