Unique palliative care needs of patients with advanced chronic kidney disease – the scope of the problem and several solutions

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Patients with advanced chronic kidney disease (CKD), including end-stage renal disease (ESRD), have a life-threatening illness complicated by high morbidity and mortality and, therefore, should be suitable candidates for early intervention by palliative care specialists. However, the average patient with CKD does not have an advanced care plan, has multiple debilitating symptoms, and does not utilise hospice care at the end of life. In this review, we outline the scope of the problem of unmet palliative care needs for patients with advanced CKD and ESRD, barriers to improving palliative care for patients with renal failure, and possible future directions for palliative nephrology.

KEYWORDS: CKD, ESRD, palliative, care models

Introduction

The World Health Organisation defines palliative care as ‘an approach which improves the quality of life of patients and their families facing life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems’.\textsuperscript{1} Patients with advanced chronic kidney disease (CKD), including end-stage renal disease (ESRD), have a life-threatening illness that is often identified very early and follows a heterogeneous disease course that can include a multitude of problems, be they physical, psychosocial, or spiritual. These problems are particularly prevalent in the setting of comorbid illness and at the end of life. Therefore, it appears likely that patients with advanced renal disease and particularly ESRD would benefit from the incorporation of palliative care into their routine nephrology care. Patients with CKD have many needs in the areas of symptom management, advance care planning (ACP) and end-of-life care. Here, we review ESRD epidemiology, key factors for prognostication, hospice care utilisation in the ESRD population, and barriers to palliative care for patients with kidney disease.

Epidemiological considerations

There are more than 2.2 million people in the world who receive dialysis, and the prevalence continues to increase because of improved survival on dialysis. There are more than 120,000 and 700,000 people with CKD5 in the UK and USA, respectively.\textsuperscript{2} Over the past 60 years, the dialysis population has transitioned from a relatively healthy ‘single-disease’ population of patients to a population with many chronic diseases and, therefore, a high burden of associated symptoms. Dialysis has transitioned from a bridge to transplant to destination therapy for many patients who will not be eligible for transplant.

Given both the presence of multiple comorbidities and an ageing dialysis population, patients have been noted to have an increasing, distressing symptom burden. The average patient on dialysis has a mean of 7.5 symptoms, with 4.5 symptoms rated as severe, based on the Edmonton Symptom Assessment Scale.\textsuperscript{3} Despite improving mortality rates over the past few decades because of improved infection control and the movement away from dialysis through catheters, only 75\% of patients on dialysis are alive 1 year after dialysis initiation, with the percentage surviving after 5 years dropping to 35\%.\textsuperscript{4} Five-year mortality rates are comparable to those of patients with localised lung cancer and congestive heart failure after myocardial infarction.\textsuperscript{5} It is notable that more patients (40\%) die from arrhythmias or cardiac arrest.\textsuperscript{4} Interestingly, there is great variation in dialysis withdrawal rates between countries, with rates as high as 18\% in the USA and Canada and 2–7\% in European countries.\textsuperscript{2}

Prognostication in ESRD

Despite the large population of patients on dialysis with well-documented morbidity and mortality, there are few clinical tools available that clinicians can utilise to accurately prognosticate for individual patients. In 2010, Cohen \textit{et al} developed a model based on data from 449 patients on haemodialysis that relied on actuarial data along with the ‘surprise question’ – “Would you be surprised if your patient died in the next 6 months?” This appeared to be an accurate tool for predicting mortality, with area under the curve of 0.87 in the derivation cohort and of 0.80 in the validation cohort.
Hospice and hospital utilisation in the ESRD population

Hospices are a variable enterprise according to geographic location. Within the USA, hospices represent a plan of care focused on comfort until the end of life for patients within the last 6 months of life. This care can be delivered in several locations, including the patient’s home, a skilled nursing facility, or a residential (inpatient) hospice facility. This care model is in contrast to the provision of palliative care, which can be provided at any point along the course of a serious life-limiting illness. By contrast, the European model of hospice and palliative medicine, has a less clear delineation between hospice and palliative care models. The European Association for Palliative Care created a task force to further evaluate palliative care across various European countries. A key goal of this task force was to homogenise terminology. In 2009, the task force published definitions of palliative care and hospice in an effort to minimise variability across European countries, which were as follows:  

- Palliative care – ‘the active, total care of the patient whose disease is not responsive to curative treatment.’  
- Hospice – ‘care is for the whole person, aiming to meet all needs – physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them.’

There is no consensus definition of a hospice within Europe. Therefore, for the purposes of this review, the US hospice model is utilised, although the authors recognise that this constrains the review.

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misaligned incentives between dialysis and palliative care, and uneven access to specialty palliative care in the USA. A survey of renal units in the UK found that there was general acceptance of conservative, non-dialytic management of ESRD, although there was variation in its scale and application between units. As noted earlier, prognostication in CKD is difficult; therefore, the current American hospice model, which is designed for patients in the last 6 months of life, might not yet be appropriate patients with advanced CKD, given their somewhat unpredictable life expectancies. Nevertheless, upstream palliative care interventions would likely be advantageous. However, a significant percentage (22–28%) of hospice utilisation for all-comers in the USA is within the last 3 days of life. Therefore, underutilisation of hospices for patients with ESRD might be representative of the greater trend of hospice utilisation in the USA. Additionally, current advanced CKD and pre-ESRD outpatient clinic models focus on dialysis preparation and are not as focussed on ACP. ACP is defined by the National Hospice and Palliative Care Organisation as ‘making decisions about the care you would want to receive if you became unable to speak for yourself,’ and includes, but is not limited to, creation of advance directives. Therefore, it logically follows that patients with ESRD have a low advance directive completion rate. Current dialysis quality metrics, such as the ESRD Seamless Care Organization Quality Incentive Program have begun incorporating ACP as a quality measure, with the goal of increasing the number of patients with advance directives and surrogate decision-makers. Despite the inclusion of ACPs as a quality metric along with measures of patient experience, quality of life and a pain assessment, the quality metrics overall contain few measures applicable to palliative care. Lastly, there is concern that a shortage of palliative care clinicians who already are primarily regionalised in larger metropolitan areas might prohibit patients from obtaining palliative care consultation.

Improved care models of palliative nephrology delivery could remove one of the major disincentives to palliative care in patients with CKD. The most developed model of outpatient palliative nephrology comes from Australia, where patients are followed by multidisciplinary teams comprising palliative care and nephrology specialists. The Australian model has been adapted to an American palliative-nephrology clinic, with adjustments focusing on upstream palliative care, staff education, involvement of hospitalists and dialysis nurses in the referral process, and establishing evaluation tools to measure the success of the clinic. As discussed earlier, nephrologists have expressed a lack of confidence with having conversations about informed consent for dialysis, prognosis and ACP. A possible source for this lack of confidence might be a lack of exposure to palliative care during fellowship training. A survey of US nephrology fellows found that the trainees felt unprepared for end-of-life care and ACP for patients with ESRD, and suggested a role for improved education in palliative care during fellowship training.

Conclusions
In conclusion, the prevalence of ESRD continues to increase and patients with ESRD have unique and unmet palliative care needs. Patients with ESRD do not often have conversations about their prognosis and all of their care options, including conservative, non-dialytic care. There are several barriers to providing palliative care for patients with renal disease. Improving the integration of palliative care and nephrology by increased use of outpatient combined care models and improving training in palliative care for practicing nephrologists and trainees are several possible solutions to this pressing and multifaceted problem.

References


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