Chapter 3: National Survey on the Prevalence and Management of Patients with Chronic Kidney Disease under the care of Nephrologists in the UK

Introduction

There is increasing awareness and focus on the management of patients with chronic kidney disease (CKD). Parts of the recently published National Service Framework Parts 1 and 2[1,2] and the soon to be published guidelines on CKD jointly developed by the Renal Association, Royal College of Physicians of London Specialty Committee on Renal Disease and the Royal College of General Practitioners are evidence of this and will stimulate even more interest. Indeed most nephrologists believe these documents will lead to an increase in the referral of patients with CKD to nephrology services. Planning for this growth area in renal care is difficult as there are few data available on the number of patients who are approaching established renal failure, both in the UK and other countries and there is very little information on the facilities available for such patients and organisation of their care. This contrasts with the situation for patients already on renal replacement therapy in the UK, about whom data are widely collected and analysed.

With this in mind, the idea for the CKD survey was conceived. The main aim was to investigate the current working practices and management models of CKD patients across all the renal units in the country and also to gather some information regarding the number of prevalent patients with CKD under the care of UK nephrologists.

Background

There are robust systems for collecting data on patients on RRT. For such patients in 2004 the UK Renal Registry had electronic linkage with 36 of the 53 renal units in England (73% coverage); all 5 renal units in Wales (100% coverage); had links with the Scottish Renal Registry and will soon cover the whole UK. In addition, since 1992, the Department of Health in England has conducted three national surveys on the provision of renal replacement therapy in the UK, collecting data on the incident and prevalent patients, the number of renal units and dialysis stations being utilised and the facilities available in terms of the number of medical and some non-medical personnel involved[3]. From 2004, similar surveys will be conducted annually by the UK Renal Registry, on behalf of the Renal Association and the British Renal Society.

The situation for chronic kidney disease is very different. This has been partly due to the lack of definition of the 'pre-dialysis' phase. Several terminologies were used interchangeably to describe this group of patients, which included chronic renal failure, chronic renal impairment, chronic renal disease and chronic renal insufficiency[4]. The publication in 2002 of NKF-KDOQI guidelines[5] defining this group of patients as 'Chronic Kidney Disease (CKD)' and outlining the definition and classification of CKD and estimating prevalence in the USA (Tables 3.1 and 3.2) is welcomed as it facilitates performance of comparative studies and analysis on this subject.

In the USA, data from 15,625 participants in the Third National Health and Nutrition Examination Survey (NHANES III) estimated that 11% (19.2 million) of the adult population in the US suffers from CKD, with 4.7% (8.3 million) in stages 3–5, with a much higher prevalence in the older age groups, diabetics and hypertensives[6]. More recently, in the UK, work by the NeoErica (New Opportunities for Early Renal Intervention by Computerised Assessment) project involving analysis of records of 22,819 patients from databases of general practitioners in East Kent, West Surrey and Salford showed an estimated prevalence of stages 3–5 CKD of 5.1% in the general population[7]. In Australia, the Australian Diabetes, Obesity and Lifestyle (AusDiab) study showed a prevalence of 11.2% of CKD stages 3–5 in

Table 3.1: Definition of Chronic Kidney Disease according to NKF-KDOQI guidelines[5]

Criteria
Kidney damage for $\geqslant 3$ months, defined by structural or functional abnormalities of the kidney with or without decreased GFR, manifest by either
Pathological abnormalities
Markers of kidney damage, including abnormalities of blood or urine or abnormalities in imaging tests
GFR <60 ml/min/1.73 m^2 for $\geqslant 3$ months, with or without kidney damage

Table 3.2: Stages of Chronic Kidney Disease, Prevalence in the USA and Recommended Action Plan[5]

Stage	Description	GFR (ml/min/1.73 m^2)	Prevalence %	Actions
–	At increased risk eg known diabetes or hypertension	$\geqslant 60$ (with CKD risk factors)		Screening; chronic kidney disease risk reduction
1	Kidney damage with normal or increased GFR	$\geqslant 90$	3.3%	Diagnosis and treatment; treatment of co-morbid conditions; slowing progression; cardiovascular risk reduction
2	Kidney damage with mild decreased GFR	60–89	3.0%	Estimating progression
3	Moderately decreased GFR	30–59	4.3%	Evaluating and treating complications
4	Severely decreased GFR	15–29	0.2%	Preparation for kidney replacement therapy
5	Kidney failure	<15 (or dialysis)	0.1%	Kidney replacement (if uraemia present)

the 10,949 patients of the cohort. Unfortunately, there was no estimation for the general population in Australia made from the available data[8].

Although there were differences in terms of the study cohort and the study methods, the data from NeoRica, NHANES III and AusDiab studies clearly show the magnitude of the problem of CKD in the general population. For each patient with CKD known to nephrologists, there are many others not referred. John *et al*[9] analysed the biochemical results from 2 laboratories in East Kent, identifying patients with chronic kidney disease using the criteria of serum creatinine $\geqslant 180\,\mu$mol/L in men or $\geqslant 135\,\mu$mol/L in women. Between October 2000 and September 2001, 3,822 patients fulfilled the criteria for chronic kidney disease, equivalent to a prevalence of 5,554 patients pmp. When cross-referenced with the renal unit database, only 15% (582 patients) were known to the renal team. The non-referred group were mainly elderly with a median age of 83 years, with 66% aged 80 or older and another 23% aged 70–79. When analysed according to estimated GFR (MDRD), the percentages of patients with stage 4 and 5 chronic kidney disease known to the renal team were poor (34.7% and 16.2% respectively), even when those aged 80 and over were excluded from the analysis (63.6% and 38.5%) (Table 3.3). If all these unreferred patients were to be assessed by nephrologists, it is calculated that an extra 300 consultant sessions/pmp/year would be needed to cope with the extra workload.

Table 3.3: Percentage of CKD Stage 4–5 patients known to renal units (adapted from John *et al*[9])

	Including patients age 80+			Excluding patients 80+		
eGFR	Men (%)	Women (%)	All (%)	Men (%)	Women (%)	All (%)
<15	42.6	29.0	34.7	71.4	57.1	63.6
15–30	21.3	12.1	16.2	39.1	32.4	38.5
30–42.8	13.7	7.0	9.6	24.2	14.8	19.0
All	20.4	11.4	15.2	36.1	26.9	31.2

The CKD Survey

With the high prevalence of CKD and the lack of information on facilities and organisation of care in mind, the CKD survey was conceived. As stated earlier the main aim is to investigate the current working practices and management models of CKD patients across all the renal units in the country, highlighting the positive points of how the care of the multi skilled renal team is being delivered but also to identify aspects of care which renal units feel are important, but still inadequate and need to be improved. From the survey it is hoped to produce the first national data for the UK in terms of the number of patients with CKD currently under nephrological care; previous studies have focused on prevalence of CKD in the community. The data collection has been limited to patients with CKD stage 4 and 5*, as these are the patients who are most likely to progress towards established renal failure requiring RRT.

Methods

The questionnaire was developed within the Demographic study group of the Renal Registry with valuable assistance from Dr Michael Ward (Freeman Hospital, Newcastle) and Dr Donal O'Donoghue (Hope Hospital, Salford). The questionnaire was piloted at several renal units – St Helier Hospital (Carshalton), Birmingham Heartlands Hospital, New Cross Hospital (Wolverhampton), Southampton General Hospital and Morriston Hospital (Swansea) – before being sent out to the rest of the country.

The initial plan was to circulate the questionnaire to all the renal units with RRT facilities in the UK and also to general physicians with an interest in nephrology working in other district general hospitals without RRT facilities. The DGH Society was approached for assistance but was unfortunately unable to provide a complete listing of general physicians with an interest in nephrology currently working in district general hospitals in the UK. Therefore the circulation was limited to the renal units in the UK. The questionnaire was sent out to all 72 renal units in the UK in June 2004 and refers to the situation in June 2004.

Data were entered and stored in a Microsoft Access database by a single operator and data were then checked by another operator to ensure correct data transfer from the paper version. Any queries from the responses were then followed up with the relevant contact person for the renal unit concerned. Data were then analysed using the SAS statistics package. Where data on RRT are used, these are either from the 2002 National Renal Survey or the Renal Registry's own database.

Results

Number of patients

Of the 72 units, 70 (97%) responded to the survey; 35 centres were able to provide data on the number of CKD patients under nephrological follow up and 25 of these centres were able to provide estimated glomerular filtration rate (eGFR) for these patients. In 21 of the units, details of all CKD patients are kept in the same database as RRT patients.

In these 35 centres, there were a total of 78,000 patients with CKD, giving a median number of 2,000 patients per renal unit (range 275–5,685). In the 25 centres with eGFR data, there were a total of 8,912 CKD stage 4 and 5 patients; a median of 321 CKD stage 4 and 5 (range 53–819).

Using data from the National Renal Survey 2002, the median CKD/prevalent RRT ratio was calculated as 3.7 and the median CKD stage 4 and 5/prevalent RRT ratio was 0.6.

Using these ratios and applying them to the total number of prevalent RRT patients in the UK in 2002 (estimated to be 37,000), it is therefore estimated that there are about 140,000 CKD patients under the care of UK nephrologists of whom 23,000 are CKD stage 4 and 5 patients.

*For this report, CKD Stage 5 refers only to patients with estimated glomerular filtration rate <15 ml/min who are not on dialysis

Multi-skilled renal (MSR) team

Few renal units have a full complement MSR team. All but 1 unit who responded have a dietitian for CKD patients. 72% of the units have a renal pharmacist and 64% have a social worker working for the unit. 87% of units have a specific person providing dialysis education and 76% and 53% of the units have anaemia and access co-ordinators respectively. Only 33% have a counsellor and just 24% a psychologist. Some units are creating more specific nursing roles for nurses such as diabetic nurse (29%) and 9% have a blood pressure nurse (Table 3.4).

In renal units that did not have the various MSR personnel in post at the time of the survey, social workers lead the list of MSR personnel needed by renal units with 91% of the centres expressing their need to have one. This is followed by dialysis education providers (89%), counsellors (78%), access coordinators (75%) and psychologists (67%).

Dietitians and dialysis education providers are the main MSR personnel attending CKD clinics in over 95% of the renal units that have one.

There are regular MSR team meetings in 47 of the 70 renal units. The frequency of the meetings varies between the units from 1 meeting per week to 1 meeting every 13 weeks, with the majority of the units either having a weekly (49%) or a monthly (36%) meeting. In 36 of the 47 units (77%), the regular MSR meetings have been in place for more than 1 year.

In 49 of the 70 renal units there are clinics for CKD patients in neighbouring district general hospitals (DGH), averaging 3 other DGHs per main renal unit. In 15 of these 49 units, CKD patients from the peripheral DGHs have to be reviewed in the main unit because the MSR team's services are only available in the main unit and not in the peripheral hospital.

Low Clearance Clinic

One model for management of patients with CKD stage 4 and 5 is the "low clearance clinic", although there are other models which provide a co-ordinated care pathway through the MSR team. In early June 2004, of the 70 units, 50 (71%) held pre-RRT clinics or low clearance clinics for managing patients approaching RRT. A further 10 centres (15%) were planning to set up similar clinics with 5 of these clinics due to start in the second half of 2004. In 10 of the 50 units with such clinics, not all the consultants were using the facilities. The median number of patients under the care of these clinics was 118, however this ranged from 25 to 850 patients. This was partly due to the different size of the centres, but may also reflect the differing criteria for referring patients to the service.

Table 3.4: Multi skilled renal team composition within renal centres

	Units with the following MSR personnel for CKD patients %		Units without the following MSR personnel that feel they are needed %		Units where MSR personnel attends clinics where CKD patients are seen %	
	Yes	No	Yes	No	Yes	No
Dietitian	99	1	0	100	94	6
Pharmacist	72	28	60	40	15	85
Social worker	64	36	91	9	47	53
Physiotherapist	22	78	27	73	21	79
Occupational Therapist	28	72	40	60	22	78
Counsellor	33	67	78	22	52	48
Psychologist	25	75	67	33	53	47
Anaemia Coordinator	76	24	31	69	76	24
Access Coordinator	53	47	75	25	66	34
Dialysis Education Provider	87	13	89	11	93	7
Diabetic nurse	29	71	58	42	33	67
BP nurse	9	91	30	70	67	33

The frequency of these clinics ranged from 1 to 3 clinics per week. The majority of these clinics (86%) have been running for more than 1 year. In 84% of these units, there is a renal nurse specialist involved in the organisation and running of the clinics. The amount of responsibility entrusted to the renal nurse specialist varies between units. From the collective survey responses, facilitating clear and efficient communication with other personnel involved in the care of CKD patients appears to be the main role of the renal nurse specialist. Some of these nurses are also involved in the delivery of CKD education, counselling, transplant assessments and prescribing and altering prescription under medical supervision. In some units, patients are reviewed by the nephrologist and the nurse specialist on an alternate basis.

Pre-dialysis education

Apart from specific dialysis education providers, education was also delivered by a variety of other professionals such as dialysis nurses, transplant co-ordinators, dietitians and pharmacists.

While subjects such as types of dialysis, dietary restrictions, fluid balance, CKD related anaemia, renal bone disease were very well covered, aspects of CVD risk factors, sexual matters and psychological support were not necessarily reported to be covered in the programme.

In various units there were education materials available in audio and Braille for the blind, and translated into Bengali, Cantonese, Gujarati, Hindi, Punjabi, Somali, Urdu and Welsh (Table 3.5).

Dialysis Access services

Fifty-five renal units (76%) had a dedicated vascular access surgical team, with 41 (59%) providing clinics for pre-access assessments and 27 (39%) providing post-access follow-up. In the 55 units with a dedicated vascular access team, the median waiting time for elective fistula surgery was 6 weeks (range 1–36 weeks), compared with 12 weeks (range 4–26 weeks) in the 14 units without a dedicated team. There were 51 units with dedicated theatre sessions for access formation and the number of sessions range between 1 session per month to 6 sessions per week.

Tenchkoff catheter insertions were performed by nephrologists in 28 renal units. In these centres the median waiting time for catheter insertion was 2 weeks (range 'within same week' – 8 weeks), compared with a median of 4 weeks (range 'within same week' – 12 weeks) in centres where nephrologists do not perform insertions. Forty units (57%) have a renal interventional radiologist.

Access coordinators were employed in 37 centres (53%) to organise and prioritise the waiting list. In 32 units (46%), information regarding access formation and problems were entered into a database.

Relating MSR team with patients' outcome

For centres participating with the Registry's activity, analysis was performed to relate the clinical variables at the start of dialysis with the presence or absence of members of the MSR team and also the presence or absence of a low

Table 3.5 Education materials available in other languages

Language	Hospitals where leaflets are available in the language
Bengali	Middlesex, Sheffield
Cantonese	Glasgow, Sheffield
Gujarati	Leicester, Sheffield, Preston, Queen Elizabeth – Birmingham
Hindi	Leicester, Middlesbrough, Sheffield, Preston, Queen Elizabeth – Birmingham
Punjabi	Coventry, Leicester, Queen Elizabeth – Birmingham, Stoke-on-Trent
Somali	Sheffield
Urdu	Glasgow, Reading, Sheffield, Queen Elizabeth – Birmingham
Welsh	Bangor, Cardiff, Rhyl, Swansea, Wrexham

Table 3.6: Comparison of haemoglobin and biochemistry results between centres with anaemia coordinators, diabetic nurses or low clearance clinic

			Median values end of quarter 1			
		Hb g/dl at start	Corrected Ca mmol/L	Phosphate mmol/L	iPTH pmol/L	HbA1c %
Anaemia coordinator	Yes	10.1	N/A	N/A	N/A	N/A
	No	10.1	N/A	N/A	N/A	N/A
Low clearance clinic	Yes	10.2	2.38	1.58	19.1	N/A
	No	9.9	2.36	1.60	22.3	N/A
Diabetic nurse	Yes	N/A	N/A	N/A	N/A	6.5
	No	N/A	N/A	N/A	N/A	6.8

clearance clinic. The Registry's data used were from 2003; therefore one major assumption here is that the situation at June 2004 largely applied in 2003.

In terms of anaemia management, the median haemoglobin at the start of dialysis was identical in centres that did or did not employ an anaemia coordinator. However the median haemoglobin appears to be slightly higher in centres utilising a low clearance clinic compared to those which did not (median Hb 10.2 v 9.9; $p = 0.001$), although the clinical relevance of this is unclear (Table 3.6).

Apart from serum creatinine, the Registry is not yet collecting other biochemical variables at the start of dialysis, therefore values at the end of the first quarter following the start of RRT have been used as a surrogate instead. Data in table 3.6 show that there were no marked differences between those centres with and without a low clearance clinic in terms of the median value for corrected calcium, phosphate and serum iPTH at the end of the first quarter.

The median HbA1c was lower in centres with a diabetic nurse compared to those without (6.5% v 6.8%; $p = 0.044$), although like the haemoglobin data, the clinical relevance of this is unclear.

Discussion

This is the first national survey in the UK to attempt to document the prevalence of patients with CKD under the care of a nephrologist and also to assess the available services for their management.

From this survey, it is estimated that there are about 140,000 CKD patients under the care of nephrologists from UK renal units, of whom approximately 23,000 are CKD stage 4 and 5 (not on dialysis). This is an approximate estimate as only 50% of centres were able to provide these data and there is at present no way of validating the data which were returned. In terms of workload for the NHS this is an underestimate, as many known CKD patients are looked after by nephrologists working in district general hospitals not attached to a renal unit and also by other specialists such as cardiologists, diabetologists and urologists. Other patients are managed solely within primary care.

Ifudu *et al*[10] showed that in the USA, receiving care from nephrologists prior to starting dialysis is associated with improved short term morbidity, a lower level of serum creatinine at the start of dialysis, needing to use less temporary access and spending a much shorter period in hospital compared to those receiving care from non-nephrologists or no medical care.

However, data on the best model for management of CKD patients are still limited. Harris *et al*[11] concluded that an intensive multi-disciplinary management approach did not offer any significant advantage in terms of progression of renal disease nor mortality rate. In contrast, the studies by Binik *et al*[12] and Devins *et al*[13], suggested that a more enhanced intensive education programme for pre-ERF patients may delay the start of RRT by at least 3 months and in a paper by Levin *et al*[14], patients who were attending a pre-dialysis clinic programme had better clinical variables at the start of dialysis and were less likely to have a problem with

symptomatic uraemia, less likely to start dialysis in an emergency manner and less likely to start dialysis as an inpatient.

Nevertheless, it is almost universally accepted that the multi disciplinary approach is the best way forward in managing the complex needs of this group of patients. The NSF for Renal Services Part 1 and 2 emphasised that the management of patients approaching dialysis should involve a multi skilled renal team rather than just nephrologists[1,2].

The report *The Renal Team: A Multi Professional Renal Workforce Plan for Adults and Children with Renal Disease*[15], outlined the personnel that constitute a multi-skilled renal team. The availability of the recommended renal team members varied between the units, with very few units having the full recommended complement recommended by the NSF. Notably lacking are social workers, psychologists and counsellors suggesting that such emotional and psychological support frequently appears to be a relatively low priority, especially in a financially constrained environment. There is no indication whether this prioritisation is driven by the perceptions of the renal team or the commissioners.

It is fashionable at present to have a low clearance clinic to streamline the management of patients approaching dialysis: 71% of the units are using this approach. From the analysis of biochemical variables in the first quarter following commencement of RRT, the potential benefit is still unclear although there is a suggestion that the median haemoglobin at the start of dialysis to be higher in patients from centres with a low clearance clinic. This highlights the need for further research to identify the most effective methods for organising care for CKD patients approaching dialysis.

Rather surprisingly not all centres have a specific dialysis education provider. This is perhaps an area that needs to be improved, as it is important to enable patients to choose the appropriate modality at the start of their RRT journey. Preparation for dialysis in terms of timely provision of vascular or peritoneal access is still not optimum, with some centres lacking a dedicated surgical team to perform these procedures.

Conclusion

Management of patients with CKD is an important issue, as increasing emphasis and awareness due to recent publication of the NSF for Renal Services and the imminent CKD guidelines developed by the Renal Association, Royal College Specialty Committee on Renal Disease, the Royal College of General Practitioners and Royal College of Physicians, will undoubtedly lead to an increase of referral to nephrologists. At present the provision of services is variable across the country with dialysis access services and socio-psychological support possibly being the two main aspects which need to be addressed. These data from this survey will serve as a good baseline to gauge the impact of the implementation of the recommendations from the National Service Framework on the service delivery both locally and nationally.

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