

# Characterizing Approaches to Dialysis Decision Making with Older Adults

## A Qualitative Study of Nephrologists

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### Abstract

**Background and objectives** Despite guidelines recommending shared decision making, nephrologists vary significantly in their approaches to discussing conservative management for kidney replacement therapy with older patients. Many older patients do not perceive dialysis initiation as a choice or receive sufficient information about conservative management for reasons incompletely understood. We examined how nephrologists' perceptions of key outcomes and successful versus failed treatment discussions shape their approach and characterized different models of decision making, patient engagement, and conservative management discussion.

**Design, setting, participants, & measurements** Our qualitative study used semistructured interviews with a sample of purposively sampled nephrologists. Interviews were conducted from June 2016 to May 2017 and continued until thematic saturation. Data were analyzed using typological and thematic analyses.

**Results** Among 35 nephrologists from 18 practices, 20% were women, 66% had at least 10 years of nephrology experience, and 80% were from academic medical centers. Four distinct approaches to decision making emerged: paternalist, informative (patient led), interpretive (navigator), and institutionalist. Five themes characterized differences between these approaches, including patient autonomy, engagement and deliberation (disclosing all options, presenting options neutrally, eliciting patient values, and offering explicit treatment recommendation), influence of institutional norms, importance of clinical outcomes (e.g., survival and dialysis initiation), and physician role (educating patients, making decisions, pursuing active therapies, and managing symptoms). Paternalists and institutionalists viewed initiation of dialysis as a measure of success, whereas interpretive and informative nephrologists focused on patient engagement, quality of life, and aligning patient values with treatment. In this sample, only one third of providers presented conservative management to patients, all of whom followed either informative or interpretive approaches. The interpretive model best achieved shared decision making.

**Conclusions** Differences in nephrologists' perceptions of their role, patient autonomy, and successful versus unsuccessful encounters contribute to variation in decision making for patients with kidney disease.

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### Introduction

Older adults begin dialysis more frequently than any other group in the United States, yet some regret initiating dialysis (1–3). For many patients with CKD over age 75 years old, dialysis may not confer a significant survival benefit over conservative management while increasing utilization of intensive end-of-life care and potentially adversely affecting quality of life (4–7). Most patients are more satisfied when engaged in decision making, and clinical guidelines encourage shared decision making with older patients (2,3,8–10). However, many nephrologists do not routinely discuss conservative management and may actively promote dialysis (11,12). Consequently, some patients do not perceive dialysis initiation as their

choice (3,13–15). Better understanding factors differentiating nephrologists who do and do not engage in shared decision making and discuss conservative management is needed to improve quality care for older patients with CKD (16–20).

In their seminal paper, Emanuel and Emanuel (21) proposed four models of physician-patient decision making emphasizing different roles. The paternalist model highlights physicians' expertise and role in determining treatment, incorporating less input from patients. In the informative model, as technical experts, physicians inform patients of options and implications without influencing treatment choice. In the interpretive model, physician-patient interactions clarify patients' self-identified values, with

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physicians then guiding patients toward treatments aligned with their values. In the deliberative model, physicians suggest why certain values are more important in treatment selection (21). These models may help explain variation in clinical care but have not been examined in the nephrology context, where these models may be present or others may emerge.

Using nephrologists' in-depth accounts of interactions with older patients and drawing on the well established typology of Emanuel and Emanuel (21), we qualitatively characterize approaches to decision making and clarify how these relate to variation in conservative management discussions. Characterizing a typology of approaches to decision-making discussions may help nephrologists better understand and overcome challenges unique to their approach.

## Materials and Methods

To explore factors influencing nephrologists' approaches to care discussions with older patients and their beliefs and practices regarding shared decision making and conservative management, a qualitative researcher with expertise in kidney disease (K.L.) and a nephrologist (D.E.W.) developed the semistructured interview guide (3,22). Responding to open-ended questions, nephrologists reflected on successful and failed clinical encounters and described how their decision-making approach evolved, allowing for domains central to the framework by Emanuel and Emanuel (21) to emerge while not constraining responses to this framework. After informing participants about study goals and researchers' interest in the topic and obtaining verbal informed consent, K.L., R.P., and A.K. conducted interviews from June 2016 to May 2017 in person or by phone. Interviews were audiotaped and transcribed verbatim. Study reporting reflects Consolidated Criteria for Reporting Qualitative Health Research (23). The Tufts University Institutional Review Board approved this study.

## Participant Selection

Starting from a list of nephrology practices compiled by three nephrologists (R.D.P., K.B.M., and D.E.W.), the qualitative team purposively sampled (sex, years in practice, practice type, and region) to capture a range of perspectives and experiences, including some with a national reputation in geriatric nephrology (24,25). Snowball sampling, in which participants recommended other nephrologists from their center, was also used (25). Interviewers did not have preexisting relationships with participants. Sampling continued until thematic saturation and sufficient variation were achieved and confirmed through deliberation (25).

## Analyses

Typological analysis is a theory-driven methodology that differentiates members of a group by their distinct approaches to a given phenomenon, such as clinical decision making (26). Using typological and thematic approaches (25,27,28), K.L. and R.P. created a preliminary codebook on the basis of the interview structure. The qualitative team (K.L., R.P., A.K., R.L., and T.O.) independently coded the first three transcripts line by line, allowing for emergent codes (29). The codebook was revised and reapplied to

initial transcripts and an additional four transcripts. After iterative deliberation yielded consensus, the finalized codebook was applied to all transcripts using NVivo (version 11; QSR International). Codes were organized into themes through a consensus process using pattern and focused coding to capture the range and variability of subthemes and characterize both confirmatory and contradictory narratives (30). In a final stage, reflecting on the typology and framework of Emanuel and Emanuel (21), researchers reread interviews and created data matrices integrating themes, yielding an initial typology of nephrologists. To validate the typology, we carefully reviewed participants' fit within a model and checked for conflicting features. Model refinement continued through deliberative consensus until each nephrologist could be assigned into one predominant model (25).

## Results

Thirty-five nephrologists from 18 centers in nine states completed semistructured interviews lasting  $36 \pm 11$  minutes (Table 1); 20% were women, 66% had at least 10 years of nephrology experience, and 80% practiced at academic medical centers.

Our typology identified four distinct approaches to decision making and conservative management: paternalist, informative (patient led), interpretive (navigator), and institutionalist. The first three models echoed those proposed by Emanuel and Emanuel (21), whereas a fourth emerged, clarifying nephrologists' role of caring for patients in the context of stewardship of institutional resources and policies. We did not find evidence for the deliberative model of Emanuel and Emanuel (21): no participant described discussing the importance of certain values over others.

Five emergent themes characterized differences among the approaches: patient autonomy, engagement and deliberation (disclosing all options, presenting options neutrally, eliciting patient preferences, and offering explicit treatment recommendation), influence of institutional norms, importance of clinical outcomes (*e.g.*, dialysis access or initiation), and physician role (educating patients, making decisions, pursuing active therapies, and managing symptoms) (Table 2).

Across models, most nephrologists supported shared decision making but varied in their interpretation and implementation. Only one third of participants routinely discussed conservative management; they followed either informative or interpretive models. In all models, nephrologists ascribed the success of a discussion roughly equally to clinicians and patients. They mentioned listening to patients, patient engagement in selecting dialysis modalities, education and patient comprehension, and adequate time for discussion. Conversely, nephrologists generally ascribed failed discussions to patients, including limited health literacy, lack of engagement, emotional responses, caregiver interference, and language barriers (Table 3).

## Paternalist Approach

Paternalists strongly identified as patient stewards or protectors. They assumed responsibility for identifying the treatment most likely to improve the patient's health and

Characteristic	Overall (%), n=35
<b>Sex</b>	
Men	28 (80)
Women	7 (20)
<b>Years since completed nephrology training</b>	
0–5	7 (20)
6–10	5 (14)
10+	23 (66)
<b>State</b>	
Arizona	2 (6)
California	2 (6)
Florida	2 (6)
Maine	3 (9)
Maryland	5 (14)
Massachusetts	13 (37)
New Jersey	2 (6)
New Mexico	4 (11)
Pennsylvania	2 (6)
<b>Dialysis facility medical director</b>	18 (51)
<b>Practice type</b>	
Large academic	24 (69)
Small academic	4 (11)
Community	7 (20)

symptom burden. They viewed patient autonomy and the solicitation of patient values as less important than improving patient health and active treatment. On choosing between dialysis and conservative management, one nephrologist remarked, “It’s usually my decision, in conjunction with them . . . You have to be the parent and say ‘Listen, I’m sorry. You have to do this’” (ID 39). Many believed that delegating decisions to patients was abdicating their duty. Paternalists typically tailored discussions to highlight their favored outcome. One said, “Where I feel that [dialysis] would not be an imposition . . . I present it in a light that they would come away thinking that they need it” (ID 93). Dedication to patients, reliance on their expertise, and a commitment to determining treatment were echoed across paternalist providers.

Compared with other models, paternalists were most likely to define successful and unsuccessful discussions by clinical factors. One said, “A successful [discussion] tends to be one where people consider the options and make a decision about what kind of active treatment they want to take, rather than opting for no treatment and a peaceful death at home” (ID 93). Because of their commitment to tailored care, some were concerned about institutional interference: “I always will do everything in my power to make sure the patient is taken care of properly not in any cookie cutter fashion. When you’re dealing with a big company, everything is protocol driven . . . Thank God my practice is still on its own and we don’t work for somebody” (ID 39).

### Informative Approach

Nephrologists following this approach viewed their role as that of an educator, enabling patient-led decision making. They were more concerned with patient autonomy than that patients pursue a specific treatment. One said,

“I see my job as being the information broker and to provide that information so that if [patients] walk away understanding at least the basic elements, even if they’re in denial, then I guess that’s okay” (ID 94). Another said, “I’ve not met anyone who has said they are not willing to make or they don’t want to make a decision about their own life” (ID 27).

To accomplish patient-led decision making, these nephrologists typically presented treatment options neutrally, often avoided specific treatment recommendations, and accepted patients’ choices: “[W]e do give the patients all the options. I think as a patient they have the right to know everything. So we are not really forcing patients or not really urging patients towards one of the options” (ID 27). They often raised conservative management as a viable alternative to dialysis. Another said, “I do present the option of not opting for dialysis as a legitimate choice” (ID 80). Eliciting patient values was seen as key to success: “I hope that they understand the pros and cons and are able to look at that in terms of their daily activities, their daily goals, their sort of long terms plans so that they can ultimately make the best choice for themselves” (ID 94). Nephrologists subscribing to the informative model cited educational factors and decision-making quality more frequently as features of successful kidney replacement therapy (KRT) discussions compared with other models. They were least likely to judge success on the basis of clinical outcomes, such as dialysis initiation. One said, “[T]he most important thing is that the patients make an educational . . . choice . . . the best or right for themselves, that lets them enjoy life and live it with dignity” (ID 58). Another said, “[T]he most important [outcome] is the patient’s autonomy. That they . . . feel that they have control of what’s of their future and what’s going to happen to them” (ID 86).

These nephrologists described the evolution of their approach, having been strongly influenced by salient cases of patient regret and poor outcomes. One said, “My colleagues and I felt very strongly about treatment options, and we were very aggressive in pushing patients into the direction that we thought was best. During my fellowship, myself and several of my colleagues and fellows experienced bad outcomes, and from that, I started to realize very early on that it shouldn’t be my decision but that my job really is to provide information and to facilitate the patient in deciding the best process and best treatment plan for themselves” (ID 94).

### Interpretive Approach

Nephrologists following an interpretive approach (interpreters) perceived their role as that of a guide steering patients toward an optional treatment option: “I think ideally, in a perfect world, patients don’t make decisions. Patients very clearly articulate their values, goals, and wishes, and physicians are able to achieve the goals, values, and wishes of the patient through the vast opportunities we have within medicine” (ID 25). They emphasized trust and understanding of patient preferences: “It’s hard for patients to articulate what . . . specific medicine that they want. So tell me what your goals are, and I’ll tell you what the best way of achieving them is . . . Developing a kind of knowledge of the patient’s wishes, and appreciation

**Table 2. Comparison of nephrologists’ approaches to treatment decision making with older patients**

Themes	Paternalist	Informative (Patient Led)	Interpretive (Navigator)	Institutionalist
Patient autonomy	Views autonomy as assenting to health improvement; values trust over autonomy	Patient autonomy is most important; patient should choose and have control over medical care	Patient autonomy is integral to decision making	Views autonomy as assenting to objective values and institutional culture
<b>Engagement and deliberation</b>				
Neutral presentation of options	No	Yes	Yes	Often not
Solicitation of patient values and preferences	Related only to treatments presented	Always for all treatments	Always for all treatments	Related only to treatments presented
Offering explicit treatment recommendation	Always on the basis of clinical experience and perceived patient preferences	Only if patient requests a recommendation on the basis of expressed patient preferences	Always; incorporating patient-expressed preferences and clinical experience	Often; influenced by practice culture, incentives, and patient preferences
Influence of institutional norms	Weak	Weak	Moderate	Strong
Importance of specific clinical outcomes	Focus on survival, active therapies (e.g., dialysis initiation); omitting discussion of conservative management	Focus on process measures, autonomy, patient education, decision-making quality, patient-reported outcomes (quality of life)	Focus on shared decision making, patient education, patient-reported outcomes (quality of life)	Focus on survival, active therapies and quality of life, patient education of dialysis modalities
Perceived role of nephrologist	Promoting their perception of patient’s wellbeing irrespective of patient’s current preferences	Providing evidence-based education and implementing patient’s selected treatment	Clarifying and interpreting patient preferences, educating patients about options, recommending option, implementing patient selection	Promoting patient wellbeing and being a good steward of institutional resources and policies

of their goals, such that you can really ... orchestrate” (ID 25).

Navigators believed that social/emotional factors drive successful KRT discussions. One said, “[W]hat feels like a success is when people acknowledge ... that they are mortal ... that they’re at peace with it and able to go on and live happy and constructive and productive, emotionally productive lives with that knowledge, and that I’ve helped them do that” (ID 90). Navigators were also the only typology to cite caregiver support as a successful outcome of KRT discussions. One said, “The ultimate outcome is that the family and the patient are in unison” (ID 23). Although many navigators engaged in shared decision making and offered treatment recommendations, some worried that offering recommendations contradicted shared decision making.

Many nephrologists described an evolution in approach, developing a navigator style over time: “I started from a very paternalistic position that we made decisions for people. I’ve gotten to the point now that I’m much more hands off about guiding people” (ID 90). One clarified his response to patients disagreeing with recommendations: “Over time, I’m sure my conversations with them have evolved in how to deal with patients not doing what you think is the best thing for the patient” (ID 21).

**Institutionalist Approach**

Practice culture and norms strongly shaped decision-making discussions by institutionalist nephrologists. They attributed challenges discussing conservative management to system-level policies and influences, such as financial incentives, limited time allotted for appointments, and lack of a common approach to conservative management within the care team. One spoke of institutional constraints affecting his behavior, including limited time: “It takes time. I think it does require a longitudinal type of system ... We don’t have somebody who’s dedicated towards long-term education and follow-up and repeated discussions about goals of care. I think it would require physician extenders. It would require somehow health systems ... to actually support some of these things financially” (ID 83). About incentives, another said, “The economic side is always important ... the division sustains on the revenue generated ... from the dialysis unit” (ID 28).

Institutionalists viewed success as having sufficient time and support from their team to engage in meaningful decision-making conversations. Their perception of failed discussions centered on lack of consistency and cohesion both among nephrologists in their practice and between nephrologists and other health care providers. One clarified, “[shared decision making] probably requires a more ... centralized or a more consistent way of

**Table 3. Salient quotes: Views of success, failure, and outcomes by decision-making model****Paternalist**

Role is to serve as patient's "guardian"

Patient trust and respect valued over strict patient autonomy

Prioritizes improving patient health over patient autonomy in decision making

Tailors discussion of treatment options to maximize likelihood that the nephrologists' recommendation is selected

On when to start KRT discussions

*"It's not so much cut and dry in my opinion, there's an art to this, and you kind of have to know your patient too. And if you know them, you know how their body is reacting to certain things; you can kind of get a sense for when you need to potentially start having those discussions"* (ID 39)

On nephrologists' roles

*"I would say paternalistic is the best word to describe it. [With] some people you have to be more confrontational to, you have to be paternalistic in a different way, you have to be somewhat browbeating, you have to be, treat them like your 10 yr old son or you know where 'you need to do this,' you know you have to lecture them. And that doesn't always work. In fact, more often than not, I would say it doesn't work, that approach, but you have to do it. You have to say, 'you don't realize it, but a year from now you're going to be, you know, horizontal, you're not going to be vertical if you keep this up'"* (ID 48)

On patient autonomy

*"People really rely on you to help make your decisions. There's a whole group of people that will follow along. 'You tell me Doctor what to do and I'll do it,' and those are a win, but it puts you in an uncomfortable spot, because they are relying on you to make their decision. So while in a way those are the easiest . . . it's a heavy burden, because they don't really want to make their own decisions"* (ID 48)

Views of success

*"People that follow our instructions . . . I think an early placement of a fistula whether or not you go onto dialysis is really important"* (ID 48)

*"Do they feel better? Did they improve clinically? Did their symptoms improve? That's the most important thing—did they get better"* (ID 39)

Views of failure

*"I guess the unsuccessful one might be the patient who doesn't want to talk about it at all. Where it's so frightening, or imposing, that they can't even deal with it and refuse to discuss . . . I haven't had a lot of people who think it over and say, 'I don't want to do any of this, you know, give me the palliative treatment and let me go'"* (ID 93)

**Informative**

Role is to serve as patient's "information broker"

Prioritizes patient autonomy in decision making and accepts patient's treatment choice

May tailor discussion on the basis of patient's values, beliefs, and wishes

On when to start KRT discussions

*"If they're approaching . . . CKD stage 4, I often want to ask sort of if they had to make a decision today . . . which way are they leaning, and if patients say that, 'I've lived a long life and wouldn't want anything done,' then I again I'll refer them to the kidney class and I'll say, 'I respect your decision; if that's your decision, I will respect that and support that, but I do want you to make sure that you understand what's involved.' . . . I also mention that this is not a hard and fast decision, so if they change their mind they're welcome to as well"* (ID 14)

On nephrologists' role

*"I hope they understand what the kidneys do and what some of the basic problems are if their kidneys are failing, and therefore, I hope they then in turn understand what dialysis will and won't do for them. I hope they understand that we're trying to work with them on a timeline that will not feel rushed and will allow them to make decisions for themselves"* (ID 42)

*"I hope I can help them clarify their goals. So . . . what do they want for themselves, and then, once they make that decision, I hope I can facilitate that transition, to whatever that is, and help them through that process"* (ID 72)

On patient autonomy

*"[The] ultimate choice of kidney replacement therapy (if it progresses to that point) is something that the patient will look back and appreciate that they made that decision"* (ID 14)

Views of success

*"I think that patients have a sense of what works best for them, and I think that sometimes patients know their diagnoses even before we've made the diagnosis. So listening to the patient really has been very helpful, and I think the outcomes are better or at least the patient experience is better"* (ID 94)

*"If somebody leaves the room feeling sort of fairly supported and that they can ask additional questions . . . moving down a path based on sort of a shared decision"* (ID 42)

*"I think the successful discussion is when you really have a conversation with both parties that are equally engaged in it, and . . . when the patient really understands what's going on with them and what will be best for them"* (ID 58)

Views of failure

*"I think there's probably a whole bunch of unsuccessful discussions we're not aware of, because we don't really understand what people took away from what we've said"* (ID 3)

*"I guess a failure of a decision would be a patient that we [nephrologists] are making [KRT] decisions, even though I've had a long relationship with them, we're making those decisions in the hospital setting, inpatient setting, rather than the outpatient setting . . . [T]he unsuccessful ones are the ones that patients either come to an early closure of decision or have not thought of any decisions . . . and by early closure, I mean like they say, 'I don't want anything done' is a traditional thing that I'll hear"* (ID 14)

*"[C]ertain times, you know people get angry at what they're hearing and sort of not involved in the decision making"* (ID 86)

**Interpretive**

Role is to guide a patient to an optimal treatment selection on the basis of a patient's values and goals

Develops a strong rapport with a patient to facilitate guided decision making

Tailors discussion of treatment options on the basis of a patient's values, beliefs, and wishes

On when to have KRT discussions

*"I begin with discussions in early CKD [stage] 4 . . . when GFRs are 30, but usually when it's in the 20s . . . [I] approach it slowly, have them think it over for a little bit, come back, talk with family members, and come back again. How have I modified [my approach from] earlier on: I had been fairly aggressive with saying, 'OK, now all we need to do is set you up with the vascular surgeon, I'd like you to talk about this, I'd like you to go visit the centers.' I think [patients] probably pushed back quickly . . . and I've backed off a little bit over the years"* (ID 81)

On nephrologists' role

**Table 3. (Continued)**

<p><i>"I will certainly tailor the information that I'm providing. I'm hoping tailoring them to an appropriate level of education, literacy, etc. . . . Sometimes, I find that patients are looking for me to have a larger role in the decision-making process in the sense of giving perhaps more concrete guidance. If that's the case, then I will try to do so in a, still making clear to them that it's their decision, but perhaps . . . to frame the decision a little more discretely or concretely"</i> (ID 7)</p> <p><b>On patient autonomy</b></p> <p><i>"I want the patient to decide what is best for them. It's not like one size fits all. It's their life, sometimes they don't want to do dialysis, which is perfectly fine. I mean, the patient's choice comes first"</i> (ID 5)</p> <p><i>"It's important to have a sense of that they've been informed to the extent that they can be about what their choices are and that they are making choices that are consistent with kind of where they're going in life"</i> (ID 26)</p> <p><b>Views of success</b></p> <p><i>"I'm happy if they've come out together . . . we've come out with an informed decision of what works best for the patient and their sort of lifestyle and what they want"</i> (ID 19)</p> <p><i>"The most important outcome is that they receive the care that they have selected, so particularly if they have selected not to receive dialysis and to have conservative care, that they do not end up on dialysis [in an emergency admission]"</i> (ID 7)</p> <p><i>"I think that the best outcomes is where they do complete that [advance directive] and have discussed it with their family, and then even better is if the family and the patient feel some relief on having gone through the process"</i> (ID 63)</p> <p><b>Views of failure</b></p> <p><i>"A suspicious patient who, who doesn't believe that they truly need dialysis, an unengaged patient, a patient who holds false belief systems, somebody believes that prayer will correct their renal failure, they don't need to engage with the discussion. A situation where you haven't developed trust"</i> (ID 68)</p> <p><i>"If they're not accepting, that makes it harder. There's a handful of patients I have that have never told their family members as to what's happening, so family members don't even know that they've been seeing a nephrologist, and they've been coming every 3 or 4 mo, and they're at the point that they need to make decisions"</i> (ID 91)</p> <p><b>Institutionalist</b></p> <p>Role is to treat patients within the norms and culture of a practice group or institution</p> <p>Cites time as a key challenge to discussions with patients with CKD</p> <p>Tailors discussion of treatment options to patients</p> <p><b>On nephrologists' role</b></p> <p><i>"You're aware in the sense a major part of the revenue comes . . . from the dialysis unit. So obviously I want people to go on dialysis, not but I don't want the wrong person to go on dialysis. So that's something which . . . although I say that I don't want the wrong person to go on dialysis, but still I feel that I'm doing it"</i> (ID 28)</p> <p><i>"We talk about quality of life to the patients; we try to gauge what is important for them. But I do believe we do a poor job because of the limits of time that we have with the patients. There are the pressures of seeing many patients, and we don't have the luxury of setting aside an hour for each follow-up visit, at least in our health system . . . Trying to align the modality choice, if it's dialysis or not dialysis, to what they want, what their expectations are, what, what their goals are, but again, I think that we don't fully explore that because of the limitations of time"</i> (ID 83)</p> <p><b>On patient autonomy</b></p> <p><i>"We try to discuss with them why this is important and uh, that their participation is key, that uh you know, that it really has, that what our goal is try to align whatever we do with what they want or what they desire out of their lives. I think we do, I do think we selectively push some modalities more than others or some depending on the individual"</i> (ID 83)</p> <p><b>Views of success</b></p> <p><i>"The dialysis staff . . . play a major role in the decision making . . . these patients and family members, they interact with those staff . . . more than their interaction with me . . . Definitely [patient] survival . . . the next thing will be the quality of life"</i> (ID 28)</p> <p><b>Views of failure</b></p> <p><i>"I think it's the patient is kind of beyond their denial. I feel so many of them are stuck in that or there is this wishful thinking that their kidneys will get better. There is this notion that if they don't feel poorly, then there can't be anything that bad, even if the blood tests show it . . . I would say that's the biggest challenge initially, and it's smoothest when the patients are accepting that they have advanced kidney failure and uh, will most likely at some point in time need dialysis"</i> (ID 83)</p>
<p>These quotes show differences in nephrologists' approaches to discussions with older patients at key points along the clinical and decision-making cascade, starting with broaching the subject of KRT followed by perceptions of nephrologists' role and patient autonomy and finally, their perceptions of successful versus failed encounters. These clinical decision points reflect key themes presented in Table 2, including patient autonomy, perceived role of the nephrologist, engagement and deliberation, importance of specific clinical outcomes, and institutional norms (captured in views of success, views of failure, and when to start KRT discussions). KRT, kidney replacement therapy.</p>

addressing that issue. Because right now, a lot of it is probably provider dependent or nephrologist dependent, how that question is asked again and how much of the exploration of patient expectations and priorities are discussed" (ID 83). Uncertain about how conservative management recommendations would be received by both patients and their institution, some noted a desire for stronger institutional norms related to conservative management discussions.

## Discussion

Among nephrologists, four distinct approaches to KRT decision making emerged, offering new explanations for

variation in decision making and access to conservative management for older patients with CKD. Differences between paternalist, informative, interpretive, and institutionalist approaches were largely on the basis of divergent perceptions of physician role, patient autonomy, and successful versus failed discussions. Understanding how these differences shape nephrologists' discussions and delineating the benefits and shortcomings of each approach can facilitate the development of improved guidance to support nephrologists caring for older patients.

Choosing whether to undergo dialysis triggers a cascade of choices determining how people with kidney failure will

live their last stage of life. In 2001, the Renal Physicians' Association and the American Society of Nephrology first issued clinical guidelines promoting shared decision making in dialysis initiation and withdrawal decisions (31). However, for reasons incompletely understood, shared decision making, although widely supported, has not been widely implemented (32,33). This typological analysis clarifies the patterning of documented barriers and facilitators to shared decision making (14,24,34), revealing disparate approaches to decision making and care for older patients with CKD.

Most nephrologists supported shared decision making but differed in their interpretation and approach to patient engagement. Whereas paternalists grappled with presenting treatment options neutrally and strayed from shared decision-making principles by constraining patients' choices, nephrologists following an informative approach struggled to provide explicit recommendations, also deviating from shared decision-making principles. Institutionalists and interpreters wanted more guidance about shared decision making. In some circumstances, nephrologists deviated from their typical approach, suggesting that approaches may be modifiable and that shared decision making could be improved, potentially with clearer guidance about patient engagement and discussion of treatment harms and benefits.

To ensure consideration of dialysis, many "paternalist" nephrologists avoided discussing conservative management, concerned that patients would react emotionally and disengage or reject dialysis outright. However, ample evidence shows that patients want knowledge about all options, prognostic information, and recommendations for care, even if they decide not to follow them (3,35,36). This includes learning about palliative options (22). Paternalist approaches favoring active, life-prolonging interventions are still embraced in emergency settings, including emergency dialysis, where time is scarce and patients' preferences cannot be ascertained. However, in the context of chronic or late life care, this approach may require modification, particularly because physicians have the opportunity to explore patients' preferences and cannot assume that interventions will not result in harm or regret. Among 584 older patients on dialysis, 61% regretted starting dialysis, and over one half reported choosing dialysis over conservative management due to their doctor's wish (2). Other studies have found that patients want more balanced information about treatment options, including conservative management, even when options seem bleak (3,19,37,38). As such, nephrologists subscribing to the paternalist model may consider eliciting patient preferences and ensuring that all options are presented.

Institutionalists valued consistency and cohesion. They often recommended active treatment and struggled to discuss conservative management because of inconsistent institutional support for palliative care. However, institutionalists encouraged patient engagement in dialysis modality selection in accordance with institutional commitment to increasing utilization of peritoneal dialysis. This model underscores the significant opportunity and importance of health system improvement. Greater coordination and communication about patients' goals of care and preferences for conservative management among

nephrologists within a practice and between nephrologists and other team members (*e.g.*, palliative care, primary care, *etc.*) could bolster efforts of institutionalists to engage in shared decision making and conservative management discussions (39). Institutionalists strongly desired clearer guidelines, stronger support, and recognition (financial and institutional) to increase shared decision making and conservative management discussions. Although Medicare issued codes in January 2016 to reimburse nephrologists for advance care planning, compensation is low, and system improvements are needed, including consistent documentation in electronic health records.

Informative approaches also have limitations, empowering patients but unnecessarily disempowering nephrologists. Nephrologists in this model avoided offering recommendations, not wanting to excessively influence patients. By offering neutral information without recommendations, nephrologists assume the role of a technical expert but not a guide (21). This approach may be effective for patients who have high health literacy or those more familiar with kidney failure treatments. However, many patients grappling with decisions regarding dialysis initiation want an explicit recommendation (3,34). Cognitive decline, complex family dynamics, and difficulty understanding long-term implications for quality of life underscore the importance of guidance from nephrologists to align patient preferences with treatment.

The interpreter model offers a balance between paternalist and patient-led approaches to decision making (3). By understanding patients' values and drawing on experience, interpreters help patients explore options, consider potential harms and benefits, and offer advice on the basis of trust cultivated through long-standing relationships. Interpreters guide patients by focusing on quality of life, engaging patients in questions about goals for the last stage of life, activities most meaningful to them, and perspectives on end-of-life care. Although the interpreter approach is most consistent with shared decision making, it may not work in every setting, including dialysis initiation in emergency settings. The interpreter approach requires significant time, training, and comfort discussing difficult topics; established doctor-patient relationships; and institutional support.

Strengths of our study include purposively sampling across multiple states. Limitations include oversampling academic medical centers; sex imbalance, which may affect communication style; and self-reported accounts, which may not perfectly reflect practice. Although not originally developed from empirical evidence, this study and others suggest that the typology of Emanuel and Emanuel (21) generally fits with medical practice. Our findings likely are transferable to nephrologists treating older patients with CKD (3) and provide a framework for improving conservative management discussions.

In conclusion, distinct decision-making models among nephrologists result in variation in patient experiences, decision making, and conservative management discussions. Many nephrologists desire better communication strategies to engage patients in difficult conversations and shared decision making (14,32,40). Achieving shared decision making may require nephrologists to adopt elements of informative and interpretive approaches and reserve

paternalist approaches to emergency decision making, where patient preferences cannot be ascertained. Nephrologists should reflect on their approach to decision making with older patients and understand the strengths and weaknesses of each model in an effort to better achieve shared decision making.

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