Chapter 13: Report of the Paediatric Renal Registry

Summary

Demography

- The growth of the paediatric ERF population has plateaued.
- Fifty percent of patients who presented to paediatric nephrology units and entered ERF had a GFR under 20 ml/min/1.73 m^2 at the time they were first seen.
- There remains a high incidence and prevalence of ERF in South Asian children.
- This is in part accounted for by an increased incidence of genetic diseases with autosomal recessive inheritance in the South Asian group ($p < 0.0001$).
- The South Asian patients are more likely to be on HD and less likely to have a functioning allograft than White patients.

Analysis of cardiovascular risk factors

- Blood pressure control in the paediatric renal transplant population was sub-optimal.
- A large proportion of the paediatric renal transplant population were overweight or obese.
- Many paediatric renal transplant patients had hyperlipidaemia.
- Longitudinal as well as cross-sectional analysis of the data in these areas suggest that these are real problems that may well have a significant impact upon patient health in the future.
- Blood pressure control in the paediatric dialysis population was sub-optimal.
- Anaemia was poorly controlled in the paediatric dialysis population with 38% remaining anaemic.
- Bone disease was poorly controlled in the paediatric dialysis population with 50% having raised intact PTH and 36% serum phosphate above the RA Standard.
- Longitudinal as well as cross-sectional analysis of these data support these findings.

Although absolute mortality rate in children with ERF is low compared with adult patients, the presence of cardiovascular risk factors is a cause for concern. Whilst accepting that paediatric RRT patients are difficult to manage, failure to meet standards in these areas is potentially creating major problems in the future for these patients from cardiovascular co-morbidity.

Introduction

Whilst utilising existing renal unit databases in some regions and looking to the installation of new data management tools in others to allow the continuous collection of paediatric data for analysis, the paediatric arm of the Renal Registry continues to collect patient demographics together with annual patient status returns. The aim is to move to continuous data collection as soon as possible.

In this report, the demographics of established renal failure in childhood in the UK are described together with a focus on cardiovascular risk factors in the paediatric ERF population.

Paediatric RRT population

The paediatric arm of the Renal Registry contains data on a total of 1,421 patients. Of these, 869 patients are male and 552 patients are female giving a male to female ratio of 1.57:1. Ninety one of these patients (42 males and 49 females) are known to have died whilst under the care of paediatric units. Others have had their care transferred to adult services. Remaining with the paediatric units in April 2003 were 776 patients (475 males and 301 females, male to female ratio, 1.58:1). This is a fall from a total of 793 patients being cared for in paediatric units in 2002 and is the first time a fall in

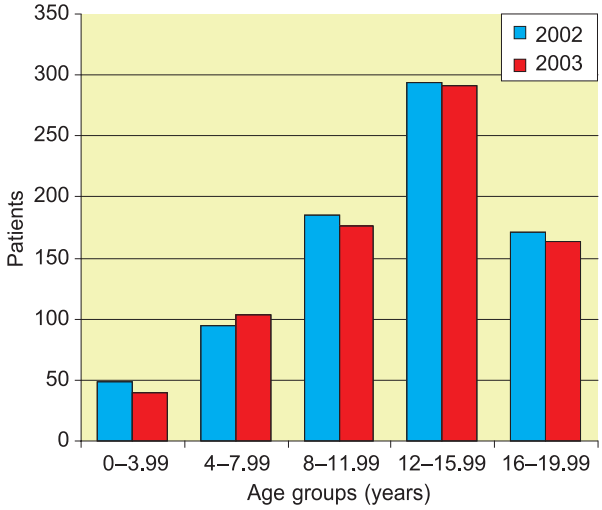

Figure 13.1: Paediatric ERF population in 2002 and 2003 by age group

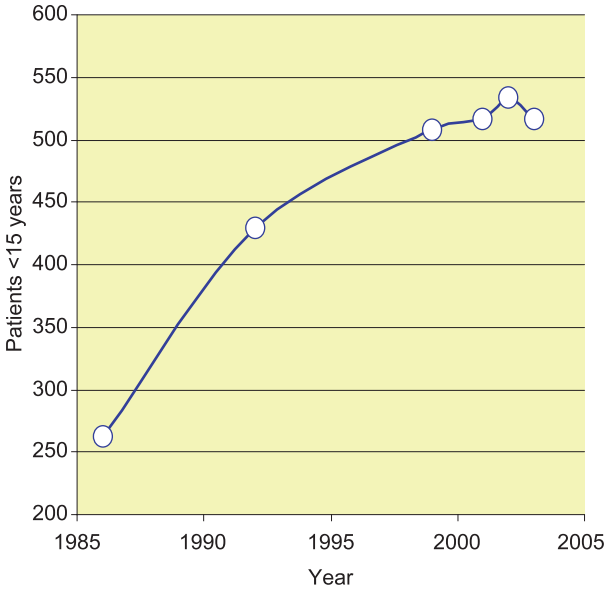

Figure 13.2: ERF patients below the age of 15 years by year of data

the prevalent paediatric RRT population has been documented.

Figure 13.1 shows the population for 2002 and 2003 broken down according to age group. It is clear that the fall in numbers is related to small fluxes in each group rather than to a specific trend in one age band. Figure 13.2 shows the numbers of patients under the age of 15 years, allowing comparisons with data collected before the Registry began. Table 13.1 shows this data in greater detail. After a significant rise in the paediatric RRT population from 1986 until the millennium, it now appears to have reached a plateau.

The gender distribution of the population, broken down according to age, is shown in Figure 13.3. As before, it can be seen that males

Table 13.1: Prevalent ERF population by age and year of data collection

Age group (yrs)	Patient prevalence data					
	1986	1992	1999	2001	2002	2003
0–1.99		16	18	13	14	10
2–4.99		55	46	56	58	56
5–9.99		150	151	146	147	141
10–14.99		208	293	301	315	310
15–19.99			253	274	259	256
Total <15	**263**	**429**	**508**	**516**	**534**	**517**
Total <20			**761**	**790**	**793**	**773**

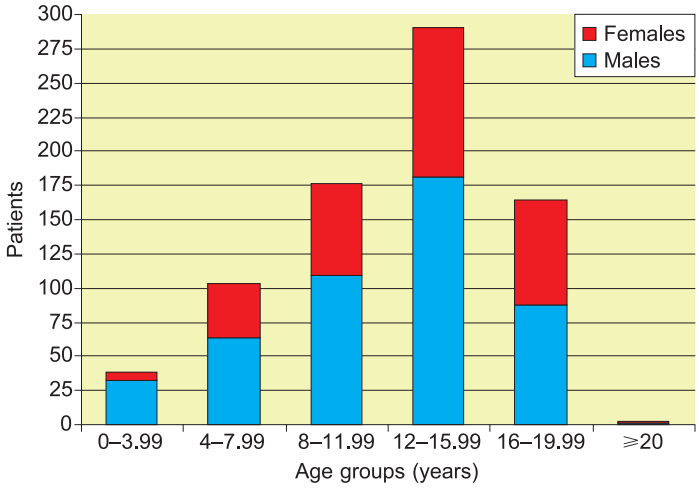

Figure 13.3: Paediatric ERF population by age and gender

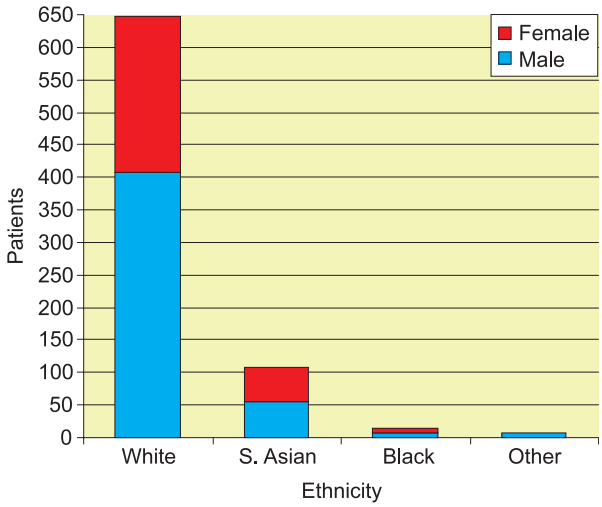

Figure 13.4: Paediatric ERF population by ethnicity and gender

predominate in the first 4 years of life and thereafter the proportion of females increases steadily but never exceeds 50%. The explanation for the gender distribution lies with the distribution of diagnoses and this is discussed below.

Figure 13.4 shows the patient distribution according to ethnicity, broken down by gender, whilst Figure 13.5 shows the distribution according to age, broken down by ethnicity. As expected, the vast majority of patients are White and a significant minority are South Asian. The proportion of South Asians exceeds their proportion in the general population and as will be demonstrated below, this relates to a higher incidence of specific inherited diseases that cause renal failure. Another effect of this is that the gender distribution of the South Asian population is different to that of the White population with almost 50% of South Asian patients in ERF being female, whilst a little over a third of White patients are female.

Prevalence and take-on rate

The prevalence of ERF amongst children in the UK is shown in Table 13.2. Within this table, the prevalence is broken down into four age-bands between birth and 16 years of age as well as showing the total prevalence in under 16 year olds and that in the UK population as a whole. It is clear that the prevalence rises

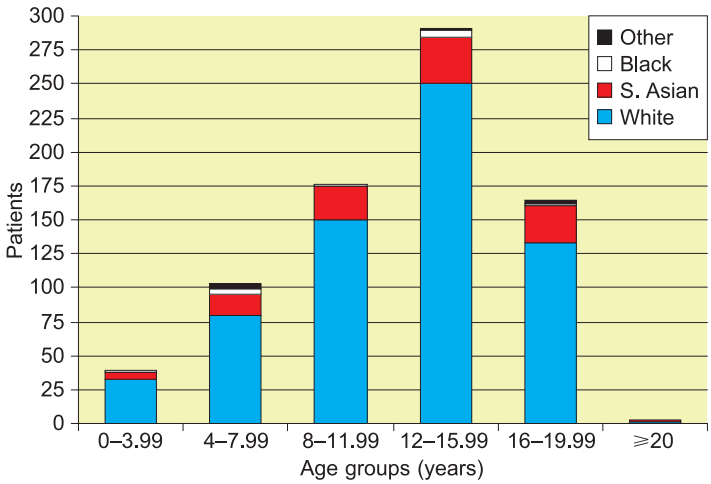

Figure 13.5: Paediatric ERF population by age and ethnicity

Table 13.2: Prevalence of ERF in the paediatric population

	Prevalence (pmp)		
Age Group (yrs)	Males	Females	Total
0–3.99	22.7	5.2	14.2
4–7.99	42.6	27.3	35.2
8–11.99	68.5	44.2	56.6
12–15.99	114.7	73.3	94.5
< 16	63.5	38.5	51.3
UK pop	13.5	7.4	10.4

Figures are pmp in each age band and per million total UK population

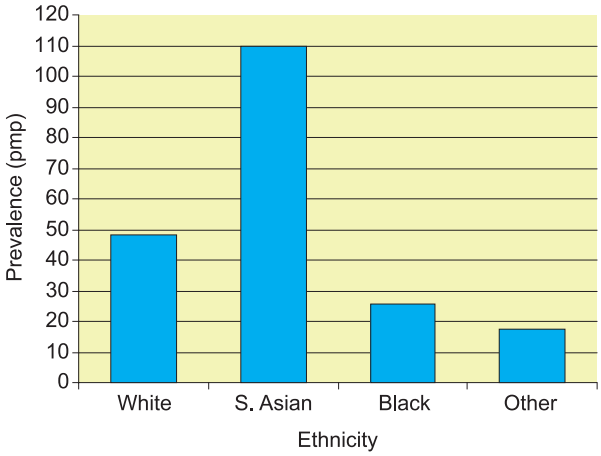

Figure 13.6: Prevalence of ERF in children by ethnicity

steadily throughout childhood. This is in part secondary to an increased take-on rate in later childhood (see below) but mainly secondary to the survival of patients with ERF throughout childhood.

Figure 13.6 shows the prevalence of RRT in the UK childhood population broken down according to ethnicity. Even taking into account the higher proportion of young people within the ethnic minority groups, the prevalence of RRT in the South Asian population is significantly greater than that of the White population, being a little over twice that of the White population. The prevalence of RRT in the Black population seems to be lower than that of the White population, but with the small numbers involved this does not reach statistical significance.

To calculate the take-on rate, the average of the number of children starting ERF treatment since data collection began 7 years ago, has been used. This allows for a more accurate calculation of take-on rate bearing in mind year-on-year fluctuations that can occur. Table 13.3 shows the take-on rate for each year from 1996 onwards. Although there are small fluctuations, there are no trends for either the total number of children starting RRT or any one gender.

Table 13.4 shows the take-on rate for the UK population, broken down according to age-groups between birth and 16 years of age. As has been demonstrated in previous reports, the peak take-on rate is in young people between the ages of 12 and 16 years.

The take-on rate in the first 4 years of life, courtesy of the significant number of children with congenital diseases, is similar to that of children between the ages of 8 and 12 years, whilst there is a fall in presentation in ERF between the ages of 4 and 8 years. The number presenting with congenital diseases falls with age whilst the peak uptake for those with acquired diseases is in the older age group.

Figure 13.7 shows the average take-on rate of patients with ERF broken down according to ethnicity. Again, despite the high proportion of children in the South Asian population as a whole, the take-on rate per million of the childhood population in South Asians is a little over 3 times that of the White population.

Table 13.3: Incidence rate for children age < 16 years, by year and gender

	1996	1997	1998	1999	2000	2001	2002	Total	Average
Male	47	64	66	47	50	73	51	398	56.9
Female	36	36	45	47	53	42	37	296	42.3

Table 13.4: Take-on rate for children age < 16 years at start of RRT

	Take on rate (pmp)		
Age group (yrs)	Male	Female	Total
0–3.99	9.5	5.7	7.7
4–7.99	4.9	3.7	4.3
8–11.99	7.9	6.8	7.4
12–15.99	11.7	10.5	11.1
< 16	8.5	6.7	7.7
UK pop	1.8	1.3	1.5

Figures are per million childhood population in each age band and per million total UK population

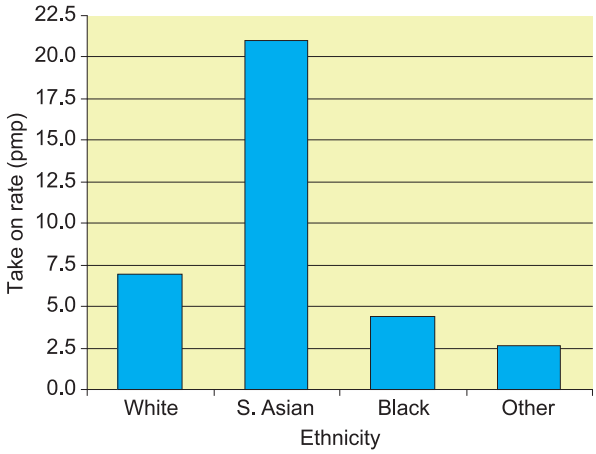

Figure 13.7: Take-on rate of children with ERF by ethnicity

Causes of ERF in childhood

The primary cause of ERF was given for 1,303 of the 1,421 patients registered (91.7%). The diagnoses are listed alphabetically in Table 13.5 and the distribution of these diagnoses is not different to previous assessments. This distribution of diagnoses does not represent the true distribution in an unselected population. The causes of renal failure in children vary with age. Those patients presenting young are over represented since patients presenting under the age of 5 years will have at least a decade with paediatric services whilst patients presenting as teenagers are transferred to adult services within 5 years. To investigate this, we have compared the diagnostic distribution of patients starting RRT from 1996 until 2003 with those who started RRT before 1996. This is shown in Figure 13.8.

For the more recent patients, there is a lower prevalence of renal dysplasia and obstructive uropathy and a higher prevalence of glomerular diseases, reflux nephropathy, tubular and metabolic diseases. Similarly, there is an increase in the prevalence of patients with chronic renal failure of uncertain aetiology, a diagnosis that tends to be made in older rather than younger children. The difference between the distribu-

Table 13.5: ERF diagnosis for 1303 patients on the paediatric RRT Registry

Diagnosis	Male	Female	Total	% Total
Acquired obstructive uropathy	3	0	3	0.2
Alport's syndrome	15	4	19	1.5
Anti-GBM disease	0	5	5	0.4
Autosomal recessive PKD	14	15	29	2.2
Bartter's syndrome	2	1	3	0.2
Branchio-oto-renal syndrome	5	2	7	0.5
Chronic renal failure – uncertain aetiology	12	14	26	2.0
Cis-platinum nephrotoxicity	1	0	1	0.1
Congenital nephrotic syndrome (DMS)	8	2	10	0.8
Congenital nephrotic syndrome (Finnish)	14	14	28	2.1
Congenital nephrotic syndrome (FSGS)	4	7	11	0.8
Congenital nephrotic syndrome (unspecified)	8	23	31	2.4
Congenital obstructive uropathy – bladder outlet obstruction (not PUV)	11	6	17	1.3
Congenital obstructive uropathy (not bladder outlet obstruction)	11	5	16	1.2
Congenital obstructive uropathy – Posterior urethral valves	180	0	180	13.8
Cortical necrosis	13	11	24	1.8
Crescentic glomerulonephritis	5	6	11	0.8
Cyclosporin nephrotoxicity	9	3	12	0.9

Table 13.5: (continued)

Diagnosis	Male	Female	Total	% Total
Cystinosis	29	22	51	3.9
Diarrhoea positive haemolytic uraemic syndrome	14	22	36	2.8
Diarrhoea negative haemolytic uraemic syndrome	3	6	9	0.7
Drug nephrotoxicity (unspecified)	0	1	1	0.1
Glomerulonephritis (unspecified)	6	6	12	0.9
Henoch Schoenlein nephritis	10	13	23	1.8
IgA nephropathy	3	5	8	0.6
Lawrence Moon Biedl syndrome	2	3	5	0.4
Megacystis megaureter	3	0	3	0.2
Membranous nephropathy	0	1	1	0.1
Mesangio-capillary glomerulonephritis Type 1	7	3	10	0.8
Mesangio-capillary glomerulonephritis Type 2	2	6	8	0.6
Mesoblastic nephroma	1	0	1	0.1
Metabolic diseases (other)	3	0	3	0.2
Microscopic polyarteritis nodosa	1	2	3	0.2
Mitochondrial cytopathy	1	1	2	0.2
Multicystic dysplastic kidneys	9	6	15	1.2
Nephrocalcinosis	0	1	1	0.1
Nephronophthisis	33	32	65	5.0
Neuropathic bladder	9	13	22	1.7
Other cytotoxic drug nephrotoxicity	2	3	5	0.4
Polycystic kidney disease (other)	4	4	8	0.6
Primary focal segmental glomerulo-sclerosis	48	52	100	7.7
Primary hyperoxaluria type 1	4	3	7	0.5
Primary interstitial nephritis	8	5	13	1.0
Proliferative glomerulonephritis	3	4	7	0.5
Prune belly syndrome	22	0	22	1.7
Reflux nephropathy	45	49	94	7.2
Renal artery stenosis	3	1	4	0.3
Renal artery thrombosis	1	1	2	0.2
Renal dysplasia	173	84	257	19.7
Renal hypoplasia	8	13	21	1.6
Renal trauma	1	1	2	0.2
Renal tubular acidosis	3	0	3	0.2
Renal vein thrombosis	9	4	13	1.0
Systemic lupus erythematosis	1	4	5	0.4
Tuberous sclerosis PKD	0	1	1	0.1
Tubular disorders (other)	1	1	2	0.2
Vasculitis (unspecified)	0	3	3	0.2
Wegner's granulomatosis	1	1	2	0.2
Wilms' nephropathy	3	1	4	0.3
Wilms' tumour	8	8	16	1.2
Total	799	504	1,303	100.0

tion of diseases in the two patient groups was significant ($\chi^2 = 30.76$, $p = 0.0006$).

Over the period from 1996–2003, 694 patients were registered, of whom 677 (97.6%) had a primary cause of ERF noted. The return rate for the recording of ERF diagnosis from the various units in the UK is detailed in Table 13.6.

With the relatively large number of patients now registered from the time of their commencement of ERF treatment, it has been

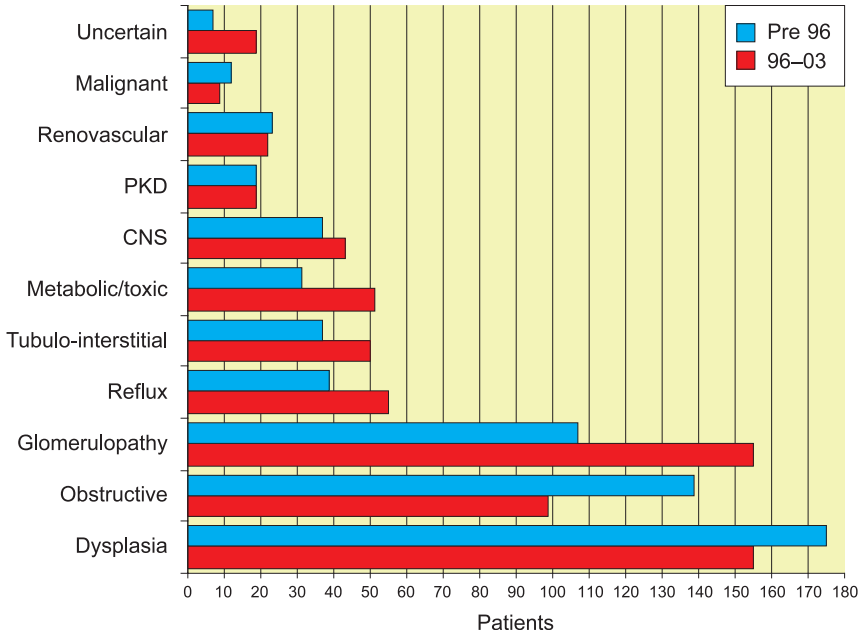

Figure 13.8: Distribution of ERF diagnoses for those starting RRT before and after 1996

possible to create a table giving an accurate breakdown of the frequency of different diagnoses. These are shown in a grouped fashion in Table 13.7. Renal dysplasia and glomerular diseases rank evenly as the major causes of ERF in children in the UK at present, these are followed by obstructive uropathy and then reflux nephropathy.

Malignancies, reno-vascular disease, metabolic disease, polycystic disease and congenital nephrotic syndrome tend to present early in childhood. Dysplasia and obstructive uropathy, although congenital diseases, present with ERF throughout childhood. Glomerular diseases, reflux nephropathy, tubular diseases and chronic renal failure of uncertain aetiology present with ERF later in childhood. Again, the differences in the distributions of diagnosis with age at ERF commencement was highly significant ($\chi^2 = 107.4$, $p < 0.0001$).

Table 13.6: Data return rate for ERF diagnosis, by centre

	ERF diagnosis data		
Centre	**Patients**	**Data available**	**% Return**
Guys	82	82	100.0
Manchester	79	79	100.0
Bristol	58	58	100.0
Belfast	21	21	100.0
Nottingham	82	81	98.8
Leeds	65	64	98.5
Newcastle	38	37	97.4
Liverpool	32	31	96.9
Southampton	30	29	96.7
Birmingham	63	60	95.2
Glasgow	34	32	94.1
Cardiff	17	16	94.1
GOSH	93	87	93.5

One feature noted in the last report was the increased incidence of some inherited diseases in patients from the South Asian subcontinent. It was felt that the increased incidence of these conditions in the South Asian population would in part explain the increased prevalence and take-on rate of members of this ethnic group. To look at this further, all the diagnoses have been classified into those with recessive, dominant, sex-linked or no definite hereditary pattern. Diseases that sometimes, but not always, follow a hereditary pattern (eg reflux nephropathy) were classified as having no definite hereditary pattern. The result of comparing recessive disorders with other disorders, broken down according to ethnicity, is shown in Figure 13.9. It can be seen that autosomal recessive diseases are more than twice as common as the cause of RRT in the South Asian population than the White population. This difference was highly significant ($p < 0.0001$, Fisher's exact test).

Table 13.7: Grouped ERF diagnoses

Diagnosis	Male	Female	Total	% Group	% Total
Renal dysplasia and related conditions					
Renal dysplasia	79	44	123	79.4	18.2
Multicystic dysplastic kidneys	5	5	10	6.5	1.5
Prune belly syndrome	8	0	8	5.2	1.2
Renal hypoplasia	4	2	6	3.9	0.9
Branchio-oto-renal syndrome	3	0	3	1.9	0.4
Lawrence Moon Biedl syndrome	1	2	3	1.9	0.4
Megacystis megaureter	2	0	2	1.3	0.3
Total with primary renal dysplasia	102	53	155	100.0	22.9
Obstructive uropathy					
Posterior urethral valves	69	0	69	69.7	10.2
Congenital obstructive uropathy (not BOO)	4	3	7	7.1	1.0
Neuropathic bladder	3	9	12	12.1	1.8
Congenital bladder outlet obstruction (not PUV)	7	2	9	9.1	1.3
Acquired obstructive uropathy	2	0	2	2.0	0.3
Total with obstructive uropathy	85	14	99	100.0	14.6
Glomerulonephritis, vasculitis and glomerulopathy					
Primary focal segmental glomerulo-sclerosis	29	32	61	39.4	9.0
Diarrhoea positive haemolytic uraemic syndrome	9	9	18	11.6	2.7
Henoch Schoenlein nephritis	4	8	12	7.7	1.8
Glomerulonephritis (unspecified)	6	4	10	6.5	1.5
Alport's syndrome	7	1	8	5.2	1.2
Crescentic glomerulonephritis	3	4	7	4.5	1.0
IgA nephropathy	3	4	7	4.5	1.0
Diarrhoea negative haemolytic uraemic syndrome	1	5	6	3.9	0.9
Mesangio-capillary glomerulonephritis Type 1	2	3	5	3.2	0.7
Proliferative glomerulonephritis	2	3	5	3.2	0.7
Mesangio-capillary glomerulonephritis Type 2	0	4	4	2.6	0.6
Systemic lupus erythematosis	1	3	4	2.6	0.6
Microscopic polyarteritis nodosa	1	2	3	1.9	0.4
Anti-GBM disease	0	2	2	1.3	0.3
Wegner's granulomatosis	1	1	2	1.3	0.3
Vasculitis (unspecified)	0	1	1	0.6	0.1
Membranous nephropathy	0	0	0	0.0	0.0
Total with glomerular disease	69	86	155	100.0	22.9
Reflux nephropathy and CRF of uncertain aetiology					
Reflux nephropathy	28	27	55	74.3	8.1
Chronic renal failure – uncertain aetiology	9	10	19	25.7	2.8
Total with reflux nephropathy and CRF of uncertain aetiology	37	37	74	100.0	10.9
Primary tubular and interstitial disorders					
Nephronophthisis	19	20	39	78.0	5.8
Primary interstitial nephritis	4	2	6	12.0	0.9
Bartter's syndrome	1	1	2	4.0	0.3
Renal tubular acidosis	1	0	1	2.0	0.1
Nephrocalcinosis	0	1	1	2.0	0.1
Tubular disorders (other)	1	0	1	2.0	0.1
Total with primary tubular and interstitial disorders	26	24	50	100.0	7.4

Table 13.7: (continued)

	Male	Female	Total	% Group	% Total
Congenital nephrotic syndrome					
Congenital nephrotic syndrome (Finnish)	7	8	15	34.9	2.2
Congenital nephrotic syndrome (unspecified)	3	11	14	32.6	2.1
Congenital nephrotic syndrome (FSGS)	3	6	9	20.9	1.3
Congenital nephrotic syndrome (DMS)	4	1	5	11.6	0.7
Total with congenital nephrotic syndrome	17	26	43	100.0	6.4
Renal vascular disorders					
Cortical necrosis	7	5	12	54.5	1.8
Renal vein thrombosis	5	1	6	27.3	0.9
Renal artery stenosis	1	1	2	9.1	0.3
Renal trauma	1	1	2	9.1	0.3
Renal artery thrombosis	0	0	0	0.0	0.0
Total with renal vascular disorders	14	8	22	100.0	3.2
Metabolic diseases and drug nephrotoxicity					
Cystinosis	16	13	29	56.9	4.3
Cyclosporin nephrotoxicity	9	3	12	23.5	1.8
Primary hyperoxaluria type 1	2	1	3	5.9	0.4
Other cytotoxic drug nephrotoxicity	2	2	4	7.8	0.6
Metabolic diseases (other)	1	0	1	2.0	0.1
Mitochondrial cytopathy	1	1	2	3.9	0.3
Cis-platinum nephrotoxicity	0	0	0	0.0	0.0
Drug nephrotoxicity (unspecified)	0	0	0	0.0	0.0
Total with metabolic diseases and drug nephrotoxicity	31	20	51	100.0	7.5
Polycystic kidney disease (PKD)					
Autosomal recessive PKD	3	11	14	73.7	2.1
Polycystic kidney disease (other)	2	2	4	21.1	0.6
Tuberous sclerosis PKD	0	1	1	5.3	0.1
Total with PKD	5	14	19	100.0	2.8
Malignant and related diseases					
Wilms' tumour	3	4	7	77.8	1.0
Wilms' nephropathy	2	0	2	22.2	0.3
Mesoblastic nephroma	0	0	0	0.0	0.0
Total with malignant and related diseases	5	4	9	100.0	1.3

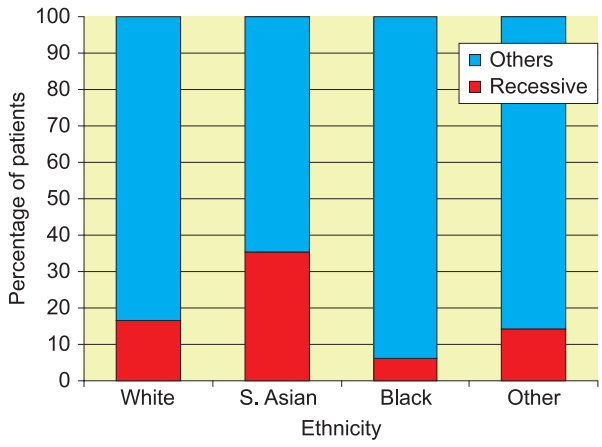

Figure 13.9: Recessive versus other diseases causing ERF by ethnicity

Presentation of patients to nephrology services

Data on the presentation of patients to renal services is important to determine the effectiveness of local referral networks in the early detection and treatment of disease, allowing the prevention of, or a delay in the onset of ERF. Currently, only a small data set around the time of presentation is collected. This data set consists of the date the patient was first seen by a paediatric nephrologist and the patients' height, weight and serum creatinine at that time. Early reports showed that the collection of this data was incomplete. Unfortunately,

Table 13.8: Return rate for presentation data by centre

Centre	Patients	Complete data	% Complete return	Partial data	% Data return
Cardiff	17	17	100	0	100
Nottingham	82	74	90	5	96
Manchester	79	67	89	6	92
Newcastle	38	33	87	2	92
Bristol	58	49	85	4	91
Leeds	65	53	82	8	94
Belfast	21	16	76	4	95
Southampton	30	21	70	2	77
Guys	82	54	66	14	83
Birmingham	63	38	60	13	81
GOSH	93	55	59	20	81
Glasgow	34	19	56	7	77
Liverpool	32	16	50	12	88

even with prospective data collection the return for this data set is not as high as desired. Table 13.8 shows the return rate for presentation data for patients starting ERF treatment after 1st April 2003. A complete return indicates the return of date, height, weight and creatinine. Recognising that it is sometimes difficult to record all parameters (eg newborns, patients seen in district clinics where at the time, there is no indication to check a creatinine) partial returns were also recorded which include the date and any one of the other three parameters.

An estimate of predicted GFR from the height and serum creatinine ($k \times Ht/Creat$), using a constant of 40 at all ages, was available in 515 of the 694 patients (74%). These GFRs are demonstrated graphically in Figure 13.10. With 29% of patients having a predicted GFR under 10 mls/min/1.73 m^2 and 21% having a predicted GFR of 10 to 20 ml/min/1.73 m^2, there is little opportunity for intervention in 50% of patients. In addition, a few of those with high predicted GFRs will have conditions such as malignancy or congenital nephrotic syndrome where early bilateral nephrectomy is planned. Earlier referral of patients, when renal impairment is mild or moderate, affords greater opportunities for secondary prevention (eg intensive feeding, growth hormone, erythropoietin, control of osteodystrophy, ACE inhibitors or angiotensin receptor blockers).

Data on height at presentation was available in 517 of the 645 patients presenting under the age of 16 years (80.2%). Height standard deviation score (SDS) at presentation is shown as a box and whisker plot (showing median,

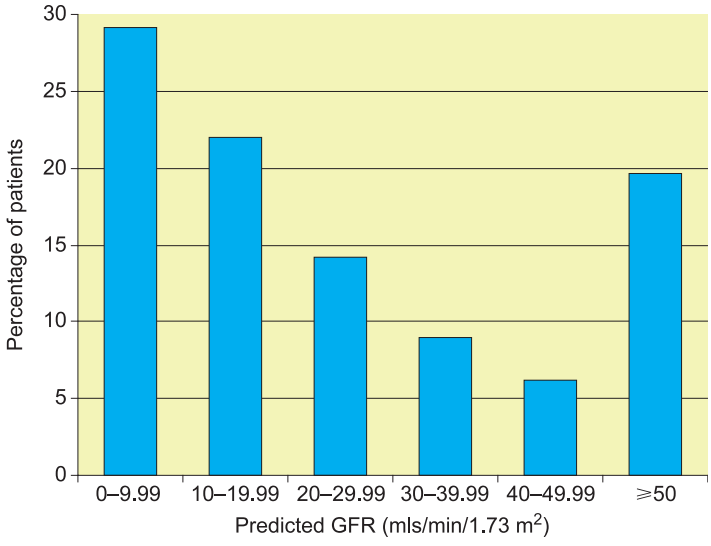

Figure 13.10: Predicted GFR at presentation to nephrology services

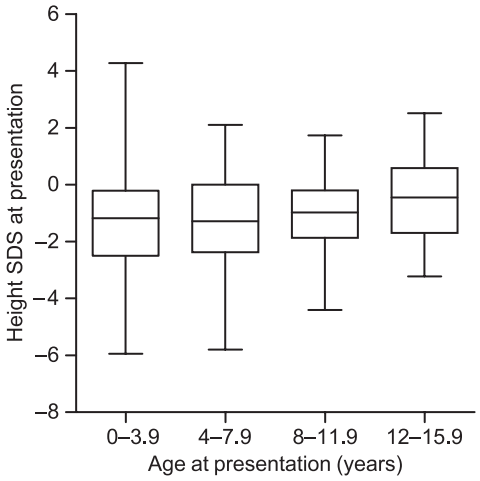

Figure 13.11: Predicted GFR at start of RRT
This includes peri-operative results on patients undergoing bilateral nephrectomy

inter-quartile range and range) in Figure 13.11. Non-parametric statistics have been used, as particularly in neonates, small errors in height measurement can lead to large changes in SDS. It is clear that the median height is below average in all groups. There is a trend for height SDS to increase with age of presentation (Kruskal–Wallis test, $p = 0.0013$).

Data on height SDS at presentation was available for 522 of 677 patients (77.1%). Median height varied significantly with the cause of ERF (Kruskal–Wallis test, $p < 0.0001$). Height SDS was lowest in patients with metabolic diseases such as cystinosis, whereas those presenting with a glomerulopathy had a distribution of heights more comparable with that of the general population (Figure 13.12).

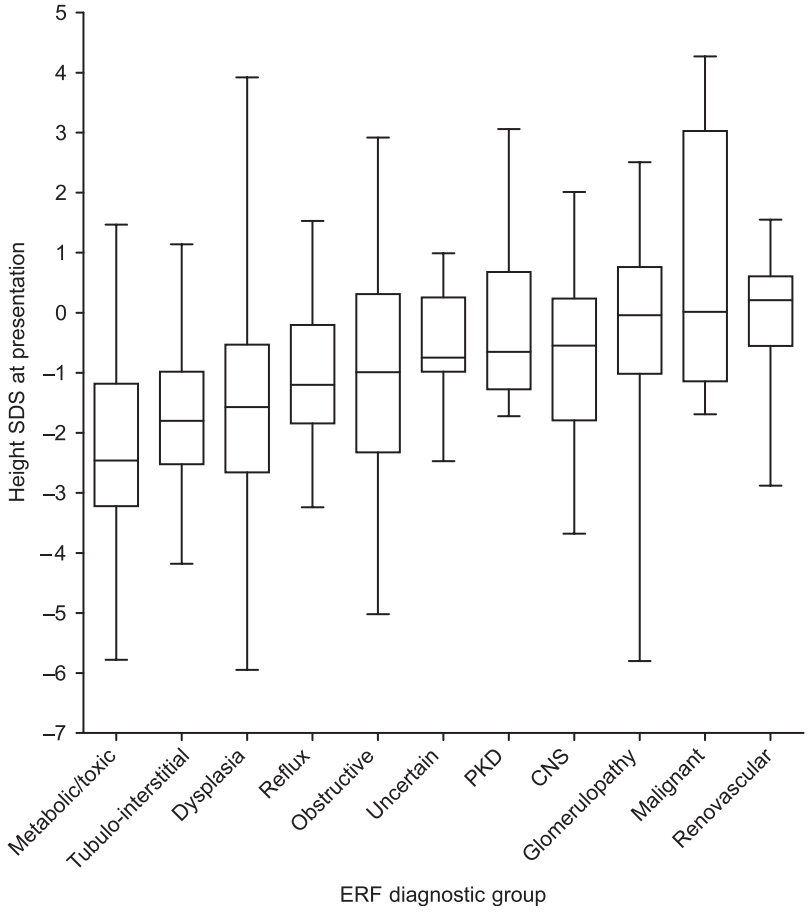

Figure 13.12: Height SDS at presentation by ERF diagnosis

eGFR, height and modality at commencement of RRT

In addition to diagnosis, which is dealt with above, the data set collected at the commencement of ERF treatment includes the date of commencement of therapy plus the patients' height, weight and creatinine at that time. Also required is the treatment modality being used 90 days after the commencement of ERF treatment. As with presentation data there are many reasons why complete data sets are not available and this particularly is the case where neonates are starting treatment. Data return rates from the different UK centres are detailed in Table 13.9.

Table 13.9: Return rate for ERF start data by centre

Centre	Patients	Data available	% Return
Nottingham	82	78	95
Cardiff	17	16	94
Newcastle	38	35	92
Belfast	21	19	91
Manchester	79	71	90
Leeds	65	58	89
Guys	82	71	87
Birmingham	63	53	84
Bristol	58	45	78
Liverpool	32	24	75
Southampton	30	22	73
GOSH	93	68	73
Glasgow	34	22	65

Predicted GFR at the commencement of ERF treatment (calculated as detailed above) was available for 608 of the 694 patients (87.6%). These data are shown in Figure 13.13. As expected, the vast majority of patients have very poor renal function with a predicted GFR under 10 mls/min/1.73 m^2 in 61%. A further 34% have a predicted GFR between 10 and 20 mls/min/1.73 m^2. A small number of patients who started treatment at the time of bilateral nephrectomy for malignant or severe protein-losing conditions account for those with a higher predicted GFR.

Data on height at the commencement of ERF treatment were available for 562 of 636 patients (88.4%) under the age of 16 years when they started treatment. These data have been subdivided by age of commencement of treatment and are presented in Figure 13.14. As with the data on presentation to nephrology services, overall height at the commencement of ERF management is below average. Median height SDS is lowest in the youngest age-group and there is a significant rise in median height SDS with increasing age at commencement of treatment (Kruskal–Wallis test, $p < 0.0001$).

Data on height SDS at presentation and ERF diagnosis were available for 612 patients. Again there was significant variation in median height

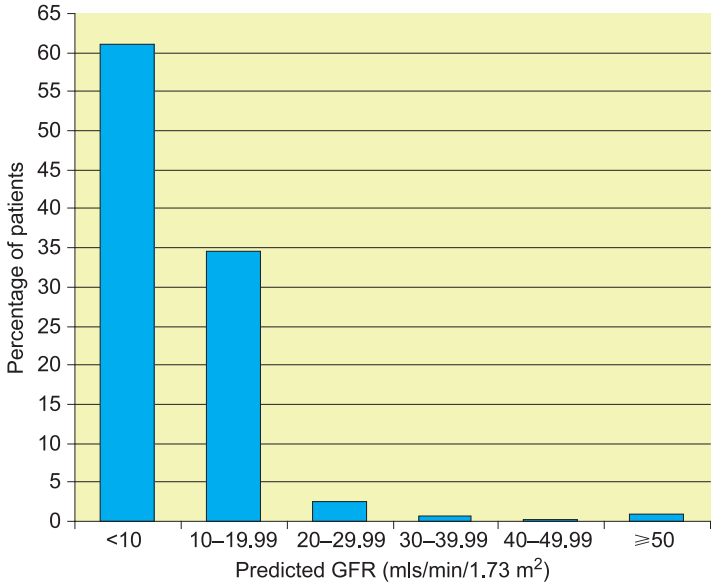

Figure 13.13: Predicted GFR at commencement of RRT
This includes peri-operative results on patients undergoing bilateral nephrectomy

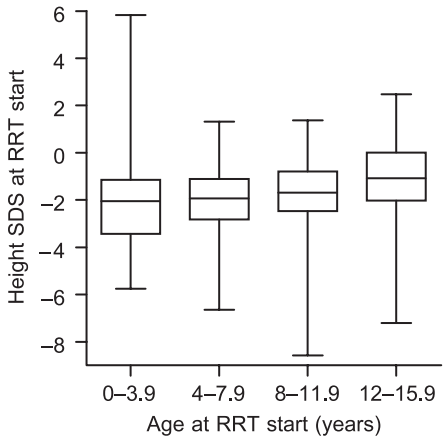

Figure 13.14: Height SDS at start of RRT by age

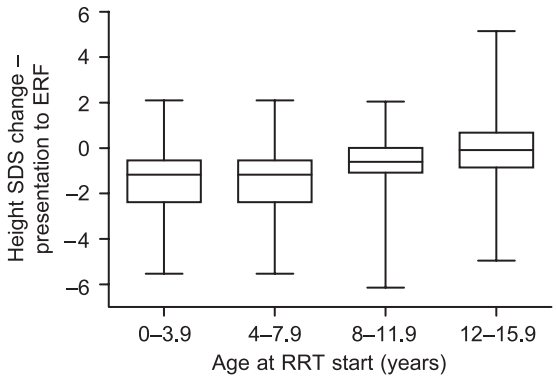

Figure 13.16: Change in height SDS from presentation to ERF by age at commencement of RRT

SDS according to diagnostic group with those groups associated with later and more acute onset disease being associated with better height at the commencement of ERF treatment (Kruskal–Wallis test, $p < 0.0001$) (Figure 13.15).

Recognising that growth is a problem in patients with chronic renal failure, it is important to assess not just the actual height SDS of patients at commencement of treatment but also the change in height SDS from presentation to ERF. Clearly, to make this assessment a reasonable period of time between presentation and ERF is required and so for this analysis only those members of the cohort of 694 patients presenting after April 1996 who came to nephrology services one or more years before the commencement of ERF treatment were considered. Data on height, both at presentation and ERF commencement, were present in 252 of 351 patients (71.8%) who met the above criteria and who were under 16 years of age at the start of ERF treatment.

Figure 13.16 shows the change in height SDS divided according to the age of ERF treatment commencement. The overall tendency was for patients to fall behind with their growth between presentation and ERF. This was worse in those starting ERF treatment in the first 8 years of life. However, the median height change was a loss of just over 1.1 standard deviations in these patients. For those starting ERF treatment between 12 and 16 years the median height loss was 0.1 standard deviations. Pubertal staging and bone age data were not

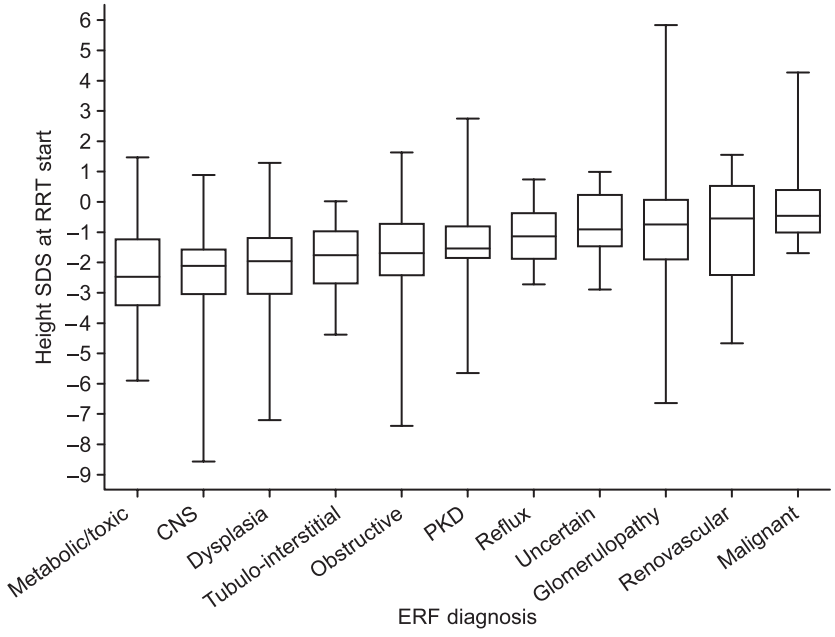

Figure 13.15: Height SDS at start of RRT by diagnosis

available for this analysis. The variation in the median height standard deviation change between age groups was significant (Kruskal–Wallis test, $p < 0.0001$).

Looking at the change in height SDS from presentation to ERF treatment starting, broken down according to the cause of renal failure, data was available for 266 patients. Of these, 5 patients were omitted as they were split between three diagnostic groups with a maximum of two in any one group. For the remaining 261 patients the change in height SDS is shown in Figure 13.17. It is interesting to note that patients with congenital nephrotic syndrome fared the worst with a median height loss of 1.24 standard deviations. The next worst group were those with a glomerulopathy who had a median height loss of 0.8 standard deviations. The other groups demonstrated little height loss. Of particular note are patients with metabolic disorders (the majority of whom have cystinosis) and tubulo-interstitial disorders (most of whom have nephronophthisis). Although these patients are generally small there was certainly no major loss of height as they progressed to RRT.

Data on treatment 90 days after entering an RRT programme were available for 667 of the 694 patients (96.1%). The most common treatment was peritoneal dialysis with 52% of the cohort being started on this. The majority of these patients were managed with cycling peritoneal dialysis whilst 20% were started on CAPD. Roughly equal numbers of patients were on haemodialysis or had received a transplant. Of the transplanted patients two thirds had received a cadaveric allograft and one third a graft from a living donor. Overall, 21% of patients had received a transplant by day 90. Approximately 95% of these were pre-emptive grafts but some will simply have been people fortunate enough to receive a graft within a short time of starting dialysis. Thirty one patients were on no treatment on day 90. These were patients who had problems with dialysis access or management and who were being managed conservatively on that particular day (Figure 13.18).

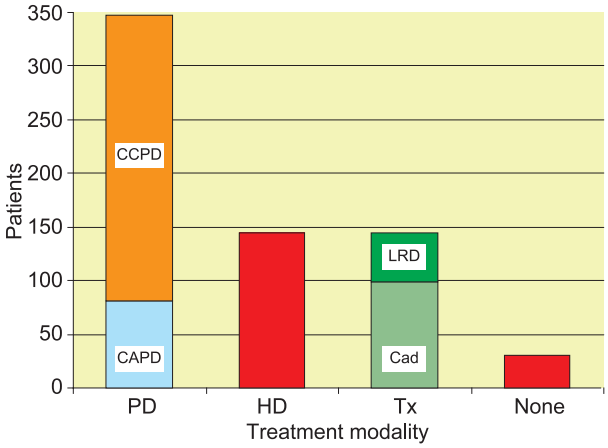

Figure 13.18: Distribution of RRT modalities at day 90

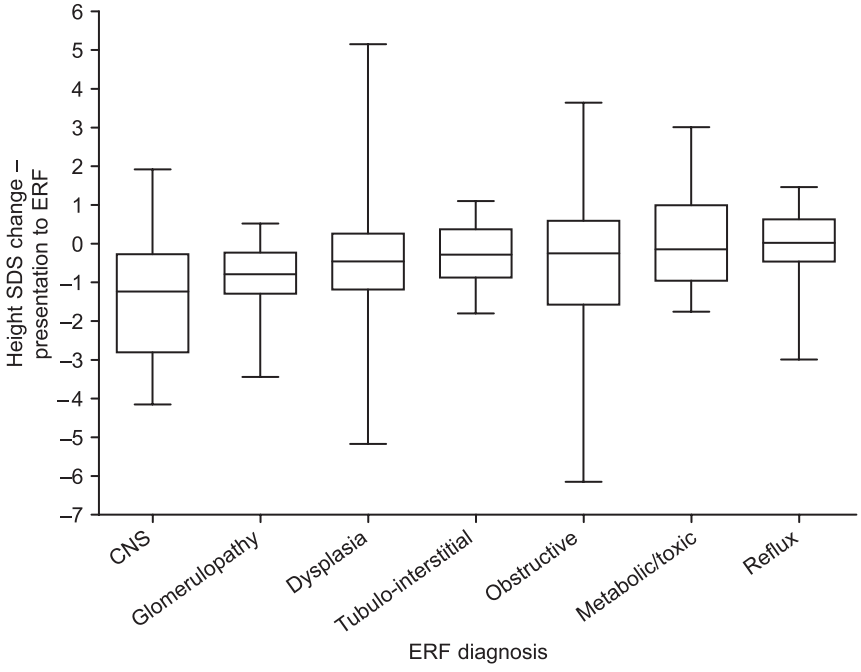

Figure 13.17: Change in height SDS from presentation to ERF by diagnosis

Current renal replacement therapy modality

Most units managed to supply a complete data set with regard to basic patient treatment in April 2003, though some units did have problems with data collection and return (Table 13.10). As a result, the treatment modality was known for 743 of 776 patients (95.7%). The distribution of treatments is shown in Figure 13.19. The vast majority of patients (76.9%) were living with a functioning allograft. Of these just over one fifth had an organ from a living donor and the remainder had cadaveric grafts. For the 173 patients on dialysis, 107 were on peritoneal dialysis and of these just 17 were on CAPD, the rest being treated with automated cycling dialysis. Sixty six patients were on hospital based haemodialysis.

There were significant differences between the South Asian and White patients with regard to current treatment modality. A greater proportion of the South Asian group were on dialysis rather than having a transplant ($p = 0.0027$). Of those on dialysis significantly more South Asian children were on haemodialysis than peritoneal dialysis ($p = 0.0117$). These data are summarised in Figure 13.20. The higher prevalence of blood group B and HLA homozygosity in this population make it more difficult to find compatible organs.

Table 13.10: Return rate for current patient modality from UK centres

Centre	Patients	Data available	% Return
GOSH	136	136	100
Manchester	88	88	100
Guys	82	82	100
Nottingham	80	80	100
Birmingham	65	65	100
Liverpool	35	35	100
Belfast	30	30	100
Cardiff	22	22	100
Bristol	45	44	98
Leeds	73	69	95
Southampton	17	16	94
Glasgow	58	48	83
Newcastle	45	22	49

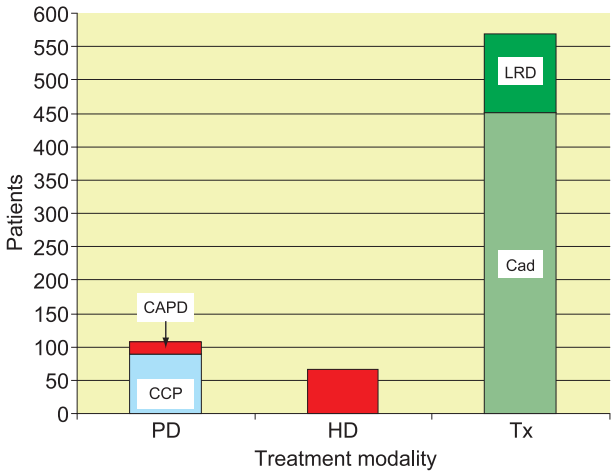

Figure 13.19: Distribution of current RRT modalities

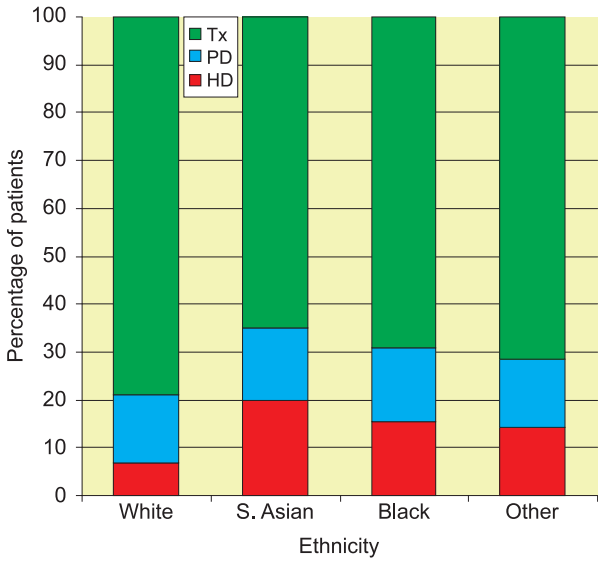

Figure 13.20: Distribution of current modalities by ethnicity

Focus on cardiovascular risk factors in paediatric ERF patients

Cardiovascular disease has been recognised as the most important cause of death in patients on renal replacement therapy. The risk of death from cardiovascular disease is elevated 30 fold for patients with ERF compared with the general population. The incidence of cardiovascular disease is also much increased after renal transplantation[1].

Young adults on renal replacement therapy die primarily of cardiac causes. The relative mortality risk from cardiac causes for a 25–34 year old on RRT is the same as that of a 75–80 year old without ERF. Amongst children with a renal transplant, cardiac disease is the single largest cause of death accounting for 35% of deaths in this age group.

The nature of cardiac disease differs from conventional ischaemic heart disease and includes a spectrum of disorders such as left ventricular hypertrophy, valvular calcification, cardiomyopathy and conduction disturbances. A study of young adults who had developed renal failure as a child, most of whom were transplanted, demonstrated that over 40% of patients had left ventricular hypertrophy and 19% had aortic valve calcification[2]. Increased arterial stiffness is a risk factor for mortality in adults with established renal failure. Carotid artery wall stiffness is increased in young adult patients with established renal failure and hypertension is one of the main determinants of this[3].

A controlled trial comparing children with chronic renal insufficiency with children on dialysis and controls demonstrated that even those with chronic renal insufficiency had evidence of impaired left ventricular diastolic function. There was an association between increased serum phosphate and calcium phosphate product and the development of left ventricular diastolic dysfunction and also between the presence of anaemia and left ventricular diastolic dysfunction[4].

Cardiovascular risk factors in paediatric transplant patients

The majority of children with ERF have a renal transplant. Thus factors contributing to cardiovascular morbidity and mortality need to be analysed. Factors available for study in the Paediatric Renal Registry are blood pressure, body mass index (BMI), lipid status and anaemia. All of these have been associated with cardiovascular morbidity and standards for care have been described in the Renal Association Standards document.

Of the 570 patients known to have functioning renal transplants and under the care of a paediatric unit in 2003, complete data, including systolic blood pressure, diastolic blood pressure and the number of anti-hypertensive medications being taken were available for 417 patients (73.2%). Most of the missing data related to diastolic blood pressure values which can be more difficult to delineate in paediatric patients. Data on systolic blood pressure and anti-hypertensive medication were available for 520 patients (91.2%).

The distribution of systolic blood pressure values across the cohort is shown in Figure 13.21. It can be seen that the distribution is shifted significantly to the right of normal with the median standard deviation score being 0.72.

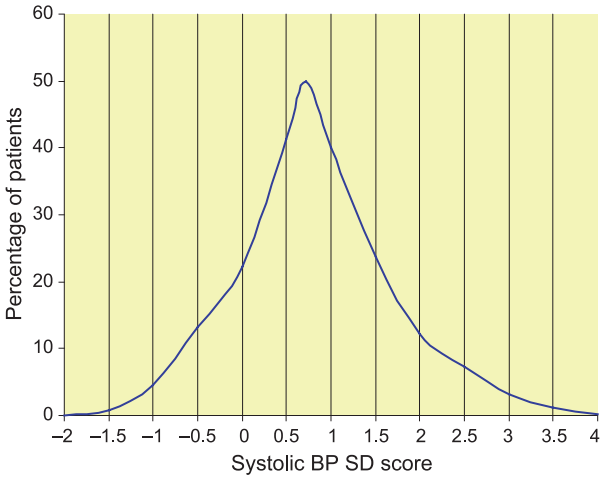

Figure 13.21: Distribution curve of systolic BP in transplant patients

The Renal Association Standard states that;

blood pressure should be kept at below 2 standard deviations (97.5th centile) from the mean for height and sex

Good practice suggest that the target systolic blood pressure should be below the 90th centile for height and sex. The standards used for this analysis are those given in the first American Task Force which relate to age and sex, rather than height and sex. The differences are in fact small but the use of these standards removes one disadvantage from renal patients in that a significant proportion are pathologically small and the use of height and sex standards can face the practitioner with unrealistically low target blood pressures in these patients. The other point that needs to be noted is that the Registry does not collect the method of blood pressure measurement. In many clinics, the norm is to use an automated oscillatory blood pressure monitor. The standards were generated using mercury sphygmomanometers. Oscillatory machines tend to give higher values for systolic blood pressures and lower values for diastolic blood pressures compared to the mercury sphygmomanometer. Although normal ranges for oscillatory machines for ambulatory blood pressure monitoring have been established, no such normal ranges have been established for casual blood pressure measurements using oscillatory machines.

Despite these caveats, it is quite clear that on this cross-sectional analysis, blood pressure control in the paediatric transplant population

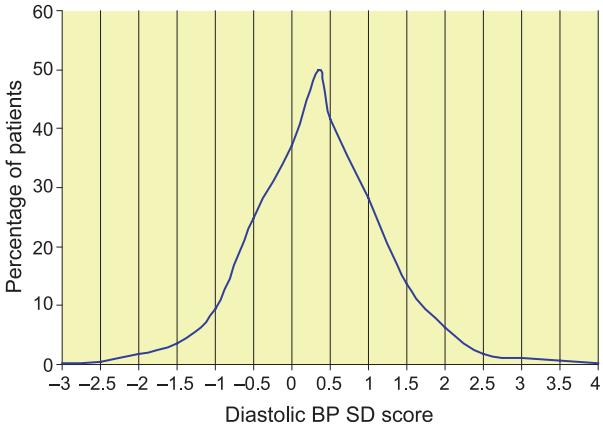

Figure 13.22: Distribution curve of diastolic BP in transplant patients

is poor. The median systolic blood pressure is shifted to the right by 0.72 standard deviations. 12.3% have a systolic blood pressure above the 97.5th centile and 20% have a systolic blood pressure in excess of the 95th centile.

The situation is similar for diastolic blood pressure (Figure 13.22). The median diastolic blood pressure is shifted to the right by 0.35 standard deviations with 6.2% having a diastolic blood pressure above the 97.5th centile and 11.3% having a diastolic measurement above the 95th centile.

The use of anti-hypertensive medication is shown in Figure 13.23. Overall, 59% of patients are on one or more anti-hypertensive medication. Just 177 patients (34%) have both a normal blood pressure and are on no anti-hypertensives, whilst 66% either have hypertension or are on anti-hypertensives to control

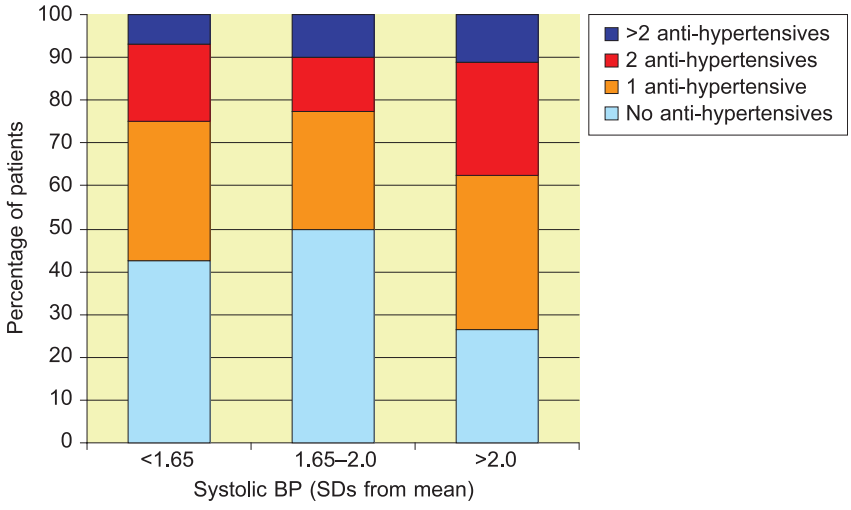

Figure 13.23: The use of anti-hypertensive medication in transplant patients by systolic BP

their blood pressure. Of those with a systolic blood pressure above the 97.5th centile, 26.5% were not on any anti-hypertensive medication at the time, whilst 50% of those with a blood pressure between the 95th centile and the 97.5th centile were not on any anti-hypertensive medication.

As data for the paediatric registry are only collected on an annual basis, it would clearly be possible to misinterpret blood pressure data as the picture faced by a clinician following a patient longitudinally might be very different from the single annual snap-shot obtained from the Registry. To study this further, all transplant patients who have had at least 3 consecutive years' of data recordings were analysed. There were 1,692 records with blood pressures available in a total of 419 patients. 193 recordings (11.4%) in 50 patients (11.9%) showed a systolic blood pressure more than the 97.5th centile. Of these, 27 patients (6.4%) had two or more years' (range 2–6) of consecutive systolic blood pressures more than the 97.5th centile. Looking at the 95th centile for systolic blood pressure, 325 recordings (19.2%) were above this value in 82 (19.5%) patients. Sixty five patients (15.5%) had 2 or more consecutive years' of systolic blood pressure above the 95th centile. Thus overall, blood pressure control in paediatric transplant patients appears to be sub-optimal.

The Registry has previously reported the problem of obesity in paediatric transplant recipients. Figure 13.24 shows the distribution of BMI standard deviation scores amongst the paediatric renal transplant population. It has been suggested that judging obesity by centiles for BMI is not appropriate. Instead a projected BMI over 30 kg/m^2 at adulthood is taken as definition of obesity whilst a projected BMI over 25 kg/m^2 at adulthood is used to define overweight patients[5]. Values for BMI were available in 520 patients, of whom 503 also had blood pressure data and details of anti-hypertensive medication. It can be seen that the curve is significantly shifted to the right with the median BMI standard deviation score being 0.9, 41.7% of the transplant population were overweight on cross-sectional analysis whilst 18.3% were obese. There was no gender difference. Fifty five patients (10.9%) were both overweight and had a systolic blood pressure above the 95th centile for age. Of these, 28 patients (5.6%) were both obese and had a systolic blood pressure above the 95th centile for age.

Although data on lipids are part of the routine paediatric registry data set, submission of these data is poor with 3 of the 13 paediatric centres not submitting any lipid data and only partial returns from the other 10 units. For 2003, data on lipids were available for just 190 transplants of whom 183 also had data on blood pressure, 183 also had data on BMI and 178 had data on BMI and blood pressure. No standards for cholesterol in children exist, other than the recommendation within the standards document that cholesterol should be measured. Fifty seven patients (30%) had a cholesterol above 5 mmol/L (the current Renal Association

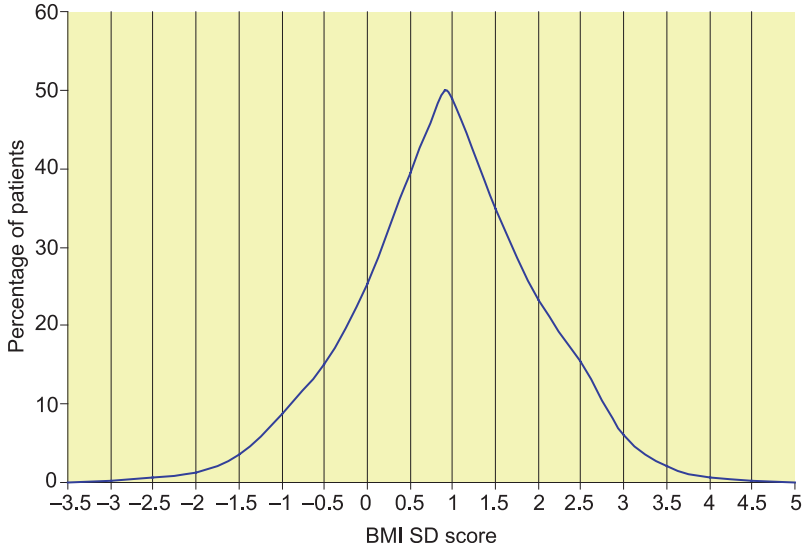

Figure 13.24: BMI SD score distribution for paediatric transplant patients

standard for adults). Of these, 17 (9.3%) also had a systolic blood pressure above the 95th centile and 29 (15.8%) were overweight, of whom 17 (9.3%) were obese. Nine patients (5.1%) had the triad of a high cholesterol, high systolic blood pressure and were overweight, whilst 5 of these patients (2.8%) were obese with this.

The final factor available to study that has been associated with cardiovascular morbidity is anaemia. This is difficult to study on a cross-sectional basis as it is chronic anaemia that leads to cardiovascular morbidity, whilst the snap-shot of haemoglobin obtained from the Registry will be affected by the patient's clinical status at the time. Data on haemoglobin were available in 542 (95.1%) patients.

The Renal Association Standard for haemoglobin advises that

for children of 2 years of age and above, the haemoglobin should be equal to or greater than 10.5 g/dl.

None of the patients in the study cohort was under 2 years of age. Ninety patients (16.6%) had a haemoglobin below 10.5 g/dl. Of these, a serum ferritin was available in only 26, of whom 9 had clearly inadequate iron stores. Three of the patients were documented to have received intravenous iron and 11 were documented to have been receiving erythropoietin.

Figure 13.25 shows the distribution of GFRs for those with a haemoglobin <10.5 g/dl and those above this value. As one might expect, the predicted GFRs in the anaemic group were significantly less than the non-anaemic group ($p = <0.0001$), although the median and inter-quartile range for predicted GFR in the anaemic group is rather higher than one would expect with non-transplanted patients with chronic renal failure. Anaemia was not a common problem amongst those with other cardiovascular risk factors with just 2.6% having anaemia and hypertension, 5.0% anaemia and obesity and 0.6% anaemia together with hypertension and obesity. Just 39 of the 90 anaemic patients had had their cholesterol measured. Of these, 9 (23%) had a value above 5 mmol/L. Four of these patients were obese of whom 2 were also hypertensive.

Cardiovascular risk factors in peritoneal dialysis patients

Of the 107 patients known to be on peritoneal dialysis, dynamic records for 2003 were available for 103 patients. With regard to the study of cardiovascular risk factors, factors available for study were blood pressure, body mass index, lipids, haemoglobin and bone chemistry parameters.

Data on blood pressure was available in 98 patients. The distribution of the systolic and diastolic blood pressures are shown in Figure 13.26. For both systolic and diastolic pressure, the median value is shifted to the right, more so

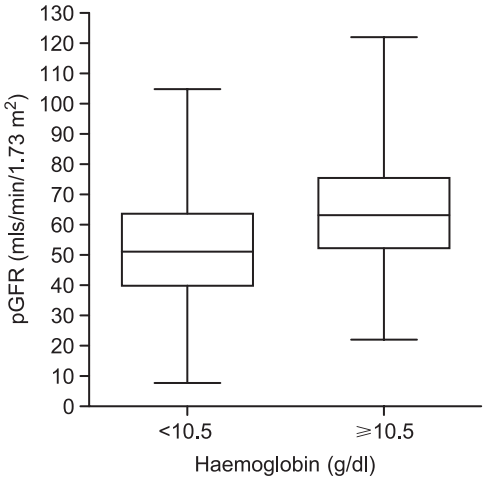

Figure 13.25: Distribution of predicted GFRs in transplant patients by Hb

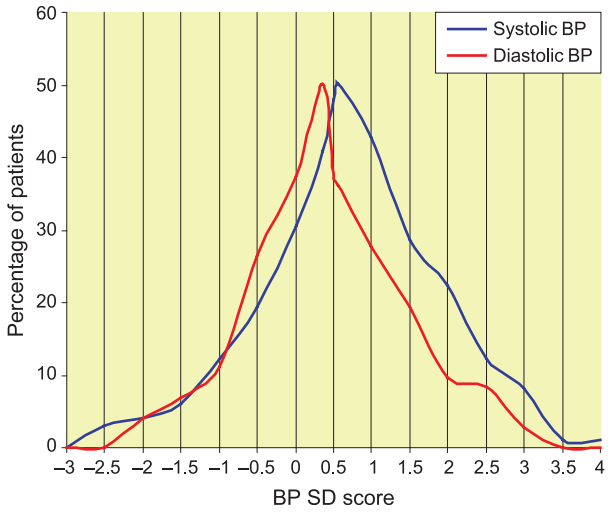

Figure 13.26: Distribution of systolic and diastolic BP in patients on PD

for systolic than diastolic values. 24.5% of PD patients had a systolic blood pressure above the 95th centile for their age, whilst 22.4% had a systolic pressure above the 97.5th centile. These values for diastolic pressures were 16.6% and 9.7% respectively. Thus, hypertension is clearly a significant problem in the paediatric dialysis population.

Data on body mass index were available in 96 patients (89.7%). The median BMI standard deviation score was very close to 0, though 17.7% of this group would be classified as being overweight whilst 5.2% fell into the obese category. Most of the patients however, did not appear to demonstrate an excessive weight for their age and the high BMI's related more to short stature in this group. Thus potentially, with improved growth, these patients would have a normal body habitus. Figure 13.27 shows the distribution of both BMI standard deviation scores and height standard deviation scores on the same axis. The height distribution is shifted markedly to the left with the median height SDS being slightly below the 5th centile for age. Despite this, only 11 patients were documented to be receiving growth hormone.

The measurement of lipids is clearly not routine in many units and only 33 patients (30.8%) had lipid measurements documented. Of these, 21 had a cholesterol level in excess of 5 mmol/L. Seven of these patients had a primary diagnosis of either congenital or acquired nephrotic syndrome. If any of these patients retained residual renal function, then this would predispose them to hyperlipidaemia. Even discounting all of these patients however, an incidence of hyperlipidaemia of 42% is concerning in a high risk group for cardiovascular morbidity.

Data on haemoglobin were available in 101 patients. At the time of data collection, none of these patients were below the age of 6 months, whilst 8 were between 6 months and 2 years and the rest were over 2 years. For those under the age of 2, all met the Renal Association Standard of having a haemoglobin over 10 g/dl. All of these patients were on erythropoietin and 3 of the 8 had also received intravenous iron therapy. For the 93 patients over the age of 2 years, 36 had a haemoglobin below the standard of 10.5 g/dl. Only 26 of these patients had a ferritin documented and this was low in 4. Nine of these patients had received intravenous iron and 32 of the 36 had been treated with erythropoietin. Amongst the 57 who met the Renal Association Standard, there were again 4 patients not on erythropoietin therapy, whilst 14 patients (a similar proportion to the anaemic group) had received intravenous iron. Forty eight of the 57 patients had a ferritin documented and of these 12 were iron-deficient according to the Renal Association Standard.

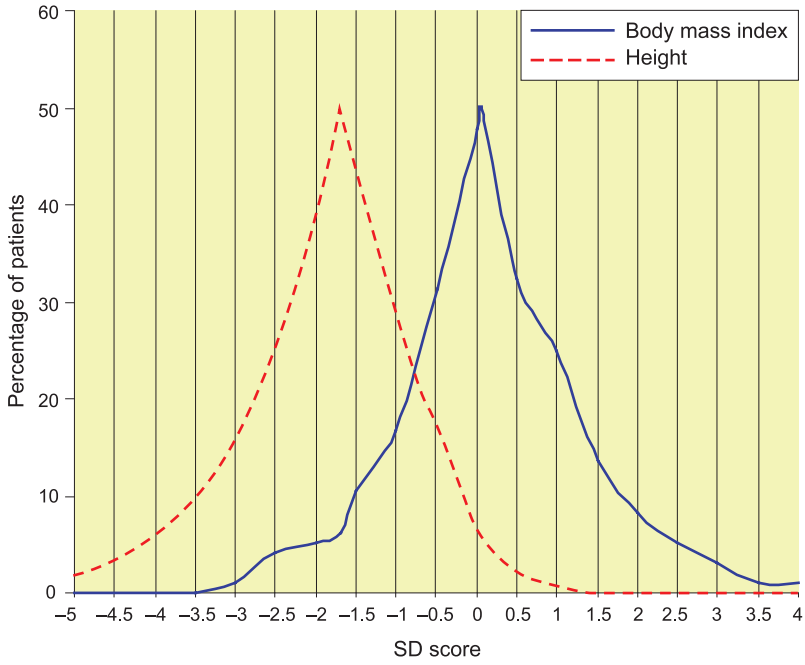

Figure 13.27: Distributions of BMI and Height SDS scores for patients on PD

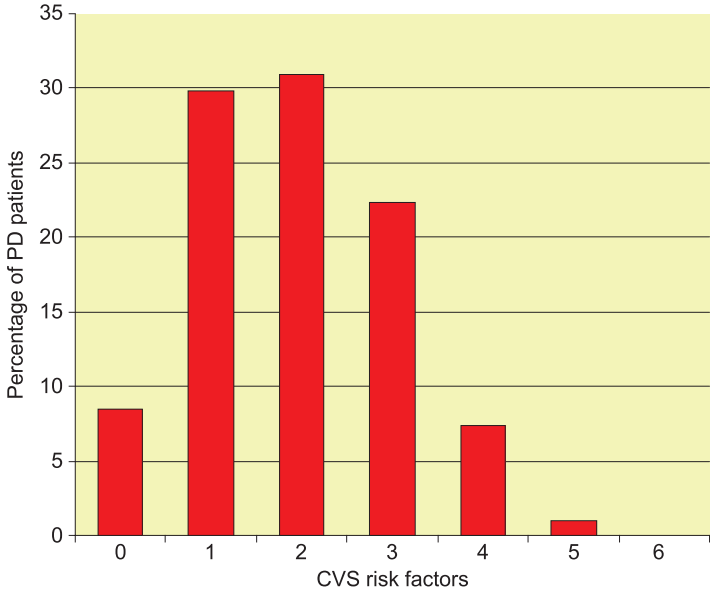

Figure 13.28: Number of cardiovascular morbidity risk factors present in PD

The Renal Association Standard for PTH states that;

PTH to be less than twice the upper limit of normal for the local laboratory

and for plasma phosphate;

plasma phosphate should be kept within the normal range for age

Measurement of PTH and phosphate levels were available in 101 and 102 of the 107 patients respectively. Fifty-one of the 101 patients had a PTH value more than twice the upper limit of normal for their laboratory, whilst 29 of these had a PTH value in excess of 4 times the upper limit of normal for their laboratory.

Phosphate is more complex to analyse as normal values for phosphate vary throughout childhood, being highest in infancy and falling to the adult normal range in early childhood. Interestingly, none of the 8 patients below the age of 2 years had a raised phosphate. For patients over the age of 2 years, 37 patients (36.3%) had a phosphate level above 1.8 mmol/L, whilst 20 patients (20.1%) had a phosphate level above 2.0 mmol/L.

Although this data only looks at a cross-section of the population rather than following the population longitudinally, it seems clear that risk factors for cardiovascular morbidity are present in a significant proportion of the population. It is not clear what the effect of the presence of more than one risk factor is on the incidence of morbidity and this is complicated by the fact that some risk factors, such as high PTH values and anaemia or obesity and hypertension, tend to be closely linked. Figure 13.28 shows the number of patients undergoing peritoneal dialysis according to the number of cardiovascular morbidity risk factors they have shown on cross-sectional analysis. Over 60% of patients in this group have two or more risk factors for cardiovascular morbidity. This figure will be an under-estimate of the true prevalence of risk factors as only a minority of patients had their lipid levels measured.

Cardiovascular risk factors in haemodialysis patients

Data were available for 45 of the 66 patients receiving haemodialysis in 2003. Of these, data on systolic blood pressure were available in 38 and as with other modalities of therapy, the tendency was towards hypertension with a median systolic blood pressure 1.1 standard deviations above the mean. 36.8% of patients had a systolic blood pressure above the 95th centile with 28.9% being above the 97.5th centile for age. These figures are more dramatic than seen in other modalities of therapy. However, the quantity of missing data was greater in

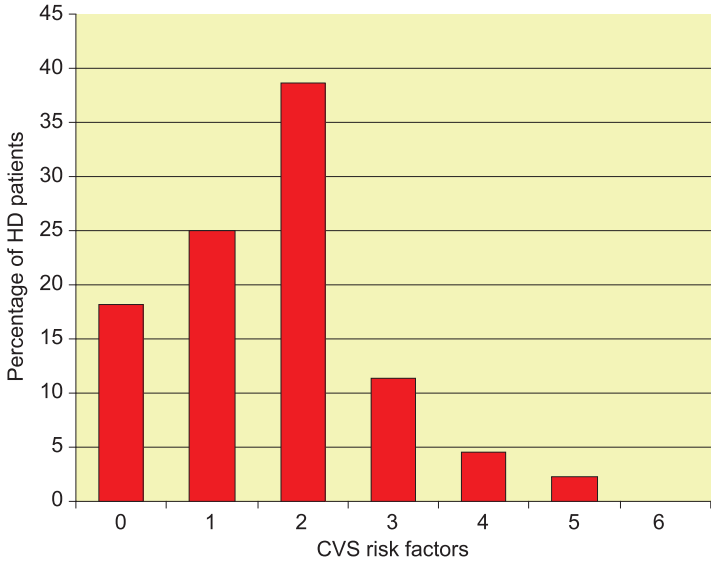

Figure 13.29: Number of cardiovascular morbidity risk factors present in HD patients

haemodialysis patients and many of these blood pressures will have been recorded prior to haemodialysis when the patients would have been at their most volume-overloaded state.

Data on body mass index were available for 36 patients, of whom 8 (22.2%) were overweight and 4 (11.1%) were obese. Lipid levels were only measured in 20 patients and 4 of these (2 of whom were patients with nephrotic syndrome as their primary diagnosis) had a cholesterol above 5 mmol/L.

Bone chemistry was recorded in 38 patients. Of these, 17 had a PTH greater than twice the upper limit of normal for the laboratory and 13 had a PTH more than 4 times the upper limit of normal for the laboratory. With regard to phosphate, 14 of the 38 patients had a phosphate level above the upper limit of normal for their age.

Data on haemoglobin were available for 44 patients, 4 of whom were under the age of 2 years (but over the age of 6 months) at the time of data entry. Two of these 4 failed to meet the Standard of a haemoglobin of 10 g/dl. All of these patients were receiving erythropoietin. One had received intravenous iron and 3 had appropriate iron stores according to their serum ferritin levels. For those over the age of 2 years, 15 of 40 patients failed to meet the target of 10.5 g/dl. Two of these patients had not yet received erythropoietin therapy and only 4 of the 15 were on intravenous iron therapy. Amongst those with a haemoglobin above 10.5 g/dl, all were receiving erythropoietin and 14 of the 25 patients were receiving erythropoietin therapy.

As with peritoneal dialysis patients, the cumulative number of risk factors in individual patients is shown in Figure 13.29. The figure shown here will be an under-estimate of the true incidence of these factors as data is incomplete in certain areas, particularly with regard to lipid levels. Even taking this into account, 56.8% of patients have at least 2 or more cardiovascular morbidity risk factors present on cross-sectional analysis.

Chronicity of cardiovascular risk factors in dialysis patients

Cardiovascular morbidity will be related to the presence of predisposing factors for prolonged periods of time. All the above assessments of dialysis patients are based on cross-sectional analyses. To investigate how persistent these risk factors were, all patients who have had 3 or more consecutive years' dialysis were analysed. 302 annual records were available for a total of 87 patients. For some parameters such as lipid levels too little data were recorded for meaningful analysis. As patients in the dialysis group do not have rapidly changing bodily proportions, data on BMI is the same as for cross-sectional analysis. This analysis has therefore been limited to looking at blood pressure control, anaemia and bone chemistry.

Data on systolic blood pressure were available from 278 records relating to 79 patients. Of these, 15 patients (18.9%) had a systolic blood pressure recorded at above the 95th centile for two or more consecutive years (range 2–5 years). The majority of these, 13 patients (16.4%), had a systolic blood pressure recorded at above the 97.5th centile for age for two or more consecutive years.

Data on anaemia were available from 295 records for 84 patients. Twenty one patients (25%) had a haemoglobin below the Renal Association Standard for two or more consecutive years. A number of adult studies have shown anaemia predicts morbidity and mortality in CRF even before dialysis has started[6]. Correction of anaemia in adult patients with CRF or on dialysis reduces morbidity and mortality[7,8]. Adult studies have also shown that anaemia in CRF is an independent risk factor for left ventricular hypertrophy, whilst LVH is a predictor of cardiovascular mortality and early correction of anaemia can lead to regression of LVH. Changes in left ventricular mass are recognised as a frequent occurrence in paediatric dialysis patients[9].

Information on the clinical effects of anaemia on paediatric ERF patients is relatively scarce. The 1996 and 2001 NAPRTCS reports revealed that in children and adolescents with CRF, a haematocrit <33% was found to be associated with accelerated progression to ERF[10,11]. Warady and Ho used the NAPRTCS database to look specifically at morbidity and mortality attributable to anaemia in 1,942 paediatric dialysis patients starting dialysis in 1992 through to 2001[12]. Overall, 68% of patients were anaemic (defined as haematocrit <33%) on day 30 after initiation of dialysis and 29.1% were severely anaemic (haematocrit <27%). Through the period 1992–2000, there was a fall in the percentage of patients anaemic at day 30 from 79.7% in 1992 to 50.6% in 2000. When compared with patients with haematocrit >33%, anaemic patients had a significantly higher mean number of days in hospital in the first year after initiation of dialysis. Anaemia was also associated with the risk of dying. There were 171 deaths in the 9 year period, giving 29 deaths per 1,000 patient years; the youngest patients aged 0–1 year at the start of dialysis had the highest mortality at 78 deaths per 1,000 patient years. Looking at all ages, being anaemic at day 30 gave a relative risk (RR) of death of 1.52 (confidence interval 1.03–2.26). Compared to those with haematocrit 33–36%, those with haematocrit <27% had a RR death of 1.80 (confidence interval 1.04–3.12). This study confirms a correlation between anaemia and both morbidity as measured by length of hospitalisation and mortality. Thus, the findings that a significant proportion of the paediatric dialysis population are not only anaemic on cross-sectional but also on longitudinal analysis, is particularly concerning.

With regard to bone chemistry, data on PTH were available from 220 records in 52 of the 87 patients, whilst data on phosphate levels was available from 290 records in 80 patients. Thirteen patients (25%) had two or more consecutive years' recordings of a PTH more than twice the upper limit of normal for the laboratory concerned whilst 21 patients (29.6%) had high serum phosphate levels for two or more consecutive years.

Looking at combinations of risk factors, 6 patients (7.6%) had chronic hypertension and anaemia whilst 12 (15.1%) had chronic hypertension and bone disease. Four patients (5.1%) had a long term combination of all three problems.

Conclusions

The patient prevalence in paediatric renal units in April 2003 numbered 776 with a male to female ratio of 1.57:1. The previously documented growth in the paediatric ERF population appears to have plateaued. The gender and ethnic distribution of the population is unchanged from previous reports. Similarly, prevalence and take-on rate are not significantly different to before. The take-on rate for South Asian patients remains 3 times that of the White population. This appears to be related to a significantly higher incidence of diseases acquired through autosomal recessive inheritance in this group ($p < 0.0001$).

Fifty percent of patients who presented to paediatric nephrology units and entered ERF had a GFR under 20 ml/min/1.73 m^2 at the time they were first seen by a paediatric nephrologist.

Patients who develop ERF tend to be smaller than average at the time of presentation, this being most marked in patients with metabolic disease and congenital renal dysplasia. By the start of ERF treatment most patients had fallen further behind with regards to height, this was most marked in the younger patients. Treatment at day 90 after commencement of ERF therapy was peritoneal dialysis in 52% of patients. Twenty one percent had functioning renal allografts, with approximately 95% through pre-emptive engraftment. With regard to current therapy 76.9% of the paediatric ERF population had a functioning renal allograft. Of the others, 61.8% were on PD and the remainder on HD. Patients of South Asian ethnicity were significantly less likely to have a functioning allograft ($p = 0.0027$) and were significantly more likely to be on HD rather than PD ($p = 0.0117$).

Examining risk factors for the later development of cardiovascular morbidity and mortality, patients with functioning renal allografts showed a shift in the distribution of their blood pressure with 20% having a systolic and 11.3% a diastolic pressure above the 95th centile for age. On longitudinal analysis, 19.5% had a systolic blood pressure above the 95th centile for 2 or more years' consecutive readings. A high BMI in transplant patients was common with 41.7% being overweight and 18.3% obese. In 30% of those with a documented cholesterol level this was over 5 mmol/L. Using the Renal Association standards, 16.6% were anaemic though only 12.2% of these patients were receiving erythropoietin. Amongst patients on PD, 24.5% had a systolic and 16.6% a diastolic blood pressure above the 95th centile for age. BMI was high with 17.7% being overweight and 5.2% obese, though this was more related to short stature than excessive weight for age with 50% of patients having a height below the 5th centile for age. Using Renal Association standards, 38.7% were anaemic, 50.4% had a raised PTH and 36% were hyperphosphataemic. Figures for the small number of HD patients were similar. Looking at patients who had a minimum of 3 consecutive years' dialysis, 16.4% had a systolic blood pressure recorded at over the 95th centile for age, 25% were anaemic, 25% had a PTH above twice the upper limit of normal and 29% were hyperphosphataemic for two or more consecutive years.

Although absolute mortality rate in children with ERF is low compared with adult patients, the presence of cardiovascular risk factors is a cause for concern. Whilst accepting that paediatric RRT patients are difficult to manage, failure to meet standards in these areas is potentially creating major problems in the future for these patients from cardiovascular co-morbidity.

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This report is presented on behalf of the BAPN.