

# Palliative care for advanced renal disease: A summary of the evidence and future direction

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## Abstract

**Background:** Patients with end-stage kidney disease can have a significant symptom burden with complex co-morbidities. Compounding this is the choice between dialysis and conservative management.

**Need for supportive and palliative care:** For individuals with end-stage kidney disease, palliative care can provide support with symptom management, advance care planning and psychological support and education for both patients and their families. Optimum management may be achieved through collaboration between renal and palliative care professionals, combining their different skills in addressing symptom and medication management. Palliative and supportive care must be patient-centred to be effective. Multidisciplinary cross-organisational input is central to address the complex care needs of these patients, particularly for those in the community.

**What is known/what is not known:** There is growing awareness of the need for research into the palliative care needs of those with end-stage kidney disease. Research has shown that patients receiving dialysis may prioritise quality of life over survival time, partly due to the constraints that they feel dialysis imposes on them. Systematic study of those opting for a conservative management pathway rather than dialysis is beginning to happen.

**Research implications:** Research is required into what underpins the preferences and priorities of patients with end-stage kidney disease to provide them with the best palliative and supportive care.

**Policy and practice:** As more patients opt to follow the conservative pathway for their advanced renal disease, a change in service provision is required, with greater regular inclusion of palliative and supportive needs to address the gap in the care provision for this growing group.

## Keywords

End-stage kidney disease, palliative care, advance care planning, dialysis, quality of life

## Introduction – the distinctive features of renal palliative care

A number of distinctive features characterise renal palliative care. First, end-stage kidney disease (ESKD) is similar to both end-stage cardiac and respiratory disease, as each of the three conditions leads eventually to death, but it differs in that life-sustaining treatment in the form of dialysis is available. The number of patients receiving dialysis in the United Kingdom increased fivefold, from 5000 in 1984 to 25,000 in 2006.<sup>1</sup> From 2006 to 2010, the

incidence rates have then levelled off.<sup>2</sup> This may be for a number of reasons, including changes to treatment thresholds and the introduction of conservative management programmes.<sup>2</sup> While there is a wide variation across the United Kingdom in the incidence of the over-75 age group commencing dialysis,<sup>2</sup> the prevalence of those who are 80 and above has increased. This prevalence increase is in line with the overall prevalence of dialysis, which increased by 4% from 2009 to 2010. This increase is con-

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sistent with the previous 10–15 years. This may be related to the decrease in mortality rates for those on dialysis, both in the United Kingdom and in the United States. Individuals with ESKD frequently have complex co-morbidities; 70% of those over 65 years of age starting dialysis have at least one co-morbidity, most frequently ischaemic heart disease or diabetes.<sup>3</sup> Diabetic nephropathy is the most common diagnosis for those commencing dialysis in 2010, accounting for 24% of all diagnoses given.<sup>2</sup>

Second, symptom burden is significant in advanced renal disease and is similar to the symptom burden in advanced cancer. However, there are differences in the type and severity of symptoms experienced.<sup>4,5</sup> While some uraemic symptoms are relieved by dialysis, the overall symptom burden of those receiving dialysis remains high.<sup>6</sup> Symptom identification and amelioration is a high priority for patients and families,<sup>7</sup> as it improves their quality of life.<sup>8</sup> Some symptoms, including those more common in the renal population, can be poorly recognised by those with little renal experience,<sup>4,6,9</sup> resulting in poor symptom management. Use of a structured symptom assessment tool, such as the Palliative care Outcome Scale–Symptoms modified for renal patients (POS-S renal) (see <http://pos-pal.org/>), can help address this deficit.

As renal function declines, expert knowledge is required to adjust the medications to manage any symptoms experienced.<sup>10</sup> Renal physicians are often responsible for managing symptoms that are both renal and non-renal in origin. Their knowledge of drug dose adjustment makes them uniquely able to do this, although optimum management may be achieved through collaboration between renal and palliative care professionals, uniting their different skills in symptom control and medication management.

Third, the trajectory to death is sometimes different in renal patients, and the ‘tipping point’, where increased medical and supportive care is rapidly needed, may be missed by staff with little renal experience.<sup>11,12</sup> In conservatively managed Stage 5 chronic kidney disease (CKD), symptom scores and functional status can often be relatively stable until 1–2 months preceding death. This is in marked contrast to trajectories for cancer patients or those with chronic obstructive pulmonary disease (COPD) or cardiac failure.<sup>13</sup>

Finally, with long-standing relationships between patient and dialysis staff, the transition from ‘living with renal disease’ to ‘experiencing deteriorating health from renal disease’ can be difficult for both patients and professionals. Negotiating this transition can be done well, but may also be challenging. Some renal units provide excellent patient and family support throughout this transition, and this continues throughout the deteriorating phase, extending into family support post bereavement. This support may be individual, but can sometimes be collective, for example, an annual memorial service for both the relatives of those who have died in the previous year and the staff.<sup>14</sup>

## Who needs palliative and supportive care?

For individuals with ESKD, palliative care can provide support in a number of areas. These include symptom management, advance care planning and in the provision of psychological support and education to both families and patients. Together, these form part of a long process of renal palliative care of which the dying or terminal care phase is only one part.

There are three main patient groups who may benefit from palliative and supportive care. One group are those who prefer to forgo dialysis to follow the conservative care pathway. Here, the emphasis is on slowing the decline in existing kidney function (by measures such as good blood pressure control) while treating the symptoms and complications of renal failure. The palliative phase may last for 1–2 years.<sup>15–17</sup> The challenge is as much about optimising quality of life as planning for their later death.

A second group are those who begin dialysis in somewhat good health. Over time, they become more symptomatic and less well able to tolerate dialysis. They require a change in the direction of care. The focus moves to symptom control. This may include a reduction in tablet burden or even in dialysis frequency. The priorities move to those of quality of life while planning for end-of-life care.

A third group are those with relentlessly progressive conditions causing renal failure, such as severely poorly controlled diabetes. While dialysis may be offered, prognosis is very poor. A combined approach of supportive symptom control and palliative care is offered.

As palliative care extends to non-malignant conditions including renal disease, this provides a learning opportunity for both specialist palliative care and nephrology. Regular symptom assessment, which is an integral part of palliative care, is of value in those with ESKD, and a shared care approach means that the patient can benefit from the expertise of both specialities.

## Person-centred rather than disease-centred management

Palliative and supportive management of patients with ESKD must be patient-centred if it is to be effective. It is essential that ESKD patients are first identified as approaching end of life. This information should then be communicated well across organisational boundaries to achieve optimal care. The creation of a register of ESKD patients whose prognosis is felt to be limited is one of the means recently developed and used to facilitate this.<sup>14</sup> This can help to ensure that care is coordinated and seamless, as well as provide support to families and carers. Coordinated care necessitates the development of a knowledge base as to what services are available at a pan-organisational level, while addressing the patients’ needs effectively.

As patients become frailer, multidisciplinary cross-organisational input plays a central role in addressing their needs, especially for those in the community. These may include symptom control, advance care planning or planning for end of life. It is crucial that this is anticipated and well coordinated, in order to address the often complex care needs of these patients. It should include professionals with both nephrology and palliative care skills but may rely on the general practitioner (family physician) and community nurses to provide the majority of health care at home. Appropriate support to the primary and community services by renal and palliative care services is essential and needs good professional relationships.

## Advance care planning

Advance care planning is a dynamic process. It involves understanding the patient, their life and their family before having discussions about future priorities and preferences for care. The focus is on improving quality of life as end of life approaches, while addressing family relationships and conflict.<sup>18</sup> These are all priorities that patients themselves rate highly.<sup>19</sup> Advance care planning allows for a more patient-centred approach rather than the focus being primarily on disease, for instance, centred around dialysis decisions.

Optimal supportive care for ESKD patients starts with honest prognostic information, tailored to the patient's information preferences. However, this is not always achieved.<sup>20</sup> The annual mortality rate of dialysis patients approaches 20%–24%. This is higher than that of prostate, breast or colorectal cancer.<sup>8</sup> Many renal patients are not aware of this and consider renal failure as curable with transplantation or treatable with dialysis. It has been proposed that open prognostic information to counter this should be offered even before dialysis is started,<sup>21</sup> but this infrequently occurs. As a minimum, advance care planning should start when the answer to the surprise question is 'no' (would I be surprised if this patient died within the next 6–12 months?).

Davison and Torgunrud,<sup>21</sup> on researching advanced care planning, showed that patients wanted more information and in non-medical language on prognosis, disease process and the impact of treatment on daily life, although renal teams may find this difficult, particularly when discussing end-of-life issues, which are less often part of their routine practice.<sup>22,23</sup> Renal professionals often need prompts to help them open up discussion about the future, as they are much less familiar with how to do this than palliative care professionals. But when sensitive, open exploration of concerns for the future is achieved, the opportunity for discussion is often appreciated by patients.<sup>14</sup>

## Dying with renal disease

Although there will always be some uncertainty, three broad categories of information aid identification of dialysis

patients likely to be in the last phase of life. First, demographic and laboratory data,<sup>24</sup> together with vascular co-morbidities including peripheral vascular disease (PVD), foot ulcers, cardiovascular disease and dementia, appear the most consistent clinical co-morbidities determining poor prognosis.<sup>25,26</sup>

Second, patient-reported measures including symptom scores and quality of life are especially useful in identifying issues that need to be addressed. Of dialysis patients, 25% die suddenly,<sup>27</sup> and for them, symptom management and an emphasis on quality of life are paramount.

Third, when the physicians are both experienced and familiar with the patients, their overall clinical judgement may be most useful, particularly with regard to the surprise question. In one study, the adjusted odds ratio for dying, in the group for whom the surprise question was 'no', was 3.5 times higher than for the group where it was 'yes'.<sup>28</sup>

Despite the commonly held belief that death from uraemia is relatively symptom free, ESKD patients on the contrary experience a significant symptom burden in the 24 h preceding death. Cohen et al.<sup>9</sup> found that 40% of patients experienced pain, 30% suffered agitation and 25% were breathless. Palliative care can significantly improve the quality of dying with reductions in pain (from 53% to 20% after intervention), agitation (from 68% to 33%) and dyspnoea (from 46% to 26%).<sup>29</sup>

When there is no residual renal function, patients who withdraw from dialysis have a very short survival, with the evidence reporting a mean survival between 8 and 10 days, with a range of 1–46 days.<sup>6</sup> Being in their preferred place of care at the end of life is very important for many ESKD patients. The conservative care pathway facilitates this much better, with one UK study showing that 33% of conservative patients die in hospital compared to 73% of dialysis patients.<sup>16</sup>

## What is not yet known

There have been no prospective randomised trials, which assess the benefit of dialysis versus conservative management. The ethical challenges that this would raise are such that a randomised trial is unlikely to occur. Only a small number of observational studies are currently available to inform practice.

There is limited evidence about the duration of survival of conservatively managed patients. One study showed that median survival from entry into Stage 5 CKD was less for conservatively managed patients (21.2 months) than for those on dialysis (67.1 months,  $p < 0.001$ ), but for patients over 75 years of age with high co-morbidity and diabetes, this survival advantage was lost.<sup>15</sup> The decision to follow a dialysis or conservative management pathway is individual to each patient. Research has shown that elderly patients with significant co-morbidity and slowly deteriorating renal function are more likely to benefit from conservative

management, whereas this may not be an appropriate pathway for an individual with no co-morbidities or a rapidly deteriorating renal function. However, quality of life is a significant contributory factor to this decision-making process and this requires further study.<sup>15</sup> This is partially because there is a lack of evidence, with most studies being service based rather than population focused.

It is also uncertain from when survival should be measured. Patients with Stage 5 CKD may not require dialysis until they start to complain of bothersome uraemic symptoms. Compounding this, when survival is documented, this may reflect the demographics, co-morbidity, and local practice of a particular renal service, rather than mortality data that can be generalised.

## Implications for practice and research

There is growing awareness of the need for research into the palliative care needs, and relevant interventions to address these needs, for patients with ESKD. Greater awareness of those being managed conservatively is also occurring, and systematic study of this population is now beginning to take place. Research has been undertaken looking at patient's experience of conservative management<sup>30</sup> and its impact on families and carers.<sup>31</sup> The majority of the research until now has been UK based<sup>13,30</sup> but requires replication internationally.

A national observational study in Australia found that about 14% (one in seven) of patients with ESKD referred to nephrologists plan not to dialyse.<sup>32</sup> A change in service provision, with greater systematic inclusion of palliative and supportive care needs, is essential to address the needs of this growing group.

Cohen et al.<sup>33</sup> studied 500 dialysis patients and found five variables associated with early mortality: age, dementia, PVD, decreased albumin and a 'no' response to the surprise question. Such work highlights the need for a parallel palliative approach in these patients, even from the outset of dialysis. Research continues to refine these tools, to create a simple quick predictive bedside test to identify those with greatest need of a palliative approach.

Morton et al.,<sup>34</sup> utilising discrete choice experiments, found that patients chose extended hours (>8 h) of dialysis if it provided a survival benefit. However, they were willing to forgo significant survival time to gain freedom from the travel constraints imposed by dialysis. This suggests that patients themselves may be much focused on the quality of their remaining time, and that longer survival is not the only consideration as they weigh up preferences and priorities.

Much work is still needed to undercover the evidence around best palliative and supportive care in ESKD, but considerable strides have been made, and implementation into practice is well under way. In England, recent

publications by National Health Service (NHS) Kidney Care outline some of the advances and illuminate the best ways forward for implementation into practice.<sup>35,36</sup>

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The authors declare that there is no conflict of interest.

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