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## Experiences of Kidney Transplant Recipients as Patient Navigators

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### Abstract

**Background and Objective**—The use of trained kidney transplant recipients as patient navigators resulted in increased completion of the steps in the transplant process by dialysis patients [1]. We sought to understand the experiences of these patient navigators.

**Setting and Participants**—Six kidney transplant recipients were hired and employed by transplant centers in Ohio, Kentucky, and Indiana. The transplant navigators received formal training as peer educators, met with dialysis patients on a regular basis, and provided tailored education and assistance about transplantation to each patient. They worked closely with the pre-transplant coordinators and social workers to learn the details of each patient's transplant work-up.

**Methodology**—We queried navigators using open-ended questions to learn about their experiences. Navigator responses were coded and common themes identified. A thematic auditor reviewed and refined the coding.

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**Results**—Two primary categories of themes emerged about the navigator experience: 1) practical comments that supported programmatic or implementation observations of the navigators, and 2) affective comments that reflected a shared experience among the navigators and patients. The navigators were able to fill voids in the transplant process that were not fulfilled by other caregivers. This was accomplished by a natural bond based upon a shared experience (of dialysis and kidney failure) between the navigator and the patient. The patient and navigator became experiential partners.

**Conclusion**—Kidney transplant recipients trained as patient navigators fill the role of a non-traditional medical provider, offer support during the transplant process, and provide an added-benefit to complement routine dialysis and nephrology care.

### Keywords

Kidney transplant; patient navigators

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## INTRODUCTION

As compared to chronic dialysis, patients with end-stage renal disease who get a kidney transplant have a longer life span and better quality of life. [2] However, disparities in access to kidney transplant for specific subgroups of patients, specifically, women, blacks and the poor has been problematic. [3,4] Several steps are involved in the process of getting a kidney transplant including patient interest, contacting a transplant center, completing the work-up and receiving a transplant. [5] Many factors serve as barriers to patients completing the pre-transplant work-up including loss of interest, feeling well on dialysis, death, concurrent illness requiring multiple hospitalizations, need for weight loss, lack of psychosocial support, or being deemed not a candidate. Upwards of 25% of patients who initiate a kidney transplant evaluation for wait listing do not complete it in one year. [6,7]

Patient navigation, a concept initially developed in the field of cancer care, has shown to reduce barriers in access to care and improve outcomes. The use of trained kidney transplant recipients as patient navigators resulted in increased completion in steps in the transplant process by dialysis patients. [1] In this study, we sought to understand the experiences of trained kidney transplant recipients as patient navigators for patients who were undergoing in-center hemodialysis.

## METHODS

### Navigator Selection

Six kidney transplant recipients were hired and employed by transplant centers in Ohio, Kentucky, and Indiana. The transplant navigators were kidney transplant recipients who were in good health, able to drive to different dialysis facilities, and able to work flexible hours.

### Navigator Training

The transplant recipients received formal training as peer educators. In-person trainings were attended by the entire navigator group. Topics of the training included research-related (e.g.

human subject protection and how to obtain informed consent), transplant-related (e.g. benefits to receiving a kidney transplant and differences between living and deceased organ donation), interpersonal-related (e.g. motivational interviewing techniques) and study-related (e.g. data collection and study protocol) information. Throughout the duration of the study, navigators participated in conferences and conference calls to review their progress with patients as well as address challenges with the study. In-person meetings for ongoing training were held.

### **Navigator-Patient Interactions**

Navigators recruited patients from local dialysis facilities and met with them on a regular basis to assess what stage in the transplant process each patient was in. Then, they delivered tailored information and assistance to each patient. The navigator also worked with transplant personnel from their center to assess patient progress and offer additional relevant resources. Examples of information and assistance included standardized handouts with transplant information, reminder phone calls about upcoming appointments, and sharing of personal experiences from the navigators' own transplant processes.

### **Navigator Interviews**

Upon completion of the study, the navigators were sent 22 open-ended questions (Table 1) via email to respond to in writing and email back to the principal investigator and coordinating study staff. The questions intentionally sought to elicit information about navigator job characteristics, training, lessons learned, patient experiences, and relationships with dialysis staff. All navigators completed the emailed interview.

### **Coding**

The navigators' written responses that were emailed back to the principal investigator and coordinating study staff and served as transcripts to be reviewed. Three independent coders (CS, JD, and AH) read through the transcripts line by line and through an iterative process, segments of coded text from individual coders were combined to form common themes. Sub-themes were drawn out from each main theme. A thematic auditor determined theme titles, organized overlapping themes, and confirmed appropriateness of themes. Member checking of the final results was employed whereby the navigators read and gave feedback about the interpretation of their responses.

The main study was approved by the MetroHealth Medical Center Institutional Review Board.

## **RESULTS**

Most of the navigators were about 50 years old, female, and received in-center hemodialysis prior to transplant. Half of the navigators received a kidney transplant from a living donor. Time on dialysis ranged from 0-42 months and navigators were anywhere from 1-14 years post transplant. (Table 2)

Table 3 summarizes the two primary categories of themes emerged from the data about the navigator experience. Overall, we found 1) affective comments that reflected a shared experience among the navigators and patients, and 2) practical comments that supported programmatic or implementation observations of the navigators. Several sub-themes emerged in each of these categories.

The affective comments described either a positive experiences of the navigators while others reflected more challenging aspects of their interactions with patients (polarity). The overall positive aspects that were described were strongly rooted in the fact that the navigators and patients shared a common connection about experiences in dialysis and with kidney failure.

“What interested me the most about the transplant navigator position was the opportunity to meet people who I could relate to on a level where most people cannot go, a commonality that most have no knowledge of and having the opportunity to assure others that there is a life after dialysis and transplantation.”

Additionally, throughout the study, there was relationship-building and many of the navigators felt a sense of personal satisfaction and enjoyed sharing in the success of the dialysis patients.

“The most fulfilling patient is one that would probably not have gone through the process without my help. We had several long talks about his fears of a transplant surgery.”

The negative aspects included dealing with patients who had mental illness, may have been non-adherent, found unsuitable for transplant, or suffered from progression of their illness and may have died.

“...how deeply connected I would become with the patients and staff. I wish I had known, and been prepared for patients passing away, having such severe infections often resulting in amputation, and good patients being found unsuitable for transplantation due to reasons beyond their control. Such as insurance issues, transportation issues, and lack of support.”

The navigators highlighted areas of process improvement mostly based upon expanding the program attributes to include interactions with patient families, and rounding nephrologists. A common set of characteristics regarding interpersonal skills were described as key characteristics for navigators. Finally, the navigators identified certain knowledge gaps that may have impaired their ability to offer information to patients.

“I was hoping for more contact with the rounding doctors at each [dialysis] facility.”

“Empathy, listening skills, compassion, patience, and knowledge about transplants.”

“...the [study] could have expanded over a longer period to continue to encourage patients that have been waitlisted and continue to provide information to those participants that needed to overcome some difficult barriers (e.g. weight loss).”

## DISCUSSION

The navigators were able to fill voids in the transplantation and dialysis care process that were not fulfilled by other dialysis caregivers. This was accomplished by a natural bond based upon a shared experience (of dialysis and kidney failure) between the navigator and the patient. The patient and navigator effectively were experiential partners.

Like the steps of getting on the waiting list for a kidney transplant, cancer care is equally complex and has a variety of factors that impact disparities on outcomes. Jean-Pierre and colleagues similarly sought to understand the experiences of patient navigators working with cancer patients and similarly found that social support and navigator-patient relationships were cornerstones of the navigation process. [8]

As a result of this study, we identified salient programmatic features that other centers that implement navigators for the pre-transplant process may want to consider. These include formal training for the navigators on coping strategies for death and mental illness. Navigators should be embedded into the transplant program so that they can optimize the use of resources (e.g. information sharing, financial eligibility, and processes) to the patients' benefit. Care paths should be developed for the navigator to be able to assist patients with common barriers to transplant including weight loss and substance abuse.

A limitation of our study is that the six navigators worked in a fairly small geographic region. Processes to be waitlisted for a transplant may vary among different transplant centers, so our results may only reflect findings from these areas. Additionally, all of the navigators in our study had overall positive transplant experiences (e.g. feeling well after surgery, few complications, positive perception of the process, and highly functional). Therefore, there may be an optimism bias that is portrayed to dialysis patients.

In the future, we can consider implementing the navigators' suggestions to deliver a more effective or broader program.

## CONCLUSION

Kidney transplant recipients trained as patient navigators fill the role of a non-traditional medical provider, offer support during the transplant process, and from the navigator perspective, provide an added-benefit to complement routine dialysis and nephrology care.

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**Table 1**

## Questions for Transplant Navigators

1.	What was it about the transplant navigator position that interested you the most?
2.	What do you wish you knew before taking the position that you know now?
3.	What would you do differently?
4.	What does the term "Transplant Navigator" mean to you?
5.	What skills or knowledge does someone need to be a successful transplant navigator?
6.	What do you enjoy most about being a transplant navigator?
7.	What is the most important lesson you have learned as a transplant navigator and why?
8.	How did you spend the majority of your time?
9.	What ongoing challenges did you face in your work as a navigator?
10.	What is the most valuable skill or resource you have that you used to do your job?
11.	Describe one patient experience that was the most fulfilling for you.
12.	Describe one of your most difficult patient experiences.
13.	What did you like most about the training you received?
14.	What part of the training did you like the least?
15.	What additional skills, information or assistance would have helped to make your job as a transplant navigator easier?
16.	What advice would you give someone who wants to become a transplant navigator?
17.	What personality traits does someone need to possess in order to be a good navigator?
18.	What was your working relationships like with the staff at the dialysis units?
19.	How were your working relationships with the transplant office staff and administrators?
20.	From your perspective, what are the major strengths of the transplant navigator project?
21.	From your view point, what if any are the weak spots in the project?
22.	Would being a navigator been easier or more difficult if it was not done as part of a research project? In what ways?

**Table 2**

## Characteristics of Navigators

Navigator	Age	Sex	Race	Months on Dialysis	Type of Dialysis	Type of Transplant	Duration of Transplant (years)
1	53	F	White	4	ICH	LR	14
2	56	F	White	0	n/a	LUR	3
3	49	M	Black	42	PD	DD	1
4	50	F	Black	30	ICH	DD	3
5	55	F	White	42	ICH	DD	9
6	28	F	Black	9	ICH, PD	LR	5

ICH=in-center hemodialysis, PD=peritoneal dialysis

LR=living related, LUR=living unrelated, DD=deceased donor



**Table 3**

## Results of Semi-Structured Navigator Interviews

Theme	Sub-Theme (Polarity)	Illustrative Quotation
Affective Comments		
	Shared Experiences (+)	"I watched some patients tense up as they saw me coming towards them in my white coat and clipboard in hand. However, once I told them that I was not a doctor but had been on dialysis and had a transplant more than 16 years ago, those shoulders would drop and they would become more relaxed immediately."
	Developed Relationships (+)	"One thing that I found so overwhelmingly awesome is being able to visit the patient a few days after their transplant. I had it happen a few times and it's a wonderful feeling. Each time, I'm invited to visit after the transplant I get that weird belly thing, my heart races, and I am very nervous. When I step into the room and make eye contact with the patient those tears of joy come flowing from my eyes. It's wonderful."
	Personal Satisfaction (+)	"Although working with all of my patients was memorable, I would have to say the most fulfilling was when I was able to offer information to a patient that he actually followed through on. I gave him information on living donors, and, the next thing you knew, he had a friend from church who agreed to give his kidney."
	Shared Successes (+)	"I also felt tremendous joy when one of my patients made a major step forward. While the accomplishment had to come from the patients themselves, the joy that I may have played a part in their success was very satisfying. I cannot even explain the feeling of when one of my patients received a transplant. You can only imagine."
	Difficult Mental Illness (-)	"I wish I would have known to expect the mental conditions of some of the patients. It was very disappointing at times when some of my patients were not able to move forward with their work – up due to their mental conditions, or, anxieties. I concluded that I would not be able to help everyone."
	Patient Non-Adherence (-)	"The challenge of what to do with those that do not want to help themselves. I could easily deal with those who are willing to make an effort to change, even if they are unsuccessful. However, I found it hard to deal with those who were capable of bettering their lives by getting off dialysis, but who were not willing to make any kidney of change in their lifestyle."
	Found to be Unsuitable for Transplant (-)	"Several years ago, Mr. X had been turned down by the transplant center because he has hepatitis C. He was very discouraged that he was not eligible for a transplant, but tried to put up a good front. ...there was no way to transplant patients with hepatitis C, but now there is. This news meant a second chance for him. For a few months everything was going well, until a complication arose that put him in the hospital. Further testing showed that his heart would not be strong enough for an operation. Depression followed, there were good and bad days. On my last visit, the patient seemed to be very ill, and perhaps fighting for his life. I am very sad because I feel that we got to him too late, that medical research and marvels that we have now for hepatitis C came too late for this patient who I call my friend."
	Progressive Illness and Death (-)	"The other difficult experience was patients enrolled in the study who passed away. Some of the patients were moving forward while others were still contemplating what they wanted to do. But, either way, you become attached to the patients and I felt a great deal of grief when they passed away."
Pragmatic Comments		
	Process Improvement	"I would push for more educational materials geared towards the family to learn more about transplantation and organ donation. I would include a patient's family in the dialysis session where I am presenting information and give a patient questionnaire that discusses family support." "I would not limit the number of patients. I would try to meet with and reach as many patients as possible."
	Navigator Skills	"It means being a cheerleader and helping patients get over barriers...It also means being present and supporting patients regardless of their decision or the outcome with regard to their transplant evaluation."
	Knowledge Gaps	"I never felt like I could answer questions about insurance issues; that subject had me completely baffled! I had a wonderful finance team so I could refer the patients to them with questions that I could not answer."