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Chronic Kidney Disease (CKD) Treatment Burden Among Low-Income Primary Care Patients

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Abstract

Objective—This study explored the self-management strategies and treatment burden experienced by low income US primary care patients with chronic kidney disease.

Methods—Semi-structured interviews were conducted with 34 patients from two primary care practices on Buffalo's East Side, a low-income community. Qualitative analysis was undertaken using an inductive thematic content analysis approach. We applied Normalization Process Theory (NPT) to the concept of treatment burden to interpret and categorize our findings.

Results—The sample was predominantly African-American (79%) and female (59%). Most patients (79%) had a diagnosis of Stage 3 CKD. Four major themes were identified corresponding to NPT and treatment burden: (1) Coherence – making sense of CKD; (2) Cognitive participation – enlisting support and organizing personal resources; (3) Collective action – self-management work; and (4) Reflexive monitoring – further refining chronic illness self-care in the context of CKD. For each component we identified barriers hindering patients' ability to accomplish the necessary tasks.

Conclusions—Our findings highlight the substantial treatment burden faced by inner-city primary care patients self-managing CKD in combination with other chronic illnesses. Health care providers' awareness of treatment burden can inform the development of person-centered care plans that can help patients to better manage their chronic illnesses.

Introduction

The prevalence of chronic kidney disease (CKD) continues to increase in response to the rise in hypertension, diabetes, obesity, and the overall aging of the US population.¹ The estimated lifetime risk of developing moderate CKD (Stages 3, 4) is 59% – considerably higher than the 33–39% lifetime risk of diabetes.² Among low income and minority groups,

especially African Americans, the prevalence of CKD is higher with a faster progression to end-stage renal disease (ESRD).³⁻⁷

Patients with CKD often have several comorbid chronic conditions or multimorbidities, especially diabetes, hypertension, and dyslipidemia.⁸ Indeed, CKD often occurs as a result of these common chronic conditions. The term “cardiovascular multimorbidity” has been used to describe the clustering of cardiovascular disease, diabetes, and CKD based on shared pathophysiology, common interventions, and frequent clinical presentation.⁹

CKD is a complex chronic illness necessitating varying levels of patient self-management as well as treatment recommendations tailored to patients’ individual circumstances including medical comorbidities.¹⁰ Patient self-management of CKD and its comorbidities may demand significant time and effort on the part of the patient, posing a formidable treatment burden.¹¹⁻¹³

The concept of treatment burden has been used to describe the self-care practices and work carried out by patients as a result of engaging in treatment for one or more chronic illnesses.^{11,13} Treatment burden is distinct from illness burden which refers to the physical and emotional symptoms and impact of one or more illnesses or conditions on an individual, the family, and health care system.^{11,12} Treatment burden entails the patient’s engagement with providers, the health care system, their family or social support network, and personal self-care regimens.^{11,12}

The treatment burden of CKD may be particularly difficult to manage for low income populations that also have a higher risk of developing CKD and its complications.^{14,15} Compared to the general population, these groups are more likely to live in disadvantaged neighborhoods and experience limited access to health care resources, low educational opportunities, and chronic unemployment.¹⁶ These social determinants of health have a deleterious impact on an individual’s ability to manage a chronic illness that requires consistent self-monitoring, adherence to regular medical care, and dietary and lifestyle changes.¹⁷⁻²¹

Normalization process theory (NPT) has been used to explain how work processes become ingrained into everyday practice, and has been applied to the concept of patient treatment burden.^{13,22-24} Although NPT has often been used to understand complex clinical interventions or business practices, it has also been used to conceptualize the tasks or “work” carried out by patients to manage chronic illnesses and the processes through which these practices become incorporated into everyday routines.^{23,24}

Normalization process theory encompasses four distinct components which have been used to elucidate the “work” or treatment burden experienced by patients managing a chronic illness.²³ These components include: (1) Coherence or “sense making work:” learning about the diagnosis, treatments, and their consequences; (2) Cognitive Participation or “relationship work:” Engaging with others; mobilizing resources to arrange support or help, transportation, prescriptions and other essential services; (3) Collective Action or “enacting work:” Implementing the self-management tasks and adapting daily activities to accommodate the illness; (4) Reflexive monitoring or “appraisal work:” Refining and

adjusting the treatment regimen as necessary and assessing whether to continue or change the current management plans.²³

The aim of this study was to explore the self-management strategies of low income primary care patients with Stage 3 and 4 CKD in the United States. We applied Normalization Process Theory to the concept of treatment burden to interpret and categorize our findings.

Methods

Setting and participants

We recruited patients from two primary care practices on Buffalo, New York's East Side: a predominantly low-income African-American community that constitutes a Health Professional Shortage Area (HPSA).²⁵ The two practices are located within 5 miles of each other, situated in similar neighborhoods, and are considered "safety net" practices. The Institute of Medicine defined safety net practices as those in which providers "organize and deliver a significant level of health care and health related services to uninsured, Medicaid, and other vulnerable patients."^{26,27} Both practices are residency teaching sites.

Recruitment

The practices used Allscripts Enterprise, the electronic health record (EHR), to generate lists of patients meeting the inclusion criteria: 18 years or older with a diagnosis of Stage 3 or 4 CKD (ICD-9 code 585.3 or 585.4) as confirmed by two consecutive eGFR values <60 mL/min per 1.73 m² at least 90 days apart.²⁸ Patients were excluded if they had dementia, as documented in the EHR, or were unable to provide consent at the time of recruitment. Eligible patients received a letter introducing the study, and were recruited in person at the practice at the time of their scheduled appointment. Interviews were scheduled for a later date at the patient's home, a public place (e.g. coffee shop) or the practice, depending on patient preference.

Data collection

The semi-structured interview protocol focused on six broad research questions: (1) How did patients learn they had CKD? (2) What do they understand about the disease? (3) Where do they go for information about CKD? (4) What types of social support, if any, do they have and use in CKD self-management? (5) What types of health care resources do they utilize to manage their CKD? (6) Which are the most common challenges or barriers to CKD self-management they encounter? The interviews were digitally recorded, with the permission of the participant, and transcribed into MS Word. All data was de-identified. Patients were assigned a unique identification code for data analysis and a pseudonym for reporting purposes. The master file linking patients to their identifier was separated from the data and maintained in a password-protected file on a secure university server. Recordings of the interviews did not contain patients' names or any identifying information.

Manual chart reviews extracted clinical data pertinent to CKD (eGFR, BP, HbA1c, BMI etc.) and co-occurring conditions. De-identified chart data was maintained in a password-protected Microsoft Access file on the secure university server. Human subjects approval for

the study was granted by The University at Buffalo Health Sciences Institutional Review Board and the Erie County Medical Center Institutional Review Board.

Data analysis

The research team used an inductive thematic content analysis approach to analyze the transcripts and identify themes.²⁹ Team members (LK, BV, TY, NM, and CC) independently reviewed the transcripts and identified themes. They conferred together multiple times regarding patterns and themes until no new themes were identified and saturation was reached.³⁰ They also looked for negative cases that challenged or contradicted the identified themes, suggesting alternative relationships.³¹ Once consensus was reached, the team developed a coding system to create an index of supporting quotations for each theme. The qualitative data was then reanalyzed and themes were reorganized in light of their direct applications to Normalization Practice Theory and treatment burden.³²

Descriptive statistical analysis of demographic and medical record variables was undertaken using IBM SPSS Statistics (Armonk, NY).

Results

A total of 53 patients were approached at the two practices and 34 (64%) agreed to be interviewed. Among the 19 patients who declined, the most common reasons were: denial that they had kidney disease, lack of interest in participating or not feeling well that day. One individual agreed to be interviewed but did not want their chart reviewed. Demographic and clinical characteristics of study participants are presented in Tables 1–3. The sample was predominantly African-American (79%) and female (59%), reflecting the populations served by the two practices. Of the 33 patients who agreed to a chart review, 26 were diagnosed with Stage 3 CKD (ICD-9: 583.3) and 7 with Stage 4 CKD (ICD-9: 585.4). Hypertension and diabetes were the most prevalent comorbid conditions.

Four broad, overarching themes were identified that corresponded to the four components of normalization process theory as applied to the concept of treatment burden:²³ (1) Coherence – making sense of CKD; (2) Cognitive participation – enlisting support and organizing personal resources; (3) Collective action – self-management work; (4) Reflexive monitoring – further refining and tailoring chronic illness self-care in the context of CKD. For each component we identified themes pertaining to barriers that hindered patients' ability to accomplish the necessary tasks or milestones (Table 4).

1. Coherence: Making sense of CKD

Coherence entails taking steps to learn about the diagnosis of chronic kidney disease and assimilating its implications.^{22–24} Roughly half of patients in the study learned of their diagnosis from their primary care physician in the context of a regular appointment or upon receipt of lab test results. However, for several patients the diagnosis came as a surprise. Four patients admitted that they didn't know they had CKD until they received a letter inviting them to participate in our study. Another eight patients learned of their condition during a hospitalization or health emergency:

Well about five years ago, I went to the hospital because I wasn't feeling good and they took my blood pressure and it was 200 over something....Then while they were trying to get my blood pressure down, they said something about my kidneys. And I didn't know the connection between high blood pressure and kidneys. (Evan, African American male, 50)

Overall, patients in our study admitted that they had limited knowledge about chronic kidney disease and expressed the desire to learn more about managing CKD. When we asked patients where they went for information they commonly reported that they preferred to consult their physician when they had questions about their health. Some patients, however, remarked that if they had an immediate question and could not reach the doctor by phone, they would consult family or friends in the healthcare field:

I would ask my wife, like because she worked in the medical field, you know, a long time, I ask her things, but that's about it. (William, African-American male, 66)

Other patients conferred with their broader social network, including friends and coworkers, for health advice. James (African-American male, 58) attended a YMCA community center where "there are older people with the same condition and I might ask them, one of them." Patients acknowledged, however, that knowledge gained from these sources was not always accurate. Claire, for example, emphasized that she trusted her doctors more than her friends:

I go to my doctors. I don't listen to them [her friends]. Are you kidding? "Oh take some ginger ale and mix it with some gin and let it soak for 14 hours." So no we don't listen to her. Everybody got a home remedy. "Go outside; get some grass, a little soap." No, no I listen to my doctor... I don't listen to folklore. (Claire, African-American female, 74)

A few patients in our study routinely used the Internet to look up health information, but still emphasized the importance of conferring with their physician: "Before I took any action based on an Internet search I would talk with my physician." (Christina, white female, 70) However, the majority of patients did not consult the Internet. In this low-income community, patients often admitted that they either did not have a computer or did not know how to use one.

Barriers to achieving coherence—Patients' limited general knowledge of the kidney's role in the human body hindered their ability to understand the progressive nature of the disease and the purpose of treatment in slowing its advance towards end-stage renal disease. Patients commonly reported that they did not know which tests were used to diagnose or monitor CKD and most admitted that they had never heard about estimated glomerular filtration rate (eGFR).

When asked to explain what was occurring with her kidneys, Nettie (African-American female, 61) said, "I guess they got shot... I don't know." Some patients associated the kidneys with urination or hyper-urination and diuretics:

I don't know too much about it [CKD], you know.... They gave us some things to read and I read some of them, but I didn't read all of them.... Only thing I do, I have

to go to the bathroom very often with the kidney pills or water pills, whatever the heck he givin' me." (April, African-American female, 64)

Patients also frequently admitted not knowing the names of their medicines or why they were prescribed:

I can't even pronounce it, so I know I don't know it. And uh, they gave me this prescription [holds out another bottle], I think this is for diabetes, would be cholesterol? Crestol? (Thomas, 69, African-American male)

Poor communication with physicians contributed to patients' confusion about the CKD diagnosis and treatment. When we asked patients to recall what their doctor told them at the time of diagnosis, many reported never having heard their doctor use the term chronic kidney disease. Patients recollect being told that their kidneys were weak, damaged or "going bad." Peter remarked, "...they said I had, you know, a kidney problem. They never said a disease." (White male, 57)

2. Cognitive participation: relationship work

Cognitive participation entails engaging with others for help and support as well as arranging medical care.²²⁻²⁴ Patients elicited the support of family, friends, and their church community to help them cope with CKD and related health issues. When we asked patients, "What helps you manage your CKD and other chronic health conditions?" most patients responded that their family played a key role. Family members provided emotional support, encouragement with dietary and other lifestyle issues, and assistance with instrumental tasks such as transportation or shopping. Many patients described family members' encouraging each other to lose weight or make healthy dietary changes. For example, in Thomas's family, everyone is encouraged to lose weight and the "biggest loser" receives a \$25 gift certificate.

In addition to encouraging healthy changes, family members provided support when patients were in the hospital and routinely checked on them at home:

... they keep watch on me. If they see anything that don't look right, they call their mother or they call the hospital, the doctor, and off I go. (William, 66, African-American male)

Other patients reported that they drew support from family members who worked as nurses or other health professionals.

The role of the church community and faith in God were frequently mentioned when we asked patients about chronic illness self-management and social support. Patients emphasized the importance of going to church and turning to their pastor for hope and support. Some patients attributed faith in God with being able to cope with their chronic illnesses as well as survive health emergencies. Latitia, a 44-year-old African-American woman, reflected: "I pray a lot, and I believe that I can get through this, you know. And I, it's, I have a condition, so, and I trust in the Lord that I'm going to get through this..."

Barriers to cognitive participation—In addition to the work involved in eliciting the support of family and friends, cognitive participation also entails arranging and obtaining appointments, prescriptions, and care from health professionals. Time and transportation barriers represented systemic obstacles to patients' ability to arrange and adhere to medical appointments and fill prescriptions.

Taking time off from work to seek medical care represented lost income to patients who were working. Patients complained that using public transportation to get to a doctor's office required significant amounts of time. They described planning half a day for a medical appointment, after calculating the time required to wait for and transfer buses – in addition to waiting in the medical office.

Matilda, a 41 -year-old African-American woman, explained that getting to a having enough money to pay for her prescriptions was difficult. She lamented, "... it's kinda hard to buy the prescriptions at times when you lose work, time from work because of your illness" She also described her fear of going to the physician knowing that her blood pressure and diabetes were uncontrolled because she could not afford a hospitalization which would result in more time off from work.

3. Collective Action: enacting management strategies

Collective action entails making lifestyle changes and following medical advice and treatment.^{22–24} When asked specifically about CKD self-management patients spoke in general about adopting healthier eating habits, incorporating exercise regimens and managing polypharmacy.

Diet and exercise: Patients spoke at length about healthy lifestyle changes they were trying to implement. When asked to describe the changes they initiated since their CKD diagnosis, patients reported reducing their salt intake and making healthier food choices. They spoke about portion control, and preparing foods by broiling or baking, avoiding fried foods, decreasing their meat intake, and eating more fruits and vegetables:

I changed my food. I changed the eating habits.... I eat not a lot of fried foods.
Bake it, we eat baked foods and broil now. And I try to stay away from the grease.
(Lisa, 66, African-American female)]

Patients commonly reported increasing their water consumption and trying to avoid sweetened beverages and juices. They also discussed reducing alcohol intake and cigarettes as part of lifestyle changes. Jerome (51, African-American male) candidly admitted that eliminating alcohol and cigarettes remained a challenge: "But if it's either that or go on dialysis, I'm throwing that out the window.... I'm going to do it, because I want to live."

Walking represented the most frequently reported form of physical activity or exercise. A few patients described using a gym or exercise equipment that they had purchased. Other patients shared their intention to begin a formal exercise program, and acknowledged that this needed to be part of their self-management routine, though they had not yet been able to incorporate it on a regular basis.

Medication Management: Patients in our study were taking a variety of medications to manage multiple chronic conditions. Given the complex medication regimens patients described, we asked whether they developed specific routines or systems. For some patients, scheduling the various medications posed a challenge:

Oh, it's just the medications that I have to take. And it's just keeping up with it. You know, I was slipping when I first. I didn't really understand the seriousness of it all. But now it's just being on time. I try to take it at the same time every day. And it's just a pain when you're used to just going about your business. (Lucy, 60, African-American female)

Some patients talked about their schedules in terms of numbers of pills, while others utilized medication containers.

Barriers to collective action

Difficulty making lifestyle changes: For some patients, changing their eating habits and increasing physical activity remained daunting challenges. These patients shared their difficulties implementing lifestyle changes. Peter (57, White male) spoke at length about wanting to maintain a healthy diet, especially while on an insulin pump. However, he confessed, "I try to eat salads and stuff, but again, I'm not going to." Nettie (61, African-American female) admitted that she drinks "a little too much juice and pop" and tries to follow her physician's advice: "Like she told me no pop, if you're going to drink something, drink diet. But diet nasty [laughing]..."

Patients also spoke about difficulties incorporating exercise or increasing their physical activity. Some patients reported that they suffered from fatigue which lowered their motivation to exercise. Lucy (60, African-American female) observed that the kidney disease makes her feel tired: "I'm not as active as I was because this kidney disease makes you feel tired all the time." Patients noted that other chronic conditions, such as low back pain, limited their ability to exercise.

Financial barriers: Even with the best intentions to alter long-standing dietary habits, not having a stable income can hinder the adoption of healthy habits. When we interviewed Evan, he was temporarily living with a family member and lamented not being able to grocery shop and prepare healthy meals:

Right now, the only problem is when I was working, when I had a better income, I was able to grocery shop myself and pick up my own foods.... But when you're... in their house ...you have to try to maneuver around what their meals are. (Evan, 50, African-American male)

Insufficient health insurance represented another formidable barrier to chronic illness self-management, limiting patients' ability to adhere to prescribed medications. Patients explained that when they were unemployed and on Medicaid (US government sponsored health coverage for individuals below a specified income level) they had few problems filling their prescriptions. However, if they began a job with limited insurance and were no longer eligible for Medicaid, they encountered difficulties purchasing their prescribed

medications. Laticia, a 44-year-old African-American woman, told us that she had a history of uncontrolled hypertension. She had recently begun a job with limited health insurance coverage, and described how she “stretched” her blood pressure medication:

Sometime I go a month without taking it. And then I just crash and have, get dizzy, lightheaded, start getting sick, real bad headaches, and stuff like that.... (Laticia, 44, African-American female)

Older patients complained about the high cost of medication co-pays under Medicare, (the US government sponsored health insurance program for the aged) that had been previously covered when they were younger and had been enrolled in other plans.

4. Reflexive monitoring: appraisal and modifying work

Reflexive monitoring entails reviewing and appraising self-care practices, including beliefs and behaviors that help to sustain one or more chronic illness self-management practices.^{22–24}

Making Linkages: Some patients made connections across comorbidities, especially hypertension or diabetes, to integrate CKD care with the other conditions. These patients told us that they viewed CKD in the context of other chronic illnesses and understood that specific self-management practices could address multiple conditions. Luke, a 45-year-old African-American man who was diagnosed with CKD during a hospitalization for a diabetic foot ulcer, emphasized, “It’s all about my diabetes.” He explained that adhering to the “diabetes diet” will also help his kidneys. Matilda commented that controlling her blood pressure also benefited her kidney condition:

One takes care of the other... I have to manage the high blood pressure in order to manage my kidneys and I have to manage the diabetes in order to manage my kidneys, so it’s all in line with each other. (Matilda, 41, African-American female)

Other patients noted that they were determined to apply the same strategies and perseverant attitude that they used to manage other chronic illnesses, such as diabetes, to managing their CKD. This was especially evident among patients who believed they had succeeded in managing their other chronic illnesses. James, a 58-year-old African-American, described himself as “a fighter,” and expressed determination to deal with his new diagnosis of CKD the same way he has managed diabetes: “Diabetes is trying to kill me every day, so I know I have to fight back every day so that’s why I exercise and try to eat properly...”

Noticing improvements resulting from perseverance with diet and exercise motivated patients to continue modifying lifelong habits to improve their health and manage their chronic conditions. Elizabeth worked hard to implement and sustain healthy changes in her lifestyle and noticed improvements: “That’s what makes it good to change...to see a difference.” (Elizabeth, 63, African-American female)

Barriers to reflexive monitoring—The “silent,” insidious nature of early CKD made monitoring difficult for some patients. The lack of symptoms specific to CKD may have contributed to a sense of complacency among some patients in our study. Several patients

stated that they were not too concerned about kidney disease because they did not feel any symptoms:

It's much easier to be concerned of something you feel. You feel pain or headache or whatever, but I don't feel anything. (Ivan, white male, 72)

Other patients remarked that as long as they did not have to go on dialysis they were not too worried or concerned about being diagnosed with CKD.

Discussion

Our study brings to light the substantial burden faced by inner-city primary care patients self-managing CKD and related comorbidities, notably diabetes and hypertension. What is striking is that patients' descriptions of CKD self-management rarely focused specifically on kidney health (e.g., eliminating ibuprofen). Instead, patients described how they monitored their diabetes and/or hypertension – in addition to general comments on improving diet and exercise. Some patients were able to make linkages between CKD and these other conditions and integrate their self-management activities. These patients understood, for example, that by controlling their blood pressure or monitoring their blood sugar they were also improving their kidney health.

We identified major themes corresponding to the four normalization process theory (NPT) components as they relate to treatment burden. These overarching themes entailed patients' coming to terms with the diagnosis of CKD and learning its implications; eliciting the support of family and their social networks; making necessary alterations to diet, lifestyle and medication adherence; and assessing how to monitor CKD and other chronic conditions.

In our study, for each NPT component corresponding to treatment burden, we also identified barriers limiting patients' ability to carry out the tasks required for chronic illness self-management. Several of these barriers were socioeconomic, including public transportation and health insurance.

Other studies of treatment burden have identified patient-level barriers similar to those we found, such as limited knowledge and poor communication with providers. In their qualitative studies on treatment burden among heart failure and stroke patients, Gallacher and colleagues' reported on the work undertaken by patients to obtain information about their medical conditions, tests, and results.^{23,24} The authors noted that poor provision of information from health professionals may impede patients' ability to plan and organize their care.²⁴

Eton and colleagues conducted semi-structured interviews among patients enrolled in medication therapy management services at the Mayo Clinic.¹³ Several factors that the researchers found to exacerbate treatment burden were also observed in our study: challenges with taking medication, financial challenges, confusion about medical information, and systemic obstacles to health care delivery.¹³ The majority of patients in Eton's study were white, had completed postsecondary education, and only a minority (13%) were on disability or leave from work -- suggesting that some of the barriers we identified may apply regardless of patient socioeconomic status.¹³

Sav and colleagues undertook a qualitative study of treatment burden in Australia that included significant representation of people from culturally and linguistically diverse backgrounds and indigenous populations.¹¹ These authors chose to investigate treatment burden among a diverse sample of patients, noting that the majority of treatment burden studies focus on older, Caucasian adults.¹¹ Sav and team identified 4 themes pertaining to treatment burden: financial burden, time and travel burden, medication burden, and health care access burden. These themes closely align with those from our study of inner-city primary care CKD patients in Buffalo, New York.

Limitations

Our study had several limitations. The small sample size limits generalization. The sample was predominantly African-American and limited to patients served by the two practices in this study on the East Side of Buffalo, New York. This was a convenience sample of patients who volunteered their time and provided self-reports of their experiences with CKD. We interviewed patients at one point in time and were not able to conduct multiple interviews longitudinally. Due to the nature of the study, we also were not able to link patient self-management strategies with clinical outcomes.

Clinical Implications

Health care providers' awareness of treatment burden can inform the development of person-centered care plans that take into account the work carried out by patients to manage their chronic illnesses, including time demands, financial constraints, and required alterations to their activities of daily living.¹² Patient capacity also needs to be considered.³³ Capacity refers to patients' cognitive and physical functioning, socioeconomic resources, family and social network, educational levels and literacy, cultural beliefs, and other factors.³³ Two patients with similar diagnoses may significantly differ in their capacity to manage their respective treatment burdens.³³

As a first step to obtaining information about patient capacity and treatment burden, providers should consider taking a comprehensive social history.³⁴ The social history can yield information about the interplay between the patient's social environment, their capacity to manage their chronic conditions, and their treatment burden³⁴ and inform good decision-making that takes into account the whole patient and their context.¹² Without it we risk a cycle of non-adherence, and avoidable hospitalization, readmission, and continuing waste that is crippling the health care system in the United States— not to mention exacerbating the patient's treatment burden by intensifying therapy when it may not be necessary.³³ Sharing social history information among all members of the patient's care team, including specialists, could facilitate the development of a person-centered care plan, informed by socioeconomic determinants of health and patient capacity, and thereby reduce treatment burden.

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Table 1

Demographic Characteristics (N = 34)

Characteristic	% or Mean (SD)
Gender:	
Female	59
Age (years)	61.7 (11.5)
Race:	
African American	79
White/Caucasian	18
Multiple races	3
Marital Status:	
Single	44
Married	29
Widowed	15
Divorced/Separated	12
Type of Housing:	
Home	62
Apartment	15
Unreported	24
Years in Neighborhood:	
>10 years	44
5 years–9 years	21
2 years–4 years	15
<1 yr	12
Unreported	9
Years of Education:	
8 th grade	6
Some high school	3
Graduated high school	38
Some college or technical school	29
Bachelor's degree	12
Master's degree	12
Employment:	
Retired	44
Disability	24
Full-time	15
Unemployed	18
Insurance Coverage:	
Medicaid	18
Medicare	29

Characteristic	% or Mean (SD)
Private Insurance	29
Multiple insurance coverage	21
Unreported	3

Table 2Prevalence of co-occurring chronic conditions among patients in the sample^{*}

Diagnosis	Stage 3 CKD (n=26)	Stage 4 CKD (n=7)	Total (n=33)
Hypertension	96%	100%	94%
Diabetes	58%	57%	56%
Anemia	23%	57%	29%
CHF	23%	43%	26%
Depression	19%	29%	21%
COPD	12%	43%	18%
Anxiety	8%	0%	6%
Bipolar Disorder	4%	0%	3%
PTSD	4%	0%	3%
Substance Dependence	0%	14%	3%

^{*} One patient did not consent to have clinical chart data reviewed

Table 3

Clinical Characteristics (N = 33*)

Value	Mean (SD)
eGFR (ml/min/1.73m ²)	45.2 (14.8)
Body Mass Index (kg/m ²)	34.6 (9.8)
Systolic Blood Pressure (mm Hg)	138.6 (18.4)
Diastolic Blood Pressure (mmHg)	83.6 (13.4)
Hemoglobin A1C (%)	7.4 (1.4)
HDL (mg/dL)	50.3 (13.1)
LDL (mg/dL)	106.0 (41.0)
Triglycerides (mg/dL)	130.3 (52.5)

* One patient did not consent to have clinical chart data reviewed

Table 4

Normalization Process Theory component and corresponding themes

NPT Component	Patient activities; “work”	Identified Barriers
Coherence (Developing knowledge and understanding)	<ul style="list-style-type: none">• Making sense of CKD• Information seeking	<ul style="list-style-type: none">• Limited knowledge about the kidney• Poor communication with doctors
Cognitive participation (Organizing resources to obtain care and support)	<ul style="list-style-type: none">• Family support• Social network support• Church and belief in God	<ul style="list-style-type: none">• Time off from work• Public transportation
Collective action (Engaging in self-management tasks)	<ul style="list-style-type: none">• Altering diet• Increasing exercise• Managing medications	<ul style="list-style-type: none">• Challenges modifying lifestyle• Economic difficulties
Reflexive monitoring (Reflecting on, refining self-management and therapies)	<ul style="list-style-type: none">• “Linking” comorbidities• Perseverant attitude	<ul style="list-style-type: none">• Lack of symptoms with early CKD