

Emotional Impact of Illness and Care on Patients with Advanced Kidney Disease

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Abstract

Background and objectives The highly specialized and technologically focused approach to care inherent to many health systems can adversely affect patients' emotional experiences of illness, while also obscuring these effects from the clinician's view. We describe what we learned from patients with advanced kidney disease about the emotional impact of illness and care.

Design, setting, participants, & measurements As part of an ongoing study on advance care planning, we conducted semistructured interviews at the VA Puget Sound Healthcare System in Seattle, Washington, with 27 patients with advanced kidney disease between April of 2014 and May of 2016. Of these, ten (37%) were receiving center hemodialysis, five (19%) were receiving peritoneal dialysis, and 12 (44%) had an eGFR \leq 20 ml/min per 1.73 m² and had not started dialysis. Interviews were audiotaped, transcribed, and analyzed inductively using grounded theory methods.

Results We here describe three emergent themes related to patients' emotional experiences of care and illness: (1) emotional impact of interactions with individual providers: when providers seemed to lack insight into the patient's experience of illness and treatment, this could engender a sense of mistrust, abandonment, isolation, and/or alienation; (2) emotional impact of encounters with the health care system: just as they could be affected emotionally by interactions with individual providers, patients could also be affected by how care was organized, which could similarly lead to feelings of mistrust, abandonment, isolation, and/or alienation; and (3) emotional impact of meaning-making: patients struggled to make sense of their illness experience, worked to apportion blame, and were often quick to blame themselves and to assume that their illness could have been prevented.

Conclusions Interactions with individual providers and with the wider health system coupled with patients' own struggles to make meaning of their illness can take a large emotional toll. A deeper appreciation of patients' emotional experiences may offer important opportunities to improve care.

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Introduction

Like other populations with chronic illness, patients with CKD can have a high symptom burden, a high prevalence of other comorbid conditions, and limited life expectancy (1). Several recent studies among members of this population suggest that the concerns of patients can be diametrically opposed to those of their providers, and that patients may experience their illness and care in ways that might be surprising to providers (2–8). These studies illuminate patients' experiences in ways that provide both impetus and direction for efforts to make care for this population more patient-centered.

The need for a more patient-centered approach to care, defined by the Institute of Medicine as "care that is respectful of and responsive to individual patient preferences, needs, and values and (ensures) that patient values guide all clinical decisions," (9) is particularly pressing for those with advanced kidney disease. Available evidence suggests that for many of

these patients major treatment decisions, such as whether and when to initiate dialysis, are often shaped more by provider- and system-level considerations than by the goals and values of individual patients (6,10).

As part of a study on advance care planning in patients with advanced kidney disease, we sought to learn about the illness experiences of members of this population, their interactions with providers and the health system, and their thoughts about advance care planning and end-of-life care. We here describe what we learned about the emotional impact of illness and care in this population.

Materials and Methods

Recruitment

The work described here was conducted as part of a single-center study on advance care planning (11,12). This study enrolled patients receiving care in the

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Nephrology clinic or dialysis unit at the VA Puget Sound Health Care System in Seattle, Washington, who had an eGFR \leq 20 ml/min per 1.73 m² on at least two occasions 3 months apart or were undergoing treatment with maintenance dialysis. Potential participants were selected purposively to ensure representation of patients who were and were not receiving dialysis. Potential participants were mailed a letter inviting them to participate in the study and providing information on how to opt out from further contact. Those who did not opt out from further contact received a follow-up phone call to explain the study and learn whether they might be interested in participating. Those interested in participating were asked to complete a mini-mental status examination and were excluded if they provided an incorrect response to four or more questions (13). Those who were eligible and agreed to participate were asked to provide informed consent. Interviews were conducted in person or by phone, depending on the participant's preference. In-person interviews were conducted in a private conference room in the Nephrology section at the Seattle VA.

Data Collection

Study participants completed a 45–60-minute semistructured, one-on-one interview that included both general questions about their illness experience and encounters with providers and the health system and more specific questions about their experience and perspectives on advance care planning (see Supplemental Appendix). Participants were prompted to provide details and examples to enhance the richness of the data. Interviews were conducted by one coinvestigator (J.S.), a study coordinator who practices part-time as a clinical psychologist and holds a PhD focused on qualitative research. The interviewer had no relationship with study participants before the interview and, at the beginning of each interview, explained to participants that she had no experience caring for patients with kidney disease. All interviews were digitally recorded and transcribed verbatim. The interviewer took field notes and used these to crosscheck with audio recordings and transcripts. Participants were not asked to review interview transcripts.

Qualitative Analysis

Data analyses were based on grounded theory methods (14). To ensure that the analysis was not biased by the researchers' expectations, we began with open coding to capture important themes from the transcripts, using an emergent rather than *a priori* approach. We used Atlas.ti software to organize the coding process (Atlas.ti; Scientific Software Development GmbH, Berlin, Germany). Each transcript was coded by at least two coauthors (J.S., A.M.O., or L.V.M.). One coauthor (J.S.) then reviewed all coded transcripts and refined, condensed, and organized open codes into code families (groupings of codes with related meaning). Emergent codes were added throughout the analysis and "*in vivo*" codes were selected as exemplars (15). Six coauthors (J.S., A.M.O., L.V.M., J.S.T., W.S., and E.K.V.) iteratively reviewed and discussed the codes and code families, returned as needed to the transcripts to ensure that coding remained well grounded in the data, and built consensus by open discussion of differing interpretations of the data, choice of codes, and/or thematic

organization. We continued to conduct interviews and analyze data until reaching saturation, the point at which no new codes were identified. The protocol for the overall study was reviewed and approved by the VA Central Institutional Review Board.

Results

Patients

Between April of 2014 and the end of May of 2016, 56 patients with advanced CKD were mailed an invitation to participate in this study of whom 27 enrolled (48%). The mean age of enrolled patients was 63 \pm 10 years (range 42–81 years); 96% were men; and most self-identified as white (56%), 33% as black, and 11% as other race. At the time of the interview, ten patients (37%) were receiving hemodialysis, five (19%) were receiving peritoneal dialysis, and 12 (44%) had not started dialysis.

Emergent Themes

We here describe three emergent themes related to patients' emotional experiences of care and illness (Table 1): (1) emotional impact of interactions with individual providers: when providers seemed to display insufficient insight into, or concern for, patients' experiences of illness, this could engender a sense of mistrust, abandonment, isolation, and/or alienation; (2) emotional impact of health system encounters: just as they could be affected emotionally by interactions with individual providers, patients could also be affected by how care was organized, which could similarly lead to feelings of mistrust, abandonment, isolation, and/or alienation; and (3) emotional impact of meaning-making: patients struggled to make sense of their illness experience, working to apportion blame, often feeling personally responsible for their course of illness, and relying on counterfactual explanations.

Emotional Effect of Patients' Interactions with Individual Providers. To patients, providers could seem insufficiently concerned about, or even oblivious to, matters of immense importance to them. This disconnect could engender, or contribute to, feelings of alienation, mistrust, abandonment, and/or isolation.

Alienation. One man spoke of his fear of undergoing a kidney biopsy: "That's a big step, to me. A big deal! I have a pinched nerve, right? They want to stick a needle in my back, you know, for that?" From this individual's perspective, his providers were not seeing him as a whole person; they had failed to understand the specifics of his situation and anticipate how preposterous their recommendations might seem to him given his other health issues.

Mistrust. When patients' kidney disease progressed, this could lead them to question the care that they had received earlier on. One man reflected on how little his provider had told him about preventing progression of kidney disease despite the dramatic implications this had for him: "Try to keep my BP down and try and stay away from . . . sodium and salt and sugar. And that's about all he said, really." Another patient spoke of how one doctor had failed to inform him about his worsening kidney function.

Abandonment. Although some patients described positive relationships with providers, comments from other patients conveyed a sense that their providers had little to

Table 1. Emergent themes		
Emergent Themes	Interview Extracts	Description
Emotional impact of patients' interactions with individual providers		
Alienation	When they started talking biopsies I really got kind of shy on that 'cuz I don't like needles. I don't like nobody sticking nothing in me that could paralyze me or something like that, you know what I'm saying? That was a decision that I said, "Well, maybe we ought to just stand by and watch and see what my kidneys do and leave the biopsy alone!" That's a big step, to me. A big deal! I have a pinched nerve, right? They want to stick a needle in my back, you know, for that? But I wouldn't even go for that! . . . No needles! I hate needles! Hate 'em! When they tell me, "Go get a lab done," oh man, that's the worst thing in the world.	Man in his 60s not on dialysis
Mistrust	Well, it's just, you know, try to keep my BP down and try and stay away from . . . sodium and salt and sugar. And that's about all he said, really. I'm really bothered by the private practice doctor who didn't tell me for several months that my function was going down—he knew it, I didn't—because I would immediately have asked, "Why? What could cause that?"	Man in his 70s not on dialysis Man in his 60s on peritoneal dialysis
Abandonment	Another thing that bothers me is that they told me that I couldn't have the "at home" dialysis because they've been chopping me up so much, that they didn't think it was a good thing. He had me take a bunch of these pills and so he said: "You know, we did it for a couple of months. I've done everything I know how to do for you. I can't go any further." Oh, so what does this mean?	Man in his 70s not on dialysis Man in his 50s on peritoneal dialysis
Isolation	I had asked (her nephrologist) if I could talk to somebody that was on peritoneal dialysis. She didn't know if she would be able to hook me up with anyone, because it is a private thing. She didn't know if anybody would be willing to talk to me. But I was at work one day . . . and I was telling one of the girls I worked with about my kidney disease and about having to go on dialysis . . . and she said "Oh, I'm on dialysis!" . . . It was nice to hear from someone who was going through that. Even though I'm still scared, it made me feel better.	Woman in her 50s not on dialysis
Emotional impact of patients' encounters with the health system		
Mistrust	I haven't really got a doctor or a nurse or anybody . . . I have had some past doctors that I don't have anymore . . . that were previous. But right now, I don't have anybody that I really, you know, want to talk over and trust them with my life. I like to have someone who I've been with for a while, right? That knows my case, right? I don't like people to come in from the blue and all of a sudden they start saying, "You need this." No, you don't know me! You haven't been around me and my health!	Man in his 70s not on dialysis Man in his 60s not on dialysis
Abandonment	So, somewhere along the line . . . she (his primary care doctor) retired or quit . . . after that, I was given a nurse practitioner, and then a little later on I was given a different nurse practitioner. I don't know how long I was seeing nurse practitioners, but it was quite a while before they ever reassigned me to another doctor. Somewhere along the line, I mean, it was like years later, like the kidney problem was totally forgotten . . . they were aware of the problem, they knew about it, and they were supposedly monitoring it whenever I had blood tests, or whatever. And somehow, the ball got dropped after (his primary care doctor) retired and I was passed on to nurse practitioners. Well, I had such a hard time with radiology . . . At one time, I had an appointment with them and I went there and they did blood work ahead of time and then they called me and said, "Oh we can't do this because your kidney function is too low." And I said, "Wait a minute, I talked to my doctor about this already. And she told me the risks. And I had decided that what I'm gaining outweighs the risk. And I want to have it done." And they were, like, "Oh, no, we're not going to do it." So, I was so upset I was crying . . . Anyways, eventually it got all sorted out and they did do the CT scan with contrast. They made me sign paperwork saying that if anything happened I wouldn't hold them responsible.	Man in his 70s not on dialysis Woman in her 50s on peritoneal dialysis

Table 1. (Continued)

Emergent Themes	Interview Extracts	Description
	<p>The only real problem I’ve been suffering with is . . . I’ve had some skin conditions . . . I’ve been through Dermatology . . . trying to get it to a point where I can live with my skin condition . . . The only thing that . . . does work well for me is steroids. But the problem is that when I was on steroids for my colitis, my gastro doctor . . . didn’t want to keep me on them for too long . . . and so they finally had determined that I may be a candidate for . . . Remicade infusions and eliminated me off the steroids . . . and it pretty much has been successful . . . but my skin condition came back the minute I went off the steroids. It got to the point where I’m not sleeping, I’m not a happy camper . . . I went back to my gastro doctor . . . and I said, “Can you put me back on steroids?” . . . And of course, he said, “Well, that’s something you’re going to have up take up with your (primary) care provider.” I went to my (primary) care provider and my care provider’s telling me that, “That is a Dermatology problem” and he wouldn’t recommend it . . . So I finally pleaded my case back to (his nephrologist) yesterday and he gave me about ten steroid pills to try and get me through what I’ve been suffering with here the last . . . 6–8 mo . . . with the instructions that if it doesn’t work then I’m supposed to make an appointment with him. Why I don’t know . . . he’s not a dermatologist . . . so I picked up the prednisone and . . . took one yesterday and took one today and my skin is probably 50% better already.</p>	<p>Man in his 70s not on dialysis</p>
Isolation	<p>About 1 yr ago, I had several appointments scheduled on one day and the appointments were to discuss my labs and discuss other elements of how to keep my kidneys healthy. Unfortunately, my appointments were scheduled backward and so I spoke to several people, including a nutritionist, who all knew my kidney function had decreased, but no one had told me. So the whole conversation was confusing. Eventually, I spoke with the doctor, the renalist, and he was the last one I had. He should have been the first appointment that day, but like I said, we had them scheduled backward somehow . . . This was the moment when he was brutally honest with me about my chances with kidney disease and what the outcome could be. Up until that moment I thought there was a chance for me to recover . . . For a very long time, well, immediately after that, I was emotionally distraught for quite some time. I have to believe that those appointments were somehow scheduled backward for a reason . . . I was feeling alone and isolated during this period. When I got this news, because the appointments were backward, it was so jarring that it forced me to re-examine a lot of things . . . One of the other patients in the predialysis education class that was in my same age range and also in my same ethnic group was similarly struggling. So, the fact that we had an opportunity to talk to one another, and both express that this was kind of unnatural that this is happening, gave us an opportunity to provide each other with the support and not feel alone in the process.</p>	<p>Man in his 40s not on dialysis</p>
Alienation	<p>I talk to whoever it is, I forget their names, they have a whole kidney care section . . . these are the people that tell you what to eat and what not to eat and be prepared for this or that. And then they take you up seeing people who are laid up there and, you know, make a spectacle out of them. “Hey, look, you’ll end up this way, you know, eventually.” Makes you feel real yuck.</p>	<p>Man in his 70s not on dialysis</p>
Emotional impact of meaning-making Apportioning blame	<p>Well, I smoked, that might have something to do with it. That’s the only thing I can think of. I never drank a lot, hardly at all, really.</p> <p>It’s been overwhelming and it took me a while, even though I understood it, to accept that it was something genetic from my family . . . and there’s nothing that could change the fact that I was going to eventually develop kidney disease. That has been a struggle, because it has been a long time I couldn’t help thinking that maybe I did this to myself.</p> <p>Well I wouldn’t have had it if I hadn’t had that operation. So, they told me at the time, when they had to operate, before the operation, that my kidneys were good. So it isn’t like I drank a lot, or did a lot of things to kill my kidneys, just came that way.</p>	<p>Man in his 80s not on dialysis</p> <p>Man in his 40s not on dialysis</p> <p>Man in his 80s not on dialysis</p>

Emergent Themes	Interview Extracts	Description
Personal responsibility	I look at it this way. This is what you need to do. This is a result of you not doing what you should have been doing . . . and so you can't hold anyone else accountable for it. It's all on you. You can't go crying about it. You are responsible and, as a result of poor decisions, this is the result . . . for the past 35 some-odd years I've been suffering from type 2 diabetes, which kind of dominated my life and I was told by my doctor at the time that if I lost some weight . . . that the diabetes would go away. Of course, I heard it, I didn't follow the advice . . . as a result, my kidneys started failing, which I was told way before that happened that it was a likelihood of happening . . . I regret that I didn't listen in time to prevent this.	Man in his 60s on hemodialysis
Undoing	Now I kind of saw that things were kind of moving off-track, but I was kind of afraid to bring it up with the doctors. So I think I would be more forceful now about "Hey something's wrong here."	Man in his 50s not on dialysis
	I wish I had known earlier that I had it. Because I was taking medications that were making the condition worse. And I would have stopped my medications, well, maybe not . . . I was taking a lot of naproxen, you know, for pain, because I have fibromyalgia. And that's really bad for the kidneys. And I didn't know that.	Woman in her 50s not on dialysis
	I was in prison . . . and I got locked up in the hole and I don't like water . . . so instead of water, you know, I was taking lithium at the time, right? . . . I used . . . soda to flush my kidneys, right? But I didn't have no soda and I don't like water, drinking as little . . . as possible and it didn't flush my kidneys, so I had an overdose on my lithium . . . and it affected my kidneys.	Man in his 60s not on dialysis

CT, computed tomography.

offer beyond their specialized repertoire of treatments and procedures, which could leave the patient feeling unaccompanied or even abandoned in their illness experience. This limited reach of patient-provider relationships could be laid bare when treatment options were narrowing. One man spoke of the limited dialysis options open to him because of what providers had already done to him: "They told me I couldn't have the "at home" dialysis because they've been chopping me up so much, that they didn't think it was a good thing." Others expressed a sense of having been abandoned at moments of greatest need. For example, one man relayed how his nephrologist told him he had nothing more to offer: "So he said: "You know, we did it for a couple of months. I've done everything I know how to do for you, I can't go any further." Oh, so what does this mean?"

Isolation. Patients also described a sense of isolation in their illness experience that providers could be powerless to address. One woman described how she had expressed a desire to meet other patients but her nephrologist did not feel able to facilitate this due to concerns about privacy. She spoke of how when she learned that one of her coworkers was on dialysis "it was nice to hear from someone who was going through that . . . it made me feel better."

Emotional impact of Patients' Encounters with the Health System. Patients could also be affected emotionally by how care was organized. Similar to interactions with individual providers, encounters with the health system could also engender, or contribute to, feelings of mistrust, abandonment, isolation, and/or alienation among patients. Faced with a fragmented care system, patients struggled to create coherence and did so in ways unlikely to have been intended by the providers caring for them.

Mistrust. When providers moved in and out of patients' care over the course of illness this could engender a sense of mistrust. One patient described how he no longer had a provider he could "trust" and another patient described his mistrust for providers who did not know him.

Abandonment. Fragmentation and discontinuity of care across providers could even be perceived by patients as having contributed to their course of illness. One man described how "the ball got dropped" on his kidney disease after his physician retired and he was cared for by a series of nurse practitioners. When providers failed to work collaboratively with their colleagues, this could cause patients immense distress. One woman described being reduced to tears when she showed up for a scan only to learn that the radiologist had cancelled the procedure due to concern over contrast nephropathy. Apparently, the radiologist was either unaware or did not care that she had already discussed this risk with her nephrologist, and desperately wanted to proceed with the study as part of her evaluation for transplant. One man described the difficulty he faced getting any of the specialists he was seeing to address the severe pruritus that was by far his most troubling concern.

Isolation. Seemingly mundane aspects of how health care was delivered could sometimes take a large emotional toll. One man described a day when the order of his visits with different providers on the same team seemed to him to be "backwards" because it was not until the end of the day, when he sat down with his nephrologist, that he learned that his renal prognosis was much worse than he thought. This experience left the patient feeling "emotionally distraught for quite some time" in part because, at the end of the day, he came to realize that "all (of the providers) knew

my kidney function had decreased, but no one had told me." He went on to explain how he felt "alone and isolated" during this period in his life and mentioned that the opportunity to talk with another patient made him "not feel alone in the process."

Alienation. Even more explicit efforts to deliver multidisciplinary care could be perceived by patients in ways unlikely to have been intended by providers. One patient who had attended the multidisciplinary predialysis education class that is offered to patients approaching dialysis at our center seemed not to distinguish among the roles and expertise of individuals on the care team, referring to them collectively as "the people that tell you what to eat and what not to eat and be prepared for this or that." This patient's reaction to the tour of the dialysis unit (that is typically scheduled at the end of the class) would probably have shocked the organizers: "... and then they take you up seeing people who are laid up there and, you know, make a spectacle out of them."

Emotional impact of Meaning-Making. The question of whether and to what extent they were responsible for the course of their kidney disease (or illness more broadly) was one with which the individuals we interviewed struggled greatly. They reflexively tried to understand who or what might be to blame for their kidney disease, were often quick to blame themselves, and assumed that their kidney disease could have been prevented.

Apportioning Blame. Whether they were personally responsible for their kidney disease could be a matter of considerable moral importance to the patients we spoke with. One man told us how, before he learned that his kidney disease was due to a genetic mutation, he "couldn't help thinking that maybe I did this to myself." Another man explained that his kidney function was normal until he went for a surgery, emphasizing that "It isn't like I drank a lot or did a lot of things to kill my kidneys."

Personal Responsibility. Study participants were often quick to assume that their illness was due to something they had done or not done. Many of the explanations patients gave for their kidney disease implied substantial faith in the power of medical advice and in their own agency if only they had received or followed this advice, underplaying what medical researchers and practitioners know about the complexities and uncertainties of chronic illness. One man expressed "regret" that he "didn't listen in time to prevent this" and said that he saw his kidney disease and other health problems as "a result of you not doing what you should have been doing... you can't hold anyone else accountable for it. It's all on you."

Even patients who understood their kidney disease to be multifactorial seemed to assume that they might have been able to do something to alter the course of disease if they had only known more. One man indicated that he believed his providers could have intervened to change the course of his illness if only he had "asked more questions" and not been "afraid" to let providers know when he saw things going "off-track."

Undoing. Some patients offered highly specific counterfactual explanations for their kidney disease that implied a belief that it could easily have been prevented. One woman spoke of how she wished she had realized that she had kidney disease earlier on "because I was taking medications

that were making the condition worse. And I would have stopped my medications, well, maybe not." In some instances, patients pinpointed a single pivotal incident or moment in time. One man described how his kidneys were damaged by a lithium overdose while he was in prison because he did not drink enough water to "flush" them. Although it is medically plausible that medications might have caused kidney disease in these patients, neither of these explanations seems to leave room for more than one causative factor, nor for any uncertainty about etiology.

Discussion

Patients' experiences of illness and interactions with providers and the health system can take a large emotional toll. Patients with advanced kidney disease interviewed for this study described feelings of isolation, abandonment, alienation, mistrust, and even self-blame that would probably be surprising to the providers taking care of them. It is striking that these themes emerged in response to open-ended questions about patients' experiences of illness and care without the use of specific probes to elicit information about their emotions. These findings underscore the critical importance of considering patients' emotional experiences in efforts to improve care. They also provide a compelling rationale for more in-depth qualitative work to understand the source of these negative emotions and determine how widespread they might be.

Our findings are consistent with a large body of work at the intersection of medicine, social science, and the humanities highlighting the limitations of the biomedical model of health that underlies much of contemporary medical education, practice, and research. This technologically focused model is often ill-equipped to address the emotional and existential needs of patients (16–20), and especially the complex needs of patients with multiple different comorbid conditions and/or limited life expectancy (21,22). The biomedical model also fosters a sharp separation between the roles, experiences, and cultures of patients and health care providers, which can make it difficult for providers to understand and acknowledge patients' suffering (16–20). Even well intentioned efforts to increase patient engagement in care (*e.g.*, efforts to promote living well with chronic disease or healthy aging) can have the unintended effect of making patients feel responsible for their ill-health or disability (2,7,23–25). One of the more insidious ways this may occur is when messaging from both within and outside the health system oversimplifies the complex "multicausal" nature of chronic conditions and underplays the inherent uncertainty and unpredictability that often characterize their course (2,7,23–25).

Improving education and health literacy among patients with kidney disease (26–29) and building communication skills among nephrology providers (30–35) will go some way toward improving communication between patients and providers. However, in complex and fragmented health systems, our findings suggest that improving communication will require that providers gain a stronger appreciation of the totality of patients' interactions with other providers and the health system and how these interface with patients' own struggles to make meaning of their illness. It will also require that providers reflect on the

unintended effects of their own actions as agents within the health system (18,19,36). Equipping providers to engage in such reflection will require that we reshape medical training and practice to place a higher premium on emotional intelligence (37), the narratives of individual patients (17,19,38), and person-centered approaches to care (e.g., listening, relationship-building, care coordination, shared decision-making, peer support) (9,19,39–47).

Perhaps most importantly, our findings suggest that, although necessary, efforts focused on individual providers will alone be insufficient to meaningfully improve the patient experience. Also needed, will be a stronger commitment to teamwork at a variety of organizational levels in order to accommodate the increasingly limited reach of individual patient-provider relationships and the large numbers of providers with whom individual patients may interact across settings and over time (11,48,49). Similar to individual providers, these groups of providers working together in a multi-, inter-, or transdisciplinary fashion and the organizational leadership of the health systems that support them must be mindful of the patient perspective and potential unintended emotional consequences of their approach to care delivery for individual patients.

The main limitations of this study relate to transferability and potential for bias. More work is needed to understand whether these findings from a single-center study among predominantly male veterans are also present in other settings and populations, especially those with a higher representation of women. A further limitation is that we only included patients who could provide informed consent and thus our results do not speak to the experiences of patients with kidney disease who have cognitive insufficiency.

Interactions with individual providers and with the wider health system coupled with patients' own struggle to make meaning of their illness can take a large emotional toll. Our findings suggest that a deeper appreciation of patients' emotional experiences may offer important opportunities to improve care and highlight the need for more in-depth work in this area.

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A.M.O., J.S., E.K.V., and J.S.T. designed the study; A.M.O. and W.S. obtained IRB approval; L.V.M. and J.S. recruited patients; J.S. conducted and recorded patient interviews; L.V.M. and W.S. transcribed interviews; A.M.O., J.S., W.S., and L.V.M. coded interview transcripts; A.M.O., E.K.V., J.S.T., J.S., W.S., and L.V.M. conducted qualitative analyses; A.M.O. prepared the first draft of the manuscript and all authors participated in manuscript revision and approved the final version of the manuscript.

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