Chapter 14
Demography of the UK Paediatric Renal Replacement Therapy population in 2008

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Key Words
Aetiology · Children · Demography · End stage renal disease · Established renal failure · Incidence · Mortality · Prevalence

Abstract
Aims: To describe the demographics of the paediatric RRT population in the UK and analyse changes in demographics with time. ***Methods:*** Extraction and analysis of data from the UK Paediatric Renal Registry and the UK Renal Registry (UKRR). ***Results:*** The UK paediatric established renal failure (ERF) population in December 2008 was 905 patients. The prevalence under the age of 16 years was 56 per million age related population (pmarp) and the incidence 7.4 pmarp. The incidence and prevalence for South Asian patients was much higher than that of the White and Black populations. Renal dysplasia was the most common cause of ERF accounting for 33% of prevalent cases. Diseases with autosomal recessive inheritance were a common cause of ERF in all ethnic groups, 23.5% of prevalent and 18% of incident cases. Whilst the incidence and prevalence of diseases with autosomal recessive inheritance in the South Asian population was 3 times that of the white population, this was not the sole reason for the increased proportion of South Asian patients with ERF, as diseases with no defined inheritance were twice as common in this ethnic group than in White patients. Prevalent mortality stood at 9.4%. Most deaths were in patients presenting with ERF early in life and mortality varied markedly according to the aetiology of ERF. The proportion with new grafts from living donors has steadily risen to 54%. Children from ethnic minority groups were less likely to have an allograft and living donation was less frequent in this population. For those on dialysis, 56% were receiving peritoneal dialysis. This was the main treatment modality for patients under 4 years of age. ***Conclusions:*** The paediatric ERF population continued to expand slowly. Incidence and prevalence rates were stable and similar to other developed nations. The high incidence in patients from ethnic minority groups will lead to a greater proportion of the population being from these groups in time. To maintain the high proportion of engrafted patients it will be necessary to encourage living donation in the ethnic minority population. Case note analysis of the factors involved in mortality would be valuable.

Introduction

As planned at the outset and 13 years after its conception, data from the UK Paediatric Renal Registry has now

been merged into the main UK Renal Registry data repository. This move will allow more complete analyses in the future, including analyses not limited by the artificial boundaries set when patients transfer from paediatric to adult centres. This will be particularly valuable when looking at the teenage and young adult population where complete data for incidence, prevalence and demographic features have been absent in the past. The amalgamation will also allow for more accurate tracking of patients for analysis of outcome.

Whilst data within the paediatric registry had always centred around a census date of the 1st April, the census date used by the adult registry has been the 31st December. This latter census date has now been adopted by the paediatric registry group for future reports as it is in keeping with both the adult registry and the EDTA. As a result of this the current report is based around the census date of the 31st December 2008. The data is thus little changed from that reported in the 2008 Report which used the census date of the 1st April 2008 [1].

Within the UK, treatment of paediatric patients with established renal failure (ERF) takes place within 13 regional centres (Scotland 1, Wales 1, Northern Ireland 1, England 10). All centres have facilities for peritoneal dialysis and haemodialysis. Ten of the 13 centres undertake transplantation for children. Due to the ongoing amalgamation of data, figures for this report have been taken from two data streams. New patients at the smallest centre (Southampton) have not been logged since 2007. The impact upon the figures of these omissions is a potential underestimate of between two and eight patients.

The term established renal failure (ERF) used throughout this chapter is synonymous with the terms end stage renal failure (ESRF) and end stage renal disease (ESRD) which are in more widespread international usage. Within the UK, patient groups have disliked the term 'end stage'; the term ERF was endorsed by the English National Service Framework for Renal Services, published in 2004.

Methods

Data collection took place across the UK looking at patient status on 31st December 2008. Some centres collected data electronically and used the data transfer channel to the UK Renal Registry for data transfer. Other centres used paper data collections which were then manually input into the current paediatric registry database (see chapter 15 for further details). Data were then extracted and statistical analyses performed using SAS 9.1.3.

Results

The UK paediatric prevalent ERF population

The UK paediatric ERF population on 31st December 2008 was 905 patients. The age, ethnicity and gender distribution is shown in table 14.1. The overall gender ratio of males to females was just over 1.5 to 1. Ethnic minority groups composed just under 22% of the population.

Using previous BAPN audits in 1986 and 1992, together with subsequent data from the UK paediatric registry it was possible to look at the growth of the paediatric ERF population. To allow direct comparison, these data only included those under the age of 15 years and are shown in figure 14.1. The population of patients with ERF under the age of 15 years continued to grow slowly. This recent growth is more in line with the ongoing growth of the general UK population with a fairly steady increase in prevalence compared to the early years where the population rose rapidly as the

Table 14.1 The UK paediatric prevalent ERF population on 31st December 2008, by age, gender and ethnicity

	Patients	Male	Female	Ratio	% total
White	711	443	268	1.65	78.6
S Asian	146*	76	65	1.17	16.1
Black	25	16	9	1.78	2.8
Other	22	11	11	1.00	2.4
Total	**905**	**546**	**354**	**1.54**	**100.0**
<18 years	840	505	330	1.53	92.8
<15 years	559	342	214	1.60	61.8

* gender unknown for 5 South Asian patients

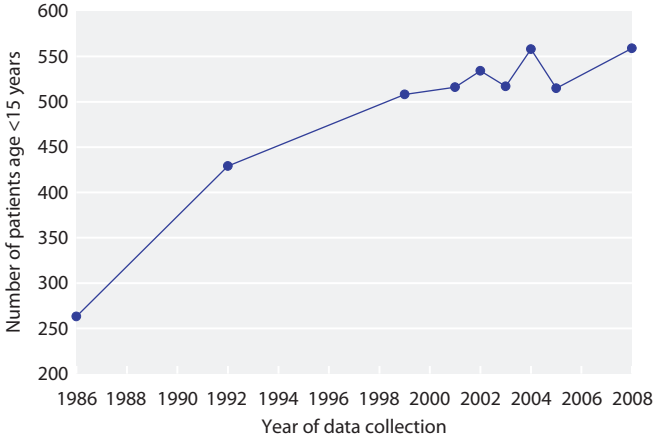

Fig. 14.1. Prevalent patients below 15 years of age on RRT in the UK (1986–2008)

Table 14.2. Prevalent paediatric ERF population by age and year of data collection

	Patient population data					
Age group (yrs)	1986	1992	1999	2002	2005	2008
0–1.99		16	18	14	14	19
2–4.99		55	46	58	45	78
5–9.99		150	151	147	157	148
10–14.99		208	293	315	299	314
15–19.99			253	259	253	344
Total <15	263	429	508	534	515	559
Total <20			761	793	768	905

potential for treatment became apparent. The age distribution of the population is shown in table 14.2. This chart is arranged with data from the census reports of 1986 and 1989 together with prevalent patient numbers every three years from 1999 when paediatric reports were issued.

The proportion of ethnic minority (EM) patients has increased (21.4% vs. 16.9%) and when compared to the previous most complete data collection in 2004, this increase was significant ($p = 0.023$). These data are shown in figure 14.2.

All patients under the age of 16 years in the UK are managed by paediatric centres. To allow meaningful comparisons and equal age distributions, patients were divided into four year age bands from birth to 20 years. These data are shown in table 14.3 for the years of 2002 and 2005 together with the data from the current analysis. Across all years, there was a rise in numbers with each increase in age band until the 16 to 20 year band when the population falls due to transfers to adult centres. In the current dataset the number of patients below the age of 4 years has risen and compared with the 2005 data the proportion under the age of 4 years is significantly larger ($p = 0.012$).

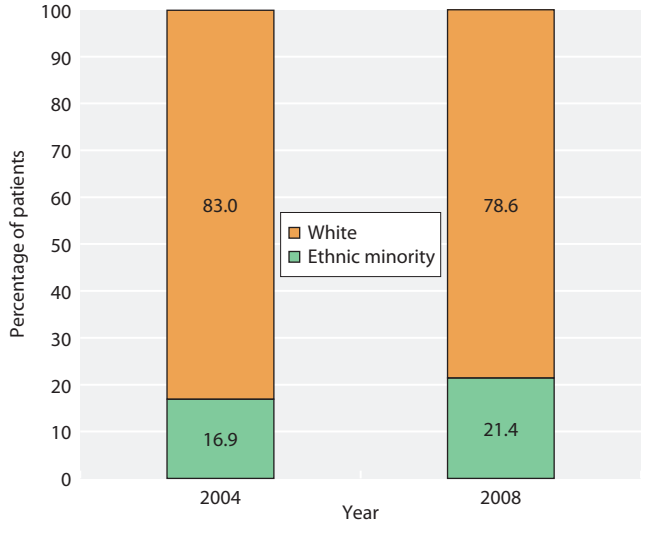

Fig. 14.2. The proportions of prevalent paediatric RRT patients in 2004 and 2008 from ethnic minorities

Table 14.3. Prevalent paediatric ERF population by age and year of data collection

	Patient population		
Age group (yrs)	2002	2005	2008
0–3.99	49	36	70
4–7.99	94	108	103
8–11.99	185	152	178
12–15.99	294	321	295
16–19.99	171	151	257

Incidence and prevalence

The incidence and prevalence of ERF in the UK has been calculated using estimated population figures for the UK from the Office for National Statistics online resource [2]. The overall prevalence of ERF in children under the age of 16 years in the UK was 56.1 per million age related population (pmarp). The prevalence was highest at 97.3 pmarp in the 12 to 16 year age group. At all ages there was a significant excess of males (table 14.4), which is also seen in the adult ERF population. Prevalence over the age of 16 years is not included in this table as many patients in this age group, particularly those over the age of 18 years, are primarily treated in adult centres.

The incidence of ERF is shown in table 14.5. Here the incidence recorded in the 16 to 20 year age group is recorded simply to demonstrate the clear underestimate of incidence in this age group secondary to mixed referral patterns. Figure 14.3 shows the trends with regard to incidence over the past 10 years by age group. Whilst there is marked year to year variability secondary to the small numbers involved, there is no clear trend. The overall incidence in the under 16 years of age population varies around 8 pmarp.

Whilst the prevalence of ERF rises steadily with age, through continued acceptance onto the programme of new patients and survival of existing patients, the

Table 14.4. Prevalence of ERF pmarp by age and gender

	All patients		Male		Female	
Age group (yrs)	Patients	Prevalence	Patients	Prevalence	Patients	Prevalence
0–3.99	70	24.1	44	29.5	26	18.3
4–7.99	103*	38.3	64	46.5	38	28.9
8–11.99	178*	61.9	109	74.1	68	48.4
12–15.99	295*	97.3	170	109.3	123	83.4
<15	559	52.1	342	62.3	214	40.9
<16	646	56.1	387	65.7	255	45.4

* gender unknown for total of 4 patients

Table 14.5. Incidence of ERF per million age related population for the last ten years

	All patients		Male		Female	
Age group (yrs)	Patients	Prevalence	Patients	Prevalence	Patients	Prevalence
0–3.99	24	8.2	15	10.1	9	6.3
4–7.99	12	4.5	5	3.6	7	5.3
8–11.99	19	6.6	12	8.2	7	5.0
12–15.99	29	9.9	17	10.9	12	8.1
16–19.99	11	2.8	6	3.6	5	3.2
<15	74	7.0	46	8.4	29	5.5
<16	84	7.4	49	8.3	35	6.2

distribution of incidence with age showed a V shaped curve with the incidence in the first four years of life being almost twice that of the second four years. This is demonstrated in figure 14.4.

Both the incidence and prevalence of ERF varied with ethnicity. The South Asian population showed a prevalence 2.5 times that of the White population. The incidence of ERF in this group is currently 1.5 times that of the White group. The prevalence and incidence of ERF in the Black population was just slightly higher than that of the White population. Those classified as Other had a prevalence almost 4 times that of the White population but for 2008 there were no new incident patients in this group (figure 14.5).

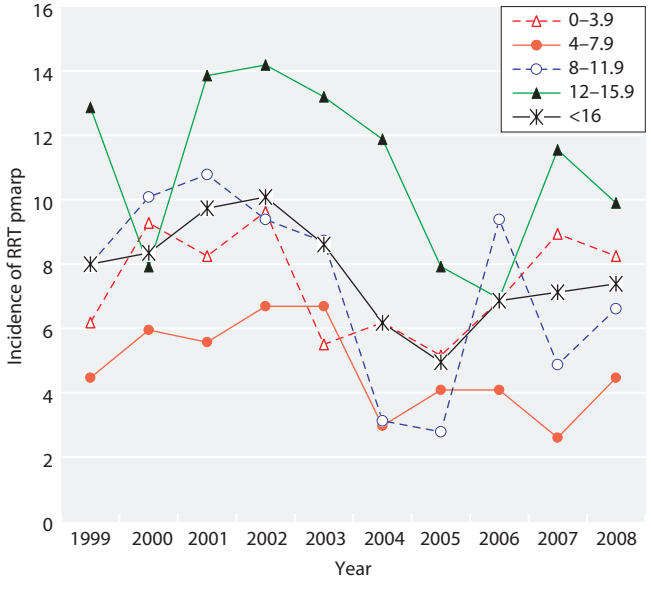

Fig. 14.3. Paediatric incidence of RRT pmarp 1999–2008 by age at onset

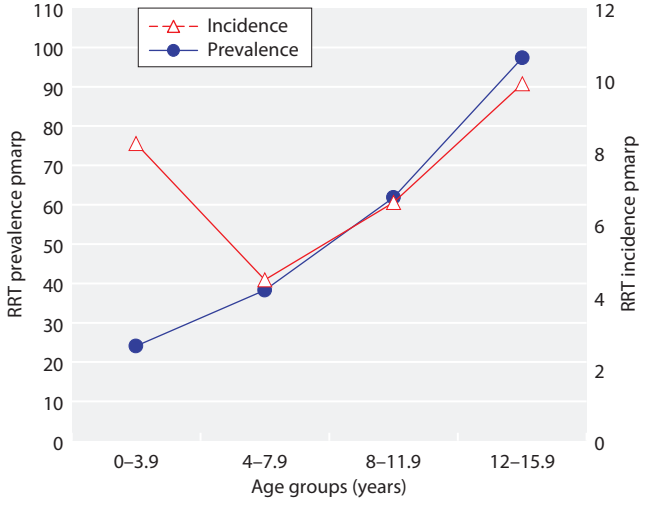

Fig. 14.4. Incidence and prevalence of RRT pmarp in 2008 by age

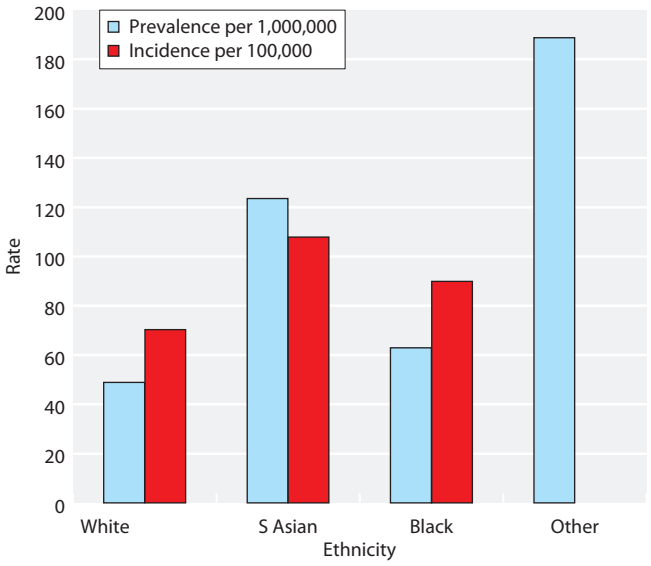

Fig. 14.5. Incidence per 100,000 and prevalence per 1,000,000 age related population by ethnicity

Causes of ERF

The causes of ERF in the paediatric population have been previously outlined [3]. The number of individual diseases and sub-classifications are numerous. For analytical purposes these are best broken down into a smaller number of disease categories. Table 14.6 shows these disease categories for 782 of the 905 current patients (86.4%) for whom a causative diagnosis was listed. Renal dysplasia with or without vesico-ureteric reflux was the predominant cause, accounting for 33% of all patients. The combination of glomerulonephritic diseases and obstructive uropathy accounted for just over a further third and the remainder was composed of the other 8 categories. The male to female ratio for patients with renal dysplasia was high and this, together with the vast excess of males with obstructive uropathy from posterior urethral valves, accounted for the overall predominance of males in the population. For this analysis the group classified as having malignancy leading to ERF has been re-examined. All but one case of malignancy involved Wilms' tumour. However, in many these were unilateral and the true cause of progression to ERF was Wilms' nephropathy. These patients have been reclassified as having a glomerulopathy rather than a malignant cause of ERF. This explains why the size of the group with malignancy as a cause has halved when compared with the last BAPN report.

There is a difference between incident and prevalent diagnoses in terms of proportion. To examine this the cause of ERF in the 428 patients starting therapy in UK centres in the five year period from 1st January 2004 until 31st December 2008 was investigated. Details of the primary cause of ERF were available in 387 patients (90.4%). These data are presented in table 14.7. Whilst the top three groups remain unchanged it is apparent that for some groups, such as congenital nephrosis, the incident percentage is rather less than the prevalent percentage of the population, whilst the reverse is true for conditions such as tubulo-interstitial disease and those with ERF of uncertain aetiology. These data are shown graphically in figure 14.6. The reason for the discrepancies between incidence and prevalence is secondary to the age of presentation of these disorders. Congenital nephrosis is rare but presents in infancy so patients spend a long time in paediatric centres increasing the prevalence. Those with tubulo-interstitial disease and those with renal failure of uncertain aetiology tend to present later in childhood and are therefore transferred

Table 14.6. Diagnostic groups and gender distribution of the prevalent paediatric ERF population

Diagnostic group	Patients	Proportion of total (%)	Male	Female	M:F ratio
Renal dysplasia ± reflux	258	33	168	90	1.87
Glomerular diseases	150	19	73	77	0.95
Obstructive uropathy	120	15	109	11	9.91
Congenital nephrosis	62	8	27	35	0.77
Tubulo-interstitial disease	60	8	30	30	1.00
Renovascular disease	33	4	22	11	2.00
Metabolic diseases	31	4	17	14	1.21
Unknown aetiology	31	4	13	18	0.72
Polycystic kidney disease	24	3	11	13	0.85
Malignancy	7	1	1	6	0.17
Drug nephrotoxicity	6	1	3	3	1.00

Table 14.7. Diagnostic groups and gender distribution of the incident paediatric ERF population

Diagnostic group	Patients	Proportion of total (%)	Male	Female	M:F ratio
Renal dysplasia ± reflux	135	33	83	52	1.60
Glomerular diseases	78	19	40	38	1.05
Obstructive uropathy	49	12	42	7	6.00
Tubulo-interstitial disease	39	10	17	22	0.77
Unknown aetiology	24	6	10	14	0.71
Metabolic diseases	18	4	9	9	1.00
Congenital nephrosis	15	4	8	7	1.14
Renovascular disease	13	3	8	5	1.60
Polycystic kidney disease	10	2	4	6	0.67
Drug nephrotoxicity	4	1	1	3	0.33
Malignancy	2	0	1	1	1.00

to adult centres after a briefer stay in the paediatric centres.

The distribution of causative diagnoses is somewhat different between ethnic groups. This in part relates to a higher incidence of autosomal recessive diseases in populations where consanguinity is more frequent than in the white population. Nineteen percent of prevalent White patients have ERF secondary to a disease with autosomal recessive inheritance, whilst 26% of ethnic minority patients have this. Table 14.8 shows the inheritance of the primary cause of ERF in the prevalent White and ethnic minority populations who were under the age of 16 years at presentation. Table 14.9 shows these data for patients presenting below the age of 16 between 1st January 2004 and 31st December 2008 to allow calculation of incidence. Whilst diseases with no defined inheritance are twice as common in the ethnic minority population than the White population, autosomal recessive diseases are three times as common.

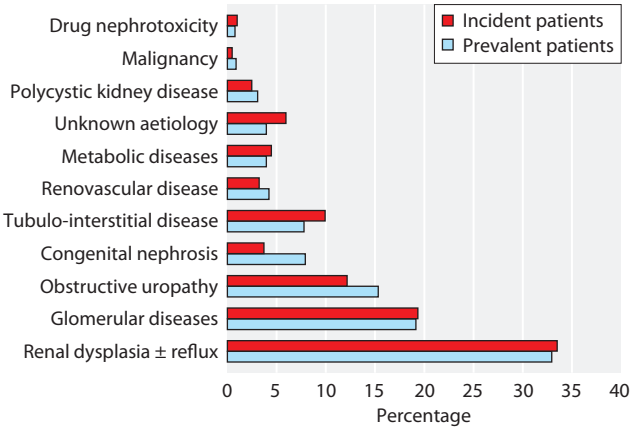

Fig. 14.6. Comparison of incidence and prevalence in different diagnostic groups

The overall figures show 20.5% of prevalent patients and 15.0% of incident patients have diseases with autosomal recessive inheritance causing ERF. This raises the question of whether there is a role for prenatal diagnosis and intervention. Just 4% of these patients were recorded as having had an antenatal diagnosis made though 10.6% had other family members affected by the disorder and 7% had another family member in ERF.

Table 14.8. Mode of inheritance of diseases causing ERF and ethnicity in the prevalent paediatric population (<16 years)

	White		Ethnic minorities	
Inheritance	N	pmarp	N	pmarp
Autosomal recessive	112	10.9	38	29.7
Autosomal dominant	8	0.8	0	0.0
X linked	8	0.8	0	0.0
Mitochondrial	4	0.4	1	0.8
None or other or undefined	448	43.8	110	86.0

Table 14.9. Mode of inheritance of diseases causing ERF and ethnicity in the incident paediatric population from 2004–2008 (<16 years)

	White		Ethnic minorities	
Inheritance	N	pmarp	N	pmarp
Autosomal recessive	45	0.9	20	3.1
Autosomal dominant	5	0.1	0	0.0
X linked	5	0.1	0	0.0
Mitochondrial	2	0.0	1	0.2
None or other or undefined	285	5.6	67	10.5

Mortality

In the previous BAPN report [1] 5 year survival of patients commencing ERF in childhood according to age was examined. In this report mortality and the demographics of patients who have not survived are analysed.

To ensure completeness of the cohort only patients below the age of 16 years at the census date were included. There were 646 current patients within this cohort. One of these patients is known to have subsequently died. Examination of the database yielded 75 registered patients who were deceased but would have been under the age of 16 years at the census date. This gives a mortality in the prevalent population (prevalent mortality) of 10.4% overall. Eight of these patients were detailed as not being accepted onto an ERF programme because of complicating features, often multiple severe comorbidities or life threatening disabilities. This will be an underestimate of patients falling into the category of having ERF but not starting an ERF treatment program as there is no compulsion to register such patients at present. After discounting these patients and only looking at those commencing an ERF programme, the prevalent mortality under the age of 16 years remained at 9.4%.

Figure 14.7 is a cumulative frequency chart of age at death. Whilst 50% of deaths occur before the age of 3 years in patients starting dialysis in infancy, the remainder die at varying ages stretching into adolescence. Data on precise cause of death was too poorly completed to allow meaningful analysis. There was no difference in the ethnic distribution of the cohort that had died compared with survivors. Twenty-two percent of survivors were from ethnic minority backgrounds compared with 26% of the deceased cohort.

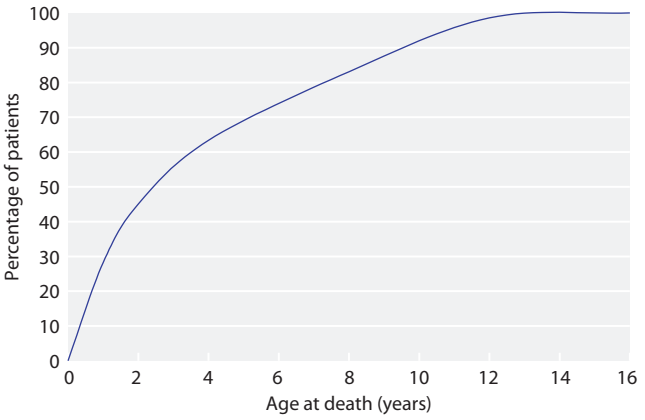

Fig. 14.7. Age at death in patients who would currently be below 16 years of age

Data on the underlying cause of ERF were available in 64 of the deceased patients (85%) and 552 of the survivors (85%). These data are presented in table 14.10. The pattern of diseases causing ERF in the deceased cohort was different from the surviving population, secondary to the large number of patients commencing RRT in infancy within the deceased cohort. Thus renal dysplasia ± vesico-ureteric reflux remained the most common diagnostic group but there were far fewer patients with glomerulonephritides and more patients with congenital nephrosis and infantile polycystic kidney disease. This analysis allows the calculation of mortality according to underlying disease and whilst for children with glomerulonephritic disorders the figure is somewhat lower than the overall figure, mortality in patients with polycystic kidney disease may be

Table 14.10. Causes of ERF in the prevalent and deceased paediatric patients

Diagnostic group	Total number of patients	Percentage	Number of deceased patients	Percentage deceased (95% CI)
Renal dysplasia ± reflux	209	33.9	21	10.0 (6–15)
Glomerular diseases	102	16.6	6	5.9 (2–12)
Obstructive uropathy	99	16.1	13	13.1 (7–21)
Congenital nephrosis	57	9.3	7	12.3 (5–24)
Tubulo-interstitial disease	38	6.2	1	2.6 (0–14)
Renovascular disease	31	5.0	4	12.9 (4–30)
Unknown aetiology	22	3.6	0	0.0 (0–15)
Polycystic kidney disease	27	4.4	8	29.6 (14–50)
Metabolic diseases	20	3.2	3	15.0 (3–38)
Malignancy	7	1.1	1	14.3 (0–58)
Drug nephrotoxicity	4	0.6	0	0.0 (0–60)
Total	**616**	**100.0**	**64**	**10.4**

high although small numbers and wide confidence intervals make interpretation of these results difficult.

Current modality of RRT

Of the 905 current patients, some details of treatment modality in 2008 were available for 879 (97.1%). Of these, 641 (72.9%) had a functioning renal allograft. Peritoneal dialysis was the active modality in 131 (14.9%) and haemodialysis was being used in 104 (11.8%). Three patients were on no active treatment at the time of audit (0.4%).

For the 641 patients with transplants, the type of allograft was known in 640. Living donation (LD) accounted for 234 grafts (36.5%) and 406 (63.3%) were from deceased donors (DD). The proportion of paediatric patients with allografts from living donors has been steadily increasing as demonstrated in figure 14.8.

Figure 14.9 shows the distribution of LD grafts and DD grafts in different ages of children. The proportion of engrafted patients whose graft has come from a living donor is highest in patients still in the first four years of life and then steadily decreases until the 12 to 16 year group where the proportion increases again.

For those on dialysis, 44.3% were having haemodialysis. For those having peritoneal dialysis, the vast majority (90%) were being treated with automated peritoneal dialysis (APD), the remainder being on CAPD. Figure 14.10 shows the distribution of all modalities according to age. Only 15% of patients in the first 4 years of life had an allograft. This figure rapidly rose to about 80% in the 8 to 12 year old group and remained at this level thereafter. Beyond the age of 4 years those on dialysis were fairly evenly split between peritoneal and haemodialysis, whilst peritoneal dialysis predominated in the first 4 years of life.

The distribution of treatment modalities was different between the White patients and those from ethnic minority groups. A significantly larger proportion of White patients had been transplanted than ethnic minority patients ($p = 0.002$). For those who had been engrafted, 38.6% of White patients had an LD graft compared to 28.3% of ethnic minority patients ($p = 0.036$). For those on dialysis, 52% of those from ethnic minority groups were on haemodialysis compared to 41% of White patients. This difference was not statistically significant. These data are demonstrated in figure 14.11.

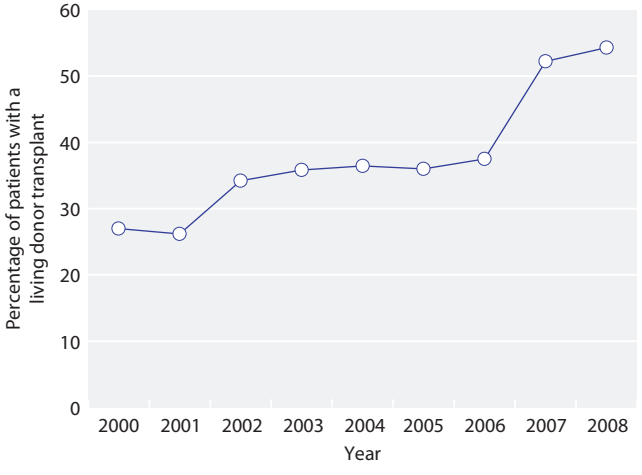

Fig. 14.8. Percentage of prevalent paediatric renal transplant patients with a living donor graft, by year (2000–2008)

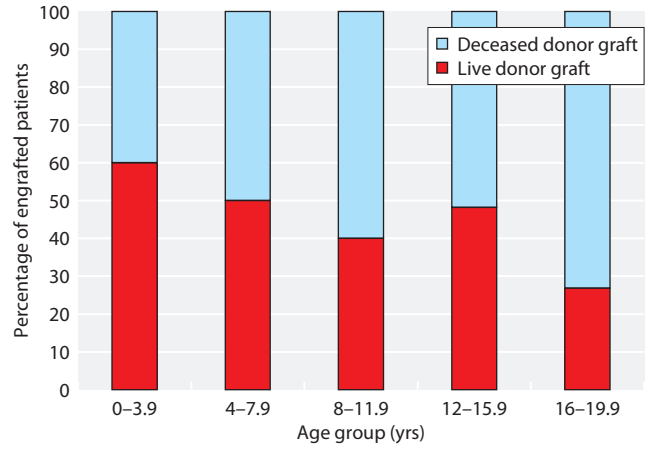

Fig. 14.9. Percentage of engrafted paediatric patients with an LD or DD graft by age

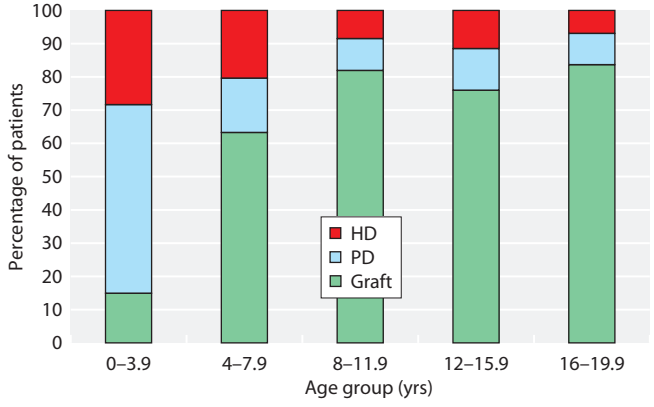

Fig. 14.10. Distribution of RRT modalities by age

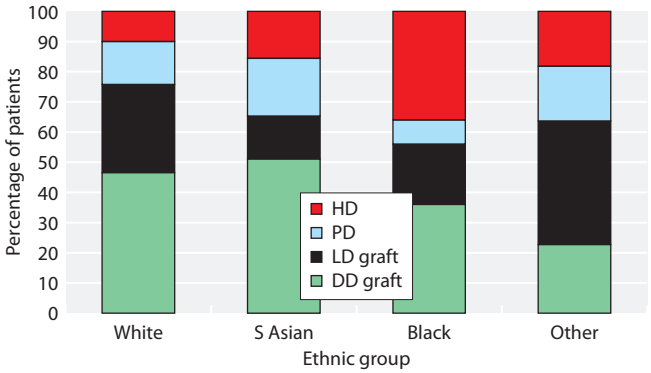

Fig. 14.11. RRT modality by ethnicity

Discussion

ERF paediatric population, incidence and prevalence

The paediatric ERF population continues to slowly grow without there being any significant trend with regards to incidence and prevalence. This will, therefore, simply represent the ongoing growth of the total UK population. The incidence and prevalence rates of childhood ERF are similar to those quoted in the ANZDATA 2008 Registry Report [4]. Comparing incidence rates to previously published rates for both European and non European countries [5], the current UK rates are within the ranges described which vary according to predisposition to particular diseases according to ethnicity and to healthcare provision.

The proportion of the population coming from ethnic minority backgrounds is rising, as would be expected with the higher incidence of childhood ERF in this population. The proportion of patients between the ages of 16 and 20 years has also risen in this analysis. Currently it is impossible to say whether this is due to a change in incidence and prevalence or, more likely, variation in the timing of transfer to adult centres. The current amalgamation of the adult and paediatric data set will allow meaningful analysis of this for the report next year.

Causes of ERF

Renal dysplasia with or without vesico-ureteric reflux remains the most common cause of ERF in the cohort, accounting for about one third of both incident and prevalent patients. Glomerular diseases and obstructive uropathy are the next most common causes. Together these three groups account for 67% of prevalent and 65% of incident cases. The proportion of incident cases from obstructive uropathy is somewhat lower than the proportion of prevalent cases as the majority are secondary to posterior urethral valves presenting with ERF in early childhood and leading to patients with long stays in the setting of the paediatric renal centre. This is even more apparent for congenital nephrosis, which always presents with early onset ERF. Similarly, diseases presenting with ERF in later childhood show a higher incidence than prevalence, the patients being more rapidly moved onto adult centres. Examples of this include tubulointerstitial diseases and those presenting with ERF of unknown aetiology (figure 14.6).

Inherited diseases are a major cause of ERF in childhood accounting for 23.5% of prevalent and 18% of incident cases. The lower proportion of incident to prevalent cases again reflects the fact that, on the whole, these are disorders causing early onset ERF. Of those with diseases where there is a recognised mode of inheritance, 88% of prevalent and 83% of incident cases relate to diseases with autosomal recessive inheritance. These are more common in the South Asian population where consanguineous marriage is more common. However, this does not account for all the difference seen in incidence and prevalence rates between the White and ethnic minority groups as diseases with no recognised pattern of inheritance are also twice as common in the ethnic minority cohort. One major implication of inherited disease is the impact on the family of having more than one affected member and perhaps more than one family member on dialysis. With 10% of families where there is an autosomal recessive cause of ERF having more than one family member affected, and two thirds of these families having more than one family member in ERF the impact upon support services is significant. This will also impact upon family decisions with regard to living donation, decisions becoming difficult when more than one family member requires a graft.

Mortality

The analysis of prevalent mortality shows 9.4% of patients accepted onto an ERF programme have died before reaching the age of 16 years. Whilst this may seem high this is not out of keeping with the survival data in the last analysis which showed 91.7% five year survival. There were also a number of patients with ERF who died without being accepted onto an ERF

programme. This figure will be an underestimate as there is no requirement to register such patients. An independent audit of patients with ERF in childhood not being accepted onto an active treatment programme would be worthwhile to analyse the factors involved in decision making and whether treatment centres have different practices.

As expected the majority of deaths occurred early in life and amongst those with an infantile onset of ERF. This is supported by the analysis of causes of ERF in the deceased population. This is the first breakdown published of underlying diagnosis in patients who have died and knowledge of prevalent mortality according to the aetiology of renal failure is going to be valuable in the counselling of parents both at presentation and after antenatal diagnosis. It is however noteworthy, that deaths occur throughout childhood, and also in children with disorders such as glomerulonephritis, where there would not necessarily be any comorbid problems. The data on cause of death was not complete enough to allow a meaningful analysis. For those where details were available recurring themes were pulmonary hypoplasia, loss of dialysis access, multiple congenital anomalies and multiple or severe disabilities. This is in keeping with the findings of Woods *et al.* [6]. As with those not accepted onto an ERF programme, an independent audit of the casenotes of patients who have died might provide valuable information, particularly with regard to counselling the families of infants and children with multiple problems being considered for ERF treatment.

Current RRT modality

The 73.2% of patients whose current RRT modality was a functioning renal allograft was slightly higher than the 71% reported by both ANZDATA [4] and the USRDS [7]. This figure has remained stable over the years of data collection by the Registry. The proportion of patients being engrafted from a living rather than a deceased donor continues to increase. For those without an allograft, peritoneal dialysis remained the most prevalent treatment though the percentage of patients receiving haemodialysis had risen to 44.3%. This is in keeping with the general trend towards increasing haemodialysis therapy in children described by Warady [8].

The proportion of patients with a functioning allograft rises steadily with age until a small fall in the group of patients between the ages of 12 to 16 years. This could represent either an increased proportion of patients entering ERF at this point or the loss of previously functioning grafts with return to dialysis. Knowing that there has been no change in incidence according to age, the latter is more likely. This is also supported by the observation that the proportion of grafts from living related donations is increased in this group. With the current trend for more grafts to come from living donors than deceased donors it is likely that this cohort is having their second graft from this source.

Patients from ethnic minority groups were significantly more likely to be on dialysis than White patients. As morbidity and mortality are higher in dialysis compared to engrafted patients [6], an education programme promoting living donation in the ethnic minority population is needed. Live donation from ethnic minorities may remain more difficult than in White groups, due to a much higher incidence of chronic kidney disease and renal failure seen in the adult ethnic minorities. Also, as mentioned above, some of these families may have more than one child in ERF, complicating the decision-making process.

Conflict of interest statement: none

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