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## “I try not to even think about my health going bad”: A qualitative study of chronic kidney disease knowledge and coping among a group of urban African American patients with CKD

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### Abstract

**Context:** African Americans with chronic kidney disease (CKD) are more likely to progress to end-stage renal disease (ESRD). However, African Americans are less likely to receive care to delay progression of their CKD and to prepare for ESRD treatment.

**Objective:** The objectives of the study are to understand knowledge among urban, African-American patients diagnosed with CKD and to discover ways they managed their illness and prepared for kidney disease progression.

**Design:** A qualitative study was conducted using structured interviews. Thematic analysis was used for data interpretation. All 23 participants identified as African American and had CKD but had not yet reached ESRD requiring renal replacement therapy (RRT). Over half of the participants were women (57%), and the mean age was 53 years old.

**Results:** Three themes emerged from the data. African Americans often did not know the severity of their CKD. They struggled to complete all of the diet, exercise and medication tasks recommended to manage their health conditions, including CKD. Finally, participants, even those with Stage 5 CKD, viewed progression to RRT in the next 12 months as unlikely.

**Conclusion:** African Americans face many barriers to CKD self-care and preparation for ESRD. Improving outcomes requires clinicians to help patients understand the severity of their CKD, to make informed choices about their care, all the while motivating patients to take actions to prevent CKD progression.

### Keywords

chronic kidney disease; qualitative research; African American

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Conflicts of Interest

Authors (Lissanu, Lopez, King, Robinson, Almazen, Metoyer, Quinn, Peek, Saunders) declare that they have no conflicts of interest.

## INTRODUCTION

Chronic kidney disease (CKD) affects 14.8% of the U.S. adult population, accounts for \$64 billion dollars in Medicare spending, and is associated with high rates of disability, morbidity, and mortality [1]. Despite the burden CKD places on patients and the US health care system, less than 10% of patients who have laboratory indicators of CKD are aware of their diagnosis. Even fewer have the knowledge and skills they need to manage CKD and its associated co-morbidities like diabetes and hypertension [1]. Furthermore, one third of patients with CKD have not met with a nephrologist or developed a treatment plan prior to developing end-stage renal disease (ESRD) [1]. Patient understanding of their CKD diagnosis may improve self-care practices (i.e., diet, exercise, and medication management and compliance) to delay the progression of kidney disease and allow those patients who do progress to ESRD to choose a treatment consistent with their preferences.

The prevalence of advanced CKD in African American patients is significantly higher than the general population [2]. Compared to non-Hispanic Whites, African Americans have equivalent incidence of CKD at earlier stages; however, they have increased prevalence of CKD at more advanced stages [3]. African Americans are also less likely to be aware of their CKD and experience a more rapid decline in kidney function compared to Whites [4] [5]. The reasons for these disparities are not fully known, but are likely multi-factorial including genetic, lifestyle and social factors [5]. For example, African Americans have a higher prevalence of diabetes and hypertension, which puts them at higher risk of developing progressive kidney failure. African-American patients still have less access to healthcare needed for the early detection of CKD. [1, 5–7] Within the health care system, African Americans may not be informed of their elevated risk or screened for proteinuria [6]. African Americans are also less likely to receive guideline recommended CKD care to manage co-morbidities and delay progression [1]. Moreover, African Americans may have barriers to implementing the self-care practices needed to manage diabetes, hypertension and/or CKD due to low health literacy, poor communication with physicians and other psychosocial and health system barriers [8] [9]. These barriers may adversely affect their self-care practices as well as their preparation for the progression to ESRD.

Patient education might help African-American patients with CKD make more informed decisions about their ESRD treatment, improve self-care, and, ultimately, delay progression to ESRD. Among urban African-American patients, we sought to better understand patients' knowledge about their CKD and to discover the ways they managed their illness and prepared for kidney disease progression. We identified gaps in participants' knowledge of their CKD trajectory and examined current self-care practices in an effort to identify how we can best improve health outcomes. We plan to use the gathered information to develop more effective education materials and programs for African-American patients living with CKD.

## METHODS

### Participant Recruitment

We recruited participants from an urban, Midwest academic medical center who met study criteria: self-identified African American patients with CKD, between the ages of 18-75

years, English speaking, and without significant cognitive impairment. We screened individuals for possible kidney disease if they had at least one laboratory estimated glomerular filtration rate (eGFR) value less than 60 mL/min/1.73 m<sup>2</sup>, and confirmed their CKD diagnosis if they had decreased eGFR (<60 mL/min/1.73 m<sup>2</sup>) on two occasions at least 3 months apart [10]. Patients were recruited either from the medical center's nephrology clinic or during inpatient visits. Patients recruited as inpatients were screened through medical records. Nephrology clinic patients, obtained through a convenience sample, were approached directly for the study. Patients who met these criteria were approached in person by a research interviewer who described the study and verbally consented patients for participation. After participant consent, eligibility was confirmed through medical record review. Recruitment took place between June and October 2016. This project was approved by the Institutional Review Board.

### Study Design and Data Collection.

**Participant Interviews**—The research interviewers conducted semi-structured, individual, in-person interviews with participants using an interview guide. Both research interviewers (LL and EA) were minorities with prior training and experience conducting health related interviews. The interview guide was informed by existing literature and was designed to assess CKD knowledge, characterize barriers and facilitators to renal replacement therapy (RRT) education, and to help inform the development of an inpatient educational intervention [11–17]. Building on the Health Belief Model, the guiding questions and potential probes focused on patient experiences, beliefs, knowledge, and preferences [18]. The interview guide included open-ended questions to assess patient knowledge and beliefs about CKD, ESRD and various methods of RRT including in-center hemodialysis, peritoneal dialysis, home hemodialysis and transplant (See Supplemental Materials). The guide included questions about whether patients had ever been told they had CKD, if they knew their level of kidney function (CKD stage, creatinine or eGFR), and if they knew the cause of their CKD. The guide also asked respondents to describe their experiences and preferences in regards to their treatment plan and care team. Although the interviews started with core questions and prompts, the open-ended nature of the questions allowed interviews to flow differently based on individual participant's CKD stage, knowledge, and concerns related to renal replacement therapy (RRT). The interview guide was field tested and revised to improve understandability and flow.

Inpatient interviews took place in the participants' private room; outpatient interviews took place in a semi-private room. All interviews were audio-recorded. Sessions took between approximately 30 to 45 minutes to complete. Patients received a \$25 gift card for study participation upon interview completion.

**Chart Review**—Participants' electronic medical records were reviewed by project staff to obtain additional medical and demographic information. We reviewed patients' medical records to abstract data on estimated glomerular filtration rate (eGFR), urine albumin, serum electrolytes (potassium and phosphorus) and renal replacement modality. Using eGFR from their medical records, we calculated CKD Stage according to the Kidney Disease: Improving Global Outcomes (KDIGO) 2012 guidelines [10]. In addition, co-morbidities

were captured from the participant problem list at the time of interview that includes patients' prior ICD-9 coded diagnoses as well as new issues captured during that clinical encounter. In order to compare participant predicted outcomes to actual outcome, participant charts were re-visited in 2018 to determine which participants had progressed to ESRD requiring renal replacement therapy.

## Analysis

Interviews were audio-recorded by project staff and professionally transcribed by an independent transcription service. The transcripts were then reviewed for completeness before being entered into NVivo8 software (QSR International, [www.qsrinternational.com](http://www.qsrinternational.com)) for storing, coding, and searching qualitative data. We used a modified template approach to analyze these interviews; five trained group members (MS, FL, AK, LL, GM) created an initial code book, initially organized by the interview guides and then iteratively amended through further data review [19]. These reviewers independently reviewed the transcripts. To ensure internal consistency among reviewers, 15% of all transcripts were reviewed in data meetings which lasted until group members reached consensus on any changes to be made to the codebook. Through this iterative process of analysis and comparison, a final codebook data agreement was reached between reviewers, which allowed for a final, in-depth analysis of all of the transcripts [20].

## RESULTS

### Respondent Demographics

Consistent with the focus on the study, all participants were African American. We interviewed 35 participants. We excluded 5 transcripts due to non-completed interviews. Of the 30 completed, eligible interviews, we present the results from the 23 (77%) participants with CKD who did not yet require renal replacement therapy. All 23 participants were patients with CKD, between the ages of 18-75 years, English speaking, and without significant cognitive impairment. Most were recruited from the outpatient nephrology clinic (n=21, 92% outpatient). Approximately half of the respondents were women (n=13, 57% female), and the mean age for respondents was 53 years. Most patients received Medicare (n=9, 39%) or Medicaid insurance, alone or with dual-eligibility, (n=16, 70%). In addition, most of the respondents had Stage 3 CKD or greater (n=23, 95%).

### Interview Themes

During our interviews exploring knowledge among urban, African-American patients of their CKD diagnosis, and ways they managed their illness and prepared for kidney disease progression, we found three major themes. First, we found that participants had gaps in their knowledge about the specifics of their CKD diagnosis. Second, participants struggled to complete all of the self-care tasks recommended to maintain their kidney health like diet, exercise and medication adherence. Finally, we found that participants, even with advanced CKD, viewed progression to ESRD as unlikely.

### Lack of Patient Knowledge of Kidney Disease

We found that almost 70% (n=16) of our study participants either did not know their CKD stage or lacked detailed knowledge about other disease markers (GFR or creatinine levels). Only a minority of patients (n=8) reported they were able to make the lifestyle changes recommend to manage their health. Knowledge of CKD and ability to make lifestyle changes seemed to be related. For example, only two of the 16 patients who were not knowledgeable about their kidney disease severity reported also being able to make necessary lifestyle changes, compared to almost all of those (6/7) who were knowledgeable. Some patients reported being willing to try to change habits but shared having barriers preventing the change.

### Challenges to Lifestyle Changes and Self-Care

**Diet**—Most patients reported making some overall lifestyle changes while also noting that there were certain foods and beverages that were too difficult to give up. When asked whether they had made any dietary changes, most respondents reported minimal changes that demonstrated some knowledge of CKD dietary recommendations. Most patients reported a slight change in diet or did not respond fully to the question.

Patients responded with varying levels of specificity when it came to their knowledge of a CKD diet. Most people knew to reduce sugar and sodium in their diet as well as to increase their water intake (n=17), but only a minority of patients mentioned they knew to monitor their protein, potassium, and/or phosphate intake. There was no pattern based on CKD severity or electrolyte abnormalities. For example, two patients, both with Stage 3 CKD, mentioned cutting down on high phosphate foods like “pop and chocolate milk.” Only one patient, a 43 year old male with Stage 5 CKD, explicitly mentioned reducing phosphate:

To keep healthy, I’m... “watching my diet, low sodium, low phosphate, low potassium. I’m staying away from foods like that.”

Another example came from a 73 year old female with Stage 3 CKD who discussed the importance of eating healthy overall and restricting protein:

“There’s so many things out here now that you don’t have to eat all the fast foods and a lot of different things. Although there are times that I do eat it. But I think being a vegetarian and all that kind of stuff, it helps a lot because therefore I’m not putting too much protein back into my diet. I have to have a certain amount in there, but it’s not like me eating meat, you know what I’m saying? So I think the vegetarian diet will help a lot with that.”

However, this patient was in the minority. Lack of knowledge about how to implement certain dietary changes may be in part responsible for the high number of respondents who only partially changed their diet.

The small proportion of respondents who completely overhauled their diet emphasized how changing their diet required not only learning more about a CKD diet, but also constant vigilance about monitoring their food and water intake. As one 55 year old female outpatient with Stage 3 CKD noted:

“I’m extremely focused on my diet. I don’t eat out much anymore unless it’s a salad or living foods. And I know more now about nutrition than I ever have known in my life.”

Patients who did not modify their diet named lack of knowledge, money, and flavor as obstacles to making any dietary change. Some patients connected their inability to manage their kidney health to their experiences with poverty and racism. One respondent, a 61 year old female with Stage 3 CKD discussed her inability to afford healthy foods as a barrier:

“Not eating and drinking the right stuff. I know that much. And it’s hard to do when you’re black and you’re poor...And, you know, they know that when we black and we poor, we got to go with what the flow, go with, okay, whatever’s on sale.”

Another patient, a 45 year old female with stage 4 CKD, described the balancing act of eating right:

“If I can find something that’s interesting for me to eat, filling-wise and price-wise...it sounds like something I can do.”

**Exercise**—About one-third of patients (n=7) reported that they routinely exercised and cited walking as their preferred type of exercise. Half of the patients who did not exercise (n=11) said chronic pain prevented them from exercising. For example, as one respondent, a 73 year old female with Stage 3 CKD in the outpatient clinic, stated chronic pain from a stroke prevented her from exercising, but she knew that exercise was important in managing their CKD and recovering from the stroke:

“The only thing is...for the pain, the stiffness, [residuals] from the stroke, I added a chiropractor. So, I think that’s what I wanted to say, exercise and all that different stuff like that. I do not basically exercise. And that’s why my walking and stuff like that, now that I want to get back into, you know, that helps a lot with illness and stuff.”

In short, complications from CKD and other illnesses cause physical limitations which make exercise difficult for many patients. In addition to physical barriers to exercise, patients also mentioned social barriers. One respondent, a 59 year old female with Stage 5 CKD stated that she could not exercise because she lived in a dangerous neighborhood:

“I don’t get out, actually, [especially] in my neighborhood. It’s kinda dangerous...I do it like in the house. I walk around the house a lot.”

**Medication**—A little more than half of the patients reported adherence to their medication regimen, while only one patient reported being non-adherent. The remaining 39% of patients did not directly mention whether they took their medications as prescribed. When asked about knowledge of their medications, the results were mixed: 1/3 of patients had detailed knowledge (n=7), 1/3 of patients had intermediate knowledge (n=8), and 1/3 of patients had no knowledge about what medications they took or what the medications did (n=8). We defined knowledge as the names, indications and dosing schedule for patients’ medications.



Intermediate medication knowledge was knowledge about 1-2 of those domains. One example of intermediate knowledge was indicated by a 65 year old male, Stage 3 CKD:

“Yeah, I take medication. I take...you’ve got me thinking now. Metoprolol, I take... Lisinopril. That helps with the blood pressure. They got me on three or four medicines. I can’t think of it right now.”

One patient, a 60 year old male with Stage 3 CKD had no knowledge of his medications, but stated his wife manages his medication regimen:

“I take about at least ten a day. You know, ten in the morning and two in the evening. [Interviewer: Is it hard to keep straight what you’re taking?] Yeah. I have, you know, my wife makes it up. You know, I have the pill box.”

A lack of knowledge about their medications did not necessarily translate into non-adherence. In fact, despite lacking detailed knowledge of their medications, over half of patients (n=13) reported they were adherent to their medication regimen. Patients also mentioned they took too many medications, frequently changed their medications, or had adverse side effects to certain medications, which often led to confusion about their treatment plan. As a 45 year old female respondent with Stage 4 CKD stated:

“[The medicine I take]...is another form of Warfarin. I mean, it’s a lot of different medications. There’s a lot of different medications. They was dealing with my insides. And now my stomach is swollen and stuff, and it’s basically because of the medications I’ve been taking.”

Many patients with CKD have a high number of co-morbid conditions including diabetes, hypertension, and cardiovascular disease which complicates their kidney health. Each of these conditions already requires that patients manage multiple medications, doctors’ visits, and lifestyle changes. An illustrative quote from a 61 year old female with Stage 3 CKD:

“Well, it’s a bunch of them. I got high blood pressure, I got kidney stones, I got the other kind of bone and one—gall bladder. They want to take one gall bladder... I’m on medicine for that. I take a lot of medicine, a lot of medicine. And now they’re talking about they want to give me another medicine, but they got to find the medicine that won’t mess with the other medicines.”

### No Expectation of Kidney Failure in the Future

Despite the majority of subjects (83%) having CKD Stage 3 or above, only one participant believed that kidney failure, defined as requiring RRT, was likely to happen in the near future. The remaining participants reported that their kidneys would not fail over the next 12 months (n=16), that they did not know whether or not their kidneys would fail, or they refrained from answering the question entirely. After further review of patient records, 5 patients (22%) progressed to ESRD requiring RRT over 24 months.

**Denial**—One 69 year old female, inpatient, with Stage 5 CKD did not view kidney failure as imminent, despite having had a fistula inserted during her hospital stay to prepare her for dialysis that week:

“Well, they [nephrologist] told me last year I had to have this fistula put in. So they didn’t know how long it was gonna be before I had, you know, dialysis. But so far everything worked out pretty good. So far. So I’m just saying I guess 50-50 chance.”

Denial, by avoiding thinking about their kidney disease or the possibility of kidney failure, was also a common theme. When asked directly about possibility of denial most people did not directly answer the question. However, three participants explicitly stated that they were in denial, and 4 participants stated that they were not in denial. Even patients who did not report denial still did not necessarily have realistic expectations about likelihood of maintaining their kidney health. For many patients with CKD, not thinking about their CKD prognosis was an important coping strategy, even though patients acknowledged denial could be harmful. For example, while one outpatient respondent, a 68-year-old male with Stage 3 CKD mentioned how harmful denial could be, he still refused to think about the deterioration of his health:

“No. I try not to even think about it, you know, because it’s...Try not to think about my health going bad. [Interviewer: So do you think that’s a form of denial?] No, not to me. Not to me. Because when you deny things, that’s when things happen to you. You know, if you don’t think about it, when it come, it just come.”

Other patients, like this 61 year old female with Stage 3 CKD, simply refused to address the possibility of future kidney failure:

“Oh, I don’t believe that...Uh-uh. No. Hm-mmm. Jesus take it away. Hm-mmm. I won’t entertain that at all.....”

When asked explicitly about denial, she reported insight into her denial:

“I’m in denial now. It’s going again, listening to that man talking about, well, you know you’re a inch from being on the kidney dialysis machine. I don’t want to do that....”

**Competing Health Risks**—Many participants had a high burden of co-morbidities. Some, like a 68-year-old male respondent with Stage 3 CKD, viewed their kidney disease as less severe than the many other comorbid chronic conditions and acute health crises they had experienced, such as asthma and a pneumonia-induced coma:

“I don’t even consider it. I don’t consider it...Yeah. I don’t consider it. ‘Cause like I said, since I’ve been...I’ve been through a lot of illnesses, different illnesses, and for some reason, you know, for some reason my body always seems to fight back.”

**Motivation to Make Lifestyle Changes**—While some patients used their knowledge of their CKD to make some positive lifestyle changes for their kidney health, others continued to struggle with habits that would worsen their kidney health. One outpatient respondent, a 69-year-old female with Stage 3 CKD, stated:

“No. I’m not in denial about it, you know. I know that after...many years out I used to drink pop and stuff. I love pop, to be honest with you. I loved it. And I love sweets, you know. But now I know it affect my kidneys and so I’ve cut—I don’t



drink the pop, like they told me to. I drink Gatorade maybe twice in a month, you know.”

Patients like this 62 year old male with Stage 3 CKD attribute low likelihood of kidney failure to the positive lifestyle changes they have already made.

“Well, no, but I’ve lost weight. I’m sticking to the diet that the kidney doctor got me on. I’m drinking plenty of fluid. I’m not going to the bathroom as much as I was a month or two months ago, so that’s what gives me the thought that it’s going to get better. Because I’m gonna follow my [nephrologist’s] advice and better taken care of. I hope not. I hope they don’t [fail]...”

## DISCUSSION

In a sample of urban, African American patients with CKD, the majority were not aware of their CKD stage. This lack of knowledge was surprising given that over 90% of patients were recruited from nephrology clinic and over 95% had CKD Stage 3 or above. Potential explanations for this lack of patient knowledge include poor patient understanding, poor physician communication, physicians not initiating explicit discussion because they do not want to worry patients, and patient denial. In our qualitative work, we were only able to probe what patients actually knew about their CKD, not what they had been told previously. Lack of knowledge about CKD severity may adversely affect a patient’s ability and motivation to engage in self-care practices to prevent the progression of their CKD.

In addition, we found that despite the high proportion of patients with advanced CKD, only one patient reported a belief that her kidneys would fail in the near future. For some patients, particularly those with CKD Stage 3 or 4, their prediction may be accurate and their kidneys may not fail within the next year [21]. However, we also found that even patients with Stage 5 CKD did not report a high likelihood of kidney failure requiring renal replacement therapy over the next 12 months. In our sample, we found one-third of the patients with Stage 4 CKD progressed to ESRD. Almost all of the patients with Stage 5 CKD who were not initially requiring renal replacement therapy were on renal replacement therapy by the end of the follow-up period. Patient denial, specifically an unwillingness to plan for kidney failure, must then serve some function for CKD patients. Denial may serve as a coping mechanism to allow patients hope or to delay grief associated with anticipated loss of health or function. In some patients, particularly those with early stage CKD, it may allow them to make positive lifestyle changes to further reduce their risk of disease progression. In other patients, particularly those with more advanced CKD, denial prevents them from preparing for kidney failure, emotionally or practically. Similar to our observations of patient denial, prior work has described that patients who coped by blunting, defined as the avoidance of threat-relevant information, had shorter times to dialysis therapy [22]. While denial helps some in the short-term to cope with the stress associated with CKD diagnosis and prognosis, lack of acceptance of the possibility of future kidney failure limits patients’ ability to create a plan in case their kidney health continues to deteriorate, and may even hasten the progression to kidney failure.

Patients also reported that the challenges of their other health conditions prevented them from making all of the lifestyle changes needed for effective CKD self-care. Many patients have co-morbidities, such as obesity, arthritis or decreased vision, which limit their ability to exercise. Most patients with advanced CKD also have diabetes, hypertension and cardiovascular disease which require multiple medications and physician visits. Patients may feel burdened by the all of the tasks required to manage their multiple conditions, or they may prioritize other conditions that cause greater symptoms or are more severe.

In addition to medical challenges, our respondents also report that everyday stressors created by poverty and structural racism create barriers to effective self-care [23]. African-American patients are significantly more likely than their White counterparts to live in poor communities, regardless of their own income [24]. These communities often lack health-promoting resources like grocery stores, recreational facilities and pharmacies [25]. These neighborhoods also often have more health reducing characteristics such as crime and disorder, fast-food restaurants or peer norms that support obesity or tobacco use [26].

Our study had limitations which should be considered. First, we interviewed a relatively small number of African Americans from a limited geographic area, one medical center on the South Side of Chicago. Although we had theme saturation among our participants, additional concepts or themes might be generated by interviewing participants in different cities or in different geographic areas e.g. rural or suburban settings. Second, we used a convenience sample of respondents, and their responses may not be representative of all African American patients with CKD. Third, we had a high proportion of non-response for particular questions like perceived likelihood of kidney failure and patient beliefs in their avoidance or denial. Despite developing and refining our data collection instrument with CKD patients and providers, non-response may have indicated that the questions were poorly understood. However, we asked open-ended questions and probed patient responses; therefore we believe patient non-response stemmed from a lack of desire to respond rather than lack of understanding.

The information we gathered from our interviews will inform key components of our pilot intervention for hospitalized African American patients with advanced CKD. First, patient knowledge of CKD stage and severity is an important barrier. The patient educator will explicitly mention patients' "advanced CKD" and explain CKD-related medical terms in plain language. Second, we want to allow patients to have hope that their kidneys will not fail, while addressing their denial about the severity of their CKD. Prior work suggests a pre-dialysis psychosocial intervention both increases patient knowledge and time to dialysis initiation [22]. We seek to not only increase patient knowledge about renal replacement therapy (RRT) options, but also to improve patient understanding and ability to prevent disease progression. To that end, we will also provide written materials which will be reviewed with the patient educator, but then given to the patient as a reference. Finally, we were reminded of the barriers that patients must navigate in managing their health. Our intervention patient educator is a racially-concordant social worker who can provide education, support, and motivation. Strategies used in the intervention will be motivational interviewing and psychoeducational techniques to increase patient understanding of their illness, and to improve patient decision-making and coping skills [27].

## Conclusion

In our study, we found that the majority of African-American CKD patients did not understand the severity of their CKD and also significantly underestimated the likelihood of kidney failure in the near future. Knowledge of these barriers will inform our intervention to identify, educate and motivate patients to increase CKD self-care and to improve communication and shared decision making between African-American CKD patients, their families and their providers about different RRT treatment options.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**

## Participant Demographics

		<b>N=23</b>	<b>Percent (%)</b>
<b>Gender</b>	Females	13	56.5
<b>Interview Location</b>	Inpatient	2	8.7
	Outpatient	21	91.3
<b>Age</b>	Age: 18-30	3	13.0
	Age: 31-45	5	21.7
	Age: 46-55	2	8.7
	Age: 56-65	8	34.8
	Age: 66-75	5	21.7
<b>Insurance</b>	Medicare	9	39.1
	Medicaid	16	69.6
	Private Insurance	2	8.7
<b>CKD Stage</b>	CKD Stage 1	0	0
	CKD Stage 2	1	4.3
	CKD Stage 3	12	52.2
	CKD Stage 4	6	26.0
	CKD Stage 5	4	17.4
<b>eGFR (Median, IQR)</b>	34 (17.5, 49)	--	--
<b>Albuminuria</b>	Macroalbuminuria	13	56.5
	Microalbuminuria	3	13.0
	No Albuminuria	7	30.4
<b>Hyperkalemia</b>	Current or Receiving Treatment	6	26.1%
<b>Hyperphosphatemia</b>	Current or Receiving Treatment	2	8.7%
<b>Co-Morbidities</b>	Hypertension	21	91.3
	Diabetes	10	43.5
	Coronary Artery Disease	3	13.0
	Congestive Heart Failure	6	26.1
	Obesity	11	47.8
	Tobacco Abuse	2	8.7
	Substance or Alcohol Abuse	2	8.7
	Depression/Anxiety	4	17.4
	Obstructive Sleep Apnea	5	21.7
	History of Heart or Lung Transplant	4	17.4
	Liver Disease	4	17.4
	Lupus	1	4.3
	Arthritis	10	43.5
	HIV	2	8.7

		<b>N=23</b>	<b>Percent (%)</b>
	Elevated Cholesterol	10	43.5

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**Table 2.**

Patient Perception of CKD Stage and Kidney Failure Risk

		<b>N=23</b>	<b>Percent (%)</b>
<b>Perceived Stage</b>	Unknown	16	69.6
	= Actual Stage	5	21.7
	> Actual Stage	1	4.4
	< Actual Stage	0	0
	Outside Range	1	4.4
<b>Reported Likelihood of Kidney Failure in Next 12 months</b>	Likely	1	4.4
	Unlikely	16	69.6
	Don't Know/Doesn't Want to Respond	3	13.0
	Unanswered	3	13.0
<b>Documented Kidney Failure within 24 months</b>	Yes	6	26.1



Table 3

Theme	Illustrative Quote
<b>Struggle to Complete Self-care Tasks</b>	
<b>People are willing and try to change their habits; sometimes they don't always have the means to do so</b>	"If I can find something that's interesting for me to eat, filling-wise and price-wise,...it sounds like something I can do." 45 year old female with stage 4 CKD
	"If I can find something that's interesting for me to eat, filling-wise and price-wise,...it sounds like something I can do." 45 year old female with stage 4 CKD
	"Yeah, quit smoking. Well, you know what else? I have a callous or something on the bottom of my foot that prevents me from doing my exercise, walking, running, what have you, so if I was to get that taken care of I would do much better." 62 year old male with stage 3 CKD
	"I know that I'm sickly... Sometime I go to church so sick that I can't hardly stand up. But you know what? By the end of the service, I can walk up out that door feeling good. You know? So sometime we have to push ourselves into doing things that we don't want to do." 61 year old female with stage 3 CKD
<b>Understanding healthy eating and drinking are major factors in patients successfully managing their kidney issues</b>	"If I had known how to eat I think I would have been all right." 46 male with Stage 3 CKD
	Well, I should say that, you know, I haven't...I don't eat sweets as much as I used to. I cut back on that, too." 69 year old female with stage 3 CKD
	"I'm extremely focused on my diet. I don't eat out much anymore unless it's a salad or living foods. And I know more now about nutrition than I ever have known in my life." 55 year old female with stage 3 CKD
<b>Patients' mobility is hindered by a chronic illness/condition</b>	"The only thing is I go to...for the pain, the stiffness, [residuals] from the stroke, I added a chiropractor. So I think that's what I wanted to say, exercise and all that different stuff like that. I do not basically exercise. And that's why my walking and stuff like that, now that I want to get back into, you know, that helps a lot with illness and stuff." 73 year old female with stage 2 CKD
<b>Patient perceptions of neighborhood safety affect their ability to exercise</b>	"Sure, I exercise. I don't get out, actually, [especially] in my neighborhood. It's kinda dangerous...I do it like in the house. I walk around the house a lot." 59 year old female with stage 5 CKD
<b>Adverse reaction/Side effects to Medication</b>	"In general, I was having this problem of finding the right medication for my blood pressure. Each time they put me on something, it may last a year or maybe six months or so. And they kept saying your kidneys are failing. And the last one they put me on was Lisinopril, which is not good if you've got bad kidneys. I'm not saying the medication did it, but it was going to go anyway, and that's not the medicine for a weak kidney. 46 year old male with stage 3 CKD
<b>Patient struggles to remember when to take meds and the correct dosage to take</b>	"Well, it's a bunch of them. I got high blood pressure, I got kidney stones, I got the other kind of bone and one—gall bladder. They want to take one gall bladder. I'm on medicine for that. I take a lot of medicine, a lot of medicine. And now they're talking about they want to give me another medicine, but they got to find the medicine that won't mess with the other medicines." 61 year old female with stage 3 CKD
	I take about at least ten a day. You know, ten in the morning and two in the evening. [Interviewer: Is it hard to keep straight what you're taking?] Yeah. I have, you know, my wife makes it up. You know, I have the pill box. 60 year old male with stage 3 CKD
<b>View Progression to ESRD as Unlikely</b>	
<b>Unlikely to Fail due to positive health changes</b>	"Well, no, but I've lost weight. I'm sticking to the diet that the kidney doctor got me on. I'm drinking plenty of fluid. I'm not going to the bathroom as much as I was a month or two months ago, so that's what gives me the thought that it's going to get better. Because I'm gonna follow my [nephrologist's] advice and better taken care of. I hope not. I hope they don't [fail]... 'Cause when I see the doctor, he always tell me that you know, your kidneys, I got a certain percentage that's all right and, you know, I take the medicine that he prescribes...Well, I remember they said it's good. You know, it's not...he don't tell me oh no, your kidneys are really bad, you know. Like he tells me, you know. He hasn't told me that yet. I hope, you know, hope he don't." 62 year old male with stage 3 CKD
	"If I don't keep myself up and on a proper diet, it's not gonna fail. I just have to keep a watch on it." 59 year old female with stage 5 CKD
	"I'm taking a series of steps to prevent that, so I'm in prevention now." 39 year old male with stage 5 CKD

Theme	Illustrative Quote
Unlikely to fail due to lack of symptoms	"I think I'm managing it well, and from day to day I feel exactly the same." 44 year old male with stage 5 CKD
Likely to fail due to increased symptoms	"Because I'm in more pain than I was before when they first diagnosed it." 66 year old female with stage 5 CKD
Uncertainty about Kidney Failure	"Well, they told me last year I had to have this fistula put in. So they didn't know how long it was gonna be before I had, you know, dialysis. But so far everything worked out pretty good. So far. So I'm just saying I guess 50-50 chance." 69 year old female with stage 5 CKD
Denial/Refusal to think about Kidney Failure	"Oh, I don't believe that... Uh-uh. No. Hm-mmm. Jesus take it away. Hm-mmm. I won't entertain that at all." 61 year old female with stage 3 CKD
	"I don't even consider it. I don't consider it... Yeah. I don't consider it. 'Cause like I said, since I've been... I've been through a lot of illnesses, different illnesses, and for some reason, you know, for some reason my body always seems to fight back." 68 year old male with stage 3 CKD
	"I'm in denial now. It's going again, listening to that man talking about, well, you know you're a inch from being on the kidney dialysis machine. I don't want to do that...." 61 year old African American female with stage 3 CKD