UK Renal Registry 15th Annual Report: Chapter 4 Demography of the UK Paediatric Renal Replacement Therapy population in 2011

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Key Words
Aetiology · Children · Demography · End stage renal disease · Established renal failure · Incidence · Prevalence · Ethnicity · Renal replacement therapy · Survival

Summary

- A total of 856 children and young people under 18 years with ERF were receiving treatment at paediatric nephrology centres in 2011.
- At the census date, 80.1% had a functioning kidney-transplant, 10.5% were receiving peritoneal dialysis (PD) and 9.4% were receiving haemodialysis (HD).
- In patients aged <16 years the prevalence of ERF was 56.8 pmarp and the incidence 8.3 pmarp.
- A third of patients had one or more reported comorbidities.
- At transfer to adult services, 86% of patients had a functioning kidney transplant.

Introduction

Established renal failure (ERF) requiring renal replacement therapy (RRT) is a rare but significant cause of long term morbidity and mortality during childhood, with specialist care being provided in 13 paediatric nephrology centres in the UK. All centres are equipped to provide peritoneal dialysis and haemodialysis, with ten centres also undertaking kidney transplantation for children. In the United Kingdom (UK), prevalence rates of treated ERF in children aged under 16 have risen steadily over the last 15 years to 59.3 per million age related population (pmarp) in 2010 [1]. Incidence rates for ERF have also shown an increasing trend during this time period rising to 8.1 pmarp in 2010 [1].

The objectives of this report are:

(i) To describe the UK prevalence, incidence, causes of ERF and modality of treatment of children on RRT on 31st December 2011
(ii) To describe trends of the same over the past 15 years, and
(iii) To describe pre-emptive transplantation rates and survival of children on RRT aged <16 years old in the UK.

Methods

Data collection was performed by all 13 paediatric nephrology centres managing children on RRT in the UK in 2011. Most centres submitted data electronically to the UK Renal Registry (UKRR) with only four centres submitting data using paper-based data returns this year. These data items were then manually entered into the current paediatric UKRR database. Southampton was only able to provide a limited electronic dataset due to recent implementation of a bespoke renal IT system.

In this report, patient groups are described as: (i) 'prevalent' group: patients who were receiving RRT on the 31st December 2011; (ii) 'incident' group: patients who started RRT between 1st January and 31st December 2011; and (iii) '5 year' groups: patients who started RRT in the periods of 1997–2001, 2002–2006 and 2007–2011.

The populations used to calculate the incidence and prevalence rates were obtained from the Office for National Statistics (ONS) [2]. The mid-2011 population estimate produced by the ONS, based on the 2011 Census, was used for calculating the 2011 incident and prevalent group rates; the 2001 Census data was used for the 1997–2001, 2002–2006 and 2007–2011 '5 year' groups.

Infants under the age of 3 months and 'late presenters' (defined as children commencing dialysis within three months following review by a paediatric nephrologist) were excluded from analyses when calculating pre-emptive transplantation rates. For survival analysis, only patients starting RRT between 1st January 1997 and 31st December 2010 were included to ensure a minimum of 1 year follow up at the date of census, 31st December 2011, and were followed up to a maximum age of 16 years.

Statistical analyses

Statistical analyses were performed using SAS 9.3, with group analyses using Chi-square test and median analyses using Kruskal-Wallis test. A Cox regression model was used in calculating hazard ratios for patient survival, adjusting for gender, age at start of RRT, and RRT modality as a time dependent variable. Survival probabilities were calculated using univariate Kaplan Meier curves.

Results

Accuracy and completeness of data returns

Significant efforts to improve the overall accuracy of the entire paediatric dataset by clinical teams, data managers and statisticians have continued this year, resulting in improved accuracy of the database, analyses and conclusions. As for data returns, the procedures for data collection and processing are still evolving but are yielding consistent results, now with near 100% data completeness achieved by all centres for a range of data items including, gender, ethnicity, treatment modality at start of RRT and age at start of RRT. Data completeness for other core items was better than previous reports and is shown in table 4.1 [1].

The UK paediatric prevalent ERF population in 2011

A total of 856 children and young people under 18 years with ERF were receiving treatment at paediatric nephrology centres in 2011. At the census date, 80.1% had a functioning kidney transplant, 10.5% were receiving peritoneal dialysis (PD) and 9.4% were receiving haemodialysis (HD).

Patients aged 16–18 years may receive their medical care either in a paediatric or in an adult nephrology centre. As data were incomplete for the 16–18 year old adolescent patients they have been excluded from the majority of subsequent analyses (particularly when describing incidence and prevalence rates). This report therefore presents data largely relating to patients less than 16 years of age.

There were 675 children under 16 years of age receiving RRT in the UK in 2011. Table 4.2 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 across all age groups

Table 4.1. Data completeness for paediatric prevalent ERF population in 2011

		Percentage completeness				
Centre	N	First seen date	Height at RRT start	Weight at RRT start	Creatinine at RRT start	Primary renal diagnosis
Blfst_P	32	93.8	87.5	87.5	93.8	100.0
Bham_P	88	96.6	94.3	98.9	100.0	100.0
Brstl_P	55	100.0	98.2	98.2	100.0	100.0
Cardf_P	22	95.5	100.0	100.0	95.5	100.0
Glasg_P	57	98.3	94.7	100.0	100.0	100.0
L Eve_P	99	99.0	63.6	69.7	70.7	100.0
L GOSH_P	178	98.9	81.5	88.2	89.3	99.4
Leeds_P	71	100.0	87.3	98.6	98.6	100.0
Livpl_P	37	91.9	75.7	81.1	78.4	94.6
Manch_P	70	100.0	88.6	100.0	100.0	100.0
Newc_P	35	100.0	74.3	88.6	91.4	100.0
Nottm_P	87	96.6	75.9	83.9	97.7	100.0
Soton_P	25	92.0	20.0	20.0	20.0	88.0
UK	**856**	**97.9**	**81.5**	**88.0**	**90.1**	**99.3**

Table 4.2. The UK paediatric prevalent ERF population in 2011, by age group and gender

	All patients		Males		Females		
Age group	N	pmarp	N	pmarp	N	pmarp	Ratio M:F
0–1.99 years	19	11.9	15	18.4	4	5.1	3.6
2–3.99 years	46	29.2	30	37.2	16	20.8	1.8
4–7.99 years	137	46.5	87	57.7	50	34.8	1.7
8–11.99 years	176	63.7	108	76.3	68	50.4	1.5
12–15.99 years	297	98.8	168	108.9	129	88.1	1.2
Under 16 years	**675**	**56.8**	**408**	**67.0**	**267**	**46.1**	**1.5**

pmarp – per million age related population

with an overall male to female prevalence ratio of 1.5. The reported prevalence rate in under 16 year olds was 56.8 pmarp.

Table 4.3 shows the ethnic origin of current RRT patients and their prevalence rates. Increasing prevalence pmarp was observed with increasing age in all ethnic groups. Children from ethnic minorities displayed higher prevalent rates of RRT when compared with White children, with South Asian children displaying the highest prevalence rates.

Table 4.3. The UK paediatric prevalent ERF population by age and ethnic group in 2011*

	White		South Asian		Black		Other**
Age group	N	pmarp	N	pmarp	N	pmarp	N
0–3.99 years	48	18.6	10	47.4	0	0.0	7
4–7.99 years	101	42.2	21	107.7	6	76.9	9
8–11.99 years	133	52.0	24	115.1	8	95.9	9
12–15.99 years	221	82.0	40	182.1	14	159.4	21
Under 16 years	**503**	**49.2**	**95**	**113.9**	**28**	**83.9**	**46**

pmarp-per million age related population
*ethnicity data missing in 3 children who are excluded from this table
**pmarp not expressed for group 'Other', as heterogeneous group

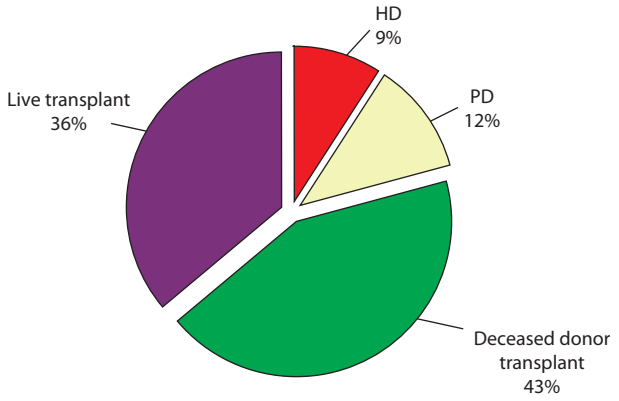

Fig. 4.1. RRT treatment used by prevalent paediatric patients <16 years old in 2011

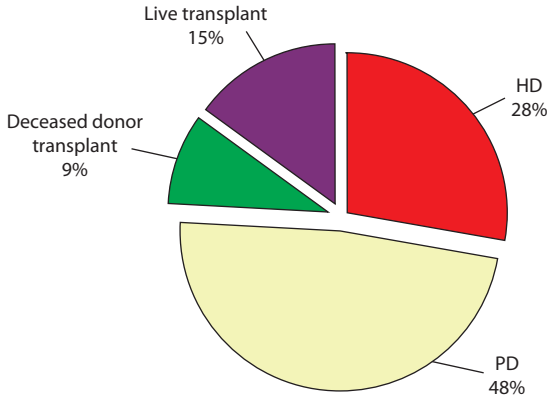

Fig. 4.2. Treatment modality at start of RRT in prevalent paediatric patients under 16 years of age in 2011

Modality of treatment

Current treatment modality in the prevalent paediatric population less than 16 years old in 2011 is displayed in figure 4.1. Of the 79% with a functioning transplant, 54% received deceased donor transplantations.

The treatment modality in use at the start of RRT is displayed in figure 4.2. This shows that 48% of patients were treated with PD at the start of RRT whilst 28% of patients were treated with HD. Twenty-four percent of children under 16 were reported to have received a pre-emptive transplant.

Further treatment modality analysis by age is shown in table 4.4 which demonstrates that in the under 2 year olds the majority of patients were being treated with PD (63.2%). This contrasts with older children in the 12 to 15.99 year age group where 85.9% had a functioning graft and where similar proportions were on HD and PD. Subsequent analysis of RRT modality by gender and ethnicity showed no difference. However as absolute sub-group numbers are small, caution is needed in conducting any comparative analyses.

Cause of ERF

Table 4.5 and figure 4.3 show the diagnostic categories for the prevalent ERF population under 16 years in 2011. There has been a marked improvement in data completeness in this category over the last few years with missing data falling to only 0.4% from 2.9% in the 2010 report [1]. Of the 675 patients, renal dysplasia ± reflux remained the commonest condition causing ERF (32.3%), whilst there were no documented patients with drug nephrotoxicity.

As for associated comorbidities at the onset of RRT, table 4.6 shows that congenital abnormalities were the

Table 4.4. Current treatment modality by age in the prevalent paediatric ERF population in 2011

	Current treatment							
	HD		PD		Live transplant		Deceased donor transplant	
Age group	N	%	N	%	N	%	N	%
0–1.99 years	5	26.3	12	63.2	2	10.5	0	0.0
2–3.99 years	10	21.7	17	37.0	15	32.6	4	8.7
4–7.99 years	13	9.5	18	13.1	52	38.0	54	39.4
8–11.99 years	10	5.7	14	8.0	64	36.4	88	50.0
12–15.99 years	24	8.1	18	6.1	111	37.4	144	48.5
16–17.99 years	19	10.5	11	6.1	57	31.5	94	51.9
Under 16 years	**62**	**9.2**	**79**	**11.7**	**244**	**36.1**	**290**	**43.0**
Under 18 years	**81**	**9.4**	**90**	**10.5**	**301**	**35.2**	**384**	**44.9**

Table 4.5. Number, percentage and gender by primary renal disease as cause of ERF in the prevalent paediatric ERF population under 16 years in 2011*

Diagnostic group	Total	%	Male	Female	M:F ratio
Renal dysplasia ± reflux	218	32.3	131	87	1.5
Obstructive uropathy	121	17.9	114	7	16.3
Glomerular disease	93	13.8	44	49	0.9
Congenital nephrotic syndrome	66	9.8	37	29	1.3
Tubulo-interstitial diseases	52	7.7	23	29	0.8
Uncertain aetiology	31	4.6	14	17	0.8
Renovascular disease	29	4.3	18	11	1.6
Polycystic kidney disease	26	3.9	10	16	0.6
Metabolic	22	3.3	11	11	1.0
Malignancy & associated disease	14	2.1	5	9	0.6
Missing	3	0.4	1	2	0.5
Total	**675**	**100.0**	**408**	**267**	**1.53**

*this year there were no patients with ERF secondary to 'drug nephrotoxicity'

commonest, reported in 9.2%, whilst both developmental delay and syndromic diagnoses each were reported in over 6% of patients. Prematurity was also frequently reported (7.1%), whilst neural tube defects were least common in 0.3% of patients. Overall 68.9% of patients had no registered comorbidities, with 20.4% having one comorbidity listed, and 10.7% having two or more comorbidities. Centre analysis showed significant variation in reporting of registered co-morbidities, with some centres, Birmingham (88%), Glasgow (83%), GOSH (80%) and Cardiff (80%) reporting no comorbidity in the majority of their patients, as compared to other centres which reported no comorbidity in a smaller proportion of patients, Bristol (43%) and Leeds (45%).

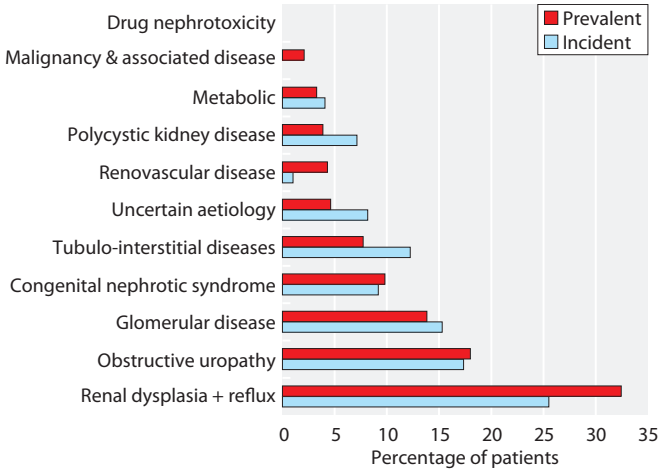

Fig. 4.3. Primary renal disease percentage in incident and prevalent paediatric ERF patients in 2011 for whom a causative diagnosis was reported

The UK incident paediatric ERF population in 2011

There were 114 patients under 18 years of age who commenced RRT at paediatric renal centres in 2011. As previously, the following analyses are restricted to the 99 patients who were under 16 years of age.

The incidence rate of RRT was 8.3 pmarp in 2011. Patients commencing RRT in 2011 are displayed by age and gender in table 4.7.

Table 4.8 shows that the reported incidence of RRT has been rising since 1997, with the highest incidence rates seen in the 12–15.99 year age group, with the 0–1.99 year age group having the next highest rates.

Table 4.6. Registered comorbidities at onset of RRT in prevalent paediatric patients aged <16 years with ERF in 2011

Comorbidity	N	Percentage all RRT patients
Cerebral palsy	11	1.6
Chromosomal abnormality	18	2.7
Congenital abnormality	62	9.2
Congenital heart disease	12	1.8
Consanguinity	24	3.6
Developmental delay	46	6.8
Diabetes	2	0.3
Family member with ERF	19	2.8
Liver disease	12	1.8
Malignancy	7	1.0
Neural tube defect	2	0.3
Prematurity	48	7.1
Psychological disorder	8	1.2
Syndromic diagnosis	43	6.4
No reported comorbidity	465	68.9
One reported comorbidity	138	20.4
Two or more comorbidities	72	10.7

Table 4.7. The incident paediatric ERF population in the UK in 2011, by age group and gender

	All patients		Male		Female		
Age group	N	pmarp	N	pmarp	N	pmarp	M:F ratio
0–1.99 years	16	10.1	12	14.7	4	5.1	2.9
2–3.99 years	10	6.3	9	11.2	1	1.3	8.6
4–7.99 years	14	4.8	9	6.0	5	3.5	1.7
8–11.99 years	25	9.0	12	8.5	13	9.6	0.9
12–15.99 years	34	11.3	21	13.6	13	8.9	1.5
Under 16 years	**99**	**8.3**	**63**	**10.4**	**36**	**6.2**	**1.7**

pmarp – per million age related population

Trends in ERF demographics

There were 1,656 children under 16 years of age who had received RRT in the UK over the 15-year period between 1997–2011. Analysis of ERF demographics for children less than 16 years of age over this period included 534 patients reported to the paediatric registry between 1997–2001, 527 between 2002–2006 and 595 between 2007–2011. Comparing the current 5 year period with the two previous 5 year periods there has been an overall increase in the number of children treated with RRT, particularly in children aged under 4 years (table 4.9). The percentage of children on RRT who are from South Asian or Black ethnic backgrounds has also increased during this period (table 4.10). The reported patient population at most paediatric renal centres has similarly grown in size since 1997–2001 with Belfast showing the largest proportional rise (table 4.11).

Table 4.8. Reported average incident 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	1997–2001	2002–2006	2007–2011
0–1.99 years	11.6	11.7	13.2
2–3.99 years	6.3	4.7	8.2
4–7.99 years	5.3	6.5	6.4
8–11.99 years	8.3	7.6	9.1
12–15.99 years	13.1	13.4	14.6
Under 16 years	**8.9**	**9.1**	**10.3**

Table 4.12 shows the number and percentage of children receiving RRT with each of the major reported comorbidities over the last 15 years. Whilst congenital abnormalities (6.9%), developmental delay (6.2%) and syndromic diagnoses (6.4%) were the most common reported comorbidities in 2007–2011, there has been little change in the percentage of children receiving RRT with a reported comorbidity over the last 15 years.

As for changes in modality at the start of RRT, figure 4.4 shows that the percentage of children who were using PD at the start of RRT has fallen from 51.5% in 1997–2001 to 44% in 2007–2011 whilst the percentage commencing RRT on HD has increased from 22.8% in 1997–2001 to 29.4% in 2007–2011. During this period the overall percentage receiving a transplant at the start of RRT has remained largely unchanged though living donation has risen from 7.5% in 1997–2001 to 16.4% in 2007–2011, with a

Table 4.9. Number and percentage of children who commenced RRT, by age group and 5 year period, at start of RRT

	1997–2001		2002–2006		2007–2011		1997–2011
Age group	N	%	N	%	N	%	% change
0–1.99 years	82	15.4	81	15.4	104	17.5	2.1
2–3.99 years	46	8.6	31	5.9	61	10.3	1.6
4–7.99 years	80	15.0	92	17.5	89	15.0	0.0
8–11.99 years	130	24.3	113	21.4	126	21.2	−3.2
12–15.99 years	196	36.7	210	39.8	215	36.1	−0.6
Under 16 years	**534**		**527**		**595**		

Table 4.10. Number and percentage of children under 16 years who commenced RRT, by ethnicity and 5 year period of starting RRT*

	1997–2001		2002–2006		2007–2011		1997–2011
Ethnic group	N	%	N	%	N	%	% change
White	413	78.4	407	78.6	436	74.7	−3.7
South Asian	78	14.8	80	15.4	88	15.1	0.3
Black	14	2.7	13	2.5	24	4.1	1.5
Other	22	4.2	18	3.5	36	6.2	2.0
Under 16 years	**527**		**518**		**584**		

*There were 7 children in 1997–2001, 9 in 2002–2006 and 11 in 2007–2011 with no ethnicity recorded and these are excluded from this table

Table 4.11. Number and percentage of children under 16 years reported to the UKRR, by renal centre and 5 year period of starting RRT*

	1997–2001		2002–2006		2007–2011		1997–2011
Centre	N	%	N	%	N	%	% change
Blfst_P	15	2.8	15	2.9	27	4.5	1.7
Bham_P	50	9.4	54	10.3	62	10.4	1.0
Brstl_P	38	7.2	37	7.0	35	5.9	−1.3
Cardf _P	14	2.6	19	3.6	16	2.7	0.1
Glasg_P	42	7.9	29	5.5	46	7.7	−0.2
L Eve_P	55	10.4	45	8.6	68	11.4	1.1
L GOSH_P	94	17.7	101	19.2	114	19.2	1.5
Leeds_P	44	8.3	52	9.9	47	7.9	−0.4
Livpl_P	21	4.0	31	5.9	19	3.2	−0.8
Manch_P	52	9.8	51	9.7	50	8.4	−1.4
Newc_P	29	5.5	27	5.1	27	4.5	−0.9
Nottm_P	59	11.1	46	8.7	64	10.8	−0.4
Soton_P	18	3.4	19	3.6	20	3.4	0.0
Total <16	**531**		**526**		**595**		

*there were 3 children in 1997–2001 and 1 in 2002–2006 with unknown centre of RRT start and these are excluded from this table

Table 4.12. Trends in comorbidity at the start of RRT in the paediatric population under 16 years, by 5 year period

	1997–2001		2002–2006		2007–2011		1997–2011
Comorbidity	N	%	N	%	N	%	% change
Cerebral palsy	5	0.9	9	1.7	9	1.5	0.6
Chromosomal abnormality	18	3.4	8	1.5	17	2.9	−0.5
Congenital abnormality	36	6.7	54	10.2	41	6.9	0.1
Congenital heart disease	15	2.8	7	1.3	17	2.9	0.0
Consanguinity	26	4.9	20	3.8	16	2.7	−2.2
Developmental delay	46	8.6	40	7.6	37	6.2	−2.4
Diabetes	3	0.6	5	0.9	2	0.3	−0.2
Family member with ERF	26	4.9	18	3.4	10	1.7	−3.2
Liver disease	0	0.0	9	1.7	13	2.2	2.2
Malignancy	8	1.5	7	1.3	2	0.3	−1.2
Neural tube defect	3	0.6	4	0.8	2	0.3	−0.2
Prematurity	35	6.6	23	4.4	29	4.9	−1.7
Psychological disorder	12	2.2	7	1.3	8	1.3	−0.9
Syndromic diagnoses	27	5.1	48	9.1	38	6.4	1.3
No reported comorbidity	363	68.0	341	64.7	440	73.9	6.0
One reported comorbidity	109	20.4	133	25.2	99	16.6	−3.8
Two or more comorbidities	62	11.6	53	10.1	56	9.4	−2.2

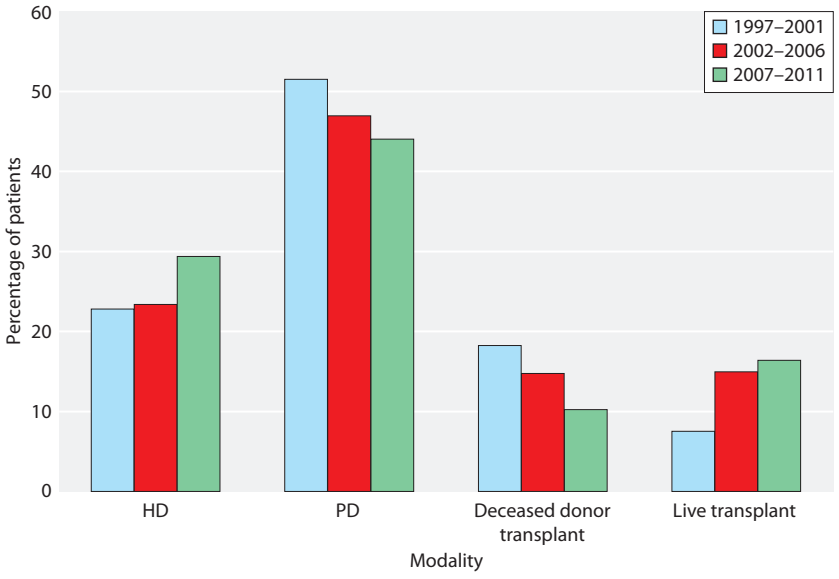

Fig. 4.4. Treatment modality at start of RRT by 5 year time period

corresponding fall in deceased donor transplantation from 18.2% to 10.2% for the same time period.

Table 4.13 shows the diagnostic categories for 523 of the 534 (97.9%) patients in 1997–2001, for 512 of the 528 (97%) patients in 2002–2006 and 582 of the 596 (97.7%) patients in 2007–2011 aged <16 years for whom a causative diagnosis was reported.

Overall there has been an increase in the percentage of children receiving RRT with unknown aetiology between 1997–2001 and 2007–2011 (1.3% vs. 6.0%) and a decrease in glomerular disease (22.2% vs. 20.1%) though absolute numbers are very small (table 4.13).

Pre-emptive transplantation

Of a total of 1,656 patients who started RRT between 1997–2011, 448 patients were excluded from analysis (93 patients were excluded due to being aged <3 months, and a further 355 patients were excluded due to being 'late presenters'). Of 1,208 patients identified as being aged 3 months to <16 years and having started RRT between 1997–201l, pre-emptive transplantation was seen to occur in 30.6% of patients and was significantly higher in males (33.6%) than females (25.8%), $p = 0.004$ (table 4.14). Ethnicity was also seen to be a significant factor, with children from Black (12.1%)

Table 4.13. 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 and observed change in proportion of patients in each diagnostic group*

	1997–2001		2002–2006		2007–2011		1997–2011
Primary renal diagnosis	N	%	N	%	N	%	% change
Renal dysplasia ± reflux	163	31.2	175	34.2	173	29.7	−1.4
Obstructive uropathy	81	15.5	78	15.2	93	16.0	0.5
Glomerular disease	116	22.2	101	19.7	117	20.1	−2.1
Congenital nephrotic syndrome	33	6.3	23	4.5	38	6.5	0.2
Tubulo-interstitial diseases	41	7.8	42	8.2	46	7.9	0.1
Uncertain aetiology	7	1.3	28	5.5	35	6.0	4.7
Renovascular disease	22	4.2	15	2.9	20	3.4	−0.8
Polycystic kidney disease	14	2.7	15	2.9	21	3.6	0.9
Metabolic	30	5.7	19	3.7	29	5.0	−0.8
Malignancy & associated disease	4	0.8	10	2.0	8	1.4	0.6
Drug nephrotoxicity	12	2.3	6	1.2	2	0.3	−2.0

*there were 11 children in 1997–2001, 16 in 2002–2006 and 14 in 2007–2011 with no PRD recorded and these are excluded from this table

Table 4.14. Demographics of pre-emptive transplantation in children aged 3 months to 16 years in the UK between 1997–2011, analysed by 5 year time period, gender, ethnicity, age at start of RRT and primary renal diagnosis

	N	N (%) pre-emptively transplanted
Total cohort analysed (1997–2011)	1,208	370 (30.6)
Time Period		
1997–2001	389	101 (26.0)
2002–2006	400	131 (32.8)
2007–2011	419	138 (32.9)
Gender		
Male	750	252 (33.6)
Female	458	118 (25.8)
Ethnicity		
Black	33	4 (12.1)
Other	49	13 (26.5)
South Asian	189	34 (18.0)
White	912	306 (33.6)
Age at start of RRT		
3 months–1.99 years	118	8 (6.8)
2–3.99 years	113	27 (23.9)
4–7.99 years	211	71 (33.7)
8–12.99 years	287	96 (33.5)
12–15.99 years	479	168 (35.1)
Primary Renal Diagnosis		
Renal dysplasia ± reflux	379	154 (40.6)
Glomerular disease	231	27 (11.7)
Obstructive uropathy	220	95 (43.2)
Tubulo-interstitial diseases	78	16 (20.5)
Congenital nephrotic syndrome	77	4 (5.2)
Metabolic	66	23 (34.9)
Polycystic kidney disease	39	16 (41.0)
Renovascular disease	32	11 (34.4)
Uncertain aetiology	31	7 (22.6)
Malignancy & associated disease	13	2 (15.4)
Drug nephrotoxicity	12	3 (25.0)

and South Asian (18%) ethnicity having significantly lower rates of transplantation than their White counterparts (33.6%), $p < 0.0001$. Analysis by age at start of RRT showed that as expected, the lowest rate of pre-emptive transplantation was in the 3 months to 2 year group (6.8%), whilst children aged 4 to 16 years had similar rates of pre-emptive transplantation. As for PRD, children with obstructive uropathy (43.2%), polycystic kidney disease (41%) and renal dysplasia ± reflux (40.6%) had the highest rates of pre-emptive transplantation, whilst those with congenital nephrotic syndrome (5.2%) and glomerular disease (11.7%) had the lowest rates. Over time there appears to have been a rise in pre-emptive transplantation rates, rising from 26% in 1997–2001 to 32.9% in 2007–2011, $p = 0.05$ (table 4.14).

Table 4.15. Modality, gender, ethnicity and primary renal diagnosis of patients transferred out of paediatric nephrology centres in 2011

	N	% distribution
Modality		
HD	8	8.6
PD	5	5.4
Transplant	80	86.0
Gender		
Female	32	65.6
Male	61	34.4
Ethnicity*		
Black	0	0.0
Other	2	2.2
South Asian	8	8.9
White	80	88.9
Primary renal diagnosis*		
Renal dysplasia ± reflux	33	36.3
Glomerular disease	22	24.2
Obstructive uropathy	11	12.1
Tubulo-interstitial diseases	7	7.7
Metabolic	6	6.6
Polycystic kidney disease	3	3.3
Renovascular disease	3	3.3
Congenital nephrotic syndrome	2	2.2
Uncertain aetiology	2	2.2
Drug nephrotoxicity	1	1.1
Malignancy & associated disease	1	1.1

*ethnicity missing in 1 patient, and PRD missing in 3 patients

Transfer of patients to adult renal services in 2011

A total of 93 patients were reported by paediatric nephrology centres to have been transferred to adult renal services in 2011. The median age of patients transferred out was 18.0 years with an inter-quartile range of 17.5 years to 18.8 years. Manchester, Leeds and Bristol had the largest numbers of adolescents transferred to adult services in 2011.

Table 4.15 shows that of the transferred patients 65.6% were male, with ethnic minorities constituting 11.1% of patients. The vast majority (86%) had a functioning renal transplant at the time of transfer to an adult renal centre. Renal dysplasia ± reflux was the primary renal diagnosis in over a third of patients.

Survival of children on RRT during childhood

Of patients under the age of 16, 1,551 were identified as starting RRT between 1997 and 2010 at paediatric

Table 4.16. Survival hazard ratio during childhood for paediatric RRT patients age <16 years in the UK adjusted for age at start of RRT, gender and RRT modality

	Hazard ratio	Confidence interval	p-value
Age			
0–1.99 years	5.13	2.62–10.03	<0.0001
2–3.99 years	2.69	1.20–6.02	0.02
4–7.99 years	1.48	0.65–3.34	0.35
8–11.99 years	1.19	0.52–2.71	0.68
12–16 years	1.00	–	–
Gender			
Female	1.31	0.88–1.94	0.19
Male	1.00	–	–
RRT modality			
Dialysis	6.04	3.28–11.15	<0.0001
Transplant	1.00	–	–

centres in the UK and were included in the survival analyses. At the census date (31st December 2011) there were a total of 104 deaths within the cohort on RRT at age <16, with a median follow up time of 3.4 years (range of 1 day to 15 years). Table 4.16 shows the survival hazard ratios after adjustment for age at start of RRT, gender and RRT modality, and highlights that children starting RRT at 0–1.99 years have the worst survival outcomes with a hazard ratio of 5.13 (CI 2.62–10.03, $p < 0.0001$) when compared to 12–16 years olds. Outcomes in the 2–3.99 age group were also significantly lower with a hazard ratio of 2.69 (CI 1.2–6.02, $p = 0.02$). Gender was not seen to have any impact on survival although being on dialysis as expected was seen to lower survival significantly compared to having a functioning transplant with a hazard ratio of 6.04 (3.28–11.15, $p < 0.0001$). Figure 4.5 shows unadjusted Kaplan Meier survival probabilities. As the maximum age of follow up was restricted to 16 years, it was not possible to calculate 10 year survival probabilities for patients starting RRT aged >8 years, or 5 year survival probability for children starting RRT aged >12 years. This figure again highlights worse outcomes for those aged 0–1.99 years.

Mortality data in 2011

There were nine deaths in renal paediatric centres in 2011. The reported mortality of children with treated ERF in 2011 in the UK at paediatric centres was 1.3% (9/675). The median age at death was 7.8 years with a range of 1.7 years to 16.9 years. Sepsis was cited as a cause of death in four patients, two of which were associated with peritonitis and one due to bowel

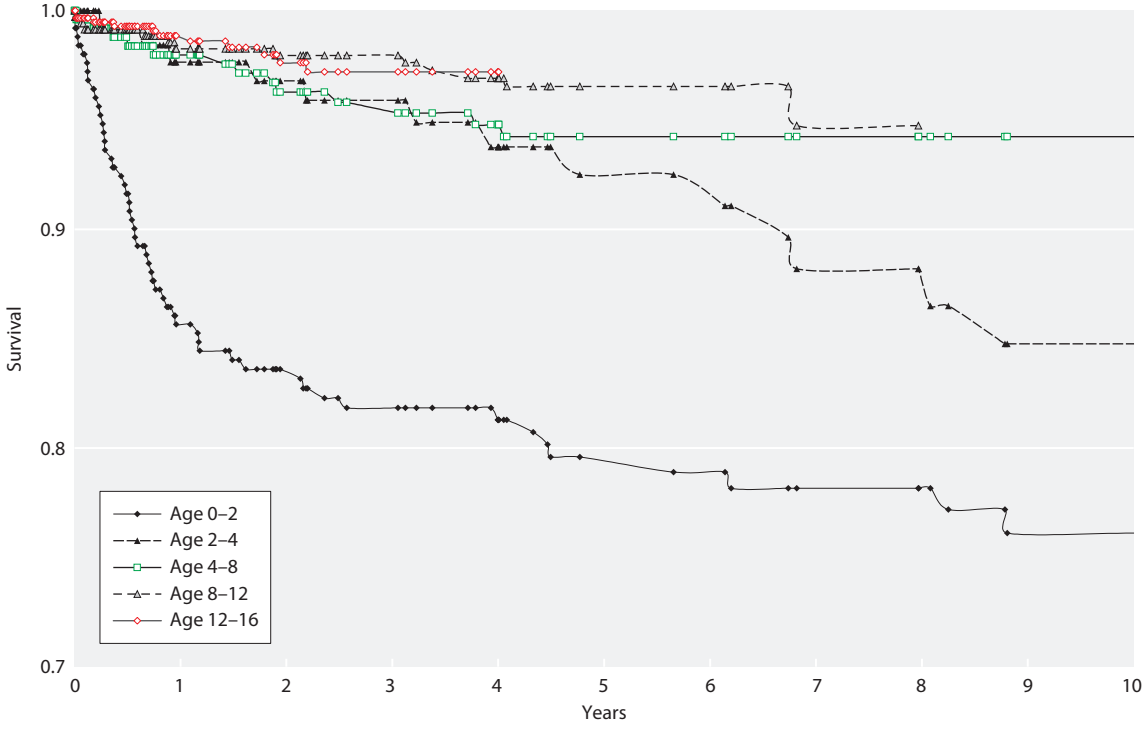

Fig. 4.5. Unadjusted KM in paediatric patients starting RRT between 1997 and 2010, by age at start

obstruction. Haemorrhage (gastrointestinal bleed and an intra-cerebral haemorrhage) was the cause of death in a further two patients. A clear cause of death could not be identified in the three remaining patients who died in 2011.

Discussion

This report from the Paediatric Renal Registry has focussed on the current demography and the demographic trends over the past 15 years of the UK paediatric ERF population.

This report includes 675 children and adolescents under 16 years of age, who were receiving RRT in 2011. The sub-section on the trends in demographics includes children and adolescents under 16 years of age on RRT; 534 from 1997–2001, 527 from 2002–2006 and 595 from 2007–2011.

Data completeness

The ongoing sustained effort to improve data accuracy must continue and the aim to move to full electronic annual returns from all centres remains. A revised data set (The NEW Paediatric Dataset) will be used for future registry returns. These ongoing efforts to improve the quality and consistency of the data received will be rewarded by enabling enhanced interpretation of centre specific measures of clinical performance.

Incidence, prevalence and trends

The incidence rate of RRT in the less than 16 year age group was 8.3 pmarp in 2011; this rate has been rising since 1997. The overall prevalence rate of RRT in the less than 16 year age group was 56.8 pmarp. The prevalence of RRT increased with age and was higher in males across all age groups. The number of children receiving RRT also continued to rise particularly in the under 2-year age group. Overall, there was a continuing trend of increased prevalence of children on RRT with increased 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 has led to a steady increase in the prevalent ERF population.

Treatment modality of ERF and observed trends 1997–2011

Peritoneal dialysis was the initial treatment modality for 48% of children at the start of treatment, 28% commenced HD and 24% received a pre-emptive transplant. Age influenced the modality of RRT with the majority of the under 2's (63%) receiving PD. Overall the majority of prevalent children (79%) on RRT had a functioning transplant.

Pre-emptive transplantation

Pre-emptive transplantation was seen to occur in 30% of children under 16 years age. The rate of pre-emptive transplantation has increased over the past 15 years (26.0% in 1997–2001 to 33% in 2007–2011). There were significantly lower rates of pre-emptive transplantation in girls and ethnic minorities and further detailed studies investigating these would be important.

Comorbidities

At the onset of RRT, 31% of patients had 1 or more associated comorbidity. This overall percentage has remained similar over the past 15 years. Of note is the significant variation in registered comorbidity rate between centres (43% to 88%, data not shown); it is likely that this is influenced by different reporting practices between centres. It is hoped that the recently agreed NEW Paediatric Dataset will help improve consistency and reliability of data submission thus improving report accuracy.

Causes of ERF and observed trends 1997–2011

As previously, renal dysplasia ± reflux (30%), glomerular disease (20%) and obstructive uropathy (16%) were the commonest listed aetiologies for children with ERF. These accounted for 66% of all patients for whom a primary diagnosis had been reported. Observation of trends over the 15-year period showed an increase in the percentage of children receiving RRT with unknown aetiology.

Transfer out and survival data

Data relating to transfer to adult renal services is included in the current report. The median age of transfer was 18.0 years. Of patients receiving RRT, 86% transferred with a functioning renal transplant. There appears to be variation in practice between centres regarding transition and transfer out arrangements; it is also likely that variability exists in reporting of 'transfer out' timelines to the registry for patients being transitioned to adult centres. Consensus regarding terminology will facilitate future comparative interpretation.

Survival data of children on ERF during childhood who commenced RRT between 1997 and 2010 highlights

the less favourable outcome for children less than 2 years of age. Longer term survival data up to 5 years was available for those <12 years and 10 year survival data for those <8 years only. For the majority of children on RRT long term survival data will need follow up in to young adulthood. This is the focus of an ongoing project of the UK Renal Registry.

Conflicts of interest: none

References

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