

## Epidemiology of Renal Palliative Care

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### ABSTRACT

**The need for palliative care for patients with end-stage renal disease (ESRD) is increasingly recognized. Patients starting renal replacement therapy are now elderly, with a median age of 65 years, and with multiple comorbid conditions. Quality of life is often poor and with advance care planning, patients can be enabled to make the choice of stopping or not starting dialysis. With planned end-of-life management patients can then choose their place of death. These discussions have to be initiated by the renal team. The involvement of palliative care professionals in patients with ESRD is therefore both educational and the provision of community and hospice care.**

### INTRODUCTION

**T**HE NEED FOR PALLIATIVE CARE for patients with end-stage renal disease is increasingly recognized. Hemodialysis has only been available for just over 50 years and was introduced in the United Kingdom in 1956. Initially, its use was limited to the treatment of acute renal failure; long-term hemodialysis only became available in the 1960s. Initially, patients selected for treatment of end-stage renal disease (ESRD) with long-term dialysis or transplantation were young, socially active, and without other comorbidities. As dialysis became more readily available, older patients with more comorbidities have been treated, and in most Western countries, all patients referred for treatment of ESRD are offered dialysis. Dialysis treatment is often burdensome for patients and their families and increasingly, doubts are often expressed by patients, families, and health care teams about the quality of life of individuals with multiple other health problems being treated. Increasingly, some patients elect not to start dialysis and have conservative treatment only; in addition, withdrawal of dialysis is becoming a more common cause of death on dialysis.

To answer the question of how many ESRD patients need palliative care and if so, for how long, we need to address the following questions:

- What do we understand by palliative or supportive care for the renal patient?
- Why is there a need for renal palliative care?
- How will palliative care help renal patients?
- How many renal patients need formal input from palliative care teams?

### WHAT IS RENAL PALLIATIVE CARE?

There is an increasing awareness among nephrologists that palliative care is not just end of life management but rather the pathway over time to a dignified end of life for an individual patient.<sup>1</sup> The various components that make up this fuller vision of palliative care are shown in Table 1. Realistically, this must be undertaken by the renal team with input from palliative care teams depending on local availability of services. Discussion with patients about their prognosis and future needs, i.e., advance care planning, is usually initiated by the nephrology team. Formal input from palliative care teams is often limited to end-of-life management with input from inpatient and community palliative care teams, or referral to hospice care. There is limited published information about models of how renal palliative care is delivered but a recent survey of renal units in the United Kingdom

TABLE 1. COMPONENTS OF RENAL PALLIATIVE CARE

Awareness that:
• Patients should be enabled to have a dignified end of life
• Patients with their families should be enabled to choose where they die
• Patients should be given choice about whether to start dialysis and to stop dialysis
Symptom and pain control
End of life management

showed that some have a renal palliative care nurse who can provide more formal links to palliative care teams and in some units there are joint renal and palliative care clinics which can provide improved symptom control for patients as required and not just at end of life.<sup>2</sup>

**WHY IS THERE A NEED FOR RENAL PALLIATIVE CARE?**

Chronic kidney disease is more common with increasing age and is mostly caused by vascular disease and diabetes. U.K. Renal Registry data show that the median age of patients starting renal replacement therapy in 2004 is 65.1 years; this has increased by 1.5 years since 1998.<sup>3</sup> Furthermore, the percentage of incident patients aged over 75 has risen from 18% to 23% over the same time period. As shown in Table 2, older patients are less likely to have a primary renal disease such as glomerulonephritis or polycystic kidneys and are more likely to have renal failure related to vascular disease. Not surprisingly, older patients have more comorbidities, as shown in Table 3.

Older patients have other problems including impaired vision, deafness, poor mobility, arthritis, and cognitive problems. They are often socially isolated, may well have financial problems and are often de-

pressed due to loss of independence or bereavement. These factors are all problematic for any dialysis modality.<sup>4</sup> For hemodialysis, the associated vascular disease results in a high risk of failure for vascular access. This results in increased reliance on central venous catheter access with all the associated risks of infection. Failure of vascular access can necessitate frequent hospital admissions for often unpleasant and painful radiologic and surgical procedures. Cardiac disease in these patients can also cause hypotension and arrhythmias while on hemodialysis. Peritoneal dialysis is a home-based treatment and causes less cardiovascular stress. Many elderly patients, however, cannot do this independently and would have to be dependent on caregivers.

Mortality rates for patients with ESRD are worse than most cancers with an overall median survival of less than 6 years, though this does vary with age. UK Renal Registry data<sup>3</sup> shows that 5-year survival after starting renal replacement treatment is greater than 90% for 18–34 year olds; 70% for 45–54 year olds; 30% for 65–74 year olds; and less than 20% for those older than 75 years.

These rates are much higher than the general population. Mortality rate for 45–54 year olds is approximately 18 times that for people of the same age in the general population. This is also true for the elderly: mortality rate for those older than 75 years old is approximately fourfold higher. In addition to increasing age, increasing number of comorbidities, poor nutrition, and poor functional state (as measured by Karnofsky score) have all been shown to predict poor survival.<sup>5,6</sup>

**HOW WILL PALLIATIVE CARE HELP RENAL PATIENTS?**

As discussed above, the increasing number of older patients developing ESRD with their accompanying

TABLE 2. PERCENTAGE DISTRIBUTION OF PRIMARY RENAL DIAGNOSIS BY AGE AND GENDER IN 2004<sup>a</sup>

<i>Diagnosis</i>	<i>&lt;65 yrs</i>	<i>&gt;65 yrs</i>	<i>All</i>	<i>M:F</i>
Aetiology unknown	18.5	27.6	23.0	1.6
Glomerulonephritis	13.3	7.7	10.4	2.4
Pyelonephritis	7.5	6.4	7.0	1.2
Diabetes	21.4	14.7	18.0	1.7
Renovascular disease	2.7	12.2	7.5	2.0
Hypertension	5.7	5.3	5.5	2.1
Polycystic kidney disease	8.0	2.8	5.4	1.0
Other	15.3	12.5	13.9	1.3

<sup>a</sup>From U.K. Renal Registry Report, 2005.

TABLE 3. PERCENTAGE OF NEW PATIENTS WITH COMORBIDITY STARTING RRT 1999–2004 (UK RENAL REGISTRY REPORT 2005)

	Age <65 yrs	Age ≥65 yrs
Cardiovascular disease	14.8	32.6
Angina	11.0	24.9
Myocardial infarct in past 3 months	1.8	3.1
Myocardial infarct >3 months	5.8	15.5
CABG/angioplasty	4.3	6.6
Cerebrovascular disease	6.4	14.7
Diabetes (not a cause of ESRD)	4.9	9.4
Diabetes as primary disease	22.8	16.2
Chronic obstructive pulmonary disease	4.3	10.1
Liver disease	2.5	1.7
Malignancy	6.2	15.5
Peripheral vascular disease	9.4	17.0
Claudication	6.1	13.9
Ischemic neuropathic ulcers	3.6	3.1
Angioplasty/vascular graft	2.1	4.7
Amputation	2.3	1.7
No comorbidity present	54.9	35.2

RRT, renal replacement therapy; CABG, coronary artery bypass grafting; ESRD, end-stage renal disease.

comorbidity burden has resulted in an ever increasing group of patients with a high mortality rate. Quality of life studies have shown that the mental quality of life of older people on dialysis is identical to people of the same age in the general population<sup>7</sup> but this does not tell us about individual patients. Patients with chronic kidney disease have many symptoms, even at early stages,<sup>8</sup> and patients with stage 5 chronic kidney disease, not yet on dialysis, have the same symptom burden as patients with cancer.<sup>9</sup> Once on hemodialysis, the majority of patients have multiple symptoms with a recent survey showing that less than 25% hemodialysis patients had 5 symptoms or less.<sup>10</sup>

It is not uncommon, however, for patients not to mention their many symptoms or that they are in pain when reviewed by their nephrologist. This is partly because the nephrologist often does not ask, and partly because the patient perceives (often correctly) that their nephrologist is more interested in their blood results. Symptom control is a key part of palliative care. The role of palliative care specialists is certainly not to see all symptomatic ESRD patients as this would be impossible. More important is to increase the awareness of nephrologists of the multitude of symptoms and to produce local guidelines for their management. Some patients will, however, have intractable symptoms or pain and would benefit from direct management by the palliative care team.

Enabling patients to make treatment decisions about whether to start or stop dialysis and about end of life management, as already discussed, is a key part of pal-

liative care. The formal term for this process is advance care planning. Physicians are often hesitant about having such conversations with their patients because of concerns about destroying patients' hope. Evidence is emerging, however, that at least for some patients, the opposite is true and that relying on healthcare professionals to initiate advance care planning and that focusing on immediate clinical care without attention to future goals are actually barriers to maintaining hope.<sup>11</sup>

Management of end of life on dialysis is often done badly. Guidelines for end of life management in renal patients have been developed in the United States,<sup>12</sup> but there is no such formal guidance in the United Kingdom. Physicians are trained to diagnose conditions and treat them, with death perceived as failure. End of life is usually not regarded as a diagnosis and therefore is not managed appropriately. The aim of increasing awareness of palliative care in renal disease is to improve the end of life for renal patients. Continuing dialysis at this time complicates management. Peritoneal dialysis patients are often too sick to carry out their own treatment; dependence on relatives or ward nurses if admitted increases the risk of peritonitis. This may result in catheter removal and a stressful transfer to hemodialysis. This may also be necessary if a patient is no longer able to live independently and has to be admitted to a nursing home. Hemodialysis patients also become more dependent and need transport to and from their dialysis; there are often increased problems of hypotension on dialysis with risk

of cardiac arrest. Vascular access often becomes problematic requiring frequent and often unpleasant catheter insertions. Advance care planning would enable patients and their families to make decisions about stopping dialysis rather than continue with multiple medical interventions often with much extended hospital stays.

The majority of nephrologists do not feel well prepared to make decisions on withholding dialysis.<sup>13</sup> Changing attitudes and improving the knowledge of renal health care professionals about palliative care are going to be the key to improve the supportive care given to renal patients. As physicians are often the lead in making "life and death" decisions, it is particularly important that they receive appropriate training. There are several ways that this will happen. There is already a renal palliative care curriculum for U.S. nephrology trainees<sup>14</sup>; in the United Kingdom, palliative care will be part of the renal curriculum being developed by the Postgraduate Medicine Education and Training Board (personal involvement) and as such will be assessed. There are now regular joint multiprofessional educational meetings for renal and palliative care health care professionals. The first of such meetings in the United Kingdom identified many of the barriers to good supportive care.<sup>15</sup> These included language, cultural and spiritual barriers between patients and support team, lack of education and training of medical team, lack of privacy, space and intimacy on the ward, lack of time to develop relationships, and lack of knowledge of local palliative care facilities. Developing links with local palliative care teams both in hospital and in the community will enable education, training, and development of local guidelines and pathways of care.

#### HOW MANY RENAL PATIENTS NEED FORMAL INPUT FROM PALLIATIVE CARE TEAMS?

This is, of course, an impossible question to answer as referral patterns will depend on local availability of palliative care services. Furthermore, as already discussed, involvement of palliative care will increase as more renal physicians, nurses, etc., receive more training in the need for and delivery of palliative care to their patients with planned end of life management. Not all U.K. renal units report into the registry as yet, but it is estimated that there are over 37,800 adult patients receiving renal replacement therapy in the United Kingdom at the end of 2004,<sup>3</sup> which gives a prevalence of 636 pmp. Ap-

proximately 21,000 of these are on dialysis. The incident rate for new patients starting treatment is 105 pmp or approximately 6300 pa. The mortality rate of dialysis patients in the United Kingdom is 15% overall, i.e., approximately 3000 pa. This does depend on age with a mortality rate of 8% pa for 18–34 year olds and 25% for 75–84 year olds.

It could of course be argued that all patients should have palliative care input during their last year of life, but this will need to be done mostly by renal teams and not palliative care professionals. As already discussed, dialysis is often stopped when patients are obviously close to death. These patients should have the options of dying at home with input from community palliative care services or in a hospice. There is some data in the 2004 U.K. Renal Registry report<sup>16</sup> suggesting that during the first year around 15% of deaths for 65–74 year olds and 25% for those older than 75 years old are due to stopping dialysis.

Patients choosing not to undergo dialysis and opting for medical care alone, i.e., conservative care, are also frequently referred to local palliative care services. A recent London-wide audit suggests that approximately 8% of patients receiving predialysis education opt for conservative care (personal communication). Many of these patients will die from a comorbid condition, most commonly vascular disease, rather than dying from uraemia. Local data (Table 4) suggests that approximately 20% of conservative care patients are known to local palliative care services (unpublished observations).

Survival of patients using palliative care services at the end of life is variable and depends on residual renal function and the general state of the patient. Death will occur from hours to approximately a week after stopping dialysis in an anuric patient with serious illness. Dying takes longer if there is residual renal function and the patient is hemodynamically stable, e.g., in a patient who elects to stop dialysis after a major stroke, but still has significant urine output.

Median survival in patients opting for conservative care is of the order of 6–9 months.<sup>6,17</sup>

TABLE 4. CONSERVATIVE CARE PROGRAMME AT WEST LONDON RENAL AND TRANSPLANT CENTRE

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Serves population of 3 million
Approximately 360 patients starting dialysis per year
Fifty-six current conservative care patients
Eight of these have been referred to palliative care (3 ppm)
Annual death rate approximately 26 per year (8 ppm)
Six patients died with palliative care input (2 ppm)

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## CONCLUSION

There is increasing awareness of the need for improvement in end of life management and options for patients in general. Renal teams are increasingly involved with symptom control, advance care planning, and end of life choices. Palliative care teams are increasingly involved with noncancer patients and are therefore providing the community and hospice support needed for renal patients. Palliative care is becoming part of the renal curriculum, so renal physicians should incorporate symptom control and advance care planning into their general management of patients with renal disease. As renal teams become better educated and appropriate management pathways are put in place, they will need palliative care physicians less for symptom control and end-of-life management in hospital. On the other hand, better communication with patients about overall prognosis and options for end of life management may well result in increasing numbers of patients opting for stopping dialysis and dying at home or in a hospice. This will require an increase in community palliative care services but will give renal patients and their families the hope of a dignified death in the place of their choice.

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