

Kidney End-of-Life Coalition: What Is It All About?

By Jean Holley

The end stage renal disease (ESRD) end-of-life coalition was developed by a diverse group of individuals committed to patient-centered end-of-life care for ESRD patients, their families, and their health care providers.

Between March 2000 and October 2001, a Robert Wood Johnson Workgroup focusing on end-of-life issues in the ESRD population addressed quality of life, quality of dying, and educational needs, culminating in a published report (1). The Workgroup developed three primary recommendations: 1) Centers for Medicare & Medicaid Services (CMS) should work with the ESRD Networks to coordinate and link dialysis and hospice care; 2) curricula on end-of-life care should be developed for nephrologists, nurses, social workers, dietitians, and technicians working in dialysis units and caring for patients and families with chronic kidney disease (CKD); and 3) networks should incorporate end-of-life care into educational outreach programs (1).

Network 5 embraced these recommendations and formed the Kidney End-of-Life (EOL) Coalition (www.kidneyeol.org). The coalition's goal is to promote effective interchange among patients, families, caregivers, payers, and providers in support of integrated patient-centered end-of-life care for chronic kidney disease patients (2). Initially the coalition was composed of workgroups (advance care planning, cardiopulmonary resuscitation, patient education, physician/clinician education, hospice, and website review) charged with delivering products to enhance end-of-life care for the target population.

Dedicated representatives from the major dialysis unit corporations, CMS, Network Forum, dialysis unit nurses, social workers, dietitians, technicians, nephrologists, midlevel providers, and administrators—working together under Network 5's oversight—composed the various workgroups. The coalition's website is the repository of these efforts and serves as a resource for anyone seeking information on end-of-life issues around CKD. Table 1 shows the categories of information and tools available on the coalition's website that can assist dialysis units and health care providers to deliver patient-centered end-of-life care.

ESRD is increasingly becoming a "geriatric" disease. The mean age of incident dialysis patients is slowly rising and the proportion of elderly dialysis patients is increasing (3). At the same

time, however, there is increased recognition of the benefits and importance of palliative care, and growing emphasis on the consideration to withhold dialysis and medically manage some elderly patients with CKD (4, 5). The newly published revised Renal Physician Association (RPA) guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, includes new recommendations addressing the need to discuss prognosis with all patients beginning dialysis (6). In addition, the guideline recommends giving any patient older than 75 years with stage 5 CKD a specific estimate of prognosis so that the patient can make an informed decision about beginning dialysis (6).

Predictors of prognosis in elderly dialysis patients include functional status, comorbidity, nutritional status (based on serum albumin), and answering "no" to the so-called surprise question "Would I be surprised if this patient died within the next six months?" (6). Although elderly patients who begin dialysis generally live longer than those who forego dialysis (4, 5), most elderly patients on dialysis experience a significant worsening of functional status (7). Thus, all CKD patients, but especially the elderly and those with a poor prognosis, should be offered the option of palliative care and ongoing medical management without dialysis. The revised RPA guideline details factors involved in such decisions and provides toolkits to ensure that patients and families can make informed decisions about their options for renal replacement therapy, including time-limited trials of dialysis and active medical management without dialysis. The EOL Coalition website provides links to patient and physician resources related to these issues.

Palliative and end-of-life care is appropriate for all dialysis patients. The EOL Coalition incorporated components of ESRD palliative care through development of its workgroups and the delivered products that are available to assist nephrologists and dialysis units. ESRD palliative care includes advance care planning, pain and symptom management, bereavement care, and end-of-life care and hospice.

Advance care planning has evolved and is now recognized as a process that occurs primarily among patients and families as a means of addressing goals, achieving control over medical processes, and strengthening family relationships (8). Although writing some sort of advance directives remains a goal of advance care planning, the creation of

advance directives is no longer the sole impetus driving the advance care planning process. Viable written advance directives include do not resuscitate (DNR) orders, health care surrogate or decision-maker designations, and, where available, physician orders for life-sustaining treatment (POLST).

The EOL Coalition website contains model policies for DNR orders, patient information sheets on cardiopulmonary resuscitation and resuscitation status, and links to other websites that provide information on specific advance directives (e.g., POLST forms) and states in which POLST is an available option. The CMS Conditions of Coverage now mandate that advance care planning be included in overall care plans for dialysis patients. The EOL Coalition is a valuable resource for dialysis units assessing and developing policies and procedures on advance directives and advance care planning.

Hospice underused by dialysis patients

Nearly all nephrologists will care for patients who choose to stop dialysis. All patients withdrawing from dialysis are potential hospice candidates and should be offered hospice care. Yet hospice is a Medicare benefit that is underused by ESRD patients (9). Many other dialysis patients may also be candidates for hospice care if they have a non-ESRD diagnosis that is expected to lead to their death within the next six months.

The EOL Coalition and its members were instrumental in advocating for appropriate hospice benefits for ESRD patients and continue to assist in clarifying the options for hospice use among patients who wish to continue dialysis. One such option, and a tenet of hospice, is bereavement care, which is offered to families throughout the year following the death of the hospice

Table 1. Information and tools on www.kidneyeol.org

Guides	Teaching patients about cardiopulmonary resuscitation Planning dialysis unit memorial services Funeral home information for dialysis units Patient resuscitation statement
Model policies for dialysis units	Do not resuscitate (DNR) Advance directives for DNR orders
Links to organizations	Medicare Benefit Policy Manual – ESRD Center to Advance Palliative Care; National Hospice and Palliative Care Organizations Advance Directives information, including Caring Connections Renal Physicians Association and American Society of Nephrology position statements on quality care at the end of life Renal Physicians Association "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis"
Frequently asked questions	
Presentations	PowerPoint slides on advance care planning, palliative care in ESRD
Links to tools	Dialysis Symptom Index Edmonton Symptom Assessment System Clinical algorithm and preferred medications to treat pain in dialysis patients Assessing Decision-Making Capacity
Links to patient information	If You Choose Not to Start Dialysis (National Kidney Foundation) When Stopping Dialysis Treatment is Your Choice (National Kidney Foundation) Choosing to Stop Dialysis (Kidney Foundation of Canada) Choosing Not to Start Dialysis (Kidney Foundation of Canada)

patient. Many in the dialysis community have recognized the importance of bereavement care, not only for the families of patients who die, but also for the dialysis unit staff and allied providers. Memorial services are offered by many dialysis programs as part of bereavement care. The Coalition provides information to assist programs wishing to plan such services (Table 1).

Another component of ESRD palliative care is symptom assessment and management. The EOL Coalition produced and made available through its website several webinars addressing these issues (Table 2). In addition, the Coalition developed an evidence-based algorithm for pain management, which is also available on the website for use by clinicians. It is clear that symptom burden is high among dialysis patients and that their symptoms are undertreated (10). Incorporating palliative care into dialysis units should lead to improved recognition and treatment of patients through a focus on symptom assessment and management.

Providing dialysis care is not simply dialyzing individuals with kidney failure. Effective treatment must include assessment of the individual patient in accordance with his or her goals and values, quality of life, and, at some point for everyone, quality of dying. The increasingly aged dialysis population offers opportunities to consider traditional palliative care principles, such as hospice and end-of-life care, bereavement care, pain and symptom management, and advance care planning, for all of our patients through all stages of their chronic kidney disease. We are fortunate in dialysis care to work within an interdisciplinary

team to provide comprehensive care for our patients. As with other important dialysis initiatives (e.g., Fistula First), nephrologists must assume leadership roles to ensure the success of this endeavor. Quality palliative and end-of-life care of CKD patients requires nephrologist leadership at the level of clinics and dialysis units. The RPA guideline (6) and the EOL Coalition are essential resources for nephrologists and other providers working with CKD and ESRD patients. ●

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Table 2. Educational material at www.kidneyeol.org

Webinars	Incorporating palliative care into the dialysis unit Symptom assessment and management Relevance of palliative care and hospice for dialysis patients Pain assessment and management
Pain management brochure	
Links	Renal Palliative Care Bibliography End-of-Life Decision-Making and the Nephrology Nurse—Educational Modules from American Nephrology Nurses Association Robert Wood Johnson Promoting Excellence: ESRD Workgroup Recommendations to the Field Core Curriculum on Palliative Care for the Nephrologist
PowerPoint presentations	Advance Care Planning Best Practices for End-of-Life Care for Dialysis Patients Did This Patient Die in Hospice? New Questions in Caring for Patients with ESRD End-of-Life Issues for ESRD Patients ESRD: When is it Time for Hospice? Hospice and ESRD: To Withdraw or Not to Withdraw Pain Management in ESRD Palliative Care for the ESRD Patient

Drug Dosing in the Elderly Patient with Chronic Kidney Disease

By Ali Olyaei

Chronic kidney disease (CKD) is a relatively common condition in the older American population. An estimated 26 million people in the United States are reported to have CKD. As the population of Americans 65 and older grows, so does the incidence of CKD. Evidence now indicates that kidney disease and aging carry a significant risk for cardiovascular complications and sudden death.

The progressive physiological changes with the aging process are inevitable: Aging-associated changes in carbohydrate metabolism and vascular atherosclerosis markedly increase the risk of developing diabetes and hypertension, and these high incidences of comorbid conditions may also lead to a higher incidence of cardio-

vascular events. Aging, directly or indirectly, has an effect on renal function and the handling of the most commonly used drugs in the geriatric population. The elderly with CKD are at a greater risk for adverse drug reactions and have a higher potential for drug–drug interactions (1, 2).

The pharmacokinetics and pharmacodynamics of most drugs are altered due to functional or anatomical changes of the renal system. These structural and functional changes are mostly multifactorial, resulting from the loss of kidney mass and exposure to precipitating factors leading to renal injury. These factors can include clinical nephrotoxins, electrolyte abnormalities, heart failure, and environmental insults.

In early adulthood, the average weight

of a kidney is 250 g (± 25 g); by age 75, kidney weight decreases to 200 g (± 25 g). This loss of mass is most noticeable at the cortex level and much less in the medulla section. Glomeruli are also affected, with biopsies indicating a thickening basement membrane with hyalinization of renal arterioles. The incidence of biopsy-proven glomerulosclerosis increases from 1 to 2 percent in early adulthood, as opposed to roughly 30 percent by age 80+. Chronic vascular disease and inflammatory stages of CKD also contribute to tubular atrophy and interstitial fibrosis in the aging kidney. Other potential causes for loss of renal function could be due to aging-related vascular calcification, the release of endothelin-1 and nitric oxide synthase, free reactive oxygen species, and metabolic

syndrome. Medication issues, including polypharmacy with the development of CKD, should also be considered for increased risk of morbidity and mortality (3).

Pharmacokinetics is the study of drug absorption, distribution, metabolism, and elimination. The drug dosing and adverse drug reactions observed in the aging CKD population is a complex combination of pharmacokinetic and pharmacodynamic variation from aging and CKD. Pathological or physiological adaptation of aging and CKD affects the pharmacokinetic behavior of most drugs. Therefore, health care providers must design a pharmacotherapeutic regimen for each patient to avoid unnecessary toxicity and

Continued on page 20