The Renal Palliative Care Program

The field of nephrology is shifting from an exclusive focus on increasing survival to one that provides greater attention to quality of life. There is an opportunity to integrate many of the advances of palliative medicine into the comprehensive treatment of these patients. — Journal of Palliative Medicine, 2006

A 75-year-old man with a 25-year history of type 2 diabetes presents for long-term treatment options. His estimated glomerular filtration rate is 16 mL per minute per 1.73 m² of body-surface area. His history is remarkable for ischemic coronary artery disease, congestive heart failure, peripheral artery disease, mild dementia, and colon cancer. He has been admitted to the hospital 4 times in the last 6 months. How should his care be managed?

In 2000, the Renal Physicians Association and American Society of Nephrology concluded that withholding or withdrawing dialysis in cases of end-stage renal disease may be appropriate if the patient gives informed consent and chooses nondenialysis therapy.1

In addition, the American Board of Internal Medicine recently launched Choosing Wisely, an initiative for medical specialties, including nephrology. The goal of the initiative is to encourage conversations between physicians and patients about the overuse or misuse of tests and procedures that offer little benefit and may, in some cases, inflict harm. One of the recommendations for nephrology was not to initiate dialysis without shared decision making with patients and their families and physicians.2 Nephrologists should take up the responsibility of helping their patients through an end-of-life decision-making process, which needs to be individualized for each patient. An interview guide and process have been created for advanced care planning to facilitate decision making and maintain satisfaction with the entire end-of-life experience.3 Physicians should recognize that functional status and expectations about future quality of life are more important to many patients than the chronological age they reach.

In the past, nephrologists believed that most patients with renal failure required dialysis to survive. Unfortunately, once a patient started dialysis s/he would continue it until days before they qualified for hospice therapy—no matter what the cost. During shared decision making, we are now trying to identify chronic kidney disease patients for whom the disadvantages of therapy (eg, multiple access surgeries, rigors of home dialysis or in-center dialysis, and more than two weeks of hospitalization per year) may outweigh its benefits (ie, prolonged survival).4,5 The landmark comparative study of survival in elderly patients, by Murtagh et al, showed that the survival advantage offered by dialysis was no longer apparent in patients with ischemic heart disease and many comorbidities.6

In the US, there are currently very few renal palliative care programs, because most nephrologists are not trained in palliative care and most palliative care physicians are not trained in nephrology. In addition, a patient may live for more than one year after declining dialysis. Most palliative care programs will only accept a patient is expected to survive less than one year and is homebound.7,8

The current obstacles to developing successful renal palliative care programs are 1) patient nonacceptance, 2) physician nonacceptance, and 3) lack of integrated care programs.9 Nephrologists and palliative care physicians need to begin advanced-care planning early for patients who may eventually need renal replacement therapy. If patients are adequately informed about their options and health status, they can make informed choices that may lead to less pain and suffering. Related to patient acceptance is social acceptance. Patients and their families may perceive renal palliative care as withholding therapy to reduce costs. For some patients, the right care may not always be aggressive and expensive.

Nephrologists’ nonacceptance will also be an obstacle to success. Most physicians entered the medical field to prolong, not shorten, life. Another challenge is developing a level of comfort when discussing palliative care issues with patients and their families. This involves 1) understanding the risks of declining dialysis and 2) understanding how to develop end-of-life care plans for these patients. For most nephrologists, this is uncharted territory.9

Two important articles about survival rates were recently published. The first, by Cohen et al,10 describes a tool (http://touchcalc.com/calculators/sq) that allows health care teams the ability to predict 6-, 12-, and 18-month end-stage renal disease survival, on the basis of 5 criteria (age, albumin level, dementia, peripheral vascular disease, and 6-month risk of death).

When this mortality calculator is used for a 75-year-old man currently on hemodialysis with low serum albumin, dementia, and peripheral vascular disease, it predicts that the probability of 6-, 12-, and 18-month survival is 51%, 19%, and 5%, respectively.

Cohen’s mortality prediction calculator has several important methodologic
Table 1. Proposed model of conservative therapy for patients with chronic kidney disease

<table>
<thead>
<tr>
<th>eGFR, mL/min</th>
<th>Survival, years</th>
<th>Teams</th>
</tr>
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<tbody>
<tr>
<td>15-30</td>
<td>0-5</td>
<td>RPCT</td>
</tr>
<tr>
<td>&lt;15 but &gt;5</td>
<td>0-2</td>
<td>RPCT, CPCT</td>
</tr>
<tr>
<td>&lt;5</td>
<td>0-0.25</td>
<td>RPCT, CPCT, hospice</td>
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RPCT = renal palliative care team; eGFR = estimated glomerular filtration rate; CPCT = community palliative care team.

limitations and has not been replicated externally. In addition, the prediction score was performed in patients already on dialysis, so its applicability to those who have advanced kidney disease is unclear.

In 2004, a 5-year follow-up study of patients with chronic kidney disease was published.11 This study reported that the 5-year survival rate for patients with chronic kidney disease, stage 4 (eGFR 15–30 mL/min), was 45.7%.11 Another study in 2002 reported median survival for patients at low, medium, and high risk (based on number of comorbidities) of 8.75, 4.3, and 2.4 years, respectively.7

At this time we do not have a good predictive tool for patients who are choosing between no dialysis therapy and renal replacement therapy. However, we can share with our patients some of the literature that shows that survival may be affected by the number of comorbidities and that in some cases there may not be a survival benefit with renal replacement therapy.

Finally, there is no easy way for nephrologists to learn how to have end-of-life discussions with patients and their families. This requires cross-training with our colleagues in palliative care. In addition, as renal palliative care programs grow, this training will need to be incorporated into renal fellowship core curricula.

We predict a surge in the number of patients choosing palliative care over the next five years. Our work in this field is just beginning. It will take time to change our culture from one that extends life at all costs to one that seeks the best comfort and quality of life for our patients. The patient presented in this paper would benefit from shared decision making during a team conference with the renal palliative care team. Because of his risk profile, dialysis may not offer a satisfactory quality of life or a survival benefit. He could be followed up by the renal team until he becomes homebound, at which time he may benefit from a referral to the home palliative care program or a local hospice program (Table 1).

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References

Should the Kidneys Fail

Bones can break, muscles can atrophy, glands can loaf, even the brain can go to sleep, without immediately endangering our survival; but should the kidneys fail … neither bone, muscle, gland, nor brain could carry on.

— Homer W Smith, PhD, 1895-1962, American physiologist and advocate for science, Professor of Physiology, and author