

Treatment Adherence in CKD and Support From Health care Providers: A Qualitative Study



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Rationale & Objective: Adherence to recommended medical treatment is critical in chronic kidney disease (CKD) to prevent complications and progression to kidney failure. Overall adherence to treatment is low in CKD, and as few as 40% of patients with kidney failure receive any documented CKD-related care. The purpose of this study was to explore the experiences of patients with CKD and their adherence to CKD treatment plans, and the role their health care providers played in supporting their adherence.

Study Design: One-on-one interviews were conducted in 2019-2020 using a semi-structured interview guide. Participants described experiences with adherence to treatment plans and what they did when experiencing difficulty.

Setting & Participants: Participants were recruited from the Chronic Renal Insufficiency Cohort (CRIC) study. All CRIC participants were older than 21 years with CKD stages 2-4; this sample consisted of participants from the University of Pennsylvania CRIC site.

Analytical Approach: Interviews were recorded, transcribed, and coded using conventional content analysis. Data were organized into themes using NVivo 12.

Results: The sample (n = 32) had a mean age of 67 years, 53% were women, 59% were non-White, with a mean estimated glomerular filtration rate of 56.6 mL/min/1.73 m². From analysis of factors relevant to treatment planning and adherence, following 4 major themes emerged: patient factors (multiple chronic conditions, motivation, outlook), provider factors (attentiveness, availability/accessibility, communication), treatment planning factors (lack of plan, proactive research, provider-focused treatment goals, and shared decision making), and treatment plan responses (disagreeing with treatment, perceived capability deficit, lack of information, and positive feedback).

Limitations: The sample was drawn from the CRIC study, which may not be representative of the general population with CKD.

Conclusions: These themes align with Behavioral Learning Theory, which includes concepts of internal antecedents (patient factors), external antecedents (provider factors), behavior (treatment planning factors), and consequences (treatment plan responses). In particular, the treatment plan responses point to innovative potential intervention approaches to support treatment adherence in CKD.

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Chronic kidney disease (CKD) is a condition that is characterized by chronic decrease in kidney function and can progress to kidney failure. Kidney failure can be life-limiting and disabling, and the most common treatment modality in the United States (hemodialysis) requires tri-weekly, hours-long sessions which often have a severe impact on quality of life.¹ CKD is growing in prevalence in the United States, with documented differences in rates of progression to kidney failure by race and ethnicity.^{2,3} There are established treatment options to delay CKD progression and associated complications. This includes controlling blood pressure, reducing proteinuria with prescribed medications (eg, angiotensin-converting enzyme inhibitors), participation in physical activity, eating a low sodium diet, and glycemic control among people with diabetes.⁴ These treatment recommendations come together to form a patient's treatment plan, require active patient engagement and adherence (ie, following the treatment plan) to be successful. However, it is estimated that only about 50% of people with chronic conditions, including CKD, adhere to long-term treatment strategies.⁵⁻⁷

According to the World Health Organization, a series of factors, rather than a single factor, impact patients' ability to follow treatment recommendations.⁸ Although many interventions have sought to impact treatment adherence in patients with chronic disease, few have focused on kidney-related conditions. The limited research has focused on patients with kidney failure and those who have received a kidney transplant, with minimal research among those with early to middle-stage CKD.^{7,9-11} A focus on the patient with early- to middle-stage CKD is critical because: (1), there is limited awareness and undertreatment of CKD in these stages,¹²⁻¹⁴ and (2) if we target this population, we have the opportunity to prevent their progression to kidney failure. Quantitative studies have identified potential risk factors for nonadherence in CKD, including age, race, and comorbid conditions, but do not provide understanding from the patient perspective of the factors that influence their adherence.^{7,11} Furthermore, it is not well understood how and to what extent patients seek and use support from health care providers for CKD treatment adherence.^{10,15,16}

PLAIN-LANGUAGE SUMMARY

It is vital for patients with chronic kidney disease (CKD) to adhere to their recommended treatment (eg, medications, diet, exercise). However, this can be quite challenging, and it is not clear if patients with CKD discuss their struggles with adherence with their health care providers. We conducted a qualitative interview study with 32 patients with CKD. As we expected, we found that patient factors (eg, motivation, outlook), provider factors (eg, attentiveness, communication quality), and patient/provider treatment planning factors (eg, proactive research, shared decision making) all played a role in a patient's willingness to communicate with their health care provider. However, treatment plan responses (eg, disagreeing with treatment, positive feedback) point to innovative new targets for future interventions to improve adherence of patients with CKD to treatment.

The purpose of this study was to use qualitative methods to explore the experiences of patients with CKD in adhering to treatment plans and the role their health care providers had in supporting treatment adherence.

METHODS

Participants for this study were drawn from the Chronic Renal Insufficiency Cohort study (CRIC). CRIC is a longitudinal nationwide CKD cohort study; study design and cohort characteristics have been described previously.^{17,18} On inclusion into the CRIC cohort, participants must be above the age of 21 years and have a diagnosis of CKD stages 2-4. Participants for this study were recruited from the University of Pennsylvania CRIC site (institutional review board approval #833179). CRIC participants were given information about this study during their annual CRIC visit. The data collection period ran from September 2019 to September 2020, and some participants had their annual CRIC visit in person whereas others were via telephone because of the COVID-19 pandemic. The only exclusion criteria for this study beyond CRIC criteria was diagnosis of end-stage renal disease and cognitive impairment, as assessed by the Modified Mini-Mental State Examination (score <80).¹⁹ All participants provided written informed consent to be interviewed and recorded. Individual interviews were chosen over focus groups so that participants would feel free to speak about their individual experience without feelings of comparison or judgement with others.

Interviews occurred 1:1 via a single telephone call, 1 week to 2 months after the annual CRIC visit. One study team member (ER) conducted all interviews with the use of a semi-structured interview guide. This interviewer is a cisgender female PhD prepared nurse who, at the time of

the interviews, was a postdoctoral fellow and who received qualitative training through seminars and research institute sessions, overseen by KBH, who has extensive qualitative research expertise. Before the interview, participants had no relationship with the interviewer, had no knowledge of the researcher's personal goals for the study, and were not provided with any interviewer characteristics. Participants were asked a series of questions about (1) their treatment plan related to their CKD, (2) any challenges in adhering to that treatment plan, (3) whether they discussed any difficulty with their health care providers, (4) how their treatment plans were created or modified (e.g., collaboratively, unilaterally), and (5) to what extent their opinions and preferences were incorporated into treatment plan discussions. All study participants were provided with definitions or clarification about terms used and given the opportunity to ask questions. The interview guide was developed by ER and KBH and was updated and modified iteratively based on participant feedback and questions during the interviews.

All interviews were audio recorded and professionally transcribed. Transcripts were supplemented by interviewer field notes. Two study team members (ER and MNC) independently coded each transcript using conventional content analysis methods as their methodologic orientation.²⁰ A preliminary codebook was established by iterative review of the first 5 transcripts. Qualitative data were assessed iteratively during data collection, and the sample size was based on attainment of thematic saturation.²¹ Both team members continued to code independently and met to review coding for consensus after every 5 additional transcripts. The codebook was updated during consensus meetings (ER, MNC), and to strengthen the rigor of the qualitative analyses and decrease bias, all transcripts were recoded with the final codebook. All coding occurred in NVivo 12 (QSR International). Participant characteristics were analyzed using Stata 16 (StataCorp LLC). Neither transcripts nor codes were reviewed by interviewees.

RESULTS

A total of 56 CRIC participants were approached for participation in qualitative interviews, and a total of 32 agreed to participate and completed their interview (rate 32/56, 57%). Participant characteristics are described in [Table 1](#). Fifteen participant interviews occurred in September 2019-February 2020, and 17 interviews occurred May-November 2020. Interview calls were an average of 20 minutes long, ranging from 8-30 minutes. Qualitative analysis revealed 4 major themes related to patient experiences with treatment adherence: patient-level factors (self-described patient characteristics), provider-level factors (patient perceptions of provider characteristics), treatment planning factors (patient experiences involving both patient and provider during the treatment planning process), and treatment plan responses (patient reactions to attempts to adhere to treatment). Definitions of all codes, case counts, and exemplar quotes are detailed in [Table 2](#).

Table 1. Characteristics of Interview Participants (N = 32)

Characteristics	Mean (range) or n (%)
Age, y	67.1 (49-85)
Gender	
Woman	17 (53)
Man	15 (47)
Race	
Black	17 (53)
Hispanic/Latinx	2 (6)
White	13 (41)
Education	
Less than high school	4 (13)
High school degree	3 (9)
Some college	11 (34)
College degree or higher	14 (44)
Employment status	
Employed	9 (28)
Not employed	23 (72)
eGFR, mL/min/1.73 m ²	56.6 (22.1-92.5)
Health literacy	
Marginal	3 (9)
Adequate	29 (91)

Note: Health literacy was measured using the Short Test of Functional Health Literacy in Adults. In that scale, scores of 0-16 are considered inadequate, 17-22 are considered marginal, and 23-36 are considered adequate. Abbreviation: eGFR, estimated glomerular filtration rate.

Patient-level Factors

Patient-level factors included patient characteristics. For “multiple chronic conditions,” participants described how other chronic conditions impeded their ability to adhere to CKD treatment. Sometimes this was because of symptoms or functional impairment caused by other chronic conditions, with fatigue and chronic pain coming up frequently. Conflicting treatment recommendations for multiple chronic conditions were also reported: “I was following a kidney diet. And then with the fatty-liver disease, there’s conflicts between the 2 diets. So, I’m frustrated, and I need somebody to figure it out or give me more guidance (Participant #30).” Participants also described “motivations” of their adherence to health behaviors, which sometimes took the form of health-related goals, whereas others framed their motivation as fear of future health consequences, which often related back to seeing the experiences of friends or family members. Some participants described general feelings of “positivity or optimism,” but often, positivity was brought up in relation to religion or spirituality, trusting in their faith: “It will be okay. God will take care of it. That’s the only way I could look at it (Participant #9).” On the other hand, some participants’ outlook was better described as “fatalistic,” that kidney function decline was inevitable, despite their best efforts at participating in self-management behaviors.

Provider-level Factors

Provider-level factors were the participants’ perceptions of their providers’ attributes. “Good communication” was

often discussed in the context of health education interactions, whereas “bad or absent communication” was often described when participants felt that they and their needs were ignored by their provider. Some providers were characterized as “attentive,” very thorough, and considerate of their health needs. Similarly, participants highlighted the importance of providers being “available and accessible” to them when needed. Although most patient comments were positive about their access to their provider, some described the opposite experience; for example, one participant stated, “I’ve called, and she hasn’t returned any of my calls (Participant #8).”

Treatment Planning Factors

Treatment planning factors included experiences in and around treatment planning conversations that occurred between the patient and provider. Many participants described experiences of “provider-focused treatment goals” with descriptions of treatment plans based on the priorities of their providers. This provider-focused approach made some participants confused or frustrated, however, other participants had no issues with this type of patient/provider dynamic: “They tell me what to do. I’m not the doctors. They are (Participant #29).” Participants also expressed that there was a “lack of plan,” wherein the participant stated that they do not have or are unaware of a treatment plan for their CKD. This was often a statement such as, “I don’t have any treatment for it (Participant #27)” or responding in the negative when asked if providers had ever discussed self-management behaviors like changes to diet or exercise. Participants also described their “proactive planning and research” around CKD treatment. Sometimes this was in response to a perceived lack of information from providers: “This is from self-research that I’ve done about chronic kidney disease... I’ve learned on my own what I should and shouldn’t eat (Participant #7).” Other times, participants took advantage of opportunities that were available to them—“I got the book from [the CRIC study] about kidney disease. I read through that and sometimes a little bit online, reputable sites like Mayo Clinic or the NIH (Participant #4).” Less frequently, participants described experiences of “shared decision making”—collaborative treatment planning which incorporated their own health goals and context.

Treatment Plan Responses

Treatment plan responses were defined as the patients’ experiences with and reactions to their efforts to adhere to treatment. The most frequent treatment plan response was “perceived capability deficit.” When discussing difficulty with adherence to primarily diet and exercise, participants engaged in self-blame and inwardly directed frustration about their lack of behavior maintenance. Some named this explicitly as lack of willpower: “It’s a little frustrating. I don’t have the will power to do it, to change my life (Participant #11).” However, others were obviously angry

Table 2. All Codes With Definitions and Exemplars

Code	Definition	Case Count	Exemplar
Patient factors			
Multiple chronic conditions	The impact of symptom burden, impaired function, or treatment conflicts related to other conditions	20	After open-heart surgery, I can't put too much stress on myself... I had to learn to walk all over again. (Participant #7)
Motivation	Factors that motivate adherence, such as goals for health or fear of future consequences	12	If you don't do it now then you worse later, dialysis or kidney transplant. I know a lot about dialysis from individuals that I know. I don't want that. (Participant #22) I used to have the doctors, they used to say, "Well, you know, it's like this." No. I don't wanna hear, "It's like this"... I want you to tell me what I gotta do to keep myself together and keep myself here. If I gotta stop doing something that I'm doing, so be it. Let's do this. I just wanna get my health back. (Participant #19)
Outlook			
Optimism/positivity	Positive attitude, sometimes due to spiritual faith	8	I do not concentrate on it and every morning get up and say "Oh, I'm stage four," which I am. But I don't. I feel good. (Participant #2)
Fatalism	Kidney decline is inevitable, there's nothing to be done	8	When I have to cross that bridge, whether it's end stage dialysis...I just deal with it. I'm pretty comfortable, I've enjoyed life, and if crap happens, then you deal with it. (Participant #14)
Provider factors			
Communication			
Good	Positive communication interactions or patterns with providers	15	He doesn't talk above you. He breaks it down, asks you how you feel and what do you think, goes over all the blood work. (Participant #24)
Bad/absent	Negative or absent communication with providers	11	This doctor never looked at me at one time. If you ask him what color I am, he couldn't even tell you. He couldn't pick me out of a lineup. (Participant #32)
Attentive	Describes provider as careful, responsive, vigilant	5	He's monitoring my blood pressure, and my cholesterol, and all that stuff. And he's on top of everything. He's a very proactive doctor. (Participant #28)
Available/accessible	The extent to which providers are easy to reach for questions or to schedule visits, accommodating	5	If you got a problem, you can call him at home. You can tell him, 'My glucose went down to 85 and I don't feel well.' He'll tell you exactly how to fix it and he'll be looking for you tomorrow morning at his office." (Participant #12)
Treatment planning factors			
Provider-focused goals	Treatment planning is provider-led, which can be the patient's preference or can also make them frustrated	25	They just told me what to do, and I just do it... I don't have any special ideas or anything. (Participant #31) Any time I mention it to doctor, they don't take it serious... it can get hard for me to get them to accept there is a problem. (Participant #10)
Lack of plan	Believe that they do not have a treatment plan for CKD, or are unsure/unaware	20	There was no real treatment or anything I had to do regarding my kidneys. (Participant #9)

(Continued)

Table 2 (Cont'd). All Codes With Definitions and Exemplars

Code	Definition	Case Count	Exemplar
Proactive patient plan/research	Independent patient research and suggestions for their treatment plan	14	I thought, well, he hasn't checked my lipid panel in a while. So, I had to suggest that to him, check the lipid panel. (Participant #14) I started getting on the internet myself. I started educating myself about this whole thing. (Participant #15)
Shared decision making	Treatment planning involves input from patient and provider, patient feels their input and goals are considered	10	He'll ask me when I'm starting a new drug, whether I'm willing to do it or not. And over the period of our 20 or 30 years together, we've stopped taking a couple that I didn't think were doing as much good as they can and tried other things in their place. (Participant #11) A few years ago I had the kidney biopsy done and they explained to me the reason why. They left it up to me whether I wanted to get it done. (Participant #3)
Treatment plan responses			
Perceived capability deficit	Self-blame, "laziness," expression of inadequacy, reluctance to name the problem, "I know what to do, but..."	15	I know what I have to do. I can counsel you on that. I know because I'm a hypocrite, okay... I could teach a class on what is the right way or what you should do. (Participant #23) Anything I want to do, I usually have enough energy to do it... I guess it's just the spirit hasn't moved me. (Participant #5)
Positive feedback			
Receiving positive feedback	Benefits or changes to their life because of adherence	6	It's easier for me to make healthy choices and stuff now that I've seen the weight come off. It just feels better. (Participant #25) I haven't had any sciatica pain for a while... I feel like this is really the right strategy. (Participant #28)
Lack of positive feedback	Do not see benefits or changes from adherence	9	I'm doing what I think I'm supposed to be doing and it's still getting worse. (Participant #8)
Lacking information	Expressing understanding that there is information that they do not know	14	I see the tests that are done and I understand sort of what they are, but I don't know what the issues are, if it were to get worse, how it really impacts your whole life, function. (Participant #13)
Disagree with treatment	Disagreement with the treatment plan, can lead to nonadherence	5	You know, they can prescribe it but I don't have to do them. I just told them no. You can write it, but I am not going to have it filled. I am not going to take it. (Participant #17)

Abbreviation: CKD, chronic kidney disease.

with themselves, calling themselves “lazy” or “trifling” and refusing to give themselves compassion about how challenging it can be to make a major lifestyle or behavior change. They also frequently referred to their knowledge and understanding of their treatment plans. When one participant was asked whether they would ask their health care providers for support with their adherence, they responded negatively: “I don't think they'd go, 'Oh, woe is me. Get out of here. Find a new doctor.' No, I don't think anybody would do anything like that, but it's just

like they look at you—'Well, you know better (Participant #12).'"

Participants who received “positive feedback” (in the form of benefits or changes to their health) from their engagement in self-management behaviors expressed this as a motivator to continue their adherence. For some this looked like weight loss or maintenance, and others reported feeling mental or physical health benefits associated with their adherence. However, the opposite was also true—those who had a “lack of positive feedback” were

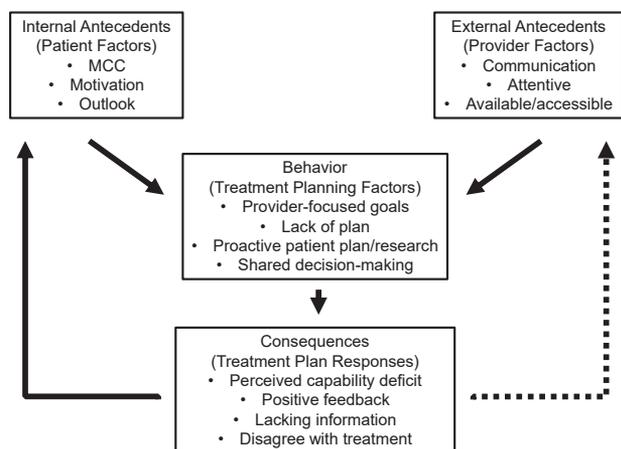


Figure 1. Mapping themes onto Behavioral Learning Theory. The themes identified in this study were mapped onto the 4 constructs of Behavioral Learning Theory—internal antecedents, external antecedents, behavior, and consequences. The solid lines indicate where we believe there are direct effects, and the dashed line indicates what we believe is an indirect effect. This figure was adapted from Figure 1 in Munro et al. 2007.²² MCC, multiple chronic conditions.

disincentivized from future adherence. Some participants expressed this as a general sentiment, whereas others were more specific, such as a participant with osteoarthritis who attempted to adhere to exercise recommendations but experienced pain when doing so: “They say walking helps, but I walk and [my knee] hurts (Participant #21).” Some participants described a “lack of information,” where they were confused or aware of a gap in their knowledge about CKD or their treatment. These participants were often embarrassed by their lack of knowledge. Similarly, participants expressed “disagreement with the treatment plan,” where they often connected their disagreement to intentional nonadherence. This was sometimes because of specific issues, such as medication side effects: “I was told you have to use the furosemide or torsemide, which I say, ‘But this medication makes me feel awful (Participant #10).”

As analysis moved from individual codes into a thematic summary, we identified that the themes aligned well with the concepts of Behavioral Learning Theory. As illustrated in Fig 1, internal antecedents (patient factors) and external antecedents (provider factors) together impact behaviors (treatment planning factors) and therefore consequences (treatment plan responses).²² These consequences then impact the internal and external antecedents.

DISCUSSION

This study increases the understanding of experiences of patients with CKD, their adherence to CKD treatment plans, and the role their health care providers played in supporting their adherence. In our analysis, we identified 4 major themes within which we organized our codes:

patient factors (multiple chronic conditions, motivation, outlook), provider factors (attentiveness, availability/accessibility, communication), treatment planning factors (lack of plan, proactive research, provider-focused treatment goals, and shared decision making), and treatment plan responses (disagreeing with treatment, perceived capability deficit, lack of information, and positive feedback). Some of our codes overlapped with the findings in a recent quantitative meta-analysis of medication adherence in patients with CKD: misconceptions about medications (lack of information), low medication use self-efficacy and polypharmacy (perceived capability deficit), poor attitude toward their treatment (disagreeing with treatment), multimorbidity (multiple chronic conditions), and lack of trust in their health care provider (could apply to several codes we identified).²³ Our findings about the importance of communication are consistent with a qualitative study of communication barriers between patients and providers in a population of US veterans.²⁴ Similarly, our findings are consistent with a qualitative study of self-management in low health literacy patients in the Netherlands, who found themes of CKD elusiveness (lack of plan), suboptimal intake of knowledge (lack of information), not taking a front-seat role (provider-focused treatment plans), and maintaining change (perceived capability deficit).²⁵

Our results highlight the potential points of intervention to support treatment adherence in CKD, both well-trodden paths and new opportunities. Many interventions to date have focused on the “patient factors” identified in this study. For example, interventions that focus on motivation and outlook have been effective at improving nonintentional nonadherence (e.g., forgetting to take medication) but generally have not assessed long-term effects of these interventions.^{26–28} Similarly, interventions that target health care “provider factors” that are resource-conscious include alternative staffing models²⁹ and patient portals (eg, MyChart) for asynchronous communication to increase provider availability and accessibility.^{30,31} On the other hand, interventions that attempt to impact provider communication skills require both provider buy-in and investment in their training.^{32,33} Many existing lines of inquiry target “treatment planning factors,” with interventions to improve patient engagement,³⁴ patient empowerment,³⁵ and shared decision making.^{36,37} These interventions can involve the patient, provider, or both, and attempt to steer the structure and function of the patient/provider clinical interaction into a more promising direction to support patient adherence.

However, interventions that target “treatment plan responses” offer novel opportunities for research and clinical innovation. Patient goals and needs are not static and will change in an iterative manner along the trajectory of behavior initiation to long-term maintenance.^{1,25,38} “Disagree with treatment” and “lacking information” occur early on in this process. The concept of a patient disagreeing with their treatment plan is inconsistent with the ideas behind shared decision making. Treatment plans

that adhere inflexibly to standardized guidelines do not work for every patient, because they do not take into account patient preferences and real-world realities.^{14,39} An example of an approach to remedy this is the Patient Priorities Care model, in which treatment plans are explicitly adapted to patient-driven goals rather than focusing on existing guidelines.^{40,41} Similarly, we believe that patients expressing an awareness of their lack of information highlights an important gap in care delivery. These patients have engaged enough in their own disease process or treatment plan to be conscious of their lack of knowledge and frustrated that that information has not been delivered to them in a way that they can understand. Some clinical spaces have used care coordinators or patient navigators to fill the educational needs gap as a way to try to improve patient outcomes.^{42,43} However, patient navigator programs remain underutilized,⁴⁴ and program evaluations infrequently assess patient experience, clinical outcomes, or costs.⁴⁵

Further along the treatment engagement trajectory, and of notable interest for future intervention, is the “perceived capability deficit.” These patients do not disagree with their treatment plans, do not feel they lack information, and do not express a lack of self-efficacy; however, have encountered difficulty when attempting to implement consistent changes to self-management behaviors in their day to day lives. This difficulty is not surprising—treatment plans for chronic conditions often ask patients to make major lifestyle changes that require creation of long-term complex behavioral change strategies.⁶ However, patients reported being ashamed and made self-blaming statements about their difficulties with treatment adherence, feeling that they failed at a task that should be easy for them to do. This can lead to the patient giving up on attempts at adherence entirely. To the best of our knowledge, the expression of perceived capability deficit is a novel finding in this field of inquiry, with no identified interventions that target this phenomenon in the literature. Future research should investigate to what extent health care providers instill or perpetuate this deficit perspective in their patients and how to make it clear that their health care providers are essential partners to support their efforts at adherence.

“Positive feedback” was the final potential target for intervention. When positive feedback makes the patient feel good (e.g., reduction in symptoms, improvement in function), it can be a powerful motivator. However, for early stages of conditions such as hypertension, diabetes, and CKD, many patients may not experience symptoms to serve as a mechanism for feedback. The rise in popularity of at-home biometric wearable technology is an opportunity for patients with low symptom burden.^{46,47} One participant in this sample highlighted that because of their participation in a clinical study, they had access to a point-of-care creatinine monitor—a dynamic method of assessing their kidney function for the first time ever. Technology (wearables, point-of-care, phone apps,

MyChart graphing functions, etc) can be used to engage patients with the same types of methods that health care providers have been using to assess their disease status. The use of this technology for patient behavior-focused interventions is a relatively new phenomenon, but interventions focused on wearable technology⁴⁸ and smartphone applications⁴⁹ have been conducted, with promising results. We believe that this could be a very effective strategy for patients with CKD.

There are incidental contextual factors that should be noted. Many patients discussed issues around multimorbidity, and some highlighted their frustrating, burdensome treatment plans (e.g., patients given so many diet restrictions for different conditions that they are left with nothing to eat). Future studies should examine these treatment conflicts and identify the extent to which they impact patients’ adherence. Furthermore, although we asked interview questions about “health care providers,” participants overwhelmingly discussed physicians in their responses. In future studies, we will take a more deliberate effort to elicit information about other providers (e.g., nurse practitioners, pharmacists). Additionally, patients alluded to the impact of COVID-19 on adherence and access to care. Patients reported a lack of access to non-pharmacologic treatment options such as hydrotherapy for chronic pain as well as inability to schedule routine bloodwork in a timely manner, which were both pervasive issues in 2020 because of the pandemic. Further, some patients described their frustration with being forced to use telemedicine to access care due to their inexperience with technology, which is consistent with other reports.^{50,51}

This study has several limitations. The sample was drawn from the CRIC study, which may not be representative of the general population with CKD. CKD disease awareness is low in earlier stages of CKD,^{12,13} and given that the CRIC sample includes only people who have actively signed up to be in a CKD study, they necessarily have a higher degree of awareness about the illness. Similarly, as one would expect from individuals who continue to participate in a long-term cohort study, we know that this sample is more adherent to treatment than the general population. Yet, it might be expected that for a non-CRIC sample the challenges raised by this population may be even more prevalent. In addition, the education level of this sample was relatively high, which is also associated with higher adherence. This reduces the generalizability of our findings. Although the conventional content analytic methods allowed for examination of a phenomenon that has not been explored with CKD and allows for themes to emerge from the data (vs predetermined) it is possible that some categories were missed.²⁰ The use of a multidisciplinary research team interpreting the findings presented here reduced the potential for discipline-specific bias. Furthermore, data collection for this study was interrupted for several months by the beginning of the COVID-19 pandemic, and data

collection resumed afterward in that context. Experiences related to COVID-19 assuredly impacted how patients thought about their chronic conditions and treatment.

In conclusion, this study explored experiences of patient with CKD attempting to adhere to treatment plans and their engagement with health care providers in that effort. These data points to key novel opportunities for clinical intervention in the treatment plan response factors.

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