Count me out: Perceptions of Black Patients who are on Dialysis but who are not on a Transplant Waitlist

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Abstract

End-stage renal disease (ESRD) is characterized by racial inequity; Blacks are 3 times more likely to develop ESRD than Whites. Transplant is the preferred treatment option since transplanted patients experience better clinical outcomes. Racial inequities persist at each of the steps required for transplantation. Despite the vast literature describing these racial inequities, it does not include dialysis patients' awareness and understanding of treatment options, specifically for transplant. To address this gap, we purposely sampled Blacks in Detroit who were receiving dialysis and who were not active on any transplant waitlist to investigate their understanding and perceptions of transplants. We used uncertainty management theory (UMT) to better understand perceived barriers to getting and remaining on a transplant waitlist. We aimed to address a critical gap in the literature to inform approaches addressing this enduring inequity. For this qualitative study, we conducted individual, semi-structured interviews with 24 Black ESRD patients, aged 34–73 years: 9 male and 15 female. Participants shared their experiences of being on dialysis, perceptions, and understanding of transplants. We describe two key findings: 1) uncertainty for these patients is prevalent and multi-layered and 2) social support can both dissuade an individual from pursuing transplant (i.e., reluctance to ask family members to be donors) and it can result in decreasing uncertainty (e.g., participants wanting to pursue transplant to be with family). We highlight the specific need to improve patient education regarding treatment options and enhancing how relevant health information can be communicated.

Keywords: End-Stage Renal Disease, Kidney Transplant Waitlist, Health Disparities, Patient Communication

Chronic kidney disease (CKD) is a prevalent condition in which the kidneys are damaged and cannot appropriately filter excess fluid and waste from the body; 37 million people, approximately 15% of the U.S. adult population, may have varying degrees of CKD, and one of three adults with diabetes and one in five adults with hypertension have CKD (Centers for Disease Control and Prevention [CDC], 2019). End-stage renal disease (ESRD), CKD that has progressed to a low level of kidney function and is being treated with dialysis or kidney transplant, is characterized by striking racial disparities. Blacks are three times more likely to develop ESRD than Whites and one-third of all ESRD patients are Black (CDC, 2019; Patzer et al., 2019). These racial disparities are driven by social factors (e.g., socioeconomic disparities), biological factors (e.g., higher prevalence of hypertension and diabetes in minority populations), and genetic factors (Crews et al., 2019).

In addition to racial disparities in ESRD prevalence, disparities are also observed in the transplant treatment option. Early stage CKD may be asymptomatic, though once detected, can be treated with dietary and other health behavioral changes to stave off disease progression. But CKD patients who develop ESRD need either renal replacement therapy (RRT), or a kidney transplant to survive. There are 500,000 individuals in the U.S. who are receiving renal replacement therapy (RRT), and the vast majority (90%) receive hemodialysis, a dialysis done multiple times a week at a dialysis center, versus peritoneal dialysis (10%), a dialysis done every day without the aid of a dialysis center (Jagdale et al., 2019). Transplant is the preferred treatment regimen over RRT when the patient is within specific clinical and psychosocial criteria because transplant patients experience better clinical outcomes, have a longer life expectancy, report higher quality of life, and incur a lower cost of care to the healthcare system (Axelrod et al., 2018). Despite these differences in both human and financial outcomes, there are only approximately 90,000 patients on waitlists for kidney transplantation, or less than 20% of all individuals receiving RRT (Kilambi et al., 2019). Consequently, a small proportion (3.0%) of ESRD patients receive a transplant (United States Renal Data System [USRDS], 2019). Racial disparities also characterize the proportions of ESRD patients who receive a transplant. Only 1.0% of Black ESRD patients receive a transplant, compared to 3.2% of White ESRD patients (Morgan, 2006). The percentage of Black ESRD patients who receive a transplant is lower than any other racial/ethnic group: Native Hawaiian or Pacific Islander (1.2%), Hispanic (1.8%), American Indian or Alaska Native (3.6%), and Asian (6.6%) (USRDS, 2019).

Transplant Eligibility

Transplant eligibility is predicated on the patient indicating their desire to pursue a transplant. If the patient does not have a living donor, they can be evaluated for placement on a waitlist (Purnell et al., 2018). There are five steps to being placed on a waitlist; they include: (Step 1) patient expresses interest to receive a transplant to clinicians at their dialysis center (e.g., social worker, nephrologist), (Step 2) patient gets a referral from dialysis facility for evaluation, (Step 3) start evaluation, (Step 4) complete evaluation, and (Step 5) placed on and remain on a waitlist (Traino et al., 2015).

Completing the steps for transplant evaluation requires that the patient attend multiple clinical appointments for medical and psychosocial evaluations to assess and confirm that the patient does not have various other disqualifying health conditions (e.g., cardiovascular disease, active cancer, and obesity) nor psychosocial contraindications as determined by various members of the care team. This evaluation process can take over a year to complete and it must be performed periodically in order to remain on a waitlist (Kazley et al., 2012).

Also, a patient may remain on a waitlist but have inactive status (i.e., “status 7”). In 2003 the Organ Procurement and Transplantation Network (OPTN) policy was amended to enable kidney transplant candidates to accumulate time on the waitlist with inactive status.

This waitlist status is used as a placeholder for patients who may not be eligible for transplant due to provisional reasons (e.g., incomplete transplant workup, beyond body mass index (BMI) threshold) (Grams et al., 2013). This status assumes that the transplant candidate will eventually move from inactive to active status. Approximately 30% of all patients on the OPTN waitlist are listed as inactive (Talamantes et al., 2017).

Racial disparities have been detailed at each step of the process to be placed on a waitlist. Black ESRD patients experience barriers at the patient, provider, and system level. For instance, Black patients are less likely to have access to transplant information and they are less likely to complete the transplant evaluation (Patzer et al., 2019). . However, the perceptions of Black ESRD patients concerning the waitlist have not been described. Understanding patient perspectives would enable improving access to information which would help patients make more informed treatment decisions.

Theoretical Framework

Various theories and frameworks describe the perceptions of individuals who may be contemplating transplantation. Uncertainty Management and Social Support are appropriate frameworks for understanding Black patients' perspectives of the transplantation process.

Uncertainty Management

A considerable level of uncertainty is deeply rooted in the ESRD treatment experience, especially for patients who may be eligible for transplantation. Uncertainty management theory has been used to both explain patient perspectives at the various stages in the transplantation process and to describe the steps individuals may take to manage uncertainty (Brashers, 2007; Scott et al., 2011).

Uncertainty is multi-layered, interconnected, and temporal (Brashers, 2001). And varying levels of uncertainty can result in conflicting emotions and motivations. The layers can include the self (e.g., individual may not want to undergo another operation/procedure), others (e.g., individual may perceive that they will not be treated fairly by clinical staff), social and/or familial relationships (e.g., individual may not want to receive a kidney from a family member), or other contextual factors (e.g., individual may be unsure of requirements of them in the process of getting a transplant). Uncertainties can also be interconnected. They may involve one topic (e.g., perceptions of clinical factors, like age, which determine eligibility) which can be connected to another (e.g., the likelihood of languishing on a waitlist). Last, uncertainties can be fleeting (e.g., on certain days an individual may not want to put themselves through another operation) or more sustained (e.g., an individual may be consistent in their preference to continue with the dialysis treatment option) because dimensions of uncertainty can change over time (Scott et al., 2011).

Individuals may reduce uncertainty by seeking health information. They may seek information directly from members of the healthcare team (e.g., dialysis nurses, social workers) (Bonner & Lloyd, 2012), from other individuals in similar clinical circumstances (e.g., dialysis peer mentoring/support) (Veinot, 2010; Zheng et al., 2010), or via others' behaviors or actions (e.g., seeking online information) (Costello & Murillo, 2014). Information seeking behavior, which includes avoiding information, can be influenced by the objectives of the individual, and their family, friends, or extended network which may include peer mentors who are also receiving dialysis. These objectives may not be consistent across these groups. For example, an individual may not be certain that they want to receive a transplant, but a family member may be convinced that they should (Brashers et al., 2002).

Social Support

In a health context, social support is vital to an individual's ability to manage the stress of both physical and mental illnesses. Social support is defined as the network of personal ties that provide aid, also referred to as "emotional caring", which enable the individual (patient) to enhance or establish personal agency; there are four types 1) emotional support (e.g., esteem, affect, trust), 2) appraisal support (e.g., affirmation, positive feedback), 3) providing health information (e.g., advice, suggestions), and 4) instrumental support (e.g., financial support, time, caregiving) (Albrecht & Adelman, 1984). Social support can be provided through both face-to-face and indirect modalities (e.g., technology/computer) (Robinson & Tian, 2009).

Despite extensive research describing the racial and other demographic characteristics of ESRD patients who do not progress to transplantation, little is known of Black patients' perception of barriers, or other factors which may influence them not being placed on, or remain on, a waitlist (Crews et al., 2019; Patzer et al., 2019). Further, the literature does not describe the perceptions of Black ESRD patients, who happen to experience inequity at each stage of the transplant process. In fact, investigations of perceptions of dialysis staff concerning these persistent racial inequities have detailed low socioeconomic status as a primary driver, as staff perceive that Black patients are unable to develop a feasible financial plan to cover pre- and post-transplant costs. Dialysis staff also believe that Black patients do not pursue the transplant treatment option in order to keep disability income (Lipford et al., 2018). Staff perceptions are vital because clinical practices commonly rely on clinical staff to initiate referral to determine transplant eligibility (Step 2) (Yuan et al., 2012). Although previous studies have examined ESRD patients' experiences of being on a waitlist (Tong et al., 2015), no investigations have examined the perceptions of Black patients, specifically those who are on dialysis but who are not active on a waitlist. Given persistent racial disparities at each stage of the transplant referral and evaluation process, it is vital to understand Black patients' perceptions of the transplantation process and transplant waitlists.

Study Hypotheses and Research Question

To address this gap in the literature we designed and completed an investigation to understand Black ESRD patients' perceptions of transplant waitlists. We posited that their perceptions would be characterized by high levels of uncertainty. We also posited that social support, across the four types, may affect their perceptions of transplantation.

A fuller understanding of Black ESRD patients' awareness and opinions will enable healthcare teams and equity researchers to design interventions to help address a persistent racial inequity that drives both human and financial costs. Thus, our primary research question is: what are the perceptions of transplantation of Black ESRD patients' who are on dialysis but not on a waitlist?

Materials and Methods

Overall Study Design

Semi-structured interviews were used to investigate dialysis patients' perspectives and understandings of ESRD treatment options, transplants, and transplant waitlists. Purposive sampling was conducted in collaboration with the National Kidney Foundation (NKF) of Michigan who provided us with contacts to help to recruit Blacks in the Detroit area who were receiving dialysis. We purposely sampled in Detroit because according to the 2010 U.S. Census, it has the highest percentage of Black residents of any major city in the U.S. (82.7%) and has one of the largest number of Black residents (670,226). The Michigan State University Institutional Review Board approved the study protocol on February 11, 2016 (IRB# x16-133e). The study protocol included participant informed consent forms which were reviewed with each participant, who signed and dated the forms.

Inclusion Criteria

Eligibility included self-identifying as Black or African American. Also, the participant could not be active on any transplant waitlist, but they may be inactive on a waitlist (status 7 or "on hold") (Grams et al., 2013). Participants may have had a prior transplant; however, they must be receiving dialysis at the time of the interview.

Data Collection Process and Instruments

The first author conducted each of the individual, in-person interviews, from March 4th through April 20th, 2016. All interviews were conducted in the participant's home except for two, which were conducted in public locations of the participant's choosing, one in a restaurant and the other in a coffee shop. Each participant was compensated $50 for their time. The interview guide included open-ended, main questions based on our hypotheses and research questions and follow-up probes. Participants were asked to share their experiences of being on dialysis, perceptions, and understanding of kidney transplants, and, for some, experiences with previous transplants and reasons why the graft failed. The semi-structured interview format remained consistent; however, insights gleaned from the initial interviews helped guide probes in subsequent interviews. Each interview was digitally recorded, and the audio recordings of the interviews were transcribed verbatim. Interviews lasted an average of approximately one hour for a total 24 hours and 47 minutes. To maintain anonymity, all identifying information was removed from each of the transcripts.

Data Analysis

The grounded theory approach was used to code, summarize, and condense the data. This approach is well-suited for the analysis of the interview data because it is conducive to understanding phenomena which is not well-described in the literature – Black dialysis patients' perceptions of transplants, and their understanding of waitlists (Creswell, 2006). The constant comparative method was used to analyze the interview data (Glaser, 1965). NVivo software (Version 12.0) was used to code the transcripts. Coding is a cyclical process, enabling the refinement and highlighting of patterns to generate categories and concepts. Line-by-line coding in the initial coding phase was completed, using in vivo codes to capture the participant meanings (Glaser, 1978). In the second coding cycle, axial coding was used to define conditions and actions (Corbin & Strauss, 2007). Consistent with grounded theory, in this second cycle, categories were developed for the first cycle codes, an approach well-suited to apply meaning to the data (Miles et al., 2014; Saldaña, 2009). Initial codes were analyzed to develop preliminary themes which were reviewed iteratively and discussed among the two authors, then they were refined by referring to the transcript data.

Results

All 24 participants except one received dialysis treatments at the same dialysis center in Detroit which is part of a large healthcare system. The other participant received dialysis at a center about 3 miles away from where the other participants received dialysis, which is part of a large, private series of dialysis centers. (See Table 1)

Insert Table 1 about here

Participants range in age from 37 - 71, 9 are male and 15 are female, all are Black and all have spent most of their lives in Detroit. All have received dialysis for more than three years, and three had already had a transplant, from a live donor who was a family member. They were receiving dialysis due to failure of the graft, which they indicated was due to their medication behavior which was inconsistent with clinical recommendations. Twenty-two participants indicate that they were living with hypertension and 13 participants indicate that they have been diagnosed with diabetes. Fourteen participants were referred to dialysis from the Emergency Room, while 10 were referred from a clinic or ambulatory care facility. Twelve participants are on a waitlist but are inactive (“on hold”), and 3 of the 12 were unsure if they would even accept a kidney at this point if they were transferred to active status. Participants refer to inactive status on the waitlist as “on hold.” No participants referred to this status as “inactive”. Participants understand being “on hold” to mean that they do not meet the necessary criteria for transplant, but they can remain on a waitlist.

There are two overall findings. First, Black ESRD patients’ perspectives on transplantation and waitlists are characterized by high levels of uncertainty. Second, social support is a factor in these perceptions.

Uncertainty is Prevalent

Uncertainty was prevalent among participants and sources of uncertainty were multi-layered, interconnected, and temporal. Participants expressed uncertainty regarding their current circumstances and about a future which may include a waitlist and/or transplant. Uncertainty about the self was reflected in lacking information about treatment options and the dismay that resulted in hearing the diagnosis. Some participants also perceived that their prognosis was better remaining on dialysis, rather than receiving a transplant.

Uncertainty at the Layer of the Self

Lack of information about waitlists and transplant option – I didn’t even know. Information barriers to kidney transplant stem from a lack of information, incomplete information, or misconceptions concerning the assessment and transplant process. For example, P14 indicated that he was receiving dialysis for five years before ever being approached by dialysis center staff to inform him of the transplant option. He indicated his reaction when the social worker shared information with him about the transplant process, “I didn’t even know that you had to go up and talk to the people and meet with the transplant team and stuff. I thought it was all automatic. I asked her ‘why am I not on the list?’.” Another participant shared her experience with not knowing that the patient must initiate the evaluation process to be placed on a waitlist, “I thought that you just get on the list. They find your kidney and that was it. But it’s more than that. No one actually told me I was supposed to go there [to the transplant team].” (P15) Several participants reported similar anecdotes in describing how they learned that the patient must indicate interest in a transplant to initiate the evaluation process. One participant expressed specifically that the onus was on the patient to be informed about the transplant process, “you gotta look into it. You gotta do some research yourself.” (P02)

In addition to the waitlists, participants shared how other treatment-related information was conveyed to them, and what it feels like to receive information this way. P11 conveyed that dialysis patients are not informed appropriately:

> [We need] something more than just them giving you a pamphlet, a bunch of material to read. There should be more classrooms, more group discussions, with people that are going through similar situations. Instead of just one-on-one, with a doctor and a bunch of nurses at a table sitting there just telling you that you need to do this, you need to do that, you got to do this, you got to do that, you’re beating down on a person that has no understanding of what’s going on. (P11)

As P11 alluded to, other participants expressed frustration with how vital information was communicated concerning recommended health behavior. P16 expressed frustration with the information provided by the nutritionist. Despite the nutritionist being present at his dialysis treatments, the information provided did not address his information needs, which centered on how to lose weight, “[the nutritionist] mostly tries to tell us what not to eat, for our kidneys… every day she's there, but it's not about weight loss. It's more about learning how to eat [while receiving dialysis], what foods you are not supposed to have."

Many participants attended group sessions to learn more about transplants and dialysis, specifically the RISE program sponsored by the NKF. P13 stated:

> The RISE program is what saved me. Before that, they wasn't telling me anything about none of my lab work or nothing. They weren't telling me the results or none of that, they were just doing it, and I didn't know what to ask them and stuff, but when I came back from the first RISE [information session] I asked him [dialysis technician] myself, 'what's my blood level? What's my creatine at this time? Where you getting all this stuff from?' So they started printing out monthly lab work and gave it to me.

Several participants were quite complimentary of the RISE program:

> If people were on dialysis Monday, Wednesday, and Friday, they would schedule a two-week program that would be held on Tuesdays and Thursdays. We would go in, sit and talk to the people about what the kidney was all about … they had people come in to do presentations. They were educating us. Not just about a transplant but how to take care of yourself, the things that you were eligible for, how you could help yourself so that you would know what was going on with the body. They talked to you about nutrition, they talked to you about what you are eligible for with social security or SSI. And it was a very educational program because a lot of people, including myself, had no knowledge of exactly what end-stage renal [disease] was about, even though we were on dialysis. (P10)

Despite several participants stating how informative the RISE program was, participants expressed regret that the RISE program no longer exists, "From what I can understand, the Kidney Foundation no longer has the money to sponsor that program." (P10)

Shock Upon Hearing Diagnosis and Uncertain about Future – I was kinda devastated. Several participants indicated that they were diagnosed with ESRD and told they would need to receive dialysis at the hospital during an emergency room visit. While these participants had heard of “kidney failure” and “dialysis,” they were shocked upon learning of the diagnosis because they did not recall a blood test, urine test, or imaging test to assess their kidney function. Many did not recall being informed of the transplant treatment option. Others were unsure how to assess if a transplant waitlist was right for them. Being told that their kidneys had “failed” was overwhelming, in part because of *how* they were told, and they had trouble interpreting what this meant for them:

> It was a shock to me because I thought it was something else, but the way they actually described it to me, he [ER physician] said “you got stage four kidney failure,” then they [ER physician and others who may have been residents] walked out the room. They didn’t tell me what dialysis was or nothing. They just walked out of the room. (P14)

Another participant described what he felt when he was told during an emergency room visit that his kidneys had “failed”. He recounted, “Well, initially, I was like...I just kind of said, ‘This was my heritage.’ That was my initial perception of it. Then, I had to kind of wrap my mind around, ‘Is this thing gonna be fatal or not?’” (P10) A participant who received his diagnosis during an emergency room visit and subsequent hospital admission shared:

> I cried a little bit, and I called my mother I told her, and I tried to see if she knew anything about it. She really didn’t know nothing about it, because ain’t nobody in our family ever been on dialysis … I guess I cried ‘cause I didn’t understand what was going on, really. And I didn’t know what dialysis was. I don’t know [why the physician did not explain it to me]. I think he was making his rounds so he was kinda... trying to get everybody taken care of. But I feel that he could have gave me a little more information. (P14)

Another participant described the emotion he felt. Although he received the ESRD diagnosis during a physician office visit, the jolt was evident, “well, I was shocked, ‘cause I didn’t really notice anything wrong at that particular time. You just say, ‘Hey, what me? How could that happen to me?'" (P03) Similarly, P08 described her experience, "I had no acceptance at the beginning, it was devastating to me you know. I was working, I was taking care of my children, and it was a critical moment for me to have to adjust my life."

Some participants also described the shock they felt when they first began receiving dialysis. One participant described her feelings when she first started dialysis, which happened to be in the same hospital where she had received her treatments for breast cancer:

> When I first went to dialysis it was kind of scary, the machines…hooking you up to the machine and stuff. And it just...I don't know. I never knew… as many times I had been to the hospital, I never knew dialysis was in there. I never thought about dialysis. I didn't know what dialysis was. (P17)

For one participant, simply walking into the dialysis center was overwhelming for her:

> I was kinda devastated because I didn't really know what dialysis entailed…when I walked into that place, I was in shock. I just stood in the middle of the clinic and just looked because I had never seen that many machines and that many people hooked up to machines. (P23)

Participants described that simply being aware of transplant information was not enough for them to make a final decision. The decision to be placed on a waitlist is significant requiring deliberation and consideration. One participant (P03) described his reaction to being told by clinicians that he should consider the waitlist, "I didn't tell them no. I just said, 'I don't think I'm ready yet.' They said, 'well ok, just keep up the good work and get yourself stabilized and we'll talk again.'" This deliberation was also associated with the decision to receive a kidney, even when a family member has agreed to donate. One participant (P14) described how his brother was willing to donate a kidney to him and his brother wanted to go through the necessary steps to be assessed, but P14 needed more time to consider the magnitude of this decision. He explained:

> I was kinda mad at first ... because I wasn't actually ready for it, because they tell you, "you can get a kidney, a transplant, a organ from a family member." But a lot of people, they will have second thoughts about it, because your body can reject it … and they can't put it back in that person [donor]. So you just got an organ for nothing. And then like a situation might come up like they end up with stage four kidney failure … then they'd need a kidney. (P14)

Despite the crushing realization upon the ESRD diagnosis and that they would need to receive dialysis, some participants were interested in transplant. And after learning about the waitlists they managed their uncertainty by reflecting on their circumstances and expressed confidence in their ability to meet the stipulations to get on, and stay on, a waitlist. P03 described how his motivation and control over his dietary behavior ultimately determined his status on the waitlist, "it's all up to me. If you wanna do it, you do the right thing. If you don't, you won't do the right thing." P03 also described he was taken off of a waitlist previously due to his own dietary choices, "I took one drink out of that Pepsi and the next thing you know. I was hooked again."

Kidney Function Will be Restored – It can come back. Some participants believe that their kidney function may be restored. They indicated that they understand that kidney function can return after starting dialysis, "they told me there was a 50% chance my kidneys can start back working." (P21) For some participants, the chance of their kidney function returning was sufficient to dissuade them from seeking a transplant. P21 also shared that he was still producing urine while on dialysis which indicated to him that his kidney function may return, "I really don't wanna take that chance of trying to get a kidney that might kill me when they're saying there's a good chance that it [kidney function] can come back." Even after speaking with a social worker, P21 expressed reluctance. The social worker asked her if she would accept a kidney if one was ready for her and P21 said, “I’m not sure … I don’t know how to deal with that.”

Survival Chances Better on Dialysis – I see more people living than dying: Participants observed the difficulties of others in receiving a transplant or in persisting on a waitlist, so they simply believe that their chances of survival are better on dialysis. “I’ve heard people say they’ve been on dialysis for 18 years…They give me the courage to go forward. Because I see more people living than I see dying.” (P23) This also illustrates how uncertainty at the layer of the self can be interconnected as the uncertainty is associated with information gathered from others who have been on dialysis.

Uncertainty at the Layer of Others

Mistrust due to Racism – We don’t trust the doctors and the nurses because of racism. Participants also reported that, as Black people, they did not trust institutions (e.g., hospitals, insurance companies) or individuals (e.g., doctors, nurses, social workers) who may have a role in their care. One participant elaborated on her frustration with how she was told about the transplant option, but she was not able to take advantage of it. This resulted in her questioning health care providers’ motivations:

> They told you you’re sick, and your kidneys no longer work. Okay,” why can’t I get some new kidneys then?” That was my first question. They said, “eventually, but you’re gonna have to deal with these other things first.” I believe they wanna guinea pig on you for a little while. Because if they really wanted to put a kidney in you, then they could probably put one in you. (P02)

Another participant (P03) described how financial incentives are a source of his mistrust:

> I thought they were putting people on dialysis on purpose. They tell us, "your kidneys are bad. We gonna put you on dialysis. Hemodialysis." Well I never thought that my kidney was bad. I mean, I'm still urinating and everything. I never thought my ass was bad. But then every day I see new faces in there, and there's so many people on [dialysis]. I don't know how to [explain it] ... The money. The money is the root of all evil, man. And they get so much money off of each dialysis patient. It ain't even funny. They charge you for that little piece of cotton and the tape that they put on your arm. Everything. If I require a Band-Aid, they write it down. I had a list one time. I usually just throw it on the dresser, but I come home one day, and I look at it, and itemized all that and it's like, about, maybe, eight, $10,000 a month for dialysis? The insurance. That's what the insurance get. Yeah, that's a lot of money. Almost better than the casino.

One participant expressed how mistrust dissuades her and other Blacks from organ donation:

> We (Black people) figure that if I agree to donate my heart or my liver or whatever, then if something happened to us and we went in a hospital, they would just take it, whether we gave them permission to do it or not. A lot of people believe that. They would just take it [kidney] without our permission. Let us die and give it [our kidney] to somebody else. (P17)

One participant (P24) expressed that mistrust kept them awake while receiving dialysis, "I'm not comfortable going to sleep at dialysis. I'm not comfortable because I fear that they're not gonna do what they're supposed to do." Another participant (P17) described how mistrust is common for Black people, "we [Black people] don't trust the system. That's what it is. We don't trust the doctors and the nurses and these people who are gonna be doing the surgery on us to remove a kidney." This participant described how racism from their past is the cause of current mistrust, "[When I was growing up] we [could only go to] the Black dentist. We didn't get the same health care [as Whites] simply because of racism."

How participants perceive that clinical staff treats them is vital given the regular contact with staff and the considerable demands of the dialysis regimen. Participants expressed discouragement when they perceived that staff was unwilling to support them. For example, P21 recounted a circumstance in which she attempted to reschedule an appointment and went to the dialysis clinical staff for help, "they'll have the head nurse up there who don't want to listen to the social worker, she wanna keep walking away while the social worker is trying to tell her [that I need to reschedule]." This participant continued with how witnessing the dialysis staff not coordinating her care appropriately made her feel, "and so, I feel like since you can't hear the important thing that's going on with me and why I can't make it here, at least I'm trying to reschedule the appointment, then why am I even gonna waste my time?" (P21) In some cases, participants would not pursue assessments for the transplant list and would avoid specific dialysis centers, because of how they were treated by dialysis staff. For example, during an assessment for a waitlist P01 described how he volunteered that he had a history of drug use, but he maintained that he was completely drug free at the time of the assessment, "it was like I became a second-class citizen after that…I just told them I wasn't interested in a transplant."

Some participants reported avoiding specific dialysis centers or hospitals and not signing up for transplant waitlists because of how they were treated by staff, "no, I don't want to go to [names dialysis center]. I did not like their attitude. If they like you, okay. If they don't care for you then you waitin'… it's like they pick and choose who gets [a kidney]." (P24) Also, P13 recalled when he believed he was going into surgery to receive a kidney, the transplant surgeon stopped the transplant because of his hypertension. He shared that his primary care physician had already documented that he had hypertension and told him that he was approved for a transplant. Because of the surgeon's decision, he had to go back through the entire evaluation process in order to return to the transplant waitlist. Afterwards, he decided to discuss this with a social worker, "the social worker said 'well you probably need to talk to the surgeon if you want to.' I said, 'No, not really…No, I don't think I want to see her.'"

Several other participants similarly expressed perceptions that they were not listened to by clinicians before their ESRD diagnosis and that lead to a delay in a diagnosis. For example, before ESRD diagnosis P11 expressed how he had reduced his caloric intake to 400 calories per day, yet he was not losing weight. His physician would not listen when he expressed that his diet was not the issue:

> To me, it came off like she thought I was lying but then when I went on dialysis and the weight came off, I told her, "look, I told you it was something else." And she said, "well, you know it's hard to diagnose." I said, "well it's easy to listen." (P11)

One participant detailed her attempts to get a kidney screen before having to receive dialysis, which she attributed to not being listened to:

> I didn't have any insurance so they sent me to a free clinic. The free clinic lady was supposed to write me out referrals but she didn't do it. And I kept calling her but they told me I couldn't come up there, "you just can't walk in here to see her." And I said, "well, I don't wanna lose my kidney. I wanna get to the referral, so I could see what's going on with my kidney." When she finally did that, it was 3 months later … and she sent me to a pulmonary doctor. So I'm [saying to myself], "why are you sending me to the lung doctor? I wanna get to the kidney doctor." She said, "This is my job and I know what I'm doing." That's what she said. So I get to the lung doctor, now my kidney is completely ate up. She said, "you have no business being here. You need to be in the kidney department." (P22)

Uncertainty at the Contextual Layer

Achieving BMI Thresholds – They want me to lose around 50 pounds. Meeting the Body Mass Index (BMI) threshold was the most commonly cited clinical barrier to eligibility for transplant. Eight participants stated that they were told to lose a specific number of pounds to be eligible for transplant. P14, who indicated that he is "on hold" (i.e., on a waitlist but inactive), recounted the discussion with the transplant team, "the doctor looked at the paper and stuff, and he said that by me being in the lower percentile [blood type and other stipulations], I could (sic) have gotten a kidney by now, but they want me to lose around 50 pounds first." Another participant indicated that she identified her cousin as a potential live donor. She confirmed that her cousin was a match, but he was not eligible to donate his kidney because of BMI, "he was too big to be a donor." (P09)

In addition to citing BMI as a barrier, participants explained the multiple reasons why meeting the BMI requirement was difficult for them. Access to exercise equipment can be difficult for those on fixed or low incomes. P16 explained her reaction to the fitness program which was recommended during a recent hospital stay, "I'm on a fixed income. I [did not have] the $200 [plus] to pay for [a health club membership]." Furthermore, participants who had access to the recommended physical activity described feeling too tired after dialysis to engage in the physical activity recommended to reduce their BMI. P11 described how he felt after beginning dialysis, "I'm too tired to do anything… I couldn't bowl anymore, I couldn't play basketball, no contact sports, no football. I would go swimming but I kept getting pneumonia."

Challenges to the recommended dietary behavior were another barrier to meeting BMI thresholds. Dialysis requires dietary restrictions which some participants indicated were too difficult for them to maintain to meet weight loss goals, "Most of the diet food we can't have…anything dark green. Any type of dietary supplements. A lot of vegetables we can't have. [We can] basically have boiled chicken. That's it. Boiled chicken and rice, all day. Could you eat boiled chicken every [day]?" (P14) Some participants recounted that they were on a waitlist but they could not maintain the necessary dietary behavior to persist, "I stopped following what I'm supposed to do. I started back to drinking all of that dark cola I wasn't supposed to drink and foods I wasn't supposed to eat." (P03)

Age – After 60 you can't even get a transplant. Uncertainty regarding age thresholds for transplant eligibility influences the decision to pursue transplant. Some participants indicated a specific age requirement for a transplant, "I think after age 60 you can't even get a transplant." (P16) Other participants expressed that older age was disqualifying without indicating a specific age, "the older I get, the less of a chance I think I have [of receiving a transplant]." (P17) Upon probing about how they learned of these age qualifiers, patients confirmed that they did not learn about them from clinicians or dialysis staff. P12 explained her understanding of how age is a factor in eligibility, "I found out later [after being on dialysis for 3 years] that a person got one [transplant] that was 80 years old." Also, some older participants expressed that they had lived life and felt that it would be better if someone else received the kidney "at my age, it [transplant] really don't matter to me. I just keep doing dialysis." (P16). Another participant expressed her perspectives on transplant, "Cause my age, I'm 70. It makes a difference. And I'd rather see somebody younger get one." (P12)

Post-Transplant Care Regimen – I don't wanna put myself through that. Participants expressed concern given their understanding of what would be required of them to maintain their kidney function after transplant. Many expressed worry concerning the required medication behavior, specifically the stipulation of taking the anti-rejection medication regularly. They were concerned because they felt that their current medication behavior was irregular, "I don't want [a transplant] because you're stuck to all these pills, every day, about

20 pills for the rest of your life. I'm bad with pills." (P03) Another participant stated, "all the pills you gotta take. I'm not good at taking pills. So if you don't take them pills, the kidney could stop. So, I don't wanna put myself through that." (P19) Participants recalled previous medical conditions with treatment regimens that included several medications, "I think I'll just go ahead on and do the dialysis…Cause I don't wanna go back to all that medicine." (P12) Another participant who had already received a kidney transplant indicated that the graft failed because she did not consistently follow the recommended medication behavior, "I stopped taking my medication…I was taking them, but I'd skip." (P07)

Another apprehension concerning the medication regimen is the ability to pay for necessary medications. Participants knew there would be changes to their existing medication regimen, and they expressed concerns with being able to afford them. Patients who need dialysis who do not have another form of insurance are eligible for Medicare; however, if they receive a transplant then their eligibility lapses three years after receiving the transplant (Centers for Medicare & Medicaid Services, 2020). Some participants were fully aware of this provision, "you must sustain yourself three years after transplantation. They automatically take you off if you're not 65. Let's say you're 50, and you get three years, and then you come off" (P02). Some also indicated reliance on disability benefits, and eligibility may be affected by receiving a transplant, "you only got like a year's time [of disability coverage]." (P01)

Multiple participants managed uncertainty by observing others' experiences of going back to dialysis after having a transplant. For some, this would be worse than never having a transplant, "I've seen people get on the waitlist, get that kidney, and be off dialysis, and it rejects, and they'd be put right back on dialysis, and have to go through that whole process again, and I don't wanna go through that, I'm not gonna go through that." (P23) One participant who had a transplant described his experience with having to go back to receive dialysis treatments, P13 who went through that process said:

> The second time, when I had the transplant, and then they said "hey you've got to go back to dialysis," man, that was, I don't get depressed, but I believe I was depressed then. Aww man, I was just sad, man. I mean, just dragging, dragging. Didn't wanna do nothing. (P13)

Several participants have already endured various health conditions, including surgeries, and the uncertainty of enduring another procedure influenced their decisions. One participant offered her experience with other medical procedures, "a surgery is not easy. You might come back out of it, and you might not." (P16) Another participant expressed the sentiment this way, "I was actually scared to have the surgery 'cause I done had so many surgeries in my life. It's just like, this is a big surgery." (P04) One participant expressed that they were not having any more surgeries, "they not cutting on me no more, period." (P19)

Certainty derived from Perceptions of Life After Transplant

Several participants expressed certainty that receiving a transplant would improve their lives. These perceptions tended to reduce uncertainty. Disdain for receiving dialysis helped inform their perspectives on how their lives would improve. Faith resulted in optimism for a better future. Through spirituality, they derived meaning from their experiences for a better future. Some expressed faith that a transplant will help them "live life" again.

Several participants expressed certainty in their dislike of receiving dialysis and this influenced their perspectives on how receiving a transplant would greatly improve their lived experience, "the good part is that you don't have to take dialysis no more. Let me tell you something, I'm being disfigured getting stuck with a needle twice, three days a week. I'll take 100 pills to stay out of dialysis." (P09) Another participant expressed just wanting to enjoy simple pleasures like drinking water, “that’s what getting me, the water part. I love water and you can’t drink so much.” (P15)

Optimism and spiritual faith provided a measure of certainty for some participants that their health will eventually improve. Their faith gave them motivation, “my experience, just have faith. You have to, I have to have a strong mind.” (P06) Religious faith provided comfort, optimism, and certainty, “I have something to believe in. When you have something to believe in, it means you know there’s something more…it’s a sense of there’s something out there that’s bigger and better than you. And you try to achieve it and you strive to go get it.” (P11) Spiritual faith elicits feelings that they will not face a challenge that they cannot meet, “He [God] is not going to let us be burdened with more than we can handle physically in our own bodies.” (P20) One participant (P09) had to receive dialysis after receiving a kidney donated by his daughter. He shared that the graft failed because he did not take the anti-rejection medication as directed. He stopped taking his medications because “he felt fine” shortly after his transplant. He recounted, “I don’t need this medication. I don’t need doctor appointments. I’m feeling good. I was feeling brand new. I was back playing ball [sports], everything was going good.” He asserted with certainty that having to receive dialysis again was a test to help him prepare mentally for his next transplant, “God is putting me through a test to say … ‘this time I’m gonna make it hard for you to do everything necessary until you realize the importance of this’.” Spirituality provided a solid source of certainty for participants.

Many participants expressed a certain desire to live life to the fullest again. P02 expressed the will to live several times as influencing his perspectives on receiving a transplant, “I like living and I like doing the things that help me do that… I don’t wanna just die!” They were certain of being able to do the various activities that they cannot do while on dialysis, and some were certain that they could follow the recommended post-transplant regimen. For example, P09 did not understand why some individuals would refuse a transplant to avoid anti-rejection medication. He recounted his retort to that concern, “don’t you wanna live a normal life...don’t you wanna be able to sleep in…don’t you wanna play with your grandkids.” P10 was also perplexed as to why some did not want a transplant, “[getting a transplant enables you to] do things like a normal person, why wouldn’t you want a kidney?” For some participants, the regular dialysis schedule made travel virtually impossible, “I wanna travel and everything, ‘cause on my bucket list is to take a cruise, but so far I haven’t found a cruise that can take me. One told me, “it’s too expensive [to provide dialysis services] for just one person.”

In addition to leisure travel, socialization was also a motivator. P22 also relayed a poignant account of traveling to Cleveland to see his brother before he died, then after he died how he could not spend as much time with his family as he would have preferred because he had to return to Detroit to receive dialysis:

> I couldn’t go straight to him on that Sunday because that Monday I had to be on dialysis. So I had to wait until that Tuesday and get up early that morning and drive to Cleveland so I could see my brother before he passed away. When he died my family was getting ready for the funeral. I wanted to be there with the family and everything but I couldn’t because Wednesday and Friday I gotta go to dialysis. So I had to go to dialysis Friday and then leave as soon as I got out [of dialysis] to go to Cleveland. What good did it do me to go there when I still couldn’t really be with the family. I gotta spend four hours out of my day just to go to dialysis.

The Role of Social Support

The level and type of social support influenced participants’ perspectives on transplant and waitlists. Unwillingness to seek or the inability to access social support (e.g., to ask family members to be a donor), and low social support impacted eligibility for some.

Barriers due to Lack of Social Support – When I got sick, she left me. Lack of social support was a factor for some participants. Eligibility for waitlists includes a psychosocial assessment, which includes having someone who commits to supporting the patient in the period following the transplant. Multiple participants described their own situations in which access to support is difficult. For example, P06 described how her grandmother was a source of support when she was on a waitlist, but when her grandmother became ill, and her mother was not able to provide support, she was forced to ask different people to attend her assessment and evaluation meetings:

> I would just choose whoever I could to come to my meetings. But my social worker just kinda said, "You know what? I know that this support is not good for you. You're bringing multiple different people each time you come to your transplant evaluation. It's not gonna work." (P06)

P06 shared that she was removed from a waitlist due to lack of support, despite having individuals present at her assessments. Because she no longer had one consistent individual, her level of support was deemed insufficient. Other participants shared accounts of how they were removed from a waitlist due to insufficient support. One participant shared how his older brother consistently accompanied him at his regular assessments, but his brother's incarceration left him without a consistent source of support, "my older brother was my support team. My older brother encountered some legal issues and he was no longer able to be the support person." (P01) Another participant described how the mother of his children and his partner of 17 years was his support. She attended his regular assessments, but when his health declined, she ended their relationship, leaving him with no one to play the support role, "I was with my children's mom for 17 years but when I got sick, she left me." (P19) His relationship ending resulted in his removal from the waitlist. Participants expressed confusion as to what constitutes sufficient social support to persist on the waitlist. Some were aware of stipulations practiced by other transplant teams which differed from the stipulations they were subject to, “I don’t really understand because I have a friend who was on dialysis with me as a child, she went to [the University of Michigan transplant center] … for her transplant and they don’t require family consultations.” (P06)

Participants indicated that having adequate social support was important in helping them follow the dialysis regimen, which includes regular attendance at dialysis treatments. Participants indicated that regular attendance was an important requirement to getting on a waitlist and persisting on it. Participants expressed that other demands, such as caregiving responsibilities, at times presents barriers to their ability to attend treatments. They also described how dialysis center staff were indifferent to their efforts to attend treatments amid competing demands. One participant offered a detailed account of her efforts to attend her dialysis treatments, but her caregiving demands at times presented barriers:

> The [dialysis] staff up there where I’m at, they expect you to be there every day. And I told them, by me going through what I’m going through … I was in the process of moving and I was going through stuff with my landlord and trying to take care of my kids. And my kids was having problems in school. I mean I understand that [I need to attend dialysis appointments], but it’s kind of hard to not take care of your responsibilities, just so I can be up there [at the dialysis center]. And I do, I try to be there as much as I can, but I don’t have no family that really can help me with the stuff I'm going through. (P21)

Participants who had experience on a waitlist also offered accounts of how insufficient social support presented barriers. One participant (P24) described how he was under a strict deadline to get to the hospital once he was notified that a kidney was available for transplant. He indicated that once his initial graft failed and he attempted to be placed back on a waitlist, he was denied because he could not travel quickly enough, “I had to get there in less than 45 minutes…I don’t have a car and my son didn’t have a car.”

Unwillingness or Inability to Access Social Support – I don’t want a kidney from my family. Participants described their experiences of having other family members who have had ESRD, so they did not want to receive a kidney from their family because family members may need both of their kidneys. P05 described how her family history of ESRD influences her decision not to want a live donor:

> My father was on dialysis, his mother was on dialysis, his brothers were on dialysis. It [ESRD] runs in my family. I don’t want a kidney from my family member, the simple fact is I got seven kids. Okay, if I get one of my kid’s kidneys, they might have kidney trouble in the [future]... So I wouldn’t want it from none of my family members.

Another participant described the stiff reaction from family members when he sought a live donor from his family, “I went to a family reunion and I told everybody that I needed a transplant, and everybody got quiet.” (P13) Another participant described concerns about organ donations from other Black people who did not have ESRD and who may be eligible to donate:

> They [other Black people] would tell you, “I may need my kidney later on. My kidney may go bad, I may need my kidney.” Or they may say, “one of my children may need my kidney” …a lot of people don’t even want their organs removed when they’re dead. They say, “I wanna go to heaven with everything. I want my body intact”. (P17)

Several participants described how they socializing and shared information bonded with others who were also receiving dialysis during the same time at the same center. These other patients who were receiving dialysis are information sources, and the stories they exchanged informed them of some of the risks and negative outcomes, “I heard bad stories about transplant, and I heard good stories. But the majority of the stories I heard have been bad…all the bad stories just got me kinda nervous.” (P18) Some participants pointed out that they do not have access to the stories of positive transplant outcomes, because those people do not return to the dialysis center and the participants indicated that they never hear about what happens to them, unless they need to return to dialysis, “some people have them [transplant] and they keep going. When they have them, you don’t hear from them no more, that’s the thing though, you don’t hear from them.” (P16)

In addition to the information from others who were receiving dialysis at the same time, multiple participants told stories of people who received a kidney transplant and had either died or the graft failed and they needed to return to dialysis, “I had a girlfriend who had a sister on dialysis, and she was on dialysis for only a year and they called her for a transplant. She had the transplant, was in the hospital for a week, and the day she was supposed to go home, she died…that was very devastating, that really scared me.” (P22)

These stories included uncertainty about the health condition of the donor, and de facto the graft, “they explained to me, ‘I might get an old lady’s kidney … and an old person’s kidney might not last as long because they’ve lived and used it’.” (P22) Another participant expressed fear that a donation may expose them to illness:

> “[I] heard different people talk and they say if somebody donated a kidney and they got AIDS, then if you get their kidney you gonna have it…and then I heard that if they got hepatitis, and they give you their kidney you gonna get it, and I was like, ‘oh no, I got enough going on.’” (P24)

Attending Dialysis is a Source of Social Support – I enjoy the people when I go to dialysis. Attending dialysis was a form of important socialization. As mentioned, the dialysis “family” is an important source of information, but the “family” also provides socialization. P12 stated, “I think I’ll just go ahead on and do the dialysis…’cause that way you know you will be with people” She elaborated:

> I mean because I’m going to dialysis I get to see them, you know. We all get together, we talk, joke, have fun. They call me the Candy Lady ‘cause I pass out the candy. I just enjoy ‘em. I enjoy the people when I go to dialysis. You know ‘cause in the morning everybody says, “Good morning. Hey. How you? What you doing?”.

If she were to receive a transplant, then she would not be able to socialize with others who are also receiving dialysis, “I wouldn’t see nobody.” She elaborated on her family, and how little contact she has with them:

> I have four children, four sons. I don’t even hear from them, they don’t call. I was in the hospital, they didn’t even come see me or call me. [I saw] the youngest about three, about four weeks ago… [he] could have stayed where he was. Yeah, but that’s alright though. I learned how to just forget ‘em. I got, I got four boys. They got kids. I got 19 grand and 10 great-grands…and I see the great grands. I seen them last year, Easter. I didn’t see them this Easter but I was with them last Easter.

While receiving dialysis may be difficult, the prospect of losing the social connection is why some participants prefer dialysis. Another participant spoke to the social connections at the dialysis center among the patients, “everybody there is talking and discussing things with each other. It’s like a big old family in the whole front area … a lot of us talk right there in the front before we go in.” (P11) Another participant shared her perspectives:

> We are all concerned about each other. When we don’t see someone, we know something’s wrong. That mean you sick, or you’ve passed away. One of the two. Basically everybody in

> my particular clinic, when they get sick they're going to Providence Hospital. When I don't see them for a day or two, I'll go to [the hospital]. I ask before I go. I'll call and ask. If they're in the hospital, I'll go and see them. (P24)

Motivation Derived From Social Support – I wanna live for them. Social support provided motivation for some participants to pursue transplant. Participants indicated that their family, peers who also receive dialysis, and dialysis staff are all motivators.

Biological family provides participants a certain motivation to pursue a transplant. P03 explained that his motivation stems from being the primary caregiver for his grandchildren, "I wanna live for them. I do not want to leave my wife in a situation where she's alone taking care of the kids, that's kinda bad. I don't want to leave my wife alone like that." Similarly, P04 cited wanting to live for her son and being able to see him grow up, "my son is the reason why I do everything, if it wasn't for my son, I would have gave up." She shared that her son wants to go to Disney World for his 12th grade trip, "so I wanna be able to go with him … but dialysis has you tied down." P19 expressed wanting to see his grandkids grow up, but he offered a sobering possibility, "you can't do that when you're dead."

Participants also described how family members provided direct motivation and a measure of certainty to continue to do what was required of them to be approved to be put on a transplant waitlist. P21 describes how his brother keeps him motivated, "my brother is my biggest support system … when it gets rough he talks to me, he encourages me to keep going." P15 shared that he needs to lose weight to be placed on a waitlist, and his daughter is encouraging him, "me and my daughter just joined the gym together."

Multiple participants had family members who expressed interest in donating their kidney. Some found creative ways to ensure that they were tested to confirm a match. For example, P09 explained his confusion when he was notified to come to an office to start the transplant process because he had a live donor match. But he was unaware who he had been matched with. Upon arriving at the office for the transplant consultations, he found his daughter waiting there and said, “I was like, ‘why, why would you?’ She said, ‘Daddy, I love you and you wasn’t doing good, and I don’t wanna lose you, and we are a perfect match’.” Similarly, P14 was uncertain about his brother donating his kidney, and afraid that he would lose the kidney his brother donated, or he was uncertain if his brother would need both of his kidneys, but P14 expressed that his brother “was insistent.”

Participants also spoke of friends who motivated them and provided them certainty to pursue the transplant waitlist. For example, P05 detailed how one of her friends motivated her, “[my friend] told me a long time ago, ‘don’t ever think that it won’t work, ‘cause if you think it don’t work, then it won’t work. You gotta keep yourself positive that it will work.’” P11 spoke about how friends who are also on dialysis served as motivation which resulted in reassurance and certainty:

> it’s helpful when you’ve got one person who’s struggling in the same fight you are, and he says, “here man, let me show you how to help, how do you do this.” And then you help the next person and then everybody’s helping. It becomes … easier.

Several participants also described the impact of the death of friends they had made during dialysis. These experiences made them more aware that getting a transplant could be lifesaving, “there’s so many of us leaving [dying] at dialysis since I’ve been on dialysis, it’s about 30 people that left, that didn’t get to [receive a kidney donation].” (P05). Participants expressed deep sorrow from seeing so many people who they used to receive dialysis with die. These deaths struck a particular loss for participants, in part because they become quite close to their peers, and participants were adamant that they did not want that to happen to them. Losing so many people that they are close enough to call “family” is upsetting and further motivated participants, “it’s kind of scary, actually, because you’ll be thinking if you're gonna be next? I know that's how I feel." (P21). Also, P22 describes her reaction to discovering that a man who also received dialysis in the chair next to her had died, she said "I cried. Each time I lose somebody I cry, and I just hope that it doesn't happen to me."

In contrast to participants who related how their experiences with dialysis staff had discouraged them from pursuing the waitlist, dialysis staff motivated some participants to get on a waitlist. P01, who had been deterred from a waitlist by his interactions with certain clinical staff after disclosing his history of drug use, described how a social worker on the transplant team encouraged him to get back on a waitlist, "she [social worker] helped me with getting past revealing my drug history." Nurses also play an integral role in encouraging patients. For example, P05 described how he had trouble with limiting fluid intake, but the nurses where he received dialysis would encourage him by saying "don't do that this weekend, watch your weight. You know you got them grandkids to live for."

Discussion

This research represents an important contribution to further understanding disparities in progress to kidney transplant for Black patients. This is the only investigation that focuses solely on the perception, understanding, and belief of Black ESRD patients who are on dialysis and who are not active on a transplant waitlist. Findings contribute to the literature by illuminating transplant perceptions and should be used to enhance current approaches of communicating treatment options and targeting health information interventions.

Participants expressed considerable uncertainty when contemplating their current health circumstances, yet they also expressed certainty about their future should they be fortunate to receive a transplant. Uncertainty derived from the layer of the self (e.g., perceptions based on their understanding of age eligibility/restrictions, ability to follow the post-transplant care regimen) and others (e.g., clinical staff informing them of BMI thresholds) and social and/or familial relationships (e.g., dialysis provides socialization/support, reluctance to ask family members to be donors). Interestingly, *unwillingness* to seek social support (seeking a live donor) and *low* social support influenced their perceptions.

Uncertainty at the layer of the self-stemmed from participants lacking information about treatment options. Participants expressed that they did not know that the transplant treatment option may be an alternative to dialysis. Participants expressed several areas in which they simply lacked information on transplant eligibility (e.g., age thresholds) and did not know that the transplant process may be initiated by the patient. Clearly, access to reliable information needs to be enhanced. Given the intense emotions upon diagnosis, particularly in the hospital setting, the timing of when to communicate health information concerning treatment options should be considered. Attending dialysis provided participants with a vital source of information. This distinction was clear, participants who were receiving dialysis had access to information, specifically the dialysis treatment option, and access to this information reduced uncertainty. This is consistent with prior studies which describe the importance of peer support, particularly in the dialysis center (Kazley et al., 2012). Simply receiving dialysis provides a source of information. Attendance at dialysis treatments also provides vital social support. Patients exchanged information at the dialysis center, both before and during dialysis; however, clinic staff did not necessarily share information concerning other treatment options, which is consistent with literature concerning information sharing in dialysis centers (Veinot et al., 2010).

Uncertainty at the layer of others was most apparent in participants' expression of racism which resulted in mistrust. Consistent with this study, previous studies have also shown that patients from racial minority groups mistrust physicians at rates higher than individuals from majority groups, due to perceived racial bias and cultural discordance (Peek et al., 2013). Previous health communication interventions have been effective in reducing mistrust between groups (Matsaganis et al., 2014). These interventions utilize peer health advocates (“peer mentors”) to bridge information gaps much like the peer mentors referenced in this study. There is a difference, however, in that peer health advocates are trained on outreach methods and how to provide pertinent health information so that they are not only trusted as a peer, but they are formally trained which may enhance their ability to provide accurate information. Utilizing these existing resources in the dialysis centers could enhance the efficacy of an intervention designed to provide treatment option information, especially after initial diagnosis. Peer mentors, situated in dialysis centers, who provide health information may also discuss with both patients and caregivers’ issues and concerns in attempts to address uncertainty.

Communicating health information concerning treatment options and assessments for transplant waitlists should include social support assessments. These assessments should be attentive to types of social support. Comprehensive assessments will include determining to what degree receiving dialysis may play in a patient’s emotional and social life. Social workers are particularly well-positioned to perform these assessments, given their proximity to dialysis patients and their caregivers (Senteio & Callahan, 2020). For some patients, receiving dialysis may provide essential socialization. Regular visits to the dialysis center represent a crucial source of social support. Further, the literature is consistent in describing the importance of social support as patients from racial minority groups attempt to follow care recommendations (Senteio & Veinot, 2014), and associations have been described between social support and health behaviors (e.g., dialysis patients’ adherence to diet restrictions) (Sousa et al., 2019). Patient education should also include the likelihood of kidney function recovery given that such a small proportion of patients who are on dialysis experience the return of their kidney function. In large study populations, rates of recovery are between 1 – 2%, and almost one-third of patients who experience recovery have a primary diagnosis of acute kidney injury as the reason for renal failure (Mohan et al., 2013).

Last, participants were quite complimentary of the RISE program, the Rehabilitation, Information, Support and Empowerment program which has been used by affiliates of the NKF. The patient education program was established in 1999 to "assist patients return to meaningful activity" (National Kidney Foundation, 1999, 2002). This program should be consulted to inform patient education and support for this population.

Limitations

There are two limitations to the study. First, we only investigated patient perceptions. We did not include dialysis staff who have experience treating this population. Future work should include investigating perspectives of individuals in clinical roles which play a vital role in providing dialysis services and referral for transplant evaluation. (e.g., nephrologists, primary care physicians, nurses, health educators, nutritionists, and nephrology social workers). Second, we did not explicitly ask about patient satisfaction surveys. Literature shows associations between dialysis patient satisfaction and quality of care at the facility level, with significant differences observed by specific providers (Kshirsagar et al., 2019). Therefore, focused efforts should be taken to collect patient satisfaction information from this population to inform interventions addressing dissatisfaction. Future research should focus on refining validated patient satisfaction instruments for dialysis patients from racial minority populations to understand the specific barriers to information and quality care they may face. Special attention should be given to mistrust and its effect on health behaviors.

Dialysis centers should develop and implement regular patient satisfaction surveys to understand the concerns and when patients may request or need additional information.

Little is known of dialysis patients' satisfaction rates and experiences of care for those that do not respond to surveys, and for those that do respond White patients report higher satisfaction than Black patients (Richardson et al., 2015). No participant indicated that they had ever responded to a satisfaction survey or had another formalized way to express dissatisfaction to dialysis staff. Since staff perceptions have such a profound influence on barriers to pursue transplantation, providing a conduit for patients to express concerns warrants immediate attention.

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Table 1. Participant Demographics (n=24)

Characteristics		
Median age (years)		55
18-34	8%	2 Participants
35-49	25%	6 Participants
50-64	46%	11 Participants
>65	21%	5 Participants
Sex		
Male	37.5%	9 Males
Female	62.5%	15 Females
Referred to dialysis by		
Emergency Department	58%	14 Participants
Clinic/Ambulatory Care		10 Participants
Previous kidney transplant	13%	3 Participants
Comorbidity		
Hypertension	92%	22 Participants
Diabetes	54%	13 Participants
3 or more comorbidities	46%	11 Participants
Kidney transplant waitlist[a]		
On a waitlist, inactive ("on hold")		
Wants to receive a kidney	37.5%	9 Participants
May not want a kidney	12.5%	3 Participants
Not on a waitlist		
Wants to be on a waitlist	37.5%	9 Participants
Does not want to be on a waitlist	12.5%	3 Participants

Note. Categories listed are based on self-reporting by participants and were not verified by the transplant team as to whether the participant was on a waitlist, inactive on a waitlist, or off of a waitlist.