

Palliative Care and Withholding and Withdrawing Dialysis

Jean L. Holley, MD

The author is with the Department of Internal Medicine, University of Illinois, Urbana-Champaign and Carle Physician Group, Urbana, Illinois.

The aging dialysis population, with its decreasing functional status, the high mortality of end-stage renal disease (ESRD), and the rise of palliative medicine as a specialty have all served to promote the importance of end-of-life care for ESRD patients. Even though nephrologists have an increased understanding of the issues involved in ESRD end-of-life care, most individuals working in dialysis know of a case in which it felt as if “the dead were being dialyzed.” An increased effort to focus on palliative care issues in ESRD, especially advance care planning, may serve to reduce the frequency of such cases.

Many factors are involved in the increasing attention given to end-of-life care for those with chronic kidney disease (CKD) and end-stage renal disease (ESRD). The aging dialysis population, the chronic high mortality of ESRD, diminishing functional status and quality of life for those on dialysis, and the rise of palliative medicine as a medical specialty have all contributed to an increased awareness of palliative care, withdrawing from dialysis, and withholding dialysis. When reported survey responses from practicing nephrologists were compared from data obtained in 1990 and 2005, it was found that significantly more nephrologists would withhold dialysis from a permanently unconscious patient in 2005 (90% in 2005 vs. 83% in 1990, $p > 0.001$) and would also stop dialysis in a severely demented patient in 2005 (53% in 2005 vs. 39% in 1990, $p > 0.00001$).¹

From this same study we learned that in 2005 most dialysis units had written formal policies on cardiopulmonary resuscitation (86% in 2005 vs. 39% in 1990) and withdrawal from dialysis (30% in 2005 vs. 15% in 1990).¹ However, as nephrologists' experience with patients stopping or choosing not to start dialysis has grown, new considerations (such as the poor functional status of elderly patients on dialysis,² the increasingly aged and disabled ESRD population,³ and the conservative or palliative management of CKD without dialysis,^{4,5}) have prompted additional consideration of the options for ESRD treatment. The

recent publication of the second edition of the *Renal Physicians Association Clinical Practice Guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* highlights the importance of these topics and the need to reassess our practices and policies in end-of-life care for ESRD patients and their families.⁶

However, despite advances in end-of-life care for ESRD patients, nearly every nurse, social worker, midlevel provider, technician, or nephrologist working in either an acute or a chronic dialysis unit has a story to tell about a patient who was continued on dialysis despite severe dementia or an expected poor prognosis. Terms such as “torture” and “dialyzing the dead” are often used by providers to describe these emotional situations. How, despite our improved understanding of prognosis, ethics in decision making, and palliative options, can we continue to be faced with such cases in dialysis programs? In order to answer that question and to provide some guidance for avoiding these circumstances, it is necessary to briefly review the factors contributing to such situations.

Factors Contributing to “Dialyzing the Dead”

Table 1 shows some of the factors contributing to situations in which dialysis is continued or started in a patient with a poor prognosis. Some of these factors cannot be

altered, but many of them are potentially modifiable, often through shared decision making and the process of advance care planning. In order for patients and families to make decisions about end-of-life care, they must be given the information needed to make those decisions. An inherent aspect of such decision making is an estimate of prognosis. Although many physicians are reluctant to discuss end-of-life care and preferences, patients generally expect physicians to initiate these discussions and an assessment of prognosis is required for patient and family decision making.⁶

There are many tools to guide assessment of prognosis but no tool is 100% sensitive or specific. We know that patient age, functional status, low albumin level, comorbidity including ischemic heart disease, diabetes mellitus, peripheral vascular disease, and answering “no” to the “surprise question” (“Would you be surprised if this patient died within the next 6 months?”) all predict poor survival among dialysis patients.^{6,7} There is even an online tool to assist in survival prediction for hemodialysis patients (<http://touchcalc.com/calculators/sq>). However, if the nephrologist never raises the issue of prognosis and the option for conservative or palliative (no dialysis) care is never discussed, the patient and family are deprived of that option. It is incumbent upon the nephrologist to include non-dialytic care in the options for patients with late stages of CKD and ESRD and such options can only be discussed within the context of advance care planning.

TABLE I. Factors that may contribute to ongoing dialysis despite dismal prognosis.

Factor	Characteristics
Patient-related	Goals, values, demographics, religious issues, capacity for decision making, lack of identified decision maker,* lack of information,* lack of advance care planning*
Physician-related	Discomfort with end-of-life issues and prognosticating survival,* fear of legal issues, religious issues, consultative nature of nephrology
System-related	Legal statutes, failure of advance care planning, transitions of care, time required for advance care planning, lack of training in communication and palliative care*

* Modifiable factors.

Similarly, although it is often more difficult to predict prognosis in the setting of acute kidney injury (AKI), the overall poor prognosis in these patients, especially in those with significant comorbidity, should raise the issue and prompt discussion of palliative options and/or defined, time-limited trials of dialysis.⁶ All patients for whom dialysis is withheld as well as those who choose to withdraw from dialysis should be offered palliative care and hospice if appropriate.

Palliative Care in CKD

Palliative care involves the comprehensive, interdisciplinary care of patients and families facing a chronic or terminal illness.⁸ Palliative care focuses on comfort and support and generally addresses spiritual and emotional aspects of pain and suffering as well as physical symptoms.

Palliative care programs for CKD and ESRD patients and their families should include pain and symptom assessment management protocols, systematized advance care planning, terminal care protocols such as hospice referral for patients stopping dialysis, psychosocial and spiritual support, and bereavement programs. Each dialysis unit will incorporate some aspects of a renal palliative care program within their policies and procedures; mandated by the conditions for coverage and, increasingly, quality care assessments, some advance care-planning process will be required of each dialysis program. Dialysis units and the dialysis unit staff may be able to avoid “dialyzing the dead” through advance care planning and the completion of written advance directives where appropriate (e.g., designation of a health care proxy or surrogate decision maker, do-not-resuscitate orders after discussion of cardiopulmonary resuscitation, or Physician Orders

TABLE II. Resources to facilitate advance care-planning processes by nephrologists and dialysis units.

Renal Physicians Association Clinical Practice Guideline, <i>Shared Decision-Making in the Appropriate Initiation of and Withdrawal of Dialysis</i> , 2nd ed., Renal Physicians Association, Rockville, MD
End-of-Life Kidney Coalition, accessible at www.kidneyeol.org
Information on Physician Orders for Life-Sustaining Treatment (POLST) or Physician Orders for Scope of Treatment (POST) where legal, accessible at www.ohsu.edu/polst

for Life-Sustaining Treatment [POLST] where legal). *Table II* shows resources that may facilitate development of advance care planning processes and completion of specific advance directives in dialysis units.

Because of individual differences in values, goals, and acceptable quality of life, some patients will make decisions for treatments and ongoing care that others may find unacceptable. Only by providing patients and families the information needed to make such decisions can we satisfy our ethical responsibilities and promote shared decision making. Through these actions we can ensure optimum care for our patients, their families, and ourselves as care providers working in the dialysis field. **D&T**

Dr. Holley will be presenting this topic at the National Kidney Foundation 2011 Spring Clinical Meetings to be held in Las Vegas, NV, April 26-30. Visit www.kidney.org for more information.

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