Conservative care of the patient with end-stage renal disease

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ABSTRACT

'Conservative care' is the management of end-stage kidney disease without dialysis, ie a palliative approach. It is now well established as the fourth treatment option alongside haemodialysis, peritoneal dialysis and transplantation, in the majority of UK renal centres.

History

In the 1970s and 80s the lack of dialysis provision in the UK was a national scandal. Under 25% of patients referred for dialysis were accepted onto a programme (less than half the rate of comparable European countries), and this was strongly correlated with the distance the patient lived from the nearest renal unit (a true postcode lottery).[1–4] To combat this shortage, there was an expansion in the number of renal units in the UK towards the end of the 1980s, and the development of the 'hub and spoke' satellite dialysis units that are common today.[5–8] Over the past 30 years, a large proportion of the increase in dialysis incidence has been due to the broadening of dialysis criteria. We have also seen an increase in survival time on dialysis. Both of these factors have led to an increase in the age of the prevalent dialysis population, and the majority of new starters on haemodialysis are now aged 65 and older.

There has, in addition, been a significant increase in the number of frail older patients diagnosed with chronic kidney disease (CKD) stages IV–V (defined in the K/DOQI CKD classification system as 'GFR <30 mL/min/1.73 m^2 on two occasions at least 90 days apart'[9]) over the past 30 years.[10] Indeed, the burden of CKD disproportionately affects older patients. These elderly patients frequently have high levels of comorbidity, and as a consequence it has become clear that dialysis is not the best option for everyone.

Traditionally, renal replacement therapy has always been seen as the logical end point for CKD (indeed end stage renal disease (ESRD) is defined as 'the point at which an individual requires treatment by dialysis or transplantation'[9]), and since the late 1990s the Low Clearance Clinic model[11–16] has been used to provide pre-dialysis patients with information about the renal replacement therapy options available to them.

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Conservative (non-dialytic) management was not seen as part of the nephrologist's remit, and patients who were not suitable for (or not willing to have) dialysis were discharged back to the community (or indeed never referred in the first place).[17–19] This meant that these patients missed out on specialist symptom management (such as anaemia management, correction of acidosis and specialist dietary advice).

The concept of 'maximal conservative management' was introduced in some renal units around 15 years ago[17,20] and is now an established treatment choice in the majority of centres in the UK. It provides symptom control, non-dialytic correction of electrolyte and fluid imbalances, anaemia management and end-of-life care. The emphasis is on maintaining quality of life for the patient and their families (described as 'rational care, not rationing care'[21]). Approximately 10–15% of older patients choose this pathway.[22–24]

Survival on conservative management programmes compared with dialysis

Survival in older renal patients is known to be poor. UK Renal Registry data show that new starters on haemodialysis who are aged over 75 have a 30% mortality rate within the first year, and more than half will be dead within two years.[25]Five-year survival is less than 20%, worse than many cancers.[26]

It could be argued that the excess mortality in older incident dialysis patients is in part due to older patients with multi-organ failure being started on dialysis inappropriately, for example because they are too frail to be accepted by the intensive care unit. However, when patients who died within 90 days of starting dialysis are excluded, the one-year survival rate for patients aged 65–74 only improves by 5%, and the survival rate for patients aged 85 and older does not improve at all.[25]

The UK Renal Registry does not currently collect data on patients who choose conservative management or who have stable CKD stage V. However, a number of smaller studies have compared outcomes for these patients.[6,21,27–34] Taken as a whole, patients who choose to dialyse do, generally, live longer that those who choose conservative management, although it does vary quite significantly from study to study, depending in part on definition of conservative management used. However, they also spend much more time in hospital (including dialysis attendances)[28] and frequently report that they are so exhausted after a dialysis session that they cannot even manage to prepare a meal.[35,36]

When we consider those patients with high levels of comorbidity however, the picture is somewhat bleaker. As Murtagh *et al* showed, the survival benefit of dialysis for patients aged >75 years disappears in those patients with high comorbidity (defined as Davies comorbidity score >2).[33] Hussain *et al's* much larger study,[37] with 172 conservatively managed patients and 269 patients managed with dialysis followed from an estimated glomerular filtration rate (eGFR) <20 mL/min (ie eliminating lead-time bias), confirmed these findings.

Quality of life/symptoms

Renal patients often report high symptom burden, whether they are CKD patients,[38] dialysis patients[39] or transplant patients.[40] Indeed, Murtagh *et al* noted that 'patients with stage V CKD have considerable symptom control needs, similar to advanced cancer populations'.[38]

Kurella Tamura *et al*[41] found that physical function declined rapidly in the three months before initiation of haemodialysis, which might be expected due to increasing uraemia. However, contrary to expectation, physical function did not appear to recover following initiation of dialysis, and patients remained significantly functionally impaired. Jassal *et al*[42] found that 30% of new starters on dialysis became more functionally dependent within the first six months of being on haemodialysis, including those patients who had previously lived independently. Although functional status did not worsen after the first six months, it did not improve either.

In contrast, Murtagh *et al*[43] found that patients managed conservatively maintained functional status until the last month of life. There is the possibility of lead-time bias here – patients were included in the study when eGFR was <15 mL/min (ie long before dialysis would usually be initiated) and eGFR at point of death was not recorded, so it is quite possible that 'last month of life' is equivalent to (or even earlier than) 'time at which patient would have started dialysis if they had not been managed conservatively'.

Unsurprisingly, given the high levels of functional dependency, depression and symptom burden, as well as quality of life, have been found to be generally poor,[44–50] particularly for those patients on dialysis. Da Silva Gane *et al*[21] found that quality of life worsens after dialysis start, particularly in haemodialysis patients. By contrast, patients managed conservatively maintained their quality of life. Brown *et al*[51] also found this to be the case. It is notable that disease intrusiveness is particularly associated with lower quality of life[52–54] – haemodialysis, requiring thrice-weekly attendance at the dialysis unit for the rest of one's life, is a particularly intrusive treatment.

Choosing conservative management

Many teams find it difficult to be explicit with patients about the poor prognosis associated with dialysis, and there is variability in the information provided by units – Tonkin-Crine *et al*[55] found that 'patients from units with a more established conservative management pathway were more aware of conservative management, less often believed that dialysis would guarantee longevity, and more often had discussed the future with staff'. In a systematic review of factors that affect patients' or healthcare professionals' decisions to commence dialysis, Hussain *et al*[56] found that many patients based their choice of dialysis modality on 'gut instinct', while many healthcare professionals were led by an instinct to prolong life. It was often only after prolonged periods on dialysis that the realities of life on dialysis were fully appreciated by patients.

The typical conservative management service

Unfortunately, there is no 'typical'! There is not even a universally accepted term – maximum conservative management, conservative management, conservative kidney care and palliative kidney care are all terms in current use in the UK,[22] and although a recent international consensus meeting recommended the use of the term 'supportive kidney care'[57] this has not yet been widely adopted.

A recent National Institute for Health Research survey of adult renal units in the UK showed a large variation in practice.[22] Unlike dialysis, there is no clearly agreed-upon point at which a patient begins conservative care – is it when they decide against dialysis, when they fall below a pre-set estimated GFR, or the estimated point at which they would have started dialysis had they chosen to do so? All of these definitions have been used in the literature, resulting in inconsistent research findings due to lead-time bias, and making comparison between studies difficult.

In general, most teams include a nephrologist, specialist nurses, renal dietetic input, and social work or psychological support. There are usually strong links with the local palliative care service, and many units have joint renal/palliative care clinics. In some centres the team may make home visits to house-bound patients, while in other units there may be a shared care agreement with local primary care services.

Key points

- The renal population in the UK is increasingly elderly and frail.
- Older, multi-morbid renal patients have extremely poor life expectancy on dialysis, and survival and symptom burden appear to be similar whether these patients are dialysed or not.
- Conservative management is now a widely accepted 'fourth treatment option' for end-stage kidney disease patients.
- Haemodialysis is an extremely burdensome intervention, particularly for frail older patients, and satisfaction with life deteriorates after dialysis initiation. By contrast, conservatively managed patients maintain their quality of life.
- In order to improve our advice to patients, standardised definitions of conservative management need to be established to enable wider comparison of different studies and the elimination of possible lead-time bias.

KEYWORDS: Haemodialysis, conservative management, end-stage kidney disease, quality of life ■

Aims of the conservative care service

The main aims of the conservative management service (as outlined in the National Service Framework for Renal Services[58]) are to slow the rate of progression to end-stage kidney disease (ESKD) and to treat any symptoms which may arise (as in the general low clearance clinic, outlined in part 1, standard 2[58]), and to plan end-of-life care (outlined in part 2, quality requirement 4[58]).

Slowing rate of progression to ESKD

To a certain extent this will depend on the cause of the CKD; however, in general terms control of blood pressure (but not too tightly, as hypoperfusion will also impair kidney function particularly in older patients with vascular calcification), maintenance of good diabetic control and avoidance of nephrotoxic medications are all important.

Symptoms

Commonly occurring symptoms include renal anaemia (which is managed to targets with iv iron and erythropoietin analogues), fluid overload (managed with diuretics, fluid restriction and low-salt dietary advice, as well as establishing and maintaining an optimal weight for the individual patient), hyperkalaemia and metabolic acidosis (managed with low-potassium dietary advice, medication adjustment and sodium bicarbonate tablets), and other symptoms such as itch (which may be due to high serum phosphate levels or due to uraemia), loss of appetite, nausea, fatigue and poor mobility. Multidisciplinary team involvement is vital for these patients – as well as regular dietetic input, they may also need physiotherapy, occupational therapy and social work input as they become less able to care for themselves at home. These patients may also have symptoms unrelated to their kidney function (due to other comorbidities), and good communication between the renal team, close persons, family members and primary care is also key.

Future planning

As previously stated, many renal centres have joint renal/palliative care clinics in which resuscitation and advance care planning discussions and decisions regarding preferred places of care can be made. Again, communication between secondary and primary care is important to ensure continuity of care. Community palliative care teams are frequently involved in the care of these patients.

Conclusion

Conservative management is a widely accepted 'fourth treatment option' for renal patients, alongside transplantation, haemodialysis and peritoneal dialysis. In older, frailer multimorbid patients, life expectancy is likely to be similar on conservative management programmes to life expectancy on dialysis, especially when days spent as inpatients or on dialysis are excluded.

Conservatively managed patients are likely to report better quality of life than dialysis patients, probably due to lower disease intrusion. Symptom levels are likely to be similar in both groups. Many patients are extremely keen to maintain their quality of life even at the expense of quantity of life, and for these patients conservative management is likely to be a better option. However, in order to deliver a good service, full multidisciplinary team support and good communication between primary and secondary care is essential.

Looking to the future, standardised definitions of conservative management must be developed in order to improve and standardise research in this area. Larger studies are also needed – many of the landmark papers involved fewer than 100 participants. ■

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