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Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study

Jane O. Schell, MD^{1,2}, Uptal D. Patel, MD^{1,3}, Karen E. Steinhauser, PhD^{2,4}, Natalie Ammarell, PhD⁵, and James A. Tulsky, MD^{1,2,4,5}

¹Department of Medicine, Duke University

²Center for Health Services Research in Primary Care, Durham VA Medical Center

³Duke Clinical Research Institute

⁴Duke Center for Palliative Care

⁵School of Nursing, Duke University, Durham, NC

Abstract

Background—Elderly patients with advanced kidney disease experience considerable disability, morbidity, and mortality. Little is known about the impact of physician-patient interactions on patient preparation for the illness trajectory. We sought to describe how nephrologists and older patients discuss and understand the prognosis and course of kidney disease leading to renal replacement therapy.

Methods—We conducted focus groups and interviews with 11 nephrologists and 29 patients older than 65 years with advanced chronic kidney disease or receiving hemodialysis. Interviews were audiorecorded and transcribed. We used qualitative analytic methods to identify common and recurrent themes related to the primary research question.

Results—We identified 6 themes that describe how the kidney disease trajectory is discussed and understood: (1) patients are shocked by their diagnosis, (2) patients are uncertain how their disease will progress, (3) patients lack preparation for living with dialysis, (4) nephrologists struggle to explain illness complexity, (5) nephrologists manage a disease over which they have little control, and (6) nephrologists tend to avoid discussions of the future. Patients and nephrologists acknowledged that prognosis discussions are rare. Patients tended to cope with thoughts of the future through avoidance by focusing on their present clinical status. Nephrologists reported uncertainty and concern for evoking negative reactions as barriers to these conversations.

Conclusions—Patients and nephrologists face challenges in understanding and preparing for the kidney disease trajectory. Communication interventions that acknowledge the role of patient emotion and address uncertainty may improve how nephrologists discuss disease trajectory with patients and thereby enhance their understanding and preparation for the future.

Index Words

Geriatric nephrology; doctor-patient communication; disease trajectory

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Address correspondence to Jane O. Schell, MD, Duke University, 2424 Erwin Hock Plaza, Ste 1105, Box 2720, Durham, NC 27705. jane.schell@duke.edu.

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Elderly patients with advanced chronic kidney disease (CKD) experience considerable disability and morbidity.^{1,2} Their disease trajectory tends to follow a similar course to other life-limiting illnesses, defined by a subtle decline over time marked by acute exacerbations.³ As their health declines, patients also experience increased symptoms and emotional burdens that further impact on outcomes.⁴⁻⁸ Patients' understanding of this disease trajectory can affect treatment decisions throughout the disease course and at the end of life. In addition, interactions with their nephrologists can strongly influence how well patients are informed about and prepared for the trajectory of kidney disease.

This relationship begins when patients are referred to nephrologists, continues when treatment plans are begun, and often ends with death. Guidelines exist to assist nephrologists in preparing patients for potential renal replacement therapy.⁹ However, less is known about how nephrologists prepare patients for understanding their individual prognoses and living with their kidney disease. Considerable research has shown that communication interventions can increase understanding of the disease course and decrease psychological distress.^{10,11}

Therefore, we conducted this study to explore how nephrologists and elderly patients at different stages of the disease trajectory view and discuss the kidney disease course. Themes identified from this qualitative work lay the groundwork for future interventions to help patients live with kidney disease.

Methods

Study Design, Setting, and Participants

We conducted focus groups and one-on-one semistructured interviews to explore how elderly patients and nephrologists understand and discuss the kidney disease trajectory and analyzed them using a qualitative approach.¹² Qualitative methods are best suited for gathering rich descriptive information about a phenomenon for which few data or conceptual understanding exist.¹³

Participants were recruited from one academic setting, Duke University Health System, and one community nephrology practice in Durham, NC. Recruitment letters were sent to 142 patients, including those with stages 3-5 CKD and those receiving hemodialysis, inviting them to participate, and within 2 weeks after receiving the letter, they were contacted by telephone. Patients were invited to attend a scheduled focus group time or a one-on-one interview if they could not attend the focus group. One home interview was scheduled to accommodate a patient who could not drive to the interview. No data were collected from patients for whom a face-to-face interview could not be arranged.

Patients were included if they were older than 65 years and, if they had CKD, had been referred to a CKD education class. Patients were excluded if they could not meaningfully interact in a focus group setting, had a history of dementia, or lacked capacity for providing informed consent. Nephrologists whose work included at least 70% clinical activity were identified and invited to participate.

Data Collection

A semistructured interview guide based on the relevant literature and clinical experience included open-ended questions to explore how nephrologists discuss the trajectory of kidney disease and how it is understood by patients^{14,15} (Box 1). Interviews were conducted until thematic saturation was obtained and no new themes were revealed.^{16,17}

Analysis

All interviews were audiorecorded and transcribed. Atlas.ti (version 5.2; Atlas.ti Scientific Software Development GmbH, www.atlasti.com) was used to store, code, and analyze the data. Descriptive subthemes emerged that later were grouped into 6 themes (3 patient and 3 nephrologist) describing how the disease trajectory is discussed and understood throughout the disease course (Item S1, available as online supplementary material). Transcripts were read and coded independently by 2 researchers (J.O.S. and N.A.); any disagreements in analysis were identified and reconciled. The study was approved by the Duke University Institutional Review Board.

Results

Letters were sent to 142 patients. Of these, 103 were called and 29 attended an interview or focus group (Fig 1). Two focus groups and one one-on-one interview were conducted for the 11 patients with CKD. For the 18 hemodialysis patients, 16 one-on-one interviews and one focus group were conducted. Hemodialysis patients preferred conducting interviews while receiving dialysis treatment, which necessitated primarily one-on-one interviews in this group. Two focus groups and one one-on-one interview were conducted with the nephrologists (Fig 2).

Of patients with CKD, only 2 had undergone preemptive vascular access placement at the time of the interview. Hemodialysis patients had been on hemodialysis therapy for a median of 3.5 (range, 1-15) years (Table 1). More than half the nephrologists practiced at an academic center and the group was mostly white and men. The 9 respondents who returned the demographic form reported seeing a median of 40 patients weekly (Table 2).

The 6 final themes were categorized according to the challenges patients and nephrologists encounter at each stage of the trajectory. A conceptual model was developed iteratively to capture these themes along the kidney disease trajectory (Fig 3).

Patient Themes

Patients Are Shocked by Their Diagnosis—Patients reported difficulty understanding their disease, often from the time they first learned about the diagnosis. First, patients reported having no preparation from their primary care physician. For many, their initial encounter with a nephrologist was the first time they learned they had kidney disease. If patients had been told they had kidney problems, most did not appreciate the seriousness of the diagnosis. One patient noted being much more concerned with his diabetes and heart disease than his kidney disease.

The absence of symptoms presented another challenge to understanding the implications of the diagnosis. Without measurable symptoms, patients found the notion of disease elusive and confusing. One patient remarked:

“If I had a kidney problem, I should have signs telling me things aren't right.”

In response to these challenges, patients routinely expressed strong emotions.

“I mean I was just in shock. When you are taken by surprise, it's hard for me to come up with the right questions.”

Patients reported that these feelings often were unrecognized by their nephrologists. One patient remarked,

“People just don't know what you got on your brain. You smiling [and] they think you're not worried.”

Some patients appeared to present a strong face to the physician while suffering internally.

Patients Are Uncertain How Their Disease Will Progress—After learning the diagnosis, patients did not know how their disease would progress over time. This was evidenced by the kinds of information discussed during clinic visits with the nephrologist. Their descriptions of these interactions tended to focus on the laboratory numbers, often without context. When patients heard a particular creatinine level, for example, they lacked understanding of the value's meaning relative to their own experience.

This confusion hindered their acceptance of future dialysis therapy. Nephrologists routinely encouraged patients to undergo pre-emptive vascular placement, yet only 2 of the 11 patients with CKD had done this. One patient described the challenge of considering surgery for access when he “feels good,” without discernible symptoms.

Patients reported that the decision to undergo dialysis therapy was often discussed without knowledge of how it would impact on their lives. Many of these patients had attended a CKD education class, yet few could describe the benefits and burdens of dialysis therapy or the effect it would have on their daily lives. One simply said, “It just wouldn't be fun.” Interactions with nephrologists typically did not improve this understanding.

“They really didn't tell me what kinds of things to expect. Before they just told me sooner or later I would go on dialysis ... to purify my blood.”

Patients lacked any information about the future, often being told only that they needed dialysis to keep them alive.

“I haven't been told what the future's like except that you go on dialysis every other day and you're supposed to ... You have to do it or you die.”

These patients approached the possibility of future dialysis therapy with little knowledge of how it would affect their current status as well as their future. Lack of information led to a sense of powerlessness.

“I say suppose I don't want to do this. The bottom line of what he said is ‘you will die.’ I said, ‘oh, then I must do this.’”

When faced with choosing between life and death, many were resigned to their futures on dialysis therapy. As a result, patients described living in fear of when dialysis would be necessary. Although most patients acknowledged the uncertainty of their disease and the limitations of their nephrologists' predictions, patients still wanted information. As one stated, “The unknown is frightening.” More knowledge is better than none.

In response to these challenges, patients coped through avoidance and false hope. Many patients focused on their current level of functioning and put off preparation for dialysis therapy. This attitude was reinforced by the stability of their clinical status and lack of symptoms.

“A big part of me says I'm going to stay stable and won't have to do it ... I'll deal with it when it comes.”

Patients Lack Preparation for Living With Dialysis—Despite preinitiation nephrology visits, the hemodialysis patients interviewed described feeling unprepared for the experience of day-to-day life on dialysis therapy and the adjustments they would eventually make. For them, entering this new phase of life presented unforeseen challenges, both mental and physical, and struggles of dealing with the unknown.

Physical challenges included discomfort experienced during the treatment followed by fatigue afterward. One patient shared his 3-year struggle with diabetic neuropathy, which prompted him to threaten withdrawing from dialysis therapy. It was only then that his pain was discussed and adequately treated. The mental adjustment to life on dialysis therapy was just as intense as the physical one. Patients reported challenges, including time limitations, dietary issues, and lack of freedom.

Despite these significant concerns, discussions with nephrologists in dialysis units typically focus on the monthly laboratory tests. Discussions of how the patients' own clinical status would progress and what the future might hold were rare.

“The only thing they say is ‘functioning fine.’ But the function of what? ... I don't know what comes after this?”

Most patients responded to these challenges and the uncertainties of dialysis therapy by focusing on the present. Others described coming to terms with a disease for which there appeared to be no clinical progress. Many responded with sentiments of resignation.

“The situation I'm in ... I think about it a whole lot because that's no way to live ... it seems like I'm going around in circles. You know I watch these people that come to dialysis and I see that's the way I am.”

Feelings of resignation persisted throughout the interviews. One patient alternated between dismissing concerns of the future and moments of somber realization of the uncertainty of his fate.

“What if something happens next, what am I going to do? But it don't bother me. It does at times, you know, bother me. I try to slough it off. I got to do this, I got to do that. Just hang in there.”

The only concrete references to the future included discussions of potential transplant. For most of these patients, these discussions emerged from stories of transplant they learned from the community or from fellow patients rather than from health care providers. With the exception of 2 patients, all hemodialysis patients believed they were either too old or too sick to receive a transplant.

“They ask me why I'm not putting myself on the list. I tell them because of my age and plus ... when I had my leg amputated and I had open heart surgery ... I have been cut through here and cut through there. I'm not going that route.”

Nephrologist Themes

Nephrologists Struggle to Explain Illness Complexity—In discussing the diagnosis with patients, nephrologists reported significant challenges to helping patients understand their disease and its implications. First, patients often arrive at their first nephrology clinic appointment having no previous information about their disease. They may not know why they are being referred to a kidney specialist, a situation that is worsened by the large amount of information that must be conveyed.

In addition, nephrologists frequently reported a sense of urgency to educate and prepare the patient. If a patient presents at an advanced stage or with rapid progression of disease, they must begin treatment preparations quickly. One nephrologist described the challenge of preparing these patients, “If they don't understand, you got to get them to understand the modalities, pros and cons, right away.” In response to these challenges, nephrologists often tailor the information that they provide based on patient factors and their perception of how well they believe the patient will handle the information.

“I tend to start talking to them depending on their education and anxiety level. It becomes clear to me what they can absorb ... and understand.”

In addition, many nephrologists report that if a patient's kidney function appears stable, they will often delay or not emphasize certain kinds of information, such as explanation of dialysis, until later.

“I try not to scare them on the first visit. If they are not facing dialysis right away, then I prepare them slowly.”

Nephrologists Manage a Disease Over Which They Have Little Control—

Beyond conveying the diagnosis to patients, nephrologists identified the challenge of caring for patients for whom, despite their management, the course is often progressive and unpredictable. Nephrologists expressed a sense of powerlessness with regard to a patient's disease course.

“You can do the best you can and know you are going to minimize [disease progression] ... beyond that whatever is going to happen happens.”

This sense of powerlessness is especially challenging as nephrologists approach discussions of disease progression and treatment preparation. They acknowledged that the disease course can be unpredictable and often asymptomatic until very late in the course. Therefore, nephrologists' discussions tended to focus on laboratory data, particularly in the context of when dialysis would be necessary.

“I spend most of my time trying to answer the question of when and try to get across the unpredictability in most cases.”

All nephrologists interviewed used laboratory trends and graphs to facilitate these conversations.

“So that they have an understanding of this on the graph, ‘This is where you are. This is where dialysis is. You're heading in that direction or you're not heading in that direction.’”

Nephrologists also reported feeling helpless in the face of patient nonadherence. Although nephrologists described giving handouts and referrals to education class, they often were frustrated when patients failed to follow through with treatment plans despite this information. Regarding preparation for pre-emptive vascular access placement, one nephrologist reported having to tell patients the information over and over again to increase the likelihood they understood. Another nephrologist judged patients' understanding of the necessity for pre-emptive access placement by whether they showed up for the surgical clinic visit.

Nephrologists Tend to Avoid Discussions of the Future—Nephrologists stated that they generally do not discuss prognosis and the future unless prompted. Two challenges to engaging in these conversations are uncertainty of the patient's course and their own perceptions of prognosis.

Just as nephrologists expressed difficulty predicting kidney progression, they also acknowledged the challenge of foreseeing how a patient will do clinically. This inability to predict a patient's course served as a barrier to conversations of prognosis and the future.

“I think it's ... where I say I don't know how they might do is the hard part ... because I don't think we can clearly say how a person is going to do on dialysis.”

Only one nephrologist reflected on the difficulty predicting how dialysis would impact on a patient's suffering and quality of life.

“It’s hard to quantify how much someone will tolerate, what they will tolerate and sort of their life plan or how they want to die.”

An additional challenge to discussions of the future was nephrologists’ own perceptions of prognosis. Many believed these discussions would be interpreted as negative and remove patients’ hope. Although discussions for younger patients were described as positive and involved the future possibility of kidney transplant, for older patients, prognosis was viewed mostly in terms of survival with or without dialysis therapy. For patients with CKD already committed to dialysis, these conversations were rare. One nephrologist viewed disclosing prognosis information at that point as unhelpful “to beat them over the head with mortality statistics.”

In response to these challenges, nephrologists tended to avoid uncertainty and engage in discussions of prognosis or end of life only when prompted. These discussions typically occurred in the setting of acute illness or hospitalization or, less frequently, prompted by patients.

“I don’t think we really talk about prognosis in patients who we think are stable and nothing is going on.”

Discussion

This study highlights how discussions and understanding of the trajectory of kidney disease are challenging for both patients and nephrologists. Patients’ strong emotions serve as a barrier to understanding their disease course and preparing for the future. Many also described lacking important information about their disease and its treatment. In turn, nephrologists expressed difficulty helping patients understand and prepare for a disease that is largely asymptomatic and difficult to predict.

Patients experience strong emotions throughout their disease course, beginning at the time of diagnosis and continuing throughout their disease trajectory. Although nephrologists recognize that patients often are uninformed regarding their disease, they often respond by tailoring the information given, rather than addressing patients’ emotions. Nephrologists are not alone in doing this as most physicians have difficulty recognizing and responding to patient emotion.^{18,19} This task becomes even more challenging because many patients express emotion nonverbally. Emotion has been associated with psychological distress and can affect patient understanding.^{20,21}

As care continues over time, patients have difficulty understanding the disease, especially in terms of its impact on their own experience and expectations. Although the progression of their disease typically is communicated through laboratory tests, patients know little about the effects of dialysis on their daily life, which can lead to both fear and false hope. Once on hemodialysis therapy, patients face new unexpected adjustments and challenges that extend far beyond their thrice-weekly dialysis sessions. These findings replicate other studies that have identified psychological stressors within this population.^{14,15,22,23} These symptoms warrant recognition and attention similar to that of kidney-related problems, such as anemia and bone mineral management.

Additionally, most patients in this study had not discussed prognosis with their physicians. Nephrologists tended to engage in these conversations with patients experiencing an “acute” event rather than patients considered “stable.” Because these conversations are not occurring, these elderly patients tended to focus on their current functioning without adequate preparation for what could happen in the future. This is unfortunate because earlier conversations of the goals of care and preferences can affect decision making at the end of

life and have been associated with less aggressive care at the end of life.²⁴ Further, timely discussions allow for palliative care services when appropriate.^{25,26}

These findings highlight the role of effective communication in enhancing patients' experiences and understanding of their disease course. Tools exist to assist physicians in identifying and responding to patient emotion (Box 2²⁷⁻²⁹). Recognizing and responding to emotion facilitates patients' ability to receive and understand information about the disease and its management. It also has been shown to increase patient trust and reduce anxiety.^{30,31}

In addition, tools exist to address patient understanding. Patients described a lack of basic understanding of their disease and its future course. Nephrologists described the challenge of having to give patients information, often having to repeat the information many times to ensure understanding. Using a communication tool Ask-Tell-Ask, discussions begin by "asking" what the patient's understanding is, then "telling" the relevant information, and finally assessing the patient's understanding of the information by "asking" the patient to reiterate what was said (Box 2). This ensures that both the physician and patient understand what has been said and understood by the patient.

Finally, patients describe uncertainty in knowing how their disease may progress in the future. This uncertainty is mirrored by physicians' own uncertainty and lack of control in predicting and managing the disease course. Such uncertainty is not unique to nephrology, yet has been discussed little in this field.³²⁻³⁵ Although nephrologists respond to uncertainty and lack of control by focusing on giving medical information and avoiding discussions of prognosis, reframing discussions of disease progression and the future in terms of the patient's goals and understanding can be more helpful and fulfilling (Box 2).³⁶⁻³⁸ Further, in the face of medical uncertainty, patients want to know about potential scenarios in language that is honest and understandable.^{39,40} When nephrologists engage in these conversations early and in a manner that addresses patient preferences, patients are better equipped to face future events, such as dialysis and end-of-life decisions.

This study shows key areas within nephrologist-patient communication amenable to interventions that address patient understanding and treatment decision making. Effective communication has been shown to enhance patient understanding, shared decision making, and implementation of care plans consistent with patient preferences and goals.⁴¹⁻⁴³ Given the impact of dialysis on mortality and quality of life, improved discussions of the kidney disease course may benefit patients at multiple points in the disease trajectory.^{37,44,45}

This is a qualitative study meant to deepen the understanding of a poorly described phenomenon and generate hypotheses for further quantitative studies. Ethnic differences between patients and nephrologists raise the question of cultural differences that may affect how these discussions occur and are understood. The patients who were called and agreed to participate in the study may differ from patients not called, patients who could not attend, or patients who did not agree to study participation. In addition, hemodialysis patients mostly opted for one-on-one interviews instead of focus group interviews due to their dialysis schedule. Although this may have deterred the stimulation of ideas that occurs when participants share thoughts within a group, one-on-one interviews provided in-depth discussion. The content between the 2 modalities did not vary and theme saturation was reached with both modalities. Although we collected data until we believed there was an adequate description of how the disease course of kidney disease is discussed, additional themes important to adequately describing this exchange may have been missed.

In conclusion, these data show the gaps that exist in how nephrologists and elderly patients discuss and understand the kidney disease course. Interventions that focus on addressing emotion, uncertainty, and understanding may improve patients' experiences. Effective

communication may enhance patient-centered care and promote greater shared decision making.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Box 1**Interview Guide****Examples of Nephrologist Interview Questions and Probes****Diagnosis**

- Using an example of a 75-year-old woman with stage 4 CKD coming to see you for the first time:
 - What topics are important for you to cover?
 - How do comorbidity and age play a role?

Disease Progression/Treatment Preparation

- How do you discuss disease progression and how things will go over time?
 - How do patients respond to these discussions?
 - How do you know if they understand what they've heard?

Dialysis/End of Life

- How and when do conversations of prognosis come up:
 - With CKD patients?
 - With dialysis patients?
- What are some of the challenges of having discussions about the future?
- What do you think the role of the nephrologist is in having these discussions with patients?

Examples of Patient Interview Questions and Probes**Diagnosis**

- Tell me about your story and how you learned about your kidney disease.
- What are some of the things you wish you had a better understanding of?
- What is your understanding of dialysis?
 - Pros and cons of dialysis
 - How your daily life would be affected on dialysis

Disease Progression/Treatment Preparation

- I'd like to hear more about your experience of living with your condition:
 - Physically
 - Emotionally
 - Quality of life
- How has this experience and understanding changed over time?

Dialysis/End of Life

- I'm curious to know how you think your kidney disease will go over time:
 - Has your kidney doctor discussed with you how your disease will go over time?

- What do you expect the course to be?
 - How important is it to talk about the future?
- Abbreviation: CKD, chronic kidney disease.

Box 2**Communication Skills****A. Identifying patient concerns****1. Eliciting concerns**

- a.** Open-ended questions (“What concerns you about your kidney disease?”)
- b.** Active listening (Allowing patient to speak without interruption; reflecting back what you hear from the patient)

2. Recognizing concerns

- a.** Informational concerns (Patient: “I’m not sure about the treatment options”)
- b.** Emotional concerns (Patient: “I’m worried about that”)

B. Responding to informational concerns: “Ask-Tell-Ask”

- 1.** Ask (“What is your understanding of your illness?”)
- 2.** Tell (After learning what the patient knows, the physician can better tell the information in a way that addresses patient concerns and needs)
- 3.** Ask (“To make sure that I explained things well, can you tell me what you understand of what I’ve just said?”)

C. Responding to emotional concerns (verbal empathy): N-U-R-S-E

- 1.** Name the emotion: “You seem worried”
- 2.** Understand: “I see why you are concerned about this”
- 3.** Respect: “You have shown a lot of strength”
- 4.** Support: “We will get through this together”
- 5.** Explore: “Tell me more”

D. Discussions about the future

- 1.** Eliciting values and preferences (“As we talk about the future, what are your hopes and what is important for me to know as your doctor?” or “When you think about the future, what concerns you most?”)
- 2.** Addressing uncertainty: hope for the best, prepare for the worst (“While we hope that you do well on dialysis, I think it’s important to prepare you in case things don’t go as we plan”)

Note: When applicable, examples are shown in parentheses. Adapted from the communication guideline “Shared Decision-Making in the Appropriate Initiation of and Withdrawal of Dialysis” by the Renal Physician Association.²⁷

Figure 1.

Patient recruitment. ^aA deliberately large number of letters were sent out in an attempt to ensure enough study participants. ^bPatients were labeled as demented by either family member answering the telephone or the dialysis unit charge nurse. No formal testing for dementia performed. Abbreviation: CKD, chronic kidney disease.

Figure 2.
Nephrologist recruitment.

Figure 3.
Trajectory of kidney disease with patient and nephrologist themes.

Table 1
Patient Characteristics

	CKD (n = 11)	Hemodialysis (n = 18)
Age (y)	68 (65-92)	72 (65-88)
Men	7 (64)	9 (50)
Ethnicity		
White	6 (55)	5 (28)
Black	5 (45)	13 (72)
eGFR (mL/min/1.73 m ²)	22 (12-48)	—
No. of nephrology visits	3 (2-20)	—
No. of patients with access placed	2	—
Duration of dialysis (y)	—	3.5 (1-15)

Note: Continuous variables shown as median (range); categorical variables are given as number (percentage).

Abbreviations: CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.

Table 2
Nephrologist Characteristics

Characteristic	Value
Age (y)	50 (34-60)
Men	10 (90)
White ethnicity	8 (73)
Practice type	
Academic	6 (55)
Private	5 (45)
Time in practice (y)	19 (2-30)
No. of patients seen per week	40 (28-60)

Note: N = 11. Continuous variables shown as median (range); categorical variables given as number (percentage).