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## Palliative Care and End-Stage Renal Disease: Universal and Disease-Specific Issues

### Abstract

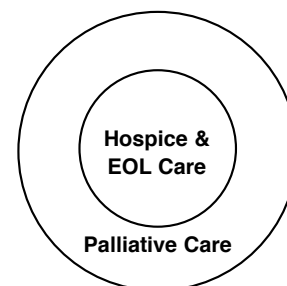
The emergence of palliative medicine as a subspecialty, coupled with the aging population of those with multiple chronic diseases and comorbid conditions, is raising the awareness of the appropriateness of palliative care for many populations. Because of its high mortality, high symptom burden and usual illness trajectory, end-stage renal disease (ESRD) patients and their families can benefit from palliative care. Moreover, ethical issues such as withdrawing and withholding dialysis frequently confront nephrologists and dialysis providers, making advance care planning and communication among providers, their patients, and patients' families clinical priorities. Palliative care encompasses the areas of pain and symptom assessment and management, systematized advance care planning, psychosocial and spiritual support, terminal care protocols such as hospice (and, in ESRD, withdrawal from dialysis) and bereavement. This article will discuss these aspects of palliative care using ESRD as an example of a chronic disease in which palliative care can complement disease-modifying medical care. The specific issues of withdrawing and withholding dialysis will also be explored.

### Introduction

Many equate hospice and end-of-life care with palliative care. However, hospice and end-of-life care are more appropriately considered a part of the larger sphere of palliative care. (Figure 1) Palliative care is comprehensive, interdisciplinary care of patients and families facing chronic or terminal illness and focuses primarily on comfort and support. Thus, the patient with newly diagnosed cancer who is beginning chemotherapy is presumably far from being considered a candidate for hospice but he or she may clearly benefit from symptom management (pain, nausea, etc.) as well as psychosocial and spiritual support that palliative care can provide. Similarly, the patient

with congestive heart failure, chronic obstructive pulmonary disease, or chronic kidney disease may be expected to live for a number of years yet he or she will also be expected to require treatment for symptoms (eg, shortness of breath) that may affect quality of life. For such patients, palliative care is also appropriate and integral to the overall care plan. In the course of each chronic disease, opportunities arise to discuss one's wishes for future care. Advance care planning is desired by those with chronic diseases yet plans of care for most patients and families fail to address such issues in a timely fashion. Encouraging patients and families to engage in the process of communication known as advance care planning is best done in non-urgent, non-end-of-life situations. Skills and techniques to foster such discussions are an integral part of palliative care and applicable to all populations. Palliative care encompasses the assessment and management of pain and other symptoms, systematized advance care planning, psychosocial and spiritual support as well as terminal care protocols (hospice and withdrawal of interventions) and bereavement programs. Because of their high mortality, high symptom burden, and increasing age, the ESRD population is an appropriate group for palliative care. These features of the ESRD population will be discussed in relation to the components of palliative care from which they can benefit.<sup>1-3</sup>

**Figure 1.** A representation of the hospice/end-of-life (EOL) and palliative care domains.



## Appropriate Patient Groups For Palliative Care:

### ESRD as an Example

Palliative care is appropriate for any patient or family facing either a chronic illness or a terminal condition. Clearly, chronic kidney disease is a chronic illness and dialysis patients have a high mortality. In general, age, gender, and ethnically-matched dialysis patients live about one third as long as non-dialysis patients. Patients with colon or prostate cancer have longer expected survivals than dialysis patients. In fact, the only cancer patients with lower expected survival than dialysis patients are those with lung cancer. The mean age of US patients beginning dialysis is progressively rising and is now 62.8 years. Moreover, the elderly is the fastest growing group of incident dialysis patients with a 57% increase in 80- and 90-year-olds beginning dialysis from 1996–1997 to 2002–2003 despite a one year mortality of 46% in this age group. In addition, up to 20% of chronic dialysis patients die each year from withdrawal of dialysis. The high mortality of ESRD and the fact that it is an aging population makes palliative care applicable to dialysis patients. In addition, dialysis patients have a high symptom burden. Symptoms such as fatigue, anorexia, pain, pruritus, sleep disturbance, restless legs, and depression are common among chronic dialysis patients. In one study of 507 Canadian dialysis patients, an average of  $7.5 \pm 2.5$  symptoms per patient was reported with moderate or severe symptoms reported as  $4.5 \pm 2.9$  symptoms per patient. Nearly half of all dialysis patients report chronic pain, primarily musculoskeletal in origin with some patients experiencing neuropathic pain. Pain is effectively treated in less than one third of these patients. Thus, the aging of the dialysis population and its high mortality and symptom burden make this group of patients and families an appropriate focus for palliative care.<sup>4-8</sup>

## Advance Care Planning: A Palliative Care Issue

### Appropriate for All Patient Groups

Traditionally, the purpose of advance care planning was the creation of a written advance directive, either an instruction directive (eg, a living will) or a proxy directive in which a medical decision-maker is designated. Contemporary views of advance care planning emphasize the multiple ways in which families and patients use advance care planning: to prepare for death, to achieve control, to relieve burdens on loved ones, and to strengthen interpersonal and interfamily relationships. Creating a specific written directive is only one aspect of contemporary advance care planning. We are moving from the goal of written

directives not only because our patients and healthcare systems do not support such goals, but also because such directives do not allow for all contingencies of modern medical care, they may not be followed and they do not correspond to the needs of an overall plan of care. The process of advance care planning (communication among patients and families) remains an important and integral aspect of palliative care. However, it is important to realize that the role healthcare providers play in this process is primarily one of educators; patients and families expect providers to raise the topic of advance care planning and to provide information needed for patients and families to make informed decisions but physicians are not considered essential to the process of advance care planning. In this respect, ESRD patients and their families mirror other patient groups. Discussions about healthcare interventions throughout the course of illness, including near the end of life, occur within the patient-family realm and not, as has traditionally been taught, within the patient-physician relationship. In addition, healthcare providers' efforts and energies should be focused on identifying health states influencing individual patient choices about possible interventions rather than on the potential interventions. Utilizing this approach to prompt patient and family discussion, providers can ask such questions as, "Under what conditions would you not want to live?" "What is most important to you?" "Is it more important to you to live as long as possible despite some suffering or to live a shorter period of time but without suffering?" Asking these kinds of open-ended questions invites the patient and his or her loved ones to consider the quality of one's life, rather than the interventions we can offer.<sup>2,3,9,10</sup>

It is important to provide the patient with the information needed to make an informed decision. This may sometimes involve expressing one's opinion based on clinical judgment. For example, discussion regarding cardiopulmonary resuscitation (CPR) could be advanced using open-ended questions such as: "If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using CPR. Are you familiar with CPR? Have you given any thought as to whether you would want it?" or, "Given the severity of your illness, CPR would in all likelihood be ineffective. I would recommend that you choose not to have it but that we continue all potentially effective treatments. What do you think?" Either is an acceptable way to begin a discussion of CPR with a patient but the second includes the provider's recommendation based on knowledge (only about 10–14% of patients receiving in-hospital CPR

survive to hospital discharge) and clinical judgment. Additionally, emphasizing an individual's health state (eg, comatose, unable to talk, in pain) as a result of illness and/or intervention rather than focusing on the intervention to be performed provides a more appropriate and useful strategy for advance care planning.<sup>3,11,12</sup>

All too often advance care planning occurs in emergent situations (during hospitalization for an acute event, when a patient faces imminent death) rather than as part of routine care. Chronic diseases like ESRD (and heart and lung failure) usually follow an illness trajectory consisting of a progressive downward course punctuated by episodes of acute illness that often require hospitalization. Such episodes are often termed sentinel events. In the chronic dialysis patient, sentinel events are common and are associated with an increased risk of death. For example, the risk of death in a dialysis patient increases seven times in the first six months after an episode of bacteremia and 2.5 to 5 times six months after a bone fracture. After a myocardial infarction, 38–44% of dialysis patients will survive one year; 49% will survive a year after a below the knee amputation. After recovery from a sentinel event a patient rarely returns to his or her previous functional status. Thus, each sentinel event offers an opportunity to introduce advance care planning and to discuss prognosis and goals of care. When seeing a patient in clinic or in the dialysis unit, if a provider replies “no” to the question, “Would I be surprised if this patient dies in the next year?” advance care planning should be introduced to the patient.<sup>13,14</sup>

Barriers to advance care planning cited by providers include lack of comfort with the topic, lack of training in communicating such issues, and lack of time for such discussions. In the dialysis unit, providers with personal experience of the loss of a loved one are more likely to engage in end-of-life discussions with patients. Although training programs in general, including nephrology fellowship training programs, do a poor job of teaching trainees about palliative care issues, increasingly training curricula for residents, medical students, and fellows are including palliative care topics.<sup>15-17</sup>

### **Withdrawing and Withholding Dialysis: Disease-Specific Issues in ESRD**

Up to 20% of patients may withdraw from dialysis and US nephrologists have an average of four patients discontinue dialysis each year. Although a reliable model predicting the likelihood of dialysis withdrawal has not been developed, there are certain features that

increase the risk for stopping dialysis. These are: older age, ethnicity (whites are much more likely to withdraw from dialysis than patients of other ethnic groups), gender (women are more likely to stop dialysis), the presence of diabetes and multiple comorbid conditions, a history of severe pain, residing in a nursing home, and being divorced or widowed. It is the relentless succession of one problem after another that finally makes the patient who lives alone and who has lost support give up and discontinue dialysis. A prospective study of 131 chronic dialysis patients who withdrew from dialysis found that chronic disease (deterioration in clinical status) was the most common reason for stopping dialysis (65%), followed by an acute disorder (eg, cerebrovascular accident) in 22%, and failure to thrive in 9%. Death occurs an average of eight to ten days after stopping dialysis and is characterized by a progressive impairment in consciousness. Patients who have some residual kidney function may live for an extended period of time after stopping dialysis.<sup>4,18-22</sup>

Because withdrawal of dialysis is a relatively common occurrence, nephrologists often confront such situations in both competent and incompetent patients. Recently, a survey addressing end-of-life decision-making was completed by 296 US and 61 Canadian nephrologists. Only 39% of nephrologists felt themselves to be very well prepared to make end-of-life decisions. Those who reported feeling well-prepared were more likely to stop dialysis in a patient with permanent and severe dementia and more likely to consult the clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. Interestingly, nephrologists practicing in 2005 were more comfortable with decisions to stop dialysis in a demented patient than were nephrologists in 1990 (53% vs 39%,  $P < .0001$ ).<sup>18,23</sup>

The clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* is evidence-based, endorsed by the Renal Physicians Association and the American Society of Nephrology and includes specific recommendations for withholding or withdrawing dialysis based on ethical principles and clinical data. According to the guideline, withholding or withdrawing dialysis is appropriate in:

- Patients with decision-making capacity who make informed, voluntary choices to refuse dialysis or request discontinuation
- Patients without decision-making capacity who previously indicated refusal of dialysis in oral or written advance directives

- Patients without decision-making capacity whose properly appointed legal agents refuse dialysis or request that it be discontinued
- Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment
- Special patient groups: those with nonrenal terminal illness with an expected survival of less than six months and those with a permanent inability to relate to others. Thus, criteria for withholding or withdrawing dialysis can be based on patient and family wishes, advance directives and the patient's neurologic status and expected survival.<sup>14</sup>

Although much has been written about withdrawal from dialysis, little has been published about withholding dialysis. One prospective study in the US found that primary care providers withheld dialysis from 22% of chronic kidney disease patients by not referring them for nephrology consultation. Reasons cited for non-referral included end-stage heart, lung or liver disease, terminal cancer, neurologic impairment, older age and patient or family refusal. In this year long study, nephrologists withheld dialysis from 7% of the patients referred to them. Thus, although dialysis is being started in an increasingly older population, some degree of selection is occurring among US healthcare providers. Compared with nephrologists in Canada and the United Kingdom, however, US nephrologists are more likely to offer dialysis when given hypothetical scenarios. A country's healthcare system seems to influence decisions to offer expensive treatments like dialysis, since in this study nephrologists practicing in the United Kingdom and Canada were more likely to cite cost (societal) and the patient's quality of life as reasons to withhold dialysis. The US nephrologists cited concern for legal action as a reason for offering dialysis significantly more often than the Canadian or United Kingdom nephrologists.<sup>4,5,24,25</sup>

## Summary

Palliative care is comprehensive care focusing on symptom assessment and management and comfort in patients and families facing chronic or terminal illness. The general components of palliative care include pain and symptom assessment and management, systematized advance care planning (including discussions about CPR and DNR), psychosocial and spiritual support,

terminal care protocols including hospice and bereavement programs. Hospice and end-of-life care is only one aspect of palliative care. Unlike hospice care, many patients and families dealing with chronic illnesses can benefit from palliative care that occurs simultaneously with disease modifying or potentially curative interventions or treatments. Patients with ESRD are appropriate candidates for palliative care because of their high symptom burden and shortened life expectancy. Evidence-based clinical practice guidelines addressing ethical issues like withholding and withdrawing dialysis can be developed and used to facilitate shared decision-making. Such guidelines not only increase the comfort providers feel when faced with these difficult clinical decisions but may also influence clinical practice over time.

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### **CME Questions 1a-d**

Please select the best answer for the following:

- 1a. Hospice and palliative care are the same thing.
  - a. True
  - b. False
  
- 1b. The expected mortality of dialysis patients is worse than many forms of cancer.
  - a. True
  - b. False
  
- 1c. There are situations in which withholding dialysis is clinically and ethically appropriate.
  - a. True
  - b. False
  
- 1d. Which of the following is a component of palliative care?
  - a. Pain assessment and management
  - b. Spiritual support
  - c. Advance care planning
  - d. All of the above