



# Family Involvement in Decisions to Forego or Withdraw Dialysis: A Qualitative Study of Nephrologists in the United States and England

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**Background:** Shared decision making may be particularly complex for the older patient with end-stage renal disease (ESRD), in part because of family involvement. Nephrologists' perspectives on the family's role in ESRD decision making have not been explored.

**Study Design:** Semi-structured, individual, qualitative interviews.

**Setting & Participants:** Practicing US and English adult nephrologists.

**Methodology:** Participants were purposively sampled based on age, race, sex, geographic location, and practice type. Each was asked about his or her perspectives and experiences related to foregoing and withdrawing dialysis therapy.

**Analytical Approach:** Interviews were audiotaped, transcribed, and analyzed using narrative and thematic analysis.

**Results:** We conducted 59 semi-structured interviews with nephrologists from the United States (n = 41) and England (n = 18). Most

participants were 45 years or younger, men, and white. Average number of years since completing nephrology training was 14.2 (SD, 11.6). Nephrologists in both countries identified how patients' families may act to facilitate or impede decisions to forego and withdraw dialysis therapy, which fell within the following subthemes: (1) emotional response to decision making, (2) involvement in patient health care/awareness of illness, (3) trust in physician, and (4) acceptance of patient wishes. Only US nephrologists raised families' financial dependence on patients as an impediment to foregoing or withdrawing dialysis therapy.

**Limitations:** Participants' views may not fully capture those of all US or English nephrologists.

**Conclusions:** Nephrologists in the United States and England identified several ways that patients' families help and hinder ESRD decision making in keeping with patient prognosis and preferences. Nephrologists should hone their communication skills to better navigate these interactions.

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Although dialysis may confer a survival benefit and improve quality of life and functional status for younger patients with end-stage renal disease (ESRD), it may not for older patients or those with poor prognoses.<sup>1-10</sup> Further, because dialysis corrects uremia but not the trajectory of decline associated with kidney disease or new life-limiting diagnoses, benefits derived from dialysis early on may wane over time. Therefore, decisions to forego or withdraw from dialysis therapy may be needed.

Shared decision making is a key component of patient-centered health care in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values. When patients lack decision-making capacity, decisions fall to family members acting as surrogate decision makers who are charged with following a patient's expressed preferences when known or acting in the patient's best interests when preferences are not known.<sup>11</sup> However, even when patient decision-making capacity is intact, patients often involve or rely on family to help make decisions about dialysis.<sup>12</sup> For the older patient with ESRD, decision making may be particularly complex because of cognitive impairment, prognostic uncertainty, and family involvement.

In prior work, nephrologists have expressed that access to established conservative management pathways (ie, medical management without dialysis) eases decisions to forego or withdraw dialysis therapy. This study focuses on the perspectives of nephrologists in England (where conservative management pathways are readily available) and the United States (where they are not) regarding the ways in which family members facilitate or impede decisions to appropriately forego or withdraw dialysis therapy. Understanding these influences could help nephrologists engage in more effective shared decision making with their older patients with ESRD.

## METHODS

### Study Design and Conduct

We used a comparative narrative design of nephrologists' beliefs and practices in the United States and England as related to dialysis decision making, as previously described.<sup>13-16</sup> We developed an interview guide using practical knowledge of the clinical arena and existing literature, with the intention of capturing factors influencing nephrologists' beliefs and practices (Box 1). The University of California, San Francisco Institutional Review Board approved the study (#13-11184).

**Box 1.** Interview Guide

- 1) Can you describe the process by which a patient outside of the hospital starts receiving dialysis? Who are the key individuals involved in making that happen? What are the local or national policies that help guide the process?
- 2) What about for the patient in the hospital? How is the process different?
- 3) Are there clinical situations in which dialysis is not routinely offered to patients? Do you agree/disagree? Are there other clinical situations when you think dialysis should not be offered? Can you tell me more about your nephrology practice in relation to not offering dialysis? Is this a topic that you discuss regularly with your colleagues?
- 4) How do you usually approach discussions about dialysis with patients? How does your approach vary from patient to patient? Do you offer your opinion? If so, how?
- 5) Tell me about a time when you did not offer dialysis (or wished you had not offered dialysis). How did this affect you at the time? Did this experience affect how you approached clinical situations going forward?
  - a. If you always offer dialysis, why do you think that is?
- 6) Tell me about a time when you managed a patient without dialysis. Whose idea was it (yours, patient's, family member's)? Did you suggest this option? How did this affect you at the time? Did this experience affect how you approached clinical situations going forward?
  - a. If you've never managed a patient without dialysis, why do you think that is?
- 7) Tell me about a time when you withdrew a patient from dialysis. Whose idea was it (yours, patient's, family member's)? Did you suggest this option? How did this affect you at the time? Did this experience affect how you approached clinical situations going forward?
  - a. If you've never withdrawn a patient from dialysis, why do you think that is?
- 8) What are the challenges and facilitators of coming to a reasonable decision regarding dialysis? Are there ways that we could overcome those challenges to enhance the practice of dialysis in this country? In an ideal world, what would you like to see changed regarding the practice of dialysis in this country?

**Participant Selection**

One investigator from England (D.O.) and one from the United States (N.R.P.) identified lead nephrologists who cared for adult patients with ESRD from dialysis units around the country to participate in the study. They in turn were asked to identify other nephrologists representing maximum variation between nephrologists by age, race, sex, and geographic location. In the United States, purposive sampling was supplemented by random solicitation of participants at a national meeting and additionally used to identify informants from the varied practice types and payment structures. We did not enroll nephrology trainees, nephrologists without a clinical practice, or pediatric nephrologists.

**Data Collection**

One investigator (V.G.) conducted individual semi-structured interviews between June 2013 and June 2014 at a time and by means (eg, in person or telephone) convenient for each participant. After providing written informed consent, participants were asked to provide basic demographic and practice characteristics and were then asked about their experiences regarding treatment decisions for patients with ESRD, specifically focused on situations involving foregoing dialysis and dialysis therapy withdrawal. Interviews were recorded and transcribed verbatim.

**Analysis**

Narrative and thematic analyses were systematically conducted by 2 investigators (V.G. and D.S.T.) using constant comparative analysis of text within and between

interviews. Codes regarding the central themes were decided by consensus after independent analysis of 9 cases, 6 from the United States and 3 from England, selected randomly to represent both countries. Subsequent interviews were then coded according to these themes, using Atlas.ti to discover the range and variability in the sub-themes and scan for new themes. Saturation of themes was achieved after half the interviews were analyzed; all remaining interviews were thoroughly examined and provided evidence confirming our findings.

**RESULTS**

A total of 59 interviews were completed among 18 English nephrologists and 41 US nephrologists. Average duration of interviews was 34 (range, 13.5-60) minutes. All English nephrologists were interviewed in person. Ten US nephrologists were interviewed in person; 10, by videoconference (eg, Skype or FaceTime); and 21, by speakerphone.

Most participants were 45 years or younger, men, and white (Table 1). Average number of years since completing nephrology training was 14.2 (SD, 11.6; range, 0-44). About half practiced within groups of 10 to 20 nephrologists. While all English nephrologists practiced within the same closed system (ie, National Health Service), only 7% of US nephrologists did so (eg, Veterans Administration). The majority of US nephrologists were in academic and private practice settings (61% and 29%, respectively). Approximately one-quarter of participants cared for large numbers (>80) of maintenance dialysis patients, including half the English nephrologists, whose practices were shared among several colleagues.

**Table 1.** Participant Characteristics, Overall and by Country

Characteristic	Overall (N = 59)	US (n = 41)	England (n = 18)
Age group			
≤45 y	34 (57.6%)	26 (63.4%)	8 (44.4%)
46-65 y	20 (33.9%)	10 (24.4%)	10 (55.6%)
≥66 y	5 (8.5%)	5 (12.2%)	0 (0%)
Male sex	45 (76.3%)	31 (75.6%)	14 (77.8%)
Race/ethnicity			
White	35 (59.3%)	20 (48.8%)	15 (83.3%)
Black	4 (6.8%)	4 (9.8%)	0 (0%)
Latino	3 (5.1%)	3 (7.3%)	0 (0%)
Asian	17 (28.8%)	14 (34.1%)	3 (16.7%)
Years since completed nephrology training			
<5	10 (16.9%)	8 (19.5%)	2 (11.1%)
5-10	16 (27.1%)	11 (26.8%)	5 (27.8%)
10-20	16 (27.1%)	11 (26.8%)	5 (27.8%)
≥20	17 (28.8%)	11 (26.8%)	6 (33.3%)
US region			n/a
Midwest	11 (26.8%)	11 (26.8%)	
Northeast	10 (24.4%)	10 (24.4%)	
South	10 (24.4%)	10 (24.4%)	
West	10 (24.4%)	10 (24.4%)	
England region		n/a	
Metropolitan	10 (55.6%)		10 (55.6%)
Town and country	8 (44.4%)		8 (44.4%)
Practice setting			
Closed <sup>a</sup>	19 (32.2%)	3 (7.3%)	18 (100.0%)
Academic	25 (42.4%)	25 (61.0%)	0 (0%)
Private	12 (20.3%)	12 (29.3%)	0 (0%)
Other	3 (5.1%)	1 (2.4%)	0 (0%)
No. of nephrologists in practice setting			
<10	23 (39.0%)	17 (41.5%)	6 (33.3%)
10-20	30 (50.9%)	20 (48.8%)	10 (55.6%)
>20	6 (10.2%)	4 (9.8%)	2 (11.1%)
Physician payment			
Fee for service only	7 (11.9%)	7 (17.1%)	0 (0%)
Salary only	45 (76.3%)	27 (65.9%)	18 (100.0%)
Salary + fee for service	7 (11.9%)	7 (17.1%)	0 (0%)
No. of maintenance dialysis patients in care			
0	6 (10.2%)	4 (9.8%)	2 (11.1%)
<20	6 (10.2%)	6 (14.6%)	0 (0%)
20-50	19 (32.2%)	16 (39.0%)	3 (16.7%)
50-80	14 (23.7%)	10 (24.4%)	4 (22.2%)
>80	14 (23.7%)	5 (12.2%)	9 (50.0%)
No. of wks of inpatient consult service			
<12	26 (44.1%)	16 (39.0%)	10 (55.6%)
12-24	20 (33.9%)	14 (34.1%)	6 (33.3%)
≥24	13 (22.0%)	11 (26.8%)	2 (11.1%)
No. of inpatient consults per wk on average, mean (SD)	25.8 (14.0)	27.4 (14.5)	22.1 (12.4)

Abbreviation. SD, standard deviation.

<sup>a</sup>National Health Service (England) or Veterans Administration (United States).

All but 9 nephrologists (3 English and 6 US nephrologists) commented on family involvement in decisions to forego or withdraw dialysis therapy. We categorized these comments as nephrologists' perceptions into how families impeded or facilitated decisions to appropriately forego and withdraw dialysis therapy. Four primary themes emerged: (1) emotional

responses in decision making, (2) involvement in and awareness of patient's illness status, (3) trust in physicians, and (4) acceptance of patient wishes. In the following sections, we detail nephrologists' views regarding how families act to impede or facilitate decisions to appropriately forego or withdraw dialysis therapy. Each section identifies themes

common to nephrologists in both countries, followed by representative quotes, including those unique to nephrologists in the United States or England. Themes and representative quotes are summarized in Table 2.

## Family Impeding Decisions to Forego or Withdraw Dialysis

### Emotional Responses in Decision Making

Nephrologists in both countries observed that family decisions to pursue dialysis were based on complex emotions that overrode consideration of the relative benefits of starting or continuing dialysis therapy.

They [family members] were not in a position mentally, spiritually, whatever otherwise to let their mother go. She

was a devoted member of the family for a long time and so irrespective of the inappropriateness of prolonging her life with dialysis, they insisted that she go on dialysis. [US nephrologist]

However, one English nephrologist refused to allow family emotion to impede what they considered an appropriate decision to withdraw dialysis therapy.

Obviously families do feel that if you include them too much that they are actually making the decision to withdraw a treatment and then there's the guilt and all the rest of it comes to that. So we've got to be much more firm about involving family I think less in the decision making really. Obviously the support and everything yes but in terms of decision [I say] 'That's it. It's not in the patient's best

**Table 2.** Emerging Themes With Representative Quotes for Family Involvement in Decisions to Forego or Withdraw Dialysis

	Factors Impeding Decisions	Factors Facilitating Decisions
Emotional responses in decision making	In one situation, I had a lady who had a malignant metastatic breast carcinoma with lymphangitic carcinomatosa. She had pulmonary edema because I couldn't take any fluid off. She was weeping when she was being transferred to the trolley to the bed in order to have dialysis, from the ward to the bed. They wanted [her] to continue dialysis. Their main fear was she would die quickly and she would die from the thing that they've been trying, to stop her dying [from] for the last decade. —English nephrologist	So I think it's always a brave decision to say that you're not going to do something. It's easy to say, 'Oh, let's do something,' but I think as long as everybody is involved and often it's the relatives at the end of the day if the patient hasn't got the capacity, and they're on board and everything, then I think it was the kindest thing to do for her. —English nephrologist
Involvement in patient health care/ awareness of illness	It's often the distant relative, the one who hasn't been around for many years who comes down and says, 'What's wrong with Dad?' or 'What's wrong with Mum?' They never used to be like this.' [Laughter] 'That's because you only see them once a year and you give them a ring and they're probably well for a few days and you don't appreciate how well they actually are.' —English nephrologist	There was one loving family where the daughter was there every time for her mother who was 86 and was deaf. She just said, 'Look, I don't think that my mom would understand. Frankly I think she'll pull the catheter, she'll pull the needles if there's access.' She had a very, very valid argument. —US nephrologist
Trust in physician	It was really challenging because I could tell that this family member was distrustful. I could tell that he felt like everyone was 'trying to pull the plug on his mother.' I really didn't think it was good to dialyze her. I felt like it was really hard to get around that or to avoid doing it. —US nephrologist	
Acceptance of patient wishes	[There was] an older gentleman who—all he did was cry, and whine and shout and with agony all the time. His wife would force him to get into an ambulance, then send him over to the clinic. He would cry and groan and moan the whole time and it was awful and horrible. We tried to convince her that what she was doing was morally unacceptable. This was really very difficult to do and we had—we, the patient and the clinic staff, had to suffer with that for several months before we finally got her to withdraw care. So it's my feeling what we were doing was immoral but it is very difficult sometimes when you understand that the consequence of stopping therapy is death, to simply override the family's wishes. —US nephrologist	He decided he just did not want treatment and he was getting weaker and weaker and we dialyzed him a few times. He said to me, 'I just want to go home and die now. I've had enough. I'm just getting worse and worse.' So we stopped [dialysis]. His wife was there. She fully understood. We took his line out and he went home and he died a couple of days later. —English nephrologist
Financial considerations <sup>a</sup>	I had a patient whose son was getting a check every month from his mom's Social Security. She was in her 90's and bed-bound. She came into the hospital with sepsis, and she was already on dialysis. He insisted that everything be done for this lady. She ended up in a long-term acute care facility with a tracheostomy and is still there now. —US nephrologist	

<sup>a</sup>Described only by US nephrologists.

interest. That's it. Sorry. It is not up to you and I'm sorry you'd be angry with me or upset but it's not up to you.' [English nephrologist]

### **Involvement in Patient Health Care/Awareness of Illness**

Nephrologists in both countries agreed that family members' lack of knowledge about the realities of dialysis, lack of involvement in the patient's care, and incomplete understanding of their loved one's true health status seriously impeded decisions to forego or withdraw dialysis therapy. This was particularly common among family members who lived away from the patient.

It's often the distant relative, the one who hasn't been around for many years who comes down and says, 'What's wrong with Dad?' or 'What's wrong with Mum? They never used to be like this.' [Laughter] 'That's because you only see them once a year and you give them a ring and they're probably well for a few days and you don't appreciate how well they actually are.' [English nephrologist]

The other main barrier would be the family's lack of knowledge of how difficult dialysis is. [US nephrologist]

Some described how family's lack of involvement created misunderstandings about the realities of dialysis for the patient. For example, a US nephrologist explained that one patient's son always said, "I want Daddy to continue dialysis," believing that dialysis was making his father more comfortable. But this misunderstanding could be overcome.

I was trying to explain to him that may not be the case and in fact we had to stop dialysis in numerous cases because his blood pressure is dropping so low. Through the course of an hour of the conversation, just kind of explaining to him and really gauging where he was in terms of why he thought that continuing dialysis is important, I think he finally realized that it probably wasn't helping his father. [US nephrologist]

### **Trust in Physician**

Nephrologists in both countries described families' lack of trust as a complex feature preventing foregoing and withdrawing dialysis therapy.

It was really challenging because I could tell that this family member was distrustful. I could tell that he felt like everyone was 'trying to pull the plug on his mother.' I really didn't think it was good to dialyze her. I felt like it was really hard to get around that or to avoid doing it. [US nephrologist]

Racial and cultural discordance may have heightened distrust, as suggested by the following quote.

[There was] a gentleman of Caribbean origin, elderly, extremely severe ischemic heart disease, and quadruple amputations who had a cardiac arrest and

was taken to the intensive care unit and was resuscitated. [His dialysis] line became infected. In [the family] meeting I proposed that we may be coming to the end of the possibilities for delivering dialysis because we had no safe access. The family disagreed and they were very keen to continue with dialysis so we went on to put in a femoral line. And so he continues to dialyze and he's just presented again with an infected line. [English nephrologist]

### **Acceptance of Patient Wishes**

Nephrologists in both countries also described circumstances in which families were unwilling to accept the patient's decision despite patient suffering or even when decisions were informed by discussions between patient and physician.

[The patient] was properly informed and she went on to our [conservative management] program and did quite well on that for quite a while. The family was never happy with that decision and put pressure on her to have dialysis. When she did come in unwell and at the stage where you would be considering morphine and palliative treatment, I think the family persuaded her to change her mind and go into dialysis. So we started her on dialysis later in the day. She was never happy...she didn't live very long on dialysis. [English nephrologist]

Only US nephrologists described financial disincentives to foregoing or withdrawing dialysis therapy.

Sometimes there are kind of perverse economic instances [to start dialysis] as well—sometimes people kind of depend on that family member for their social security income and the dying patient owns the house. [US nephrologist]

I go to some extreme issues for quality of life of the patient, but sometimes the family circumstances are such that if that patient goes for hospice then they go on the street. So the family is living on the patient, so their survival is an issue too. [US nephrologist]

### **Family Facilitating Decisions to Forego or Withdraw Dialysis**

#### **Emotional Responses in Decision Making**

Nephrologists in both countries described the family's ability to integrate their emotions in making decisions as a facilitator.

So I think it's always a brave decision to say that you're not going to do something. It's easy to say, 'Oh, let's do something,' but I think as long as everybody is involved and often it's the relatives at the end of the day if the patient hasn't got the capacity, and they're on board and everything, then I think it was the kindest thing to do for her. [English nephrologist]



A US nephrologist suggested that this ability for family to set aside their emotional objections could be developed with time.

Her son was adamant that, 'You have to do it,' but after talking to him for about 45 minutes and bringing the focus back to her, he was agreeable to not do dialysis. [US nephrologist]

### **Involvement in Patient Health Care/Awareness of Illness**

Nephrologists thought that family members who had been integrally involved in the patient's care and had witnessed the illness trajectory drew on this experience to make the decision to forego or withdraw dialysis therapy.

There was one loving family where the daughter was there every time for her mother who was 86 and was deaf. She just said, "Look, I don't think that my mom would understand. Frankly I think she'll pull the catheter, she'll pull the needles if there's access. She had a very, very valid argument. [US nephrologist]

Some described how they influenced family's involvement and awareness of the patient's illness by preemptively explaining the illness trajectory.

When [the patient] first came on to dialysis we had conversations about what was achievable and what wasn't achievable, so she already had that background. She spent a good five years on dialysis but towards the tail end of that had increasing problems both on dialysis and at home. She essentially spent most of her time in the hospital and her quality of life was just appalling. So her family brought up [stopping dialysis] but again we'd had the conversation well before, so her family knew that they could bring it up. [English nephrologist]

Interestingly, one US nephrologist described situations in which family was so involved they served as facilitators for stopping dialysis even when the nephrologist was promoting aggressive care.

There have been many cases where I have insisted that family members may not make the decision to withdraw dialysis, but there's dissent and they switched from me to other nephrologists or even withdraw. [US nephrologist]

### **Trust in Physician**

Families' ability to trust the nephrologist's recommendation was also described as an important facilitator in decisions to forego and withdraw dialysis therapy. An English nephrologist described how comprehensive evaluation could build trust through an experience in which the nurse had visited the patient in his home environment and got to know the family before recommendation.

I think the group approach with doctors and nurses that they knew really helped because they realized we've made a very thorough assessment and they trusted our opinion. Whereas if we only met him once and just said, 'Well, we don't think dialysis is appropriate' then we might not have been able to reach the same agreement with them. [English nephrologist]

Similarly, trust could be built through providing a detailed rationale for recommendations, as a US nephrologist witnessed while in training.

Although [a patient in her mid-80s with dementia] had opted to not resuscitate, there was no clear discussion about what to do if the kidneys fail and the family—a big family, but the main person who was making decisions for his mother wanted dialysis as a therapy because he thought since his mother did not actually voice exactly what she wanted, he was not feeling comfortable saying that 'I don't want to give dialysis,' but I remember [attending nephrologist] actually handling it so well in terms of the evidence and in terms of 'futility of offering this treatment at this point,' and after multiple family meetings over a period of 4 to 5 days, they understood the rationale and agreed. [US nephrologist]

### **Acceptance of Patient Wishes**

Nephrologists described families who were able to focus on the patient's wishes rather than their own as a facilitator for foregoing and withdrawing dialysis therapy.

[The family] felt that [dialysis] wasn't what their relative would have wanted if he was in a position to make up his own mind anyway. We were able to move him into a conservative management system. [English nephrologist]

However, a US nephrologist also described an experience in which the lack of readily available access to a conservative management pathway may have given the perception that a family was not willing to accept a patient's wishes when they truly were.

She was a blind diabetic and absolutely refused to have dialysis. I remember her family brought her into the emergency room in a uremic coma. I told the family to listen to her wish, which I knew very well was not to have dialysis. So I can do it, but I have a feeling that she's going to be angry if we do that and the family said, 'Oh, yes, we understand. You know, we just really can't care for her at home. We don't want her to die at home.' So she got admitted and died in the hospital [without dialysis]. [US nephrologist]

## **DISCUSSION**

In this qualitative study of US and English nephrologists, we found several themes for how families facilitated or

impeded the decision making for initiating or withdrawing dialysis therapy. Themes that emerged were: (1) integrating emotional responses into decision making, (2) involving patient health care/awareness of illness, (3) trusting the physician, and (4) accepting patient wishes. This study affirms the importance of family involvement in the decision to forego or withdraw dialysis therapy and, by virtue of its qualitative design, provides insights into nephrologists' practices and perspectives with more depth than could be gained from traditional research designs.<sup>17-19</sup>

Unlike prior work in which the variability of US nephrologist perspectives of system-level factors for dialysis decision making was wide ranging while English nephrologist perspectives were more similar, nephrologists in both countries voiced similar perspectives regarding family-level factors. This finding, along with the finding that 85% of participants described family-level factors that influence ESRD decision making, point to the pervasiveness of family involvement in patient decisions about dialysis. That 9 nephrologists did not describe family-level factors may be due to a lack of family involvement but may also suggest that they do not routinely consider foregoing or withdrawing dialysis therapy.

The Renal Physicians Association developed clinical guidelines that encourage shared decision making between patients, families, and health care providers to make decisions about the appropriate initiation and withdrawal of dialysis therapy.<sup>20</sup> These guidelines support adherence to patient wishes, but prior studies show that family members often lack knowledge about patient values and preferences. Further, though health care providers often lament family's insistence that "everything" be done in clinically dire situations, little evidence exists about effective ways to achieve shared decision making. Reinforcing this reality are published guides that focus on helping nephrologists' interactions with patients or other clinicians but not with family members.<sup>21,22</sup>

However, nephrologists in this study who perceived family behaviors as facilitators elucidate how clinicians may better interact with family to achieve shared decision making; namely, by engaging family early and often in a patient's disease course and by returning the focus from family emotion back to the patient's wishes and goals. Another behavior that may improve interactions with family is providing information about the most likely trajectory of the patient's illness, which could lessen the surprise that some nephrologists describe when family members hear the need to consider foregoing or withdrawing dialysis therapy.

There was only one striking difference between US and English nephrologists, in that several US nephrologists raised the idea that financial considerations were barriers to foregoing or withdrawing dialysis therapy. In these circumstances, US nephrologists suspected that the

family's dependence on the patient's income or assets led them to make decisions that kept the patient alive, perhaps incongruent with the patient's wishes. Because one of the roles of hospice is to help patients organize their affairs, including property holdings, greater hospice utilization could ameliorate this particular financial consideration.

Strengths of our study are purposeful sampling across variable participant characteristics (including representation from all age categories, race/ethnicity, years of experience, geography, practice settings, and payment sources) and 2 countries. However, not all points of view may be represented given that informants nominated other informants in their network.

This study demonstrates that while much emphasis is placed on the need for more patient-centered communication skills training in nephrology fellowship programs, practicing nephrologists struggle with negotiating decision making with patients' families as well. Training in family-centered relationship building, communication, and skills to navigate conflictual decision making within families is essential for the current nephrology work force and for the next generation of nephrologists.

## ARTICLE INFORMATION

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## REFERENCES

- Carson RC, Juszczak M, Davenport A, Burns A. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol*. 2009;4(10):1611-1619.
- Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant*. 2011;26(5):1608-1614.
- Hussain JA, Mooney A, Russon L. Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliat Med*. 2013;27(9):829-839.
- O'Connor NR, Kumar P. Conservative management of end-stage renal disease without dialysis: a systematic review. *J Palliat Med*. 2012;15(2):228-235.
- Verberne WR, Geers AB, Jellema WT, Vincent HH, van Delden JJ, Bos WJ. Comparative survival among older adults with advanced kidney disease managed conservatively versus with dialysis. *Clin J Am Soc Nephrol*. 2016;11(4):633-640.
- Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant*. 2007;22(7):1955-1962.
- Smith C, Da Silva-Gane M, Chandna S, Warwicker P, Greenwood R, Farrington K. Choosing not to dialyze: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract*. 2003;95(2):c40-c46.
- Kurella Tamura M, Covinsky KE, Chertow GM, Yaffe K, Landefeld CS, McCulloch CE. Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med*. 2009;361(16):1539-1547.
- Grubbs V, Moss AH, Cohen LM, et al. A palliative approach to dialysis care: a patient-centered transition to the end of life. *Clin J Am Soc Nephrol*. 2014;9(12):2203-2209.
- Kurella M, Covinsky KE, Collins AJ, Chertow GM. Octogenarians and nonagenarians starting dialysis in the United States. *Ann Intern Med*. 2007;146(3):177-183.
- Feely MA, Albright RC, Thorsteinsdottir B, Moss AH, Swetz KM. Ethical challenges with hemodialysis patients who lack decision-making capacity: behavioral issues, surrogate decision-makers, and end-of-life situations. *Kidney Int*. 2014;86(3):475-480.
- Hussain JA, Flemming K, Murtagh FE, Johnson MJ. Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research. *Clin J Am Soc Nephrol*. 2015;10(7):1201-1215.
- Gubrium JF, Holstein JA. *Analyzing Narrative Reality*. Los Angeles, CA: Sage; 2009.
- Josselson R. Narrative research: constructing, deconstructing and reconstructing the story. In: Wertz FJ, Charmaz K, McMullen LM, Josselson R, Anderson R, McSpadden EM, eds. *Five Ways of Doing Qualitative Analysis*. New York, NY: Guilford; 2011:224-242.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101.
- Grubbs V, Tuot DS, Powe NR, O'Donoghue D, Chesla CA. System-level barriers and facilitators for foregoing or withdrawing dialysis: a qualitative study of nephrologists in the United States and England. *Am J Kidney Dis*. 2017;70(5):602-610.
- Lambie M, Rayner HC, Bragg-Gresham JL, et al. Starting and withdrawing haemodialysis—associations between nephrologists' opinions, patient characteristics and practice patterns (data from the Dialysis Outcomes and Practice Patterns Study). *Nephrol Dial Transplant*. 2006;21(10):2814-2820.
- McKenzie JK, Moss AH, Feest TG, Stocking CB, Siegler M. Dialysis decision making in Canada, the United Kingdom, and the United States. *Am J Kidney Dis*. 1998;31(1):12-18.
- Moss AH, Stocking CB, Sachs GA, Siegler M. Variation in the attitudes of dialysis unit medical directors toward decisions to withhold and withdraw dialysis. *J Am Soc Nephrol*. 1993;4(2):229-234.
- Renal Physicians Association. *Shared Decision-Making in the Appropriate Initiation of and Withdrawal From Dialysis*. 2nd ed. Rockville, MD: RPA; 2010.
- Koncicki HM, Schell JO. Communication skills and decision making for elderly patients with advanced kidney disease: a guide for nephrologists. *Am J Kidney Dis*. 2016;67(4):688-695.
- Schell JO, Cohen RA. Communication strategies to address conflict about dialysis decision making for critically ill patients. *Clin J Am Soc Nephrol*. 2018;13(8):1248-1250.