Chapter 15: Report of the Paediatric Renal Registry

Compiled by Dr M.A. Lewis and Mrs Jo Shaw

Summary

The data collected for this report were from a single time point between September 1999 to May 2000 and represents the first set of dynamic data returns. Data were analysed from 621 patients. There were 755 patients entered on to the database when it was initiated in 1999. The data analysed in this report is incomplete but in future years we aim to report on more complete data as the process of data entry improves

Transplantation is the treatment modality of choice for paediatric patients and cross sectional analysis reveals 76% of patients had a functioning graft. Of. This group, 405 (86.7%) were cadaveric and 62 (13.3%) from living related donors There was a significant increase in live related grafts, 30% in the last year compared to 10% previously. 103 (22%) patients had pre-emptive grafts. 83 (17.8%) of 467 grafts had been performed in the previous 12 months. Graft outcome was excellent with over 85% having very good function (GFR > 40mls/min/1.73 m2) and only 1.6 % having poor function with the likely need for return to dialysis soon.

Although over the age of five years the ratio of dialysis to transplanted patients is 4:1, under the age of five years there are more children on dialysis than transplanted. This group of children in particular require enormous support from all members of the multi-disciplinary team Of the 148 patients on dialysis 94 (63.5%) were on peritoneal dialysis. Of those on peritoneal dialysis 88.4% were on automated cycling dialysis as opposed to CAPD.

Comparing the prevalence and treatment modality of children receiving renal replacement therapy with that reported in 1992 BAPN report 'The provision of services in the United Kingdom for Children and adolescents with renal disease' there has been a 23% increase in the numbers of children receiving treatment. Although there has been a fall in the proportion of children on dialysis from 34% to 25% there has been an increase in the proportion of children on haemodialysis from 26% of the dialysis population to 41%. This could have significant resource implication.

Normalisation of growth and nutritional status are important goals of treatment in children. 37.5% of patients on PD and 43.8% of those on HD were less than 2 s.d. below the mean for height. 20.6% of dialysis patients were receiving growth hormone. Linear growth was improved with transplantation with 29% of those with functioning grafts being less than 2 s.d. below the mean for height

Most dialysis patients had a normal BMI, only 4.4% being less than 2 s.d. below the mean.. However 23% of patients with a functioning graft had a body mass index (BMI) of >2 s.d. above the mean. 4.3% had a BMI >3 s.d. above the mean. This is an area of particular concern for long term morbidity and needs further evaluation.

Introduction.

The incidence, prevalence and geographical distribution of renal failure in childhood make it an excellent candidate for specialty advancement through the use of a national registry. Data from national registries can be presented in a number of ways. There can be presentations on a cross-sectional basis of incidence, prevalence and patient demography. Data on management can be presented cross-sectionally across the population or longitudinally following patient progress. Longitudinal studies can encompass all aspects for the whole population or can be split to look at specific factors in specific subgroups. Last year we reported on the demography of renal failure in childhood looking specifically at the incidence and prevalence of renal failure according to age and diagnosis. We reported details on presentation and initial treatment. This year we are again taking a cross-sectional view, but this time at current treatment and outcome measures, such as growth. Over the next few years, with ongoing data collection, longitudinal studies will become possible. Standards mentioned in this report are provisional. New standards for paediatric patients are being reviewed currently and are due to be published shortly with the new adult standards. Data from this and future reports will help guide the provision and audit of these and future standards.

Population studied.

Data was collected from all 14 centres (13 in the UK and 1 in Eire) that participate in the registry. Data was collected from a single time point between September 1999 and May 2000. Only patients below the age of 18 years of age at the time of data collection were used in the analysis. Analysable treatment data was available on 621 patients, 82% of the estimated total population of 755. Figure 15.1. shows the age distribution of the population studied. As with the data in the 1999 report the fall off in numbers after the age of 15 years reflects the variable age of transfer to adult units and the variable referral of new patients between 16 and 18 years to adult or paediatric units.

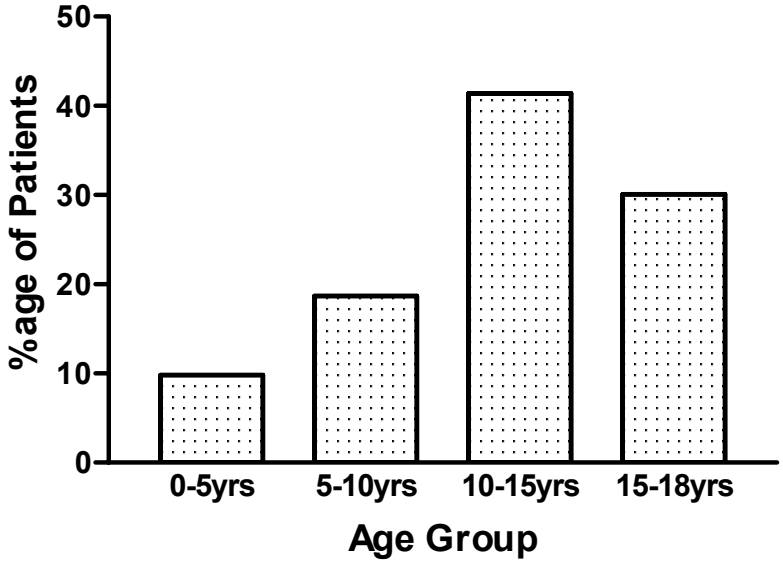


Figure 15.1 Age distribution of population.

The majority of patients looked after in paediatric units present at a young age, as demonstrated in Figure 15.2. This is secondary to the high prevalence of congenital rather than acquired disease as the cause of ESRF in childhood (renal dysplasia 27%, posterior urethral valves 16%). The prevalence of ESRF in childhood remains unchanged at 12.2 per million of the population, as does the annual take on rate at 1.7 per million of the population. The age distribution of the patients presenting in the past year is shown in Figure 15.3. the difference between this and Figure 15.2. is due to the prolonged duration of care the younger patients receive in the paediatric unit compared with the older patients.

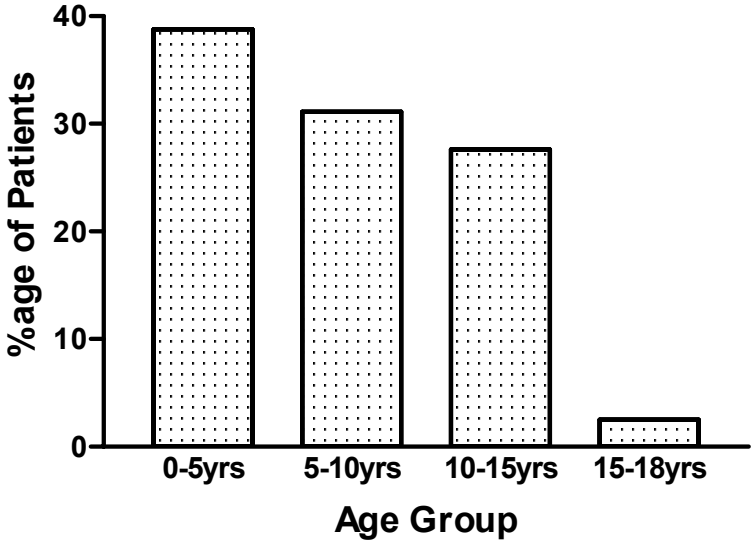


Figure 15.2 Age distribution of the patients at presentation with ESRF.

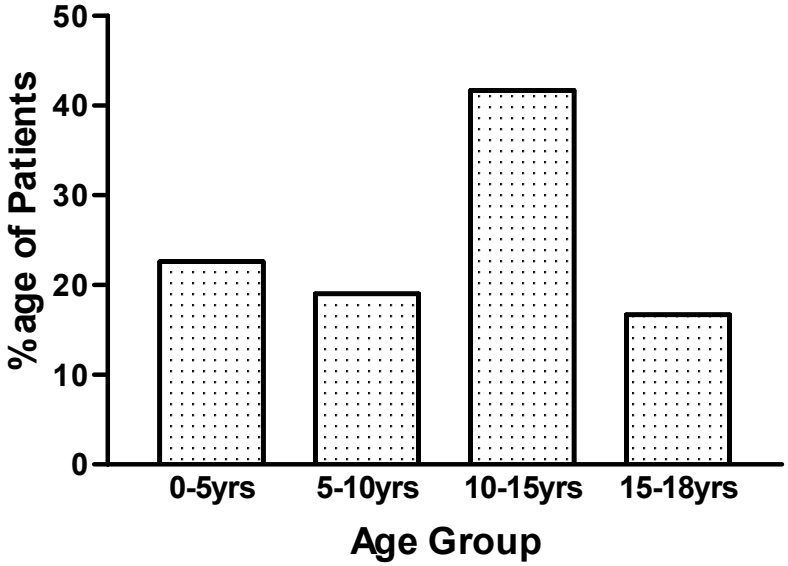


Figure 15.3 Age distribution of patients presenting with ESRF in the previous year.

The under 15 year old population ought to represent a complete cohort of paediatric patients as few will be treated in adult units under this age. Table 1. shows a comparison of the total number of under 15 year olds in the year 2000 compared with 1992. This has been broken down according to treatment modality. There has been an overall increase in the cohort of

23% as reported last year. There has also been a significant change in the distribution of patients between treatment modalities (Chi-squared = 15.77, p=0.0004). This change is composed of two swings. First there is a significant increase in the proportion of the total population with a functioning allograft (p=0.0053, Fisher's exact test) and second there has been a significant swing towards haemodialysis in those without functioning allografts (p=0.0078, Fisher's exact test). The reasons behind the second trend are explored further below.

Year	Total	HD	PD	Transplant
1992	429	38	108	283
2000	528	56	79	393

Table 15.1 Comparison of patient stock and treatments between 1992 and 2000.

Treatment modality.

Transplantation is clearly the treatment of choice for paediatric patients and on cross sectional analysis 76% of patients had a functioning renal allograft. The age distribution of the patients broken down according to whether they are on dialysis or have a functioning renal allograft is shown in Figure 15.4. The distributions of patients are significantly different from each other (Chi-square = 38.24, p<0.0001) with that of the transplanted patients mirroring that of the total population whereas the distribution of dialysis patients is fairly flat. Under the age of 5 years there are more dialysis patients than transplant patients, beyond this age there is an approximately 4:1 ratio of transplanted to dialysis patients. Thus even with growth of the total numbers it will be some time before the total number of dialysis patients across the UK exceeds 200. This, together with the knowledge that even fewer patients are on long-term dialysis and they are split between peritoneal and haemodialysis, emphasises the need for national or even international studies of treatments to provide analysable outcome data.

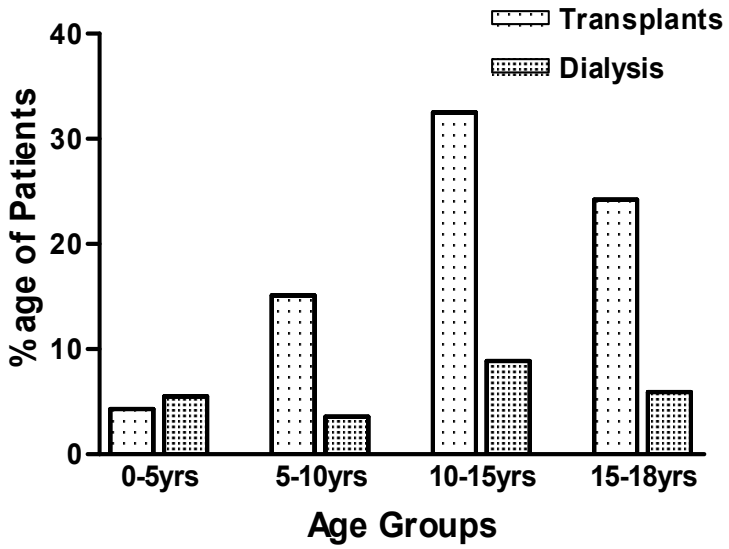


Figure 15.4 Age distribution of the patients according to treatment.

Transplant origins and immunosuppressive regimes.

Data on transplant origin was available for 467 grafts, 98.7% of the total. The vast majority, 405 (86.7%) were cadaveric with just 62 (13.3%) from living related donors. These figures represent point prevalence rather than incidence and, as the overall outcome and longevity of graft survival is longer with living related allografts the incidence of LRD transplantation will be less than the 2:13 ratio demonstrated here.

The emphasis on transplantation being the treatment modality of choice for paediatric patients is also shown by the prevalence of pre-emptive transplantation in anticipation of the need for dialysis. 103 patients with functioning grafts had received that graft pre-emptively (Figure 15.5.)

Transplantation is a major activity area within paediatric nephrology and 83 of the 467 grafts (17.8%) had been performed over the previous 12 months. The breakdown of these according to whether they were cadaveric or from living related donors and the numbers of pre-emptive transplants are shown in Figure 15.6. It can be the seen that the proportion of pre-emptive transplants remains unchanged at a little over 20%. The proportion of transplants from living related donors is significantly higher however at 30% of those transplanted over the previous 12 months compared with 10% of those transplanted before this ($p<0.0001$, Fisher's exact test). This could be due to an overall increase in the rate of transplantation or an increased awareness and usage of living related donor kidneys due to the overall shortage of available grafts. The latter is more likely and future reviews of the data will be able to confirm this and demonstrate the size of the trend.

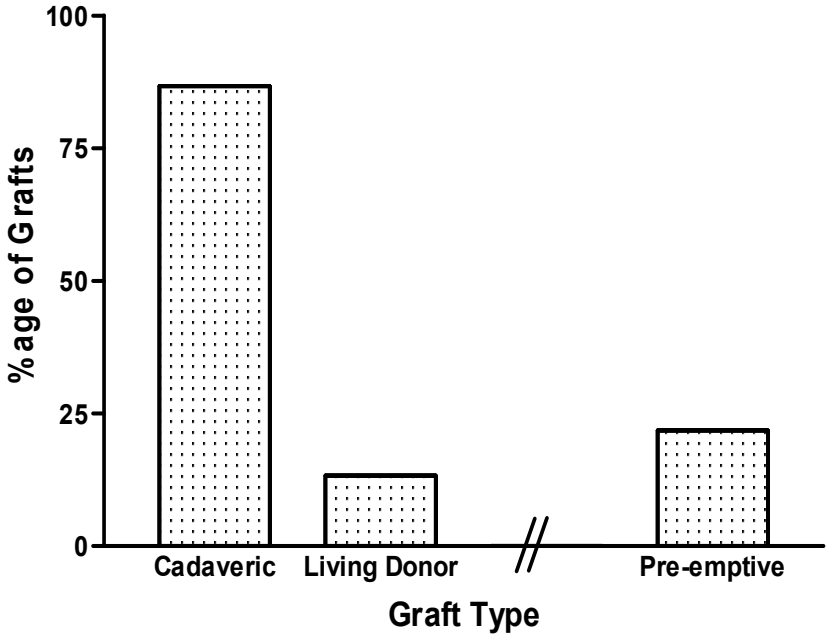
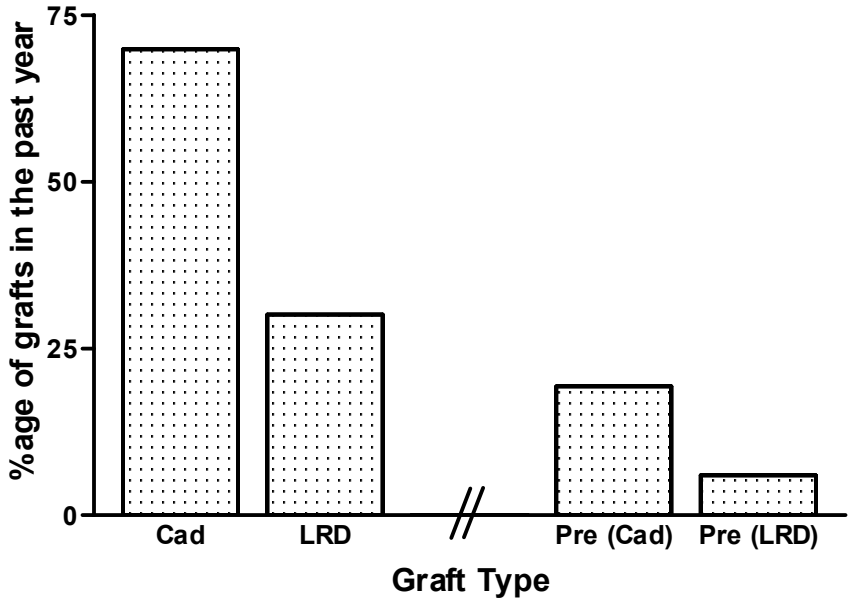


Figure 15.5 Types of graft used.



(cad = cadaveric, LRD = Living related donor, Pre = pre-emptive).

Figure 15.6 Types of graft used over the past year

Details of maintenance immunosuppressive regimes were available for 459 patients (97% of the cohort). Regimens were fairly uniform across the country. The vast majority of patients, 84.7%, were receiving triple therapy with a calcineurin inhibitor, steroids and either azathioprine or mycophenolate. 11.6% were receiving dual therapy with a calcineurin inhibitor and steroids, whilst 1.3% were on monotherapy with a calcineurin inhibitor. The remaining 2.4% were on varied regimes without a calcineurin inhibitor. Despite only recently being the subject of a randomised controlled study, and perhaps because of its side-effect profile, Tacrolimus based regimens have become rapidly popular with almost 1 in 4 patients receiving a calcineurin inhibitor being on Tacrolimus rather than Cyclosporin A (Figure 15.7.). There was no significant difference in the breakdown of regimes used comparing those on Cyclosporin with those on Tacrolimus (Figure 15.8.). Although virtually all patients were receiving steroids as a single alternate day dosage only 1.3% of patients were receiving no steroid. This may be an important factor with regard to growth and weight gain.

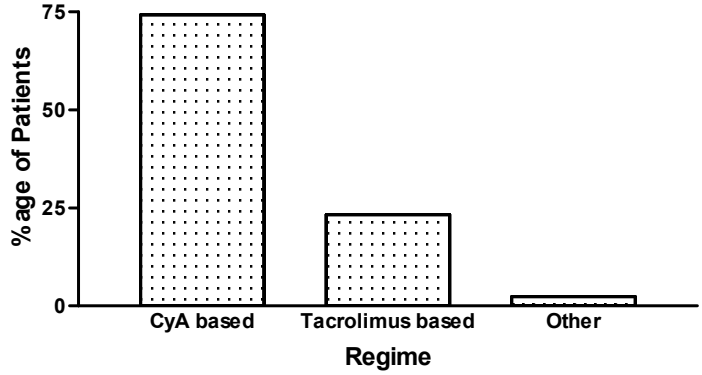
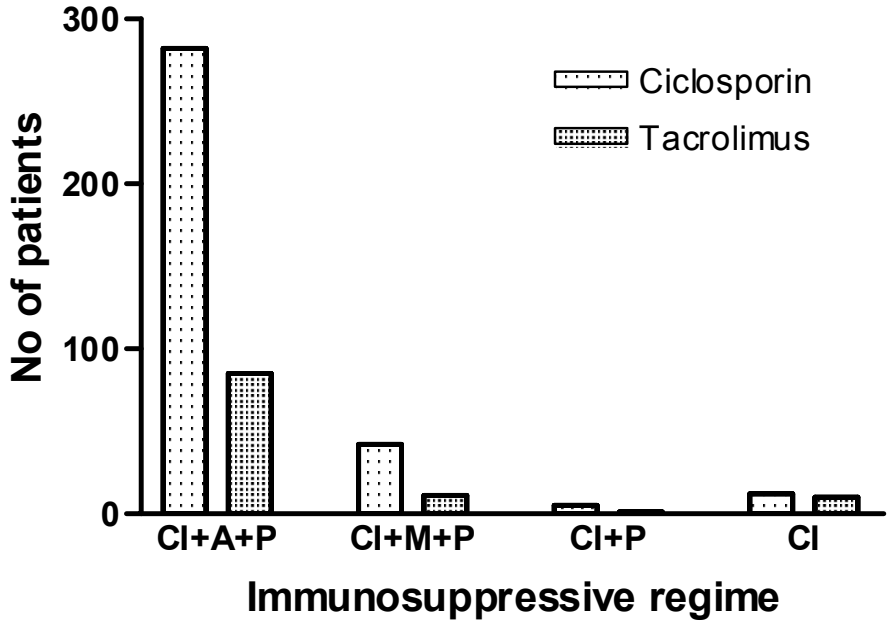


Figure 15.7 Basic immunosuppression regimens.



. (A = azathioprine, M = mycophenolate, P = prednisolone)

Figure 15.8 Breakdown of immunosuppressive regimes split according to the calcineurin inhibitor (CI) used

Renal function in patients with transplants.

Clearance in patients with functioning renal allografts has not been formally measured on a regular basis. Some units measure GFR formally on an annual basis and obtaining a formal GFR measurement on all transplant patients annually is worth consideration. The best estimate of glomerular filtration rate (GFR) available is that calculated using the Schwartz formula (40 x height / creatinine). This predicted GFR (pGFR) is a better estimate than the creatinine alone as it takes account of the different normal ranges of creatinine expected for patients of different sizes.

Both a serum creatinine and a height measurement on the same day were available for 443 patients and 4 patients had a measured GFR result available, giving data in 94.5% of those with functioning allografts. Renal function was divided into bands of 20mls/min/1.73sq.m. Those with a pGFR <20mls/min/1.73sq.m were deemed as having poor function whereas those with a pGFR >60mls/min/1.73sq.m were deemed as having excellent function (normal range 80-120mls/min/1.73sq.m). Figure 15.9. Shows the breakdown of patients according to these bands. It is pleasing to see that 43% of patients have excellent function and over 85% have very good function with only 1.6% being in a situation where function is poor and either dialysis or re-transplantation is going to be required soon.

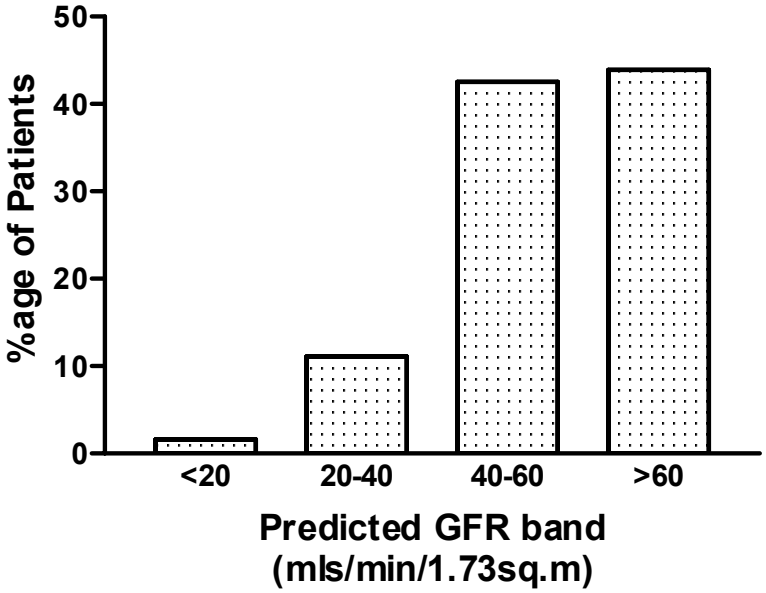


Figure 15.9 Predicted GFR in patients with functioning allografts.

Growth and nutrition in patients with transplants.

The normalisation of growth, nutritional status and development are three of the major goals of paediatric nephrologists. Difficulty in achieving these goals on dialysis is one of the reasons for the high incidence of pre-emptive transplantation. Audit of how often these goals are met after transplantation is therefore essential.

Due to changes in the normal ranges for height, weight and body mass index with age, all values have been converted to standard deviation (SD) scores from the mean for age. Thus an average value would be 0 and the accepted normal range between –2 and +2 SDs from the mean. Growth can be judged by height on the whole, though with variability in the age of puberty and its associated growth spurt correction for bone age could be justified. Bone age is not a part of the current data set and so no correction has been made in the analysis of this data. Consideration needs to be given to the inclusion of bone age in future data collections. Weight alone can be a misleading measurement of nutritional status. Ideally estimates of skinfold thickness and lean body mass would be obtained. On a practical basis the best estimate of nutritional status is given by body mass index (BMI) (weight / (height)^2). This measurement has been validated across the normal population and automatically takes account of low weight secondary to short stature rather than under-nutrition.

Data on height was available in 443 patients, 93.7% of those with functioning allografts. Figure 15.10. shows a breakdown of heights according to standard deviation score. The two columns to the left divide the population into those who were above -2 SDs from the mean (i.e. within the normal range) and those whose height lay below -2 SDs from the mean. A total of 128 patients, 29% of those with functioning allografts, were below -2SD's from the mean. The two columns on the right break this 29% down further into those who were between -2 and -3 SDs from the mean and those who were very small at below -3 SDs from the mean. There were 38 patients, 8.6% of the group who fell into this category. Some conditions causing renal failure in childhood (such as cystinosis) are associated with extreme short stature. However, these conditions account for fewer than 5% of those with renal failure in childhood and, therefore, is not an explanation for the high proportion of small children in

this cohort. Growth hormone has been used to help growth both before and after transplantation in children. The central column in Figure 15.10. shows the proportion of children receiving growth hormone at the time of data collection. Though there are some concerns about side effects of growth hormone after transplantation it was surprising to find that with 29% of the population being below the normal range for height only 11 patients (2.3%) were documented to be receiving growth hormone at the time of data collection. The low rate of usage of growth hormone in transplant patients reflects concern about both the safety and efficacy of this agent in this group of patients. The development of guidelines by the BAPN followed by audit of outcome would be beneficial.

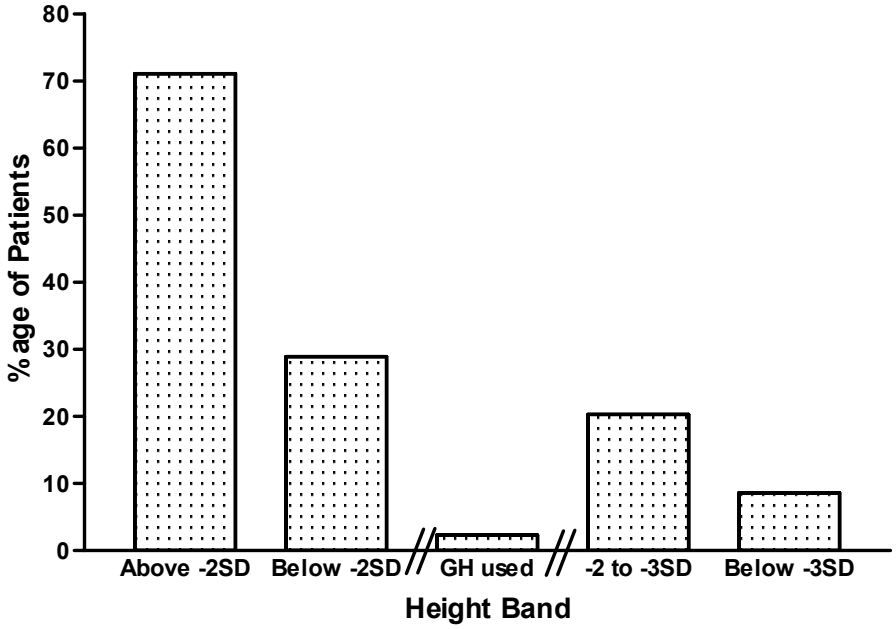


Figure 15.10 Growth in patients with a functioning allograft.

Poor nutrition (BMI more the -2SD's from the mean) was not a problem in patients with a functioning allograft but obesity was. A total of 102 patients, 23%, were significantly overweight with a body mass index of more than 2 SDs above the mean. Of these 21, 4.7%, were very obese at more than 3 SDs above the mean (Figure 15.11.). Although the general population trend in children is towards increasing weight and relative obesity, these results are very concerning. Cardiovascular disease is a major cause of death and co-morbidity in adults with renal failure and the combination of obesity with immunosuppressive drug induced hyperlipidaemia and hypertension form a potentially lethal triad for future years when these patients are young adults. More work looking at longitudinal profiles is required to trace the origins of obesity. Immunosuppressive regimens may need review in the light of this data. The BAPN is considering extending its data set to include data on lipids, so that multi-factorial analysis looking at the three parameters detailed above can be performed.

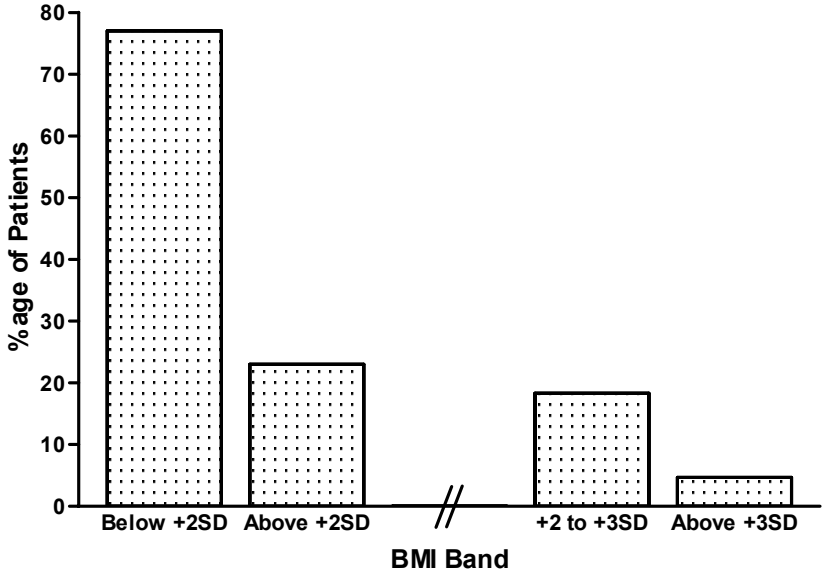


Figure 15.11 Body mass index in patients with functioning renal allografts.

Dialysis modality and access.

For patients on dialysis, peritoneal dialysis (PD) has always been the preferred mode of treatment within paediatrics. Of the 148 patients on dialysis in this cohort 94 (63.5%) were on PD. Figure 15.12. shows a breakdown of the modality of dialysis used according to age. It can be seen that although the proportion of patients on peritoneal dialysis is higher in most age groups, there are more patients on haemodialysis (HD) in the 10-15 year old band.

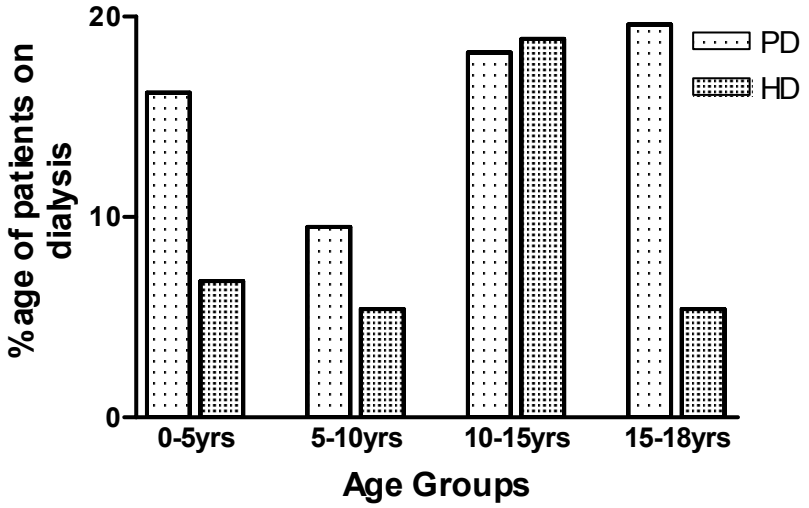


Figure 15.12 Distribution of patients between PD and HD currently.

Moreover, comparing the distribution of dialysis treatments at presentation (Figure 15.13.) to the current distribution it is clear that as the number of older patients increases (i.e. the number who have had a long history of ESRF increases) the number on haemodialysis increases. This would suggest that, either through choice or necessity, (e.g. loss of peritoneal access or function) patients with more longstanding ESRF are being treated with haemodialysis. This needs further investigation with longitudinal rather than cross-sectional

studies as it has major implications for the planning of the provision of dialysis services. More importantly, if this trend turns out to be secondary to loss of peritoneal function, this will have major implication for adult services inheriting these patients. This is particularly the case as most haemodialysis access is through central venous lines, which can jeopardise long-term vascular access.

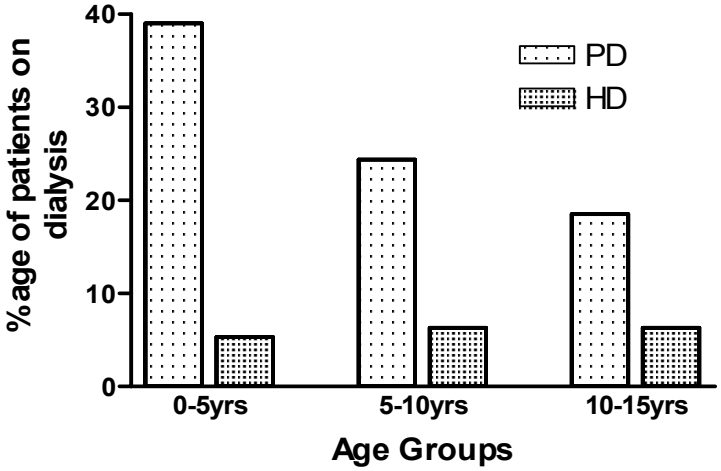


Figure 15.13 Distribution of patients between PD and HD at Day 90 of ESRF.

Details on haemodialysis access were available for 50 of the 54 patients on HD (92.6%). Access was broken down according to whether the patient was being dialysed through a central line (CL), an arterio-venous fistula (AVF) or some form of arterio-venous graft (AVG), be this synthetic or using one of the patient's veins. The distribution of types of vascular access is shown in Figure 15.14 below. It is noticeable that no children below the age of 10 were on regular haemodialysis through an arterio-venous fistula and even in the older 10-15 year old age-band, two thirds of the children had central lines for dialysis. In the light of the well-recognised published complications of central venous access for dialysis, an audit of dialysis access sites no longer available in young adults transferred to adult dialysis facilities would be well worthwhile. Further thought needs to be given to the difficulties of establishing vascular access in small children.

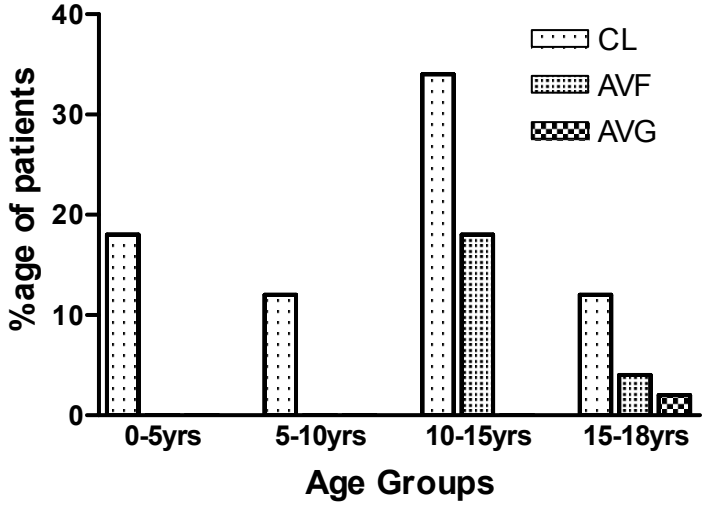


Figure 15.14 Vascular access for dialysis in different age-groups.

For those patients on peritoneal dialysis, automated cycling dialysis is clearly preferred over CAPD. Figure 15.15 shows a breakdown of the type of peritoneal dialysis used according to age-group. In this particular cross-sectional analysis, there were no children under the age of 5 on CAPD. After the age of 5 the proportion on CAPD steadily rises but the overall number of children on CAPD is only 11.6% and even in the 15-18 year old group, the proportion on CAPD rather than automated PD is still less than one third.

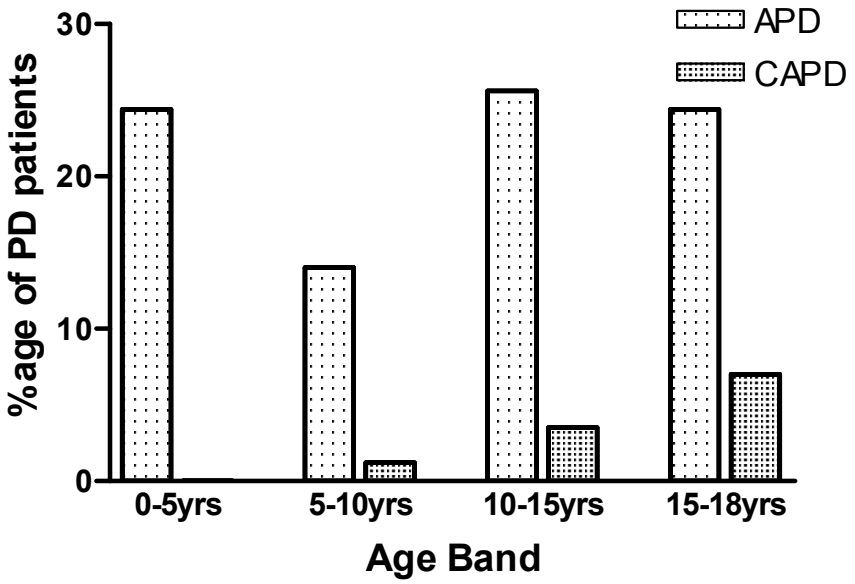


Figure 15.15 Division of PD patients between automated PD (APD) and CAPD.

Dialysis efficiency.

The original data set defined for the Paediatric Registry did not contain any specific measures of dialysis efficiency. Although the vast majority of paediatric patients with ESRF are transplanted and those on dialysis are only treated in this way for short periods of time, it is clear that more specific measures of dialysis efficiency are going to be required for the assessment of dialysis effectiveness in the small number that require long term dialysis. These will also be of value in the assessment of growth and nutrition in children. Measures of dialysis efficiency are being included in the new specification for the Paediatric Registry and data from this will become available over the next 12-24 months.

On a day-to-day basis judgements about dialysis efficiency are made on the patient's biochemistry and particularly the serum creatinine and calculated pGFR as detailed in the section on transplant renal function. These will clearly both take account of the patient's native renal function as well as the clearance provided by dialysis but they will not allow separation of these two factors. Although GFR is usually expressed in mls/min/1.73sq.m it is more usual to look at dialysis clearance in terms of litres/week. Table 2. below converts the mls/min values as calculated into litres/week.

GFR in mls/min/1.73sq.m	Clearance in litres/week/1.73sq.m
5	50.5
7.5	75.6
10	100.8

Table 15.2 Comparison of standardised GFR with clearance in litres/week.

Figure 15.16. gives a breakdown of the clearances obtained in both PD and HD patients. In the PD patients the samples will have been obtained whilst in a steady state. In HD patients the samples were obtained before dialysis. It can be seen that the majority of patients have an apparently good clearance when combining their dialysis component with native renal function. Until more data is collected on residual native renal function and dialysis efficiency, it is not going to be possible to correlate these figures with other measures of outcome.

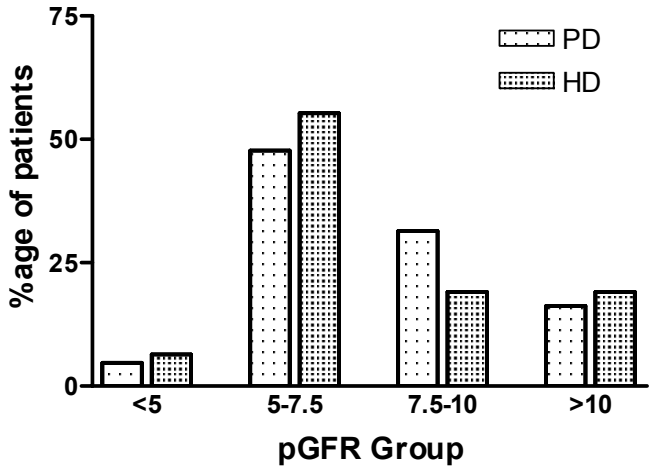


Figure 15.16 Dialysis efficiency as measured by pGFR in HD and PD patients.

Growth and Nutrition in Dialysis Patients.

Data with regard to height, weight and body mass index were available in 48 of the 54 patients on haemodialysis (88.9%) and in 88 of the 94 patients on peritoneal dialysis (93.6%). As with the section on growth in transplant patients the data has been broken down into those who had heights more than 2 SDs below the mean for their age and those who were less than 2 SDs below the mean for their age. Those who were more than 2 SDs below the mean were then subcategorised into those who were small and those who were very small at more than 3 SDs below the mean for their age. As before, data on bone age was not available and therefore no corrections for this or pubertal status have been made.

The four columns to the left-hand side of Figure 15.17. show the patients divided according to their dialysis modality and also according to whether they were more than 2 SDs below the mean for height or above this level. It can be seen that 37.5% of PD patients and 43.8% of HD patients were small for their age. The four columns to the far right of Figure 15.17. show the further breakdown of the short stature group. A total of 22 patients were more than 3 SDs below the mean for height for their age, this being 16% of the cohort. The central columns show the numbers of patients being treated with growth hormone. It is clear that with 28 patients (20.6%) of the group receiving growth hormone therapy, concern about short stature is much greater in the dialysis population than in the transplant population.

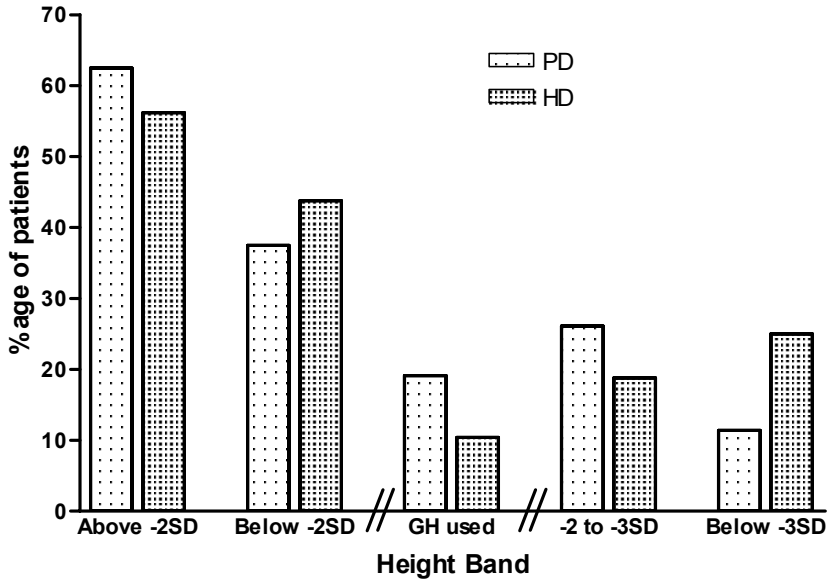


Figure 15.17 Height achievement in dialysis patients.

Figure 15.18. shows a comparison of height achieved in dialysis patients compared with height achieved in transplant patients. Overall, as detailed above, many children with transplants remain small, despite this height achievement in dialysis patients was significantly worse ($p = 0.02$, Fisher's exact test). On the basis that very few transplanted patients are receiving growth hormone, this is presumably an effect of transplantation itself. Further studies sub-dividing patients according to their primary diagnosis, duration of renal failure and time spent on dialysis will be required to clarify this further.

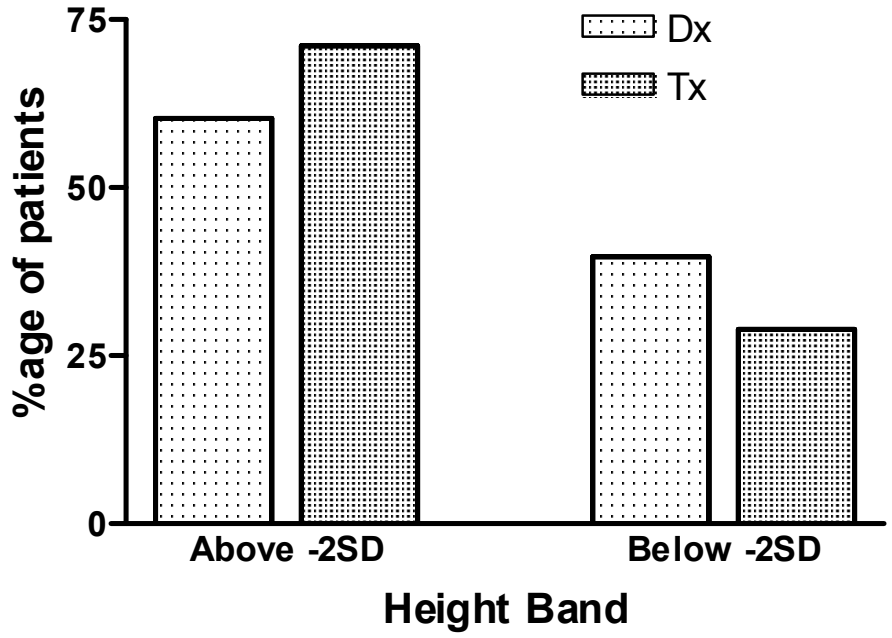


Figure 15.18 A comparison of height achieved in dialysis (Dx) vs transplant (Tx) patients.

The achievement of adequate nutrition is a major hurdle in paediatric nephrology. The use of supplementary feeds either through a naso-gastric tube or via a gastrostomy have become commonplace. Inadequate nutrition is closely related to increased co-morbid complications

and was previously felt to be a major element of the growth failure suffered by so many patients with ESRF. Figure 15.19. below shows that, with the close attention currently given to nutrition, the vast majority of patients have a normal body mass index.

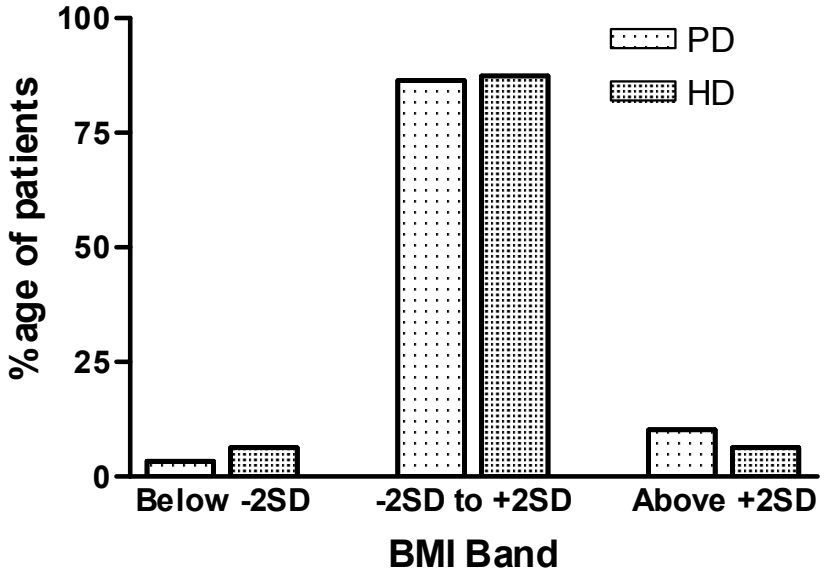


Figure 15.19 Body mass index in patients on dialysis.

Only 6 patients (4.4%) had a BMI more than 2 SDs below the mean for their age. Twelve patients (8.8%) actually had a high BMI at over 2 SDs above the mean for their age and were therefore overweight. No dialysis patient was more than 3 SDs above the mean for their age and comparing BMI in dialysis patients with transplant patients it is clear that obesity is significantly more common in this latter group (p=0.0002, Fisher's exact test)

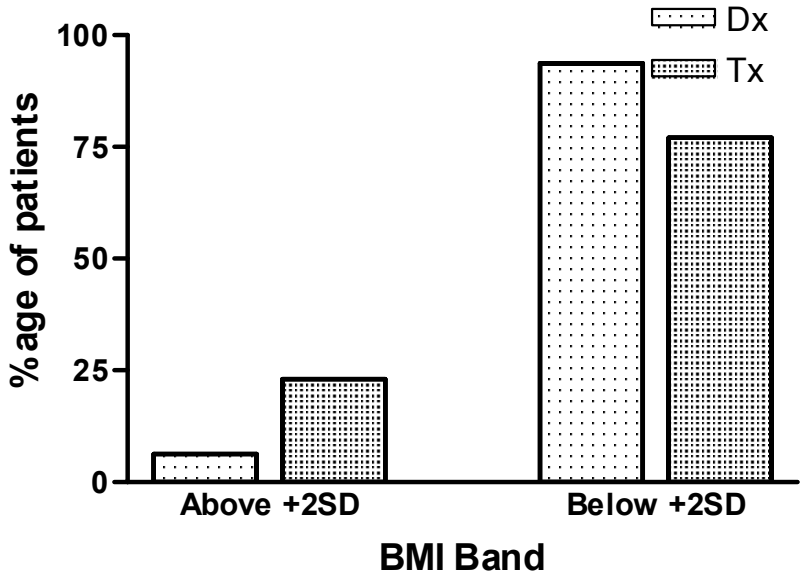


Figure 15.20 A comparison of BMI in dialysis (Dx) vs transplant (Tx) patients.

Bone disease, PTH and phosphate.

Although control of renal osteodystrophy and maintaining a normal serum calcium and phosphate would be considered an essential part of the management of dialysis patients (particularly where striving to achieve adequate growth), these factors were amongst the most incomplete data items submitted. Serum phosphate was available in 91.2% of dialysis patients but PTH was only documented in 49.3%

Serum phosphate is naturally higher in infancy than in children and adults. Although the Renal Association standards suggest that phosphate is kept within the normal range for age this is difficult to achieve in practice and data from the Renal Registry report in 1999 suggested that co-morbid complications in adults increased significantly once the serum phosphate was above 2.1mmol/l. Figure 15.21. Shows the percentage of dialysis patients with a serum phosphate above and the percentage with a serum phosphate below 2.1mmol/l. The groups are split according to dialysis modality. No infant actually had a serum phosphate above 2.1mmol/l so the figures were not skewed for the worse because of the different normal range in this group. It can be seen that overall 25% of patients had a serum phosphate above 2.1mmol/l. Phosphate control in haemodialysis patients was significantly worse than that in peritoneal dialysis patients (p=0.0077, Fisher's exact test). Although this could be in part due to the fact that blood sampling in PD patients was performed whilst they were in a steady state whereas blood sampling in HD patients was pre dialysis, this effect has not been noted before. It may well be that phosphate is better removed in PD patients, alternatively this group might be more adherent to their dietary restrictions. Whichever, phosphate control as a whole needs improvement in the paediatric dialysis population. Much of the difficulty lies with the difficulties in administering phosphate binders to children and trials of new agents are urgently required.

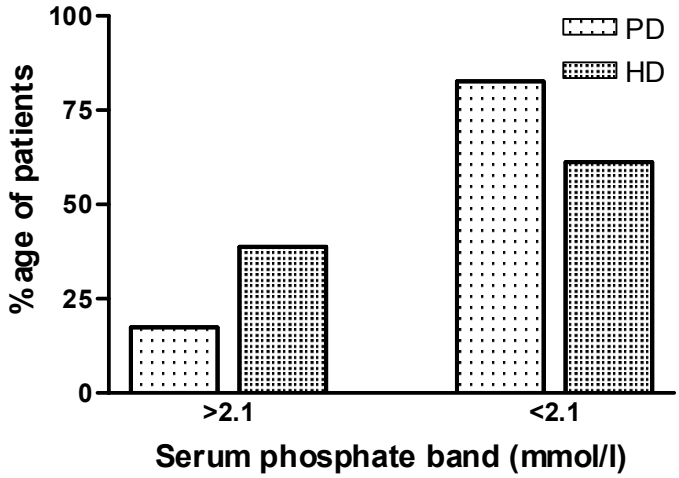


Figure 15.21 Serum phosphate in dialysis patients split according to dialysis modality.

Within adult practice the norm is to try to maintain PTH above the normal range to avoid adynamic bone disease but below three times the upper limit of normal to prevent renal osteodystrophy. There is no information as to whether adynamic bone disease is a problem in children or not. Therefore setting a lower limit for PTH is not possible. Renal osteodystrophy and hyperparathyroidism are definite problems in children with renal failure. Formal standards for PTH will be issued in the forthcoming standards document. Figure 15.22. shows the percentage of patients with a PTH above and the percentage of patients with a PTH below 3 times the upper limit of normal, split according to dialysis modality. It can be seen that

overall 29% of patients had poor control of bone disease with a PTH over 3 times the upper limit of normal. With regard to this parameter HD patients faired significantly better than PD patients (p=0.036, Fisher's exact test). However, with less than 50% of the data being returned this statistic needs to be interpreted with caution.

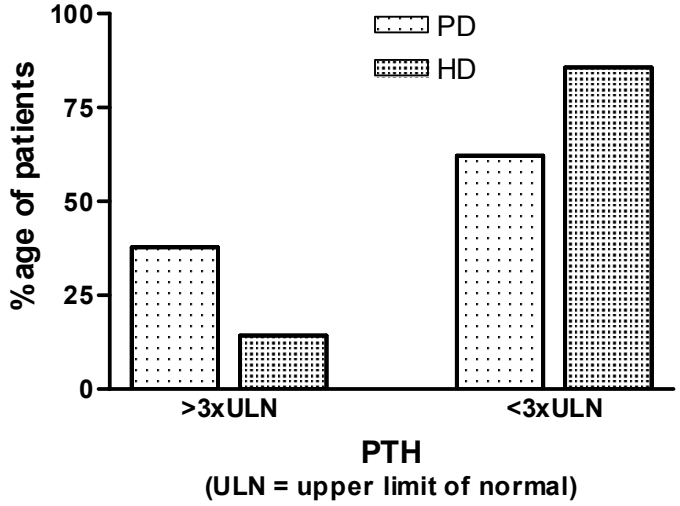


Figure 15.22 Serum PTH in dialysis patients split according to dialysis modality.

Haemoglobin and erythropoietin usage in dialysis patients.

Data on haemoglobin and the usage of erythropoietin was available in 138 patients, 93.2% of the dialysis patients. Erythropoietin was documented as being used in 119 of these (80.4%). Other patients may well have received erythropoietin but were not doing so at the time of the completion of the record because of a high haemoglobin or some other factor. The distribution of haemoglobins is shown in Figure 15.23. There was a trend towards higher haemoglobins in peritoneal dialysis compared with haemodialysis patients but this was not statistically significant. Again standards for haemoglobin will be appearing in the new standards document. These will vary according to age as normal haemoglobin levels vary with age. All the standards are likely to be at or above 10g/dl. Overall 67% of patients had a haemoglobin over 10g/dl whilst just 5% had a haemoglobin under 8g/dl. Information on the usage of intravenous iron supplementation was not available for this data collection but will be recorded in future collections.

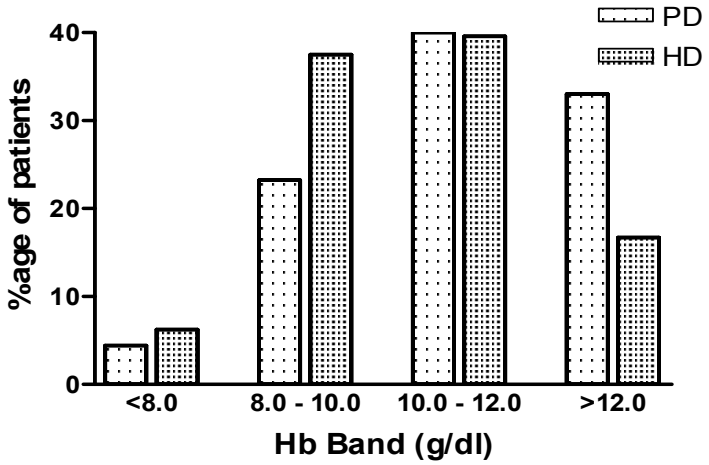


Figure 15.23 Haemoglobin in dialysis patients split according to dialysis modality.

Conclusion.

These data presented above clearly demonstrates the potential value of a paediatric renal registry. Data collected from any one individual unit cannot provide a view of trends and achievements as small numbers and individual patient circumstances prevent the formation of a global overview. There are some potential negative points within this report such as height achievement, obesity in transplant patients and haemoglobin levels in dialysis patients. There are, however, many positive points and these are outlined in the message box below. Improvement in the paediatric service can be achieved through the use of this data, the setting of appropriate standards for children based on our current knowledge and the creation of an audit cycle through further data collections by the registry. Paediatric Standards are currently being set and will be published as a part of the new Adult Standards document. Next year we will be able to gauge performance against these standards.

Positive aspects of the year 2000 analysis.

- 76% of children with ESRF have a functioning renal allograft.
- 86% of transplant patients have a pGFR >40mls/min/1.73sq.m.
- 71% of transplant patients are achieving heights within the normal range.
- 95% of dialysis patients are achieving a pGFR >5mls/min/1.73sq.m.
- 87% of dialysis patients are optimally nourished.

This report was reviewed and revised by the BAPN registry subcommittee.
It is presented by that committee on behalf of the BAPN.

The subcommittee consists of :-
Dr Jane Tizard, Bristol
Dr William van't Hoff, London
Prof Adrian Woolf, London
Dr David Hughes, Liverpool
Dr Malcolm Lewis Manchester

Mrs Jo Shaw has been responsible for much data collection and collation and helped with construction of the manuscript.
All correspondence to Dr Malcolm Lewis at malewis@doctors.org.uk

We would like to thank Roche for their financial support of the Registry.