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African American and Non-African American Patients' and Families' Decision Making About Renal Replacement Therapies

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Abstract

We conducted focus group meetings of African American and non-African American patients with end-stage renal disease (six groups) and their family members (six groups), stratified by race/ethnicity and treatment. We elicited differences in participants' experiences with shared decision making about initiating renal replacement therapy (RRT; that is, hemodialysis, peritoneal dialysis, or a kidney transplant). Patients were often very sick when initiating RRT, and had little, if any, time to make a decision about what type of RRT to initiate. They also lacked sufficient information about alternative treatment options prior to initiation. Family members played supportive roles and shared in decision making when possible. Reports were similar for African American and non-African American participants. Our findings suggest that a greater emphasis on the improved engagement of patients and their families in shared decision making about RRT initiation is needed for both ethnic/racial minorities and nonminorities.

Keywords

African Americans; communication; medical; decision making; illness and disease; chronic; illness and disease; experiences; minorities; nephrology

African American patients with end-stage renal disease have utilized self-care dialysis (for example, peritoneal dialysis and home hemodialysis) and transplant renal replacement modalities at consistently lower rates than their non-African American counterparts, despite evidence that these therapies improve clinical outcomes (Alexander & Sehgal, 1998; Gore, Danovitch, Litwin, Pham, & Singer, 2009; Kasiske et al., 2002; Prakash et al., 2010). Lower utilization has been postulated to result, in part, from African Americans' poorer knowledge about different renal replacement therapy (RRT) modalities and their suboptimal engagement in shared (with health care providers and family) and informed decision making about RRTs prior to RRT initiation (Ayanian, Cleary, Weissman, & Epstein, 1999; Boulware et al., 2005; Finkelstein et al., 2008). Evidence suggests that patients who are well informed about the potential risks and benefits associated with different RRT modalities and who involve their families and physicians in the process of choosing RRT modalities are

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more likely to make decisions that are consonant with their personal values. As a result, these patients are better prepared for RRT initiation and make greater use of self-care dialysis and transplantation, as well as a more frequent choice of conservative (no dialysis or transplant) medical management (Binik et al., 1993; Cavanaugh, Wingard, Hakim, Elasy, & Ikizler, 2009; Devins et al., 2000; Lindberg et al., 2005; Marron et al., 2005; Mehrotra, Marsh, Vonesh, Peters, & Nissenon, 2005; Visser et al., 2009; Wuerth et al., 2002).

The extent to which ethnic/race differences exist with regard to RRT initiation, and patients' and families' engagement in decision making about RRT, is unclear.

Previous studies have explored factors affecting patients' selection of RRT modalities, including patient knowledge about RRT, family engagement in decisions, and the time available to make decisions about RRT modalities, but they have not examined potential ethnic/race differences in these factors (Morton, Tong, Howard, Snelling, & Webster, 2010). Differences in experiences with decision making about RRT among patients receiving different RRT modalities and their families have also been poorly explored. Therefore, studies elucidating experiences with regard to ethnic/racial minorities' and nonminorities' engagement in shared and informed decision making about RRT among patients receiving different RRTs and their families could help identify viable strategies for addressing these disparities in utilization of self-care dialysis therapies and kidney transplantation. We performed a qualitative study of African American and non-African American patients and their families receiving care involving various RRTs to ascertain their self-reported experiences with shared and informed decision making prior to RRT initiation.

Methods

Overall Study Design

As part of a study to develop and test the effectiveness of culturally sensitive educational interventions to improve patients' shared and informed decision making about initiating RRT, we conducted focus group meetings involving African American and non-African American patients with end-stage renal disease and their family members or friends for the purpose of eliciting their experiences with decision making concerning their choice of RRT. We hypothesized that participants' perspectives on decision making about RRT initiation might differ according to their ethnicity/race, as well as their status as a patient or family member. We also hypothesized that experiences with RRT initiation might vary according to treatment modality (hemodialysis, perito-neal dialysis, transplant). We therefore conducted focus groups stratified by race/ethnicity, patient/family member status, and current treatment modality.

Because we hypothesized that participants' recalled experiences regarding decisions about RRT initiation might vary based on the length of time since initiation, we recruited only patients who had been on their RRT for 12 months or longer. We believed that patients offered conservative medical management for their end-stage renal disease might differ significantly (that is, might be older and/or significantly more ill) from patients offered RRT, and therefore we did not recruit patients receiving conservative treatment to participate in our study. We set up a total of 12 focus groups: six groups were composed of African American or non-African American patients who were on hemodialysis (one group for African Americans and one for non-African Americans), on peritoneal dialysis (also one group for each ethnicity), or who had already received a transplant (again, one group each). Their family members made up the other six corresponding focus groups.

Participant Recruitment

We recruited patient focus group participants from three community-based and academic nephrology practices affiliated with nine dialysis facilities and one academic kidney transplant center in the Baltimore, Maryland, metropolitan area. We chose recruitment sites to ensure an ethnically and socioeconomically diverse patient population. Nephrology practices treated predominantly African American populations, with more than 75% of patients receiving in-center hemodialysis and approximately 10% receiving home hemodialysis or peritoneal dialysis. Patients were eligible to participate if they spoke English and were aged 18 to 70 years. Nephrology practices and the transplant center provided us with lists of potentially eligible participants who had been on their therapies for at least 12 months prior to recruitment. Transplant recipients had all received kidneys from living donors. Once patient participants were recruited, we asked them to identify one family member or friend (termed “family member”) who was involved in the treatment decisions for their kidney disease. The Johns Hopkins Medicine Institutional Review Board approved the study.

Participant Characteristics

Of the 398 patients and 88 family members initially contacted, 50 African Americans (27 patients and 23 family members) and 43 non-African Americans (23 patients and 20 family members) agreed to participate. A majority of participants in each group were of non-Hispanic ethnicity, with median group ages ranging from 45 to 63 years. Participants’ levels of education and marital status varied from one group to another. Family member groups were comprised primarily of patients’ spouses, siblings, and friends (see Table 1).

Focus Group Conduct and Analysis

Trained moderators led focus groups by using a standard moderator's guide to direct discussions, which lasted approximately 90 minutes each. After participants had completed written questionnaires assessing their demographic characteristics, moderators posed four open-ended questions to elicit participants’ experiences with decision making regarding the initiation of RRT. Moderators also asked family members to describe their roles in decision making about patients’ RRTs. See Table 2.

We audiotaped and transcribed verbatim all group discussions for data analysis. We employed thematic qualitative analysis to identify the core themes emerging from these discussions. Two reviewers closely and independently read the transcripts and grouped participants’ responses into themes and subthemes. After the initial review, the two reviewers met to discuss their findings. A third reviewer adjudicated differences between the two initial reviews, with discussion among all three reviewers to establish consensus on themes (Krueger & Casey, 2009). The findings were then discussed with other research team members, who provided critiques addressing the clarity, consistency, and exhaustiveness of the identified themes. Revisions in the analysis were addressed by rereading and recoding passages and codified groups of passages until a final consensus was reached on placement in a thematic group. We then selected emblematic quotations from transcripts to illustrate the final themes.

Results

Emerging Themes Regarding Decision Making Related to RRT Initiation

Themes emerging from patient and family focus groups included (a) patients’ frequently urgent initiation of hemodialysis as an initial RRT modality; (b) the minimal time available for patients’ or families’ engagement in shared and informed decision making because of the urgent need for dialysis; (c) patients’ and families’ frequent lack of awareness of

nonhemodialysis RRT modalities prior to initiation; (d) patients' and families' inaccurate initial comprehension of what their current RRTs would entail; and (e) family members' commonly supportive and shared roles in patients' decision making. Patients' and families' experiences varied according to the patients' current treatment modality. No clear ethnic/race differences in experiences emerged between African Americans and non-African Americans.

Theme One: Frequent urgency in initiation of hemodialysis—Many patients and their families reported confronting an urgent need to initiate hemodialysis when patients were extremely ill. One African American patient on hemodialysis reported,

I learned [about hemodialysis] when I ended up in the emergency room, that's when I found out. Yeah, doctors told me that I would have ended up in a coma, and three weeks later I would have died if I didn't come.

Many patients currently receiving peritoneal dialysis or transplantation also reported initiating RRT on hemo-dialysis under similarly urgent circumstances. Patients currently receiving peritoneal dialysis often reported learning about this option for RRT through various mechanisms; for example, through other patients or health care professionals who were not involved in their care. One non-African American peritoneal dialysis patient reported, "After I had started on hemo [hemodialysis], then one of the [other patients] that was on hemo with me told me about peritoneal."

In contrast, (then) current transplant patients more frequently reported that they had considered transplant as a treatment option early in their hemodialysis treatment, with hemodialysis being commonly initiated as an intermediate or "bridge" therapy while they awaited transplantation. One non-African American kidney transplant recipient reported,

It was talked about that it might still be a possibility that I might need a transplant, and I was just a forward reaching person with research I looked into it . . . I started dialysis because I didn't want to feel completely run down while I waited for the kidney.

Theme Two: Little time for shared and informed decision making because of urgent hemodialysis initiation—Patients and their families frequently associated their urgent initiation of hemodialysis with a lack of time to engage in shared and informed decision making about their initial RRTs. A non-African American patient receiving hemodialysis reported, "I went into the hospital very sick, and the day I was there, they put the thing in my chest, and then the next day I did dialysis." Some patients receiving peritoneal dialysis reported that their urgent initiation of hemodialysis limited the time they had to make decisions about therapy, and might have delayed their initiation of the peritoneal dialysis they would have preferred. An African American patient reported,

I didn't have a choice at that particular time, but as I look back I wish that I had had the choice. . . . I wish I had started on peritoneal. . . . Now the other thing is that the doctor told me after the fact that I was an emergency situation.

Some transplant recipients reported that the initiation of hemodialysis provided them with greater time to make decisions about transplantation. Others felt that the urgent initiation of hemodialysis was responsible for their missing the opportunity to initiate the transplant process in a more timely manner. One non-African American family member of a transplant recipient stated,

No, [we didn't have enough time]. In hindsight, we should have looked into the transplant immediately, and my wife and I talked about the fact that if things come that she needs another one [transplant], we want to jump on it right away.

Theme Three: Poor awareness of alternative RRT options—We saw varying levels of awareness of alternative treatment modalities among both patients and their families at the time the patients had initiated their then-current modalities. Patients receiving hemodialysis commonly reported having only limited awareness of alternative treatment options at the time of RRT initiation, and they frequently reported that they acquired knowledge of alternative options some time after they had initiated hemodialysis. A non-African American patient receiving hemodialysis relayed the following:

I was vaguely aware of all the treatment options, but nobody in my medical team had talked to me about them. . . . When I first started hemo, I was having a lot of problems. [Another patient] looked at me and said, “. . . [Y]ou ought to look at the peritoneal dialysis,” and that was the first I had heard of it.

Patients who reported that they had participated in structured education or had experienced family involvement prior to RRT initiation more often reported being aware of other treatment options and participating in shared and informed decision making. One African American hemodialysis patient reported,

Me and my wife went to all the classes and everything, and so they showed us all the options and everything, but I wanted to do the home dialysis, right, but my wife refused, and so I came to dialysis because I thought I could handle that.

Patients receiving peritoneal dialysis often reported being told that they should begin their initial RRT on hemodialysis and later switch to peritoneal dialysis. Some patients reported believing their choice of peritoneal dialysis was predetermined by their health care provider, before they had a chance to consider alternative therapies. One non-African American patient receiving peritoneal dialysis stated,

I learned I had to go on dialysis. It was about six months before I actually started dialysis that I learned about it. I wasn't told about hemo. My nurse told me that she thought I'd do better with the PD [peritoneal dialysis], and that was the only thing I was ever shown.

In contrast, preemptive transplant recipients commonly reported that they were aware of dialysis alternatives prior to receiving their transplants. A non-African American transplant recipient reported, “Although I never went on dialysis for either of my transplants, I was given the choice of peritoneal or hemodialysis.”

Theme Four: Inaccurate understanding of what RRTs would entail—Patients and their families reported varying levels of understanding of their current RRTs prior to initiation. Many patients receiving hemodialysis and their families reported that they did not have an accurate understanding of hemodialysis. One African American family member of a patient receiving hemodialysis said, “[I didn't understand it] at all because it was, they gave me brochures. They didn't tell me what I was going to expect or what to look for or what to do. I learned eleven years on my own.” In contrast, patients receiving peritoneal dialysis commonly reported a good understanding of their treatment prior to initiation. One African American patient receiving peritoneal dialysis stated,

I understood it very well before I had the first peritoneal treatment, because when they gave me the catheter it took a while for it to be ready to use, so I had some time. My [family] brought books and everybody got on board as to what it was about and what it would take for my care.

Transplant recipients and their families often reported that they felt they understood what the transplant process would entail, but family members of transplant recipients commonly

reported that patients were unprepared for the side effects of posttransplant medications. A non-African American family member of a transplant recipient reported,

I don't think the emphasis was placed on what the steroids and all the drugs was going to do to the person. The fatty deposits, everything getting a little rounder, and my wife didn't take that well. It's a big difference psychologically for a woman.

Theme Five: Family members' supportive involvement in RRT decisions—

Several family members reported being involved in treatment decisions with patients. They often reported their role in decision making was supportive and shared, helping family members deliberate about the potential pros and cons of decisions and providing patients with reassurance about decisions. One African American family member of a patient receiving perito-neal dialysis reported,

[The patient] talked to me first, and then told me what he wanted to do and [asked me if] I think is it the right thing for him [to switch] from hemo to PD. I said, "Well, because the PD frees you up you'll be able to move around," because he was spending with the hemo all day. He talked about [it] and asked me should he, so I said, "Sure, that would be fine. That would be fine."

Similarly, a non-African American family member of a transplant recipient reported, "With my wife, it was kind of like a partnership. She would ask me my opinion of the transplant and dialysis and stuff like that, and then we would also do like Internet research and stuff on that together."

Discussion

We found that African American and non-African American patients' experiences regarding their engagement in shared and informed decision making regarding RRTs were similar to and revolved around patients' often urgent initiation of hemodialysis, with little time to engage in shared or informed decision making about RRTs. Although the patients remaining on hemodialysis reported that they often did not know about alternative treatment options at the start of their hemodialysis, the patients receiving peritoneal dialysis and transplants more often reported being aware of alternatives prior to initiating those therapies. Patients on hemodialysis reported feeling very unprepared for the hemodialysis experience and requiring a prolonged period of time to learn about the treatment. In contrast, patients on perito-neal dialysis more commonly reported feeling prepared for their therapy, particularly if they had attended classes before initiation. Transplant recipients more frequently reported feeling knowledgeable about the transplant process prior to receiving their transplants, but they felt unprepared for posttransplant experiences, such as medication side effects. Family members who participated in decisions reported that they played a supportive and shared role in decisions.

A recent systematic review of qualitative studies of factors related to patients' and families' decision making regarding RRT identified patients' concerns regarding confronting mortality, perceived or actual lack of choice regarding RRTs, obtaining knowledge about treatment, and the degree to which patients weigh the pros and cons of alternative treatment options as important to decision making (Morton et al., 2010). However, the studies included in the review were often performed among non-minorities and did not simultaneously ascertain influences on both patients' and families' experiences with patients' initiation of three different RRT modalities. In the present study, we extended prior work by providing a more comprehensive view of circumstances surrounding and influencing decision making from the family perspective among a group of patients with different cultural backgrounds and diverse treatment experiences.

Patients' reported lack of knowledge of RRT options and lack of understanding of their initial treatment could reflect several factors, including (a) failure on the part of health care providers to engage patients in informed and shared decision making about RRT, and (b) providers' ineffective execution of informed and shared decision making. We believe our findings have several potential implications for future efforts to improve the delivery and quality of decision making for patients initiating RRT (see Table 3). First, although hemodialysis might be the only option for many patients in the United States who are extremely ill at the time of RRT initiation, efforts are needed to ensure that patients who initiate hemodialysis urgently have an opportunity to engage in informed and shared decision making once they have achieved stable clinical status. We did not ask participants recalling their urgent dialysis initiation experiences to distinguish between their experiences with shared and informed decision making before their urgent hemodialysis initiation and those they might have had after initiation. However, our findings suggest that these patients often learned about the various treatment options over a prolonged time period and from various sources, such as other patients. Assistance from health care professionals (for example, social workers and psychologists) could help patients cope more effectively with the catastrophic nature of urgent dialysis initiation and support patients' engagement in shared and informed decision making (Christensen, Smith, Turner, & Cundick, 1994; Wolf & Mori, 2009).

Second, efforts are needed to improve providers' engagement of patients in shared and informed decision making early in their disease progression; that is, before patients urgently require RRT. Several factors might have contributed to the inadequate engagement of patients and families (particularly ethnic/racial minorities) in shared and informed decision making, including a lack of recognition of progressing chronic kidney disease by primary care physicians (Boulware, Troll, Jaar, Myers, & Powe, 2006), late referrals to nephrology care (Kinchen et al., 2002), patients' denial of their need for RRT (Lunsford et al., 2006), and a lack of engagement in education about the range of available treatments for RRT (Ayanian et al., 1999). Although many providers might want to engage patients in shared and informed decisions, some might avoid such discussions if they are unsure of their patients' likelihood of progression toward end-stage renal disease; others might miss opportunities to engage patients who progress very rapidly.

The clinical practice guidelines recently issued by the Renal Physicians' Association (Moss, 2010) and the National Kidney Foundation (2000) recommend that physicians engage in practices (including partnering with patients in the decision-making process, assessing patients' desired roles in decision making, and discussion of evidence regarding risks and benefits of treatment options) that will encourage shared and informed decision making prior to RRT initiation. These recommendations place substantial emphasis on the importance of providers applying these skills in the context of end-of-life planning and the consideration of conservative medical management (no initiation of dialysis or transplantation) when appropriate. Our findings suggest that providers' application of these skills could improve patients' decision making regarding the use of all RRT modalities.

Third, improved patient education about chronic kidney disease and RRT initiation could aid decision making. Development of training sessions to help patients and families simulate the experience of in-center hemo-dialysis, similar to those offered to patients considering home dialysis therapies (peritoneal dialysis or home hemodialysis), could enhance patients' and families' understanding of the differences between the dialysis therapies. Evidence suggests that patient education can help patients slow chronic kidney disease progression and improve their consideration of self-care dialysis at RRT initiation (Binik et al., 1993; Devins, Mendelssohn, Barre, & Binik, 2003; Devins, Mendelssohn, Barre, Taub, & Binik, 2005). Involvement of professionals from multiple health care disciplines (nurses, dieticians,

and health education specialists) in education efforts could help patients understand the potential impact of different RRTs on their daily lives, such as treatment-associated dietary restrictions and therapies' self-care demands. Informational resources that impart balanced information on RRTs, providing a full discussion of the risks and benefits of all potential choices and addressing patients' diverse health literacy, numeracy, and linguistic needs might help patients and families develop more accurate views of what different RRTs entail prior to initiating therapy.

Fourth, family members' involvement in shared decision making about RRT might be particularly important for patients with end-stage renal disease because of the often significant roles these individuals play in arranging, supporting, and delivering patients' RRT. Patients often rely on family members for transportation to dialysis centers and medical appointments, for assistance with home dialysis therapies, and for live kidney donation. Family members' involvement in the shared decision-making process could help patients consider the constraints associated with their respective family's circumstances, such as the amount of support available to carry out tasks related to different RRT options. Their contributions to the decision-making process could also help patients realize their potential to pursue options such as living related kidney transplantation. However, we did not design our study to identify the barriers that individual families might have experienced that could have affected their patients' final decisions. Because families' resources (such as transportation, storage facilities, and family members' available time to assist patients with self-care dialysis) for supporting certain types of RRT might vary, future studies assessing the influence of family resources on decision making regarding RRT could provide insight into ways shared decision making regarding RRT can be improved for families facing a variety of challenges to implementing RRT.

The fact that we found no race-related differences in the patients' and families' experiences with shared and informed decision making about RRT suggests that African Americans' more frequent reports of poor preparation for RRT initiation (Ifudu, Dawood, Iofel, Valcourt, & Friedman, 1999; Kinchen et al., 2002) might be related to the frequency or timing of their engagement in shared decision making with nephrologists, rather than differences in the quality of their engagement. However, because only half of our focus group meetings were made up of ethnic/racial minorities receiving various RRT treatments, we might have limited our capacity to reach saturation on themes that could have differed between minorities and nonminorities receiving these treatments. Prior studies have demonstrated that African Americans are less knowledgeable about RRTs than are non-African Americans, and they are less likely than non-African Americans to engage in discussions about therapies such as transplantation with their physicians (Ayanian et al., 1999). In a recent study, African American patients stating that they had wanted a kidney transplant reported engaging in shared and informed decision making with their physicians at suboptimal rates (Boulware et al., 2005). A separate study showed that African Americans with progressing kidney disease were less likely than nonminorities to be referred early for nephrology care, limiting their opportunities to participate in shared decision making (Kinchen et al.). Efforts to improve the frequency of ethnic/racial minority patients' and families' engagement in shared and informed decision making might represent an important mechanism through which disparities in access to self-care dialysis and transplantation can be addressed.

Our study has several potential limitations. First, the experiences of patients recruited from our highly diverse community and academic sites might not reflect the experiences of other patients with end-stage renal disease and their family members. For example, we recruited patients who had already been receiving RRT for at least 12 months. It is possible that participants' recollections regarding decision making about RRT initiation could have

changed over time. Also, the fact that some of the participants in this study had experience with multiple RRT modalities could have altered their recollections regarding the initiation of a single RRT modality. Second, patients' engagement in shared and informed decision making might have varied as a result of several factors that we did not capture in this study, including provider characteristics (for example, interpersonal communication skills or quality of delivered pre-end-stage care), practice characteristics (such as resources for providing patient and family education prior to RRT initiation), and characteristics of the patient–physician relationship (including the length of time that patients had known their nephrologists prior to RRT initiation).

Third, we did not capture information regarding other potentially important influences on the occurrence of shared and informed decision making, including information about how long patients had been on their current treatment modality, the frequency with which they had switched modalities, their eligibility for transplant at the time of RRT initiation, or whether they discussed conservative medical management with their physicians. Fourth, we did not ask patients or families about any interactions they might have had with a broad array of nonphysician health care providers (for example, nurses, dieticians, or physician assistants) who might have also engaged them in decision-making discussions. Finally, we asked patients to identify one family member to participate in our study; it is possible that other family members who did not attend the family focus groups might have had different perspectives on the decision-making process. Other studies about end-of-life decision making have suggested that family dynamics might significantly influence discussions about treatment preferences as well as the process of decision making (Glass & Nahapetyan, 2008; Peisah, Brodaty, & Quadrio, 2006). Nonetheless, to our knowledge, ours is the first study to explore differences in experiences with decision making about RRT among a diverse group of patients and their families.

In summary, we found that the experiences reported by African American and non-African American patients and families with regard to initiating RRT were similar. Efforts to engage all patients in shared and informed decision making early in their chronic kidney disease course or after urgent hemodialysis initiation, as well as efforts to improve the quality of patients', families', and health care providers' engagement in shared and informed decision making, could improve patients' access to self-care dialysis and transplantation, and narrow ethnic/racial disparities in access to these therapies.

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Table 1

Characteristics of Study Participants

Characteristics	Patients' Current Renal Replacement Therapy (RRT) Modality					
	Hemodialysis		Peritoneal Dialysis		Transplant	
	Patient (n = 7)	Family (n = 7)	Patient (n = 9)	Family (n = 7)	Patient (n = 11)	Family (n = 9)
African Americans						
Hispanic ethnicity, n (%) ^a	1 (14)	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)
Age, median (range)	56 (27-65)	55 (46-67)	53 (33-69)	45 (45-75)	50 (37-61)	56 (39-68)
Female gender, n (%)	3 (43)	5 (71)	6 (66)	4 (57)	6 (55)	5 (55)
At least 2 years of college education, n (%)	7 (100)	2 (28)	7 (77)	5 (71)	7 (64)	5 (56)
Family Member Relationship to Patient, n (%)						
Spouse	—	1 (14)	—	1 (14)	—	3 (33)
Parent	—	2 (28)	—	0 (0)	—	1 (11)
Child	—	1 (14)	—	0 (0)	—	1 (11)
Sibling	—	2 (28)	—	4 (57)	—	0 (0)
Cousin	—	0 (0)	—	0 (0)	—	2 (22)
Friend	—	0 (0)	—	2 (28)	—	1 (11)
Parent-in-law	—	0 (0)	—	0 (0)	—	1 (11)
Non-African Americans						
Hispanic ethnicity, n (%) ^a	0 (0)	0 (0)	1 (25)	1 (33)	0 (0)	2 (18)
Age, median (range)	65 (55-80)	63 (44-80)	59 (53-74)	56 (50-62)	55 (18-65)	60 (23-79)
Female gender, n (%)	4 (50)	5 (83)	0 (0)	3 (100)	8 (73)	3 (27)
At least 2 years of college education, n (%)	4 (50)	2 (33)	1 (25)	1 (33)	9 (82)	8 (73)
Family Member Relationship to Patient, n (%)						
Spouse	—	4 (67)	—	3 (100)	—	8 (73)
Parent	—	0 (0)	—	0 (0)	—	2 (18)
Child	—	1 (17)	—	0 (0)	—	0 (0)
Sibling	—	0 (0)	—	0 (0)	—	0 (0)
Cousin	—	0 (0)	—	0 (0)	—	0 (0)
Friend	—	1 (17)	—	0 (0)	—	1 (9)
Parent-in-law	—	0 (0)	—	0 (0)	—	0 (0)

^aPercentages might not total 100% because of missing values.

Table 2

Questions Assessing Experiences With Shared and Informed Decision Making About Renal Replacement Therapy (RRT)

Question Topic	Patient Questions	Family Member Questions
Circumstances surrounding RRT education about current RRT modality	Think back to when you first learned about [patient's current treatment]. ^a How sick you were when you first learned about [patient's current treatment]?	Think back to when you first learned about [patient's current treatment]. How sick was your family member or friend when you first learned about [patient's treatment]?
Information available about alternate treatment options	Did you also learn about other treatment options? By other options, I mean hemodialysis, peritoneal dialysis, or kidney transplant, before you started [patient's current treatment]?	Did you also learn about other treatment options? By other options, I mean hemodialysis, peritoneal dialysis, or kidney transplant, before your family member or friend started [patient's current treatment]?
Reflection on time to make a decision	Looking back now, do you think you had enough time to make a decision about what treatment to start?	Looking back now, do you think your family member or friend had enough time to make a decision about what treatment to start?
Reflection on understanding of current RRT modality	Looking back, how well do you think you understood [patient's current treatment] before you started treatment?	Looking back, how well do you think you understood what [patient's current treatment] would mean before your family member or friend started treatment?
Family member role in decisions	—	Now think back again to when your family member or friend first started [patient's current treatment]. What has been your role in helping your family or friend make any decisions about treatment?

^a Stated as “hemodialysis,” “peritoneal dialysis,” or “transplant” in moderators’ guides.

Table 3**Implications of Study Findings for Improving Informed and Shared Decision Making in End-Stage Renal Disease Care**

Findings	Implications
Patients' frequently urgent initiation of hemodialysis with poor engagement in shared decision making prior to initiation	Engage patients and families in shared decision making after urgent hemodialysis initiation to facilitate access to alternative modalities if desired Involve trained experts (for example, social workers, psychologists) to help patients cope with urgent RRT ^a initiation and support shared decision making
Patients' and families' poor awareness and understanding of alternative RRT options prior to hemodialysis initiation	Engage patients and families in shared decision making before patients urgently require RRT Improve patient education about RRT options for all patients with advancing kidney disease Incorporate balanced educational materials (discussing all RRT modalities' pros and cons) tailored to meet needs of diverse communities (special attention to health literacy, numeracy, and foreign language needs) Consider training/evaluation sessions for all RRT modalities, including in-center hemodialysis Involve health professionals from multiple disciplines in education (for example, dietitians, nurses) to inform impact of RRTs on considerations such as dietary adjustments and self-care needs
Family members played supportive and shared roles in RRT decisions	Encourage family involvement in shared decision making throughout the decision-making process

^aRRT = renal replacement therapy.