

## Original Article

### Complications

# Symptoms among patients receiving in-center hemodialysis: A qualitative study

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#### Abstract

**Introduction:** Assessment of dialysis-related symptoms is not currently a requirement for hemodialysis (HD) providers in the United States. The purpose of this study was to describe patients' perspectives on symptoms associated with end-stage chronic kidney disease treated with thrice-weekly, in-center HD.

**Methods:** We performed a qualitative study using interpretive description. Interview questions were based on a KDIGO (Kidney Disease Improving Global Outcomes) controversies conference and a literature review. Semi-structured interviews were analyzed for characterizations of symptoms.

**Findings:** Fifty participants (48% female; 42% Hispanic; 30% American Indian; 14% Black; 12% non-Hispanic White) were recruited from six outpatient dialysis centers (four urban, two rural) in the southwestern United States. Median HD duration was 4 years. Of 13 symptoms assessed, nearly all participants reported difficulties with muscle cramping, fatigue, or both. Negotiating fluid removal with dialysis personnel helped to manage cramping. Some participants tried to adjust dialysis days and shift to mitigate fatigue. Most participants reported having experienced depression early in the course of dialysis; for some, it was a persistent or recurrent problem. Relatively few participants reported using antidepressants or counseling to cope with depression. Itching was highly distressing for those who experienced it frequently. Topical treatments, antihistamines, dietary modifications, and phosphate binders were identified as potentially helpful by some participants.

**Discussion:** The major symptoms attributed to HD treatment by participants were cramping, fatigue, depression, and itching. Greater attention by health care providers to the most common and bothersome symptoms could positively impact daily life for HD patients.

**Key words:** hemodialysis, quality of life, self-management, symptoms

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## INTRODUCTION

For patients receiving in-center hemodialysis (HD), symptoms have a substantial physical and emotional effect on quality of life (QoL).<sup>1-4</sup> Symptom assessment and management have been identified as priorities for research on clinical care for patients receiving HD or who are likely to need dialysis in the near term.<sup>2,4</sup> The recent KDIGO (Kidney Disease Improving Global Outcomes) controversies conference on supportive care in chronic kidney disease (CKD) advocated for routine screening of HD patients for symptoms related to end-stage renal disease.<sup>2</sup> Although a number of validated tools are available to assess symptoms generically,<sup>5,6</sup> common symptoms associated with dialysis,<sup>7,8</sup> and symptoms as a component of QoL in CKD,<sup>9,10</sup> effective treatment strategies are limited.<sup>4</sup>

The lack of reliable treatments for common CKD- and HD-related symptoms (e.g., itching, lack of energy, cramping, sleep disturbance) appears to be of greater concern to HD patients than to their health care providers.<sup>4</sup> In addition, there is evidence that health care providers underestimate the extent and severity of HD patients' symptoms.<sup>11-13</sup> Symptoms matter to patients because they are unpleasant and distressing, interfere with physical and social activity, and are not always predictable; patients also view symptoms as "body signals" that they want to understand and trust as indicators of how well or poorly they are doing.<sup>14</sup>

The purpose of this study was to describe patients' perspectives on symptoms related to HD that were important to them, how those symptoms impacted well-being, and how participants managed their symptoms and treatment experiences. To that end, we conducted semi-structured interviews with a diverse sample of prevalent in-center HD patients and used qualitative methods to analyze their responses. This report focuses on symptoms that were viewed as important to participants and to what extent providers assess and help to treat those symptoms.

## MATERIALS AND METHODS

### Design, setting, and participants

We conducted semi-structured interviews (N = 50) to explore patients' views on HD-related symptoms and their potential effect on QoL. The interview guide was informed by the KDIGO Controversies Conference,<sup>2</sup> a review of the literature, discussion and consensus among the investigators, and consultation with nephrologists.

The study was approved by the Human Research Protections Office of the investigators' university (HRPO #14-161);

all participants provided informed consent to be interviewed and Health Insurance Portability and Accountability Act authorization to access recent clinical information from their electronic medical record. Participants were recruited from six community HD clinics (four urban, two rural) in New Mexico. Dialysis center staff and consulting nephrologists helped to identify potential participants who were at least 18 years of age, spoke English, and had sufficient cognitive capacity to provide informed consent and respond to interview questions. A recruitment poster and materials were made available at each site to advertise the study and allow patients to self-identify their desire to participate. At an initial contact, potential participants received a recruitment brochure and a copy of the consent. In a follow-up contact several days later, a member of the research team provided additional information about the study, answered questions, and scheduled an interview with those who remained interested. A majority of those who were contacted agreed to participate.

### Data collection

All participants were offered the option to be interviewed either during a scheduled HD treatment or in a private room at their dialysis center. All of them chose to be interviewed during a dialysis session. Prior to beginning the interview, the purpose of the study was explained again, and informed consent was obtained. The one-on-one, in-person interviews were conducted using a semi-structured interview guide (Box 1) and were audio-recorded. Interviews lasted from 17 min to 1½ h (median, 43 min; interquartile range, 34–52 min). Interview participants received a \$25.00 gift card.

The first author trained the other interviewers and supervised their initial interviews. The interview guide was also pilot-tested during this period. Following the first round of interviews, the research team met to discuss the interview guide in relation to the initial findings. It was apparent at this point that patients prioritized the more severe symptoms, although we asked about a full range of symptoms. Therefore, we decided to continue with the existing interview guide with the provision that we would focus our probes on exploring those symptoms that patients found the most troublesome. Data collection and analysis continued throughout the study as an iterative process.

The recruitment and interviewing process continued until thematic saturation was achieved. Demographic and clinically relevant health data obtained from the patient's medical record were entered into Research Electronic Data Capture (REDCap<sup>TM</sup>), an encrypted, web-based data platform.<sup>15</sup> Once data analysis was complete, we reviewed and verified the findings with five participants from different sites.

### Box 1 Interview Guide

I would like to start by asking you to take me back to the time when you first learned that you had kidney disease. Please tell me about that experience of receiving your diagnosis.

How long have you had chronic kidney disease? What aspects of your life have changed for better or worse since you were diagnosed? Could you please help me understand what your life is like as a person receiving treatment for chronic kidney disease by sharing with me what you think the most important things that I should know about what that experience is like.

People with chronic kidney disease often have a variety of symptoms. Can you tell me which of your symptoms troubles you the most?

Tell me about your experience with [most troublesome symptom]:

Potential probes:

- When did you start experiencing it?
- What makes it better or worse? For example, is it better or worse at certain times of day?
- How does it affect your day-to-day life?
- What kinds of help do you have from your friends/family in managing [symptom]?
- How helpful or understanding have your health care providers been? Are they meeting your expectations? Are there things they could do differently that might make things better? (When possible, ask participant to illustrate with stories or examples.)

There are several additional symptoms that people with kidney disease often experience. I would like to read a list to you and have you tell me which of these are symptoms that you experience that you think are related to your kidney disease or dialysis. We'll then go back and talk about the symptoms you identify.

- Itching
- Fatigue, tiredness, or weakness
- Pain
- Loss of appetite
- Nausea, vomiting, or diarrhea
- Constipation
- Problems sleeping (e.g., restless legs or sleep apnea)
- Muscle cramps
- Headache
- Depression or anxiety
- Thirst
- Problems with urination or urine output
- Problems with having sexual relations

For each symptom endorsed: Tell me about your experience with [symptom] (Follow with probes as above).

What should I have asked you that I didn't? Or is there anything else you would like to tell me about your experiences with chronic kidney disease (or dialysis)?

### Data analysis

We analyzed verbatim transcripts of interviews and field notes using the method of qualitative interpretive description defined by Thorne et al.<sup>16,17</sup> The purpose of interpretive description is to systematically and rigorously explore human health and illness experiences that arise from clinical practice, with the goal of informing the understanding of issues that concern patients.<sup>17</sup>

Transcripts of the recorded interviews were validated by the research team. NVivo 10 (QSR International, Melbourne, Australia) software was used to store, code, and analyze the interview data. Interview responses pertaining to symptoms were initially coded and analyzed under common symptom labels to represent how participants characterized symptom experience and their attempts to cope with or manage symptoms. Transcripts were coded

by members of the research team over the course of data collection, and a coding tree was developed based on discussions during regularly scheduled team meetings. Agreement on themes identified through analysis was achieved through a process of discussion and consensus. A codebook was developed to ensure consistency of theme and subtheme development over time.

Demographic data were obtained during the interviews. Length of time since beginning HD, Medical Outcomes Study Short Form 36 Health Survey (SF-36) responses, and single-pool Kt/V (spKt/V) were abstracted from electronic medical records and analyzed with descriptive statistics using IBM SPSS® Statistics (version 23; IBM, Armonk, NY).

## RESULTS

Demographic and clinical characteristics are summarized in Table 1. The average participant age was 54.6 (SD = 13.4) years. The sample was diverse: approximately 40% were Hispanic, and 30% were American Indian; nearly 40% of participants were interviewed at one of the two rural HD units. A majority had been on HD for 4 or more years and were receiving adequate dialysis as measured by the spKt/V. All but two participants had been receiving HD for at least 6 months. The Physical and Mental Component Scores from the SF-36 were available for 40 participants and reflected moderate impairment of physical health and no impairment of mental health relative to US population norms.

Although we inquired about a variety of symptoms (Box 1), we found during the interviews that participants focused heavily on those that were the most bothersome and challenging to manage: muscle cramping, fatigue, itching, and depression. In order to cope with those symptoms, participants utilized two basic strategies. These included working in partnership with the dialysis team and “taking control” of their own self-management.

### Partnership with the dialysis team

#### *Muscle cramping*

Dialysis-related muscle cramping was described by nearly all participants as being the most bothersome symptom. There was general agreement that cramping was closely related to the volume of fluid removed during a dialysis session (Box 2). At worst, these cramps “locked up” the stomach, torso, arms, hands, and legs, and resulted in nausea or vomiting and fear or anxiety. When painful cramping occurred during dialysis, a technician or nurse was usually summoned to adjust the machine: “Like if

**Table 1** Demographic and clinical data<sup>a</sup> (N = 50, except as noted)

	N (%)
Sex	
Female	24 (48.0)
Male	26 (52.0)
Age group (years)	
20–44	10 (20.0)
45–64	29 (58.0)
65–74	7 (14.0)
75+	4 (8.0)
Ethnicity	
Hispanic or Latino	21 (42.0)
Not Hispanic or Latino	29 (58.0)
Race	
American Indian/Alaska Native	15 (30.0)
Black/African American	7 (14.0)
Non-Hispanic White	6 (12.0)
Hispanic White	11 (22.0)
Other/none of the above <sup>b</sup>	9 (18.0)
More than 1 race	2 (4.0)
Marital status	
Single	21 (42.0)
Married	11 (22.0)
Divorced or widowed	18 (36.0)
Education attainment	
Less than high school	8 (16.0)
High school or GED	26 (52.0)
Some college or associate’s degree	9 (18.0)
Bachelor’s degree or higher	7 (14.0)
Employment status	
Employed (full- or part-time)	7 (14.0)
Unemployed or disabled	31 (62.0)
Retired	12 (24.0)
Dialysis center location	
Urban	31 (62.0)
Rural	19 (38.0)
	Mean ± SD
Years of ESRD treatment (n = 49)	4.4 ± 3.6
SF-36: PCS score (n = 40)	35.7 ± 9.3
SF-36 MCS score (n = 40)	47.8 ± 12.0
spKt/V (n = 49)	1.7 ± 0.3

<sup>a</sup>Values for categorical variables are given as No. (%); values for continuous variables are given as mean ± standard deviation.

<sup>b</sup>All participants who responded “other/none of the above” to race self-identified as Hispanic or Latino in ethnicity.

Abbreviations: ESRD = end-stage renal disease; MCS = Mental Component Score; PCS = Physical Component Score; SF-36 = Medical Outcomes Study Short Form 36 Health Survey; spKt/V = single-pool Kt/V (urea clearance).

### Box 2 Muscle Cramping

*It depends on how much water they pull from me. If they pull too much, then you really cramp, you know, you really. It's not good.*

*It depends again if they take more than. . .two kilos of, um, fluid out of me, it happens a lot. I get cramps and then I feel a lot more tired afterwards. But if it's anything under two then I feel fine, . . .no effects. But I always know when they're taking out too much liquid because my hands start cramping. . .that's the first one. I'll look at the time and I'll say "okay my hands are cramping, I only got half an hour, I think I can bear through it." But if it's a whole hour before [dialysis is over], I'm not gonna make it!*

*How I prevent it [cramping]? Because I'm keeping up with my dry weight. . .but if I come in and they took off the normal 2 kilos, and I got dried out, then I start getting cramps. I would say well, I must have gained weight because you're taking off the normal two and now I'm getting muscle cramps and that's the indication that the muscles are dry or dehydrated. So that's also an indication that I must have lost weight, so instead taking 2.0 off they need to take off 1.5, and leave some fluid on there. Just a little bit. If you picked up weight or if you lost weight you gotta keep tabs on it. So I keep tabs on mine pretty well.*

*I've learned a lot from the techs about dry weight and when you gain weight and when you're losing weight. . .and how much they should take off. I'm the one that tells them [the techs] because I know what I can handle now.*

### Box 3 Fatigue

*I'm toast. I'm kind of OCD about my house. It has to be clean and organized and everything, so it's frustrating. Right now there's dishes in the sink because I didn't have the energy to put the dishes away yet. But overall, I can still do everything, just at a slower pace and I have to take breaks. If I'm folding laundry, I get really exhausted, so I have to stop and lay down. Laying down seems to solve everything for me I can't go to public grocery stores without a scooter because I can't shop otherwise. Or I'll just have my kids buy me something. You know, can you go to the store for me?*

*So I've been thinking about transferring on to the night shift because I don't like the way I feel afterwards. I've got deeds I want to get done. . .if it was at night, I come in at 4, get off by 8 or so, I would still have energy to stay up until about 11 or 12 and then go to sleep.*

*When I first started, I would go home really tired. . .most of the time they took out too much liquid. . .and I always told them I think my dry weight's not right. So they calibrated the weight for me, and now I feel good.*

they take out a little too much fluid then my legs start cramping. And they'll turn me off just for a little bit and then it'll go away." Being attuned to weight gain since the end of the previous session helped some to communicate with the nurse or technician to target the amount of fluid removal during a session. Discussing these concerns at the start of a treatment or during a session helped to mitigate the severity of cramping episodes (Box 2).

Adjustments in fluid removal were also effective in decreasing fatigue. Participants learned more about the process as time went by and began to work with the nurses and technicians regarding their dialysis routine. According to one man, "If I talk about my dialysis and how much it affected me, then they finally made adjustments. . .and I felt better."

#### Fatigue

Many participants reported significant fatigue directly following treatment and said that it often persisted for hours

or until the day following treatment: "When I leave here, I'm exhausted!" There was considerable variation in participants' experience of fatigue, but it had a significant impact on QoL because it affected participants' ability to work, socialize with others, and engage in activities of daily living (Box 3). For those with extreme fatigue, a change of HD schedule often helped them to cope by allowing them to manage their sleep and activities better.

#### Itching

Itching (Box 4) often resulted in a relentless need to scratch and was very distressing for those who experienced it frequently: "The itch I get right after dialysis is the worst." In contrast to cramping and fatigue, itching was a symptom for which most who experienced it relied on medication. Some patients used antihistamines or "creams" to control itching, adding that "without these treatments, life would not be tolerable!" Phosphate

**Box 4 Itching**

*I feel like there's spiders crawling on me. So that's irritating and I don't like that feeling because it makes me itch and I'm just there constantly. . . every few minutes I'm there just scratching where it itches.*

*With my legs I noticed when my phosphorous went up it would dry out my skin and cause itching. So right away I was, okay, what caused that? Sodas, hot dogs, and stuff like that, so I cut those down quite a bit. I snapped to that.*

*They gave me a bunch of pills one month [for itching] and then I ran out and the insurance wouldn't cover them, so I had to go a couple weeks without it. And going without the phosphorous pills, boy, I just went crazy.*

*When I don't take it, I pay for it. I was having trouble because I was on Renvela, which worked. When I took it faithfully, it worked beautifully. But I couldn't afford it. And so they put me on PhosLo, which is cheaper and. . . I'm trying really hard not to mess up, so I'm taking it very good and I do itch but not like before. Like now I could itch and I could just do like this and it goes away, and before it was like, oh, oh, everything. Oh, it was so bad. And now I'm. . . it's getting controlled better with the PhosLo because I can afford it.*

*Participant: They had me on hydroxyzine and any kind of itch medicine I had to take. Like it was. . . but the itching is because of our phosphorous. If we don't take care of our phosphorous, yeah, we're gonna itch. So that's one of the main symptoms with high phosphorous, very bad itching.*

*Interviewer: And is that something that still troubles you?*

*Participant: Sometimes, sometimes I get just and I want to just tear my legs up, they itch. And I can't do that to myself.*

*Interviewer: Yeah. So what do you do? You mentioned. . .*

*Participant: Benadryl, Benadryl and hydroxyzine really do help.*

*And sometimes you just got to be like, well, I've already had two showers today but I'll just stand in there and let the water hit me, dude. And it helps just some hot water, soak.*

binders often helped to control the itching, but the cost could be prohibitive (Box 4).

**Other aspects of partnering with providers**

In addition to symptom-focused aspects of partnering with the dialysis team, participants identified more general aspects of the patient-provider partnership. These fell into two broad categories: positive aspects of partnership and areas for improvement (Box 5).

**Self-management strategies**

Although some of the most severe symptoms could be controlled by working directly with the dialysis team, many participants found that they had to “take control” of their own symptom management to improve their QoL.

**Managing fluid and dietary restrictions**

According to some participants, episodes of severe cramping could be prevented or reduced in frequency and severity by adhering to fluid and dietary restrictions. Others reported relief from drinking pickle juice: “It has the acid that your body needs. I'll take a bite of a pickle and it [cramping] disappears.”

Careful adherence to the “kidney diet” was also viewed as a key factor in controlling the onset of itching episodes. Some participants reported that avoiding high-phosphorus foods, such as “hot dogs, pizza, and stuff like

that” was helpful. Many participants reported that the severe itching episodes improved over time as they learned to control their diets.

**Managing fatigue**

For some patients, fatigue could not be managed effectively enough to do things they wanted to do. Sleep disruptions contributed to fatigue. Although some patients were able to “have energy the next day” by eating and napping after dialysis, others stated that napping created problems with getting a full night's sleep: “I have a hard time sleeping. I think a lot of it is because I'm sleeping in the daytime so I have a hard time sleeping at night. . . a lot of times I've got to take a sleeping pill to go to sleep at night.” Cramping was also related to fatigue. Cramps often occurred at night, waking the patient up and disrupting sleep: “My legs and in my hands. . . if I go home at night, I cramp, too. It's just so hard. It's like I'm a total wreck.” Strategies to relieve the cramping included “jumping out of bed,” straightening or rubbing the legs, and stretching and/or walking around the room.

**Managing depression**

Spending 4 h on a dialysis machine 3 days per week had a profound effect on participants' mental and emotional health. Some said that they struggled with depression and to make sense of the life they were leading (Box 6). A number of participants complained that the uncertainty of

### Box 5 Partnering with providers

#### Positive aspects of partnership

*Techs, they would tell me. . . I know a lot about the machine. And I can tell that and have them (inaudible). I can tell them what's going on.*

*They're teaching us how to be more control about what's going on with us, what's going on with the machine, what's going on with our doctors. . . and saying this is what I think we need to do.*

*Everybody here has actually been very helpful and understanding and I try to help them understand me more and they have been helpful to helping me understand, uh, more, too, about what's going on with me and. . . helping me cope with this really because I need. . . good technicians and I need understanding.*

*They listen to me and I think that's very important. I ask her questions and stuff, you know, if I want to know something and she really helps me out.*

*I trust them and I like, I like, you know, them, you know, working with me and stuff like that that I know what they're doing.*

#### Areas for Improvement

*If they had more time to spend more time with the patients. Because you know 10 or 15 minutes is not enough time.*

*They wanted to put me on blood pressure pills and I said, uh, you know, that's not a good thing because my blood pressure drops even when I'm at home but not as bad as it does here. But they're still pushing to put me on. . . blood pressure medicine.*

*Yeah people are like cars but then you gotta look and say okay, well this, this person, it doesn't work for him that way, we gotta tweak this or we gotta tweak that, we gotta stop this or we gotta stop that, you know? But first of all they gotta listen.*

*Pay more attention to what I'm asking you and. . . clarify it for me. You know, make me feel better about the question that I'm asking you. You know, don't give me the runaround.*

*You know, make me feel better. Make me understand that what you're saying.*

*She just comes and she just looks at our clipboard, at our paper and says, okay, you're fine and then she goes. But um, you know, there are some times that I will ask her a question and. . . she does answer my question. But she still leaves and me thinking, well, she didn't answer the question.*

*They think, well, you're in a schedule. You need to stay on that schedule. And that sort of pisses me off because I could still go to like dances or. . . stuff where my family's around and it's like pulling teeth in order to get them to change.*

*Sometimes doctors just gives us some medicine, oh, because you have to take one. See, sometimes you have to take one for your heart. Sometimes you have to take one to pee. Sometimes you have to take one for your kidney. So, so many. But if we don't get education on it sometimes like from the doctors or something, as dialysis patients, but they say we can't let it out.*

*I love Google so I'm always researching everything and so I don't know if there's like websites, like some people are more comfortable with websites, some are more comfortable with handouts so I really don't know. I just don't think those handouts that they always give us are very user-friendly.*

symptoms and of their health in general contributed to depression. Life was like a “rollercoaster” where they would feel good for a while, but at times when managing symptoms seemed insurmountable, they would quickly plummet into depression.

Participants reported using different strategies for dealing with depression. Some took antidepressants on a regular basis (Box 6), whereas others preferred to avoid them: “I didn't want to get addicted to them. . . I don't want to see myself going down that path.” Although some participants saw counselors or social workers for talk therapy, others relied more on their own resilience or support from family. Others found spirituality helpful: “It kept me in prayer. I have a tendency to pray a lot. When I'm frustrated, I will pray until I have a release. That's

why I think I don't get depressed.” For those who were less physically disabled, going for a walk, doing artwork, or getting out and engaging socially were strategies for coping with or preventing depression (Box 6).

### Other symptoms

Less frequently reported symptoms included gastrointestinal problems (nausea, vomiting, diarrhea, or constipation), thirst, restless legs, weakness, and dizziness. Relatively few participants reported loss of appetite, headache, anxiety, or concerns about loss of urinary function. Concerns about sexual functioning were heterogeneous. Some participants indicated they were no longer interested in sex. A larger number indicated that they were

### Box 6 Depression

*The only thing that makes me feel depressed is that I gotta be here. You just sit here and, because you get four hours to think, what I could I be doing? You know I could be doing so much more and this is my way to live, and if I'm not here I'll die. And so it's weird that they call it dialysis, it should be called livealysis because it makes you live, you know?*

*I got to deal with the way it is now. I'm – and don't get me wrong. When I get out of here, like I'm so sick. I feel bad. Like yesterday, I just went home and I cried, because I was throwing up like crazy.*

*And I take that mainly because I guess being a dialysis patient some people get really depressed and stuff like that, but I just take a 40-milligram tablet once a day and tend to be fairly humorous over the whole thing.*

*When I feel that way, I just leave the house and go and go for a walk and do something, you know, but not just staying there thinking, thinking of other things. I just, I just deal with it better. I don't like take medications, 'cause I tried like three or four different medications that the doctor gave me here, but none of them worked out with me.*

*I don't find it necessary to go and broadcast my issues with everybody. I might bring it up in passing with my mom or my sister but it's not like. . . I don't find it necessary to go talk to a counselor. You just kind of deal with it.*

*Every now and then I would [get depressed]. But then, you know, again I would just tell myself that I'm a strong woman, that I can handle it, and my kids and their dad are the ones that motivate me every day.*

sexually active. Of those, most indicated that the frequency of sex had decreased, but they had made other adaptations to maintain intimacy. Additional participants' comments about symptoms are available online in Supporting Information.

## DISCUSSION

We assessed a range of symptoms that have been reported as common among patients receiving HD, but found the greatest impact on daily life was from muscle cramping, fatigue, itching, and depression. Partnering with dialysis center staff was reportedly useful for ameliorating problems with cramping and fatigue. However, with respect to self-management outside of the HD center, participants reported often having to find things out on their own or through interactions with other HD patients in terms of discovering techniques to alleviate symptoms or attenuate their impact.

Symptoms have a major impact on QoL in chronic health conditions generally<sup>18</sup> and particularly for patients with CKD receiving HD.<sup>8,19–21</sup> Even so, it is not unusual for symptoms experienced by patients to be undertreated by health care providers.<sup>11–13,22,23</sup> When providers do not inquire about which symptoms are most bothersome, patients may be left with the impression that nothing can be done to diminish symptom frequency and severity or to enhance self-management.

Incorporation of symptom measures into clinical care potentially can help with communicating to patients that their symptoms are important to providers and are a legitimate focus of attention and treatment. A variety of symptom measures are validated for use with patients who have CKD, including those receiving HD. Most symptom self-report measures ask patients to recall for some

relatively brief interval (commonly within the past 24 h–4 weeks)<sup>7,9,24</sup> symptoms that have been present (symptom prevalence)<sup>20,25,26</sup> in conjunction with ratings of intensity,<sup>1,5,26</sup> severity of distress or bother,<sup>7,9,20,24,25</sup> or how frequently the symptom was experienced.<sup>24,25,27</sup> A count of the number of symptoms endorsed may be useful for making judgments about how common various symptoms are relative to others,<sup>7,8,25,27–29</sup> but prevalence estimates essentially give all symptoms equal weight. Weighting symptoms according to distress or frequency overcomes that limitation to some extent, but distress may be underestimated among patients who happen to be reasonably stable over the time frame the instrument covers.

Our interview questions about symptoms did not restrict the time frame, and it was very clear from the interviews that fatigue, muscle cramping, itching, and depression had a more dramatic and disproportionate impact on patients' lives than most other symptoms. Thus, although symptom measurement is an important component of patient-centered care, it should be viewed as a means for enhancing communication and, perhaps, for tracking progress with symptom management over time, but it does not replace the need for careful exploration with patients of which symptoms they find most troublesome or disruptive. On the whole, participants were satisfied with their care. They noted that their physicians and dialysis center staff were willing to listen to their concerns, but some felt that unless they brought symptoms up, their physicians and dialysis center staff generally focused on more objective features of their condition than on their symptoms.<sup>11,13,19</sup> Patients frequently communicated they wanted additional time to speak with providers, because they had unaddressed questions or concerns or did not understand their treatment plan. Participants' educational needs remained unmet or were met through

knowledgeable nursing and technician staff or by alternative means, such as Internet searches. Although participants stated they usually received printed information to reinforce patient education, their views about the value of such information ranged from helpful to “ridiculous.”

Additional time for interaction with providers can also ensure that patients’ concerns about their treatment plan and symptoms are fully addressed. One participant suggested these interactions best occur before dialysis in a location that allows for more privacy. During these interactions, providers should focus on individualized approaches for treatment and management of patient symptoms, including pharmacologic and nonpharmacologic approaches. Providers and dialysis team members together provide a multidisciplinary approach for addressing patients’ concerns related to their treatment and symptoms.

As with any qualitative study, this investigation has a number of limitations. Participants self-selected and were willing to be interviewed. All interviews were conducted during a dialysis session, which may have influenced responses (e.g., the salience of cramping or willingness to speak about issues pertaining to pain or sexuality). Although other researchers have found issues revolving around sexuality and sexual performance to be common in dialysis,<sup>20,30–33</sup> relatively few of our participants identified sexual performance as a major or distressing concern. It is possible that conducting interviews during dialysis may have had an effect on some participants’ willingness to discuss sexual concerns.

The goal of qualitative research methods is not to attain representativeness as conventionally understood; rather, the focus is on sampling to achieve a range of perspectives in some depth. The research was conducted in dialysis units in a single state affiliated with a public university. Thus, our findings may not be reflective of patients in other regions or in dialysis units without any academic affiliation.

Despite those limitations, there were several strengths to this study. The interviews were conducted by three nursing faculty and a physician who were not directly involved in dialysis care and, therefore, had few preconceptions about patients’ concerns. In addition, substantial proportions of our sample were Hispanic and American Indian.

We attempted to focus on the symptoms that participants reported as having the greatest impact on their lives. From the point of view of participants, symptoms were often interrelated in terms of their impact on daily activities.<sup>34–37</sup> Health care providers can play a more active role in helping patients to control dialysis-related symptoms by inquiring regularly about which symptoms are most bothersome, listening carefully, and partnering with

patients to enhance their ability to self-manage symptoms and their impact.

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