ASSESSING PALLIATIVE CARE NEEDS IN END-STAGE KIDNEY DISEASE

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This article outlines the various issues that need to be considered in providing palliative care for patients with stage 5 chronic kidney disease (CKD). The importance of good symptom management in end-stage disease is emphasised, as well as ensuring that patients have the opportunity to discuss their wishes regarding end-of-life care.

The most appropriate time to move patients with long-term conditions to a palliative pathway is not always obvious but, even when death is imminent, many patients with kidney disease and their families have little or no opportunity to discuss their wishes for end-of-life care (Noble and Rees, 2006). As kidney disease reaches stage 5, crucial decisions need to be made regarding patients’ future care. As the number of older people starting dialysis increases, there is a need for increased experience in managing these patients and treatment outcomes need to be identified. It has become clear that offering dialysis to some patients does not prolong their life and, in some instances, contributes to a significant deterioration in quality of life.

REACHING A CONSENSUS ON TREATMENT DECISIONS
Choosing the treatment pathway most likely to optimise individual well-being is not always obvious but we have identified certain principles that make this more likely:

Being realistic: A number of people reaching stage-five chronic kidney disease are clinically unsuitable for dialysis. This is generally due to functional decline, frailty and/or coexisting conditions such as heart failure, all of which make successful dialysis therapy very unlikely. There may be little benefit in offering some people treatment if it is likely to be futile. In these circumstances, patients and carers need to understand the reasons and feel involved in the decision-making process.

Engaging patients and relatives/carers in decision-making: Although it seems obvious that patients should be involved in treatment decisions, in our experience it has proved vital that families are aware of the possible outcomes, disease progression and prognosis is necessary. The ongoing facilitation and continuity of future management decisions need proactive coordination.

Communicating decisions to other services: In lieu of the single patient record, it is important to ensure that any services involved in patients’ care are aware of treatment decisions and the reasons for them. Care plans should be recorded in patients’ hospital records, their GP should be informed and they should be registered on the Gold Standards Framework register (Thomas and Department of Health, 2005).

MANAGEMENT
Increasingly, patients with stage 5 CKD are managed in specialist ‘conservative or supportive management’ clinics. These are typically multiprofessional and, as well as managing kidney disease, facilitate treatment options with patients and families, and support the decisions that are made. Increasingly, these services include a palliative pathway for patients in which discussions regarding future care typically occur over a period of time, and extend to home visits and involve palliative and primary care services where appropriate.

PEOPLE CHOOSING TO WITHDRAW FROM DIALYSIS
Patients who start dialysis have to endure its associated symptoms, as well as those associated with ageing and co-morbidities such as diabetes. Both the burden of the
BACKGROUND

- The UK annual incidence of stage 5 chronic kidney disease (CKD) is 100 per million of the population (Hamer, 2006). As well as being older, patients with CKD often have several co-morbidities including diabetes, congestive heart failure and malignancy.
- Although palliative care programmes have traditionally focused on supporting people with cancer, the need for similar programmes for people with life-limiting long-term conditions is well recognised.
- The National Service Framework for Renal Services includes a section on end-of-life-care, which focuses on the need to expand integrated palliative care services for people with CKD (see www.dh.gov.uk for details).

INTINTEGRATED CARE PLANNING

Where possible and appropriate, patients should be managed in the community. Various national initiatives aimed at optimising end-of-life care locally are available, including the Liverpool Care Pathway (Marie Curie Palliative Care Institute, 2008) and The Gold Standards Framework (Thomas and DH, 2005). The Liverpool Care Pathway has recently been revised and another version will be launched as the Renal Liverpro Liverpool Care Pathway, specifically aimed at those who are dying with end-stage renal disease.

Patients’ care plans should include details of the professionals who are involved in their care delivery, triggers for review and named people to contact for advice and support. Care plans are held by patients but other services, such as GPs, community palliative care teams and out-of-hours services, will need to be aware of them.

The elements of a good death for people with kidney disease are similar to those for people with other conditions who are dying and include: time to say goodbye; a brief death; maintaining dignity; choice over place of death; easy access to palliative care; and bereavement services for relatives (Germain et al, 2007).

SYMPTOM MANAGEMENT

It is increasingly recognised that poor symptom control in people with stage 5 CKD is due to focusing on the disease itself, rather than the symptoms. Symptoms may be related to co-morbidity rather than renal disease. Good symptom control needs to be proactive and include detailed and thorough assessment at regular intervals (Murtagh et al, 2006).

Pain: The pain experienced by patients with stage 5 CKD is often caused by co-morbidities as well as the renal disease itself. It can include ischaemic pain from peripheral vascular disease; neuropathic pain, often related to diabetes; and bone pain from osteoporosis. The World Health Organization’s analgesic ladder approach to managing pain should be used (Murtagh et al, 2006).

Pruritus: Uraemic pruritus is a common problem for people who have renal disease but the available evidence supporting pharmacological treatments is limited (Murtagh et al, 2006). Management may include: exclusion of other causes of pruritus, including systemic or dermatological causes; correction of biochemical imbalances, such as high calcium or parathyroid levels; and identification of xerosis (dry skin) and the use of liberal emollients. For details on possible options for pharmacological management, see nursingtimes.net. Pruritus remains difficult to treat but it can have a significant impact on patients’ quality of life. Therefore, agreeing a management plan with them and conducting a trial of different interventions to identify those who benefit may be helpful (Murtagh et al, 2006).

For advice on managing anaemia, fluid overload, nausea, vomiting and anorexia, insomnia, fatigue and lethargy, restless legs and muscle cramps, see nursingtimes.net.

Terminal phase

Detailed and skilled palliative care planning in the terminal phase of CKD is paramount. It is equally important to ensure the plan is communicated to all relevant parties and is regularly reviewed. Establishing patients’ wishes and family support before the event and over time is key to optimising patient care at this difficult time. Whether the place of care is a hospice, hospital or the patient’s home, extensive liaison between renal specialists, patients and families, and other care providers is essential if we are to help all patients have ‘a good death’.

REFERENCES


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