Supportive care for the renal patient

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This review summarizes the major topics discussed at a recent meeting ‘Supportive Care for the Renal Patient’ held in London, and the first such meeting to bring together nephrologists, renal nurses, renal counsellors, psychologists, social workers, and palliative care psychologists, social workers, and palliative care

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An increasingly elderly population with renal failure

The management of patients with end-stage renal disease (ESRD) is changing. The average age of patients starting dialysis is increasing, and an increasing proportion of patients are now over 75 years of age. In the UK Renal Registry, almost 20% of patients starting dialysis were between 75 and 84 years old in 2001 [1]. These demographic trends have led more patients and doctors to ask whether everyone benefits from dialysis, whether resources are required to support other interventions and what additional support patients might reasonably need to maintain a high quality life in the face of renal failure. This is clearly a huge change in the nature of nephrology from the 1950s, when dialysis emerged as a life-saving therapy for renal failure.

Not unexpectedly, older patients have poorer survival on dialysis. In the North Thames Dialysis in the Elderly study, 50% of patients over the age of 80 years had died in 12 months, compared with 20% of those between 70 and 74 years old [2]. Older patients with renal disease have increasing prevalence of co-morbidities; for example, the prevalence of ischaemic heart disease doubles between the age of 45 and 80, body mass index falls by 20% and serum albumin falls. Measures of quality of life based on physical functioning in this population are significantly worse than for an age-matched population without ESRD, but, importantly, measures of mental quality of life are unchanged as patients cope with physical decline. Thus the balance emerging is to provide life-sustaining therapy (dialysis) to all who might benefit, but ensuring that quality of life is a fundamental outcome measure, not simply weeks or months of life gained.

Managing end of life on dialysis

Although dialysis is life sustaining, patients will still die. Unfortunately, doctors are not good at recognizing the process of dying (as opposed to its end result), and therefore fail to appreciate what should be done for a given patient, rather than what can be done (Table 1). Specifically, patients dying on peritoneal dialysis may be too sick to carry out exchanges, may no longer be able to live independently, may become malnourished and have an increased risk of peritonitis. Patients on haemodialysis often have enormous problems with vascular access, requiring frequent and unpleasant temporary lines, become more dependent for daily care, and require transport to and from dialysis. They have increasing problems with hypotension on dialysis, may have increasing confusion and be less able to cope with the dialysis itself. It is in these circumstances that nephrologists need to learn from palliative care physicians, and should change the direction of their interventions from curative or life prolonging to life maintaining and supportive. A multidisciplinary team approach is vital to support patients at this time, involving nephrologists, palliative care doctors and nurses, counsellors, community nurses, the family and hospices.

Supportive care

Supportive care was defined in 1990 by the WHO as ‘the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative or supportive care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with conventional care for the renal patient’ (modified from the WHO definition, 1990) and should be embedded in the care of all patients.

There are a whole variety of symptoms which might be present in patients with ESRD and which are generally not well managed, including pruritus, nausea, constipation, fatigue, neuropathy, cramps, pain, anxiety, depression and psychological concerns over dependence, sexuality, role change and finances. It should be obvious therefore that supportive care is not solely of use at the end of life, but should be an adjunct to the management of patients at all stages of their illness. Supportive care should be available to patients at the time of diagnosis, for pre-terminal symptom control, for symptom relief and psychological support in limb ischaemia (for example) as well as at the end of life. It does not simply mean conservative care in place of dialysis and does not mean no treatment. For example, the use of erythropoietin or darbepoeitin has a major role in the supportive care of patients, and can be especially useful in those not wanting dialysis for control of symptoms of lethargy and fatigue.

Management of pain

Pain control is another example of crucial supportive care, but in this case one generally badly achieved by
nephrologists. Pain is common in patients on dialysis (occurring in up to 50% of patients), occurs from many causes, and can be severe. Pain occurs from concurrent co-morbidity, which may or may not be related to the renal disease (e.g. diabetic neuropathy and arthritis), from primary renal disease (e.g. polycystic kidneys), from complications of renal failure (e.g. renal osteodystrophy and calciphylaxis) and can be directly dialysis related (e.g. abdominal pain in peritoneal dialysis, pain from fistula, cramps and headaches on dialysis). Pain, not uncommonly, has been reported to be so severe as to make patients consider stopping dialysis. Management of pain is similar to that for patients with normal renal function. It requires good assessment of the type of pain and likely causes, explanation to the patient of the plan, setting realistic goals, ongoing monitoring, discussion of psychosocial issues and treatment of depression, and institution of analgesia using the WHO analgesic ladder as a guide. Pain can be difficult to treat in renal patients; physicians are wary about drug dosing and drug accumulation, patients are taking multiple other medications and have co-morbid conditions, and pain management is not well taught to nephrologists. The first step drug remains paracetamol, which is safe in renal failure. Adjutants include neuropathic agents (which often need dose modification), and non-steroidal anti-inflammatory agents, which can pose a problem in ESRD. Step 2 agents include codeine (significantly increased half-life in renal failure, but can be used with care) and tramadol (safe and effective, but needs 50% dose reduction). For more severe pain (step 3), chronic use of all opioids needs close monitoring. Anecdotal evidence suggests hydro-morphone orally and fentanyl and alfentanil parentally (subcutaneously) may be associated with less toxicity. Morphine, oxycodone and buprenorphine should be used with extreme care, and chronic pethidine use avoided. Transdermal fentanyl is particularly useful when pain is stable and the patient can tolerate a dose of strong opioid equivalent to 60–120 mg of oral morphine/24 h. The most common reasons for stopping opioids are adverse effects, especially respiratory depression, hallucinations and confusional states, constipation, nausea and vomiting. At the end of life especially, there is no reason for withholding analgesics delivered by syringe-driver, if needed, and regularly reviewing the patients and their needs.

Non-dialytic treatment of ESRD

Over the last few years, increasing data has emerged of the importance of co-morbidities in determining likely outcomes in ESRD, both morbidity and mortality. Data from the Lister hospital (Stevenage, UK) has shown that performance score is a strong predictor of outcome in patients with ESRD, those with poor functional abilities at start of dialysis having extremely poor survival [3]. Patients with ESRD, poor functional status and extensive co-morbidities do not in general live longer when dialysed than when managed conservatively, but are more likely to have repeated admissions (for sepsis, access difficulties, etc.) and to die in hospital [4]. Patients therefore require careful counselling about the most appropriate treatment option, on an individual basis. Such discussion should involve senior nurses, renal counsellors and social workers as appropriate, and should lead to the formulation of an individual treatment plan. It is important to assess the patient’s understanding of their illness, their functional capacity and dependency, and their family and social support, and to provide education about the illness, its prognosis and treatment options, and counselling as appropriate. The option of not having dialysis must be an explicit part of this discussion, and should be supported by a plan to offer ongoing support to the individual and family, including community agencies such as hospices, social services, community nurses, family doctors and outpatient clinics. This is not rationing dialysis, but rational dialysis, i.e. limiting the use of dialysis therapy in circumstances that render them futile or even detrimental. Conservative management should aim to improve quality of life and treat uraemic symptoms, while fully supporting the patient and answering all their questions.

Barriers and solutions to good supportive care

During discussions, a number of barriers to good supportive care were highlighted (Table 2) but, more importantly, a host of solutions already in use in different centres were explored (Table 3), although demonstrating unequivocal benefit of these strategies will be difficult [5]. The main benefit of the meeting was clearly, however, the presence of nephrologists, nurses, palliative care physicians, renal counsellors and psychologists in the same room, enabling the development of interdisciplinary communication, an interface which has perhaps been lacking in most renal units.

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<thead>
<tr>
<th>Table 2. Barriers to good supportive care</th>
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<td>Personal</td>
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<tr>
<td>Lack of common language between professiona l, and inter-professional liaison</td>
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<td>Language, cultural and spiritual barriers between patients and support team</td>
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<td>Lack of education and training of paramedical team</td>
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<td>Fear of ‘getting it wrong’</td>
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<td>Poor interface with primary care</td>
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<td>Cognitive impairment in patients</td>
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<td>Environmental</td>
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<td>Lack of privacy, space and intimacy (on ward, for example; both physical and from interruptions, etc.)</td>
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<td>Lack of time (to develop relationship, communication, follow-up, ongoing support)</td>
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<td>Work load for staff (numbers of patients)</td>
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<td>Lack of long-term relationship with patient when hospitalized as an in-patient</td>
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Infective endocarditis: a frequent disease in dialysis patients

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The epidemiological profile of infective endocarditis (IE) has changed dramatically over the last few years [1]. Once a disease affecting young adults with previously well identified valve disease (mostly rheumatic disease), IE is now affecting older patients, a significant proportion of whom have no previously known valve disease and develop IE as the result of health-care associated procedures [2]. Actually, if IE was commonly classified in four categories, namely native valve IE, prosthetic valve IE, IE in i.v. drug users (IVDUs), and nosocomial IE, health-care associated IE should probably be added as a fifth category in the near future because of its increasing incidence. Within this new category, IE in chronic haemodialysis (HD) patients appears to be the most important subgroup [3,4].

Incidence and risk factors

The most convincing demonstration that HD patients are increasingly developing IE was provided recently by Cabell et al. [4] who performed trend analyses in the IE database of the Duke University Medical Center in the 1993–1999 period. Not only did they show that the overall proportion of HD patients in their sample of 329 IE patients was as high as 20%, but also that the proportion of HD patients increased from 6.7 to >20% over the 7 year study period. This was associated with a significant increase of Staphylococcus aureus IE from 10 to 68% (P-value for trend <0.001). Finally,