

# A Qualitative Pilot Study of the Perceptions in Older Adults with End-Stage Kidney Disease on Hemodialysis\*



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## ABSTRACT

### Background

Little is known about the perceptions of older adults with end-stage kidney disease (ESKD) on chronic hemodialysis (HD) even though this could potentially influence how treatment is received. This study explores the perceptions of older adults with ESKD on HD, specifically their decision to initiate HD, preconceptions and expectations of HD, perceived difficulties with HD, and coping strategies.

**Design:** Cross-sectional

**Setting:** Outpatient chronic dialysis units

**Participants:** Older adults with ESKD on HD

**Intervention:** Open-ended interviews were conducted with 15 participants. Inclusion criteria were age 60 years and older, HD duration of at least three months, and ability to consent and participate in the interview process.

**Results:** We report on four identified domains: decision to initiate HD; preconceptions and expectations of HD; drawback of HD; and coping strategies. All participants were reluctant to initiate HD, but made the decision on advice from their physicians for varying reasons. Trust in physicians' opinions also played a role for some. Some participants had positive preconceptions of HD, while a few had negative preconceptions or unrealistic expectations. Even though the majority of participants identified several difficulties with being on HD, they also had positive coping strategies, and the majority indicated that they would make the same decision to initiate HD.

**Conclusion:** As clinicians are turning more to patient-centered medicine, understanding patients' perceptions of HD is of crucial importance. Our study highlights the importance of improving pre-hemodialysis education to ensure that patients' expectations are realistic, as well as identifying individualized coping strategies by patients.

**Key words:** older adults, perceptions, end-stage kidney disease, hemodialysis

## INTRODUCTION

Prevalence of end-stage kidney disease (ESKD) has steadily increased in the last three decades with over 700,000 prevalent cases in 2015, an increase of 80% since 2000.<sup>(1)</sup> According to the 2017 United States Renal Data System report, approximately 40% of all patients with ESKD requiring renal replacement therapy (RRT) are 65 years and older.<sup>(1)</sup> RRT modalities utilized in older adults are hemodialysis (HD), peritoneal dialysis (PD) and, to a lesser extent, kidney transplantation. A recent systematic review<sup>(2)</sup> of studies on adults age 65 years and older with ESKD requiring RRT revealed that there are very limited data on their perceptions of RRT, with highly variable opinions ranging from very high expectations that hemodialysis would help make them feel better and maintain their independence, to feeling that it was the only way to stay alive as they saw no other alternatives. Also, in a study by Stringer and Baharani,<sup>(3)</sup> 55% of older adults with ESKD on starting hemodialysis had a change in the perception of the treatment modality, finding it unacceptable. Even less is known about health satisfaction in these older adults, with the few extant studies revealing widely varying views.<sup>(4,5)</sup>

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It is important for clinicians to know and understand the perceptions of older adults on RRT as this could potentially affect adherence to RRT, and also influence how RRT is received and tolerated. Ultimately, clinical outcomes of older adults on RRT may be impacted by their perceptions and satisfaction with these modalities.

In this qualitative study, we explore the perceptions of older adults with ESKD on HD, specifically their decision to initiate HD, preconceptions and expectations of HD, perceived difficulties with HD, and coping strategies.

## METHODS

We conducted preliminary open-ended interviews with 15 ESKD patients who were receiving chronic hemodialysis (HD) in two local outpatient chronic dialysis units. Inclusion criteria for participants were age 60 years and older, ability to consent for participation in the study and interview process, and duration of at least three months on HD. The university institutional review board for social and behavioral sciences approved the study. A total of 16 participants were approached for inclusion in the study, of which 15 agreed to participate and one declined. Four investigators (NM, MB, AB, and ID) conducted the interviews using a semi-structured interview guide (see Appendix A) to ensure uniformity in the questions asked. The interview guide was developed based on findings in a systematic review by Balogun *et al.*<sup>(2)</sup> on perceptions of older adults with end-stage kidney disease. Interviews were conducted in person while participants were receiving hemodialysis in the chronic dialysis units. The unit nurses helped the interviewers identify patients who met the inclusion criteria and introduced the researchers. Each interview was audio-recorded and lasted 30–60 minutes. The interviewers had no prior relationship with the participants or knowledge of their medical history. MB transcribed all interview recordings verbatim, and interviewers reviewed the transcripts for accuracy. MB and NM conducted grounded theory analysis of the data, which is a well-established method of conducting qualitative research focusing on creating conceptual frameworks through developing analytic categories directly based on the data.<sup>(6)</sup> Initial domains based on the interview protocol topics were developed. Both researchers then generated subdomains independently, compared their analyses, and created a mutually agreed upon set of subdomains. They repeated this process until a final set of domains and subdomains emerged.

## RESULTS

Participants were 63–92 years old (mean: 75.1 years) and had been on chronic hemodialysis for a mean of 4.5 years (range: 6 months to 14 years). Eight of 15 (53%) participants were female. The majority (53%) of the participants were African American, while 47% were Caucasian (Table 1). We report on four main identified domains: decision to initiate HD;

TABLE 1.  
Demography of participants

Age Range (years)	63 – 92 (mean: 75.1)
Gender (n)	Female: 8 (53%) Male: 7 (47%)
Race (n)	African American: 8 (53%) Caucasian: 7 (47%)
Duration of time on hemodialysis range (years)	0.5 – 14 (mean: 4.5)

preconceptions and expectations of HD; drawback of HD; and coping strategies.

### Decision to Initiate Hemodialysis

In Table 2, we summarize the interview data regarding participants' decisions to start HD. All of the participants were reluctant to go on HD, but made the decision on advice from their physicians for varying reasons. Some voiced that they felt this was the only option to prolong their lives. Others made the decision to avoid a painful death, to manage symptoms, or to appease the wishes of family members. Most patients started HD when it became clear that there was no medical alternative and that, without treatment, they might die: "It's pretty much dialysis or nothing". One participant voiced: "I thought it [kidney disease] was a death sentence," as an explanation for his decision to start on HD. A few participants commenced HD for symptom control or as medical emergency during inpatient hospitalization: "I just was sick every day. Throwing up and stuff." These participants felt they had little choice in the decision to start hemodialysis and that the decision was made for them by their medical provider. One participant did not believe she required HD because she was asymptomatic:

"I woke up in the hospital one morning and they said I was going to be on dialysis. I said, 'Ain't nothing wrong with my kidneys 'cause I still go to the bathroom, I still urinate.'"

Some participants made the decision to initiate HD because they trusted their physicians' opinions. Longer term doctor-patient relationships and the accompanying higher trust levels typically made patients more comfortable with their decision to begin treatment. All of the participants admitted that their family or friends influenced their decision to go on hemodialysis. Some cited reasons include wanting to see their grandchildren grow up or that they were caregivers for spouses or children who were dependent upon them for their own survival:

"That's right. You've got to understand, I am a single parent and I'm all they have. So whatever it is they would like for me to do to stay with them,

TABLE 2.  
Decision to initiate hemodialysis

<i>Themes</i>	<i>Subthemes</i>	<i>Representative Quotes</i>
Followed physician's advice	To manage symptoms	<i>"My kidneys started going so they put me in here. I had another doctor; my kidney doctor. She put me in here. And...Because I was swelling. I was swelling. I couldn't, couldn't...I mean they had on me on Lasix. It just didn't do anything."</i>
	Felt there were no medical alternative	<i>"And then when I went to, went to have a doctor's appointment...I went to the doctor and they done an ultrasound and that's how I found it out. And I told them, 'Ah, I don't feel like it,' and he said, 'You might not feel like it, but you've got one kidney that is just barely working any at all and the other's at 30-percent, at 30- or 35-percent."</i>
	Trusted doctor's advice	<i>"And, it was much easier, I think, than if you have some, you know you're thinking, "Oh, he's just trying to make money" or, you know, whatever. But I trusted her [my doctor]."</i>
	To prolong life	<i>"No, I didn't want to do it, but I knew that in order for me to prolong my life that that's what I had to do...to follow his instructions."</i>
	To avoid a painful death	<i>"My sister-in-law got, oh 50 years ago, found out she was going on dialysis and she was on there maybe two or three months. And she said, 'No, not going to do it anymore.' And she swoled up and literally drown in the fluid around her heart... See, I had already seen that and I said, 'No way, José.'"</i>
	Felt there was no choice in decision	<i>"They ain't give you no decision whether to go on or nothin', they just tell you. It's like 'cause if your kidney goes, you go'</i>
	Family wanted patient to begin dialysis	<i>"They wanted me to do it but they get mad 'cause I said I'm not, I'm gonna stop going and all that. It's just my children, my grandkids the ones that always worry about me though</i>
	Wanted to see grandchildren grow up	<i>"Well my brother he had just had, about three or four months ago, his tenth grandchild. His daughter gave him a little boy. So, now... And you've got to see them grow up, you know."</i>
	Used outside sources of information	<i>"Yeah. And um, but I had heard – see I got a first cousin that died of the same thing. I went to the hospital to see him. And I went home and heard he had died. And um, and I thought it was a death sentence."</i>
	Observed experiences of family and friends	<i>"Yeah. All my friends were telling me, 'Man, I wouldn't take it. You can die from it.'</i>
Relied on religious faith/spirituality	Conversations with family & friends	<i>"Then I came up here and I talked to everybody. I do believe that they could be a little more honest when they talk to people about the pain."</i>
	Talked to other dialysis patients	<i>"Yes, so I mean that's it. I mean, you know, whatever it is, it is. If it can be fixed we'll fix it. If it can't be fixed, we'll just deal with it 'til the day end."</i>
	Placed outcome in hands of higher power	

I'm going to do that. Whatever it is God would like for me to do to stay with them, I will do that. It has nothing to do with a human being."

For some who were reluctant to start HD, the insistence and support of immediate family played a key role in overcoming their initial resistance. "I'm doing what [my family] wanted," and "because they wanted me here longer", reflect predominant themes in the decision-making process. Some participants also relied on their religious faith in making a decision.

A few felt they had adequate information prior to commencing hemodialysis. While majority did not feel they received adequate information prior to starting HD, they however acknowledged that they became more knowledgeable afterwards. Some participants felt they had received inaccurate (or misleading) information from their providers. In addition to information from their doctors and health educators, a few participants received information from health brochures and the media. However, participants more often relied on their family and friends' experiences with kidney disease for information in their decision-making process. The tragic death

of a sister-in-law who refused to continue dialysis treatments served as a deciding factor for one participant:

"My sister-in-law ... found out she was going on dialysis and she was on there maybe two or three months. And she said, 'No, not going to do it anymore.' And she swoled up and literally drown in the fluid around her heart ... See, I had already seen that and I said, 'No way, José.'"

Participants placed great value on information that came from patients who were already receiving HD treatments: "Well, you talk to the people that are going through it and you know it's not going to be the blessing that everybody thinks it is, but..." said one who made the decision to begin treatment based on these conversations. Some participants also felt that other HD patients were likely to provide an accurate account of their experience on HD. Some participants admitted that the accuracy of this real-world information is difficult to determine, and one participant likened it to trying to figure out what's wrong with a car in need of repair: "You can walk down the street, and before you can see the end, you'll have about 20 answers."

Follow-up with doctors and health educators to sort through the wide array and quality of information was considered important. All participants, except two, stated that they would make the same decision to start on hemodialysis if they were given the choice again, and their reasons reflected their initial decisions to begin HD. Relieving symptoms, wanting to make family members happy, and prolonging life—"I love to live ... I love living"—typically played key roles in their decision. A few indicated that they wish they'd made different lifestyle choices in order to avoid starting on hemodialysis altogether. One patient reflected on her family's reaction if she should decide to stop treatments:

"I usually do what I want to do. If I say, 'I don't want to do it anymore,' I think they'd have a cow, but it would be my decision."

### **Preconceptions and Expectations of Hemodialysis**

Participants' preconceptions and expectations of HD fell into three categories: negative, positive, and neutral, as summarized in Table 3. Few participants had negative preconceptions of HD prior to starting on it. They generally formed these opinions from either different media sources, health-care providers or, more often, the negative experiences of others. Hemodialysis "has a bad reputation" said one patient who was disturbed by a newspaper article he had read. Others related stories of friends, family, or people they had heard of who did not fare well on HD. "Yeah. All my friends were telling me—Man, I wouldn't take [hemodialysis] ... you can die from it." Not surprisingly, these stories lowered expectations of positive outcomes for patients who were about to begin treatments.

Some participants had positive preconceptions of HD and felt hemodialysis would make them feel better: "... because they said I'd feel great and after you get doing it (hemodialysis) for a while, you do feel great. Better, not great." Two participants hoped that hemodialysis would cure their kidney disease. One woman said she had hoped "that in a week or two my kidneys would start working again."

The preconceptions of majority of participants were influenced by the experience of family members or friends on hemodialysis, patient education programs or through discussions with their physicians. Only two participants had no preconceived ideas about HD or its effects, and neither had any exposure to others on HD prior to starting treatment.

### **Drawback of Hemodialysis**

Participants identified several difficulties with being on hemodialysis, as summarized in Table 4. The majority of participants felt that hemodialysis was too time consuming and significantly limited their independence. Other difficulties cited were the limited activities to keep them occupied while on hemodialysis, lack of energy, dietary restrictions, difficulty with the AV fistula graft, and poor relationship with the HD team. One participant, who was not sure why she required HD, also did not feel that it was beneficial:

"To me, it (hemodialysis) feels the same to me. They say it's working, but I don't see how.... I ain't fighting to die ... just tired of going up here getting treatment. Ain't doing no good."

### **Coping Strategies**

We identified four main positive coping strategies in our participants: reliance on family and friends; reliance on spirituality; self-care; and engaging in activities that foster well-being (see Table 5). Participants also described specific strategies for coping while getting HD treatments including socializing with staff and other patients, watching TV, staying calm or sleeping.

Some participants rely on family and friends, both for the supportive relationships they offer and for their willingness to help with chores, transportation, and more. Although most patients strived to maintain their independence, they rely on family and friends to help with instrumental activities of daily living such as cooking, mowing the grass, shoveling snow, grocery shopping, and providing transportation to treatments, doctor appointments, and physical therapy sessions. Relationships with family and friends were sustaining, both in a general way, but also during HD treatments. In addition to providing encouragement to continue HD, some family members accompanied patients to HD treatments and education sessions or showed support in other ways:

"I came in heavy today, but my friend brought me some lemon pound cake last night. Yesterday evening she came for a visit, and it was so good."

TABLE 3.  
Preconceptions and expectations of hemodialysis in older adults with ESKD

Themes	Subthemes	Representative Quotes
Negative preconceptions	From media	<i>"The one was the Washington Post thing which, in truth, they probably shouldn't have published it without something countering it. Because it was very, very grave. And most people, if you, if I simply casually mention dialysis, say, 'Oh God' or something like that. It has a bad reputation."</i>
	From negative experiences of others.	<i>"Oh, honey, she didn't...there was nothing about it she liked."</i> <i>"I felt hopeful. But I didn't look for much. 'Cause so many people I knew had died."</i> <i>"Well, you talk to the people that are going through it (hemodialysis) and you know it's not going to be the blessing that everybody thinks it is, but..."</i>
Positive preconceptions	Information from doctors and educators	<i>"The education here, not only was helpful in itself, bringing several of us together... this was prior to beginning so that we could ask questions. And it was particularly helpful for having an "Afro-American" man who was, I think he works here, but I'm not certain at what, talk about it. He's, I think, been on dialysis for something like a period of twenty years and to give us his phone number if we wanted to talk to him. That was all very helpful, but it captured a different light on what dialysis was like."</i>
	Dialysis would prolong life	<i>"They claimed it would [prolong my life], but I don't know. I just say take it a day to day. Take it as you go."</i>
	Expected to feel better	<i>"The doctor when he told me it was going to help me, so I feel better since I got on dialysis."</i> <i>"No, because they said I'd feel great and after you get doing it for a while, you don't feel great. Better, not great."</i>
No knowledge or had neutral preconceptions	Expected to be cured	<i>"I hoped that my kidney would come back. But I think they said it would not come back. But there's some people have been taken off dialysis."</i>
	No preconceptions	<i>"I didn't know what would be the result."</i>
Didn't know people on dialysis		<i>"No, I made friends after I got on dialysis."</i>

Some participants found joy in having close relationships with grandchildren. While others felt that their faith or religion played an important role in their ability to cope with their medical diagnosis and with being on hemodialysis:

*"Then one doctor came in and told me that I was going to, uh, die in a few weeks. And uh ... that was still a bit shocking. Then after that I started getting happy. I said, "I wonder when is this going to happen?"*

*"... I wouldn't call myself religious, but I believe in God and Heaven, so I want to be with my lord. But I started feeling better after dialysis, and I just couldn't believe it."*

One participant arranged her dialysis schedule so that she could continue to with her church activities. Engaging

in activities that foster well-being and self-care were other positive coping strategies for participants. Examples of such activities include exercises, playing or listening to music, adopting a pet, occasional 'cheating' on dietary restrictions, and maintaining as normal a routine as possible. Participants also shared ways that they lessen the pain and boredom of dialysis treatments. Most watched television or slept during their treatments, but others enjoyed socializing with the other patients and staff. One participant who resides in a long-term care facility looked forward to "getting out of the nursing home" and meeting new people at the hemodialysis center. She also indicated that group activities and exercise classes in the nursing facility play a key role in her ability to cope with her medical condition. One patient talked about how staying calm during treatments helped him, and another said his interest in medicine made the dialysis treatments bearable.

TABLE 4.  
Drawback of hemodialysis

Theme	Subthemes	Representative Quotes
Impact on daily life	Time consuming	<i>"Yes, the great objection to it (hemodialysis) that, um, is just saying that it is something that intrudes heavily in your life. It really takes three days because I come in at 10:30 and I'm out around 4:00. It really just cancels three days of the week...And there is almost nothing that I can do before and I really am tired afterwards. So, I think that is the strongest feeling against it, but it's..."</i>
	Limits independence	<i>"....I worked and came to dialysis from 2003 to 2004. Then in 2004 it got to be too much for me, so I quit work. And, just, I've been on disability ever since....."</i> <i>"Being on dialysis, it confines you."</i>
	Limits ability to travel	<i>"I just, I just can't travel now. Um, to the various layouts and things that we used to. Because there are certain days that I have to come to dialysis and they have meetings I can't attend with them"</i>
	Dietary Restrictions	<i>"Then there is a thousand things. Like they give you a paper that says, "now you can't eat any of this, you can't"... and, a lot of times, they are so conservative about my kidneys that they forget that I am diabetic too... You should see the list. I've got one list that's things that I can't have on dialysis. The other list is the things I can't have on, when I'm being diabetic. So, a lot of times it's just, "don't eat that."</i>
Drawback during treatment	Lack of energy	<i>"Um, it wipes you out, but still I try to go on. You know? And sometimes it wipes me out more. And um, weakens you down so. Most of the time when I go home and, you know, do a few things. And then I just sit and rest"</i>
	Boredom	<i>"Uh-huh. Yeah, you get bored here."</i> <i>"I've just been laying in this one position and I'm glad to get out of here."</i>
	Difficulty with AV fistula/graf	<i>"...have you ever seen a dialysis arm? I wish I could show you. Great huge bumps. It's, they're weird colors. Ah, and, um, so anyway it's not a pretty thing."</i> <i>"I don't like the sight of blood, don't like none of the pain with it. I just sit up here and take it. When they stick me, I just go on and take it....."</i>
	Poor relationship with hemodialysis team	<i>"I don't even get to see the kidney doctors, he come once in a while, they come here and there. I ain't had nothing to do with him since I got on the kidney machine."</i>

## DISCUSSION

Patients with ESKD receiving HD treatments face many challenges, including those directly related to HD treatments such as muscle pain and cramping, gastrointestinal distress, problems with fistula/graf, inactivity, and boredom during treatments.<sup>(7,8)</sup> In addition, they experience symptoms related to the disease process itself, such as fluid overload, fatigue, sleep disturbance, depressed mood, and decrease in sexual libido.<sup>(9,10)</sup> Furthermore, they must also cope with the amount of time HD treatments require which typically is three treatments each week, with each treatment lasting between 3–4 hours in duration. With transportation to and from the outpatient dialysis units and the resultant fatigue after each HD treatment, patients usually tend to devote three full days a week to their ESKD care. With all of these factors, one would expect a significant negative impact on ESKD patients, particularly in older adults who also have other medical problems and less physiologic reserve. We sought to learn about older ESKD

patients' perceptions of HD and how they coped with threats to their independence and wellbeing. While all participants commenced hemodialysis on advice from their physician, they did so for varying reasons including viewing HD as the only option to prolong their life, for symptom control or due to influence from family or friends. This is consistent with findings from another study of predialysis ESKD older adults in which they tended to delay making a decision on HD initiation until they were either symptomatic, facing a life-threatening clinical situation or had paternalistic guidance from their physician.<sup>(11)</sup>

High levels of trust in physicians' opinion also played a major role for some participants and were largely present in those who had longer term doctor–patient relationships. A few participants who commenced HD in the hospital as an emergency procedure felt they had no control in the decision-making, and only a quarter of our participants felt that they had adequate information prior to commencing HD. However, the majority of the participants had positive or neutral

TABLE 5.  
Positive coping strategies of older ESKD adults on hemodialysis

Themes	Subthemes	Representative Quotes
Reliance on family and friends	Supportive relationships	<i>"I've got my family supporting me. My church is supporting me and it makes a big deal, a big difference."</i>
	Family members and friends take on chores	<i>"Because with no, not having any legs, my stove is kind of high up and [my husband] wouldn't, he's afraid I'd get burnt, so he does the cooking. But he doesn't, I help him do everything else."</i>
	Moved near to or in same household as family members	<i>"[My brother] said, 'I'll come and get you and, um, you live down here with us.' And I said, 'Okay.'"</i>
Reliance on spirituality	Maintain important relationships	<i>"My oldest granddaughter, she's a captain in the Army, only been there three years. I am, every time she can come, I call her when I go home today. I hadn't called her yesterday. I got one grandson that calls me every day, never fails."</i>
	Faith in God	<i>"There's a lot of people that are, have diabetes that are in here and they've lost legs, arms... you know... If it comes to that, I've got to have faith because it would help me and protect me. I don't know what people do without it to tell you the honest truth."</i>
Self-care	Religious community	<i>"I like to go to church and do church things. Do church functions. I'm very active in the church."</i>
	Diet	<i>"I think I myself, I read it somewhere, your diet is one of the best things you can do. It's your diet. Keep up with your diet, try to do things the right way, like they tell you, you'll feel better."</i>
	Exercise	<i>"I can get up and walk. Shoot, I get up and walk all the time. The doctor told me it was the best thing I could do. Get out and walk."</i>
Engaging in activities that foster well being	Monitoring fluid intake	<i>"Well if they tried to take five off, then I started getting cramps. And now I am learning, after five or six years, don't drink so much and you won't have that problem!"</i>
	Nature/outdoors	<i>"And then, when it's pretty (son's name) takes me out to the front... and I sit there. The other day it was, it was yesterday, and it was just so great. It was cold in the morning, but I sat out there for almost two and a half hours. And there's um, they've got, um real pretty flowers and different things you can...and there's birds everywhere and I like doing that."</i>
	Music	<i>"I play guitar for the church and I got back to that, so I'm playing that now. Singing some."</i>
Maintain normal routine	Travel	<i>"Yeah, I wore out. But I still travel and do what I want to do though."</i>
	"Cheats"	<i>"Well, I have my treats, 'cause I've got my candy. And, um, sometimes I cheat and get a bag of, um, oh what are they called? Goldfish. I love those silly things. I can't eat a lot of them, 'cause, but yeah I cheat on that."</i>

preconceptions of HD which were largely influenced by the experience of family members or friends on hemodialysis, patient education programs or through discussions with their physicians. The negative preconceptions of a few participants were based on information from different media sources, health-care providers or, more often, the negative experiences of others on HD. Also, very few participants had unrealistic expectations that HD would cure their kidney disease.

The positive coping strategies utilized by these participants were very revealing and likely explain their ability to overcome some of the physical and psychosocial difficulties related to HD. Their reliance on faith or religion, family and friends were particularly notable, but not surprising, as previous studies have found that many patients with chronic or serious diseases depend on their religious faith or spirituality as a way to cope with their medical conditions.<sup>(12)</sup>

Understanding patient perceptions and factors that may affect these perceptions is of utmost importance as they can affect patients' adaptability to their illness and well-being.<sup>(13)</sup> In addition, this knowledge helps to better inform clinicians on how best to meet the needs of this vulnerable subset of the population.

While we recognize that several limitations of our qualitative pilot study including small participant sample size, lack of geographic representation make it difficult to draw generalizable conclusions in this patient population. In addition, our data were based on retrospective recollection of older adults already on hemodialysis and who may have very different perceptions from those with pre-dialysis ESKD. This underscores the need for further studies to examine these factors in a more representative robust patient sample.

Furthermore, patients' perceptions of various therapeutic modalities of RRT are of crucial importance in patient-centered clinical care of this subset of the population. Our study also underscores the importance of appropriate patient education prior to HD to better align patients' perceptions and expectations with reality, as well as identifying individualized patient coping strategies with the ultimate aim of better personalized care.

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## CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

## APPENDICES

### Appendix A: Interview Guide

Thank you for agreeing to participate in this interview about your experience with kidney disease and treatment. I am especially interested in the story of your kidney disease and how the dialysis (RRT, "this treatment") experience has been for you. If you're ready, let's get started.

1. Please tell me about your overall health.
  - a. What major diagnoses have you had?
  - b. How do you feel overall?
  - c. Would you say that you are satisfied with your current health?
    - i. Could you feel better, do you think?
    - ii. If yes, what do you think would help you feel better?
2. Next, I would like for you to tell me the "story" of your kidney disease.
  - a. When and how were you diagnosed?
  - b. How did you know that you were sick with kidney disease?

- c. Once your doctor told you that you had kidney disease, what happened next?
  - i. How did you react? Emotions. Reaction of family and friends.
  - ii. What treatment did you receive? Did you receive it right away?
  - iii. How has that treatment changed over time?
  - iv. How long have you been on dialysis?
3. Now I'd like to learn more about your decision to go on dialysis (renal replacement therapy).
  - a. How did you decide that this was the right therapy for you?
    - i. Doctor's influence
    - ii. Family member's influence
    - iii. Friends' influence and knowing others who are on RRT
    - iv. Other reasons
  - b. Did you feel that you had enough help and information to make the right decision for you?
  - c. What did you hope would be the result of dialysis?
    - i. Feel better
    - ii. Save my life
    - iii. Cure me (?)
4. Now let's talk about the treatment (dialysis, RRT, "this treatment) itself and how it's affecting you.
  - a. Do you think this treatment is working? Why or why not?
  - b. How does this treatment make you feel?
    - i. Prior to coming for treatment
    - ii. During treatment
    - iii. After treatment
  - c. Do you ever have any side effects?
    - i. If yes, what are they?
      1. Fatigue
      2. Nausea/vomiting
      3. Depressed mood
      4. Other
    - v. How often do you get these side effects?
    - vi. How severe are they?
    - vii. Do you think these side effects are normal? To be expected?
  - d. Is there anything about the treatment that has surprised you?
  - e. Has the treatment improved your functional status? Are you able to do more things or fewer things now than you were before the treatment? Or is it about the same? Please tell me more about that.
  - f. Has the treatment had a positive or negative impact on your quality of life?
    - i. Function
    - ii. Relationships
    - iii. Finances
    - iv. Independence

- g. If you could do it all over again, would you make the same decision to receive this treatment?
- 5. Could you describe to me what your dialysis days are like? Start when you get up in the morning and walk me through your day.
  - a. If there were something (anything!) we could change about your dialysis experience, what would that be?
- 6. How would you describe your relationship with your kidney doctors and nurses?
  - a. Are there things that you would like them to continue to do?
  - b. Are there things that you wish they would do differently?
- 7. Do you have access to all the services that you need?
  - a. If yes, what services are you using?
  - b. If not, what services would be helpful to you?
- 8. And finally, if you had a friend or relative, or even a total stranger, who had the same diagnosis as yours, what would you tell them about the decision to have dialysis treatment?

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