Chapter 5
Demography of the UK Paediatric Renal Replacement Therapy population in 2009

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Key Words
Aetiology · Children · Demography · End stage renal disease · Established renal failure · Incidence · Prevalence · Ethnicity · Treatment modality

Summary

- There were 751 children under 16 years reported as receiving RRT in 2009.
- In 2009, 70% of patients had received a transplant, 19% were on PD and 11% HD.
- The annual incidence of RRT has increased over the last 14 years from 8.1 pmarp (1995–1999) to 9.6 pmarp (2005–2009).
- Renal dyspasia ± reflux (34%), glomerulornephritis (16.9%) and obstructive uropathy (16.2%) were the commonest aetiologies.

Introduction

Established renal failure (ERF) requiring renal replacement therapy (RRT) is a rare but significant cause of long term morbidity and mortality during childhood. In the United Kingdom (UK), the annual incidence of treated ERF has remained stable at between 5 to 10 children per million age related population (pmarp) each year over the past 20–25 years although the prevalence rates have increased steadily to 56.1 pmarp in 2008 [1]. This increase in prevalence is likely to be a result of improved survival of children across the paediatric age range as a result of advances in the delivery of care with more effective dialysis, improved nutrition and the availability of better immunosuppressive medications following renal transplantation.

Accurate evaluation of the demographics of this cohort is important to inform further improvement in delivery of care and to form the basis of well designed research analysis. The objectives of this report are:

i) To describe the prevalence, incidence, causes of ERF and modality of treatment of children on RRT in the UK on 31st December 2009 and
ii) To describe trends of the same over the past 15 years.

Methods

Data collection took place across the 13 paediatric nephrology centres in the UK that provided care to all children on RRT in 2009. Some centres collected data electronically and submitted this to the UK Renal Registry (UKRR) with the remaining centres reporting data using 'paper-based' data returns. These data were then manually entered into the current paediatric UKRR database.

This year, five centres supplied data on paper returns with the remaining centres providing electronic files that were uploaded directly into the current paediatric UKRR database. Southampton provided an electronic file but due to technical difficulties was only able to send a limited dataset.

In this report patient groups are described as follows: patients who were receiving RRT on the 31st December 2009 are the 'prevalent group', patients who started RRT between 01/01/2009 and 31/12/2009 are the 'incident group' and patients that started RRT in the periods of 1995–1999, 2000–2005 and 2005–2009 are the '5 year groups'.

The populations used to calculate the incidence and prevalence rates were obtained from the Office for National Statistics (ONS) [2]. The mid-2009 population estimate produced by the ONS, based on the 2001 Census, was used for calculating the incident and prevalent group rates and the 2001 Census data was used for the 1995–2000 and 2000–2005 '5 year groups' and for the breakdown of the population into ethnic groups.

Statistical analyses were performed using SAS 9.2.

Results

Completeness of data returns

The procedures for data collection and processing are still evolving but there was good completion of the core data items as shown in table 5.1.

The UK paediatric prevalent ERF population in 2009

A total of 999 children and young people under 18 with ERF were receiving treatment at paediatric nephrology centres in 2009. At the census date, 67% had a

Table 5.1. Data completeness for paediatric prevalent ERF population in 2009

	Percentage completeness						
Centre	First seen date	RRT start date	Height at RRT start	Creatinine at RRT start	Treatment modality at 90 days	Ethnicity	Gender
Blfst_P	80.0	88.6	84.3	100.0	94.3	100.0	100.0
Bham_P	92.1	93.1	94.7	97.3	94.1	100.0	96.9
Brstl_P	91.1	100.0	92.5	97.4	100.0	100.0	98.2
Cardf_P	94.4	88.9	88.9	100.0	94.4	100.0	100.0
L GOSH_P	65.2	78.7	9.7	100.0	94.2	100.0	99.0
Glasg_P	85.5	87.0	92.8	100.0	89.9	100.0	100.0
L Eve_P	98.1	97.2	99.2	99.4	98.1	100.0	100.0
Leeds_P	97.5	96.2	93.1	100.0	100.0	100.0	98.7
Livpl_P	92.9	85.7	100.0	100.0	97.6	100.0	100.0
Manch_P	89.1	94.6	100.0	100.0	100.0	100.0	100.0
Newc_P	95.6	93.3	92.5	100.0	100.0	100.0	100.0
Nottm_P	88.0	99.0	30.8	100.0	98.0	100.0	100.0
Soton_P	97.2	36.1	0.0	7.1	40.3	100.0	100.0
UK	**86.8**	**87.0**	**75.3**	**50.0**	**92.6**	**100.0**	**99.3**

Table 5.2. The UK paediatric prevalent ERF population in 2009, by age group and gender

	All patients*		Males		Females		
Age groups	N	pmarp	N	pmarp	N	pmarp	Ratio M:F
0–1.99 years	34	21.6	24	29.8	8	10.4	2.9
2–3.99 years	57	38.3	33	43.3	23	31.7	1.4
4–7.99 years	139	50.1	86	60.5	52	38.4	1.6
8–11.99 years	195	70.5	122	86.4	72	53.3	1.6
12–15.99 years	326	110.5	192	127.0	132	91.8	1.4
Under 16 years	**751**	**65.0**	**457**	**77.3**	**287**	**50.9**	**1.5**

pmarp – per million age related population.
* 7 patients with missing gender are included in the 'all patients' column but not the gender columns.

Table 5.3. The UK paediatric prevalent ERF population by age and ethnic group in 2009

	White		South Asian		Black		Other	
Age groups	N	pmarp	N	pmarp	N	pmarp	N	pmarp
0–3.99 years	74	28.6	13	61.6	1	11.9	3	106.7
4–7.99 years	108	45.1	23	117.9	4	51.3	4	153.8
8–11.99 years	152	59.4	30	143.9	8	95.9	5	179.9
12–15.99 years	253	93.9	54	245.9	11	125.2	8	273.2
Under 16 years	**587**	**57.4**	**120**	**143.9**	**24**	**71.9**	**20**	**179.9**

functioning transplant, 15% were receiving peritoneal dialysis (PD) and 9% were receiving haemodialysis (HD). The modality was unknown in a further 9%.

As incomplete data was available for the 16–18 year old adolescent patients they have been excluded from these analyses. This report therefore presents data relating to patients less than 16 years of age only.

There were 751 children under 16 years of age receiving RRT in the UK in 2009. Table 5.2 shows the number of patients receiving RRT by age group and gender plus rate of RRT pmarp. The prevalence of RRT increased with age and was higher in males. The reported prevalence rate in under 16 year olds was 65 pmarp.

Table 5.3 shows the ethnic origin of current RRT patients. Increasing prevalence pmarp was observed with increasing age in all ethnic groups but children from ethnic minorities displayed higher prevalent rates of RRT when compared with White children.

Modality of treatment

Current treatment modality in the prevalent paediatric population less than 16 years old in 2009 is displayed in figure 5.1. Seventy percent of current paediatric patients had a functioning transplant and 30% were reported as being on dialysis.

The treatment modality in use at 90-days following commencement of RRT is displayed in figure 5.2. This shows that 51% of patients were treated with PD at 90 days whilst 20% of patients were treated with HD. Twenty-two percent of children under 16 were reported to have received a transplant either pre-emptively or by 90 days.

Table 5.4 demonstrates that in the under 2 year olds the majority of patients were being treated with PD

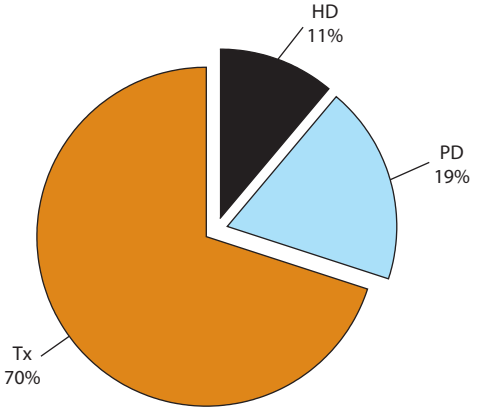

Fig. 5.1. The current RRT treatment used by prevalent paediatric patients less than 16 years old in 2009
* All patients from Southampton were excluded because of incomplete data.

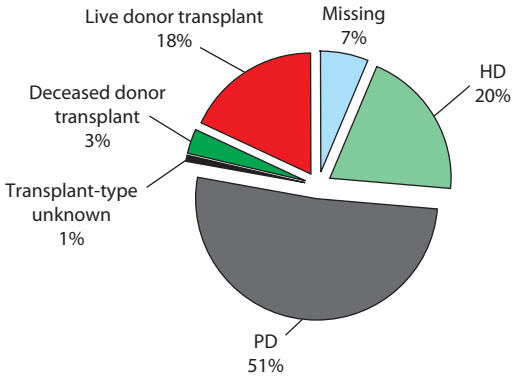

Fig. 5.2. Treatment modality at 90 days following commencement of RRT in prevalent paediatric patients under 16 years of age in 2009
* Patients from Southampton were excluded from this figure because of incomplete data.

(75%). This contrasts with older children in the 12 to 15.99 year age group where 81% had a functioning graft and almost as many people were on HD as PD.

Cause of ERF

Table 5.5 and figure 5.3 show the diagnostic categories for 635 of 751 current patients aged <16 years for whom a causative diagnosis was reported. Renal dysplasia ± reflux at 34% (216/635) was the commonest condition causing ERF with children commencing RRT across the paediatric age range.

Nearly 7% of the current RRT patients have been reported to have developmental delay and an additional 8% with congenital abnormality. Almost 1% other patients have cerebral palsy. Six percent of children receiving RRT were born prematurely (table 5.6).

Table 5.4. Current treatment modality by age in the prevalent paediatric ERF population in 2009

	Current treatment					
	HD		PD		Transplant	
Age groups	N	%	N	%	N	%
0–1.99 years	6	21.4	21	75.0	1	3.6
2–3.99 years	15	28.8	23	44.2	14	26.9
4–7.99 years	22	17.6	30	24.0	73	58.4
8–11.99 years	9	4.8	27	14.4	151	80.7
12–15.99 years	27	8.5	34	10.7	258	80.9
Under 16 years	**79**	**11.1**	**135**	**19.0**	**497**	**69.9**

Patients reported by Southampton have been excluded from this table.

Table 5.5. Number, percentage and gender by primary renal disease as cause of ERF in prevalent paediatric ERF population in 2009

Diagnostic group	Total	%	Males	Females	M:F ratio
Renal dysplasia±reflux	216	34.0	145	71	2.0
Glomerular diseases	107	16.9	50	57	0.9
Obstructive uropathy	103	16.2	97	6	16.2
Tubulo-interstitial	40	6.3	17	23	0.7
Uncertain aetiology	37	5.8	15	22	0.7
Metabolic	16	2.5	6	10	0.6
Congenital nephrotic syndrome	55	8.7	29	26	1.1
Reno-vascular disease	27	4.3	20	7	2.9
Polycystic kidney disease	21	3.3	7	14	0.5
Drug nephrotoxicity	3	0.5	1	2	0.5
Malignancy	10	1.6	3	7	0.4

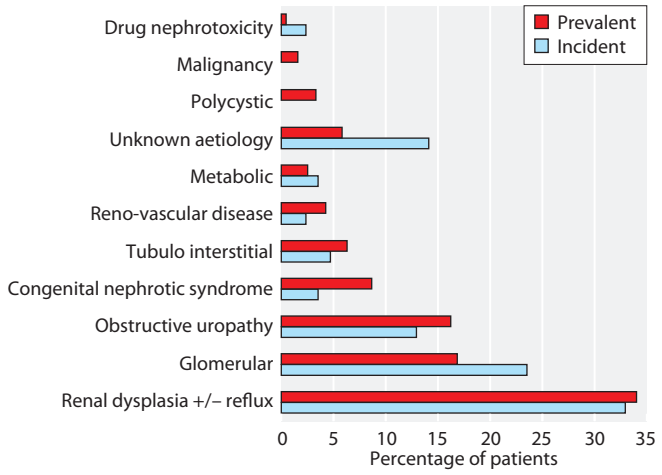

Fig. 5.3. Primary renal disease percentage in incident and prevalent paediatric ERF patients in 2009 for whom a causative diagnosis was reported

Table 5.6. Registered comorbidities at onset of RRT in prevalent paediatric patients with ERF in 2009

Comorbidity	Number of children	Percentage all RRT patients
Cerebral palsy	7	0.9
Chromosomal abnormality	18	2.3
Congenital abnormality	61	7.8
Congenital heart disease	21	2.7
Consanguinity	24	3.1
Developmental delay	49	6.3
Diabetes	3	0.4
Liver disease	13	1.7
Malignancy	9	1.1
Neural tube defect	5	0.6
Family member with ERF	17	2.2
Prematurity	48	6.1
Psychological disorder	3	0.4
Syndromic diagnosis	47	6.0

Table 5.8. Reported average incidence rate by age group, in 5-year time periods, of children under 16 years of age commencing RRT

	Per million age related population		
Age group (years)	1995–1999	2000–2004	2005–2009
0 to <4	8.4	8.7	10.8
4 to <8	4.6	6.0	6.4
8 to <12	8.2	8.4	7.8
12 to <16	11.0	12.4	13.4
Under 16 years	**8.1**	**8.9**	**9.6**

The UK incident paediatric ERF population in 2009

There were 133 patients under 18 years of age who commenced RRT at paediatric renal centres in 2009, as previously, the following analyses are restricted to the 107 patients who were under 16 years of age.

The incidence rate of RRT was 9.3 pmarp in 2009. These patients commencing RRT in 2009 are displayed by age and gender in table 5.7.

Table 5.8 and figure 5.4 show that the reported incidence of RRT has been rising since 1995. Observed incidence rates from one year to the next though are quite unstable because of small numbers. The highest incidence rates are seen in the 12–16 year old age group with the 0–4 year age group having the next highest rates. The average incidence rate per year in 5 year time periods is shown in table 5.8.

Trends in ERF demographics

Analysis of ERF demographics for children less than 16 years of age over the past 15 years confirmed there were 511 patients reported to the paediatric registry between 1995–1999, 580 between 2000–2004 and 627 between 2005–2009. Comparing the current 5 year

Table 5.7. The incident paediatric ERF population in the UK in 2009, by age group and gender

	All patients		Males		Females		
Age groups	N	pmarp	N	pmarp	N	pmarp	M:F ratio
0–1.99 years	18	11.5	12	14.9	4	5.2	2.9
2–3.99 years	8	5.4	4	5.2	4	5.5	1.0
4–7.99 years	20	7.2	16	11.3	4	3.0	3.8
8–11.99 years	20	7.2	12	8.5	7	5.2	1.6
12–15.99 years	41	13.9	17	11.2	23	16.0	0.7
Under 16 years	**107**	**9.3**	**61**	**10.3**	**42**	**7.5**	**1.4**

pmarp–per million age related population
* 4 children had missing gender

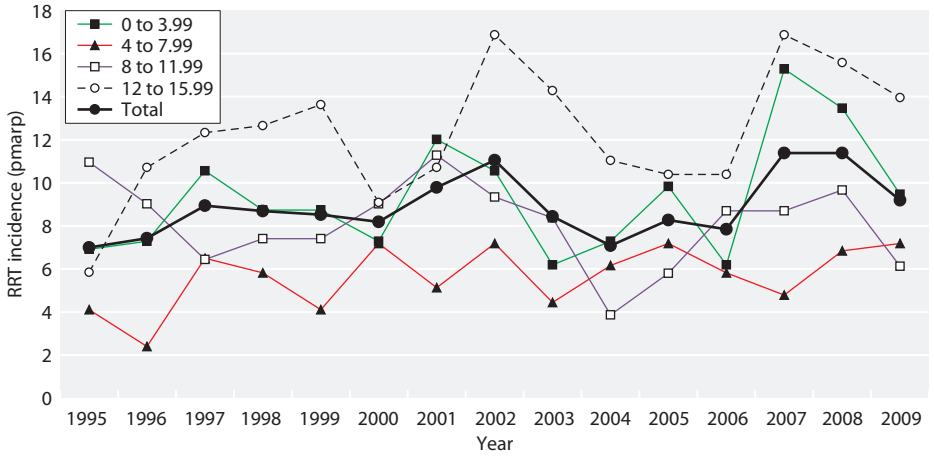

Fig. 5.4. The incidence rate per year of paediatric patients commencing ERF by age group and year at start of RRT

period with the previous 5 year periods there has been an overall increase in the number of children treated with RRT, particularly in children aged 12 to 16 years (table 5.9). The percentage of children on RRT who are from South Asian or Black ethnic backgrounds has increased during this period (table 5.10). The reported patient population at each paediatric renal centre has grown in size since 1995–1999 with the smallest increase seen in Cardiff and Belfast (table 5.11).

Table 5.12 shows the number and percentage of children receiving RRT with each of the major reported comorbidities to the UKRR over the last 15 years. In 2005–2009, 7.2% of children had a diagnosed syndrome, 5.4% had developmental delay and 7.3% had a congenital abnormality. The percentage of children receiving RRT with a reported comorbidity has remained stable over the past 5 years except for those with liver disease, malignancy and psychological disorders.

The percentage of children who were using PD at 90 days has fallen from 58% in 1995–1999 to 47% in 2005–2009 while the percentage commencing RRT on HD has increased from 19% in 1995–1999 to 23% in

Table 5.9. Number and percentage of children under 16 years who commenced RRT, by age group and 5 year period, at start of RRT

	1995–1999		2000–2004		2005–2009		
Age groups	N	%	N	%	N	%	% change
0–1.99 years	77	16.0	74	14.0	107	18.6	2.6
2–3.99 years	39	8.1	45	8.5	46	8.0	−0.1
4–7.99 years	68	14.1	88	16.7	93	16.1	2.0
8–11.99 years	128	26.6	130	24.6	122	21.2	−5.4
12–15.99 years	170	35.3	191	36.2	208	36.1	0.8
Under 16 years	**482**		**528**		**576**		

* There were 29 children in 1995–1999, 52 in 2000–2005 and 51 in 2005–2009 with no age at start of RRT and these are not included in this table

Table 5.10. Number and percentage of children under 16 years who commenced RRT by ethnicity and 5 year period of starting RRT

	1995–1999		2000–2004		2005–2009		1995–2009
Ethnic group	N	%	N	%	N	%	% change
White	420	82.2	464	80.0	486	77.5	−4.7
Asian	72	14.1	91	15.7	105	16.7	2.6
Black	10	2.0	15	2.6	21	3.3	1.3
Other	9	1.8	10	1.7	15	2.4	0.6

Table 5.11. Number and percentage of children under 16 years reported to the UKRR, by renal centre and 5 year period of start

	1995–1999		2000–2004		2005–2009	
Centre	N	%	N	%	N	%
Blfst_P	18	3.5	13	2.2	20	3.2
Bham_P	43	8.4	49	8.4	66	10.5
Brstl_P	39	7.6	50	8.6	35	5.6
Cardf_P	18	3.5	16	2.8	19	3.0
L GOSH_P	88	17.2	94	16.2	119	19.0
Glasg_P	35	6.8	32	5.5	50	8.0
L Eve_P	58	11.4	64	11.0	67	10.6
Leeds_P	47	9.2	56	9.7	58	9.3
Livpl_P	19	3.7	30	5.2	19	3.0
Manch_P	56	11.0	66	11.4	55	8.8
Newc_P	24	4.7	30	5.2	28	4.5
Nottm_P	53	10.4	57	9.8	74	11.8
Soton_P	13	2.5	23	4.0	17	2.7
Total	**511**		**580**		**627**	

2005–2009. The percentage receiving a transplant before 90 days has remained similar for the last 15 years.

Table 5.13 shows the diagnostic categories for 500 of the 511 (97.8%) patients in 1995–1999, for 553 of the 580 (95.3%) patients in 2000–2004 and 508 of the 627 (81%) patients in 2005–2009 aged <16 years for whom a causative diagnosis was reported.

There has been a decrease in the percentage of children receiving RRT with obstructive uropathy between 1995–1999 and 2005–2009 (17.4% vs. 13.2%) and an increase in unknown aetiology (4.0% vs. 9.1%) (table 5.13).

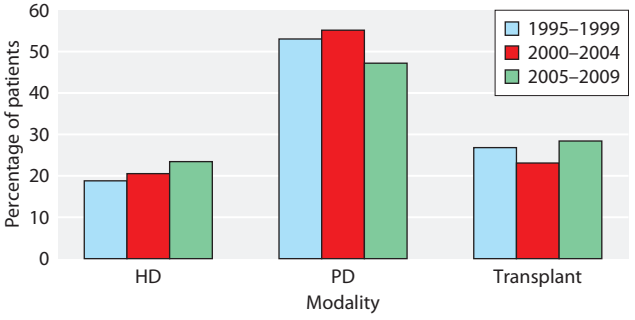

Fig. 5.5. Treatment modality at day 90 after starting RRT by 5 year time period

Table 5.12. Trends in comorbidity at the start of RRT in the paediatric population under 16 years, by 5 year period

	1995–1999		2000–2004		2005–2009	
Comorbidity	N	%	N	%	N	%
Cerebral palsy	2	0.4	9	1.6	6	1.0
Chromosomal abnormality	14	2.7	16	2.8	13	2.1
Congenital abnormality	35	6.8	46	7.9	46	7.3
Congenital heart disease	11	2.2	12	2.1	16	2.6
Consanguinity	21	4.1	22	3.8	14	2.2
Developmental delay	55	10.8	50	8.6	34	5.4
Liver disease	0	0.0	7	1.2	13	2.1
Malignancy	8	1.6	10	1.7	4	0.6
Neural tube defect	5	1.0	1	0.2	6	1.0
Family member with ERF	27	5.3	21	3.6	10	1.6
Prematurity	31	6.1	26	4.5	20	3.2
Psychological disorder	14	2.7	11	1.9	2	0.3
Syndromic diagnosis	32	6.3	34	5.9	45	7.2

Table 5.13. Number and percentage of children under 16 years for whom a primary renal diagnosis had been reported as a cause of ERF, by 5 year time period along with observed change in proportion of patients in each diagnostic group

	1995–1999		2000–2004		2005–2009		1995–2009
Primary renal diagnosis	N	%	N	%	N	%	% change
Renal dysplasia ± reflux	165	33.0	172	31.1	170	33.5	0.5
Glomerular diseases	107	21.4	130	23.5	103	20.3	−1.1
Obstructive uropathy	87	17.4	79	14.3	67	13.2	−4.2
Tubulo-interstitial	35	7.0	44	8.0	42	8.3	1.3
Unknown aetiology	20	4.0	24	4.3	46	9.1	5.1
Metabolic	19	3.8	24	4.3	20	3.9	0.1
Congenital nephrotic syndrome	31	6.2	24	4.3	25	4.9	−1.3
Reno-vascular disease	13	2.6	25	4.5	13	2.6	0.0
Polycystic kidney disease	14	2.8	12	2.2	12	2.4	−0.4
Drug nephrotoxicity	7	1.4	13	2.4	5	1.0	−0.4
Malignancy	2	0.4	6	1.1	5	1.0	0.6

Discussion

This report from the Paediatric Renal Registry has focussed on the description of the current demography and the demographic trends over the past 15 years of the UK paediatric ERF population. Over the past few years a sustained effort has been made by the members of the BAPN and the Paediatric RR sub-committee to improve data quality by (i) involving a data manager and a statistician as well as paediatric nephrologists in the team processing the data (ii) merging all available datasets into the larger adult UKRR database and (iii) aiming to have annual returns from all paediatric centres electronically. The benefits of this strategy of electronic data returns are obvious and have been discussed in previous UKRR reports [3, 4]. The recent mandating of reporting to the registry by the Department of Health has helped in implementing this policy locally at individual trusts.

On this background of ongoing 'process transition', 72.6% (569/751) of patients from 8 of 13 paediatric nephrology centres (Birmingham, Bristol, Cardiff, GOSH, Leeds, Manchester Nottingham and Southampton), had their data submitted electronically. Similarly, the merger of paediatric and adult UKRR databases remains as 'work in progress' with incomplete data for the majority of 16–18 year old patients, as they transition variably to adult colleagues across the UK. Further, subjects in this age group may present directly to adult services. Finally, although data for the paediatric ERF population from the UK has been reported pre-1990 [5] it was excluded from this report as it is likely to have been significantly under reported impacting on accuracy of analyses. This report therefore focuses on 751 children and adolescents <16 years of age, who were receiving RRT in 2009. The sub-section on the trends in demographics includes 511 from 1995–1999, 580 from 2000–2005 and 627 from 2005–2009 children and adolescents <16 years of age on RRT.

Completeness of data

As shown in table 5.1, completeness of data was >85% for key variables but two particular key data items 'height or length at start of RRT' and 'plasma creatinine at start of RRT' had lower completion rates at 75.3% and 50% respectively. Lack of these values has implications for the quality of any future reports that aim to analyse the impact of RRT on important variables such as growth. Further in this report is the somewhat surprising finding of little change in prevalent comorbidities listed in table 5.13 in children on RRT over the past 15 years. These data perhaps highlight the need for maintaining efforts to improve quality of data returns to and data processing within the UKRR. The authors are optimistic that the commitment of the clinical teams together with improved access to renal IT systems will help to improve data completeness.

Incidence, prevalence and trends

As shown in tables 5.7 and 5.8, the incident paediatric ERF population <16 years of age was stable at 9.3 pmarp. This was higher than that reported in the 2009 Registry Report [6]. Reviewing trends in incidence rates over the past 15 years suggests fluctuations from year to

year but a significant increase in average 5-year incident rates during this time period (table 5.8). Although yearly fluctuation has been described in recent reports from other renal registries [7] the increasing trend in average 5-year incidence rates of children on RRT does not appear to have been reported previously.

Analysis of the incidence rates in 4-year age bands as displayed in table 5.8 suggests this has been maximal in the 12–16 year age band followed by the 0–4 year age band with children less than 2 years old making up the larger proportion of these. A possible explanation for these observed demographic trends is that a greater proportion of children and adolescents <16 years now receive their RRT at paediatric nephrology centres only and that an increasing number of infants and young children are being considered for RRT as a result of improvements in techniques to provide nutritional support and dialysis therapy in this cohort. The increased take on rates in infants contributes significantly to workload as this is a particularly challenging group of patients to manage. A national audit of the care of these infants will provide greater detail.

The prevalence of children on RRT as shown in table 5.2 increased with age in keeping with improved survival with increasing age. This coupled with an increase in the number of children receiving RRT over the past 15 years (table 5.9) has led to a steady increase in the prevalent ERF population. This trend has been observed nationally and across all paediatric nephrology centres (table 5.11). Factors underlying the centre variation seen in the rise in reported patient numbers over time may include variations in the incidence of renal disease related to changes in ethnicity of the local population, changes in referral patterns and variations in the systems in place to support data collection.

Treatment modality of ERF and observed trends 1995–2009

In 2009, the treatment modality at 90 days for peritoneal dialysis was 51%, haemodialysis 20% and transplantation at 22% (figure 5.2). Analysis of these trends in 'modality at 90 days' over the past 15-years is displayed in figure 5.5 and shows an increase of 4% in patients on haemodialysis (from 19% in 1995–1999 to 23% in 2005–2009) and a reduction of 6% in peritoneal dialysis (53% in 1995–1999 to 47% in 2005–2009). There has been little change in the proportion of patients who have commenced their RRT careers with transplantation (27% in 1995–1999 to 28% in 2005–2009) with almost no observed change in the proportion of subjects commencing RRT following live-donor transplantation. At present it can only be speculated on the reasons for these observations. Some reasons include the increasing incidence of ERF in the youngest patients (<4 years of age) who are commencing RRT (table 5.9) and in whom dialysis often is the only possible modality, increasing incidence in ethnic minorities now commencing RRT (table 5.10) and in whom rates of live-donor transplantation remain low [6] and possible paediatric specific reasons including associated comorbidities, family and social issues for which there is little information but would benefit from more detailed review.

The majority of prevalent children (70%) on RRT have functioning transplants with a steady increase in prevalent children with a functioning transplant seen over the past 15 years (data not shown).

Comorbidities

Informally, paediatric nephrologists report they are managing children with increasingly complex medical problems. It is therefore perhaps surprising to see the relatively low rates of the listed comorbidities reported to the UKRR which have remained stable over time. The small increase in the number of ERF children with liver disease reflects the development of paediatric hepatology and liver transplantation over this time period. The reporting of psychological disorders has decreased but the authors feel this may be related to a lack of consistency in reporting comorbidities to the UKRR. It is difficult to make any comparisons of this data with other national registry reports as there remains no uniformity across registries for reporting and definition of comorbidities [8].

Causes of ERF and observed trends 1995–2009

Overall, renal dysplasia ± reflux at 34.0%, glomerulonephritis at 16.9% and obstructive uropathy at 16.2% were the commonest listed aetiologies for children with ERF accounting for 67.1% of all patients for whom a primary diagnosis had been reported. Renal dysplasia and obstructive uropathy were both more common in males with a male:female ratio of 2:1 and 16:1 respectively. Observation of trends over the 15-year period showed reduction in ERF secondary to obstructive uropathy (table 5.13), perhaps reflecting improvements in care as a result of early diagnosis and co-ordinated nephro-urological care for these children across the UK.

Conflicts of interest: none

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