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## Should there be an expanded role for palliative care in end-stage renal disease?

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### Abstract

**Purpose of review**—In this review, we outline the rationale for expanding the role of palliative care in end-stage renal disease (ESRD), describe the components of a palliative care model, and identify potential barriers in implementation.

**Recent findings**—Patients receiving chronic dialysis have reduced life expectancy and high rates of chronic pain, depression, cognitive impairment, and physical disability. Delivery of prognostic information and advance care planning are desired by patients, but occur infrequently. Furthermore, although hospice care is associated with improved symptom control and lower healthcare costs at the end of life, it is underutilized by the ESRD population, even among patients who withdraw from dialysis. A palliative care model incorporating communication of prognosis, advance care planning, symptom assessment and management, and timely hospice referral may improve quality of life and quality of dying. Resources and clinical practice guidelines are available to assist practitioners with incorporating palliative care into ESRD management.

**Summary**—There is a large unmet need to alleviate the physical, psychosocial, and existential suffering of patients with ESRD. More fully integrating palliative care into ESRD management by improving end-of-life care training, eliminating structural and financial barriers to hospice use, and identifying optimal methods to deliver palliative care are necessary if we are to successfully address the needs of an aging ESRD population.

### Keywords

end-stage renal disease; hospice; palliative care

### Introduction

Recent studies have highlighted the burden of physical and emotional symptoms in patients with end-stage renal disease (ESRD) treated with chronic dialysis. At the same time, rates of advance care planning and hospice use remain low, highlighting an opportunity to improve clinical care by more fully integrating palliative care into ESRD management.

## The rationale for expanding palliative care

When Medicare coverage was extended to patients with ESRD in 1972 after an amendment to the existing Medicare law, it removed barriers to life-extending dialysis therapy and greatly expanded access to dialysis care. One of the rationales for providing universal health insurance coverage for this single category of disease was the hope and expectation that dialysis therapy would not only extend life, but enable many patients disabled by ESRD to return to work or their normal activities [1,2\*]. This goal was restated a decade later in legislation articulating responsibilities of the ESRD networks [3].

Since then, the landscape of ESRD care has changed dramatically. Today, patients over the age of 75 have higher incidence rates of ESRD than younger patients and constitute the fastest growing segment of the ESRD population in the United States [4]. Up to one third of elderly patients with ESRD have four or more chronic health conditions when they reach ESRD [5] and most are not considered candidates for kidney transplantation owing to their coexisting conditions, lack of living donors, and long waitlist times. Thus, the vast majority of elderly patients with ESRD face the prospect of lifelong dialysis therapy without the option for cure. Even for younger patients, the promise of rehabilitation after dialysis initiation has not been achieved. For example, recent data indicate that only 19% of the patients under the age of 55 are employed [6]. Potential explanations for this abound, but progress has been hard to achieve.

Life expectancy for many patients with ESRD is similar or worse than that associated with common cancers, and dialysis initiation may not substantially prolong life for some patients. For example, in two studies, median survival was similar among elderly patients receiving nondialytic management of ESRD as compared with elderly patients who started dialysis with coexisting ischemic heart disease [7], or elderly patients who started dialysis after emergency referral [8\*]. Despite knowledge of poor survival after dialysis initiation, advance care planning occurs infrequently [9,10]. Rates of hospice use before death among patients with ESRD are less than half of those seen among patients dying of cancer, even among patients with ESRD who choose to withdraw from dialysis before death [11]. Most patients with ESRD die in the hospital, often in an intensive care setting after undergoing expensive and invasive medical tests and therapies, while suffering with pain or other distressing symptoms. A recent study from the United Kingdom noted that among patients over the age of 70 starting dialysis, much of the survival benefit associated with dialysis initiation versus nondialytic therapy was explained by additional days in the hospital or in the dialysis unit [8\*]. One might legitimately wonder whether this 'medicalization' of the dying process is necessary. By contrast, in other life-threatening illnesses, users of hospice care and their families report improved symptom control and a high level of satisfaction with the dying process [12]. Economic rationales for expanding palliative care are controversial. Proponents of hospice care suggest it delivers quality care at a potential cost-savings, detractors dispute this claim and often equate such assertions with rationing [13\*,14].

Although dialysis therapy may extend life, it is now increasingly clear that it often fails to restore health and that many patients suffer from distressing symptoms or disability prior to death. Half of all hemodialysis patients report pain symptoms, which are often inadequately controlled with medication [15,16]. One in five patients have depressive symptoms and up to one-third have severe cognitive impairment [17,18]. Physical disability is also common and frequently severe. Among nursing home residents starting dialysis, we recently demonstrated that dialysis initiation was associated with a substantial and sustained decline in functional status at the start of dialysis in addition to very high mortality [19\*]. Similar findings have been noted in community-dwelling elderly patients [20]. Underscoring the physical and psychological toll of ESRD, almost 25% of patients with ESRD choose to

discontinue dialysis before death [4]. In a recent survey of Canadian ESRD patients, 60% said they regretted beginning dialysis; just over half of these patients indicated that they began the treatment because of the urging of their physician [21\*]. In sum, the data point to an urgent need to alleviate the physical, psychological, and existential suffering of this patient population.

At the same time, studies of quality of life in elderly patients receiving chronic dialysis offer reason to believe that dialysis therapy is not uniformly unsatisfactory in the elderly. In several studies, although physical aspects of quality of life are reduced compared with younger ESRD patients or healthy elderly, mental aspects of quality of life are preserved [22,23]. Accordingly, the question is not whether palliative care should play an expanded role in ESRD management – clearly it should. The question is how to expand palliative care in a way that is appropriate for an individual patient's stage of disease and congruent with his or her preferences and values.

### **What does palliative end-stage renal disease care consist of?**

Before considering how to expand palliative care in ESRD, it is useful to first understand what palliative care is and what it is not. The WHO defines palliative care as treatment that strives to improve quality of life and relieve suffering for patients with life-threatening illness and their families [24]. It is characterized by a focus on relieving pain and other distressing symptoms rather than curing disease or delaying disease progression. Other aspects include integration of psychosocial and spiritual needs with medical care, coordination of medical and social services, and creation of a support system to help the patient and family cope with illness and prepare for death [25]. Palliative care can be delivered at any point during the course of an illness and can be provided in conjunction with curative or life-extending therapy. In the United States, palliative care delivered in a hospice setting is often distinguished from nonhospice palliative care, primarily owing to the way hospice services are reimbursed. The delivery of palliative care services involves several discrete and ongoing steps: estimation of prognosis and explanation of treatment options, advance care planning, symptom assessment and management, and timely hospice referral and bereavement support.

Although physicians are often hesitant to discuss prognosis, studies show that ESRD patients and their families strongly desire this information but rarely receive it [21\*,26]. This hesitation may arise from a desire not to take away hope, although studies indicate that this concern is generally unfounded [27]. Nephrologists are also uncertain about the accuracy of prognostic information. Recently, Cohen and colleagues [28\*,29] developed and validated a simple prognostic instrument for predicting 6-month mortality among ESRD patients receiving hemodialysis that incorporates five elements: age, serum albumin, peripheral vascular disease, dementia, and the 'surprise question' (would I be surprised if this patient died in the next year?). Couchoud *et al.* [30\*] have also reported a clinical risk score for predicting 6-month mortality in elderly French patients starting dialysis. Because these tools focus on prediction of short-term mortality, they offer an advantage over other commonly used comorbidity indices typically used for risk adjustment (e.g. Charlson index) in terms of identifying ESRD patients who may benefit from palliative and hospice care [31]. Additional studies are needed to determine whether these prognostic indices have similar performance characteristics in patients with stage 5 chronic kidney disease (CKD) who have not started dialysis.

A discussion of prognostic information can often facilitate advance care planning. The purpose of advance care planning is to help the patient identify his or her goals and prepare for healthcare needs as the disease progresses. Within this context, a discussion of whether

starting or continuing dialysis might best achieve those goals is appropriate. ESRD patients who have end-of-life discussions with a healthcare provider are more likely to complete advance directives [9,10]. In studies of patients with other life-limiting illnesses, patients who had end-of-life discussions with a healthcare provider accrued fewer healthcare costs, used less invasive or burdensome procedures, and entered hospice care earlier and more frequently [12,13,32]. A patient-centered advance care planning model for ESRD has been described by Davison and Torgunrud [33]. In this model, the focus is on ensuring that end-of-life care is consistent with patient preferences, rather than on completing advance directives.

Limitation of space precludes an extensive discussion of symptom management and assessment, but these issues are covered in detail in the first textbook on the supportive care of ESRD patients, which has just been revised and reissued in a second edition [34]. As symptom burden and functional limitations increase, timely referral for hospice services allows for better control of pain and other symptoms, and provides the patient and family time to prepare for death. ESRD patients spend an average of only 14 days in hospice, in contrast to the average of 59 days for patients with other diseases, suggesting that they are referred late in the dying process [35]. In part this may be owing to financial and structural barriers to accessing hospice care (see below), but it also suggests a failure to recognize and openly acknowledge the terminal stages of disease. In order to provide timely referrals for palliative care and hospice, much more needs to be learned about the pace of CKD progression and the significance of acute kidney injury and other sentinel events in the elderly.

### **Barriers to implementing palliative end-stage renal disease care**

Studies show there is substantial variation in attitudes toward and practice of end-of-life decision making among nephrologists, although these differences seem to be lessening over time [36,37]. Underlying these variations are marked differences in training. In one survey of United States and Canadian nephrologists, those who reported being better prepared to make end-of-life decisions were more likely to stop dialysis in several hypothetical scenarios and more likely to have stopped dialysis in the preceding year [38]. If palliative care is to be expanded, deficits in training during nephrology fellowships are among the highest priorities to tackle [39,40].

Several initiatives are addressing this specific problem. In 1991 the Institute of Medicine suggested developing clinical practice guidelines to evaluate patients for whom the burdens of dialysis substantially outweigh the benefits [22]. In response, the Renal Physicians Association and the American Society of Nephrology (ASN) published practice guidelines and laid the foundation for contemporary palliative care initiatives in ESRD [41]. The original guidelines (available at: <http://www.renalmd.org>) have nine tenets and begin with a patient–physician relationship that promotes shared decision-making, and concludes with efforts directed at achieving a ‘good’ death. This year will mark publication of newly revised guidelines expected to include an updated toolkit for advanced care planning. A recent survey indicated that nephrologists who were familiar with the guidelines were more likely to feel prepared for end-of-life decision making [38]. Other notable developments on this front include the formation of the ASN Geriatric Nephrology Advisory Group and publication of the Geriatric Nephrology Curriculum (available at [http://www.asn-online.org/education\\_and\\_meetings/geriatrics/](http://www.asn-online.org/education_and_meetings/geriatrics/)), addressing end-of-life decision making and other issues relevant to the aging patient with kidney disease [42].

Beyond improving knowledge of palliative care, there are also structural and financial barriers to expanding palliative care in general and hospice care in particular to ESRD

patients. Although palliative care can in theory be delivered in any healthcare setting, in the United States it is most often delivered in the acute care setting or in a hospice program. Nephrology practices not affiliated with academic medical centers, particularly those in rural settings, may have limited access to palliative care specialists. To qualify for the Medicare hospice benefit, two physicians (including the hospice medical director) must certify that the patient has a life expectancy of 6 months or less if the qualifying disease takes its normal course. For ESRD patients with a terminal diagnosis other than ESRD, both dialysis and hospice care can be provided through Medicare benefits. For patients whose terminal diagnosis is ESRD, hospice care can be provided through two routes: patients may choose to withdraw from dialysis and enroll in hospice care, or if a patient elects to continue dialysis then the hospice provider must be willing to accept responsibility for the cost of dialysis and supplies. Although extensive data documents that many patients receiving dialysis have life expectancies that would qualify them for hospice services, in our experience hospice programs frequently view continuation of dialysis as financially problematic and incompatible with organizational goals. As a result of these barriers, ESRD patients who might benefit cannot access hospice services. Because rules for reimbursement are not likely to soon change, clinical trials are needed to establish the optimal strategies for delivering palliative care in ESRD.

## Conclusion

Over the last few years, great strides have been made in illuminating the need for palliative care in patients with ESRD, and in identifying the outlines of a palliative care model. Testing, refining, and disseminating these models into clinical practice will not be easy, but these are challenges that we must meet.

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## References and recommended reading

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- of special interest
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Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 000–000).

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