MOKP COST CONTAINMENT GRANT
FINAL REPORT

Project Title: Helping Recipients Ask: The Effectiveness of Improved Health Education on Increasing Living Donation.

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BACKGROUND

National kidney organizations and the transplant community recommend that all eligible kidney transplant recipients and their donors be educated about transplant options, the surgical process, and the medical risks involved with transplantation. Education can also serve to motivate patients toward choosing a recommended treatment option. Dialysis patients who are transplant-eligible but who never present for transplant evaluation may miss a critical opportunity to be educated about the benefits of transplant compared with remaining on dialysis. It is unknown how many transplant-eligible dialysis patients fail to present to the transplant center, and how their decision-making about transplant differs from those patients who do. In preparation to design an educational program to promote living donation for dialysis patients, the purpose of this study was to understand transplant-eligible dialysis patients' willingness to pursue deceased and living donation, their use of health education to learn about transplant, their transplant knowledge, and factors affecting their transplant decision-making.

METHODS

Study Participants.
As part of a larger study of 345 transplant-eligible dialysis center patients at 24 dialysis centers referring to the St. Louis area, we utilized Missouri Kidney Program Cost-Containment funding to expand the study to survey an additional 157 patients in 5 dialysis centers in Columbia (1 center), Springfield (1 center), and Kansas City (3 centers). This expansion enabled us to learn more about dialysis patients across the state of Missouri.

Inclusion and Exclusion Criteria. All dialysis patients identified as transplant-eligible by the Medical Director of their dialysis facility were eligible to be interviewed. We excluded those who had already received a solid organ transplant of any kind, had psychological or developmental problems that prevented us from administering the

survey, minors, those who could not see, hear, or speak English, and those who could not be awakened after multiple attempts.

Questionnaire.
The 81-question survey was designed by the research team based on focus group and quantitative research conducted with over 500 transplant recipients. The questionnaire measured patient demographics, time spent using educational resources to learn about transplant (i.e., reading brochures, talking to medical professionals), their transplant knowledge using a set of 16 questions (i.e., how long does the average patient wait on the waiting list to get a kidney from a deceased donor?), and 30 potential advantages and disadvantages to transplantation that might affect patients' decision-making (i.e., Does getting off dialysis affect your decision-making about transplant "strongly," "slightly," or "not at all?").

The survey also measured patients' pursuit of transplant in several ways. We first assessed whether patients had been evaluated for transplant previously. We then measured their willingness to pursue deceased or living donation based on the Transtheoretical Model of Behavior Change (TTM)[1]. The TTM is based on the belief that behavior change happens through five stages of change, from not thinking about taking any action, to considering it, to planning for the action, to actually taking and maintaining the action. For this study, we defined patients' pursuit of deceased or living donation into one of five stages:

- Precontemplation (not ready to seriously consider pursuing a type of transplant)
- Contemplation (thinking about pursuing a type of transplant)
- Preparation (beginning to seriously consider pursuing a type of transplant)
- Action (have made the decision to pursue a transplant and are in action contacting the transplant center)
- Maintenance (have already contacted the transplant center and are pursuing transplantation)

Procedure. Trained interviewers administered the questionnaire chairside while participants were being dialyzed, or by telephone if requested. Each interview lasted approximately 45 minutes including obtaining written informed consent. A $10 gift card was given to all participants as compensation for their time. The Washington University School of Medicine's Institutional Review Board approved this study.

Data Analysis. Using the Statistical Package for the Social Sciences Version 12.0 (SPSS Inc., Chicago IL) and Statistical Analysis Software Version 9.3 (SAS Institute, Inc., Cary, NC), we conducted basic descriptive analyses to determine transplant-eligible dialysis patients' willingness to pursue deceased and living donation, and their use of health education to learn about transplant. We controlled for the dialysis center clustering factor by using the Rao-Scott test of association to determine differences between patients who had been evaluated or not on their transplant knowledge and factors affecting their transplant decision-making.

STUDY RESULTS

Patient Demographics. We surveyed 157 patients at 5 dialysis centers (Response rate: 83%). Patients were primarily African-American (64%), male (59%), with a high school education or less (54%), and had been on dialysis for 2.5 years (Table 1).

Pursuit of Transplant. Of all surveyed patients, only 59% were in the process of or had been evaluated for a transplant (Table 2). Patient who had not been evaluated were older (56 years vs. 49, $p<0.001$) and less likely to perceive themselves as being in good health (30% vs. 70%, $p<0.001$) compared to patients who had been evaluated.

Over half of transplant-eligible dialysis patients were in the process of being evaluated (26%) or already on (28%) the deceased donor waiting list. Older patients were significantly less likely to pursue deceased donation than younger patients (55 years vs. 49, $p<0.001$).

When considering living donation, most patients were in the TTM stages of precontemplation or contemplation, meaning they were not considering or still considering whether they would accept living donor volunteers (55%) or ask someone to donate (62%). Half were completely unwilling to ask someone to be a living donor for them (50%). Older (53 years vs. 47, $p=0.04$) and Caucasian (12% vs. 88%, $p=0.008$) patients were more unwilling to ask than younger and non-Caucasian patients, respectively.

Previous Transplant Education and Knowledge. Patients varied considerably in how they learned about transplant and in the amount of time they spent learning. Patients were most likely to speak with medical staff (76%), family and friends (73%), recipient mentors (63%), and read donation brochures (61%) to learn about transplantation (Table 3). However, patients using these resources spent a median of 2 hours or less using each resource. It was interesting to note that while only 11% of participants browsed internet websites to learn about transplant, those who did used this educational type for the longest period of time (a median of 3.25 hours).

Participants who had not been evaluated for a transplant were less knowledgeable about transplant than patients who had been evaluated (Table 4). Specifically, patients who had not been evaluated for transplant were less likely to know reassuring information about being a living donor— that donors could return to their normal activities after transplant in 4-8 weeks (34% vs. 70%, $p<0.001$), that donors did not have to pay for testing and hospitalization related to kidney donation (47% vs. 65%, $p=0.01$), and that donors were not more likely to get kidney disease after donating their kidneys (64% vs. 82%, $p=0.009$). They were also less likely to understand that kidney patients who get transplants generally live longer than patients who stay on dialysis (41% vs. 66%, $p<0.001$).

Concerns about Transplant. People who were not evaluated for a transplant also had more concerns regarding living donation than those who were evaluated (Table 5).

Participants not evaluated for a transplant were most concerned about what the pain and stress of the surgery would be like for both themselves (25% vs. 3%,$p<0.001$) and the donor (37% vs. 17%, $p<0.001$) compared to evaluated patients. Patients not evaluated for a transplant also saw fewer benefits to transplant than those who were evaluated, reporting that they were less motivated to get off dialysis (58% vs. 82%, $p<0.001$), and less likely to perceive that a living donor might personally benefit from donating, in some way (36% vs. 53%, $p=0.008$).

CONCLUSIONS

The number of transplant-eligible dialysis patients not pursuing transplant was profound; Over 41% of patients, most commonly older patients, had never called a transplant center to begin evaluation. Patients were much less likely to pursue living than deceased donation. While over half of participants in our study were currently taking action to get on the deceased donor waiting list, only approximately 20% were taking action to have a living donor transplant. Half of patients reported that they wouldn't or couldn't ask a potential donor to be evaluated directly.

In addition, these patients were found to lack important knowledge about transplant that might motivate them to pursue it. Patients not getting evaluated were less likely to know that patients who get transplants generally live longer than patients who stay on dialysis or to see advantages to getting off dialysis. Also, many patients reported wanting to wait for a deceased donor kidney rather than face the discomfort of asking or accepting offers of living kidneys from their friends and family. This high discomfort has also been found in other research[2-4], and may be due to concerns about harming the donor's health, pressuring the donor, or because of a lack of patient skill-building training regarding how to make such an unusual and difficult request[2, 3].

More transplant education is needed in dialysis centers, since education from the transplant center cannot reach dialysis patients who do not present. At least one-quarter of patients reported that they had not spoken to their health professionals about the possibility of transplant. Finally, although patients spent approximately 500 hours at a dialysis center yearly and most had been on dialysis over 2 years, they had only spent a median of 8 hours total learning about transplant. Past studies have also shown that potential kidney patients want detailed information about both the donor and recipient's transplant evaluation and surgical process.

Since 46% of patients had not taken action to pursue deceased donation and 79% of patients had not pursued living donation, what, then, can we do to help more patients pursue transplantation? Since patients who were not evaluated for a transplant were significantly more concerned about what the pain and stress of the surgery would be like for both themselves and the donor compared to evaluated patients, intensive education on these topics is needed. Educating patients that 95% of transplants work for at least one year could also be reassuring. With health provider conversation shown to be the primary source of transplant education for patients in this study, improved transplant educational training may also be needed for dialysis providers. According to the TTM,

people fail to change their behavior because they do not have adequate motivation to do so, are resistant or defensive about taking new actions, or because they have had past negative experiences with a particular health behavior[5, 6]. The TTM model recommends inviting patients to take small, non-threatening actions to begin thinking about why they would want to pursue deceased or living donation, with the assumption that patients who begin taking these actions will move along the stages of change towards action. Educational programs that include the entire family and discuss the psychological issues affecting and practical advantages to living donation also have been shown to result in greater number of living donor transplants (Rodrigue, JR, Cornell, DL, Lin, JK, Kaplan, B, Howard, RJ. A Randomized Controlled Trial of a Home-Based Educational Intervention. American Journal of Transplantation, in press).

We are currently developing an educational intervention based on the TTM called, "Plan Your Journey: Exploring Your Transplant Options." This campaign focuses on the final portion of the renal journey where a patient learns about different renal replacement treatments (i.e., deceased and living donor transplantation). Treatment options that will be discussed include: remaining on dialysis and not pursuing transplant, getting on the transplant waiting list, and/or pursuing a living donor transplant. The overall goal of the campaign is to help transplant-eligible patients make an informed decision regarding the treatment option best suited for him or her after understanding the benefits of transplant over other modalities. For a kidney patient interested in learning about transplantation, administration of the education campaign requires four meetings which occur while s/he is undergoing dialysis where dialysis patients will watch videos, read education materials, and participate in learning activities and discussions with health educators, transplant recipients, and living donors. This program will be made available for dialysis providers to implement in their centers directly.

As the incidence of renal patients increases every year, to better meet the need for kidneys for transplant, it is imperative that we understand how to promote living donation ethically and effectively. While these results are an important first step in understanding dialysis patients' attitudes, decision-making, and educational needs regarding transplantation and living donation, additional study is needed to learn whether improved dialysis patient education can actually increase transplant and living donation rates. Only then can all eligible patients truly make an informed choice about transplant as a treatment option.

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Table 1. Patient Demographics

Demographics (N=157)	Mean (SD)	# (%)
Age	52 (13.9)	
Gender		
- Male		93 (59%)
- Female		64 (41%)
Race		
- Black		101 (64%)
- White		49 (31%)
- Other		7 (5%)
Marital Status		
- Married/Partner		79 (50%)
- Not Married		78 (50%)
Education		
- High School or less		84 (54%)
- Some College		52 (33%)
- College Graduate		21 (13%)
Income		
- < $20,000/yr		62 (46%)
- $20,000-$40,000/yr		43 (32%)
- > $40,000/yr		29 (22%)
Perceived Health Status		
- Excellent/Very Good		40 (26%)
- Good/Fair/Poor		117 (74%)
Years on dialysis	2.5 (2.5)	
Evaluation Status		
- Evaluated/In Process		93 (59%)
- Not Evaluated		64 (41%)

Table 2. Willingness to Pursue Deceased and Living Donation

Stage of Change	Get on the Deceased Donor Waiting List	Accept Living Donor Volunteers	Ask Living Donors
Precontemplation I won't/can't pursue donation	12%	**13%**	**50%**
Contemplation I might pursue donation	17%	**42%**	**12%**
Preparation I will pursue donation	17%	27%	17%
Action I am in the process of pursuing donation	**26%**	9%	1%
Maintenance I already have pursued donation	**28%**	9%	20%

Table 3. Patient Use of Health Education Resources to Learn about Transplant

Health Education Resources Used	**% Who Used Education Resource**	**If used, Median Hrs of Use**
Spoke with Medical Staff about Transplant	76%	1 hours
Spoke with Family or Friends about Transplant	73%	2 hours
Spoke with a Recipient Mentor	63%	1.5 hours
Read Donation Brochures	61%	2 hours
Watched Television or Videos about Transplant	55%	1 hour
Browsed Internet Websites about Transplant	11%	3.25 hours
Attended Kidney Disease Support Group	11%	3 hours
Overall Use of All Education Types		8 hours

Table 4. Transplant Knowledge Differences in Patients Evaluated and Not Evaluated

Knowledge about Transplant	**Not Evaluated for a Transplant**	**Evaluated for a Transplant**
Donors can return to their normal activities 4-8 weeks after surgery.**	**34%**	70%
People with transplants generally live longer than people who stay on dialysis.**	**41%**	66%
Donors do not have to pay for testing and hospitalization related to kidney donation.**	**47%**	65%
After a transplant, the government does not pay for all medications for the rest of a patient's life.**	**58%**	80%
Once donors donate their kidneys they are not more likely to get kidney disease.**	**64%**	82%

*p<.05, **p<.01

Table 5. Transplant Decision-Making in Patients Evaluated and Not Evaluated

Concerns Strongly Influencing Decision-Making	**Not Evaluated for a Transplant**	**Evaluated for a Transplant**
The donor surgery would be too painful or stressful.**	**37%**	17%
The surgery would be too painful or stressful for you.**	**25%**	3%
You have already lived a full life so you don't want someone to donate.*	**17%**	7%
Benefits Strongly Influencing Decision-Making		
A living donor kidney often lasts longer than a kidney from someone who has died.**	27%	**47%**
If you got a transplant, your donor would also benefit since you would be around a lot longer.**	36%	**53%**
A donor would donate for you because you would do the same for him or her if the situation were reversed.**	39%	**65%**
You will not have to be on dialysis.**	58%	**82%**

*p<.05, **p<.01