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Palliative and end-of-life care issues in chronic kidney disease

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Abstract

Purpose of review—Patients with progressive chronic kidney disease (CKD) have high morbidity, mortality, and symptom burden. Cardiovascular disease (CVD) and congestive heart failure (CHF) often contribute to these burdens and should be considered when providing recommendations for care. This review aims to summarize recent literature relevant to the provision of palliative and end-of-life care for patients with progressive CKD and specifically highlights issues relevant to those with CVD and CHF.

Recent findings—Dialysis may not benefit older, frail patients with progressive CKD, especially those with other comorbidities. Patients managed conservatively (i.e., without dialysis) may live as long as patients who elect to start dialysis, with better preservation of function and quality of life and with fewer acute care admissions. Decisions regarding dialysis initiation should be made on an individual basis, keeping in mind each patient's goals, comorbidities, and underlying functional status. Conservative management of progressive kidney disease is frequently not offered but is likely to benefit many older, frail patients with comorbidities such as CHF and CVD.

Summary—A palliative approach to the care of many patients with progressive CKD is essential to ensuring they receive appropriate quality care.

Keywords

cardiovascular disease; chronic kidney disease; conservative management; dialysis decisionmaking; end-stage renal disease

INTRODUCTION

Worldwide, chronic kidney disease (CKD) poses a significant public health burden. In the USA, the prevalence of CKD and end-stage renal disease (ESRD) continues to rise annually, with Medicare ESRD costs in 2011 rising to US \$34.3 billion, comprising 6.3% of the

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Conflicts of interest

There are no conflicts of interest.

Medicare annual budget [1]. CKD and ESRD both confer tremendous morbidity and mortality. Patients on dialysis have a mortality rate that is estimated to be 6.5–7.9 times greater than that of the general Medicare population, with an annual unadjusted mortality rate of 22–25%. In 2011, 30-day all-cause rehospitalization rates among Medicare patients with and without ESRD were 36 and 17.4%, respectively [1]. Furthermore, only 52% of hemodialysis patients in the United States were alive 3 years after initiating dialysis therapy in 2006 [1].

Cardiovascular disease (CVD) and kidney disease are intricately connected as CVD continues to be the most common cause of morbidity and mortality in patients with CKD and ESRD. Despite continued advances in dialysis technologies and in cardiovascular therapies, cardiac death due to arrhythmia continues to be the largest attributable cause of death in both incident and prevalent dialysis patients [1]. Similarly, among ESRD patients on hemodialysis, the incidence of congestive heart failure (CHF) continues to rise, most recently to 655.5 per 1000 patient-years in 2011, and the rate of acute myocardial infarction has plateaued at 73.1 per 1000 patient-years [1]. Given the substantial morbidity and mortality of these intertwined diseases, adapting a palliative approach to the care of patients with progressive CKD and CVD is of foremost importance to assure that patients make informed medical decisions and receive the care that best meets their needs.

PALLIATIVE CARE IN PATIENTS WITH CHRONIC KIDNEY DISEASE

Similar to CVD and CHF, the rate of progression of CKD is highly variable and can follow any number of trajectories [2,3,4■]. Therefore, it is important that the initiation and integration of palliative care services – that is, the management of patients' symptoms, the discussion of renal replacement therapy options including both dialytic and nondialytic management of ESRD, and the outlining of patients' end-of-life treatment preferences – start early and continue to be readdressed throughout the disease course [5,6■,7–9]. Relying on expected survival as a marker to start these discussions will inevitably result in having to make urgent decisions that may not be consistent with patients' treatment preferences and goals.

SYMPTOM BURDEN IN PATIENTS WITH CHRONIC KIDNEY DISEASE

Patients with advanced CKD have a high symptom burden, similar to that experienced in cohorts of patients with CHF, chronic obstructive pulmonary disease, or cancer [10–12]. Most commonly, patients report high rates of fatigue, dyspnea, insomnia, pain, anxiety, and depression [13,14], all of which overlap with the most prevalent symptoms in patients with CHF. These symptoms greatly affect patients' health-related quality of life (HRQL). In a recently published scoping review of the literature on pain in CKD, the mean prevalence of chronic pain across multiple worldwide cohorts of prevalent hemodialysis patients was 58.6% and, similarly, the prevalence of pain was 53% in a cohort of ESRD patients in the United Kingdom managed conservatively without dialysis [15■]. These symptoms are often unrecognized and undertreated [16]. Barriers to recognition and treatment of these symptoms are multifactorial and include poor provider awareness of symptoms, provider perception of difficulty in treating symptoms, and providers feeling that symptom control is

out of the scope of their particular role in patient care [17]. Patient-reported HRQL is inversely proportional to symptom burden, [13,14,18,19] and symptom management has been identified as a top CKD patient-ranked priority [20]. Incorporating palliative care services in the care of patients with ESRD will likely decrease patient suffering by detecting and treating these symptoms and improving their HRQL [13,21].

DECISION-MAKING FOR PATIENTS APPROACHING END-STAGE RENAL DISEASE

Only a small fraction of patients with CKD progress to ESRD before death [22]. For those with progressive CKD, it is important that providers use an individualized approach when discussing the available options and elicit and incorporate each patient's values and goals when making recommendations for care [22,23,24,25,26,27]. There is increasing evidence that not all patients with CKD who progress to ESRD will benefit from renal replacement therapy (i.e., peritoneal dialysis, hemodialysis, or transplant). Particularly for patients older than 75 years with ischemic heart disease, those with multiple comorbidities, and those who are frail, starting dialysis may not increase lifespan and may put them at higher risk for other comorbidities. For these patients, dialysis is unlikely to improve their symptoms and may negatively impact their HRQL and functional status [28–30,31,32,33,34]. Compared with those managed medically, older patients on dialysis spend more time in the hospital and are at increased risk for infectious and cardiac complications of dialysis [28]. Additionally, when patients initiate dialysis, they may be unknowingly committing to a more 'intensive' medical environment, not only because of the inherent complications of dialysis but because many medical providers may perceive their ongoing dialysis therapy as an implied consent to other intensive medical procedures. One recent study demonstrated that when compared age-matched Medicare patients with CHF or cancer, older patients on dialysis are more likely to be hospitalized, receive ICU care, spend more days in the ICU, and die in a hospital in the last 30 days of their life [35]. These statistics are not consistent with the care ESRD patients want at the end of life; when surveyed, most report preferring care that focuses on treating symptoms and preserving HRQL and want, where possible, to die at home or in an inpatient hospice setting [36].

For patients with progressive CKD who also have CHF, dialysis initiation is often considered when volume overload becomes a recurrent issue. In this scenario, it is important to consider the potential negative implications discussed above associated with dialysis initiation, including the association with increasing morbidity such as more frequent hospitalizations, the higher risk for infection, and the potentially negative effects on patient HRQL and overall physical function. There is limited literature that evaluates the risks and benefits of dialysis initiation for patients with CHF and ESRD. In one retrospective study of data from the United States Renal Data System, the authors analyzed characteristics of older patients who started dialysis either early (estimated glomerular filtrate rate (eGFR) >10 ml/min/1.73 m²) versus late (eGFR <10 ml/min/1.73 m²). Those starting chronic dialysis early were more likely to have multiple CHF admissions. Early initiation was associated with greater all-cause, cardiovascular, and infectious mortality and with greater all-cause and infectious hospitalizations [37]. Consideration of the long-term effects of dialysis is often

neglected when initiating dialysis in patients with CHF and progressive CKD in the acute setting. Both cardiology and nephrology care providers need to be aware of these risks and present them to their patients when discussing and making decisions about dialysis initiation.

Many experts recommend offering a time-limited trial of dialysis when it seems unclear whether a patient may benefit from dialysis. In a time-limited trial, the provider and the patient or their decision-maker identify objective goals (for example, improvement in symptoms as measured by an objective symptom screening tool or decreased need for hospitalization) and set a specific date at which to reevaluate how the patient is faring on dialysis and whether the patient is meeting the specified goals. If, at the specified date the patient is not meeting the predefined goals, the patient discontinues dialysis and pursues aggressive medical management of ESRD [27]. However, it should be emphasized that the act of dialysis, particularly hemodialysis, dramatically accelerates the rate at which patients lose their residual kidney function. Therefore, a trial of dialysis, even for a short period of time, is likely to also accelerate the rate of decline of kidney function, and, if dialysis is stopped, leave the patient with decreased residual renal function that has been clearly shown to impart increased mortality. As such, a time-limited trial should not be considered an entirely benign procedure. The majority of patients in these scenarios can make an informed decision about dialysis without needing a time-limited trial if options are adequately and appropriately discussed with astute clinicians. This is most successfully done when the clinician and the patient start discussing these issues early in the course of their disease, continue to revisit the decision, and make a plan to successfully carry out the decision if and when their CKD progresses.

CONSERVATIVE MANAGEMENT OF END-STAGE RENAL DISEASE

Too often, patients perceive they have no choice but to start dialysis when their CKD progresses. Multiple qualitative studies and surveys exploring patients' and their caretakers' perceptions regarding dialysis decision-making reveal that they feel shocked about their diagnosis and feel unprepared about what to expect in the future, that they are unaware that they have a choice in renal replacement therapy modality, that they have unrealistic expectations about what dialysis will achieve for them, and that most are not offered the option of nondialytic (conservative or medical) management of their CKD [38–41]. Interestingly, when surveyed, CKD patients in multiple metropolitan and rural renal clinics in Australia reported that they would be less likely to choose dialysis over conservative care if an increase in the number of visits to the hospital was required or if there were more restrictions in their ability to travel. Specifically, patients were willing to forgo 7 months of life expectancy to reduce the number of required hospital visits or 15 months to increase their ability to travel [42]. Clearly, nephrology providers have a lot of room for improvement in the task of adequately presenting and communicating all treatment options to their patients (dialytic and nondialytic), identifying which option is most consistent with a particular patient's goals, and outlining reasonable expectations for their future [43■].

Conservative kidney management is planned, comprehensive, patient-centered care for patients with ESRD, which integrates palliative care principles [such as advance care

planning (ACP), completion of advance directives or physician orders for life sustaining treatments, aggressive symptom management, and psychosocial and family support] with interventions to delay progression of CKD and minimize complications without dialysis. Ideally, this involves care by a multidisciplinary team of physicians, nurses, social workers, and caretakers. Provision of conservative care looks different depending on where care is provided, but it is important that providers, patients, and their caretakers receive adequate support in this endeavor. In countries such as the United Kingdom, Canada, and Australia, some kidney programmes have incorporated conservative management pathways into CKD clinics, where dedicated teams care for these patients and help coordinate care with the required primary and palliative care services. Regardless of the model of care delivery, care should be patient centered in that it is based on shared decision making and respectful of individual patients' goals and values [44].

END-OF-LIFE CARE

Like in other areas of medicine [45–47], patients with CKD have a poor understanding of palliative and hospice care. One recent study found that only 22.2 and 17.9% of patients surveyed in a university-based kidney programme in Alberta, Canada, correctly identified the role of palliative and hospice services, respectively, and perceptions were mostly negative. However, when correctly explained to the same patients, 89.7% thought these services were valuable [48■]. One aspect of this misinformation is that few nephrology providers discuss end-of-life care preferences with their patients [9], despite the fact that patients are amenable to these discussions [49]. Additionally and not surprisingly, when surveyed, many nephrologists reported that they felt unprepared to have end-of-life discussions with their patients [50]. At the very root of the issue is poor end-of-life care education during medical training. In a recent survey of renal fellows in the USA, most reported that they received little education in palliative and end-of-life care, but nearly all thought it was important to learn to provide this care [51■].

In order to provide adequate end-of-life care, patient preferences need to be discussed and goals of care documented. Although there are no studies that conclusively demonstrate the most effective way to incorporate ACP into CKD care [52], new tools to aid in facilitating ACP are available based on ESRD patients' perspectives of the salient elements of ACP discussions [53]. ACP is a dynamic and fluid process, should be discussed at an individual patient's own pace, and should include the patient's designated surrogate decision maker. ACP for CKD patients includes discussion about health states in which patients would not wish dialysis. As many as 73% of dialysis patients have moderate or severe cognitive impairment [54], which impacts their ability to participate meaningfully in shared decision making. Unpredictable illness trajectories and progressive cognitive decline highlight the importance of early ACP in CKD with ongoing communication and reevaluation throughout the illness, especially with sentinel events such as hospitalizations, acute illness, and decline in functional status or HRQL, to ensure that end-of-life crises are avoided and care remains consistent with patients' wishes [55]. These discussions can be legally documented via an advanced directive or with a physician orders for life sustaining treatments form. Facilitated ACP in CKD through the provision of timely, appropriate information can enhance patients' hope [56].

It is important to communicate to patients on dialysis that they have the option at any point in the course of their treatment to discontinue dialysis. In the USA, between the years 2008 and 2010, greater than 50000 patients chose to discontinue dialysis before death [1]. Approximately half of these patients enrolled in hospice at the time of dialysis discontinuation. A recent study showed that in those patients who discontinued dialysis and enrolled in hospice, the mean survival after enrollment was 7.4 days (range 0–40 days) [57]. Hospice services are especially recommended in patients discontinuing dialysis as they can help manage symptoms, provide emotional and spiritual support to patients and their loved ones, offer grieving services to survivors after death, and offer additional medical and nonmedical services to patients and their support systems.

CONCLUSION

CHF and CVD are common in patients with progressive CKD. It is important that providers recognize these patients have high rates of morbidity and mortality and approach decision-making and provision of care with careful consideration of how each patient may or may not benefit from offered interventions. In particular, dialysis may not benefit older patients with CHF or CVD. A palliative approach to care of patients with CKD is essential to ensure that patient's goals are elicited and translated into the care that best meets their needs.

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Box 1**KEY POINTS**

- The importance of adequate palliative and end-of-life care in patients with CKD is highlighted by their high mortality, as dialysis patients have an annual unadjusted mortality rate of 22–25%, with CVD being the most common cause of death.
- Similar to patients with CHF, patients with advanced CKD have a high symptom burden with high rates of pain, fatigue, dyspnea, insomnia, anxiety, and depression, but dialysis, especially in older patients, may not ameliorate these symptoms.
- For many older patients with progressive CKD, including those with ischemic heart disease, dialysis provides no benefit and managing these patients conservatively (i.e., without dialysis) may actually prolong survival with better preservation of function and quality of life and fewer acute care admissions.
- Consideration of the long-term effects of dialysis must be considered carefully when initiating dialysis in patients with CHF, especially in the acute setting, as early dialysis initiation to manage volume in patients with CHF and CKD appears to be associated with increased rates of hospitalization and mortality.
- In order to provide quality patient-centered care, clinicians and the patient should start discussing dialysis options early in the illness trajectory so individual patient preferences can be clarified and goals of care that best meet patients' needs can be established long before an acute medical crisis arrives.