

UCSF

UC San Francisco Previously Published Works

Title

“Maybe They Don't Even Know That I Exist”: Challenges Faced by Family Members and Friends of Patients with Advanced Kidney Disease

Permalink

<https://escholarship.org/uc/item/25s3233n>

Journal

Clinical Journal of the American Society of Nephrology, 12(6)

ISSN

1555-9041

Authors

O'Hare, Ann M
Szarka, Jackie
McFarland, Lynne V
et al.

Publication Date

2017-06-01

DOI

10.2215/cjn.12721216

Peer reviewed

“Maybe They Don’t Even Know That I Exist”: Challenges Faced by Family Members and Friends of Patients with Advanced Kidney Disease

Ann M. O’Hare,^{*†‡} Jackie Szarka,^{*} Lynne V. McFarland,^{*} Elizabeth K. Vig,^{*§} Rebecca L. Sudore,^{¶¶} Susan Crowley,^{**} Lynn F. Reinke,^{*†} Ranak Trivedi,^{††††} and Janelle S. Taylor^{§§}

Abstract

Background and objectives Family members and friends of patients with advanced chronic illness are increasingly called on to assist with ever more complex medical care and treatment decisions arising late in the course of illness. Our goal was to learn about the experiences of family members and friends of patients with advanced kidney disease.

Design, setting, participants, & measurements As part of a study intended to identify opportunities to enhance advance care planning, we conducted semistructured interviews at the Veterans Affairs Puget Sound Health Care System with 17 family members and friends of patients with advanced kidney disease. Interviews were conducted between April of 2014 and May of 2016 and were audiotaped, transcribed, and analyzed inductively using grounded theory to identify emergent themes.

Results The following three themes emerged from interviews with patients’ family members and friends: (1) their roles in care and planning were fluid over the course of the patient’s illness, shaped by the patients’ changing needs and their readiness to involve those close to them; (2) their involvement in patients’ care was strongly shaped by health care system needs. Family and friends described filling gaps left by the health care system and how their involvement in care and decision-making was at times constrained and at other times expected by providers, depending on system needs; and (3) they described multiple sources of tension and conflict in their interactions with patients and the health care system, including instances of being pitted against the patient.

Conclusions Interviews with family members and friends of patients with advanced kidney disease provide a window on the complex dynamics shaping their engagement in patients’ care, and highlight the potential value of offering opportunities for engagement throughout the course of illness.

Clin J Am Soc Nephrol 12: 930–938, 2017. doi: <https://doi.org/10.2215/CJN.12721216>

Introduction

Improvements in public health, health care delivery, and medical technology in recent decades have helped to extend life, but often at the price of increasing patients’ dependence on the health care system (1,2) and on the support of formal and informal caregivers (1,3–7). This is especially true at the end of life. Fewer patients are now dying in the hospital and much of the care previously provided there has shifted to the home and other nonacute settings (8,9). At the same time, the intensity of inpatient care during the final months of life continues to escalate, and the menu of different “life-prolonging” procedures offered late in the course of illness continues to expand (1,8,10–16). Because many patients are unable to participate in medical decision-making as they approach the end of life (17), their family members and friends must now engage with the health care system in ways unimaginable for previous generations, assisting with ever more complex medical care and treatment decisions (17–24).

In their study of bereaved family members of patients who had withdrawn from dialysis conducted almost three decades ago, Roberts *et al.* concluded that providers “must care not only for the patient, but for his or her family and even friends.” (25) This sentiment is echoed in more recent qualitative studies describing the experiences and perspectives of caregivers and family members of patients with advanced kidney disease as they pertain to specific treatments (*e.g.*, hemodialysis, supportive care) (26–31), advance care planning (ACP) (32), and end-of-life care (33–35). To our knowledge, no prior studies have attempted to characterize more broadly the experiences of family members and friends of patients with advanced kidney disease.

Materials and Methods

As part of an ongoing qualitative study designed to identify opportunities to enhance ACP for patients with kidney disease at the Veterans Affairs Puget

*Center of Innovation for Veteran-Centered and Value-Driven Care, †Hospital and Specialty Medicine Service, and ‡Geriatrics and Extended Care, Veterans Affairs Puget Sound Health Care System, Seattle, Washington; §Departments of †Medicine and ‡Anthropology, University of Washington, Seattle, Washington; ¶Department of Medicine, Division of Geriatrics, University of California San Francisco, San Francisco, California; **Department of Medicine, San Francisco Veterans Affairs Medical Center, San Francisco, California; ††Veterans Affairs Westhaven and Yale University, New Haven, Connecticut; †††Center for Innovation to Implementation, Veterans Affairs Palo Alto Health Care System, Palo Alto, California; and ††††Department of Psychiatry and Behavioral Sciences, Stanford University, Palo Alto, California

Correspondence:

Dr. Ann M. O’Hare, Hospital and Specialty Medicine Service, Nephrology Section, Veterans Affairs Puget Sound Health Care System, 1660 South Columbian Way, Seattle, WA 98108. Email: ann.ohare@va.gov

Sound Health Care System in Seattle (VAPSHCS), Washington (36), we learned about the experiences of family members and friends identified by enrolled patients. Potentially eligible patients were receiving (or had received) care in the renal clinic or dialysis unit at the VAPSHCS and had an eGFR < 20 ml/min per 1.73 m² on at least two occasions 3 months apart or were undergoing maintenance dialysis.

Patients who agreed to participate in the study were asked to provide contact information for one or more individuals knowledgeable about their illness and care who were then invited to join the study. Also invited to participate in this study were next of kin listed in the medical record of recently deceased patients with advanced kidney disease cared for at our center. All study participants provided written informed consent. The protocol for the overall study was reviewed and approved by the Department of Veterans Affairs (VA) Central Institutional Review Board.

Study Participants

Between March of 2014 and May of 2016, 56 patients with advanced CKD were invited to participate in this study. Of the 27 patients who agreed to enroll, 23 provided contact information for at least one family member or friend. We also invited three bereaved family members of two patients who had been treated with dialysis at our center before death. Of the 29 family members and friends invited to participate, 17 (59%) enrolled, nine could not be reached, and three declined to participate.

Data Collection and Analysis

All participants completed a 45–60-minute semistructured one-on-one interview (Supplemental Appendix) conducted in person or by phone by one team member (J.S.), digitally recorded with their consent, and transcribed verbatim. The interview questions were open-ended and participants were prompted to provide details and examples. Atlas.ti software was used to organize and code the data (Atlas.ti, Scientific Software Development GmbH, Berlin, Germany) and data analyses were based on grounded theory (37). To guard against bias, the analysis began with open coding using an emergent rather than *a priori* approach. Interviews with family members and friends were randomly assigned to and coded by two of the research team members (A.M.O'H., L.V.M.). A third team member (J.S.) then reviewed all coded interviews and refined, condensed, and organized primary codes into code families (groupings of codes with related meanings). Five members of the research team (A.M.O'H., J.S., L.V.M., E.K.V., and J.S.T.) iteratively reviewed the ongoing data organization to clarify meanings of refined codes and reach consensus on code families. During team debriefings, we returned to the interview transcripts and recordings as needed to ensure that coding refinement remained well grounded in the data and to build consensus in instances where there were differences in opinion between study team members. We continued to conduct interviews and analyze data until reaching saturation, the point at which no new codes were identified.

Results

Participants in this study shared a variety of different relationships with the patient and included spouses (23%),

other relatives (65%), and friends (12%). Their mean age was 60 ± 13.6 years, most were women (77%), 53% were white, and 35% were black (Table 1). Below, we describe three overlapping themes that emerged from interviews with these family members and friends.

Theme 1: Roles of Family Members and Friends Were Fluid over the Course of Illness

Involvement of family and friends in patients' health care was dynamic, shaped by what the patient needed in order to be able to interact effectively with the health care system, their willingness to involve those close to them, and the ability of those persons to be involved, all of which could change over the course of illness.

It was not uncommon for family and friends to be involved in patients' care primarily because the patient needed their help getting to clinic appointments. Their involvement might also be driven by the patient's need for more specific help interacting with providers (Table 2, quotation 1, subject A).

Deteriorating patient health and acute illness were common triggers prompting greater involvement of family and friends. One patient's mother described the "long, hard year" she had spent caring for her son after a long hospitalization and rehabilitation after bowel surgery. She spoke of how her own role had shifted during the course of his illness, depending on whether he could make decisions for himself, and how, at times, she had prioritized his care above all else (Table 2, quotation 2, subject B).

Greater involvement of family and friends could also reflect their evolving understanding of the patient's needs and limitations in interacting with the health care system. The bereaved wife of a man who had received peritoneal dialysis during the final years of his life told the story of how she first became involved in his care when she "realized he wasn't telling her (the doctor) anything." From that time onward, she resolved to keep notes on his complaints, accompany him to all of his clinic appointments, and speak up when he did not (Table 2, quotation 3, subject C).

Involvement of family and friends was also critically dependent on the patient's readiness to involve them, which could change over time. A patient's wife described how her husband "knew for a period of time that his kidneys were failing but he didn't tell me until he had to pretty much go on dialysis" and went on to describe how she became more involved in his care thereafter (Table 2, quotation 4, subject D). Another patient's mother described his growing isolation from family members over the course of illness (Table 2, quotation 5, subject E).

Theme 2: Involvement of Family and Friends Was Strongly Shaped by Health Care System Needs

The roles played by family and friends were also strongly driven by the needs of the health care system, which could change over the course of illness. Family members and friends described filling gaps left by the health care system that might be invisible to, or taken for granted by, providers. A daughter described having to make judgment calls about whether to send her mother to the hospital when contacted by nursing home staff, "She'll say, 'call my daughter and ask her'" (Table 3, quotation 1, subject A).

Table 1. Characteristics of enrolled patients and family members and friends

Characteristics	Patients (n=27)	Family Members and Friends (n=17)
Age, yr		
Mean±SD	63.2±9.8	60±13.6
Range	42–81	40–83
Men, %	96	23
Race/ethnicity, %		
White	56	53
Black	33	35
Other	11	12
Dialysis status, n (%)		NA
Not on dialysis	12 (44)	
Hemodialysis	10 (37)	
Peritoneal dialysis	5 (19)	
Relationship type, n (%)	NA	
Spouse		4 (23)
Other relative		11 (65)
Friend		2 (12)
NA, not applicable.		

She also described her work to discuss treatment preferences with her mother (Table 3, quotation 2, subject A). Another patient's mother described a stressful situation where another member of their family had to track the patient down after he had been hospitalized and provide key information about his medical history not accessible to the health care system (Table 3, quotation 3, subject E).

Beyond filling gaps left by the health care system, the explicit roles that family and friends could play were at times constrained, and at other times expected by providers. Earlier in the course of illness, family and friends described accessing providers and otherwise engaging with the health care system on the patient's behalf as quite challenging. A patient's mother expressed frustration that the health care system did not reach out to her directly. Her comments reflect a lack of familiarity with the inner workings of the health care system that might be expected for someone excluded from the patient's care: "That's why I say I get upset with the VA, because I think . . . they should contact me . . . maybe they don't even know that I exist, they must because you are calling me. So, I feel that the family should be involved in all of this" (Table 3, quotation 4, subject E).

The daughter of a man receiving peritoneal dialysis recalled the challenges of staying involved in her father's medical care before he started dialysis. Her comments illustrate how family members and friends must often operate within the inflexible structure of a health care system built around face-to-face interactions between patients and providers. She also spoke of how her ability to participate in her father's care was limited by competing priorities in her own life (Table 3, quotation 5, subject F). Once her father started peritoneal dialysis treatments she found it much easier to access his providers and to be

involved in his care, and she reflected on how this would have been helpful to her earlier in the illness trajectory.

Comments from other study participants reinforce that when patients had advanced illness or were facing critical treatment decisions, family members and friends encountered fewer barriers to involvement, with providers seeming to welcome, and even count on, their involvement. The bereaved wife mentioned earlier reflected on how later in the course of his illness, her husband's providers "fell in love" with her because her work to articulate his concerns had allowed them to "get their job done" (Table 3, quotation 6, subject C).

At times of critical treatment decisions, family and friends might even function almost like emissaries of the health care system, convincing patients to accept treatments that were being offered (Table 3, quotation 7, subject G). In emergency situations, family members could find themselves in the position of having to assist with major treatment decisions despite having little or no prior involvement in the patient's health care. A patient's sister voiced her understanding that providers would "hunt people down" for assistance with end-of-life decision-making when patients were incapacitated, and suggested that this might be "a bad time to have to hunt people down . . . for that" (Table 3, quotation 8, subject H). She described how one of their family members had been faced with making end-of-life decisions for a relative and "didn't even know she was next in line."

Theme 3: Sources of Tension and Conflict

Family members and friends described multiple sources of tension in their interactions with patients and the health care system. In speaking of her frustration that her husband was slow to "trust" his providers in matters concerning his health, the bereaved wife mentioned earlier commented: "you're not allowed to put a gun to his head and say 'This is the way it has to be'" (Table 4, quotation 1, subject C). Interactions with patients and the health care system sometimes required that family and friends tread a fine line between upholding the patient's wishes and doing what they felt was in the patient's best interest. A daughter spoke of how she felt conflicted about her mother's desire to be resuscitated "when I know that she should, at some point, let go" (Table 4, quotation 2, subject A). Another patient's mother worried that she might not be able to set aside her own wishes in order to support his desire not to be resuscitated (Table 4, quotation 3, subject B).

Interactions with the health care system on the patient's behalf could also be a source of embarrassment or discomfort for family members and friends. A patient's mother complained about providers addressing her rather than her son in matters pertaining to his care (Table 4, quotation 4, subject B). Some described pressure to fulfill roles for which they did not feel qualified. For example, a daughter explained how when reviewing information from providers with her mother she would "try not to put in too much. I'm not a doctor" (Table 4, quotation 5, subject A).

Some family members and friends described situations in which they found themselves almost pitted against the patient in interactions with the health care system. A mother spoke of her son's anger after his niece reported to providers that he had told her he was suicidal (Table 4,

Table 2. Roles of family members and friends were fluid over the course of illness (Theme 1)

No.	Quotation	Subject	Relationship to Patient
1	I always go to the doctor with her. Every time. And I sit in on anything . . . almost all her visits, I go. And then when they are talking, I listen carefully because I know from her bad hearing . . . she can sit there and you think she is following something just fine, but she didn't hear any of it.	Subject A, woman in her 60s	Daughter of a woman in her 90s not on dialysis
2	That was back in March . . . that whole year, my whole year, my whole life was spent trying, praying with him, being there with him, it was a long, hard year . . . I couldn't go no place, I couldn't do anything. I was there. He wanted me there . . . almost every day. And I would be so tired, I would say "Grandma's getting tired" . . . I kept getting tired and tired. Finally he started getting to where he could take care of himself . . . When he was kind of out of it and didn't know about it, I made the decision. But now that he is awake and alert . . . and knows what is going on I let him make it because he should be the one to make it. I am just there to support him, with whatever he does. That's what I do.	Subject B, woman in her 80s	Mother of a man in his 60s not on dialysis
3	I just wish I had been a bit more with it when he first went, because I let him go on his own. Yeah, until I found out that he wasn't telling the doctor the truth. When she'd say "How are you?" he'd say "Oh, I'm fine." . . . He would come home and he'd still be in the same position. Still feeling the same way. And I would say, "What did the doctor say?" "Nothing" and then I realized he wasn't telling her anything. Of course she didn't tell him anything. She's not a mind-reader. (Probe: did you start going to the appointments then?) Oh yes. And he didn't know that I wrote things down. So when . . . she said "How are you (patient's name)?" And he said "Oh, just fine." I said, "Excuse me!" And he looked at me and I started reading what I wrote down. Yeah, he about had a heart attack when he realized that I wrote everything down. Yeah . . . From then on, he never got to go to the doctor by himself. I was there all the time.	Subject C, woman in her 60s	Bereaved wife of a man in his 80s who had been on peritoneal dialysis
4	OK, well my husband knew for a period of time that his kidneys were failing but he didn't tell me until he had to pretty much go on dialysis . . . he just didn't. He just doesn't like people to ask lots of questions and so he just chose not to tell me until, you know, his kidneys were failing more . . . and then I started going to his doctor appointments with him.	Subject D, woman in her 60s	Wife of a man in his 60s on peritoneal dialysis
5	And the thing about my son is that he is a very private person and he does not share a lot, even with me (I'm probably the closest person to him) and he is even reluctant (I have to pull stuff out of him). I can only do it in a casual manner . . . it bothers him to have to be sick and to have to talk about it . . . For a while after that . . . we could all of us (his older daughter and I) could talk to him about that. But now he doesn't really involve her in anything.	Subject E, woman in her 80s	Mother of a man in his 50s not on dialysis

Table 3. Roles of family members and friends were shaped by the needs of the health care system (Theme 2)

No.	Quotation	Subject	Relationship to Patient
1	When she was in assisted living, she falls and they want to call 911. She'll say, "call my daughter and ask her."	Subject A, woman in her 60s	Daughter of a woman in her 90s not on dialysis
2	I've been working on my mother for years over these things! You know little bits and pieces . . . I finally even said "where are you going to be buried?" . . . she is a veteran obviously . . . and I would say, "do you want to be buried with your parents?" And she said "Well, I don't know, I don't know." Finally, I said to her one time, my friend is going to be cremated so they can be put in The Wall (this was in San Diego) . . . And her time in the Navy . . . it was the best time of her life. And so, that finally rang a bell and she said, "That wouldn't be a bad idea!"		
3	And he was so sick that he didn't take any identification with him . . . he just went to the hospital. And he wasn't able to tell them about his history. He was that sick. So . . . when my daughter came home from work that night, the house was unlocked, his truck was here, he wasn't here and there were signs in the living room that there had been a problem . . . She searched all around the house and all around the yard for him in the neighborhood. And then she finally called 911 . . . and found out that he was in the hospital . . . she went to the hospital and kind of explained to them his history and also that he was being treated at the . . . VA. And the hospital called the VA to get his history and they didn't get any response from the VA for 2 days!	Subject E, woman in her 80s	Mother of a man in his 50s not on dialysis
4	So, sometimes I get really mad at the VA. Sometimes when he will have an appointment with the VA and I'll say (I had to get really upset with him one day) "I don't particularly care about prying into your affairs, but as far as the medical thing is concerned, I need to know what is going on . . . just so that I can deal with it." . . . Oh, boy! If you have someone that won't communicate with you, that's pretty hard. But I think if people were encouraged to involve the family a little bit more. I don't know how much . . . I know that the doctors and the staff, they are busy people, they don't have time to just sit and talk to somebody but I am sure (there must be) someone from social services there? . . . That's why I say I get upset with the VA, because I think . . . either they should contact me . . . maybe they don't even know that I exist, they must because you are calling me. So, I feel that the family should be involved in all of this.		
5	I think having the opportunity to meet with his doctor earlier in the process would have been helpful . . . I was sending him (with) questions to ask but sometimes he would ask them and sometimes he wouldn't, and I didn't have a way to get information, especially being the VA. I would have had to have been with him, but he wasn't always sure when he was going in if he was going to see his doctor or if he was just going to have some lab work or a check-up or just go to the appointment. So being a family member but also being a mother and I have to work outside of the home as well. So it would have needed to be something that I could schedule and then planned to be at, rather than just start going with him to all his appointments . . . he goes downtown to the Seattle VA for his appointments, so those are not quick appointments . . . But when we were actually in the program and I was with him for that 2-week training, everyone was very generous with the "Here's my card, call me if you need anything or if you have any questions." And so by that point I did feel connected into the system, where at least I knew the initial call of who I could get a hold of. But prior to that, not. That would have been helpful.	Subject F, woman in her 40s	Daughter of a man in his 60s on peritoneal dialysis
6	I think they fell in love with me, because I finally told the truth. Yes, they (could) get their job done.		
		Subject C, woman in her 60s	Bereaved wife of a man in his 80s who had been on peritoneal dialysis

No.	Quotation	Subject	Relationship to Patient
7	I told him “if you don’t do it you are going to die.” And I told him he should do it and he said, “Ok, I’ll do it. I don’t want to” but I said “Dad, you need to do it. You either do it or you die!” And he did it. I’m glad he did.	Subject G, woman in her 40s	Daughter of a man in his 70s on hemodialysis
8	A cousin of mine just went through this. Her father got sick, and she was in Detroit. So he was on dialysis (when) he went out. Her sister was 16. He called her in Detroit to tell her she had to make decisions on what to do next . . . she got him down here just two days before he died. It put her at a disadvantage, you know. She didn’t even know she was next in line . . . Well, when they figured it out, it couldn’t be the sister because he had a daughter, he didn’t have a wife, so it fell to her. And that’s a bad time to have to hunt people down, you know, for that.	Subject H, woman in her 50s	Sister of a woman in her 50s on peritoneal dialysis

VA, Department of Veterans Affairs.

quotation 6, subject E). There could also be conflict between patients and their family members and friends around information-sharing and truthfulness that might be exposed during interactions with providers. A patient’s friend described a tense moment during a clinic visit when she learned that the patient’s kidney function was much lower than he had been telling her: “So yeah, basically he is lying and keeping things from me. So, it was not a good scene” (Table 4, quotation 7, subject I).

Discussion

Our findings provide a window on the complex dynamics shaping the involvement of family members and friends in care and planning for patients with advanced kidney disease. The picture that emerges is of a multidimensional—sometimes chaotic—process of engagement comprised of several interrelated dynamics, each of which may shift during the course of illness. These include the help that patients need to interact with the health care system, the readiness of patients to involve those close to them and of these individuals to be involved, and the willingness of providers and health care systems to engage patients’ family members and friends.

The time when the health care system actively sought out family and friends—which tended not to occur until late in the course of illness—did not always coincide with the time when they were ready to be involved, or when patients were ready to involve them. Lack of harmony between these separate but related dynamic processes created situations where family and friends could be alternately excluded when they wanted to be more involved, or expected to assume roles for which they were not prepared. Our findings echo the jarring and asynchronous patterns of interaction with the health care system described almost two decades ago by bioethicist Carol Levine, who noted how her visibility as a caregiver varied depending on how sick her disabled husband was (38). The strong role of the health care system in scripting interactions with patients’ family members and friends noted in our study also resonates with findings of anthropologists Ann Russ and Sharon Kaufman (23). A bereaved wife enrolled in their

study recalled how she would receive a phone call from the hospital “whenever they wanted consent for something” but otherwise had great difficulty reaching her husband’s providers. Our findings regarding the work of family members and friends to fill gaps left by the health care system also echo the ethnographic work of Bookman and Harrington who found that family caregivers of older adults function as a “shadow workforce” striving to fill “dangerous gaps” in a fragmented health care system (39).

The experiences of patients’ family and friends may frame more than just individual recollections. They may determine perceptions of the equity and quality of delivered care, and thus shape public opinion of the health care system (40). Yet, they are easily missed in a system built around interactions between patients and providers, and designed to protect patient privacy and autonomy (18,41,42). Aasen *et al.* described how the next of kin of elderly patients on hemodialysis “must struggle with both the patients and the health team to be included in the decision-making process.” (29) Family members and friends enrolled in our study described similar struggles to be involved in the patients’ care, but also spoke of situations in which their involvement was more or less expected by providers on the basis of health care system needs. Some described being caught in the middle between the patient and the health care system and even pitted against the patient (30,31,42–46). These findings serve to illustrate how failing to engage family and friends in a way that meets their needs may result in both undue distress and missed opportunities to improve care by shaping their understanding of the health care system and the patient’s care plan.

Our findings beg the question of whether health care systems and providers should be more proactive in seeking to engage family and friends in care and planning throughout the course of illness, in ways reflecting not just the needs of the health care system but also those of patients and those close to them. Although a family-centered approach is intuitive to some specialties and contexts (*e.g.*, palliative care, pediatrics, geriatrics, dementia care), our findings among family members and friends of patients

Table 4. Sources of tension and conflict (Theme 3)			
No.	Quotation	Subject	Relationship to Patient
1	But, it's up to the patient to decide who they are going to trust . . . you're not allowed to put a gun to his head and say "This is the way it has to be." Yeah, so it's up to the patient. The patient has to decide to trust.	Subject C, woman in her 60s	Bereaved wife of a man in his 80s who had been on peritoneal dialysis
2	It's going to be a very difficult decision, when I know that she should at some point let go or do some of these things, and she has made it very clear that she is saying "No, you have to do everything."	Subject A, woman in her 60s	Daughter of a woman in her 90s not on dialysis
3	Well it would be hard on me . . . not to have him put on a respirator, because I want my son on the respirator, because I want everything done for him that is possible, and if it fails, then you know I would have tried . . . if we don't put him on that, he is going to go. I don't know. I don't know what I would do. I think I would ask them to put him on it. I really don't know. That's one thing I don't know. That would be so hard. Then I would call the family, his sisters and brothers. I know they all love each other and they would say "Put him on the respirator, mother." I know that's what they would say . . . That mother instinct kicks in. That's your job.	Subject B, woman in her 80s	Mother of a man in his 60s not on dialysis
4	Several times he's called a couple of doctors and he said "I'm the patient, you need to talk to me." So, that's really important, to talk to the patient . . . if they are confused, it's different . . . It's harder if the doctor comes in and starts talking to me and not looking at him and he gets upset . . . He needs to be in full control.		
5	Yeah. I have to reinterpret, trying to be as close as to what the doctor said as possible . . . so it's her . . . decision, you know. And she'll come back to me with "What do you think about that?" . . . and I always . . . try to give her input and . . . repeat . . . "this is what they say, this is what they say might happen . . . and so you need to decide." So that I kind of reword whatever it is they were telling her. I try not to not put in too much. I'm not a doctor.	Subject A, woman in her 60s	Daughter of a woman in her 90s not on dialysis
6	She asked, "What are you going to do?" And he said "I'm going to kill myself." So, of course, she reported it to someone at the VA, because that's what you are supposed to do. And so since then he was very angry that she told them about that because they admitted him to the Psych ward . . . so he was very angry about that. He still is angry with her about that.	Subject E, woman in her 80s	Mother of a man in his 50s not on dialysis
7	Like his last appointment he had looked at me and said "I'm so glad you weren't there." Because he had a feeling that if I had heard the news that he heard while . . . there with him, I would have been upset and angry at him (Probe: why would you be angry at him?) Oh, because one of the doctor's visits I went with him he had been telling me his kidney function was around 20%–25%. And so when we were talking to the doctor he said "Well, you're down to 15%." And I looked at him and said "How can that be? You were at 20–25%?" And so I asked the doctor what was the number at his last visit and he said . . . "Oh, 18%." And I'm like, "what?" So yeah, basically he is lying and keeping things from me. So, it was not a good scene.	Subject I, woman in her 40s	Friend of man in his 40s not on dialysis

VA, Department of Veterans Affairs.

with advanced kidney disease suggest substantial room for improvement in the delivery of family-centered care. Such an approach might involve more systematic and open-ended strategies toward learning about who patients consider important in their lives, with the understanding that this may not be their legal next of kin (47), offering opportunities for those individuals to become involved in their care, learning about and acknowledging the unspoken

expectations and hidden work and challenges they may be facing, and educating patients about what might be expected of these individuals in the future (48). This could perhaps begin with steps to make existing care processes more welcoming to patients' family members and friends (21), especially those that may affect them most directly (*e.g.*, ACP, dialysis modality selection, and kidney transplant), and reimagining how existing resources (*e.g.*, social

workers) could be better leveraged to foster a more socially-embedded approach to care. Such endeavors may both afford opportunities for family and friends to become involved in other aspects of the patient's care and provide a foundation for developing more creative and flexible approaches to engagement (49).

The main limitations of this study relate to transferability and potential for bias. It is possible that this single-center study among family members and friends of patients with advanced kidney disease—primarily female relatives of male veterans—may not be transferable to other settings and populations, especially because the study was not designed to examine systematic differences between participants with differing characteristics (e.g., sex, race). Nevertheless, we suspect that the challenges of engaging family and friends in care and planning for patients with advanced chronic illness likely cut across populations, specialties, and disciplines (44). Because our study only included patients who could provide informed consent, further research is needed to characterize the experiences of family members and friends of patients who lack decisional capacity. More than half of all family members and friends invited agreed to participate and they were often eager to do so, perhaps reflecting their desire to be heard. However, we were not able to capture the perspectives of family and friends who did not agree to participate or those whom patients did not want us to contact (50). Some of the themes identified here (e.g., tension and conflict) are nevertheless all the more striking for having emerged from interviews with the select group of family members and friends who were identified by patients and did participate in this study.

In conclusion, the comments of participants in this study provide a window on the complex dynamics shaping the involvement of family members and friends in care and planning for patients with advanced kidney disease, and highlight the potential value of offering opportunities for engagement throughout the course of illness.

Acknowledgments

We would like to thank Ms. Whitney Showalter for administrative support for this project, Dr. Joan S. Teno at the University of Washington for providing helpful comments on several earlier drafts of the manuscript, and Dr. Robert Pearlman, Chief of Ethics Evaluation at the Department of Veterans Affairs (VA) National Center for Ethics in Healthcare and Staff Physician at the VA Puget Sound Healthcare System for supporting this project. We are extremely grateful to the patients with advanced kidney disease and their family members and friends who participated in this study.

This work was supported by the VA Health Services Research and Development Service (VA IIR 12-126, principal investigator A.M.O'H.). R.T. was supported by a VA Health Services Research and Development Service Career Development Award (CDA-09-206, principal investigator R.T.).

The funding sources had no role in the design and conduct of the study, including collection, management, analysis, and interpretation of the data; in preparation, review, or approval of the manuscript; or in the decision to submit the manuscript for publication.

Disclosures

None.

References

- Kaufman SR: *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*, Durham, London, Duke University Press, 2015
- Reuben DB, Tinetti ME: The hospital-dependent patient. *N Engl J Med* 370: 694–697, 2014
- Levine C: *Rough Crossings: Family Caregivers' Odysseys through the Health Care System*, New York, United Hospital Fund of New York, 1998
- Levine C, United Hospital Fund of New York: *Always on Call: When Illness Turns Families into Caregivers*. 2nd, Updated and expanded Ed., Nashville, Vanderbilt University Press, 2004
- Mattingly C: The terrible adventure of rehabilitation. *Second Opin* 20: 40–45, 1994
- Mattingly C, Grøn L, Meinert L: Chronic homework in emerging borderlands of healthcare. *Cult Med Psychiatry* 35: 347–375, 2011
- Reinhard SC, Levine C, Samis S: *Home Alone: Family Caregivers Providing Complex Medical Care*, Washington, DC, AARP/ United Hospital Fund, 2012
- Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V: Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 309: 470–477, 2013
- McDonald J, McKinlay E, Keeling S, Levack W: How family carers engage with technical health procedures in the home: a grounded theory study. *BMJ Open* 5: e007761, 2015
- McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD: Bereaved caregiver perspectives on the end-of-life experience of patients with a left ventricular assist device. *JAMA Intern Med* 176: 534–539, 2016
- Bhattacharya J, Shang B, Su CK, Goldman DP: Technological advances in cancer and future spending by the elderly. *Health Aff (Millwood)* 24[Suppl 2]: W5R53–W5R66, 2005
- Goldman DP, Shang B, Bhattacharya J, Garber AM, Hurd M, Joyce GF, Lakdawalla DN, Panis C, Shekelle PG: Consequences of health trends and medical innovation for the future elderly. *Health Aff (Millwood)* 24[Suppl 2]: W5R5–W5R17, 2005
- Shim JK, Russ AJ, Kaufman SR: Late-life cardiac interventions and the treatment imperative. *PLoS Med* 5: e7, 2008
- Shim JK, Russ AJ, Kaufman SR: Risk, life extension and the pursuit of medical possibility. *Social Health Illn* 28: 479–502, 2006
- Kaufman SR, Shim JK, Russ AJ: Revisiting the biomedicalization of aging: clinical trends and ethical challenges. *Gerontologist* 44: 731–738, 2004
- Butler K: *Knocking on Heaven's Door: The Path to a Better Way of Death. First Scribner Hardcover Edition*, New York, Scribner, 2013
- Silveira MJ, Kim SY, Langa KM: Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 362: 1211–1218, 2010
- Drought TS, Koenig BA: "Choice" in end-of-life decision making: researching fact or fiction? *Gerontologist* 42: 114–128, 2002
- Swetz KM, Ottenberg AL, Freeman MR, Mueller PS: Palliative care and end-of-life issues in patients treated with left ventricular assist devices as destination therapy. *Curr Heart Fail Rep* 8: 212–218, 2011
- Mueller PS, Swetz KM, Freeman MR, Carter KA, Crowley ME, Severson CJ, Park SJ, Sulmasy DP: Ethical analysis of withdrawing ventricular assist device support. *Mayo Clin Proc* 85: 791–797, 2010
- Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K: Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* 22: 1274–1279, 2007
- Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K: Beyond substituted judgment: How surrogates navigate end-of-life decision-making. *J Am Geriatr Soc* 54: 1688–1693, 2006
- Russ AJ, Kaufman SR: Family perceptions of prognosis, silence, and the "suddenness" of death. *Cult Med Psychiatry* 29: 103–123, 2005
- Wolff JL, Feder J, Schulz R: Supporting family caregivers of older Americans. *N Engl J Med* 375: 2513–2515, 2016
- Roberts JC, Snyder R, Kjellstrand CM: Withdrawing life support—the survivors. *Acta Med Scand* 224: 141–148, 1988

26. Walker RC, Howard K, Morton RL, Palmer SC, Marshall MR, Tong A: Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study. *Nephrol Dial Transplant* 31: 133–141, 2016
27. Walker RC, Morton RL, Tong A, Marshall MR, Palmer S, Howard K: Patient and caregiver preferences for home dialysis—the home first study: a protocol for qualitative interviews and discrete choice experiments. *BMJ Open* 5: e007405, 2015
28. Walker RC, Hanson CS, Palmer SC, Howard K, Morton RL, Marshall MR, Tong A: Patient and caregiver perspectives on home hemodialysis: a systematic review. *Am J Kidney Dis* 65: 451–463, 2015
29. Aasen EM, Kvangarsnes M, Wold B, Heggen K: The next of kin of older people undergoing haemodialysis: a discursive perspective on perceptions of participation. *J Adv Nurs* 68: 1716–1725, 2012
30. Low J, Myers J, Smith G, Higgs P, Burns A, Hopkins K, Jones L: The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: contested discourses of ageing. *Health (London)* 18: 613–630, 2014
31. Ekelund ML, Andersson SI: “I need to lead my own life in any case”—a study of patients in dialysis with or without a partner. *Patient Educ Couns* 81: 30–36, 2010
32. Goff SL, Eneanya ND, Feinberg R, Germain MJ, Marr L, Berzoff J, Cohen LM, Unruh M: Advance care planning: a qualitative study of dialysis patients and families. *Clin J Am Soc Nephrol* 10: 390–400, 2015
33. Noble H, Brown J, Shields J, Fogarty D, Maxwell AP: An appraisal of end-of-life care in persons with chronic kidney disease dying in hospital wards. *J Ren Care* 41: 43–52, 2015
34. Tong A, Cheung KL, Nair SS, Kurella Tamura M, Craig JC, Winkelmayr WC: Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in CKD. *Am J Kidney Dis* 63: 913–927, 2014
35. Cohen LM, McCue JD, Germain M, Kjellstrand CM: Dialysis discontinuation. A ‘good’ death? *Arch Intern Med* 155: 42–47, 1995
36. O’Hare AM, Szarka J, McFarland LV, Taylor JS, Sudore RL, Trivedi R, Reinke LF, Vig EK: Provider perspectives on advance care planning for patients with kidney disease: Whose job is it anyway? *Clin J Am Soc Nephrol* 11: 855–866, 2016
37. Glaser BG, Strauss AL: *The Discovery of Grounded Theory: Strategies for Qualitative Research*, London, Weidenfeld and Nicolson, 1968
38. Levine C: The loneliness of the long-term care giver. *Caring* 18: 54–57, 1999
39. Bookman A, Harrington M: Family caregivers: a shadow workforce in the geriatric health care system? *J Health Polit Policy Law* 32: 1005–1041, 2007
40. Kutney-Lee A, Smith D, Thorpe J, Del Rosario C, Ibrahim S, Ersek M: Race/ethnicity and end-of-life care among veterans [published online ahead of print August 30, 2016]. *Med Care* doi: 10.1097/MLR.0000000000000637
41. Aasen EM, Kvangarsnes M, Heggen K: Nurses’ perceptions of patient participation in hemodialysis treatment. *Nurs Ethics* 19: 419–430, 2012
42. Ho A: Relational autonomy or undue pressure? Family’s role in medical decision-making. *Scand J Caring Sci* 22: 128–135, 2008
43. Mattingly CF: *The Paradox of Hope: Journeys Through a Clinical Borderland*, Oakland, CA, University of California Press, 2010
44. Lawlor MC, Mattingly CF: The complexities embedded in family-centered care. *Am J Occup Ther* 52: 259–267, 1998
45. Mattingly C: Pocahontas goes to the clinic: Popular culture as lingua Franca in a cultural Borderland. *Am Anthropol* 108: 494–501, 2008
46. Mattingly C: Becoming Buzz lightyear and other clinical tales: Indigenizing disney in a world of disability. *Folk* 45: 9–32, 2003
47. Farrell TW, Widera E, Rosenberg L, Rubin CD, Naik AD, Braun U, Torke A, Li I, Vitale C, Shega J; Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society: AGS position statement: Making medical treatment decisions for unbefriended older adults [published online ahead of print November 22, 2016]. *J Am Geriatr Soc* 10.1111/jgs.14586
48. Sudore R, Le GM, McMahan R, Feuz M, Katen M, Barnes DE: The advance care planning PREPARE study among older Veterans with serious and chronic illness: study protocol for a randomized controlled trial. *Trials* 16: 570, 2015
49. D’Ambruoso SF, Coscarelli A, Hurvitz S, Wenger N, Coniglio D, Donaldson D, Pietras C, Walling AM: Use of a shared mental model by a team composed of oncology, palliative care, and supportive care clinicians to facilitate shared decision making in a patient with advanced cancer. *J Oncol Pract* 12: 1039–1045, 2016
50. Ashby M, op’t Hoog C, Kellehear A, Kerr PG, Brooks D, Nicholls K, Forrest M: Renal dialysis abatement: lessons from a social study. *Palliat Med* 19: 389–396, 2005

Received: December 12, 2016 **Accepted:** February 21, 2017

Published online ahead of print. Publication date available at www.cjasn.org.

This article contains supplemental material online at <http://cjasn.asnjournals.org/lookup/suppl/doi:10.2215/CJN.12721216/-/DCSupplemental>.