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Inter- and Intrapersonal Barriers to Living Donor Kidney Transplant among Black Recipients and Donors

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Abstract
Context End-stage renal disease (ESRD) is more common among Blacks, but Blacks are less likely to receive a live donor kidney transplant (LDKT).
Objective The objective of this study is to identify barriers and coping mechanisms that Black LDKT recipients and donors experienced while receiving or donating a kidney.
Design A qualitative study was conducted using structured interviews. Thematic analysis was used for data interpretation.
Participants All 20 participants identified as Black, with two participants identifying themselves as multiracial. The mean age for the 14 recipients was 60, and the average age for the 6 living donors was 47.
Results Themes emerging from the data suggest both recipients and donors faced barriers in the LDKT experience. Recipients faced barriers associated with their denial and avoidance of the severity of their ESRD, their desire to maintain the privacy of their health status, and their refusal to approach potential donors. Donors encountered negative responses from others about the donors' desire to donate and the initial refusal of recipients to accept a LDKT offer. Recipients identified faith as a coping mechanism, while donors identified normalization of donation as their method of coping. Various types of social support helped donors and recipients navigate the transplant process.
Conclusion Black LDKT recipients and donors must overcome barriers prior to receiving or donating a kidney. Most of these barriers arise from communication and interactions with others that are either lacking or undesirable. Future interventions to promote LDKT among Blacks may benefit by specifically targeting these barriers.

Keywords Living donor kidney transplant · End-stage renal disease · Blacks, Communication · Barriers to donation · Barriers to transplantation

Introduction

The best treatment for end-stage renal disease (ESRD) is usually a living donor kidney transplant (LDKT) [1]. Unfortunately, Blacks are much less likely than non-Blacks to receive LDKTs [2]. In 2012, Blacks received 30.8 % of deceased donor kidney transplants (DDKTs) but just 13.4 % of LDKTs [3]. Furthermore, the percentage of LDKT recipients who are Black has failed to improve, remaining around 13 % each year since 2000 [4]. In the USA, no transplant center (out of 275) achieves racial parity in its performance of LDKTs [5].

Prior studies have delineated some of the specific barriers to LDKT among Blacks, but which barriers are most important remain unclear. In focus groups [6–9] and surveys [10, 11], transplant candidates and recipients state that one large barrier to accepting an offer from a live donor is their understandable concern for the donor's future, post-donation health. Transplant recipients also express guilt and concerns that donation will inconvenience the living donor and living donor's family [7, 8, 10].

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Living kidney donors may also face barriers that impede donation. Potential live donors, especially those who are Black, harbor concerns about their future health if they donate [12–14]. Potential donors who are Black also reported concerns about the financial costs of donation [13, 15]. Other possible barriers, such as cultural beliefs or interpersonal interactions, have rarely been examined among Black donors.

In this study, we performed qualitative interviews among Blacks who either donated a kidney or received a LDKT to further explore barriers to live kidney donation and live donor kidney transplant.

Methods

Participants

Participants were recruited from the patient population of Saint Barnabas Medical Center in Livingston, New Jersey. Saint Barnabas is a high-volume kidney transplant center in the Northeastern USA that has recently averaged over 200 kidney transplants per year. Study participants had to have either received a LDKT or donated a living kidney between January 1, 2005 and October 22, 2013. For inclusion in the study, participants needed to (1) be identified as Black in our transplant database; (2) have received a LDKT or have donated a live kidney at Saint Barnabas Medical Center; (3) speak and understand English; (4) be able and willing to give informed consent for an audio-taped interview; and (5) have a current mailing address in our transplant database.

A total of 128 recipients were initially identified, of whom 34 patients were excluded due to graft failure ($n = 11$), death ($n = 7$), and previous non-adherence ($n = 16$). Non-adherent patients are those who either fail to take their transplant medications or are generally difficult to follow up with for other necessary medical care. As such, these patients would be a difficult population to reach for an optional interview. The recruitment letter, explaining the study, was mailed out to the remaining sample of 94 recipients, of whom ten recipients were excluded due to incomplete or incorrect addresses ($n = 6$) or long distance from the transplant center ($n = 4$). This resulted in a final sample of 84 recipients of which 14 participated in the final recipient interviews.

A total of 119 donors were identified, of whom 55 donors were excluded due to incomplete or incorrect addresses ($n = 24$) or long distance from the transplant center ($n = 31$). This resulted in a final sample of 64 donors of which six participated in the final donor interviews.

Interviews

The interviews were designed to facilitate open-ended responses and discussions from the participants. All interviews were conducted by a trained researcher. The interviewer used a structured guide to help ensure that all the relevant issues were discussed (see Appendices 1 & 2). Each interview included (1) an introduction, in which the interviewer explained the purpose of the interview and (2) open-ended questions to probe study participants' views on the barriers to LDKT or barriers to live donation. The interview guide was created in collaborative consultation by three transplant nephrologists, a senior researcher with experience in health disparities research, and the director of this transplant center's Living Donor Institute. The specific questions were selected to help identify barriers to LDKT that we might be able to address through improved donor and recipient education practices. Two of the interviews were conducted by phone to accommodate participants who were unable to meet in person. The interviews ranged in length from approximately 12 min to 1 h and 8 min. The average (mean) interview length was 32-min long. All interviews were audio-recorded and transcribed verbatim.

Analysis

A thematic content approach and standard qualitative data analysis techniques were utilized, in which three reviewers went through cycles of reading, summarizing, and re-reading the data [16, 17]. Analysis of the interview data followed common dictates of qualitative data analysis: data reduction, data display, and conclusion drawing and verification [17]. Study themes and concepts were derived after thoroughly reviewing the transcripts multiple times and comparing meeting notes. Through the process of coding, significant statements and concepts were identified and grouped together to form themes.

Results

Participant Demographics/Procedure

All 20 participants (14 recipients of a LDKT and six living kidney donors) self-identified as Black, with two participants identifying themselves as multiracial (part American Indian and part American Indian and White). Women comprised the majority of living donors (83 %) and LDKT recipients (57.1 %). The mean age for recipients was 60 years (SD = 8.93), and the mean age for living donors was 47 years (SD = 13.37) (see Table 1).

Barriers to LDKT among Recipients

When asked about challenges they faced pre-transplant, LDKT recipients identified three main barriers to transplantation and LDKT: (1) rejection of the sick role (denial of disease

Table 1 Participant demographics

Age	Recipients $N = 14$ $M = 59.93$, SD = 8.93	Donors $N = 6$ $M = 46.67$, SD = 13.37
Marital status		
Never married	2	2
Married/partnered	5	0
Divorced	5	3
Widowed	1	0
Separated	1	1
Education		
8th Grade or less	0	0
High school or equivalent	2	0
Some college	6	1
Bachelor or associate degree	3	3
Some post-college	1	0
Master's or other post-college degree	2	2

severity), (2) protective disclosure (privacy regarding health condition), and (3) unwillingness to approach potential donors (Table 2).

Denial and Avoidance (Rejection of the Sick Role/Denial of Disease Severity)

For the transplant recipients whom we interviewed, the experience of sickness due to kidney disease varied greatly, from no noticeable physical symptoms to outright immobility. Recipients with few symptoms often reported that they had been in denial. According to one recipient:

> "Well, they said, 'Daddy, I'm going to give you a kidney, and you're going to have the transplant.' And I said, 'No.' …the night before the operation they pulled me out of the car, I was headed to Carolina…because I didn't get sick. I didn't believe it…I was in denial."

Many found it difficult to accept that they had a chronic disease. Some transplant recipients reported such grave states of denial that they nearly missed out on the opportunity for a LDKT. This extreme level of denial was especially common in the male recipients, all of whom found it difficult to accept their illness. Several patients described this denial as reflective of the Black male experience with healthcare overall.

In addition to experiencing denial of disease, recipients noted that Black males avoided the healthcare system in general. Patients identified, in retrospect, how their pride, denial, and avoidance harmed their health and may have accelerated the progression of their illnesses.

Privacy and Use of Protective Disclosure

Denial of the sick role was often accompanied by a second and related recipient barrier: a desire for privacy. Our LDKT recipients reported that they preferred to remain private about their medical problems and need for transplant. Several patients noted that they did not tell many people that they were sick because of the anticipated reaction from others. According to one patient, "I didn't let a lot of people know I was sick…because I didn't want anybody feeling sorry for me…You can't do anything but empathize and feel sorry for me is all. I didn't tell anybody." As illustrated in this case, some recipients chose to limit their disclosure for fear of being pitied.

Patients' desire for privacy and the ensuing limited disclosure of their kidney disease may have served a protective function. Limiting disclosure of their kidney disease may have protected the patients from feeling vulnerable. In addition, patients saw their limited disclosure as a way to avoid burdening others with their illness. One patient stated:

> I never told them. Because I don't want people worrying about me…don't feel sorry for me, don't pity me. Just let me be me, treat me the way you always treat me. I don't want that difference singled out.

Others identified this desire for privacy as a major barrier to LDKT in the Black community. Despite knowing that a LDKT is the best treatment option for kidney failure, recipients often maintained a high level of privacy in discussions about their treatment.

Unwillingness to Request a Living Donor Kidney

Along with a desire for privacy, recipients did not actively pursue potential donors. When asked how they found their donor, none of the recipients reported making a direct request for a kidney. Recipients reported that they were reluctant to ask others to donate, due to fears of either being rejected or harming their relationship with a potential donor. Instead, the recipients reported that their living donors volunteered to donate, without being asked by the recipient. One recipient stated, "…I never asked anyone. I don't want to put anybody on the spot. That to me was like the roughest part."

Barriers to Living Kidney Donation among Donors

For some of the living kidney donors, the donation process was rather simple. Other donors, however, faced significant obstacles that were created by family, friends, and even the intended recipients. Two barriers reported by Black living donors were (1) the negative responses to living donation by their family and friends and (2) the transplant recipients' initial refusal to accept a LDKT (Table 2).

Table 2 Barriers

Group	Theme	Representative quote(s)
Recipients	Rejection of the sick role/ denial of disease severity	"… I wasn't going to take it [dialysis] and actually…I didn't believe that I had kidney disease because I was asymptomatic. I never got sick; I was still jogging and walking." "…That's because most African-Americans … males…we refuse to go to the doctor until it's too late. You know if I'd went to a doctor early, I probably could have prevented it [kidney disease]… but most of us, we think we are Superman, and it's not true…if you go to the doctor, you can avoid most illness."
Recipients	Privacy and the use of protective disclosure	"And as far as the African-American community, I don't think we talk about much, you know. We keep everything private, secret, secret. And other cultures, they explain to their kids and younger generation about what's going on."
Recipients	Unwillingness to ask for a kidney	"…I never actually discussed with her [my living donor], asked her … 'Will you donate, be a donor for me?' No I didn't. I didn't."
Donors	Negative responses from others	"Other people were like, 'What's wrong with you?'… 'You can't make that decision.'…that's the only thing that bothers me about this whole process. It was negative…I couldn't tell you the how many times I heard, 'Okay, just because it's your mother.' And from people that are close to me and that I love." "People don't understand. They don't get it…I had to understand and really get it that these people are afraid…fear and ignorance will make people say anything…the moment, the day after surgery…it's like a light switch…but that's how I learned that it's fear. It's fear or ignorance."
Donors	Recipient rejection—overcoming the "no"	"I knew before going in that I wanted to do it, but once I got the information…it was more to convince my mother because she really didn't want me to do it…"

Negative Responses from Others

Black living kidney donors reported that a major barrier to living donation was the negative response that they received from family and friends. Many donors reported that they needed resolve and tenacity to overcome the social hurdles they encountered. Several donors commented on their surprise at the negativity elicited by their decision to donate, with one donor noting succinctly, "People don't get it." Due to an initial negative response from their family and friends, some donors stopped discussing their donation decision with their social circles. Donors recounted stories of concerned loved ones not only questioning their decisions, but also, in some extreme cases, trying to change their minds regarding donation.

After deciding to donate, many donors found that they had to defend and justify their decision, even months after the actual donor evaluation was completed. For example, one donor who donated to her daughter found that she had to defend her decision to her husband, saying "I mean I lost my marriage, too. My husband…he just couldn't understand how I can consume myself into our kid, and I don't know how anybody doesn't get that." Donors were able to cope with the negative reactions of others by realizing that these reactions were not a reflection on the donors but more based on the fear. In order to successfully go through with donation, Black donors may require perseverance to overcome the surprising negativity they face along the way to donation.

Recipient Rejection—Overcoming the "*no*"

The majority of the donors reported that their recipients initially refused the offer of a living donor kidney. The recipients' initial refusal to accept an organ frustrated the donors. In spite of this initial refusal by the intended recipient, one donor stated that her mind, "was made up, it didn't matter… I never did have a second thought…it was like we gotta get this done." In order to successfully donate, donors required persistence and determination in their interactions with the recipient. All of the donors involved in this study volunteered to donate (without being asked by the recipient), so many of the donors had to help their recipients overcome the fears and concerns about the potential harm to the donor.

Recipient Coping Mechanisms

Many recipients identified faith as a coping mechanism that was integral in helping them to overcome barriers to LDKT (Table 3).

Faith

Faith provided both a source of and focus for hope as recipients dealt with the uncertainties of the transplant process. By putting outcomes "in God's hands," recipients were able to find reassurance and peace during the transplant process. One recipient stated that:

> "Even with family members, as we well know, sometimes there's not a good match. But for me it was by divine ordinance because when I look back over everything that happened, I said God had his hand in every single step."

Faith also allowed recipients to contextualize and give meaning to their experiences throughout the donation process. Indeed, faith served many functions as a pillar of support, as well as prompting some recipients to look for ways in which they could advocate for others facing kidney disease and transplantation.

Donor Coping Mechanisms

Donors also relied on coping mechanisms to help them move past barriers to LDKT. They identified normalization of donation as a key coping mechanism during the LDKT process (Table 3).

Normalization of Donation

Many donors normalized or minimized the extraordinary nature of living donation. According to one donor,

> "It's embarrassing to me that people think it's something special, 'cause to me it wasn't. It was just something that needed to be done."

Donation was often framed as unremarkable or second nature. For some donors, living donation was both an opportunity for giving and a way to demonstrate that they were looking out for family members, just as the donors presumed other relatives would do for them. For other donors, donation brought heightened attention that conflicted with their view of donation as a practical, unremarkable act. Donors often had to emphasize to others the normalcy of their choice to donate.

Social Support

Both donors and recipients noted the importance of having support throughout the transplant and donation processes. This support often came in the form of tangible and emotional support. Recipients reported receiving most of their support from family and friends. Donors spoke of the support they received from the transplant center as integral to their successful completion of the process.

Social Support for Recipients

Recipients frequently emphasized the importance of support from their social network, given the many barriers to transplant throughout the multi-step transplant process. This support took many forms, from small gestures to direct statements or actions affirming the importance of social or familial bonds. Friends and family were often able to reframe situations for recipients, thus enabling them to take a more constructive view of their circumstances, either for the donation process or to support other aspects of their well-being.

Social Support for Donors

The transplant center was a major source of support for donors as they navigated the donation process. Many donors stated that the thoroughness of the transplant education process at the transplant center made them feel more at ease with their decisions and provided reassurance.

> "They gave me every bit of information I needed to know about her and how she was doing in the process, all the information I needed to know on my side. …I had; I can't think of names right now, but, you know, I had people calling me just to go, 'Hi, how you doing?' you know? And that, you know, kind of cheered me up, especially during that time where, you know, I felt like I didn't have support…, you know. 'Well, we're just calling to make sure everything is okay and you're doing okay.' You know, I didn't get the feeling like, yeah, they're coming after my kidney. …I didn't get that feeling. I just got that feeling that maybe they listened to me when I was with them, or they may have seen, heard some concerns that I might've had and they were just checking on me."

As with the normalization of donation discussed above, the frequency of the transplant operation and donor nephrectomy and efficiency of the transplant center created a sense of normalcy with regard to the surgery itself, which in turn reassured potential donors. The combination of education, surgical volume, and psychosocial support created a positive environment that was helpful in navigating the evaluation and recovery processes.

Discussion

In this qualitative study, we interviewed Blacks who were either living kidney donors or recipients of LDKTs to

Table 3 Coping mechanisms

Group	Theme	Representative quote(s)
Recipients	Faith	"… And, you know, I just prayed God that if…you know, if she donate this kidney that it was going to work. …You know? Everything was going to be okay because,… you know, I mean I just…, you know, had that kind of faith to believe that…, you know, God is able to do…, you know, anything up there. So that's what I had that faith."
Donors	Normalization of donation	"Family. You know, you do that for family. That's my big brother, and I'm sure if the situation was reversed, I was in some type of lifesaving situation, he would do the same for me." "It's a huge decision. I'm not making light of it at all, but it's not as big as people probably make it out to be. …I think that we can ascribe all these huge oh my God and it is life changing. I'm not saying it's not life changing, but it's life-changing in a way that is manageable. There's other things that can happen to you that will be worse. This actually could be a good thing. I definitely don't think people will look at it that way."

determine barriers to LDKT among Blacks. The LDKT recipients reported that they denied the extent of their ESRD, utilized protective disclosure to maintain their privacy, and were unwilling to approach potential living kidney donors. The living donors reported that they had to overcome negative feedback from others about their desire to donate and persevere against the intended recipient's objections to donation. Recipients emphasized the role of family and faith as sources of support through their transplant experience. Donors tended to downplay the extraordinary nature of their gift and instead treated donation as a normal act. Donors also noted the importance of support from the transplant center in both informing their decision and setting them at ease.

Several LDKT recipients downplayed or outright denied the severity of their ESRD. Although denial can serve an adaptive function in certain situations, it can also delay or impede both access to treatment and frank conversation among the ill person and loved ones [18]. The adverse effects of denial upon patients' medical care have been shown in other patient populations. For example, among cancer patients, denial can decrease willingness to seek treatment and can increase interpersonal distance between patients and loved ones [19].

Many transplant recipients expressed that they did not want to be viewed as different or ill, indicating attempts at managing both their public identities and self-concept. Denial may serve as a way for transplant candidates to assert themselves [20]. Rejection of the sick role is actually associated with better coping skills in ESRD patients [21]. However, if ESRD patients deny their illness and fail to take steps toward receiving a LDKT, then this rejection and denial may decrease the patients' chances of receiving a LDKT.

Along with denial, privacy was a major concern for some recipients. Previous studies found that Blacks may delay seeking medical care [22] as part of a culture that normalizes privacy regarding medical concerns [23]. Some recipients commented specifically on male avoidance in seeking preventive care and how admitted illness could damage one's self-perception of strength and autonomy. Black men, in particular, utilize fewer healthcare resources compared to both Black women and Whites [24]. These findings in LDKT recipients are supported by previous literature highlighting the common struggles individuals face when choosing to share their private information with others [25].

Disclosure research suggests that sharing information, especially in close relationships, can strengthen bonds and foster greater feelings of connection between parties [26–28]. However, when individuals are coping with chronic illnesses such as kidney disease, the rules of disclosure often change, as patients weigh the consequences of disclosure against sharing information with their loved ones. Most recipients who reported trying to conceal the severity of their illness explained that they did not want to burden their loved ones.

Indeed, kidney patients viewed the failure to disclose their need for a kidney as a protective act, which has also been noted in communication literature, albeit in different contexts. For example, patients may keep their medical problems private in order to reduce or minimize stress among those that they care about the most. In this context, disclosure is not seen as a tool for building intimacy, but rather as a strategy to maintain stability within the relationship [28]. Recipients expressed a disinclination to impose their health problems on others as well as a desire to avoid scenarios that could pressure others into becoming living donors. Disclosure can be a process coupled with feelings of anxiety, uncertainty, and fear, so individuals are often cautious and deliberate in choosing who they select to be partakers, and ultimately joint owners, of their information [29]. Additionally, males believed that an admission of illness could threaten their "positive face" (also considered their self-esteem), leading them to cling on to their information in hopes of maintaining their image in front of others [30].

A surprising and interesting finding in our study was that prior to donating, living donors had to overcome negative reactions from others about donation as well as resistance to LDKT from their intended recipients. It is possible that one factor separating successful donors from those who do not complete the process is the resolve to push ahead despite social consequences. The personality traits displayed by the successful donors—including optimism, confidence, and perseverance—allowed them to navigate through the uncertainty and outright negativity of others.

Furthermore, even though living donors are rightfully viewed and labeled as “heroes,” living donors conceptualized their donation as an unremarkable act. This cognitive framework may have made it easier for donors to continue with the donation process, because it may be easier for individuals to complete an act that they perceive as ordinary rather than something considered out of the ordinary or heroic. Another reason why donors may view donation as a normal event is to minimize the disconnect between external adulation for donation and the donors’ feelings that donation is necessary and a natural consequence of their relationship with the recipients.

Study Limitations

This study should be interpreted in light of its limitations. In addition to a small sample size, the number of donor interviews, compared to the amount of recipient interviews, was low (6 vs. 14). Participants were recruited from a single transplant center in the Northeastern USA, and their views may not be representative of the views of Black kidney transplant recipients or living donors nationally. Additionally, the participants were those who had a successful outcome as either a recipient or donor, which may have led to a positive bias in the interviews.

Future Directions

This study limited itself to interviews with actual recipients of LDKTs and actual living donors post-donation. Future studies can examine other transplant populations (e.g. DDKT waiting list patients and potential donors in the midst of evaluation), which may perceive different barriers to LDKT and living donation. Performing qualitative interviews prospectively, rather than after donation or transplant, could also help minimize the potential for memory or recall bias among participants.

Another area of exploration would be further examining how recipients perceive themselves as a burden to others and how this perception hinders the search for potential living donors. A more nuanced understanding of patients’ perceptions may help with the development of future intervention and support materials.

Interventions to assist Black patients in their pursuit of LDKT should include education regarding the possible need for self-disclosure when trying to identify living donors. Providing ESRD patients with practical strategies on how to begin and facilitate discussion with potential living donors can help build transplant candidates’ confidence in having these conversations. Providing ESRD patients with education may also address patients’ concerns about burdening the potential donors. Interventions can also utilize strategies for self-reflection that can help patients to explore their beliefs regarding privacy and protective disclosure. Such interventions could be led by a peer educator, such as a community member who has successfully had a LDKT.

Donors may also benefit from education that prepares them for potentially negative responses from others and offers strategies on how to deal with these responses. Providing information and coping strategies for possible negative reactions from loved ones may also give the donors an additional sense of social support, in that the center is aware of this issue and would “have their backs” by proactively addressing it.

Conclusion

In this study, living donors and LDKT recipients who are Black reported facing barriers to LDKT that were largely based on interpersonal communication. The lack of communication or protective disclosure from ESRD patients to potential donors may delay or prevent ESRD patients’ receipt of transplant. For donors, it was negative, often fear-based communication from others that served as a barrier to donation. In order to successfully navigate the transplant process, recipients and donors had to rely on their support networks and individual perseverance. With a deeper understanding of the barriers experienced in pursuit of LDKT, interventions can be developed to tailor education that bolsters the self-efficacy of both donors and recipients regarding asking someone to be a donor and completing the donation process.

Compliance with Ethical Standards

Ethical Approval All procedures performed in the studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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Appendix 1

Barriers to LDKT: Interview Guide for LDKT Recipients

1. How did you find out you had kidney disease? With kidney disease, most people have a few treatment options, transplant being just one of them. What made you decide to get evaluated for a transplant?
2. What kind of information did you receive about deceased donor transplant?
3. What kind of information did you receive about living donor transplant?
4. What did you think were the benefits of LDKT?
5. What did you think were the risks of LDKT
6. What were your concerns about LDKT? *[**PROBE**: some concerns might include worries about future health after donation; body image; ability to become pregnant (if female); financial concerns [regarding amount of time out of work]*
7. What, if any, concerns did your family have about live donor kidney transplant? What, if any, concerns did your friends have about live donor kidney transplant?
8. What barriers did you face while you were pursuing living donor transplant?

PROBE the following to move the discussion along:

a. Barriers identifying donors
b. Barriers to completing evaluation
c. Barriers with the actual transplant surgery
d. Barriers following your transplant
e. Financial barriers
f. System barriers

9. What, if anything, do you know now that you wish you knew before you got your living donor kidney transplant? Did you feel that all of your questions about transplant were answered?

Appendix 2

Barriers to LDKT: Interview Guide for Actual Live Kidney Donors

1. Who were you originally interested in donating a kidney to?

    a. What made you interested in donating?
    b. [*If intended recipient was not an immediate family member*] How did you know this person?

2. How did that situation present itself? How did you find out that this person needed a kidney?
3. Tell me about how you decided to come forward as a possible donor of a living kidney for [name of intended recipient]. *[**PROBE:** How did you make the decision to become a living donor? Did you just decide right away that you wanted to donate? Did you take the take the time to think through the decision? If you took time to decide, did you use any specific information or resources to help you with your decision? If so, what did you use to help you make your decision?]*
4. What was your motivation for volunteering to donate?
5. In your opinion, what were the risks of being a living donor?
6. What were your concerns about donation? *[**PROBE**: some concerns might include worries about future health after donation; body image; ability to become pregnant (if female); financial concerns [regarding amount of time out of work]*
7. What, if any, concerns did your family have about live donor kidney transplant? What, if any, concerns did your friends have about live donor kidney transplant?
8. Think back to the time that you went to the transplant center and met with a nurse. How was the experience? Can you tell me about that visit? ***[PROBE:** Were there any specific parts of the evaluation process that were particularly difficult? If so, what made them difficult?*
9. What barriers did you face while you were pursuing live kidney donation? ***[PROBE:** Barriers with completing evaluation (*e.g. *time to do tests to come here to SBMC OR own health issues that prevent or hinder completion of evaluation); Barriers with the actual transplant surgery; Barriers following the surgery; Financial barriers; System barriers]*
10. How did you feel about donating? ***[PROBE:** What were your positive thoughts about donating? What were your negative thoughts about donating?]*
11. Were there any specific parts of the donation process that were particularly difficult? If so, what made them difficult?
12. How did your family react when they found out that you were donating? How did your friends react? ***[PROBE:** Did you tell them about your decision, or did they find out some other way?**]***
13. How did your intended recipient react when he/she found out you were donating? [***PROBE***: Did you tell him/her about your decision, or did they find out some other way?]

How did volunteering to donate affect your relationship with the intended recipient?

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