

Conservative care for end-stage kidney disease: joint medical conference with the Renal Association, British Geriatrics Society and Association for Palliative Medicine

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ABSTRACT – Conservative care is one of the fastest-changing areas of renal medicine. Non-dialytic therapy is now established as a treatment option in most renal units in the UK. This conference reviewed the history of conservative management and examined the state of current practice. The challenges now faced include expanding the evidence base in this area, improving the information given to patients and their families to help them make a decision about treatment, and responding to changes in NHS funding to ensure continued provision of high-quality care.

KEY WORDS: Chronic kidney disease, conservative management, end-stage kidney disease, palliative care

Introduction

Dr Aine Burns of the Royal Free London NHS Foundation Trust opened the conference, explaining that dialysis for end-stage kidney disease has become available to a much wider range of patients over the past 30–40 years. However, it has become clear that it is not the best option for everyone and, in some patients, it does not prolong life or even improve quality of life. Conservative (non-dialytic) management is now an established treatment option in most renal units in the UK. This conference brought together clinicians from nephrology, elderly care and palliative medicine to share knowledge and discuss current practice in this area.

Historical perspectives on conservative care

The first lecture, by Prof Ken Farrington of East and North Herts NHS Trust, told the story of renal replacement therapy in the UK from its beginnings in the late 1940s. As the premature death of Jean Harlow in 1937 demonstrated, prior to this – no matter how rich or famous, young or attractive you were – end-stage renal failure was a death sentence.

The first dialysis machines, such as the Kolff-Brigham kidney used during the Korean War, were for short-term dialysis only and were used as a stop gap until recovery of native renal function in patients with acute kidney injury.

Even then, they were primitive and certainly not widely available. By the 1960s, with the development of shunts and arteriovenous fistulas, the idea of chronic dialysis therapy had gained ground, leading to the selection of the famous ‘lucky 13’ – 13 patients hand-picked by the Royal Free Hospital to receive regular chronic dialysis. The criteria for acceptance onto a chronic dialysis programme were certainly more stringent in those days – patients had to be aged between 20 and 45 years, emotionally stable, either working or in education, with no other comorbidities (including high blood pressure, which is almost universal in patients with end-stage renal failure) and preferably with residual renal function. By these standards, practically none of our current dialysis population would be accepted!

As time went on, chronic dialysis became more widely established internationally, but dialysis in the UK was still confined to a few tertiary centres. By the 1980s the lack of provision in this country had become a national scandal. Less than 25% of patients referred for dialysis in the UK were accepted onto a programme (less than half the rate of Sweden), and this was strongly correlated with the distance the patient lived from the nearest renal unit (a true postcode lottery). To combat this shortage there was a concerted expansion of 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.

Over the past decade, it has been widely felt among nephrologists that the pendulum has swung too far the other way. Survival in elderly patients with multiple comorbidities is little better in patients who undergo dialysis than in those who choose not to do so.^{1,2} Quality of life on dialysis for many of these patients is poor – comparable to that of patients with cancer.³

Conservative management is now an established treatment choice in most renal units. It provides control of symptoms, non-dialytic correction of electrolyte and fluid imbalances, management of anaemia and end-of-life care. The emphasis is on maintaining quality of life for the patient, their families and other people close to them. For patients in high-risk groups, survival on conservative management may be no worse than on dialysis.^{1,2,4} Some patients who would perhaps see an increase in survival on dialysis prefer to sacrifice longevity for a better quality of life.⁵ For most patients this remains a very personal decision.

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Decision-making – evidence and practice

Dr Robert Elias of King's College Hospital NHS Foundation Trust explained that decision making is currently a hot topic within the health policy world, with books such as *Nudge: improving decisions about health, wealth and happiness*⁶ (in which two economists discuss ways of persuading consumers to make the 'right' choices) finding their way to the top of the Department of Health's reading list. Equally, there is pressure for doctors to become less paternalistic and to involve patients more in their own care, with laudable campaigns such as 'No decision about me, without me'.

In reality, however, much medical work happens away from the patient – both in multidisciplinary team meetings and when blood and radiology results are reviewed after clinics. There is also a deep reluctance among medics to prognosticate, with the result that patients are asked to be involved in decisions with no understanding of the realistic outcomes of the treatment to which they are agreeing. Decisions regarding renal replacement therapy are also deeply personal and there simply may not be enough time to explore fully all of a patient's concerns in an average 15-minute clinic visit.

In contrast, Ms Sheila Johnston of the Royal Free London NHS Foundation Trust discussed the opportunities of shared decision making and demonstrated some of the practical decision aids and option grids that are available to patients at www.nhs.uk. She emphasised the important role of palliative care teams in delivering the goal of shared decision making and, indeed, renal/palliative care joint clinics are increasingly common. Given the frailty and multiple comorbidities of the majority of conservatively managed patients, there is also a need for buy-in and involvement of primary care. During the subsequent discussion, several audience members pointed out the value of the long-term relationship between patients and their general practitioners (GPs).

A population-based perspective on conservative care

Dr Damian Fogarty gave the UK Renal Registry's perspective on conservative care using data from the UK Renal Registry Report,⁷ which highlighted that the burden of chronic kidney disease (CKD) disproportionately affects elderly patients. Despite this, most elderly patients die with CKD, not from it. The UK Renal Registry currently focuses on those patients receiving renal replacement therapies rather than those who choose not to initiate it, are not offered it or are dissuaded from it. One problem is the lack of clear definitions in conservative management, which is vital in order to compare outcomes in any meaningful way. There are also problems with accurate coding, even in the population who commence renal replacement therapy. Many deaths within 90 days of starting dialysis actually result from withdrawal from dialysis, which may be patient or physician-led. Similarly, there seems to be wide variation in practice between renal units, although it is unclear whether this variation is due to true differences in practice or differences in coding. Dr Fogarty

recognised the need for the UK Renal Registry to capture relevant data before initiation of renal replacement therapy, perhaps when patients enter CKD stage 5 (estimated glomerular filtration rate [eGFR] <20 ml/min). However, he acknowledged the logistical and financial challenges in fulfilling this aspiration and the value of enriching such information with data about patient and doctor motivation behind the CKD pathway and choice of modality (in some cases the decision is purely down to patient choice, and in others the option is not available).

Dr Fliss Murtagh of Cicely Saunders Institute, King's College London, then described the international picture. She agreed that the main challenge remains clearly defining conservative management, and therefore the study population, in order to carry out meaningful research into patient outcomes. She also highlighted the lack of longitudinal data in this area and welcomed the growing number of qualitative studies that have been carried out. As nephrologists, we are not used to interpreting and using qualitative data; however, this approach has yielded very interesting results over the past few years and is an area of focus given our small patient numbers and heterogeneous population.

In the discussion that followed, many participants highlighted the issue of funding for good conservative management programmes. It was argued that funding needs to follow the patient – at present, especially in the US, there are perverse financial incentives both for the patient (eligibility for Medicaid) and the physician (higher tariffs) for starting haemodialysis.

When is conservative care the right treatment option?

Dr Werner Kleophas of the Dialysis Center Karlstrasse in Düsseldorf, Germany, suggested that data demonstrates good outcomes on haemodialysis if patients are adequately prepared through predialysis counselling, prompt vascular access, avoidance of malnutrition, control of renal bone disease and intervention for social factors. He discussed tools that can be used to predict which patients will do well on haemodialysis and which will not – based on the Renal Epidemiology and Information Network (REIN) registry data⁸ – and use of the surprise question ('Would you be surprised if this patient died in the next six months?').⁹

Lessons from the NHS Kidney Care projects

Dr Katie Vinen of King's College Hospital NHS Trust and Bev Matthews of NHS Kidney Care discussed the outcomes of several key NHS Kidney Care projects. Patients and their families need honest information so they can make good choices and giving good information well can increase hope – not destroy it. A study by Sara Davison¹⁰ found that, contrary to physician belief, patients do want to talk about end of life and prognosis. However, there is a disjunct between patient perception of survival on dialysis and actual survival. We need to be honest about what dialysis can achieve for very frail elderly patients. Patients on haemodialysis spend about 47% of their

days attending hospital, whereas the figure is closer to 4% for conservatively managed patients.⁴ Recovery time after each dialysis session is, on average, about 8 hours – and for some it is much longer.

For those who do initially thrive on dialysis, it is important to recognise that they may subsequently decline later in life (which depends very much on their comorbidities). It is important that patients on haemodialysis have access to advanced care planning in the same way as patients managed conservatively. Assessment of the deteriorating dialysis patient is important – such as by routine use of the surprise question and other tools such as the Memorial Symptom Assessment Scale and EuroQOL, which are validated for use in renal populations. There may be a huge unidentified and unmet need among patients who opt for renal replacement therapy.

The important role of renal palliative clinical nurse specialists, who have been shown to save resources and avoid hospital admissions, was reviewed. There was animated discussion about establishing what patients themselves want at the end of life – such as their chosen place of death and other preferred priorities of care – and ensuring those wishes are respected. Early involvement of palliative care in patients with cancer has been shown to improve quality of life, extend survival and reduce costs.

Panel discussion

A panel discussion chaired by Prof Donal O'Donoghue from the Department of Health, involving Bev Matthews, Dr Aine Burns and Dr Werner Kleophas and based on questions from the audience then ensued. Several speakers touched on the appropriateness of attempting vascular access in elderly people, with clear tension between the unnecessary morbidity caused by creating fistulas in patients who may never start dialysis and the poorer outcomes when starting haemodialysis via a line. Some speakers were concerned that financial penalties for renal units mean that patients are encouraged to have fistulas created when this may not be in their best interests.

The costs of haemodialysis vs conservative management were also discussed. In-centre haemodialysis costs more than £30,000 per annum. Conservative management in the community, when well executed, is not a cheap option. However, by preventing unnecessary admissions, particularly during the last year of life, it is likely to result in more appropriate use of scarce healthcare resources.

The problem of declining cognitive function in these patients was also discussed. Multiple factors such as uraemia, vascular disease and depression lead to difficulties in processing complex information as executive function declines in elderly patients with CKD. The audience discussed practices in their own units in terms of dementia screening and referral to the memory clinic and elderly care services. It may be necessary to tap into the expertise of elderly care, primary care and palliative care teams to facilitate true 'shared' decision making instead of just leaving the decision to the bewildered patient.

What is the future of conservative care?

Prof O'Donoghue reiterated that our renal population is aging and growing increasingly frail. The NHS is also increasingly incentivising patient-centred care, which has manifested in the drive for shared decision making and has had an impact on provision and commissioning of renal services. Physicians should strive to meet quality standards for end-of-life care regardless. However, the evidence base is still inadequate in elderly patients with renal disease. Moving forward, however, Prof O'Donoghue felt that it would be increasingly important to forge alliances with other teams, such as community heart failure services, who face similar challenges and with whom there is significant overlap of both clinical aims of treatment and actual patients.

Prof O'Donoghue warned that funding is likely to be based increasingly on demonstrated value of services. It is vital that this value should be defined by patients and carers. However, we do not currently adequately capture data on which outcome measures matter most to patients and their families, which is likely to become an increasingly pressing problem. This change of focus will be driven by commissioning and must be matched in our units.

Closing remarks

Dr Fliss Murtagh, one of the conference organisers, concluded with the observation that the research and clinical picture has changed beyond recognition in the past 10 years. Despite the lack of larger studies, a huge quantity of small-scale and qualitative research has changed the perception of elderly patients' experience of end-stage kidney disease and legitimised conservative management as the fourth option for end-stage renal failure along with haemodialysis, peritoneal dialysis and transplantation. However, we must not become complacent. We must build on this research, with more large-scale epidemiological studies. We must collaborate with our colleagues in primary care, palliative care and geriatric medicine. And we must ensure that our services remain responsive to the needs and wishes of our patients and their families.

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