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# "I Wish Someone Had Told Me That Could Happen": A Thematic Analysis of Patients' Unexpected Experiences With End-Stage Kidney Disease Treatment

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## Abstract

**Background:** Preparedness regarding prognosis and treatment options enables patients to cope with uncertainties, make value-based treatment decisions, and set treatment goals. Yet, little is known about the expectedness of end-stage kidney disease (ESKD) patients' treatment experiences beyond their desire for better treatment education. **Objective:** To describe unexpected adverse treatment experiences among ESKD patients. **Method:** The authors conducted 7 focus groups with 55 dialysis patients and living-donor kidney transplantation recipients receiving medical care in Baltimore, Maryland. Data were analyzed thematically. Themes present in different treatment groups were highlighted to provide insight into common experiences. **Results:** The authors identified 5 themes: (1) psychological reactions, (2) constrained freedom of choice, (3) treatment delivery and logistics, (4) morbidity, and (5) finances. **Conclusion:** Patients were unprepared for nonclinical, logistical, and clinical aspects of ESKD treatment. The need for providers' use of tailored preparatory techniques and the development of pretreatment interventions to help patients know what to expect from and feel psychologically prepared for treatment, particularly with respect to nonclinical implications, is critical. These efforts have great potential to improve patients' treatment experiences.

**Keywords**
kidney disease, dialysis, transplantation, patient perspectives, treatment experiences, qualitative

## Introduction

Patients who are approaching end-stage kidney disease (ESKD) face a difficult and complex treatment decision-making process (1). There are several treatment options to choose from, each of which has different advantages, limitations, and implications for patients' survival, quality of life, psychological well-being, physical health, and engagement in usual activities (2–6). This complicated process is often further complicated by insufficient treatment-related support and information provision to patients before the onset of ESKD (7).

Consequently, patients' lived experiences with and perspectives on ESKD treatment have been the subjects of a growing number of qualitative studies to gain insight that

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may inform person-centered practice, policy, and research (8). These studies have advanced understanding of patients' day-to-day experiences, needs, concerns, challenges or difficulties, responsibilities, beliefs, attitudes, values, priorities, and coping strategies related to ESKD treatment (9–13).

Still, very little remains known about the expectedness of patients' experiences with ESKD treatment. Yet, patients express a desire for better education about what to expect from this treatment, and their perceived preparedness regarding prognosis and treatment options enables them to cope with uncertainties, make value-based treatment decisions, and set treatment goals (14,15). Further, studies in other illness populations have shown that feeling prepared for or knowledgeable about what to expect from treatment may empower patients; reduce uncertainty and unmet information and support needs; improve coping ability, quality of life, physical and psychological outcomes, and treatment compliance; support self-management; increase self-efficacy and satisfaction with care; and lower risk of 30-day hospital readmission and poor survivorship outcomes (16–21). Prior research also suggests that patients' preparedness for and expectations of treatment may be more influential for their satisfaction with treatment outcomes than objective therapeutic success (22). The authors therefore examined unexpected adverse treatment experiences among dialysis patients and transplant recipients to understand how providers and pretreatment interventions can better prepare patients for ESKD treatment.

## Methods

### Design

This study formed part of the intervention development phase of the Providing Resources to Enhance African American Patients' Readiness to Make Decisions about Kidney Disease (PREPARED) trial, which developed and tested culturally sensitive interventions to enhance patients' shared and informed treatment decision making (23–28). In this phase, we conducted 7 focus groups stratified by patients' treatment (hemodialysis, home hemodialysis, peritoneal dialysis, or living-donor kidney transplantation) and self-reported race (African American or non-African American) to examine their treatment experiences. There were 2 groups per treatment experience with the exception of the home hemodialysis group;there were too few non-African American home hemodialysis patients to form race-stratified groups. The study was approved by the Johns Hopkins Institutional Review Board (#00022055) and follows the consolidated criteria for reporting qualitative research checklist (29).

### Sampling and Recruitment

Trained research staff recruited patients in person from purposively selected community-based and academic nephrology practices affiliated with dialysis facilities and an academic kidney transplant center in Baltimore, Maryland, to provide an ethnically and socioeconomically diverse population. Staff did not know patients prior to approaching them about the study. Eligible patients spoke English, were at least 18 years old, and had been undergoing dialysis or had undergone living-donor kidney transplantation (posttransplant) in the year before study recruitment. Recruitment sites provided lists of potentially eligible patients. Staff obtained informed consent using an oral consent protocol. Reasons for dropout included inconvenient meeting times, lack of time, and no-shows.

### Data Collection

Focus groups met between October 2008 and March 2009 at the same venues where patients received their medical care. Two female researchers trained in the conduct of focus groups led the 90-minute meetings. They had no relationship with patients prior to study commencement. Only moderators and patients were present during meetings. Prior to discussions, patients completed a brief survey assessing their sociodemographic characteristics. Moderators then assigned each patient a unique numeric identifier to preserve confidentiality when speaking.

Moderators initiated discussions using a scripted interview guide based on the aims of the PREPARED trial and its guiding conceptual framework, the PRECEDE-PROCEED model; focus groups addressed predisposing factors in the model (30). The guide included introduction, discussion, and conclusion stages. In the introduction stage, moderators provided brief information about their respective research positions and reiterated the rationale for the meeting. During the discussion stage (Supplementary Material), moderators asked, "After you started dialysis/received your transplant, were there negative things about dialysis/transplantation that you did not expect?" In the conclusion stage, patients could provide additional comments and received US$50 for participating. Moderators also wrote field notes regarding their impressions of group discussions. Discussions were audio-recorded and transcribed by an outside company.

### Analysis

Microsoft Excel 2016 was used to manage the data. In accordance with inductive thematic analysis procedures (31), N.D. and A.C. individually read the same transcript line-by-line, manually coded the data for themes and subthemes, and developed a preliminary coding scheme. They compared their codes and established consensus. They repeated this iterative, systematic process for each transcript. Coding saturation was achieved after N.D. and A.C. agreed additional coding modifications were unnecessary. N.D. selected exemplar quotations to illustrate themes. To provide insight into common experiences, the authors present themes relevant to discussions from different treatment groups.

**Table 1.** Patient Characteristics Overall and by Treatment-Based Focus Group Assignment.[a]

| Characteristics | Overall (N = 55) | Hemodialysis (n = 15) | Home Hemodialysis (n = 5) | Peritoneal Dialysis (n = 13) | Posttransplant (n = 22) |
|---|---|---|---|---|---|
| Age[b] | | | | | |
| Mean (range) | 55 (18-80) | 59 (27-80) | 58 (38-78) | 54 (33-74) | 50 (18-65) |
| Gender[b] | | | | | |
| Female | 28 (51%) | 7 (47%) | 1 (20%) | 6 (46%) | 14 (64%) |
| Race[b] | | | | | |
| African American | 31 (56%) | 7 (47%) | 4 (80%) | 9 (69%) | 11 (50%) |
| Caucasian | 23 (42%) | 8 (53%) | 1 (20%) | 3 (23%) | 11 (50%) |
| Other | 1 (2%) | 0 (0%) | 0 (0%) | 1 (8%) | 0 (0%) |
| Education | | | | | |
| Less than high school | 1 (2%) | 0 (0%) | 0 (0%) | 1 (8%) | 0 (0%) |
| High school graduate | 23 (42%) | 11 (73%) | 1 (20%) | 5 (38%) | 6 (27%) |
| At least 2 years of college | 14 (25%) | 2 (13%) | 2 (40%) | 3 (23%) | 7 (32%) |
| College graduate | 7 (13%) | 1 (7%) | 0 (0%) | 2 (15%) | 4 (18%) |
| Graduate or professional school | 10 (18%) | 1 (7%) | 2 (40%) | 2 (15%) | 5 (23%) |
| Marital status | | | | | |
| Married/living with partner | 32 (58%) | 7 (47%) | 3 (60%) | 6 (46%) | 16 (72%) |
| Divorced/separated | 8 (15%) | 4 (27%) | 1 (20%) | 2 (15%) | 1 (5%) |
| Never married | 11 (20%) | 2 (13%) | 1 (20%) | 4 (31%) | 4 (18%) |
| Widowed | 4 (7%) | 2 (13%) | 0 (0%) | 1 (8%) | 1 (5%) |
| Health insurance[b] | | | | | |
| Insured | 54 (98%) | 14 (93%) | 5 (100%) | 13 (100%) | 22 (100%) |

[a] Percentages are shown unless otherwise noted. Focus groups were stratified by patients' treatment experiences in the past year (hemodialysis, home hemodialysis, peritoneal dialysis, and posttransplant) and self-reported race (African American or non-African American), thereby resulting in 2 groups per treatment experience with the exception of the home hemodialysis group. The home hemodialysis group was only stratified by patients' treatment experiences given that all but one patient identified as Caucasian; therefore, there was one focus group meeting for all 5 home hemodialysis patients. This stratification approach resulted in 7 focus groups.

[b] Missing patient data for age (n=2, posttransplant), gender (n = 1, home hemodialysis), race (n = 1, peritoneal dialysis), and health insurance (n = 1, hemodialysis).

## Results

### Patient Characteristics

The 7 focus groups comprised 55 patients ranging in age from 18 to 80, with an average age of 55. Most patients were African American, female, married or living with a partner, high school graduates, and medically insured. Four to 11 patients participated in each group (Table 1).

### Unexpected Adverse Experiences With ESKD Treatment

Five themes underpinned patients' unexpected adverse experiences with ESKD treatment: (1) psychological reactions, (2) constrained freedom of choice, (3) treatment delivery and logistics, (4) morbidity, and (5) finances (Table 2).

### Theme 1: Psychological Reactions

All treatment groups discussed unexpected psychological treatment reactions. The most intense reactions included depression and suicidal ideation:

> It was devastating. I wanted to die . . . In my mind I was so down and depressed and I . . . I'm going to kill myself. I didn't think I was going to get through this. (Hemodialysis patient 6)

Relatively less intense reactions involved struggling with body image (eg, feeling self-conscious about catheters) and feeling different from others. For example:

> I want to be like everybody else who's not on dialysis and I'm not. (Home hemodialysis patient 3)

### Theme 2: Constrained Freedom of Choice

All treatment groups talked about unexpected losses or limitations in freedom of choice. Undergoing treatment precluded patients from partaking in recreational activities. They experienced difficulties adjusting to these changes:

> I was very active in sports and things like that and being independent, doing what I want, go when I want . . . I can't do those things anymore because I have to be here . . . it was a big bummer . . . whole life changing kind of. (Hemodialysis patient 6)

Losses in freedom of choice extended to employment:

> I had to give up my work. I'd been used to working for 30 some, 40 years, and all of a sudden, you're not working. And when you're . . . putting in 45, 55, 60 hours and all of a sudden, you're down to nothing that just blows your mind. (Hemodialysis patient 7)

**Table 2.** Unexpected Adverse Treatment Experiences Among Dialysis Patients and Living-Donor Kidney Transplantation Recipients.

| Themes | Subthemes | Illustrative Quotations | Contributing Groups | | | |
|---|---|---|---|---|---|---|
| | | | HD | HHD | PD | T |
| Psychological reactions | None | "I became very depressed . . . I committed myself for a week." (HD patient 7) | ● | ● | ● | ● |
| Constrained freedom of choice | None | "I can't go to the beaches. I've been so used to taking bubble baths, relaxing in the tub after work and I can't do it anymore. Bicycle riding—I can't do that anymore because I can feel the pull on my stomach. I go to the gym but the only thing I can get on now is the treadmill." (PD patient 2) | ● | ● | ● | ● |
| Treatment delivery and logistics | Difficulties with self-management | "The same things that are good about home hemo are really the same things that can be bad about it, meaning the consumption. Because you know the machine is there. You know you're going to take it off. I love to drink, not alcohol, just fluid period, and I'll drink a little more than I should, eat a lot of the wrong things that I shouldn't because I know it's there and I know I'm going to be able to get it all. So, I may indulge a little more in that sense. You get a false sense of feeling good with the home machine because you dialyze, and you're doing well, you're feeling good . . . and I know I'll get on a good stretch of feeling good, things are going well, ah, I'll skip this day. I'm still feeling good. The next day rolls around. I know I should have dialyzed and I didn't. So, I know, okay, I'll just go on a little bit of a diet, not eat as much and I'm still in the same boat. I'll miss another day. I'll miss like a weekend, boom, two days in a row. Now I'm in a predicament because that fluid can hide, and it hides on you in places you wouldn't believe. Then all the sudden, what's wrong with me? I ain't been on the machine in two days. So, that's when you run back and it checks you. It lets you know, hey, you're still a patient. You still need to be on point. So, I get in that trap once in a while, get to feeling good or, you know, or even overextend myself as far as how much I'm going to attempt to do in a day, you know, and not schedule properly to get back to do it. And I'll just blow the day, and before you know it, you know, those times count up on you. Then when you go in for your monthly blood work, and it's like ah, 'jeez' and you can see it that way.<br>So, just being diligent about it is paramount, but you're feeling good, and you want to be like you were prior. It's a hard thing to not want to go back to that and to realize, you know, I still need to do this. So, that's the negative side for me." (HHD patient 5) | ● | ● | ● | ● |
| | Needle-related complaints | "And also, so the people who said that they were not pleased about taking the Aranesp—I have to take it every other week. And that is the strongest, stingiest thing that you can shoot into you, but I close my eyes and grit my teeth and just push the thing in. That's the only way I can get through that." (PD patient 5) | ● | ● | ● | - |
| | Insufficient treatment information | "I have something I want to share. I went out of town to dialysis and when I went down my pump sped up. Most of the patients are familiar with this. I don't know if you are or not, but the machines are supposed to, some of the machines go up to 500 and our machines sometimes won't go high enough, 400, 450. So a nurse in [redacted], when I went to visit my father, said I know why you can't get 500 because they're using the wrong needles on you and this is the largest needle that this hospital has and she said it was the wrong needle, which is what every patient uses, which is the 15-gauge needle. I went to [redacted], they started me 3 months ago on 14-gauge needles, which is bigger than a 15-gauge needle. Let me tell you, it don't feel no different. Let me tell you what it did, I just need to share this with the patients because I am the only patient in this hospital that uses that needle and I've been using it now for how long I've been back, about two months. And my blood work has been 78 since I've been using 14-gauge needles. It's the bigger the hole, the bigger the blood flow, the cleaner it gets, the more blood comes out. So I just wanted to share that because I don't know if they're testing them on me to see if this is really going to work before they introduce it to the other patients, but I'm telling you, I'm telling you, you got to ask for yourself. Because I came back and asked [redacted] and he said, 'You sure you want that? You're a big woman, you can handle that because the needle is big.' And I said whatever they offer for dialysis, I want the best that my insurance will pay for because pain is something you endure no matter how big or how small that needle is that's going in your arm, but I wanted to share the 14-gauge needle. Mostly everybody uses 15-gauge, but it is a 14-gauge needle that gives you a better treatment." (HD patient 2) | ● | ● | ● | - |

*(continued)*

**Table 2.** (continued)

| Themes | Subthemes | Illustrative Quotations | Contributing Groups HD | HHD | PD | T |
|---|---|---|---|---|---|---|
| | Logistical inconveniences | "I got a two-bedroom bungalow and the dining room is full. My wife has threatened me that me and the boxes both might have to go." (PD patient 1) | ● | ● | ● | - |
| | Poor quality care | "You know, I want to bring out what this gentleman said about being treated at the center like a number where they have that cart, and they ask how you're doing and do nothing for you at all. I've never seen so many heartless doctors as nephrologists. And even other nephrologists will tell you, they'll spend no time with you at all. [Redacted] at least talks to me. When you're in the center, and even at [redacted], they're terrible. They're terrible. You ask them more than one question, man, you're holding them up. You're holding them up, but he's getting paid. It's pitiful. It's absolutely pitiful the way they treat you. 'How you doing?' And then he moves two more feet down to the other person, 'How you doing?' And if you ask him more than one question, he starts looking at his watch. Now, is that the kind of doctor—is that the kind of physician you want? No. So, that was one of the deciding factors on why I wanted to get away from there." (HHD patient 4) | ● | ● | ● | - |
| Morbidity | Treatment complications | "I thought it was all going to be rosy, you know, boy, I know this isn't a cure, I've got that in my mind because I know, you know, it's just an alternative to end-stage kidney disease, but it took me at least a year to feel human. As the doctor said, it could be part of my age, but I didn't want to admit to any of that, but I stayed infected with one of my kidneys, my native kidneys, just one after the other, after the other, and then they were afraid that I would get the problem with having too many antibiotics. So finally they took out one of the native ones about eight months after my transplant, but then that operation threw me back into even more tiredness and not perking up." (T patient 1) | ● | ● | ● | ● |
| | Comorbidities | "I've been on high blood pressure medicine for the last 30 years, and I think being on the high blood pressure medicine is what caused me to be on dialysis . . . and I still have a heck of a time controlling the pressure. Some days it's good and some days it's, you know, it's high, you know . . . so, with me, pressure is a problem." (HHD patient 6) | ● | ● | - | - |
| Finances | None | "Well, I had a wrist fistula operation first and you know, up here—upper chest. [Redacted] told me, we'll start with the wrist, you know, it will work well there, you'd have a good vein, 98% success rate. Well, it never worked and then they said well, it only works half the time. So, I mean it's like if you go and buy a car and the car doesn't work, you want some money back, but their attitude is, oh it's okay, we'll just do another one and charge you another US$500, US$600. So that wasn't a very good start." (HD patient 5) | ● | ● | - | - |

Abbreviations: HD, hemodialysis; HHD, home hemodialysis; PD, peritoneal dialysis; T, posttransplant.
● Bullets symbolize the themes or theme-subtheme combinations relevant for each group.

## Theme 3: Treatment Delivery and Logistics

The treatment delivery and logistics theme characterized patients' perceptions of unexpected situations they considered challenging, painful, problematic, and inconvenient.

*Self-management difficulties.* All treatment groups discussed unanticipated difficulties with self-management behaviors. They particularly struggled with adhering to dietary recommendations:

> I didn't expect things like the diet and the diet plan . . . it was hard for me to keep focused on it. (Peritoneal dialysis patient 5)

Patients also experienced difficulties adhering to medication regimens:

> I didn't know it was going to be that much medications . . . sometimes I feel like, what if I skip? Will something happen to me? So, sometimes I don't have it. (Posttransplant patient 2)

Some patients described a pattern of poor self-management behavior that began once they started feeling better, which had negative implications:

> As I started to feel better, I still continued to do things I had no business doing until I lost control of my legs because of my phosphorus and no potassium . . . me and the floor kissed each other and the ambulance had to come and get me . . . they said you lucky you didn't die. (Hemodialysis patient 3)

Others expressed discomfort with the self-management skills and responsibilities associated with delivering treatment to themselves as well as emphasized the consequences of not taking these responsibilities seriously:

> I hate setting up the machine. I hate breaking it down. I don't like checking for the chloramines. I don't like the fact that . . . when you're making a batch, you've got to make sure you're timing it so you can get all three of your treatments in that day . . . that's the part I liked when I was going to the center. I just came, washed my arm, sat in a chair, and walked out . . . The onus was not on me. Everything that has to do with that machine, everything supposed to have been dialyzed falls on me . . . it's a commitment because your care is essentially in your hands . . . the patient has to realize this is serious because you really can kill yourself. (Home hemodialysis patient 3)

*Needle-related complaints.* Dialysis patients expressed their dislike for needlesticks. They considered the pain, blood loss, and bruising that accompanied needle insertions to be particularly unpleasant experiences:

> I dislike sticking the needles in my arm . . . it's painful. That's the part that kind of turns me off . . . I thank God when it's over. (Home hemodialysis patient 2)

*Insufficient treatment information.* Dialysis patients discussed how insufficient treatment information from providers prompted unexpected experiences. Whereas some patients unintentionally discovered valuable information their provider had not shared with them, others experienced panic due to a lack of forewarning:

> One thing that frightened me was . . . that I had a little blood in my bag . . . after having intercourse . . . That scared me to death. I wish someone had told me that could happen so I wouldn't have been so panicked. (Peritoneal dialysis patient 9)

Unsurprisingly, these patients advocated for more information:

> There needs to be more general information given out to people, period. Because unless you are aware of somebody that is on dialysis you know nothing about it. (Hemodialysis patient 6)

*Logistical inconveniences.* Dialysis patients discussed 3 unanticipated logistical inconveniences. One inconvenience was time constraints imposed by treatment:

> This is time consuming . . . I wanted it to be convenient . . . it's not always convenient to dialyze five days a week. (Home hemodialysis patient 3)

Another unforeseen logistical inconvenience was managing treatment supplies. Some patients dealt with constant supply orders, deliveries, and the disposal of packaging materials as well as sacrificed space in their homes to store supplies:

> My apartment looks like a clinic. It's got boxes, it's got the machine, and the boxes coming every two weeks. I'm looking at the different people coming in and you have to call and put your order in before you know it and it's just madness. (Peritoneal dialysis patient 3)

The third logistical inconvenience was noisy dialysis machines:

> This machine is noisier than the other one. And in the middle of the night, in the dark—and I'm by myself—I hear this groaning. (Peritoneal dialysis patient 8)

*Poor quality care.* Dialysis patients reported receiving poor quality care, which contradicted their expectations. These experiences prompted patients to question providers' competence, compassion, and communication skills:

> When I first started on dialysis I very quickly changed my nephrologist because I didn't like the way he told me that I was at end-stage renal disease . . . I said, oh no, he doesn't know how to talk to people . . . you would think he would be a little bit more

> sympathetic . . . they do need to learn how to talk to people, have a little bit more care. (Home hemodialysis patient 3)

Many patients reported dissatisfaction with the care they had received in dialysis centers. Consistent receipt of suboptimal care led some patients to contemplate pursuing treatment at home:

> Well, they don't read your report and if you tell them, they get like . . . you're hurting their feelings, but I'm the one that's sick. They're not sitting in that chair. I am. And there is a technician who I don't really care to touch me . . . that's why I am going to go on home dialysis . . . I trust my husband more than the technicians. They're more interested in going outside smoking than staying inside and watching their patients. (Hemodialysis patient 9)

Likewise, other patients described how poor quality care prompted them to undergo treatment at home:

> I just felt like I was a number in the center . . . they didn't give me the impression that they really cared . . . it was just all about numbers and money at the center. I think that doctor there-was one of the worst physicians I've ever encountered . . . I felt that if I stayed at that center that I was going to perish. (Home hemodialysis patient 2)

Further, some patients attributed providers' negligence to fistula complications and infections. For example:

> I have a permacath right now . . . I didn't know what to expect from it . . . And I kept asking why it was constantly draining and they just kept changing the dressing and wondering about it, but never did anything about it . . . It was infected. So now I'll watch it to make sure there isn't any drainage because I don't want them cutting me to put another one in there for foolishness . . . I feel like these are professionals, they're supposed to know. I didn't know. (Hemodialysis patient 8)

### *Theme 4: Morbidity*

The morbidity theme described patients' unexpected experiences with treatment complications and comorbidities.

*Treatment complications.* All treatment groups referenced unanticipated treatment complications. Some patients encountered problems with fistulas and catheters that required clinical intervention:

> Well, I've had five catheters put in and three fistulas . . . They just fail me . . . I've had a lot of operations. (Home hemodialysis patient 4)

Others mentioned increased hospitalizations from treatment complications and infections:

> I wasn't expecting, after my second transplant, all the infections that I got. I didn't have that after my first transplant but after my second one I seemed to have been hit with just infection after infection. (Posttransplant patient 7)

*Comorbidities.* Dialysis patients discussed how treatment unexpectedly exacerbated or complicated comorbid conditions, specifically asthma and high blood pressure. For example:

> I've had two slight asthma attacks since I've been coming [to the dialysis center] and I haven't had an asthma attack in 55 years . . . one of them began during the treatment. (Hemodialysis patient 6)

### *Theme 5: Finances*

Dialysis patients discussed unexpected treatment expenses. Some patients expressed frustration with paying for ineffective procedures (eg, fistula operations). Others described the financial strain that resulted from being too ill to work. Patients also talked about the cost of hiring caregivers to assist with treatment delivery at home:

> It's very difficult to do your home dialysis with just yourself . . . so I've got to pay somebody else to do it . . . But I'm an [redacted] and I've done fairly well . . . but to the other people, it's tough for them. (Home hemodialysis patient 4)

## Discussion

Dialysis and posttransplant patients described a broad range of unexpected adverse experiences with ESKD treatment. The majority of experiences, however, reflected nonclinical aspects of treatment, including how treatment induced negative emotions, restricted autonomy, created practical challenges and inconveniences, and caused financial strain. These experiences may result from a mismatch between treatment aspects prioritized by providers and those prioritized by patients (32). Prior research suggests that providers tend to emphasize clinical factors (eg, mortality) whereas patients strike more of a balance between clinical and nonclinical factors, at times prioritizing quality of life over mortality (27, 32–34). Providers who disseminate treatment information primarily about clinical factors may leave patients unprepared for treatment experiences that are meaningful to them. These findings underscore the importance of providers minimizing the mismatch between their own and patients' treatment information priorities.

Notably, some patients attributed unexpected treatment experiences to a lack of forewarning from providers, and others called for providers to supply more treatment information. Still, not all patients want preparatory information despite its benefits (21,35,36). Individual variation in patients' preferences for preparatory information highlights the need for providers to use person-centered preparatory techniques (37). In light of time constraints that may preclude providers from engaging in sustained, personalized conversations with patients (22), the experiences described here may serve as a starting point for informing preparatory discussions. Further, providers can improve patients' access to preparatory information by recommending educational materials that may help them formulate questions and feel more knowledgeable about treatment. Given that patients' preferences for preparatory information may change over time, providers should evaluate their preferences throughout the treatment trajectory.

Additionally, our findings highlight the necessity of helping patients psychologically prepare for ESKD treatment. While other studies have similarly observed adverse psychological treatment reactions among patients (38), this study shows that these reactions are not always expected. If patients do not foresee their own reactions, they are likely unprepared to cope with them. This notion is concerning, as psychological problems are linked to poorer clinical outcomes, lower quality of life, and increased risk of mortality in ESKD patients (39–41). Pretreatment psychological preparation interventions should equip patients at risk of developing ESKD with behavioral coping strategies, emotional coping strategies, and coping appraisal skills, as these techniques have been helpful in reducing treatment-related distress for other chronic disease patients (42). Once patients develop ESKD, proactive psychosocial care is pivotal. Findings lend support for providers' use of brief screening tools to assess patients' psychological well-being; these tools can help providers identify patients who would benefit from further evaluation by mental health professionals (43). Moreover, providers should consider the potential for psychological health to affect self-management behavior (44). Acknowledgment that noncompliant patients may be experiencing difficulty accepting or adjusting to treatment could facilitate detection and subsequent management of psychological problems.

### *Limitations*

Limitations of this study warrant mention. First, data collection occurred several years ago. However, ESKD treatment has not significantly changed since the study was conducted. Second, the sample comprised patients receiving medical care in one geographic area, which could limit the generalizability of the results to patients from different geographic areas. Third, some patients experienced multiple treatment modalities; familiarity with different treatment modalities could have altered recollections of experiences specific to one modality. Notwithstanding these limitations, this study constitutes an initial step toward filling an important gap in the literature by describing patients' unexpected experiences with ESKD treatment. The findings reported here lay the groundwork for future research on ESKD treatment preparedness and provide insight that may improve providers' delivery of person-centered care.

## Conclusion

Dialysis and posttransplant patients described various unexpected adverse experiences with ESKD treatment. The need for providers' use of person-centered preparatory techniques and the development of pretreatment interventions to help patients know what to expect from and feel psychologically prepared for treatment cannot be understated. These efforts have great potential to improve patients' appraisals of and satisfaction with treatment experiences.

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### Supplemental Material

Supplemental material for this article is available online.

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