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# Communicating Prognosis in the Dialysis Consent Process: A Patient-Centered, Guideline-Supported Approach

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**Recent guidelines recommend shared decision making between patients and nephrologists as the model for dialysis decision making. A key component of this shared decision making is obtaining informed consent. As part of this process, nephrologists have an obligation to inform patients with chronic kidney disease of their prognosis. Ideally, patients themselves should be involved in the decision-making process; however, some patients will not possess decision-making capacity, and others may be unwilling to participate. Determining what to tell patients about prognosis requires tailoring the conversation to the individual patient's preferences. Conversations about prognosis need to occur in a timely fashion so that patients have the opportunity to consider options and make decisions before dialysis is inevitable. Communication strategies are available to assist nephrologists in breaking the bad news of the need for dialysis and its associated burdens. The approach described in this article should help nephrologists discuss prognosis with their patients in a way that is patient centered and in accordance with clinical practice guideline recommendations.**

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**Index Words:** Prognosis; communication; chronic kidney disease; informed consent.

A 75-year-old woman was referred to the nephrology clinic by her primary physician for evaluation of chronic kidney disease (CKD) with progressively worsening kidney function. She had a 20-year history of diabetes mellitus complicated by retinopathy, neuropathy, and peripheral vascular disease, requiring recent toe amputation. She had multiple other comorbid illnesses including hypertension, cryptogenic cirrhosis with liver failure, pancytopenia (believed by her hematologist to be secondary to massive splenomegaly from portal hypertension), a history of colon cancer status post colon resection and adjuvant chemotherapy 9 years previously, Parkinson's disease, an aortic valve replacement 7 years previously, and a history of massive gastrointestinal bleeding secondary to esophageal varices 3 years previously.

The patient required assistance with all activities of daily living except feeding and was residing in a nursing home. She had decision-

making capacity and no family other than a sister whom she had named her medical power of attorney representative. Laboratory data revealed an estimated glomerular filtration rate (GFR) of 15 mL/min and a serum albumin of 3.2 mg/dL. Although she had no uremic symptoms, it was obvious she would progress to end-stage renal disease (ESRD) soon. The patient had been a nurse before retirement and seemed to have some understanding about her diagnosis. The nephrologist discussed options for ESRD treatment with the patient. As the discussion progressed, the patient made it clear that, despite her poor prognosis, she wanted hemodialysis when needed.

This case shows the challenges nephrologists face in daily practice. They are obligated to inform patients with CKD about their prognosis. Increasingly, incident ESRD patients are older and have multiple comorbid conditions that contribute to a patient survival that is only one-third to one-sixth that of age-matched persons in the general United States population.<sup>1</sup> Nephrologists must provide truthful, realistic information to patients while maintaining some element of hope as they help patients make decisions about initiating and/or withdrawing from dialysis. In a 2001 to 2002 cohort study of ESRD patients, the United States Renal Data System noted that

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21.5% of dialysis patient deaths were preceded by dialysis withdrawal (Collins AJ, personal communication, August 2004). Nephrologists report that they make decisions regarding withholding and withdrawing dialysis several times a year.<sup>2-4</sup> Clearly, decision making is at the heart of the relationship between nephrologists and their patients.

Over 2 decades ago, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research proposed that medical decisions for individual patients should be shared between the physician and the patient.<sup>5</sup> More recently, the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) published a clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, to assist nephrologists in making decisions regarding initiation and withdrawal of dialysis.<sup>6</sup> The first recommendation in this guideline was for nephrologists to participate in shared decision making with the patient. The guideline defined shared decision making as "the process by which physicians and patients agree on a specific course of action based on a common understanding of the treatment goals and risks and benefits of the chosen course compared with reasonable alternatives (RPA/ASN Clinical Practice Guideline, p 7)." The second recommendation was that patients' consent for or refusal of dialysis should be informed and voluntary. The third recommendation was that nephrologists should estimate prognosis for patients with ESRD and that these estimates should address life expectancy and quality of life. The purpose of this article is to describe how nephrologists can implement these recommendations and best communicate prognosis with their patients.

### **Ethical and Legal Principles**

There are many ethical and legal principles that are relevant to dialysis decision making; however, for the purposes of this article, it is possible only to briefly discuss 2 principles: respect for patient autonomy and nonmaleficence. Respect for patient autonomy is the principle that places importance on allowing

persons to make important decisions for themselves. It is the principle that primarily undergirds the obligation of nephrologists to inform their ESRD patients about prognosis. Application of this principle occurs through the process of informed consent. Informed consent requires that the physician (1) determine whether the patient has decision-making capacity; (2) disclose all information about the medical condition including risks, benefits, and consequences of all available treatments as well as consequences of no treatment; (3) ensure that the patient has understood the information disclosed; (4) make a recommendation among the possible options based on the patient's condition and values; and (5) obtain a voluntary decision by the patient.<sup>7</sup> Obtaining informed consent is legally required to enable patient self-determination. If the nephrologist determines that a particular patient has an extremely poor prognosis and that starting dialysis is likely to cause more harm than good, the nephrologist, motivated by the ethical principle of nonmaleficence, which requires physicians to refrain from harming patients, should recommend against dialysis. A time-limited trial of dialysis may be recommended if the benefits of dialysis for a patient are unclear or if the patient wants dialysis despite the nephrologist's inclination, as in this case.

### **Who to Tell**

Ideally, the patient is the individual with whom discussions about prognosis should occur. A first step in deciding "who to tell" involves assessment of the decision-making capacity of the patient. Nephrologists may make this clinical determination or may prefer to consult a psychiatrist or psychologist for assistance. Psychiatrists or psychologists may also help identify underlying illnesses such as depression or personality disorder that could influence patients' decision making. If a patient lacks decision-making capacity, then physicians must have discussions and make decisions with the patient's legally specified agent (eg, durable power of attorney for health care). If no such legal agent has been appointed by the patient, then the discussions and decisions must occur with a surrogate

appointed according to the law in the state in which the care is being provided.

A significant number of older dialysis patients may not lack decisional capacity but instead have diminished cognitive abilities, which limit their capacity to make health care decisions. In a study of hemodialysis patients over 65 years old, 39% had Mini-Mental State Examination scores lower than the published norms.<sup>8</sup> In addition, a majority of these patients did not know basic information relative to self-care, suggesting that diminished cognitive capacity may hinder patients' abilities to understand or retain information. There appears to be a greater need for involvement of family members or other trusted individuals in the informed consent process, particularly for patients of low educational background, advanced age, and/or diminished cognitive capacity.<sup>9</sup>

Although many dialysis patients place a high value on self-determination, others do not. In one study, most hemodialysis patients (96%) wanted information about their medical condition, but fewer (82%) actually wanted involvement in decision making.<sup>10</sup> In another, 75% of patients agreed with statements indicating a desire to be informed about conditions and treatment options, but there was less agreement with statements supporting patient involvement in decision making.<sup>8</sup> Thus, another important step in determining "who to tell" involves asking the patient whether or not they want to hear the information regarding prognosis and whether or not they want to participate in the decision-making process. If the answer to these questions is "no," then it is necessary to determine whom the patient would prefer to receive the information and make decisions on his/her behalf.

### When to Tell

Timing of when to tell the CKD patient about the prognosis of ESRD may be a contentious issue. Certainly, it seems premature to discuss life expectancy with the patient who has stage 2 CKD whose GFR, although diminished, has remained stable over an extended period of time. On the other hand, it is not reasonable to withhold discussions of prognosis until the

issue of whether or not to initiate dialysis must be broached.

There appears to be some reluctance on the part of nephrologists to make patients aware of the need for dialysis, let alone their prognosis on dialysis. In a survey of dialysis patients over age 65, only 30% reported they had been notified that they would need dialysis at least 6 months in advance, and 34% reported they had less than 1 week's notice.<sup>11</sup> Because CKD is typically a slow process with a measurable progression, there should be only rare circumstances in which nephrologists have not discussed prognosis well in advance of the need for dialysis.

The importance of determining patients' wishes in advance is underscored by the disagreement among nephrologists in managing incompetent dialysis patients with unclear prior wishes.<sup>4</sup> Although 90% of nephrologists would agree to stop dialysis for incompetent patients with clear prior wishes, only about 60% of nephrologists would stop dialysis for an incompetent patient with unclear prior wishes. An effective way to avoid this situation is initiation of discussions about prognosis and patients' wishes earlier in the course of a patient who has progressive disease, coupled with encouraging patients to document their wishes in advance directives. In the completion of advanced directives, patients find it easier to specify health states such as coma or advanced dementia in which they would not want to continue dialysis or other forms of life support rather than make statements about which life-sustaining treatments they would want.<sup>12</sup>

### What to Tell

The major issue in deciding what to tell regarding prognosis in ESRD is how much the patient wants to know. This can be easily addressed by asking, "Mrs. Jones, how much would you like to know about your kidney failure and what is in store for you in the future?" This enables the nephrologist to tailor the conversation to fit the patient's preferences. Discussing ahead of time how individual patients would like to receive test results, how much detail they would like to know about their clinical course, and whom else

they would like to be informed can help to guide future conversations.<sup>13</sup> Because patients from different cultures and ethnic groups may have particular preferences for disclosure of information, nephrologists need to be mindful of these differences and ready to tailor disclosure to accommodate these preferences.<sup>14</sup>

The RPA/ASN guideline recommends that discussions about starting or stopping dialysis should contain an estimate of prognosis, life expectancy, and likely quality of life. Prognostic information is often the single most important piece of information that patients need to make informed choices.<sup>15</sup> Although there is not yet a single mathematical formula to combine all risk factors to provide a numeric estimate of life expectancy, there are factors identified by multivariate analyses that are significant predictors of mortality for ESRD patients including age, serum albumin level, functional status, and comorbid illnesses (usually measured by Charlson Comorbidity Index or Index of Coexistent Diseases).<sup>16,17</sup> The RPA/ASN guideline has a concise review of the most significant predictors of mortality in ESRD patients.<sup>6</sup>

Most nephrologists have encountered patients with poor predicted survival on dialysis who have exceeded life expectancy estimates. Thus, a complicating factor is clinical uncertainty. Physicians may choose a path of non-disclosure, nondiscussion, or oversimplification at times because of the difficulty in communicating uncertainty.<sup>18</sup> Nevertheless, the need for conversations about prognosis, including uncertainty, is well established. Physicians have a moral duty to prognosticate. According to Christakis,<sup>19</sup> for physicians not to do so is to shirk their professional responsibility as a physician. In fact, it is in situations of clinical uncertainty that patients most want to introduce their own extramedical values to assist in the decision-making process; thus, candor about the uncertainty of prognosis may encourage shared decision making.<sup>18</sup>

Discussions regarding prognosis or end-of-life issues may be difficult for the physician to initiate. Patients, their families, and clinicians collude to avoid mentioning these topics. Nephrologists tend to focus their discussions with patients on the aspects of care least likely

to create conflict.<sup>20</sup> Nonproblematic topics may include discussion of dialysis modality or kidney transplantation. Problematic topics include refusing dialysis, dying of kidney failure, or the right to a short-term trial or termination of dialysis. One series of patients reported discussing nonproblematic issues 53% of the time as opposed to discussing problematic issues only 20% of the time. Although most patients reported having discussed modes of dialysis, few discussed issues relating to death, including the choice of forgoing or terminating treatment. Another study of ESRD patients over age 65 years examined what patients had been told before initiation of dialysis.<sup>11</sup> Many patients lacked even basic understanding of the cause of their kidney failure or its irreversibility. This was paralleled by very little knowledge of the dialysis modalities themselves. When patients were queried about what they had been told regarding treatment options, only 32% reported being told they could refuse dialysis, and 17% reported being told they could stop once they had started. In another series of dialysis patients of all ages, nephrologists reported regularly discussing terminal care preferences, but patients did not report having such conversations.<sup>21</sup> Although destroying hope is feared by physicians and a major reason why they are reluctant to broach end-of-life issues, few data support the notion that providing truthful information will destroy hope.<sup>15</sup>

## How to Tell

Sharing information about prognosis to patients with CKD would certainly fall into the category of "breaking bad news." Guidelines have been published regarding breaking bad news, but most are based on opinion.<sup>22</sup> One widely used method for breaking bad news was developed by Buchman and Kayson.<sup>23</sup> This 6-step approach involves (1) giving news in person, in private, with sufficient time and without interruption; (2) finding out what the patient already knows about the diagnosis; (3) finding out what the patient wants to know; (4) sharing the information with a caring and honest attitude by first giving a warning shot ("I am afraid that I have some bad news for you"), and then providing a small amount of

information in simple language at a pace the patient can handle; (5) responding to the patient's feelings and concerns; and (6) planning follow through with determining next steps, identifying sources of support, and making an early follow-up appointment. From a patient's perspective, satisfaction when receiving bad news is greater when physicians attend to making the environment comfortable, taking plenty of time with the patient, and attempting to empathize with the patients' experiences.<sup>24</sup>

### The Case Revisited

Applying the approach recommended in this article to the case presentation would result in the following process. Before having a discussion about prognosis and dialysis, the nephrologist should first estimate the patient's prognosis. The patient's calculated Charlson Comorbidity Index (range from 0 with no comorbid illnesses to greater than 8 with multiple illnesses) is 9 (1 point for congestive heart failure, 1 point for peripheral vascular disease, 2 points for diabetic end-organ disease, 2 points for severe kidney disease, and 3 points for severe liver disease), placing her in the highest risk category for starting dialysis. From this index alone, she would be expected to have a mortality rate equal to or greater than 0.49 per patient year.<sup>16</sup> Her age, limited functional status, and serum albumin would increase her predicted mortality rate further. Because of her thrombocytopenia and past history of gastrointestinal bleeding, the patient could be forecast to have a high risk of major bleeding with hemodialysis. Peritoneal dialysis would not be an option because of her massive splenomegaly. With these facts in mind, and after ascertaining that the patient wanted to be fully informed, involved in the decision making about dialysis, and started on dialysis when needed, the nephrologist should recommend a time-limited trial of dialysis. This recommendation is consistent with her overall medical condition and her wish to undergo dialysis. Initiating dialysis on a time-limited basis signals to the patient and the renal care team that it is not clear whether dialysis will benefit the patient, and that after a short trial of dialysis, perhaps a month, the

patient's course will be reviewed, and a recommendation made regarding whether or not it should be continued. A time-limited trial gives the patient a better understanding of dialysis and its benefits and burdens and provides the renal care team with a more informed assessment of the likelihood of the benefits of dialysis outweighing its burdens.

### Conclusions

Communication about prognosis with CKD/ESRD patients is of cardinal importance in the nephrologist's daily practice. Shared decision-making involves the process of informed consent, and this process should not occur without disclosure of prognosis. This disclosure, however, must be individualized based on each patient's preferences for information and participation. The available data suggest that there is room for improvement for nephrologists in adequately informing patients (or their specified legal agents) of their prognosis and involving them in shared decision making. The approach described in this article should help nephrologists discuss prognosis with their patients in a way that is sensitive to patients' preferences and in accordance with clinical practice guideline recommendations.

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