Chapter 15: Report of the Paediatric Renal Registry 1999

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Introduction

In parallel with the creation of the National Renal Registry, the British Association for Paediatric Nephrology (BAPN) has established a Paediatric Registry. The pattern of diseases and requirements of paediatric patients are very different to those of adult patients and care is much more centralised in regional units. Although patient numbers are relatively small, gathering data is problematic as, unlike adult units, there was no one predominant information management system in use from which data can be downloaded. Therefore a separate Paediatric Registry was created to facilitate data collection, and knowing that overall numbers were small, a separate database was written. This database was created so that it would specifically deal with all paediatric requirements and automatically calculates important parameters, such as predicted glomerular filtration rate (pGFR), height, weight and body mass index standard deviation scores. The field format of the database is compatible with the National Registry, so that it will be possible to download paediatric data as a block into the National Registry. This will become important as more children with renal failure reach adulthood and hopefully it will allow a complete data set to be available within the National Renal Registry for these patients.

Over the past 3 years, the database has been written and installed in all 13 centres in the United Kingdom dealing with children with end stage renal failure (ESRF). It has also been installed in Dublin and the data set to be presented includes data from Dublin which deals with all paediatric ESRF for Eire.

This report includes a complete data set of demographic data, details of diagnoses and details of initial ESRF management from all centre involved. The data refer to patients under the age of 18 years and currently under treatment up to August 1999.

The BAPN recently commenced the collection of time-line data on all current patients and this will be available for analysis in the next 12 months.

The paediatric ESRF population

Assessment of the size of the paediatric ESRF population is hampered by varying patterns of referral for teenagers and varying attitudes to ESRF in neonates. There is probably complete referral of patients between the ages of 1 and 15 years to paediatric nephrology centres. Between the ages of 15 and 18 years, referral is incomplete and many patients will be referred directly to an adult nephrology centre. In some cases, this of course, will be entirely appropriate, in others it could lead to a failure to look in detail at specific paediatric problems, such as, growth and puberty. It will only be possible to ascertain the extent of this problem when the paediatric data sets and adult data sets are both complete and are amalgamated. With regard to infants with ESRF, not all neonatal units would routinely refer such patients to paediatric nephrology

centres as attitudes to ESRF management from birth vary. In addition, there will be a number of patients who either commence management but die before 90 days of age or in whom, because of associated abnormalities or specific complications, a positive decision is made not to pursue ESRF management. At present, there is no estimate of the size of this group. To try and ascertain this for the future, a specific field has been added to the paediatric database to allow entry of these patients so that this subgroup can be subsequently analysed. Initially this will provide data on those infants who are referred to paediatric nephrology centres but either die early or are not offered ESRF treatment for positive reasons. To define the group of patients not referred will need specific liaison with all neonatal and paediatric units.

The ESRF population, under 18 years of age on the 1st August 1999 is shown in Table 15.1 with the population broken down according to age and sex. It can be seen that the total under 18 year old population stood at 755. Of these, 532 were under the age of 15. This is an increase of 24% since 1992 when an audit placed the number at 429. As with all other studies of paediatric ESRF, males far outweigh females; the male to female ratio being 1.76:1, which is similar to the adult ratio. There is still a great male predominance when specific diagnoses, such as, posterior urethral valves and prune belly syndrome are excluded from the data analysis. This appears to be explained by a higher incidence of renal dysplasia in males (see Diagnosis section). Figure 15.1 shows the age distribution of the patients graphically. There is a steady increase of population size with age reflecting both the continued presentation of ESRF throughout childhood and the prolonged survival of patients with renal failure in the first few years of life. The fall in numbers after the age of 15 years, reflects both the variable referral of older patients to Adult Units and the variable age at which patients who commence ESRF management in childhood are referred on to Adult Units.

Age Group	Males	Females	Total
<2 years	11	7	**18**
2 – 5 years	37	11	**48**
5 – 10 years	103	52	**155**
10 – 15 years	188	123	**311**
15 – 18 years	142	81	**223**
All Ages	**481**	**274**	**755**

Table 15.1 Age and sex distribution of the paediatric ESRF population

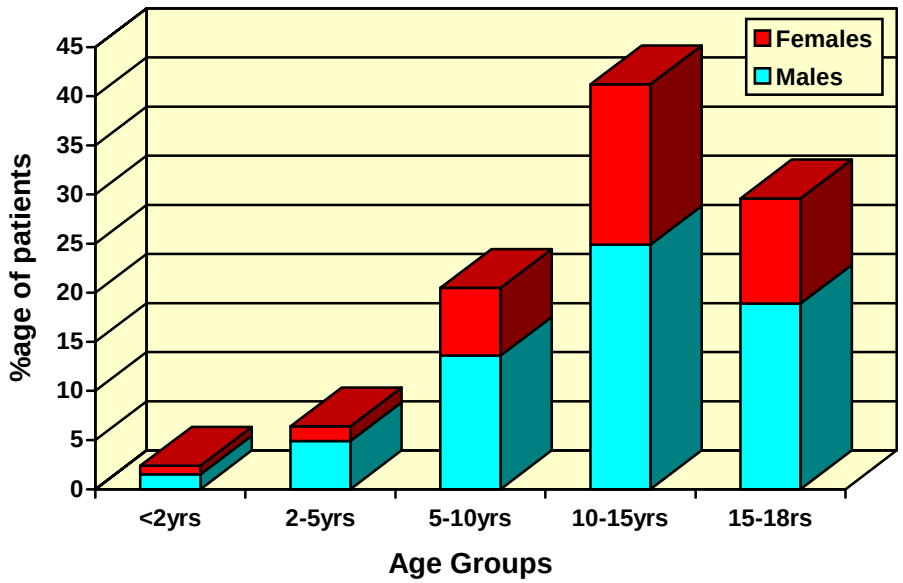

Figure 15.1 Age distribution of the current paediatric ESRF population

Table 15.2 shows the prevalence of ESRF in the paediatric population and the annual take-on rate as judged by an average of the last 3 years. For this analysis, patients from Eire were excluded. It can be seen that within the UK the prevalence is 12.2 per million of the population with a take-on rate of 1.7 per million total population. When looked at in terms of the paediatric population, the take-on rate across all ages is between 5.2 and 7.5 per million children. The prevalence varies from 13.6 per million in the under 4 year old population to 53.4 per million in the under 18 year old population. This latter figure will almost certainly be an under-estimate due to the direct referral of young people between the ages of 15 and 18 years to adult services.

	Population	Patients	New Patients	Prevalence (per million)	Take On Rate (per million)
Whole UK Population	59,236,522	725	101	12.2	1.7
Population <18yrs old	13,582,356	725	101	53.4	7.4
Population <14yrs old	11,379,835	434	82	38.1	7.2
Population <9yrs old	7,584,382	169	41	22.3	5.5
Population <4yrs old	3,670,665	50	21	13.6	5.7

Table 15.2 Prevalence of ESRF and take on rate to the paediatric ESRF programme

Reporting of ethnicity was incomplete and data was only available for 690 patients (91.4% of the population). Table 15.3 shows this broken down into a crude sub-grouping of patients from the Asian sub-continent, Black patients, White patients and Others. The percentages in each group have been compared to data obtained from the Office for National Statistics for 1995-7. It can be seen that patients from the Asian sub-continent are very much over-represented. This is presumably secondary to an increase in inherited disorders related to a high frequency of consanguineous marriage.

Also attitudes to termination of pregnancy after antenatal diagnosis vary widely. Finding a 10% prevalence of Asian patients with ESRF in the paediatric population has significant implications for health care and provision.

	Males	Females	Total	% age Patients	Population Distribution
Asian Subcontinent	40	31	71	10.3%	4.7%
Black	7	6	13	1.9%	3.0%
White	380	210	590	85.5%	90.6%
Other	11	5	16	2.3%	1.7%

Table 15.3 Ethnic mix of the paediatric ESRF population

Primary ESRF diagnoses in prevalent patients

Primary ESRF diagnoses were available in 683 (90.5%) of cases. To avoid erroneous coding a specific diagnostic list was created by the BAPN Registry Sub-Committee and these word terms were then mapped to ICD 10 Read 2 and EDTA codes. Diagnoses were selected from sub-categorised pick-lists to avoid the entry of misleading or variable terminology. In all, 73 diagnoses were available; these being divided amongst 7 diagnostic groups.

For the patients coded 52 diagnoses were used. Table 15.4 lists the diagnoses in alphabetical order together with the frequency of their usage and sex distribution. Table 15.5 shows the same data in a sub-categorised format**.** The most common cause of renal failure in the paediatric population is renal dysplasia; this accounting for almost 28% of cases. In 20% this was isolated renal dysplasia and in the rest it was renal dysplasia associated with other conditions. Overall, there was a 2:1 ratio of males to females with renal dysplasia and even discounting syndromic diagnoses, such as, prune belly syndrome which only occur in boys, the ratio remained 1.8:1.

Obstructive uropathy was the next most common cause accounting for 20.2% of cases. Of these, 15.7% were secondary to posterior urethral valves. Once this latter condition had been excluded, there was no difference in the incidence of renal failure secondary to obstructive uropathy between the sexes. The finding that 48% of paediatric ESRF is secondary to either renal dysplasia or obstructive uropathy is not new and emphasises the need for research in these specific areas to allow the potential of antenatal diagnosis and treatment.

Glomerulopathies, the most common cause of renal failure in adult practice, accounted for 17% of the paediatric population. As can be seen the spectrum of disease is quite wide and the only frequently seen condition is primary focal segmental glomerulo-sclerosis at 6.4% of the total population.

Reflux nephropathy, previously one of the most common causes of ESRF, now accounts for only 7.2% of cases and even if including those patients presented with unexplained ESRF, the total only amounts to 9.2%. This may be due to increased awareness of the problems of urinary tract infection in childhood and earlier intervention. Alternatively it may be due to altered classification. Nephronophthisis, a condition often associated

with renal failure of uncertain aetiology and a frequent differential diagnosis in a patient presenting with small kidneys and renal failure in later childhood, was stated to be the primary cause of ESRF in 5.3% of cases. Thus the total frequency of reflux nephropathy, nephronophthisis and renal failure of uncertain aetiology is 14.5%.

Congenital nephrotic syndrome is a condition which was always associated with early death and is most frequently seen in Finland. With the advent of aggressive therapy, including daily intravenous albumin infusions followed by early bilateral nephrectomy and dialysis and transplantation, the numbers of children surviving with this condition are increasing. In this survey, congenital nephrotic syndrome accounted for 6.9% of patients. It was noticeable that there was marked geographic variability in the frequency of this condition, the maximum being in Ireland, where it accounted for 18.6% of all the cases of ESRF.

Cystinosis and recessive polycystic kidney disease are the other two common inherited disorders seen but these each only account for 2% of cases.

Diagnosis	Males	Females	Total
Acquired obstructive uropathy	2	0	**2**
Alport's syndrome	6	2	**8**
Anti-GBM disease	0	2	**2**
Autosomal recessive PKD	7	5	**12**
Barrter's syndrome	1	1	**2**
Branchio-oto-renal syndrome	1	1	**2**
Chronic renal failure - uncertain aetiology	6	8	**14**
Cis-platinum toxicity	1	0	**1**
Congenital nephrotic syndrome (DMS)	5	1	**6**
Congenital nephrotic syndrome (Finnish)	10	8	**18**
Congenital nephrotic syndrome (FSGS)	1	4	**5**
Congenital nephrotic syndrome (unspecified)	4	14	**18**
Congenital obstructive uropathy - Bladder outlet obstruction (not PUV)	4	3	**7**
Congenital obstructive uropathy (not bladder outlet obstruction)	5	3	**8**
Congenital obstructive uropathy - Posterior urethral valves	107	0	**107**
Cortical necrosis	9	4	**13**
Crescentic glomerulonephritis	1	5	**6**
Cyclosporin Nephrotoxicity	2	0	**2**
Cystinosis	8	6	**14**
D+ Haemolytic uraemic syndrome	10	10	**20**
D neg Haemolytic uraemic syndrome	2	0	**2**
Glomerulonephritis (unspecified)	3	1	**4**
Henoch Schoenlein nephritis	7	4	**11**
IgA nephropathy	1	2	**3**
Lawrence Moon Biedl syndrome	2	2	**4**
Megacystis megaureter	1	0	**1**
Mesangio-capillary glomerulonephritis Type 1	2	1	**3**
Mesangio-capillary glomerulonephritis Type 2	2	4	**6**
Mesoblastic nephroma	1	0	**1**
Multicystic dysplastic kidneys	8	7	**15**
Nephronophthisis	24	12	**36**
Neuropathic bladder	6	8	**14**
Other cytotoxic drug nephrotoxicity	0	1	**1**
Polycystic kidney disease (other)	3	0	**3**
Primary focal segmental glomerulo-sclerosis	23	21	**44**
Primary hyperoxaluria type 1	2	1	**3**
Primary interstitial nephritis	5	3	**8**
Proliferative glomerulonephritis	2	3	**5**
Prune belly syndrome	15	0	**15**
Reflux nephropathy	21	28	**49**
Renal artery stenosis	2	2	**4**
Renal artery thrombosis	1	1	**2**
Renal dysplasia	92	47	**139**
Renal hypoplasia	7	6	**13**
Renal trauma	1	1	**2**
Renal tubular acidosis	3	0	**3**
Renal vein thrombosis	6	4	**10**

Diagnosis	Males	Females	Total
Tubular disorders (other)	1	0	**1**
Vasculitis (unspecified)	0	3	**3**
Wegner's granulomatosis	0	1	**1**
Wilms' nephropathy	1	1	**2**
Wilms' tumour	4	4	**8**
Totals	**438**	**245**	**683**

Table 15.4 Diagnoses causing ESRF in the paediatric population

Diagnostic Group	Males	Females	Total	% of Total
Renal Dysplasia and related conditions				
Renal dysplasia	92	47	**139**	**20.4%**
Multicystic dysplastic kidneys	8	7	**15**	**2.2%**
Prune belly syndrome	15	0	**15**	**2.2%**
Renal hypoplasia	7	6	**13**	**1.9%**
Lawrence Moon Biedl syndrome	2	2	**4**	**0.6%**
Branchio-oto-renal syndrome	1	1	**2**	**0.3%**
Megacystis megaureter	1	0	**1**	**0.1%**
Total with Primary Renal Dysplasia	**126**	**63**	**189**	**27.7%**
Obstructive Uropathy				
Posterior urethral valves	107	0	**107**	**15.7%**
Neuropathic bladder	6	8	**14**	**2.0%**
Congenital obstructive uropathy (not BOO)	5	3	**8**	**1.2%**
Congenital bladder outlet obstruction (not PUV)	4	3	**7**	**1.0%**
Acquired obstructive uropathy	2	0	**2**	**0.3%**
Total with Obstructive Uropathy	**124**	**14**	**138**	**20.2%**
Glomerulonephritis, Vasculitis and Glomerulopathy				
Primary focal segmental glomerulo-sclerosis	23	21	**44**	**6.4%**
D+ Haemolytic uraemic syndrome	10	10	**20**	**2.9%**
Henoch Schoenlein nephritis	7	4	**11**	**1.6%**
Alport's syndrome	6	2	**8**	**1.2%**
Crescentic glomerulonephritis	1	5	**6**	**0.9%**
Mesangio-capillary glomerulonephritis Type 2	2	4	**6**	**0.9%**
Proliferative glomerulonephritis	2	3	**5**	**0.7%**
Glomerulonephritis (unspecified)	3	1	**4**	**0.6%**
IgA nephropathy	1	2	**3**	**0.4%**
Mesangio-capillary glomerulonephritis Type 1	2	1	**3**	**0.4%**
Vasculitis (unspecified)	0	3	**3**	**0.4%**
Anti-GBM disease	0	2	**2**	**0.3%**
D neg Haemolytic uraemic syndrome	2	0	**2**	**0.3%**
Wegner's granulomatosis	0	1	**1**	**0.1%**
Total with Glomerular Disease	**59**	**59**	**118**	**17.3%**
Reflux Nephropathy and CRF of Uncertain Aetiology				
Reflux nephropathy	21	28	**49**	**7.2%**
Chronic renal failure - uncertain aetiology	6	8	**14**	**2.0%**
Total with Reflux Nephropathy and CRF of Uncertain Aetiology	**27**	**36**	**63**	**9.2%**
Primary Tubular and Interstitial Disorders				
Nephronophthisis	24	12	**36**	**5.3%**
Primary interstitial nephritis	5	3	**8**	**1.2%**
Renal tubular acidosis	3	0	**3**	**0.4%**
Barrter's syndrome	1	1	**2**	**0.3%**
Tubular disorders (other)	1	0	**1**	**0.1%**
Total with Primary Tubular and Interstitial Disorders	**34**	**16**	**50**	**7.3%**
Congenital Nephrotic Syndrome				
Congenital nephrotic syndrome (Finnish)	10	8	**18**	**2.6%**
Congenital nephrotic syndrome (unspecified)	4	14	**18**	**2.6%**
Congenital nephrotic syndrome (DMS)	5	1	**6**	**0.9%**
Congenital nephrotic syndrome (FSGS)	1	4	**5**	**0.7%**
Total with Congenital Nephrotic Syndrome	**20**	**27**	**47**	**6.9%**
Renal Vascular Disorders				
Cortical necrosis	9	4	**13**	**1.9%**
Renal vein thrombosis	6	4	**10**	**1.5%**
Renal artery stenosis	2	2	**4**	**0.6%**
Renal artery thrombosis	1	1	**2**	**0.3%**
Renal trauma	1	1	**2**	**0.3%**
Total with Renal Vascular Disorders	**19**	**12**	**31**	**4.5%**
Metabolic Diseases and Drug Nephrotoxicity				
Cystinosis	8	6	**14**	**2.0%**
Primary hyperoxaluria type 1	2	1	**3**	**0.4%**
Cyclosporin Nephrotoxicity	2	0	**2**	**0.3%**
Cis-platinum toxicity	1	0	**1**	**0.1%**

Diagnostic Group	Males	Females	Total	% of Total
Other cytotoxic drug nephrotoxicity	0	1	**1**	**0.1%**
Total with Metabolic Diseases and Drug Nephrotoxicity	**13**	**8**	**21**	**3.1%**
Polycystic Kidney Disease				
Autosomal recessive PKD	7	5	**12**	**1.8%**
Polycystic kidney disease (other)	3	0	**3**	**0.4%**
Total with Polycystic Kidney Disease	**10**	**5**	**15**	**2.2%**
Malignant and Related Diseases				
Wilms' tumour	4	4	**8**	**1.2%**
Wilms' nephropathy	1	1	**2**	**0.3%**
Mesoblastic nephroma	1	0	**1**	**0.1%**
Total with Malignant and Related Diseases	**6**	**5**	**11**	**1.6%**

Table 15.5 Grouped ESRF diagnoses for the paediatric population

Commencement of ESRF treatment

Data on the age of commencement of ESRF management was available in only 79.2% of cases. In part, this is an expected problem due to an attempt now to document patients who may have been in renal failure for 10 years or more and whose early history is missing. It is to be hoped that with prospective data collection this figure will increase significantly. There is, however, a significant difference in the completeness of records between individual units and this is being addressed. Table 15.6 and Figure 15.2 show the age at commencement of ESRF treatment broken down according to age group and sex. It can be seen that the picture is very different to that shown in Figure 15.1. Although only 8.7% of the current ESRF population are currently under 5 years of age 38.8% of patients commenced ESRF treatment below the age of 5 years. The difference between these two distributions clearly shows the high incidence of ESRF in early childhood as one might expect from the diagnoses causing renal failure. The larger percentage of older patients in the age distribution of the population is a testament to the success of ESRF treatment in young patients and an explanation for the increase in the total population over the past decade. Figure 15.2 also clearly shows the preponderance of males which is most marked in those starting ESRF management early due to the timing of ESRF in the male predominated diagnoses of renal dysplasia and posterior urethral valves.

ESRF start age	Males	Females	Total	% of patients
<1yr	57	16	73	12.2%
1-2yrs	38	18	56	9.4%
2-5yrs	75	28	103	17.2%
5-10yrs	113	73	186	31.1%
10-15yrs	87	78	165	27.6%
15-18yrs	11	4	15	2.5%

Table 15.6 Age distribution of patients at the start of ESRF treatment

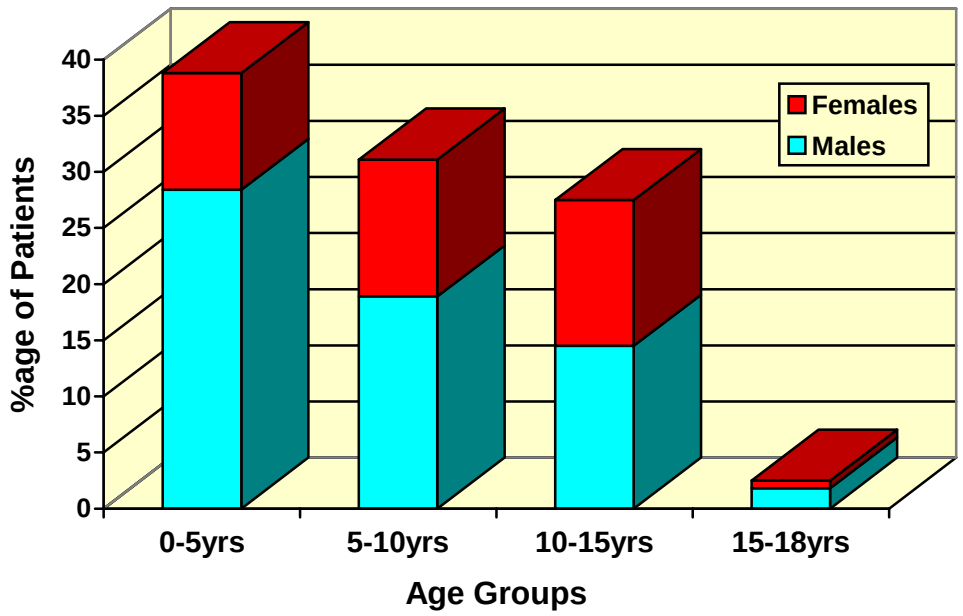

Figure 15.2 Age and sex distribution at the start of ESRF treatment

Details of treatment modality 90 days after entering an ESRF programme were available for 564 (74.7%) of patients. Again, it is to be hoped that the incompleteness of data in this field is secondary to the difficulty in extracting historic details and with prospective data collection, a more complete data return should be possible. Figure 15.3 shows the frequency of the different treatment modalities broken down according to age. Automated peritoneal dialysis is the most popular intervention in the infant and young child. After the age of 5, CAPD and haemodialysis become more common, though haemodialysis is the least common treatment over all age ranges. The proportion which have received a renal transplant by day 90, rises rapidly through childhood, reaching almost 30% in the 10-15 year old group. This represents the popularity of pre-emptive transplantation in paediatric practice though the number receiving renal transplants prior to any form of dialysis cannot be ascertained from this data set. Throughout the age ranges, between 3 - 7% of patients are receiving no dialysis and do not have a transplant on day 90. This group demonstrate the difficulty in maintaining dialysis in paediatric patients and the frequency with which patients are between interventions at any one point.

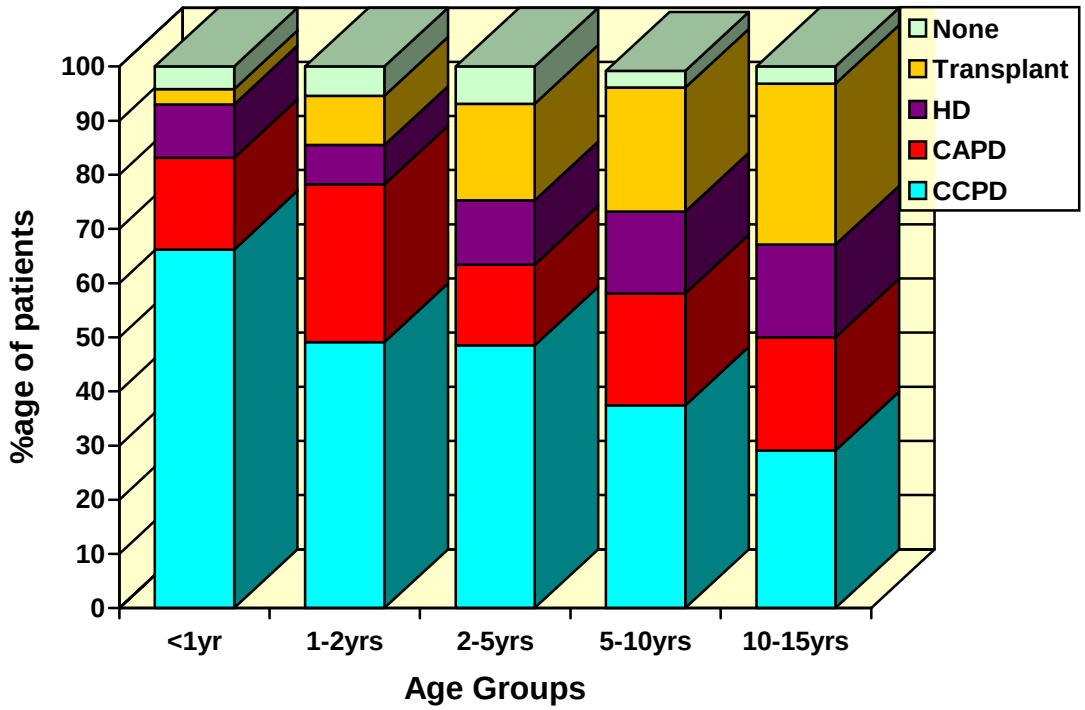

Figure 15.3 Treatment modality at day 90 according to age

Estimation of renal function has been made using the predicted GFR as calculated by the Schwartz formula to try to take account of varying size and body mass. The pGFR at the start of ESRF treatment was quite variable. Some of this is secondary to decisions based on rate of change of GFR, some to the need to perform bilateral nephrectomies (e.g. in congenital nephrotic syndrome) and some due to variability in symptomatology and growth. Figure 15.4 shows the median, interquartile range and range of pGFR at the start of ESRF management for patients broken down according to age group and whether the initial treatment was dialysis or a transplant. It can be seen that on the whole pGFR in those who had been transplanted by day 90 was higher than that in those on dialysis. This reached statistical significance in the 5 to 10 year old group (p=0.0157 Mann-Whitney U test) and in the 10 to 15 year old group (p=0.0008 Mann Whitney U test) and presumably reflects pre-emptive transplantation in these groups where patients are placed on the list in anticipation of needing dialysis and are transplanted before dialysis has become necessary.

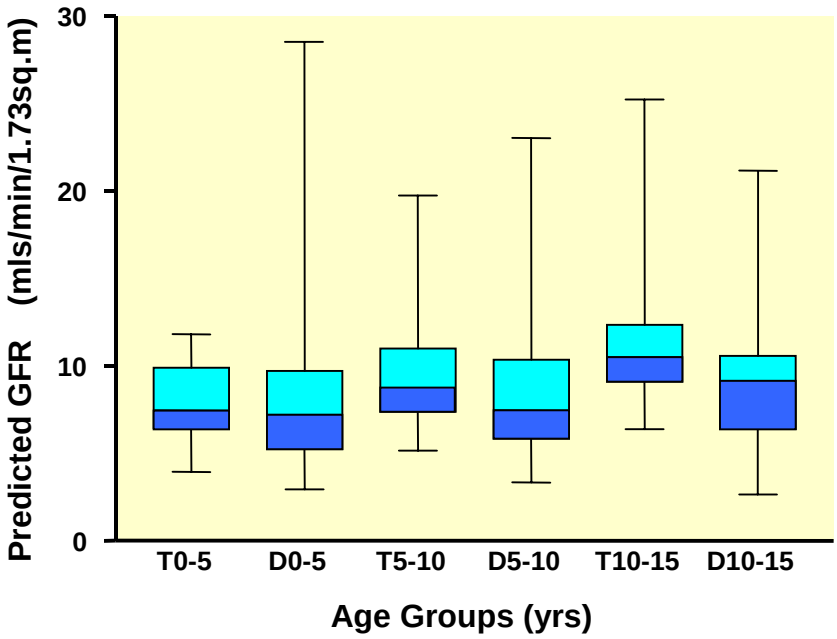

Figure 15.4 Predicted GFR start of ESRF treatment (Tx-y = transplant, Dx-y = dialysis)

Growth

Growth is a major problem in paediatric patients with renal failure. This was studied by heights with standard deviations (s.d.) from the mean for age and the change in standard deviation score from the mean with time. Many factors contribute to stature at the time of commencement of ESRF treatment including the duration of chronic renal failure, the presence of confounding biochemical problems such as acidosis, the severity of renal osteodystrophy and the presence of underlying conditions associated with growth failure (such as cystinosis). Figure 15.5 shows the percentage of children greater than 3s.d., 2-3 s.d., 1-2 s.d. and 0-1 s.d. below the mean for height at the start of ESRF treatment. Overall 45% of this cohort were more then 2 s.d. from the mean for height and 21% were more than 3 s.d. below the mean for height at the start of ESRF treatment. The proportion which was very small decreased steadily as the age of ESRF treatment commencement increased. This is because of the greater contribution of patients with acquired rather than congenital diseases in the older paediatric population. Limited data is presented below on the time between presentation to a paediatric nephrologist and the commencement of ESRF treatment but the true effect of paediatric nephrological care and appropriate use of agents such as growth hormone will only become apparent when full time-line data becomes available in the future.

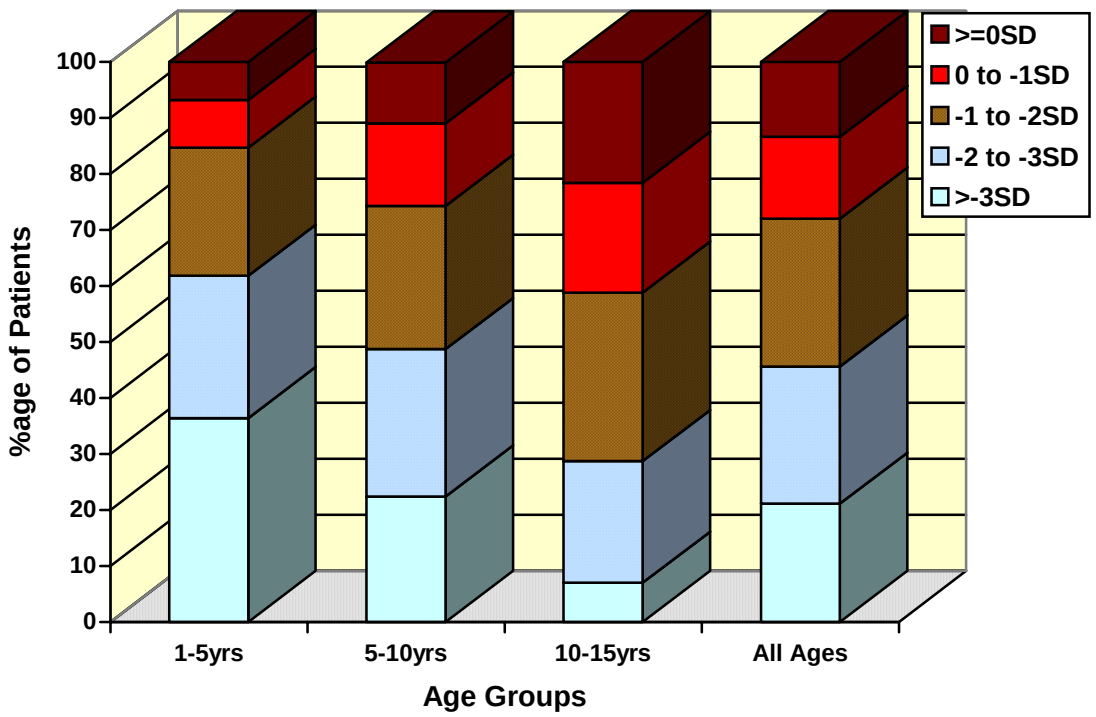

Figure 15.5 Percentage of children below the mean for height at start of ESRF treatment

Presentation to paediatric nephrology services

The database collects data on age, height, weight and creatinine at presentation to the paediatric nephrology service. These data will turn out to be important to see whether intervention by paediatric nephrologists prevents co-morbid complications, loss of height and delays the decline into ESRF. For the current cohort, collection of this data has been inevitably retrospective and with many patients having long histories and voluminous notes, the data is incomplete. Prospective collection of the data in the future ought to allow for more reliable analysis.

Currently, data were available on only 432 patients (57.2% of the population). Figure 15.6 shows the predicted glomerular filtration rate at the time of presentation split into groups of those with a predicted GFR >50, 20-50, 10-20 and <10mls/min/1.73m². It can be seen that over one third of patients were at ESRF at the time of presentation and a further 25% were almost at end stage with a GFR of between 10-20. Only 13% of patients had a GFR above 50 at the time they were first seen. As many of the diagnoses are congenital lesions which can be identified early and lead to a steady progressive decline in renal function, there is clearly scope for establishing a pattern of earlier tertiary referral.

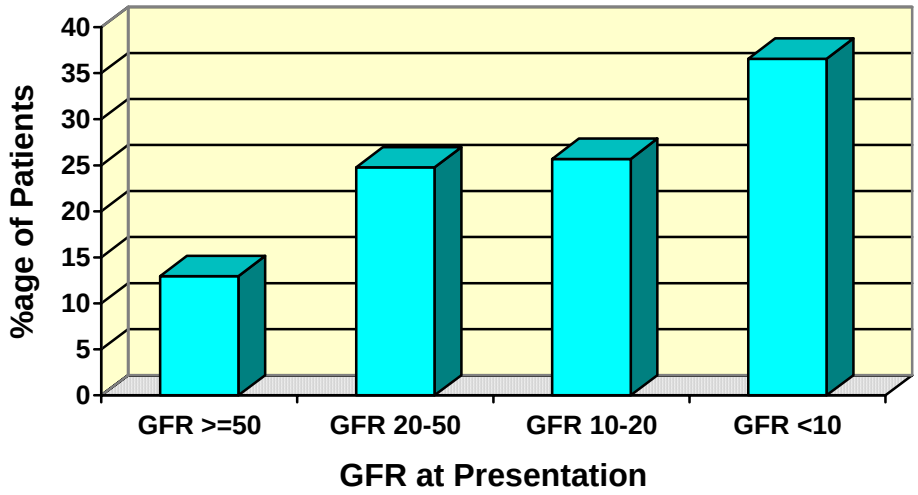

Figure 15.6 GFR at presentation to a paediatric nephrologist

Data on height at presentation and then subsequently when entering ESRF was even more sparse. To judge change in height, only patients where complete data was available and where there was a gap of at least one year between presentation and commencing end stage treatment were studied. This limited the analysis to 210 patients which at just 27.8% of the population means that the results of this analysis need to be interpreted with caution. The data is shown in Table 15.7. It is pleasing to see that 36% of patients either maintained their height percentile or crossed percentiles in a positive direction. 50% of patients lost height and fell up to two standard deviations from their starting point. Almost 14% of patients suffered major growth problems falling over two standard deviations from the point at which they started. Unfortunately, the numbers of patients with complete data available were too small to allow sub-analysis according to age at presentation, diagnosis and time from presentation to end stage.

Height change	>3 s.d. loss	2-3 s.d. loss	1-2 s.d. loss	0-1 s.d. loss	Stable or gain
Patients	11	18	40	65	76
% Patients	5.24	8.57	19.05	30.95	36.19

Table 15.7 Height change between presentation and end stage renal failure

Co-morbidity & death

Data on co-morbidity and death were very sparse and collection of this data to date has been too incomplete to allow meaningful analysis. As these are important factors in the planning and prevention of health care services, extra effort is going to be required in these areas in the future. Prospective rather than retrospective data collection, as ought to be the case from now on, will hopefully aid this.

Within co-morbidity, one area of particular note will be exact ascertainment of the prevalence of significant developmental delay at commencement of renal failure therapy as this varies significantly in the reporting to date from zero to 20% of patients. Consanguinity has clearly been under-reported when judging the diagnoses within

certain families and this highlights the major defects that exist in all our hospital case notes.

Whilst building this data set the emphasis has been on collecting data on current patients. This will have inevitably meant the omission of some patients who have died during the past 2 years of data collection. Despite this, there has been a minimum of 20 deaths over the past 2 years, giving an annual death rate of in excess of 0.7%. The most frequent cause of death appears to be elective treatment withdrawal after loss of dialysis access sites.

Conclusion

Collection of data in paediatric patients with end stage renal failure has previously been limited to that collected by the EDTA and the specific data collected by UKTSSA. This project is the start of the first comprehensive data collection exercise for the whole of the United Kingdom and Ireland. The creation of a specific database and the personal installation of this in all centres has led to an excellent reporting rate, but despite this obtaining a complete data set in all areas has been difficult. The limited numbers of patients with ESRF in childhood make the collection and maintenance of such a database essential if we are going to accurately study management trends and interventions and not be misled by the false promises of trends in small local populations.

The collection of this static data set has led to clear definition of the patient numbers and disease spectrum leading to end stage renal failure in childhood. It has also clearly shown trends in the age at which end stage renal failure management is instigated and which therapies are used initially. Over the next 12 months the paediatric Registry will be prospectively collecting static data and will add to this time-lines of treatments including dialysis modality, the use and results of growth hormone and erythropoietin therapy and transplantation statistics. Use of these data over next 5 years, will allow examination of trends and success rates, both within individual patient groups and between centres.

This report has been compiled by the BAPN Renal Registry Subgroup and the BAPN Registry Data Co-ordinator on behalf of the BAPN.
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