Facing an epidemic of chronic kidney disease

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Following hard on the heels of the epidemics of obesity, diabetes and vascular disease comes yet another: chronic kidney disease (CKD). It is well established that renal impairment is under-recognised, and that late referral to nephrologists is expensive and associated with worse patient outcomes. The rising number of UK patients receiving renal replacement therapy (RRT) (ie dialysis and transplant recipients), from 7,119 in 1982 to 37,439 in 2003, are consuming an ever-larger share of limited NHS budgets. However, an appreciation of just how prevalent CKD is, and how significant its impact on morbidity and mortality, is relatively new. This timely conference focused on how we can improve not only the provision of treatment for RRT, but also the early identification and subsequent management of patients with CKD, with the goal of implementing evidence-based preventative therapies.

Epidemiology of CKD and the National Service Framework for Renal Services

The National Service Framework (NSF)¹ for Renal Services was a welcome initiative from the Department of Health in England, despite the poorly defined targets, and lack of associated funding. Part 1 dealt with dialysis and transplantation, which affects a small but expensive group of patients. Part 2 concentrated more on prevention. A key recommendation is that all biochemistry laboratories should report an estimated glomerular filtration rate (eGFR) whenever serum creatinine is measured. The inverse relationship of serum creatinine with GFR leads to misinterpretation of 'mild' elevations, and the correlation with muscle mass leads to a systematic underestimation of renal impairment in women and the elderly (Fig 1). The well-validated MDRD (Modification of Diet in Renal Disease) formula allows the estimation of GFR from serum creatinine, age and gender, with a correction factor for race.^{3,4} A widely adopted classification of CKD is based on GFR (Table 1). Population studies have shown a prevalence of 4–5% of stage 3 CKD in both the USA and the UK.^{6,7} There is an increasing prevalence with age, and an association with other co-morbidities such as diabetes and vascular disease. One study showed that although only 1.3% of stage 3 CKD patients progressed to dialysis, 24.3% died from cardiovascular disease over 5 years,⁸ emphasising the

need to address the dramatically increased cardiovascular risk associated with CKD, as well as slowing progression of the disease itself.

Patient-centred services in CKD

Doctors may know how to improve the management of diseases, but to improve patients' lives the patients themselves need to be involved. Communication is a key concern to patients. They expect consistent messages from the whole nephrology team, and effective interaction with other parts of the health and social services. This has to be based on an open partnership with the patient, which will require considerable improvement in information sharing. Partnership, of course, gives responsibilities and rights to both groups. Choice is a major concern to patients, but for dialysis patients this does not mean being given the option to travel 100 miles to a different provider: it means the choice of a dialysis unit close to home; choice of dialysis modality not constrained by resources; choice of treatment times to allow work and holidays during a life-long therapy. Holistic care requires recognition of the emotional and financial impact of CKD, but unfortunately inadequate social work and psychology provision prevail. Patients with chronic disease do not want to see the nephrologist on Monday, the cardiologist in a different hospital on Wednesday, and the diabetologist in a third hospital on Thursday. They want integrated, planned care with shared information: in other words, chronic disease management.

Improving communication and education for patients with kidney disease

Most patients want information about their condition, and informed patients make more effective partners in care. The British Renal Society and the National Kidney Research Fund are developing web- and DVD-based educational resources for patients with the content determined by a UK-wide patient survey. The NHS Plan in 2000 made it mandatory to copy letters to patients but this has been mostly ignored. An impressive project in Birmingham has taken the next logical step, writing letters to renal patients, and copying them to general practitioners. Another innovative project, Renal PatientView, allows patients to see their own blood results,

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This joint
conference with
the Renal
Association was
held at the Royal
College of
Physicians on
14 June 2005

Clin Med
2005;5:521–5

Fig 1. The relationship between serum creatinine and glomerular filtration rate. Note that 28% of men, and 81% of women with stage 3 CKD had a serum creatinine <120 µmol/l. Few men and hardly any women had serum creatinine >150 µmol/l, which many would incorrectly interpret as 'mild' renal impairment. GFR = glomerular filtration rate. (Reproduced with permission of Dr RJ Middleton and colleagues from data presented at the Renal Association, September 2004.)²

medications and letters live on the web.⁹ These are dramatic developments in NHS culture, with patients changing from being passive recipients of care to active and informed participants. Some professionals may find this challenging, but ask yourself, what would you expect of your lawyer or builder?

Setting and monitoring standards for patients with CKD

The Renal Association first produced its respected standards document in 1995, and is now developing its fourth edition in several modules which will be updated on a rolling basis.¹⁰ The Renal Registry collects an extensive range of data on dialysis and transplant patients quarterly from most renal units in England and Wales,¹¹ and has produced annual reports since 1998. Simply setting standards and reporting how units perform has already improved quality of care, for example in raising the proportion of patients achieving the recommended target haemoglobin of ≥10g/dl (Fig 2). One remaining challenge is how to formally close the audit loop by systematically identi-

fying genuine good and bad outliers so that best practice can be identified and disseminated. Another is the expansion of the Registry's activity to acute renal failure and CKD.

Commissioning – the key to improving local renal services?

Renal services are commissioned on behalf of groups of primary care trusts (typically for a population of 1–2 million) by specialist commissioners. Their goals are to identify and prioritise health needs, and then secure services to address those needs within the available budget. Commissioners need a strategic vision, if renal services are to advance despite changing policy and funding pressures. Not all specialist commissioners are knowledgeable about nephrology, and it remains the responsibility of clinicians to engage and educate them. It remains to be seen how a universal chronic disease management network can be created in the context of a fragmenting NHS in England, with Foundation Hospitals, mandatory offers of private sector care, and independent treatment and diagnostic centres.

Table 1. The USA National Kidney Foundation's K/DOQI classification of CKD.⁵ Kidney damage is defined as pathological abnormalities or markers of damage, including abnormalities in blood or urine tests or imaging studies. Note that even with a mildly reduced GFR, kidney damage must be present to diagnose CKD, whereas stages 3 to 5 require only a reduced GFR. Reduced GFR and/or kidney damage must be present for ≥3 months to make the diagnosis of CKD.

Stage	Description	GFR (ml/min/1.73m ²)	Prevalence	Focus of care*
1	Kidney damage with normal or increased GFR	>90	3.3%	Diagnosis and disease-specific therapies
2	Kidney damage with mildly impaired GFR	60–89	3.0%	Slowing of progression and reduction of cardiovascular risk
3	Moderately impaired GFR	30–59	4.3%	Addressing complications of CKD
4	Severely impaired GFR	15–29	0.2%	Preparation for dialysis
5	Established renal failure	<15 or on dialysis	0.2%	Dialysis, transplantation or conservative care

Prevalence data are from Ref 6.
CKD: chronic kidney disease; GFR: glomerular filtration rate. K/DOQI: Kidney Disease Outcomes Quality Initiative.
*Each stage also incorporates the areas of care of the stages above it.

Fig 2. The increasing percentage of dialysis patients achieving the Renal Association target of a haemoglobin ≥ 10 g/dl from 1997 to 2003, England and Wales. CI = confidence interval; Hb = haemoglobin. (Reproduced with permission of the UK Renal Registry.)

A global perspective on the CKD epidemic

Provision of dialysis in the UK has lagged behind other Western countries for many years. However, problems in the developing world are on a different scale. It is estimated that only 15–20,000 patients receive treatment for end-stage renal disease in India, a country with a population over 17 times larger than the UK, where 37,000 people are currently treated. Even with a per capita gross national income less than 2% of the UK, India is far from being the poorest nation in the world. Ambitious plans to establish a global fund with contributions from industry and the richer nations may help. Whilst the industrialised world is only now turning its attention to the prevention of CKD, it is self-evident that this has to be the main focus for poorer countries.

Improving care for children with CKD

Although a GP practice of 10,000 may expect to have six patients on RRT, fortunately a practice would need to have one million patients to see a similar number of paediatric patients with advanced CKD. These small numbers, however, create challenges for audit, even with highly centralised units. The speed of recent medical advances in the management of these children has been remarkable, but sadly there has yet to be similar progress in the handling of the attendant complex psychosocial issues. The transitional phase through adolescence to adult clinics can be a particularly difficult time. The long-term commitment and burden of responsibility carried by the parents of these children are remarkable, and the availability of appropriate respite care remains in many places inadequate. On a more positive note, a number of recent randomised trials, particularly in transplantation, have specifically aimed at optimising therapeutic regimens in the paediatric population. It should come as no surprise that, as with the management of many other diseases, these children cannot simply be regarded as 'small adults'.

Interactive session with case histories

The day-to-day dilemmas presented in the case histories again underlined the need for patient involvement in decision making. Notably, the emphasis placed by patients on duration of dialysis when deciding who should receive a renal transplant was clearly greater than that of the conference attendees (and indeed UK Transplant), who in general favoured the utilitarian approach of the kidney going to the recipient with the closest tissue type match, and therefore longest predicted graft survival.

Guidelines for the management of CKD

Many patients with CKD are not managed by nephrologists, but by physicians, urologists, general practitioners and others. Many of the required investigations and management are more appropriately delivered in primary care. UK guidelines for assessment, management and, where appropriate, referral of patients with CKD have now been developed by the Renal Association and this College's Joint Specialty Committee on Renal Disease.¹² Referral criteria are based on simple tests: the eGFR and its rate of deterioration, urinary protein-creatinine ratio, dipstick haematuria and blood pressure. A comprehensive review of appropriate investigations for both newly diagnosed and known patients, and management targets for slowing progression and reducing cardiovascular risk were also presented. Dissemination and, more importantly, implementation of these guidelines will be of major importance over the coming years.

Managing CKD in primary care

There simply are not enough nephrologists to see the large numbers of patients with CKD stages 1 to 3. The scope for involvement of general practitioners in the management of CKD is broad, and may be aimed at prevention, early identification of

patients, retarding progression, enabling timely hospital referral, reducing cardiovascular risk and improving quality of life. The necessary IT infrastructure has progressed apace, facilitating identification of patients and their registration for regular structured review. The key importance of the reporting of eGFR by biochemistry laboratories was again emphasised. A number of potential models of integration between primary and secondary care were proposed, with the involvement of primary care clinics for chronic disease management, specialist nurses, virtual nephrology and appropriately timed shared care. Incorporation

of CKD-related targets into the General Medical Services contract would aid implementation, and is being actively sought.

Lessons from diabetes

The integration of patient management between primary and secondary care in the follow-up of renal patients remains in its infancy. It may be 10–20 years behind that of patients with diabetes, but there is scope to speed up progress by learning from their experience. A strong evidence base existed for various interventions in diabetes, but systems of registration and review had to be implemented in primary and secondary care to allow those benefits to be achieved. IT has been a key component in much of the progress made, crossing traditional organisational boundaries. The imperative is now for improved patient communication and education, in order to increase patient understanding of their disease and empowerment. The impact on disease control was particularly impressive following the introduction of ‘tele-carers’, lay people trained to advise patients by telephone using defined algorithms. In addition to improvements in HbA_{1c}, this system proved very popular with over 80% of patients, leading to increased efficacy and confidence in their own disease management. Further integration to incorporate management of diabetes, vascular disease, CKD and other chronic illnesses in a true chronic disease management programme¹³ is a challenge ahead.

The Government view

Reassuringly, the view from the top is remarkably similar to that at the front line, with an emphasis on patient-orientated care, ideally provided conveniently in the local community. The English Minister of State for Health, Rosie Winterton, appreciated the importance of sophisticated and robust IT services in the efficient and integrated management of patients between primary and secondary care. She emphasised the need for hospitals not to exist as isolated islands, and encouraged further promotion of a patient-led NHS. Unfortunately, there is no prospect of reform of prescription charges, which affect renal patients disproportionately.

Conclusion

There is much cause for optimism about the future care of renal patients. Professionals from all groups are aware of the challenges to be faced, and there is much excitement about developing improvements in services. The increasing emergence of a more holistic approach, with an emphasis on patient involvement in management decisions, is to be applauded. However, given the increasing age and comorbidity of patients with renal disease, a tailored approach will always be necessary to give each individual patient the amount of information and responsibility appropriate to them. The next time you assess someone for renal disease, ask yourself what is the eGFR? What is the rate of decline of eGFR? What is the urinary protein–creatinine ratio? If you can answer these questions routinely, care of patients with CKD will already have advanced dramatically.

Conference programme

■ Keynote Address

Ms Rosie Winterton MP, Minister of State, Department of Health

■ Epidemiology of chronic renal disease and Renal NSF Parts 1&2

Dr Donal O'Donoghue, Joint Lead Renal NSF; Consultant Nephrologist, Hope Hospital, Salford

■ Patient centred services in chronic kidney disease

Mr Bob Dunn, Carer NSF RAG; Carer & Patient Advocate, National Kidney Research Federation

■ Improving communication and education for patients with kidney disease

Dr Steve Smith, President, British Renal Society

■ Setting and monitoring standards for patients with chronic renal disease

Dr Chris Winearls, Clinical Vice President, The Renal Association

■ A global perspective on the CKD epidemic

Professor SC Dash, All India Institute of Medical Sciences, New Delhi, India

■ TEALE LECTURE: Improving care for children with chronic kidney disease

Dr Bob Postlethwaite, Consultant Paediatric Nephrologist, Royal Manchester Children's Hospital

■ Interactive session with case histories

Led by Dr Colin Geddes, Consultant Nephrologist, Western Infirmary, Glasgow

■ Commissioning – the key to improving local renal services?

Dr Jenny Scott, Head of Commissioning, Cheshire and Merseyside Specialised Services Commissioning Team

■ Guidelines for the treatment of early chronic kidney disease

Dr Charlie Tomson, Consultant Nephrologist, Southmead Hospital, Bristol

■ Managing chronic kidney disease in primary care

Dr Steve Blades, NSF RAG, Professional Executive Committee, Newcastle PCT; General Practitioner, The Grove Medical Group, Newcastle upon Tyne

■ Lessons from diabetes

Dr Bob Young, Consultant Diabetologist, Hope Hospital, Salford

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