

Advance Care Planning: A Qualitative Study of Dialysis Patients and Families

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Abstract

Background and objectives More than 90,000 patients with ESRD die annually in the United States, yet advance care planning (ACP) is underutilized. Understanding patients' and families' diverse needs can strengthen systematic efforts to improve ACP.

Design, setting, participants, & measurements In-depth interviews were conducted with a purposive sample of patients and family/friends from dialysis units at two study sites. Applying grounded theory, interviews were audiotaped, professionally transcribed, and analyzed in an iterative process. Emergent themes were identified, discussed, and organized into major themes and subthemes.

Results Thirteen patients and nine family/friends participated in interviews. The mean patient age was 63 years (SD 14) and five patients were women. Participants identified as black ($n=1$), Hispanic ($n=4$), Native American ($n=4$), Pacific Islander ($n=1$), white ($n=11$), and mixed ($n=1$). Three major themes with associated subthemes were identified. The first theme, "Prior experiences with ACP," revealed that these discussions rarely occur, yet most patients desire them. A potential role for the primary care physician was broached. The second theme, "Factors that may affect perspectives on ACP," included a desire for more of a connection with the nephrologist, positive and negative experiences with the dialysis team, disenfranchisement, life experiences, personality traits, patient-family/friend relationships, and power differentials. The third theme, "Recommendations for discussing ACP," included thoughts on who should lead discussions, where and when discussions should take place, what should be discussed and how.

Conclusions Many participants desired better communication with their nephrologist and/or their dialysis team. A number expressed feelings of disenfranchisement that could negatively impact ACP discussions through diminished trust. Life experiences, personality traits, and relationships with family and friends may affect patient perspectives regarding ACP. This study's findings may inform clinical practice and will be useful in designing prospective intervention studies to improve patient and family experiences at the end of life.

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Introduction

An estimated 90,000 patients with ESRD die each year in the United States; life expectancy is comparable to that of patients with cancer (1). Pain, depression, infection, blindness, and amputation affect the quality of life of patients with ESRD (2–4). Given the extent of comorbidity, matching patients' goals of care with the care provided throughout their disease course is of particular importance for dialysis patients. Engaging patients and families in iterative discussions about advance care planning (ACP) across the course of their illness can help increase the likelihood that patients' care goals are met (5–7).

Many dialysis patients and their families wish to discuss ACP with their health care providers, and such discussions are associated with positive patient outcomes (7). However, despite the existence of tools to foster such discussions (8), ACP for dialysis patients remains suboptimal (7,9,10). Barriers to dialysis team members initiating ACP discussions exist, but many are modifiable (7).

Families' experiences with dialysis have been described (11,12), but we know of no studies that have assessed dialysis patients' and families' perspectives on ACP congruently, or sought recommendations from these dyads on how best to approach ACP. Understanding how dialysis patients from racial/ethnic minority and lower socioeconomic status (SES) populations perceive ACP may be of particular importance given the disparities in morbidity and mortality experienced by these groups (13,14).

In this qualitative study, we held in-depth interviews with a diverse sample of dialysis patients and their families/friends. The overarching goal was to inform the development of an intervention focused on improving ACP. The primary aim was to elicit recommendations for how dialysis teams should discuss ACP. We also explored participants' satisfaction with their dialysis care and prior experiences with ACP so that we could better understand the context of their recommendations.

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Materials and Methods

Population and Recruitment

We purposively sampled participants from participating dialysis units to achieve diversity in age, sex, race/ethnicity, life expectancy, SES, cognitive status, and degree of social support. Units were located in Massachusetts and New Mexico and included those with rural, urban, profit, and nonprofit designations. Potential participants were contacted by their unit's social worker or nephrologist. If a patient expressed interest, one of the study's research coordinators obtained informed consent and scheduled his or her interview; health care proxies signed consent for patients with cognitive impairment. Two patients declined to participate (female/black and male/Native American). Participants were invited to bring up to two family members and/or friends to the interview; health care proxies of patients with cognitive impairment could elect to be interviewed without the patient present. Interviews were conducted in a private room at the dialysis units or in a nursing home according to the participant's preference. This study followed the Criteria for Reporting Qualitative Research guidelines for conducting and reporting qualitative research (15) and was approved by both the Baystate Medical Center and University of New Mexico Institutional Review Boards.

Interviews

Members of the research team (S.L.G., L.M.C., M.J.G., N.D.E., and R.F.) developed an interview guide (Supplemental Appendix A) that was pretested with a palliative care expert, each site's Patient Advisory Board, and the study's Stakeholder Advisory Board. The Patient Advisory Boards were composed of dialysis patients from each site and were led by a palliative care physician (New Mexico) and a family advocate (Massachusetts) (16). The Stakeholder Advisory Board was composed of representatives from the study sites' dialysis chains, hospice, nursing, and nephrology. The boards met primarily by teleconference both regularly and on an *ad hoc* basis. They interfaced with the study team through the board leaders, providing input and feedback on all aspects of the study.

One of two study team members (S.L.G. or N.D.E.) conducted the interviews. S.G. is a female general internist-pediatrician with qualitative research experience (17–19). N.D.E. (female) was a nephrology fellow when the interviews were conducted and studies the effect of health literacy on patient outcomes. R.F. (female), a research coordinator, observed interviews and participated in the analysis with S.L.G. and N.D.E. S.L.G. trained both N.D.E. and R.F. in techniques for conducting in-depth interviews, coding, and theme development. S.L.G. held practice interviews with N.D.E. and observed all but one interview led by N.D.E. None of the participants were familiar with the interview team. At least one team member (S.L.G., N.D.E., or R.F.) observed interviews and took field notes. Interviews were audiotaped and professionally transcribed verbatim.

Statistical Analyses

Transcripts were uploaded to Dedoose, a qualitative software program (20) and parsed into discrete blocks of text. Applying grounded theory (21), we developed a provisional codebook using the first three transcripts; S.L.G., N.D.E., and R.F. independently coded each transcript in

an iterative process. Differences in coding were resolved through discussion and codes were annotated in an "audit trail" to reflect decisions about coding. S.L.G. and N.D.E. then tested the provisional codebook by independently coding the next two transcripts, again resolving differences through discussion. This codebook was then applied in an iterative process to the remainder of the transcripts; new codes were added as they were identified. Interviews were conducted until theoretical saturation was reached and goals for participant heterogeneity achieved. Emergent themes were identified both deductively and inductively and were discussed as line coding progressed; notes (memos) were attached to lines of coded text to identify these emerging themes. Emergent themes were then organized into major themes and subthemes during secondary (axial) coding to explain the data and to describe hypotheses generated by this analysis. We mailed a summary of the results to participants, inviting them to comment if they felt important elements of their interview were missing or not accurately represented.

Results

We interviewed 13 patients and nine family/friends during 15 interview sessions; two of the sessions were conducted with family/friends only. Two patients did not appear for their scheduled interviews (men, Hispanic and white, limited life expectancy). Patients' ages ranged from 42 to 88 years (mean 63, SD 14). Patients were on hemodialysis between 1 and 10 years (mean 4.1, SD 3.3). Three patients were women, five patients had education levels of high school or less, and of the nine who reported income, seven patients made <\$40,000 annually (Table 1). Ten patients reported major comorbidities (*e.g.*, diabetes, cancer, amyloidosis, cardiovascular disease) and 10 had an estimated life expectancy of <1 year.

Major Themes and Subthemes

The analysis generated three major themes with associated subthemes. Exemplar quotes are provided in Table 2.

Theme 1: Prior Experiences with ACP

Prior Discussions with Dialysis Team or Family. No patients or family/friends reported discussing prognosis, life goals, or options/preferences for care (*e.g.*, pain management, do not hospitalize orders, hospice) when their disease worsens with their nephrologist or other members of their dialysis team. Two patients preferred not to have such discussions, but the rest welcomed the opportunity if it were offered. Some patients recalled being given a do not resuscitate form by the social worker; many had neither returned the form nor discussed it with anyone on their team. One health care proxy of a patient with cognitive impairment reported that his wife's team discussed discontinuing her dialysis with him, but he did not do so because he was unsure of her wishes, having never discussed them with her when she was able to. Some patients had discussed preferences with family, but these discussions generally focused on pragmatic matters, such as burial plans or financial arrangements; several shared that their family was reluctant to discuss their wishes with them.

Characteristic	Patients (n=13) ^a	Family/Friends (n=9) ^a
Mean age, yr (range [SD])	63 (42–88 [14])	54 (43–78 [12])
Years in hemodialysis (range [SD])	4.1 (1–10 [3.1])	N/A
Women	3	7
Race/ethnicity		
Black	1	0
Hispanic	2	2
Mixed (black, Native American, Irish)	0	1
Native American	2	2
Pacific Islander	1	0
White	7	4
Education		
Less than high school diploma	1	1
High school degree	4	1
Some college/2-yr college degree	5	4
4-yr college degree	2	2
Graduate degree	1	0
Income, \$		
<20,000	3	2
20,000–<40,000	4	5
40,000–75,000	1	0
>75,000	1	1
Site		
Massachusetts	7	3
New Mexico	6	6
Patients with cognitive impairment	1	2 ^b

N/A, not applicable.
^aFor columns that sum to less than the total, participants declined to provide data.
^bOne family member completed interview without spouse with cognitive impairment.

Role of the Primary Care Physician. Several patients and family/friends commented that they had a good relationship with their primary care physicians (PCPs), had discussed ACP with them, and felt they were the best people with which to have such discussions. However, there was no communication of the patient's wishes to the nephrologist either by the patient, family/friend, or the PCP.

Theme 2: Factors That May Affect Perspectives on ACP

We identified a number of factors that could potentially affect patients' or family/friends perspectives regarding ACP. These included patient-specific factors and factors related to the patient-family/friend dyad.

Dialysis Experiences. Patients and family/friends described positive and negative experiences in the dialysis unit, including experiences related to communication with the dialysis team. With regard to positive experiences, several patients reported good rapport with the dialysis staff and/or their nephrologist and satisfaction with both communication and care provided by the dialysis team. The dialysis unit was viewed as a "community" by some patients. Others felt that the nephrologist could not realistically take the time to hold ACP discussions because he or she takes care of many patients.

With regard to negative experiences, many patients and family/friends expressed a desire for more contact and personal connection with the nephrologist. Much of this discussion centered on not knowing when the nephrologist would be in the unit, the limited time spent with each

patient, the focus of conversations on lab results, and the feeling that there was limited personal connection. Patients and family/friends also expressed discontent with dialysis staff, including perceived favoritism by staff, understaffing, and suboptimal training. Some patients felt that staff minimized the seriousness of being on dialysis and others expressed displeasure with what they felt were falsely optimistic general statements about their prognosis. Some patients felt that staff could do more to reduce feelings of humiliation and dependency that they experienced as dialysis patients. Many patients expressed a desire for better education about what to expect from dialysis and more opportunities to participate in making decisions about their care; many felt this needed to be initiated by the dialysis team early on in the dialysis process. With few exceptions, families/friends expressed dissatisfaction with their dialysis experience. Most desired improved communication about care, prognosis, and ACP.

Life Experiences and Patient Traits. Patients' life experiences potentially influenced their dialysis experiences and their views of ACP. Several patients described how an experience with the death of a family member or friend made them think more concretely about their own preferences for ACP. Patients also described how the suffering they observed in the dialysis unit and deaths on the unit affected their views.

We observed patient traits that might contribute to dialysis experiences and ACP perspectives. For example, patients who described themselves as optimistic and/or described knowledge-seeking behaviors tended to report more positive

Table 2. Sample quotes

Theme	Quote
<p>1: Prior experiences with ACP Prior discussions with dialysis team or family</p>	<p>“Yeah, it [ACP] was really something to think about. But when you have to say – take her off [dialysis] and she’s not going to be with you anymore. You know you really have to think about that. And this is something I have to live with. I have to say. . . I don’t want to see my wife suffer any more than what she is, but I also don’t want to have a guilty conscience.” [interview 6, family, male, white, health care proxy for patient with cognitive impairment]</p> <p>“Well, I try to be as honest and. . .sometimes that’s the problem everybody don’t like to hear. I try to set up what my wishes are. I told them I don’t want a funeral. They don’t want to discuss that. I’m like we got to get that planned so the last time I tried to bring it up they all started arguing with me and crying. I’m like this is something to needs to be discussed.” [interview 8, patient, male, Hispanic]</p> <p>“I’ve talked about it with her [daughter] as well and if something happens to me she knows what to do. My grandchildren on the other hand they’re not trying to hear anything because they’re still young, still invincible.” [interview 1, patient, female, Black]</p> <p>“I have a DNR.” [And who did you speak to about this?] “My wife. She knows it.” [interview 11, patient, male, white]</p> <p>“ . . .I made a lot of. . .preparations. . . the house I live in. My wife and I bought it some years ago and I put the house in my sons’ names, insurance is in their names, just about everything, I have a car, everything is in their names.” [interview 3, patient, male, white]</p> <p>“As a retired Service man... we’ve already talked about burial.” [interview 2, family, female, white, patient with cognitive impairment]</p>
<p>Role of the primary care physician</p>	<p>“She’s [primary care physician] the one that listens to us. . . She’s the one that really pushed to. . .find out what was going on with his kidneys. . . the one that has really pushed a lot of things.” [interview 13, family, female, Native American]</p>
<p>2: Factors that may affect perspectives on ACP Dialysis experiences <i>Positive</i></p> <p><i>Negative</i></p>	<p>“I don’t worry about it [ACP]. . . adjust it [dialysis] and run day by day and work with these nice people. I’ve been very happy here – never consider making a change.” [interview 5, patient, male, white]</p> <p>“Well, I couldn’t believe because he [nephrologist] lives in XXX – quite a little drive out there and he came to see me [in the hospital] on a Sunday. . .he came in there that evening and he sat down and we just spent an hour talking.” [interview 13, patient, male, white]</p> <p>“They’re [social worker and nutritionist] very open and honest and you can catch one of them when they’re going by or make an appointment to see them. They’re both very responsive to your questions and very helpful. XXX has helped me a lot over the years with different things. . . I would find difficult to do—for instance helping me with transportation. Yeah, they’re very easy to communicate with.” [interview 4, patient, female, white]</p> <p>“And these nurses are so busy all the time. Many times I’ve been in conversation with them and it just gets started and a bell goes off. They have to go take care of that immediately and they can’t always come back to listen to me or anybody. . . they just don’t have the time.” [interview 7, patient, male, white]</p>

Table 2. (Continued)

Theme	Quote
	<p>“... [You] can tell when you start talking to people that they’re not really interested [in what you are saying] by their actions. So, no I don’t talk to too many people [on the dialysis team] about it [stress related to dialysis]. It kind of turns them away.” [interview 14, patient, male, white]</p>
	<p>“... [S]he [charge nurse] used to work on the unit but I always felt that she didn’t really like [me]. . . I don’t know maybe my own personality, maybe I didn’t joke enough. She’s never actually talked to me unless she was in charge of the unit and then she would have to ask if I had any problems. I feel there’s a lot of favoritism.” [interview 12, patient, female, white]</p>
	<p>“The social worker gave me all the numbers to call [to get services for brother on dialysis], but they wouldn’t listen to me. . . you needed a title.” [interview 10, family, male, Native American]</p>
	<p>“There’s things that happen to you that’s a whole new territory because it’s a subculture and the thing that I would like to see happening is a better educational kind of thing. For example, they told me I had to be on dialysis because. . . I had too much creatinine in my system, but nobody ever gave a class on Medicare.” [interview 3, patient, male, white]</p>
	<p>“I’m not an educated person by no means and I dropped out of high school and stuff, but there’s some ignorant people that are taking care of you [on dialysis unit]. I mean they know exactly what they were told and nothing else.” [interview 13, patient, male, White]</p>
	<p>“And so I was always grief stricken to death over how rude, how desperately rude everything [in the dialysis unit] was.” [interview 12, patient, female, Hispanic]</p>
	<p>“It didn’t make sense to me [family not allowed on dialysis unit] because I think he would have been more comfortable and I would have been more comfortable when he first started to have been there and seen the process and been part of the process and being able to say—OK, now I understand where you’re coming from. Because when he tells me stuff I’m sitting there going—no frame of reference. I don’t even know what that back room looks like. I know you got TV and that’s all I know. I don’t even know what the machine looks like.” [interview 14, family, female, Native American]</p>
Life experiences and patient traits	<p>“I told you my dad was on it [dialysis]. He had a stroke. . . Well, they had to put him on a feeding tube and then—you want to know what that sheet of paper [DNR status] is good for? We sit around, me, my brother and. . . my two sisters and hashed over at what point are we going to take him off this stuff. And we’re sitting there. . . and my mom’s sitting there. . . this has gone on for 2 weeks. She hands us a piece of paper and it says right there—Do not put him on a feeding tube and we felt sick. But she—she had never read it. . . We said—well, he’s answered our questions. . . and within 42 hours [of stopping life supporting measures] he passed.” [interview 13, patient, male, white]</p>
	<p>“I see people here—they’re blind. . . they don’t have hands and feet. A lot of them can’t walk, a lot of them have diabetes in addition to the dialysis and I’m looking at them thinking—uh, thank you god [crying].” [interview 7, patient, male, white]</p>
	<p>“I’m an easy going person. I don’t worry about it too much. I just do it and that’s it. I say anything personal here it is so easy for me that it’s really a pleasure to work with ‘em you know.” [interview 5, patient, male, white]</p>

Table 2. (Continued)

Theme	Quote
Relationships with family/friends <i>Independent with active support</i>	<p>“I’m a happy-go-lucky character as far as I’m concerned. Enjoy all the things that a typical older male would enjoy—or a younger male because I feel young. . .” [interview 3, patient, male, white]</p> <p>“I don’t question a lot. I feel that they [doctors] know more about what they’re doing than what I know. . . if it’s going OK, if it’s not too painful, I’m good.” [interview 1, patient, female, black]</p>
<i>Independent with limited support</i>	<p>“I go by what he thinks. He doesn’t look back. He looks forward . . . I just go along with him and help him as much as I can.” [interview 2, family, female, white]</p> <p>“Most people here [at dialysis] have their sons or daughters. I don’t have a [social] support group, so I’m on my own here.” [interview 9, patient, male, Pacific Islander]</p>
<i>Dependent</i>	<p>“I do 95% of the talking [for patient] because . . . he forgets things a lot. I remember virtually everything. . . I have to remember everything: doctor’s medications, appointments, my day calendar is my lifeline.” [interview 14, family, female, Native American]</p> <p>“She [wife] works with them more than I do because I get pissed off or I get angry. . . I say the wrong thing. It’s best. . . if I got a question I ask her [wife] basically.” [interview 14, patient, male, white]</p>
<i>Estranged</i>	<p>“And there really is no family member right now. My mother and three siblings have died in 18 months. . . My family was already not close in any way. . . and then when that happened, there’s just a war going on. . . it really is like a lonesome time. I don’t feel anything with them.” [interview 12, patient, female, Hispanic]</p> <p>“Especially around the holidays. Christmas, Thanksgiving—last year I was alone for those two. On Christmas I cried a lot.” [interview 4, patient, female, white]</p>
Potential threats to trust	<p>“If you are traditional Native born and raised on the Res., if they tell you to do this you’re going to do this. They tell you to do that you’re going to do that. Whatever you’re told to do is pretty much what you’re going to do because that’s just the way you were raised.” [interview 14, family, female, Native American]</p> <p>“Some of these patients out here have a problem standing up for themselves so they’re burdened by all the shit that happens, but they won’t do nothing about it. They’re worried more about getting kicked out of this place [dialysis unit] and not having treatment after that.” [interview 14, patient, male, white]</p>
3: Recommendations for discussing ACP Who	<p>“The conversation with the doctor would need to get to the point where I feel comfortable telling him anything that was on my mind and right now I don’t have a doctor that I feel comfortable talking to other than Dr. XXX [primary care].” [interview 3, patient, male, white]</p> <p>“For me I would like to hear it first so then if I have to tell it to my wife and my mom. . . it would be better. . . coming from me and then maybe have them meet with the doctor or the social worker or the nurse. . . So they know what’s going to happen. If I tell them—OK, we going to do Do Not Resuscitate, at least they know that’s my wishes and they know the doctor or the nurse or whoever knows already. . .” [interview 8, patient, male, Hispanic]</p> <p>“I would like to sit down with a physician who is compassionate but direct. Give me the fine points. That way I can make a good decision. Know what she [mother] wants. Hearing what’s available.” [interview 1, family, female, mixed]</p>

Table 2. (Continued)

Theme	Quote
What, when, and where	<p>“... I wish there was somebody that could play the role I play on your [patient’s] behalf for each patient, that can ask [the patient] tough questions in a compassionate way and say—you need to deal with this. In regards to your family [conflicts] you need to deal with this... So I wish that there were a social worker that... had their own file on every patient and was able to go and routinely ask tough questions and give you answers like—you really need to get to a lawyer and do this. And you need to go to your minister or your church and do this. You need to go to XXX mortuary and do the advance package there... you need somebody that’s objective to the situation... third party that’s not a family member. Walking people through checklists of end of life.” [interview 12, friend, female, white]</p> <p>“In my mom’s case I think a family member should be invited [to ACP meetings] because of her hearing and she can’t really read. We have to read for her... she won’t say nothing if she doesn’t hear.” [interview 15, family, female, Hispanic]</p> <p>“A lot of these things [prognosis and ACP discussions] doesn’t come up and you just don’t think about them. It’d be good to learn about a few of these things and keep them in mind.” [interview 5, patient, male, white]</p> <p>“I would like to know [my mother’s prognosis] and I would think there would be somebody to communicate with me knowing that—you got my number, give me a call somebody.” [interview 1, family, female, mixed]</p> <p>“... [C]an there be a spiritual aspect to all of this? I would have a very different conversation with someone who very much fears death and is looking to cling to any hope of kidney transplant and life... as opposed to someone who’s okay with it so would want someone counseling me to take that into account. It is very different to talk to someone who is scared to death to die and someone who is at peace about it.” [interview 12, patient, female, Hispanic]</p> <p>“They say he’s [nephrologist] here on Wednesdays, but he’s probably busy on Wednesday so how you going to barge in if he’s busy? So an appointment would be better.” [interview 15, family, female, Hispanic]</p> <p>“There’s no doubt that my wife and I waited too long to have that discussion and part of that is—my wife is very quiet. We never really communicated that well, I mean we got along fine we’ve been married for 55 years. So we never really had that discussion. And before I realized it was kind of too late.” [interview 6, family, male, white, health care proxy for patient with cognitive impairment]</p> <p>“... [B]ut make it as an initiation, not something later... but part of—let’s go over your plan. It should be part of your care plan... What do you want us to do—a DNR isn’t offered and should be and explain to people that’s what it should be. I had to do my own. They have them, but it’s not offered.” [interview 11, patient, male, white]</p> <p>“... at least 15 minutes [to discuss ACP]. They could do three or four each visit [to the dialysis unit]. You wouldn’t have to do them all at the same time.” [interview 4, patient, male, white]</p> <p>“It probably would be [best to do in the dialysis unit]. . . Personally I don’t like to go out evenings and do things like that.” [interview 5, patient, male, white]</p>

Theme	Quote
How	<p>“I would guess in the office. . . private. . . Don’t make it like it’s a death sentence. Somewhere comfortable. . . like a doctor visit or something.” [interview 8, patient, male, Hispanic]</p> <p>“I would certainly suggest not having it in a group. Talk to the individuals like we are now because I think a lot of people are afraid to express their personal feelings about things or about people in a group. I think that’s pretty natural. I would certainly suggest doing it individually.” [interview 7, patient, male, white]</p> <p>“I think it really does have to be organized and it really does have to be concerted and it really has to be serious and it really has to be paperwork and a true official document. . . who will do that here [dialysis unit]?” [interview 12, patient, female, Hispanic]</p> <p>“I think that discussion should come before you get to the critical point. . . Yeah, things are going good OK, but things could turn too. At the jump of a dime things could turn so I think the more prepared you are the better you could handle things when situations get tough.” [interview 1, family, female, mixed]</p> <p>“. . . [I]n my mind the only way that you’re going to reach. . . people is to reach them on a personal level. You need to get to know them. They need to get to know you and that’s. . . critical. You can get to know them if you can get them to talk about themselves. Usually it’s pretty easy to get somebody to talk about themselves, but they need to trust you. . . It takes time. It just flat-out takes time and many, many conversations. And when I say conversation I mean exactly that—two ways. Not just talking—a conversation.” [interview 7, patient, male, white]</p> <p>“. . . I would like my doctor or somebody to ask me—and they [doctors] do more than social workers do—. . . How’s my care at home? . . . How’s your daily life going? Are you happy with your treatment?” [interview 9, patient, male, Pacific Islander]</p> <p>“A questionnaire might be good. Then it would be very private, but with me I am very open and if they just wanted to come and talk to me about it that would be all right. But I’m sure most people would like a survey.” [interview 4, patient, female, white]</p> <p>“So grandma may be taken back there and told this, that and the other thing and she may not be understanding what they are saying. And she tries to tell granddaughter or grandson who’s taking care of her and they may be the quiet type born and raised on the Rez. [reservation] and they’re not going to question it. In my opinion when you ask. . . about engaging people on the prognosis I think it has to be a group effort really.” [interview 14, family, female, Native American]</p>
<p>ACP, advance care planning; DNR, Do Not Resuscitate.</p>	

experiences with dialysis and a belief that the dialysis team could conduct meaningful ACP. Others described themselves as difficult to get along with, had experienced depression, and/or were angry about the care they received; these individuals expressed less confidence in the dialysis team’s capacity to engage in ACP. Patients who were less critical of their dialysis experience tended to have higher education/income levels, or were older patients. Although the majority of patients felt ACP is important and wanted to participate in it, the few that did not were closer to the end of life.

Relationships with Family and Friends. We identified four types of patient-family/friend interactions that could

potentially affect ACP: (1) independent with active support, (2) independent with limited support, (3) dependent, and (4) estranged. Patients whose dyad was classified as “independent with active support” expressed opinions about their preferences, described loving relationships with family members, and engaged in warm back-and-forth discussions with the family/friend who was present for the interview. Those classified as “independent with limited support” had no family or friend present at the interview, described neither close nor negative relationships, and expressed comfort and satisfaction with managing decisions themselves. “Dependent” patients had family members

present, contributed little to the discussion, and expressed reliance on family for decision-making. Finally, “estranged” patients described antagonistic relationships with their family and expressed negative feelings regarding these relationships.

Among the interviews conducted with both the patient and a family/friend present ($n=5$), most had congruent dialysis experiences (positive or negative) and felt similarly about ACP. One dyad differed markedly in both their experiences and preferences, but engaged in respectful discussion about this disagreement during the interview.

Potential Threats to Trust. The aforementioned negative dialysis experiences, including lack of a personal connection to the nephrologist, dissatisfaction with communication, and disenfranchisement, may diminish trust in the dialysis team. Patients and family/friends also shared how perceived power differentials may negatively affect communication, and possibly trust, as well. For example, a family/friend shared that the “older generation” Native-American culture is more likely than the “younger generation” to accept a physician’s recommendations without question due to a perceived power differential, thus potentially making it more difficult for physicians to engage them in shared decision-making. Another patient commented that he felt many patients in his unit would not speak up about concerns they had about care because of fear of retribution and losing their bed in the unit.

Theme 3: Recommendations for Discussing ACP

Patients and family/friends offered recommendations about who should lead ACP discussions, who should be present, what should be discussed, when and where discussions should take place, and how ACP should be operationalized.

Who. Most patients and family/friends felt that the nephrologist should lead ACP discussions. Patients felt that the person should be someone they trusted, whom they could speak freely with, and who knew them as a person. Some patients did not currently feel this way about anyone on their team, but stated they would like to develop that kind of relationship, particularly with their nephrologist. Peer mentorship was recommended as a means to provide support for ACP. A family member suggested use of a “patient navigator” to serve as a patient and family educator and advocate in the dialysis units. Patients generally felt a family member should be able to join ACP discussions if this was the patient’s preference.

What, When, and Where. Most patients and family/friends felt that all of the options available for end-of-life care should be discussed as part of ACP, although some did not want to hear prognostic information. Specific information desired included hospice care, pain management, making a will, and resuscitation preferences. Most felt ACP discussions should be held in a private space at the dialysis unit on a nondialysis day.

How. Patients and family/friends who felt ACP was important indicated it should be an iterative process started early in the disease course and followed up annually. Some participants felt that because patients’ preferences differ and may change over time, patients should be asked first whether they were interested in discussing ACP, but others felt it should be a routine part of care for all patients. Several participants suggested that the conversation be direct, yet

gentle and compassionate, and should be planned ahead of time with adequate time allowed for questions.

Discussion

In this qualitative study of dialysis patients and their family/friends, we found that most participants felt ACP is important and should start early in the disease course, but that it rarely takes place at all (22,23). Although the need for ACP for dialysis patients is becoming more widely recognized (7,24–26), and interventions to improve ACP have begun (27,28), this study begins to address the important question of how to develop and test broadly applicable strategies for implementing patient-centered ACP for all dialysis patients and their families. This study also raises questions about the role of both patient-family/friend interaction styles and patient-provider relationships in ACP.

Prior research has demonstrated the importance of family in ACP with dialysis patients (29); by interviewing family/friends and patients together in this study, we were able to identify four distinct patient-family/friend interaction styles. Developing further understanding of how a particular dyad’s style may affect a patient’s needs in the decision-making process may help health care providers better tailor their approach to ACP discussions. For example, a “dependent” patient may prefer to have a family/friend more involved in decision-making than a patient with an “independent” interaction style. Efforts to further classify these styles, determine their stability for a given dyad, and identify additional styles will help further understand the role of these relationships in ACP.

Most participants felt that trust, a key element of shared decision-making (30–33), was important for ACP. The integrated subtheme “Potential threats to trust” highlights areas in which trust in the dialysis team may be suboptimal for some patients. Lack of a personal connection to the dialysis team, particularly the nephrologist, was seen across sampling strata, and may inhibit ACP. Patients and family/friends with lower SES and/or minority status expressed dissatisfaction with care and disenfranchisement more often than those with higher education/income levels. Issues related to communication and respect expressed by this vulnerable population warrant further exploration of how best to address their unique educational and communication needs. Doing so may increase satisfaction with care (34), begin to address disparities in care and outcomes (35–38), and ultimately increase the likelihood that end-of-life care is consistent with their preferences. Finally, the perceived power differential patients and family/friends described could inhibit ACP through diminished trust as well (39). Although this perception can also affect patients with higher SES (39), we learned that patients with low SES, and patients from cultures that have historically been disenfranchised, may experience greater feelings of powerlessness. It is incumbent on the medical community to be aware of and make explicit efforts to increase trust and minimize the potential effects of perceived power imbalances (40). Patient/family advisory boards, dialysis team training, and use of patient navigators (41), as one patient suggested, could ultimately improve ACP through improved communication and trust.

Patients and families generally felt that ACP should be a routine part of care and that discussions should start early

in the disease course. (8,42,43) Some patients suggested that the PCP might be the best person to lead ACP discussions. Preferences discussed with the PCP could then be shared with the dialysis team in an integrated care model. Older, sicker patients in this study were less eager to discuss ACP, similar to findings in nondialysis populations (44). This suggests that the otherwise logical practice of offering ACP when patients have limited life expectancy may not best meet some patients' needs.

The findings in this report should be judged in light of several limitations. First, this study was hypothesis generating and the results should be viewed primarily as indicators of potential areas for further study. Second, although theoretical saturation was reached, it is possible that additional insights may have been gleaned with additional interviews, particularly given the number of characteristics included in the purposive sampling strategy. Third, although a broad range of races/ethnicities and other participant characteristics were represented, the findings in this study may not reflect experiences outside of the geographic regions studied.

This study identified important considerations for ACP with dialysis patients and their family/friends. Further studies to determine how patients' and family/friends' satisfaction with care affect ACP are warranted; a deeper understanding of how family dynamics affect decision-making may also be informative. We learned that ACP protocols that rely on completion of standardized forms without discussion may not sufficiently address dialysis patient needs (45). We also learned that although numerous studies have highlighted the importance of discussing dialysis withdrawal as part of ACP (46–48), patients also want to discuss ways to improve quality of life well before they reach this point, consistent with palliative care tenets. As strategies for improving ACP evolve, efforts to disseminate and implement best practices will need to consider the heterogeneity of patient and family experiences and needs. These results support the position that the communication of prognosis and patient-centered ACP may improve alignment of care provided with patient preferences.

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Disclosures

None.

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See related editorial, "Advance Care Planning for Patients with Advanced CKD: A Need to Move Forward," on pages 344–346.

Appendix A

Interview Guide: Shared Decision Making in Renal Supportive Care

Moderator:

- Introduce self and other research team member(s).
- Express appreciation for participation in study.
- Explain overall study purpose/goal of today's interview.
- Note that we are recording answers so we don't miss any details and that no identifying information will be included in written transcripts so none of what is shared can be traced back to participants.
- Remind there are no right answers; we want to find out what people really think and feel about this subject.
- Acknowledge that patients and families may have different opinions about the topics we are discussing and we hope everyone is able to respect those differences.
- Remind participants may decline to answer any question and may stop their participation at any time.
- Provide a reminder to please let whomever is speaking finish his or her thoughts before we move on to the next person's input.
- Let us know if they would like a break and we can pause at any time.
- Ask if there are any questions before starting,

Interview:

1. I would like to start by having you tell me a little bit about yourself/yourselves.
(Warm-up)
2. Thank you. Now I would like to ask what your understanding is about where you are with your kidney disease.
3. Now could you tell me a little bit about what living with kidney disease has been like for you and your family. (Prompt memories of first being told about the diagnosis, changes in work, activity, relationships)

Ask family (if present) for their thoughts after patient for each question.

4. Thank you. Now, I'd like to ask how you feel about the communication between you and your dialysis team. (Prompt positive/negative, what has made it good or needing improvement)
5. Now if you could tell me a little about how much you want to know about what likely lies ahead with your illness. (What could be good about talking about this? What might be difficult?)
6. Have you had a chance to discuss what likely lies ahead with your team?

(If yes) Please tell us about this discussion. (Probe who/where/when/what worked/what didn't/what would be better)

(If no) Do you feel this is something you would like to have the opportunity to discuss or might you prefer not to? (probe why or why not/why do they think it hasn't been discussed yet)

7. Have you had a chance to think about what your most important goals are if your health situation worsens?

(If yes) Can you share your thoughts about this? (Probe any actions taken to make wishes known)

8. Thank you. Now I'd like to know whether you have had a chance to discuss your goals of care (define) with your dialysis team?

(If yes) Could you tell me about that experience? (Probe who/where/when/what worked/what didn't, what options were discussed such as hospice, DNR, DNH/how could do better)

(If no) Do you feel that you would like to have the opportunity to discuss your goals? (If yes) How would you prefer these discussions be carried out? (Prompt timing, who would initiate, with whom discussions occur, whether the option of hospice should be part of discussion).

9. Thank you, this is very helpful. Now I would like to get your feedback on the plan for the intervention part of this study that will take place later this year.

All patients who participate in the second part of this study will have an opportunity to meet with a member of the social work team to discuss the status of their kidney disease and their goals if their health situation worsens.

What should the social worker know about the patient before the meeting?

Who else should be there?

Where should it take place?

How should the research team follow up after the first discussion?

10. Thank you. Do you have any other thoughts you'd like to share that you think may help dialysis care teams do the best job possible talking to patients about what likely lies ahead with their kidney disease and their goals of care if their health situation worsens?