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The patient perspective and physician's role in making decisions on instituting dialysis

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Shared decision making describes an approach to medical decision making that lies between paternalism and autonomy [1]. This model of decision making, described recently as the 'pinnacle of patient-centered care' [2] is quickly becoming the

preferred approach to medical decisions, where there is no one 'best' treatment option. In these circumstances, involvement of patients in decision making helps us to ensure that treatment decisions reflect the patient's preferences and values.

Shared decision making consists of two components. The first component provides patients with information on their treatment options. The second, often overlooked, component facilitates an informed decision. To accomplish the latter, providers need to elicit patient preferences, suggest options that reflect those preferences and help patients move to a decision [3]. Effectively communicating information and engaging patients not only increase the likelihood of true shared decision making, but these also improve trust in the doctor–patient relationship and increase self-care skills [4, 5].

For dialysis decisions, a shared decision-making approach has been endorsed by several professional organizations, including the Renal Physician's Association, the American Board of Internal Medicine and the American Society of Nephrology [6, 7]. These recommendations reflect recognition that maintenance dialysis therapy involves trade-offs which individual patients may weigh differently, and that dialysis is not always the 'best' treatment option. Are patient perceptions of the dialysis decision-making process consistent with the ideals articulated in practice guidelines?

In this issue of *Nephrology, Dialysis and Transplantation*, Song *et al.* present findings from semi-structured interviews on the dialysis decision-making process in 99 patients receiving maintenance dialysis [8]. The sample was recruited for a randomized clinical trial on end-of-life communication from 15 dialysis centers in a single US state. To be eligible for the parent study, patients had to be receiving dialysis for at least 6 months, have a Charlson Comorbidity Index of at least 6 (5 if recently hospitalized), be English-speaking and not have serious cognitive impairment. The investigators developed 10 questions covering various aspects of the content of dialysis discussions, including the cause of end-stage renal disease (ESRD), the available treatment options and anticipated life expectancy, the availability of conservative (non-dialytic) care, daily life on dialysis, patient values and preferences, and level of understanding. The context of dialysis discussions was probed using open-ended questions.

The mean age of the sample was 61 years, 48% were males and 77% were African Americans. The sample had a median vintage of 4 years, and nearly all patients were on hemodialysis. A majority of patients were informed that their condition could progress to ESRD prior to starting dialysis, though not all were aware of the implications of progression. Nephrologists were most often the first medical professional to address the need for dialysis decisions and roughly half of the time these discussions occurred in the inpatient setting.

With respect to the content of dialysis discussions, the news is mixed. On the positive side, nearly all patients (83%) understood the lifelong need for dialysis therapy in the absence of transplantation. A majority of patients (60%) were presented with both hemodialysis and peritoneal dialysis options, though many would argue that this figure should be much higher. Most patients (75%) felt their doctor was trying to make sure they understood the information he or she delivered.

However, other results suggested clear areas for improvement. In particular, the findings suggest that nephrologists provided information, but did not engage in the second and

very important component of shared decision making – facilitating a decision by serving the function of a choice architect. Specifically, less than half of patients were informed of the benefits and burdens of different dialysis modalities, how dialysis might affect their daily life and what values or preferences patients considered most important to the decision. Only one patient was presented with the option of not starting dialysis.

Several aspects of the study design and cohort should be considered when interpreting these results. First, the study examined patient perceptions of dialysis discussions rather than the actual content. While perceptions certainly matter, it makes it difficult to determine whether important information was not presented during discussion, or whether it was presented and patients did not understand it or did not remember it. Second, subjects were predominantly African Americans and relatively young, with a mean age of 61 years, limiting the applicability of the findings to the fastest growing segment of the worldwide dialysis population, Caucasian patients over age 75. Third, subjects had been receiving dialysis for an average of 4 years when they enrolled in the study, and so they are likely to be much healthier than the average patient who engages in these discussions. The length of time elapsed between the dialysis discussion and study interview, and the relative health of the study cohort raise concern for recall bias, a systematic error due to differences in the accuracy (or completeness) of remembering past experiences.

Determining the direction that recall bias might be operating is more difficult. On the one hand, healthier patients might be more likely to have positive recollections of dialysis discussions, in which case these findings might raise even greater concern. On the other hand, patients who have been receiving dialysis for a long period might be less likely to remember more detailed aspects of the discussion such as whether the burdens of dialysis, their daily life on dialysis and the option of not starting were discussed, and might be more apt to remember the big picture aspects of the discussion, such as the lifelong need for dialysis and the general perception that the doctor tried to make information understandable.

Perhaps, the most important message from this study is that >60% of patients felt that the decision-making process could have been improved through more information and/or more sensitive delivery of bad news. Here, the findings are largely in line with earlier research on patients' knowledge (or lack thereof) of renal replacement modalities [9–11]. Several of the barriers to shared dialysis decision making have been described, including language and cultural differences, poor cognition or health literacy, clinical urgency and uncertainty, and clinician worries about taking away hope. So what can be done to bridge the gap between the principles articulated in guidelines and the practical challenges faced in many patient encounters?

First, providers should be trained in how to effectively deliver bad news concerning the diagnosis of (or likely progression to) ESRD. A standard protocol like SPIKES or formal communication skills training can be very effective when delivering bad news [12, 13]. Importantly, the rush to reach a treatment decision should not interfere with the need to attend to

patient emotion. Though uncertainty about prognosis and the clinical course often lead to avoidance of goals of care discussions until decisions are urgent, early and ongoing engagement is preferable. By identifying surrogate decision makers and articulating their values before they are acutely ill, patients can become better prepared for in-the-moment decisions [14]. This may be especially relevant for patients with a high likelihood of dying from other comorbidities before progressing to ESRD. Indeed, discussions which broadly address values rather than narrowly considering specific treatments, such as dialysis, may prepare patients to consider the role not only of dialysis, but also of other life-extending or invasive treatments such as mechanical ventilation, cardiopulmonary resuscitation and feeding tubes should such decisions arise.

Second, providers need a better understanding of what information is helpful to patients who are confronting ESRD and modality choices. Here, the study by Song *et al.* makes an important contribution by indicating what type of information patients want but are not currently receiving. Patients want information not only on how or whether dialysis will affect survival, but also how it will make them feel, and how it will affect their lifestyle and the life of their caregivers. It is vitally important to describe predictable consequences of peritoneal dialysis and hemodialysis, including the need for a regulated diet, the fact that patients will likely need occasional hospitalizations for access procedures and the potential travel

restrictions imparted by dialysis schedules. It is also very important to describe dialysis as a treatment and identify the typical circumstances when the ‘treatment’ (dialysis) could be withheld or withdrawn (Table 1).

Third, in order to facilitate true informed consent and shared decision making, it behooves the physician to skillfully play the role of a choice architect [15]. Patients are more likely to make choices that are congruent with their values if they are given a clear and well-designed set of options that are specifically tailored to their unique circumstances. Designing these options is what is known as ‘choice architecture’. Recent research confirms that how treatment decisions are framed influences the choices patients make. For example, in one study which asked surrogates to participate in a web-based simulated family meeting to decide their loved ones’ code status, surrogates were less likely to choose cardiopulmonary resuscitation when ‘Do Not Resuscitate’ was framed as the social norm, or when the alternative to cardiopulmonary resuscitation was ‘Allow Natural Death’ rather than ‘Do Not Resuscitate’ [16]. While some may balk at the role of choice architect, the truth is that physicians assume this role whether we like it or not; indeed as dialysis experts we are often consulted for this very reason.

We stress the fact that the physician should carefully consider the benefit and burden of each potential option based on their prior knowledge about the patient’s health-related

Table 1. Sample scripts for discussing, withholding and withdrawing dialysis

Clinical situation	Sample script
Discussing circumstances when dialysis can be withdrawn	‘Mrs Smith, when I start dialysis on any patient, I also like to describe if and when we would stop dialysis. There may come a time in the future when you may want to stop dialysis. This typically happens due to worsening health and other complications of dialysis. You have the right to stop dialysis at any time and when that time comes, I will be able to help you and your family with that decision-making process.
Discussing circumstances when withholding dialysis may be a viable option	‘Mrs. Smith, I think we are at a point in your health where we have to make a decision about starting dialysis. One option is to start you on dialysis (now describe the details about the benefits and burdens of dialysis and the future circumstances when dialysis would be stopped). Another option is to not start dialysis. You have a few other diseases already and you also have difficulty completing your activities of daily living. Some patients in your situation may not want to start dialysis at all. What is your understanding of dialysis as a treatment option and do you see yourself undergoing dialysis?’
Clarifying values in patients with a high likelihood of dying before progression to ESRD	‘Mrs. Smith, when you were in the hospital (for heart failure) did this situation change your opinion about the ways of being that would be unacceptable or a state worse than death?’ ‘If you were in this situation again, what would you hope for? What would you be most worried about?’ ‘Your health has changed over time. Sometimes patients can get used to these changes and sometimes they cannot. In the past, you told me that (e.g. staying out of the hospital) was important to you.’ ^a

^aAdapted from [14].

behaviors and social support network. Options presented should also be tailored to give freedom of choice for the patient while acknowledging that presenting patients with more options confers a greater cognitive burden. The idea is to 'create an environment that counteracts cognitive biases and inaccurate perceptions' [17], so that patients can make informed decisions which reflect their values and goals.

The all too pervasive view of dialysis as the default therapy for ESRD has impeded the process of helping patients understand their treatment choices, and ultimately, adapt to life, and eventually death, with ESRD and dialysis. We hope this window into dialysis decision making will spur reflection on the role physicians play in the decision-making process and stimulate the development of decision aids and other tools to improve shared decision making.

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CONFLICT OF INTEREST STATEMENT

We have had no involvements that might raise the question of bias in the work reported or in the conclusions, implications or opinions stated.

(See related article by Song *et al.* Patient perspectives on informed decision-making surrounding dialysis initiation. *Nephrol Dial Transplant* 2013; 28: 2815–2823.)

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