

Registry Report

Demography of Dialysis and Transplantation in Children in Europe, 1984

Report from the European Dialysis and Transplant Association Registry*

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Abstract. The demography of treatment of children by renal replacement therapy in Europe is presented based on returns of individual patient questionnaires to the EDTA Registry up until the close of 1984. Patient questionnaires for 1984 were completed by all centres which defined themselves as special paediatric units. A total of 4983 patients have been reported to the Registry up until 31 December 1984 as having commenced renal replacement therapy under the age of 15. Of these, 1570 were known to be alive on a defined form of treatment at the end of 1984 and still under the age of 15. The numbers of these patients kept alive by different forms of treatment in individual countries are presented. The stock of patients aged under 15 at the end of 1984 exceeded 30 per million child population in Belgium, France, Iceland and Luxembourg. The highest age specific acceptance rates for children onto renal replacement therapy during 1984 were noted in those aged between

10 and 14 at first treatment. Age specific acceptance rates for children varied greatly between individual countries, and 18 countries reported no new patients under the age of 5 during 1984. Transplant activity in paediatric patients during 1984 has been analysed and results on re-grafting presented. Proportional distribution of primary renal diseases amongst children commencing therapy in 1984 is shown according to age at start of treatment. Haemolytic uraemic syndrome was reported as the cause of end-stage renal failure in 12.0% of children commencing treatment under the age of 5, and 12.3% of children between 5 and 9. Finally, information on cause of death in paediatric patients dying during 1984 is presented, and shows cardiovascular disease was the leading cause of mortality.

Key words: Chronic renal failure; Haemodialysis; Transplantation; CAPD; Demography

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Introduction

The Registry of the European Dialysis and Transplant Association—European Renal Association (EDTA Registry) has regularly presented data on children treated by renal replacement therapy since 1972 and has published a series of 14 Combined Reports on Regular Dialysis and Transplantation in Children in Europe in the Proceedings of the EDTA-ERA. The last of these appeared in 1985 [1].

This report on treatment of children, the first to be prepared by the Registry for the new journal, is based exclusively on data provided on individual patient questionnaires and relates to treatment up until 31 December 1984. Analyses were carried out on the Registry's files at the time of the preprinting of the 1985 questionnaires, the point in the Registry's annual cycle when the data base is in its best form.

Methods: the Paediatric Registry data base

All patients who commence renal replacement therapy under the age of 15 are defined as paediatric. In the year of any particular report, many of these will have reached adult age, and so the word 'children' has been adopted to describe patients who commence therapy under 15 and who are still under that age on 31 December in the year under consideration.

Patient questionnaires completed on children are handled in the same way as those for adults, and the Registry's main patient file contains data on all individually registered patients irrespective of age at start of treatment. The information collected and the method of handling forms and notification of new centres are described in the preceding paper. A distinction between children and adult patients is only made at the time analyses are carried out. A special paediatric file has been created to link data from individual patient questionnaires on children to those obtained from the special paediatric enquiry which goes out to selected centres each year. Information from the special file is not included in this report.

Results: demographic statistics

Children may be treated in either non-specialised or specialised paediatric centres. These are self-defined on the Registry's centre questionnaire. The completeness of the paediatric survey for 1984 may be assessed from Table 1 of the general demographic article which precedes this. This shows the total number of centres known in countries reporting to the Registry and the proportion which returned patient questionnaires for 1984. In the 1984 centre questionnaire, 97 units defined themselves as specialised

paediatric centres. Patient questionnaires for 1984 were returned by all of these 97 units.

Up to 31 December 1984, 4983 patients were reported to the Registry as having commenced renal replacement therapy under the age of 15. Of these, 3405 were alive on a known method of treatment and 1570 were under the age of 15 (Table 1).

Table 2 shows the stock of patients aged under 15 on 31 December 1984, alive on a known form of renal replacement therapy. Both absolute numbers and total per million child population (PMCP) are given. Data on child population were obtained from the WHO Statistics Annual using the most up to date information available for each country.

Age and sex specific acceptance rates for children onto renal replacement therapy in 1984 are given by country in Table 3. An age-sex specific rate is calculated by dividing the number of new patients in each age and sex category by the total number of children in the general population of the

Table 1. Summary of patients reported to the Registry who commenced renal replacement therapy under 15 years of age. Total number, number alive at the end of 1984, and number known to be alive at the end of 1984 still aged under 15 are given

Country	Total number of paediatric patients	Paediatric patients alive 31 Dec. 1984	Paediatric patients alive 31 Dec. 1984 aged 0-14 years
Algeria	14	10	9
Austria	68	45	19
Belgium	174	136	78
Bulgaria	45	14	8
Cyprus	5	3	0
Czechoslovakia	35	14	8
Denmark	79	45	18
Egypt	22	12	9
Fed. Rep. Germany	685	491	194
Finland	38	31	11
France	966	714	348
German Dem. Rep.	127	72	33
Greece	61	18	6
Hungary	16	9	6
Iceland	2	2	2
Ireland	37	26	11
Israel	101	66	31
Italy	540	341	156
Lebanon	4	1	0
Libya	10	2	0
Luxembourg	8	4	3
Morocco	1	1	1
Netherlands	207	153	67
Norway	52	40	16
Poland	98	47	29
Portugal	51	35	23
Spain	467	347	183
Sweden	81	60	23
Switzerland	85	63	24
Tunisia	6	4	2
Turkey	33	13	9
United Kingdom	761	537	218
Yugoslavia	104	49	25

Table 2. Stock of children alive on 31 December 1984 in individual countries. Numbers on different forms of renal replacement therapy given together with the total number per million child population (PMCP)

Country	Patients on treatment at 31 December 1984				Graft	Total	PMCP
	Hosp. HD	Home HD	IPD	CAPD			
Algeria	7	0	0	1	1	9	1.6
Austria	11	0	0	1	7	19	12.6
Belgium	18	0	1	3	56	78	39.0
Bulgaria	8	0	0	0	0	8	4.1
Cyprus	0	0	0	0	0	0	0
Czechoslovakia	4	0	0	0	4	8	2.2
Denmark	7	0	1	3	7	18	17.4
Egypt	6	0	0	0	3	9	0.6
Fed. Rep. Germany	66	4	8	19	97	194	18.0
Finland	2	0	0	2	7	11	11.3
France	175	6	0	16	151	348	30.2
German Dem. Rep.	26	0	0	0	7	33	10.0
Greece	2	0	0	2	2	6	2.8
Hungary	1	0	1	0	4	6	2.5
Iceland	2	0	0	0	0	2	31.8
Ireland	3	0	0	2	6	11	10.8
Israel	5	0	0	8	18	31	24.1
Italy	88	0	4	20	44	156	11.9
Lebanon	0	0	0	0	0	0	0
Libya	0	0	0	0	0	0	0
Luxembourg	1	0	0	0	2	3	43.5
Morocco	0	0	0	0	1	1	0.1
Netherlands	21	0	0	15	31	67	21.6
Norway	1	0	0	0	15	16	17.9
Poland	19	0	3	4	3	29	3.4
Portugal	19	0	0	2	2	23	8.4
Spain	106	4	6	15	52	183	18.8
Sweden	2	0	1	3	17	23	14.4
Switzerland	6	0	0	5	13	24	19.6
Tunisia	1	0	0	1	0	2	0.8
Turkey	9	0	0	0	0	9	0.5
United Kingdom	45	5	1	49	118	218	18.9
Yugoslavia	23	0	0	0	2	25	4.6

same age and sex. The data are given for three age groups, those aged between 0 and 4 years at first treatment, those aged 5-9, and finally, those aged 10-14. Acceptance rates are shown separately for males and females in each age category. The table also gives the total number of children who commenced replacement therapy in 1984. This figure will include children whose sex was not registered. There were a total of 522 new paediatric patients in 1984.

Transplantation activity during 1984 in children is summarised in Table 4. This divides the grafts according to source, live donor or cadaver, and shows the numbers which were first, second or third grafts. A total of 353 grafts in children were reported in 1984. Table 4 shows the graft according to the country where the child was last registered. This does not necessarily indicate where the transplant was performed.

The proportional distribution of primary renal diseases leading to end-stage renal failure amongst children commencing renal replacement therapy in 1984 is given in Table 5. The results are shown according to age at start of treatment for three age categories. Among 75 children

who commenced treatment under the age of 5 in 1984, glomerulonephritis was the most common primary renal disease diagnosed. Haemolytic uraemic syndrome accounted for a further 12.0% of primary renal diseases in this age group. In children aged 5-9 years at first treatment, glomerulonephritis accounted for 17.2% of primary renal diseases, whereas pyelonephritis/interstitial nephritis was the diagnosis in just over a quarter of cases. Haemolytic uraemic syndrome accounted for a further 12.3%. In the oldest of the three age categories, glomerulonephritis was the primary renal disease diagnosed in 32.4% of children, while pyelonephritis/interstitial nephritis was reported in 29.8%.

Table 6 shows cause of death in patients who died in 1984 under the age of 15. There were a total of 62 deaths and both the absolute number for each of 46 different causes and their proportional distribution are given. The most common cause of death was cardiac arrest, cause unknown, which accounted for 14.5% of mortality. As a group, cardiac causes were the most common, accounting for almost half the deaths. Infection was reported as cause of death in

Table 3. Age and sex specific acceptance rates for male and female children commencing renal replacement therapy in 1984. Acceptance rates are given by sex for three age groups. Total number of children commencing therapy in 1984 also given

Country	Acceptance rates 1984 PMCP according to age at start of treatment						Total (n)
	0-4		5-9		10-14		
	Male	Female	Male	Female	Male	Female	
Algeria	0	0	1.1	0	2.4	2.6	7
Austria	0	0	6.6	0	3.0	12.7	7
Belgium	3.1	3.2	3.0	11.5	29.7	18.1	26
Bulgaria	0	0	0	0	6.3	3.3	3
Cyprus	0	0	0	0	0	0	0
Czechoslovakia	0	0	0	0	5.3	1.9	4
Denmark	0	0	0	0	19.4	15.2	7
Egypt	0	0	0	0.5	0.6	2.0	5
Fed. Rep. Germany	3.9	2.0	2.8	2.4	3.8	6.0	49
Finland	0	0	5.8	0	15.5	5.4	5
France	3.1	4.9	7.0	6.3	11.0	12.0	92
German Dem. Rep.	4.2	2.2	5.1	12.5	4.3	4.5	19
Greece	0	0	2.6	0	8.1	2.8	5
Hungary	0	0	0	0	12.1	3.2	5
Iceland	0	0	0	0	0	90.9	1
Ireland	0	6.1	11.8	6.2	11.9	0	6
Israel	4.2	0	0	0	17.0	42.2	12
Italy	3.7	0.5	1.3	4.6	6.7	6.6	53
Lebanon	0	0	0	0	0	0	0
Libya	0	0	0	0	0	0	0
Luxembourg	0	0	0	0	0	0	0
Morocco	0	0	0	0	0	0	0
Netherlands	8.4	0	1.6	6.9	6.3	10.0	19
Norway	0	7.1	5.9	0	12.1	6.4	5
Poland	0.6	0.7	3.0	3.1	3.0	6.3	22
Portugal	0	2.3	2.2	0	2.1	13.2	10
Spain	7.2	7.0	3.6	3.2	11.2	10.4	68
Sweden	7.2	3.8	0	14.4	3.4	0	8
Switzerland	0	0	4.4	9.3	3.9	8.1	6
Tunisia	0	0	0	0	0	2.7	1
Turkey	0	0	0	0	0.4	0.8	3
United Kingdom	3.1	0.6	3.5	3.7	11.3	6.2	62
Yugoslavia	2.1	1.1	2.2	0	5.3	2.2	12

17.7% of children who died in 1984, and malignant disease accounted for a further 9.7% of mortality.

Discussion

Completeness of the survey

The data in this paper are all derived from the patient questionnaires of 4983 individually registered paediatric patients. Completeness of returns on paediatric patients is difficult to judge because of the absence of an accepted definition of a paediatric unit. On the 1984 centre questionnaire, 97 centres defined themselves as specialised paediatric units. There are a great many more which are known to treat children but did not define themselves as specialised. Ascertainment of whether a unit treats children or not depends upon return of patient questionnaires. It is therefore not possible to calculate what coverage of

paediatric patients the Registry achieves because there is no denominator. The only information that is readily available is that the 97 centres which define themselves as specialised paediatric units all returned patient questionnaires in 1984.

Trends in renal replacement therapy

At the close of 1984 there were 1570 individually registered children alive on all methods of renal replacement therapy. There were a further 1835 who had commenced treatment under the age of 15 but at the end of 1984 were aged more than 15 years. This represents an increase of 26% over the stock of paediatric patients registered alive at the end of 1983. In 1984, 522 children commenced renal replacement therapy throughout Europe. The acceptance rate per million child population varied greatly from country to country (Tables 4 and 5 of the preceding report). Overall,

Table 4. Grafts reported to the Registry in children in 1984 by individual country. Grafts are shown according to source and number in overall graft sequence

Country	Live donor				Cadaver				All grafts
	1st	2nd	3rd	Total	1st	2nd	3rd	Total	
Algeria	0	0	0	0	0	0	0	0	0
Austria	1	0	0	1	3	0	0	3	5
Belgium	15	0	0	15	7	2	1	10	25
Bulgaria	0	0	0	0	0	0	0	0	0
Cyprus	0	0	0	0	0	0	0	0	0
Czechoslovakia	0	0	0	0	2	1	0	3	3
Denmark	2	0	0	2	6	2	0	8	10
Egypt	4	0	0	4	0	0	0	0	4
Fed. Rep. Germany	2	0	0	2	27	8	0	35	37
Finland	1	0	0	1	4	0	0	4	5
France	3	1	0	4	50	6	0	56	63
German Dem. Rep.	0	0	0	0	6	0	0	6	7
Greece	1	0	0	1	0	0	0	0	1
Hungary	0	0	0	0	3	1	0	4	4
Iceland	0	0	0	0	0	0	0	0	0
Ireland	6	0	0	6	1	1	0	2	8
Israel	2	0	0	2	2	0	0	2	5
Italy	4	0	0	4	12	2	0	14	18
Lebanon	0	0	0	0	0	0	0	0	0
Libya	0	0	0	0	0	0	0	0	0
Luxembourg	1	0	0	1	1	0	0	1	2
Morocco	0	0	0	0	0	0	0	0	0
Netherlands	1	0	0	1	15	0	0	15	16
Norway	2	0	0	2	2	2	0	4	6
Poland	1	0	0	1	2	0	0	2	4
Portugal	0	0	0	0	1	0	0	1	1
Spain	8	1	0	9	30	6	2	38	47
Sweden	5	0	0	5	1	0	0	1	6
Switzerland	0	0	0	0	6	1	0	7	7
Tunisia	0	0	0	0	0	0	0	0	0
Turkey	0	0	0	0	0	0	0	0	0
United Kingdom	6	0	0	6	43	17	0	60	67
Yugoslavia	2	0	0	2	0	0	0	0	2

acceptance rates of children were highest in those aged 10–14 at first therapy. The highest acceptance rate for paediatric patients in 1984 was recorded in Belgium, where 26 children commenced therapy in total. The age specific acceptance rates for male children aged under 5 reached 8.4 in the Netherlands and 7.2 in Spain and Sweden. In 18 of 33 countries no children under the age of 5 were accepted for replacement therapy in 1984.

Acceptance rates for male children aged between 5 and 9 at first therapy reached 11.8 in Ireland, compared with 14.4 in Sweden for females of the same age group. In Belgium, the age specific acceptance rate for male children aged 10–14 reached 29.7 and for females, 18.1. The highest acceptance rate for females in this age category was reported in Iceland but this represented only one patient.

Primary renal diseases

Information on primary renal diseases leading to end-stage renal failure was provided in 496 of 522 paediatric patients who commenced therapy in 1984. These diseases were ana-

lysed according to age at start of treatment and interesting differences noted. The proportion of children reported with a diagnosis of chronic renal failure, aetiology uncertain, declined with increasing age at start of treatment, from 9.3% of children commencing therapy under 5 years to 4.7% among those who started treatment between 10 and 14 years of age. Haemolytic uraemic syndrome was the primary renal disease reported in 12.0% of children starting treatment under 5 and 12.3% of those aged between 5 and 9. Among children aged 10–14, it was reported in less than 1% of cases.

Causes of death

In children, as in adults, the leading causes of death are cardiac, accounting for 46.8% of deaths in children on renal replacement therapy in 1984. Vascular causes of death are less important than in adults and no deaths from liver disease were reported in children in 1984. The proportion of deaths in children defined as uncertain, not determined or unknown, is very similar to that reported in adults.

Table 5. Proportional distribution (%) of causes of end-stage renal failure in children starting renal replacement therapy in 1984 according to age at start of therapy

Causes of end-stage renal failure	Age at start treatment 1984 (%)		
	0-4	5-9	10-14
Chronic renal failure, aetiology uncertain	9.3	5.7	4.7
Glomerulonephritis—histologically <i>not</i> examined	12.0	3.3	8.4
—histologically examined	18.7	13.9	24.0
Pyelonephritis/interstitial nephritis—cause not specified	4.0	4.9	4.3
—associated with neurogenic bladder	0	3.3	2.7
—due to congenital obstructive uropathy with or without vesico-ureteric reflux	8.0	17.2	13.0
—due to acquired obstructive uropathy	0	0	0.7
—due to vesico-ureteric reflux without obstruction	0	4.1	8.4
—due to urolithiasis	0	0	0.7
—due to other cause	0	0	0
Nephropathy—caused by drugs or nephrotoxic agents—cause not specified	0	0	0.3
—due to analgesic drugs	0	0	0
Cystic kidney disease—type unspecified	0	0.8	0
Polycystic kidneys—adult type	2.7	0	0.3
—infantile and juvenile types	0	0.8	1.3
Medullary cystic disease, including nephronophthisis	8.0	7.4	6.7
Hereditary/familial nephropathy	14.7	9.9	10.4
Hereditary nephritis with nerve deafness (Alport's syndrome)	1.3	0	2.0
Cystinosis	0	4.1	1.3
Oxalosis	0	2.5	0.7
Renal vascular disease—type unspecified	0	2.4	0
—due to malignant hypertension (<i>no</i> primary renal disease)	1.3	0	0
—due to hypertension (<i>no</i> primary renal disease)	0	0	0.3
—due to polyarteritis	0	0	0
Wegener's granulomatosis	0	0	0
Diabetes—insulin dependent (type I)	0	0.8	0.7
—non-insulin dependent (type II)	1.3	0	0
Myelomatosis	0	0	0
Amyloid	0	0	0
Lupus erythematosus	0	0	1.3
Henoch-Schönlein purpura	0	0.8	3.3
Goodpasture's syndrome	0	0	0
Scleroderma	0	0	0
Haemolytic uraemic syndrome (Moscowitz syndrome)	12.0	12.3	0.7
Multisystem disease—other	0	0.8	0.3
Cortical or tubular necrosis	0	0.8	0.3
Tuberculosis	1.3	0	0
Gout	0	0	0
Nephrocalcinosis and hypercalcaemic nephropathy	1.3	0.8	1.0
Balkan nephropathy	0	0	0
Kidney tumour	1.3	0.8	0.3
Traumatic or surgical loss of kidney	0	0.8	0
Other identified renal disorders	2.6	1.6	1.7
Total patients with diagnosis available	75	122	299

Table 6. Proportional distribution of causes of death in children dying in 1984. Absolute numbers are also given

Causes of death on renal replacement therapy	Deaths under 15 years, 1984	
	Total (n)	Percent (%)
Cause of death uncertain/not determined/unknown	4	6.5
Cardiac:		
Myocardial ischaemia and infarction	0	0
Hyperkalaemia	3	4.8
Haemorrhagic pericarditis	2	3.2
Other causes of cardiac failure	4	6.5
Cardiac arrest, cause unknown	9	14.5
Hypertensive cardiac failure	4	6.5
Hypokalaemia	0	0
Fluid overload	7	11.3
Vascular:		
Pulmonary embolus	0	0
Cerebrovascular accident	2	3.2
Haemorrhage from graft site	0	0
Haemorrhage from vascular access or dialysis circuit	0	0
Haemorrhage from ruptured vascular aneurysm	0	0
Haemorrhage from surgery	0	0
Other haemorrhage	1	1.6
Infection:		
Pulmonary infection (bacterial)	4	6.5
Pulmonary infection (viral)	0	0
Pulmonary infection (fungal)	0	0
Infections elsewhere	0	0
Septicaemia	3	4.8
Tuberculosis	0	0
Generalized viral infection	2	3.2
Peritonitis	2	3.2
Liver disease:		
Viral hepatitis	0	0
Drug toxicity	0	0
Cirrhosis—not viral	0	0
Cystic liver disease	0	0
Liver failure—cause unknown	0	0
Gastro-intestinal:		
Gastro-intestinal haemorrhage	0	0
Mesenteric infarction	0	0
Pancreatitis	1	1.6
Sclerosing (or adhesive) peritoneal disease	0	0
Perforation of peptic ulcer	1	1.6
Perforation of colon	0	0
Social:		
Patient refused further treatment	0	0
Suicide	0	0
Therapy ceased for any other reason	2	3.2
Miscellaneous:		
Uraemia caused by graft failure	0	0
Bone marrow depression	0	0
Cachexia	1	1.6
Malignant disease	6	9.7
Dementia	0	0
Accident:		
Accident related to treatment	0	0
Accident unrelated to treatment	0	0
Other identified cause of death	4	6.5
Total patients with known cause of death	62	100

Acknowledgements. This work was supported by grants from the Governments or National Societies of Nephrology of Austria, Belgium, Bulgaria, Cyprus, Czechoslovakia, Denmark, Egypt, the Federal Republic of Germany, France, the German Democratic Republic, Greece, Iceland, Ireland, Israel, Luxembourg, the Netherlands, Norway, Sweden, Switzerland, Tunisia and the United Kingdom.

Grants were also made by Asahi Medical GmbH, B. Braun Melsungen AG, Bellco S.p.A., Cobe Laboratories, Inc, CD Medical International, Ltd, Enka AG, Fresenius AG, Gambro AB, Hospital, Ltd, Sandoz AG, Sorin Biomedica S.p.A. and Travenol Laboratories, Ltd.

We acknowledge the co-operation of UK Transplant Service, Bristol, United Kingdom.

We thank those doctors and their staff who have completed questionnaires. Without their collaboration this Report could not have been prepared.

Reference

1. Broyer M, Rizzoni G, Brunner FP et al. Combined report on regular dialysis and transplantation of children in Europe, XIV, 1984. *Proc Eur Dial Transplant Assoc* 1985; 22: 55-79