Nephrology Dialysis Transplantation

Registry Report

Demography of Dialysis and Transplantation in Children in Europe, 1985

Report from the European Dialysis and Transplant Association Registry

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Abstract. At the end of 1985 there were 5482 patients known to the Registry who started renal replacement therapy (RRT) between the ages of 6 months and 15 years. Of these, approximately 25% had died, 30% were still aged less than 15 years, and the other 45% were older. The acceptance rate of new patients over the last 10 years has slowly but steadily increased; six new paediatric patients per million child population probably represents the likely needs of the near future.

Hospital haemodialysis remained the main form of renal replacement therapy in new patients, while 3 years after start of RRT, transplantation became the most frequently used replacement therapy; CAPD appeared to be used mainly in children with a short waiting time for transplantation.

Out of the 384 grafts reported in 1985, only 16% were from living related donors; among 321 cadaver grafts, 24% were second and only 3% were third grafts. Glomerulonephritis and pyelonephritis accounted for

50% of all primary renal diseases. During the last 5 years, the proportion with glomerulonephritis seems to have decreased slightly. Hyperkalaemia and fluid overload have still to be considered the main causes of death. Only in 17% of all cases was the cause of death reported as unknown or undetermined.

Key words: Children; Demography; Dialysis; End-stage renal failure; Transplantation

Introduction

Since 1972, data collected by the EDTA Registry on children treated by renal replacement therapy (RRT) have been presented annually and published in the Proceedings of EDTA-ERA. The data up to 31 December 1984 were published in the journal of the Association [1].

This report is based on data provided on individual patient questionnaires and relates to treatment up to 31 December 1985. Demographic data on patients who commenced treatment for end-stage renal failure aged less

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than 15 years are presented. Numbers of patients alive on different forms of therapy and numbers of new patients accepted for treatment are given. Types of therapy used in the treatment of children, causes of end-stage renal failure, and causes of death in these patients are also discussed.

Methods

The Paediatric Registry Data Base

The methods of data collection used by the EDTA Registry have previously been described [1]. The term 'specialised paediatric centre' has been used for those centres which defined themselves as a specialised dialysis centre for paediatric patients in response to a question on the centre questionnaire. Demographic data are

Table 1. Number of patients ever accepted for treatment of end-stage renal failure aged more than 6 months and less than 15 years. The number of these patients alive on 31 December 1985 is also given. Data from patient questionnaire

Country	Total number of paediatric patients registered	Untraced*	Alive on 31 Dec. 1985
Algeria	17	6	9
Austria	71	2	48
Belgium	185	9	141
Bulgaria	46	4	10
Cyprus	5		5
Czechoslovakia	38		17
Denmark	85	11	48
Egypt	31	2	18
Fed. Rep. Germany	723	78	479
Finland	42	2	29
France	1050	88	756
German Dem. Rep.	139	1	79
Greece	66	28	17
Hungary	25		16
Iceland	2	_	2
Ireland	43	2	32
Israel	115	8	71
Italy	582	51	396
Lebanon	4	3	0
Libya	10	3	2
Luxembourg	8		4
Morocco	I		1
Netherlands	224	42	153
Norway	53	_	45
Poland	124	8	72
Portugal	66	1	52
Spain	519	30	389
Sweden	86	2	64
Switzerland	95	I	74
Tunisia	6		4
Turkey	47	5	16
United Kingdom	854	92	548
Yugoslavia	120	19	57
Total	5482	498	3654

^{*}Lost to follow-up. not updated or current method of treatment unknown, uncertain

expressed both as absolute numbers and per million child population (PMCP). Data on child populations were obtained from the World Health Organisation Statistics Annual, using the most up-to-date information available for each country.

Results and Comments

On 31 December 1985, the Registry held records for 5482 patients who started RRT aged more than 6 months and less than 15 years (Table 1). After excluding 498 patients who were lost to follow-up, whose records had not been updated, or where there was an invalid treatment code, 3654 patients were registered alive at the end of 1985 on a known form of therapy; after excluding patients who had recovered their renal function, 1616 were still aged less than 15 years, and 2003 were older than 15 on that date. A total of 1330 patients had died. For the total Registry,

Table 2. Number of new paediatric patients accepted onto renal replacement therapy in 1985 shown according to age group. The Table is based on information provided on the 1985 patient questionnaire, and shows the total number of new patients per million child population (PMCP)

Country	Age g	groups		Total	PMCP	
	0-4	5–9	10–14	-		
Algeria	0	0	0	0		
Austria	0	0	5	5	2.8	
Belgium	4	5	7	16	7.2	
Bulgaria	0	0	0	0		
Cyprus	0	0	0	0		
Czechoslovakia	0	1	2	3	0.9	
Denmark	1	2	3	6	5.2	
Egypt	0	5	3	8	0.5	
Fed. Rep. Germany	9	17	29	55	4.1	
Finland	0	1	2	3	2.8	
France	17	31	49	97	7.9	
German Dem. Rep.	2	l	9	12	3.4	
Greece	0	2	2	4	1.8	
Hungary	0	5	3	8	3.7	
Iceland	0	0	0	0		
Ireland	0	2	.2	4	4.1	
Israel	3	3	5	[1	9.7	
Italy	12	14	31	57	4.2	
Lebanon	0	0	0	0		
Libya	0	0	0	0		
Luxembourg	0	0	0	0		
Morocco	0	0	0	0		
Netherlands	7	8	5	20	5.8	
Norway	- 1	3	l	5	5.2	
Poland	3	7	18	28	3.4	
Portugal	0	3	10	13	5.4	
Spain	5	15	30	50	5.2	
Sweden	2	2	3	7	4.1	
Switzerland	1	i	5	7	5.0	
Tunisia	0	0	0	0		
Turkey	2	0	8	10	0.5	
United Kingdom	7	20	46	73	5.6	
Yugoslavia	3	6	5	14	2.5	
Total	79	154	283	516		

Table 3. Stock of paediatric patients alive on a known form of renal replacement therapy on 31 December 1985. The number of patients who have recovered sufficient function of own kidneys to make dialysis unnecessary is recorded separately. The Table only includes patients who commenced treatment under the age of 15 and who were still aged less than 15 at the end of 1985. The number of patients alive per million child population (PMCP) is also given. Data from patient questionnaire

Country	Hospital HD	Home HD	IPD	CAPD	Graft	Total	PMCP	Recovery*
Algeria	7	0	0	0	0	7	1	0
Austria	9	0	0	0	9	18	12	0
Belgium	22	0	0	3	47	72	37	0
Bulgaria	5	0	0	0	0	5	2	0
Czechoslovakia	3	0	0	0	5	8	2	0
Denmark ·	5	0	i	7	6	19	19	0
Egypt	6	0	1	ī	6	14	1	1
Fed. Rep. Germany	44	3	6	26	96	175	18	4
Finland	2	0	0	2	7	11	11	0
France	171	6	4	21	153	355	30	5
German Dem. Rep.	31	0	0	0	8	39	13	3
Greece	2	0	0	3	2	7	3	0
Hungary	8	0	0	0	4	12	5	0
celand	1	0	0	1	0	2	33	0
reland	1.	0	0	1	12	14	14	0
srael	4	0	0	7	28	39	28	0
Italy	73	3	3	26	55	160	13	3
Luxembourg	1	1	0	0	1	3	50	0
Могоссо	0	0	0	0	1	1	0	0
Netherlands	17	0	0	21	38	76	25	0
Norway	1	0	0	2	12	15	19	1
Poland	28	0	0	11	7	46	5	0
Portugal	24	0	1	3	1	29	13	2
Spain	77	1	2	15	79	174	18	3
weden	1	0	0	2	20	23	15	0
Switzerland	8	0	0	6	12	26	24	1
Γunisia	1	0	0	0	0	1	1	0
Turkey	11	0	0	0	0	11	1	0
Jnited Kingdom	32	6	2	53	133	226	20	2
Yugoslavia	24	0	0	2	2	. 28	5	0
Γotal	619	20	20	213	744	1616		25
6	38	1	1	13	47	100		

^{*}Recovery of function.

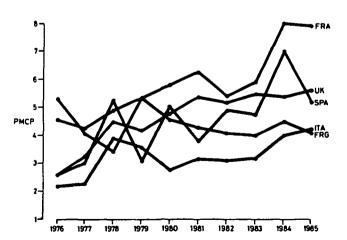


Fig. 1. Acceptance rate of new paediatric patients on renal replacement programmes in the five largest European countries between 1976 and 1985, expressed per million child population (PMCP). FRA, France; UK, United Kingdom; SPA, Spain; ITA, Italy and FRG, Federal Republic of Germany.

information was available for 89.5% of known live paediatric patients. Of patients aged less than 15 on 31 December 1985, 94% had updated records. The number of patients who started RRT aged less than 15 and who were alive at the end of 1985 varied widely between countries when expressed per million child population. In those countries where a programme for the treatment of children with end-stage renal failure (ESRF) began in the early seventies, it ranged between 30 and 60 PMCP. There were 89 (4.5%) centres defining themselves as specialised units on the centre questionnaire in 1985. It is interesting to note that 86 (97%) returned 1985 patient questionnaires. The proportion of all children who were treated in these specialised units varied between countries, but in the majority, more than 80% of patients aged less than 15 were treated in specialised paediatric centres.

New Patients in 1985

During 1985, 516 new paediatric patients were reported to have been accepted for treatment; 15% were aged less

Table 4. Percentage contribution of different modes of therapy to the treatment of children at specified intervals after start of renal replacement therapy shown for selected countries. All children commencing RRT in 1981-85 are included. An asterisk (*) denotes less than 30 patients at risk. Nordic countries are Denmark, Finland, Norway and Sweden

		Start RRT	6 months	l year	2 years	3 years	4 years
France	Hosp. HD	76	79	73	58	48	41
	Home HD	0	4	6	6	5	4
	CAPD IPD	15 8	12 3	10 2	8 2	4 2	4 1
	Graft	ì	2	8	26	41	50
	n	390	356	328	296	190	102
Fed. Rep.	Hosp. HD	75	64	57	46	38	28
Germany	Home HD	1	1	3	4	4	3
	CAPD	15	17	14	10	4	1
	IPD	7	5	5	3	2	1
	Graft	4	12	22	37	52	66
	n	252	228	220	186	127	68
Home CAPD IPD	Hosp. HD	74	68	60	53	49	48
	Home HD	0	2	3	.5	6	.7
		19 4	21	20 1	15	12 2	11 2
	Graft	3	2 7	16	1 27	31	31
	n	202	174	160	131	94	54
Nordic	Hosp. HD	37	25	22	23	24	
countries	Home HD	0	1	1	0	0	
	CAPD	29	31	25	17	5	
	IPD	14	1	0	5	0	
	Graft	20	41	51	54	70	
	n	94	80	76 	74	37	•
Spain	Hosp. HD	65	66	62	55	46	41
	Home HD	0	<1	2	3	4	4
	CAPD	12	16	13	9	4	4
	IPD Graft	21 3	6 11	4 19	2 32	1 46	2 50
***************************************	n	234	219	201	170	154	56
United	Hosp. HD	45	33	26	24	17	14
Kingdom	Home HD	0	2	4	.5	4	10
	CAPD	30	35	27	19	17	19
	IPD Graft	14 11	3 27	2 40	2 50	0 62	1 55
	n	333	312	306	295	174	91

than 5 years, 30% were 5-9 years old, and 55% were more than 10 but less than 15 years (Table 2). The acceptance rate in 1985 varied widely between different European countries, even amongst the larger countries (4.2 new patients PMCP in Italy to 7.9 PMCP in France). Nevertheless, it is important to note that there has been a gradual overall increase in the acceptance rates over the past 10 years in all countries (Fig. 1). Some countries, such as France, may have a very high acceptance rate due to

the acceptance of foreign patients. Even so, it appears reasonable to assume that 6 new children PMCP probably represent the likely needs for the near future; this figure is supported by the results of the Canadian Paediatric Registry which obtains comprehensive data on children with end-stage renal failure in that country [2]. However, this figure may be influenced over the next 10 years by a decrease in the birth rate or increased quality of conservative treatment or by the likely increase in the acceptance

Table 5. Transplant activity in 1985, based on data from patient questionnaire. The Table gives the number of grafts performed during 1985 in children aged less than 15 at time of grafting

Country	Live d	onor		Cadaver donor					All
	lst	2nd	Total	lst	2nd	3rd	4th	Total	grafts
Austria	1	0		4	3		0	8	9
Belgium	3	1	4	6	1	0	0	7	11
Czechoslovakia	0	0	0	2	0	0	0	2	2
Denmark	0	0	0	2	1	0	0	3	3
Egypt	3	0	3	0	0	0	0	0	3
Fed. Rep. Germany	4	0	4	24	12	i	0	37	41
Finland	0	0	0	2	1	0	0	3	3
France	3	1	4	47	11	0	0	58	62
German Dem. Rep.	0	0	0	7	1	0	0	8	8
Greece	1	0	ī	0	0	0	0	0	1
Hungary	1	0	1	0	0	0	0	0	1
Ireland	5	0	5	1	2	I	0	4	9
Israel	2	0	2	8	1	0	0	9	11
Italy	7	0	7	12	4	0	0	16	23
Netherlands	1 .	0	1	14	3	0	0	17	18
Norway	2	0	2	1	2	0	0	3	5
Poland	3	0	3	5	0	0	0	5	8
Portugal	0	0	0	2	0	0	0	2	2
Spain	9	0	9	45	10	1	0	56	65
Sweden	6	2	8	3	0	0	0	3	11
Switzerland	0	0	0	3	I	0	0	4	4
Γunisia	0	0	0	1	0	0	0	1	1
United Kingdom	5	1	6	45	23	6	1	75	81
Yugoslavia	2	0	2	0	0	0	0	0	2
Total .	58	5	63	234	76	10	1	321	384

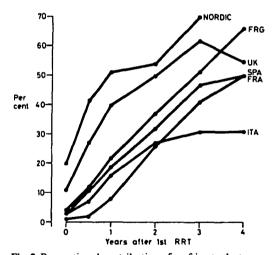


Fig. 2. Proportional contribution of grafting to the treatment of children who commenced renal replacement therapy between 1981 and 1985 at different intervals after first treatment. Results are given for six countries or groups of countries. NORDIC: Denmark, Finland, Norway and Sweden: FRG, Federal Republic of Germany; UK, United Kingdom: SPA, Spain: FRA, France; ITA, Italy.

rate of younger children and infants with end-stage renal failure.

Mode of treatment on 31 December 1985

Table 3 shows the mode of treatment used in patients aged under 15 on 31 December 1985, and alive on a known

form of renal therapy on that date. Almost half of these patients were alive with a functioning graft; the majority of the remaining patients were treated by hospital haemodialysis, and a small proportion by CAPD; home haemodialysis and IPD accounted for only 2% of all renal replacement therapy in this group of patients. If only new patients are considered, the proportional contribution of CAPD becomes more important and accounts, on average, for 20% of new patients [3] although there are striking differences between countries (Table 4).

Treatment Mode in Relation to Time on RRT

The methodology developed by Dr Neville Selwood and previously described [4] was used to analyse the proportional contribution of different modes of renal replacement therapy to the treatment of children at specified intervals after the start of RRT. In this analysis therefore the starting point for each patient was the date of the first treatment. All children commencing RRT in 1981 (85 aged less than 15) were included. Only 4% of children commenced with transplantation, hospital haemodialysis accounted for 67% of first treatment, IPD 11%, and CAPD 17%. By 3 years the pattern was very different, with functioning grafts now maintaining 46% of those

Table 6. Proportional distribution of causes of end-stage renal failure in patients aged less than 15 when commencing renal replacement therapy 1981-85. Numbers of patients with each cause of end-stage renal failure are also shown

Causes of end-stage renal failure			
Chronic renal failure, aetiology uncertain		135	5.7%
Glomerulonephritis		611	25.8%
histologically not examined	131		
severe nephrotic syndrome with focal sclerosis	161		
IgA nephropathy (proven by immunofluorescence)*	11		
dense-deposit disease (proven by immunofluorescence and/or electronmicroscopy)**	18		
other glomerulonephritis, histologically examined	290		
Pyelonephritis/interstitial nephritis		574	24.2%
cause not specified	77		
associated with neurogenic bladder	31		
due to congenital obstructive uropathy with or without vesicoureteric reflux	237		
due to acquired obstructive uropathy	19		
due to vesicoureteric reflux without obstruction	184		
due to urolithiasis	12		
due to other causes	14	.	
Hereditary/familial nephropathy		370	15.6%
cystic kidney disease, type unspecified	11		
polycystic kidneys, adult type (dominant)	10		
polycystic kidneys, infantile (recessive)	28		
medullary cystic disease, including nephronophthisis	150		
other specified type of cystic kidney disease	9		
hereditary/familial nephropathy, type unspecified	15		
hereditary nephritis with nerve deafness (Alport's syndrome)	38		
cystinosis	75		
primary oxalosis	22		
other hereditary nephropathy	12	***	12 604
Congenital hypoplasia/dysplasia		319	13.5%
congenital hypoplasia, type unspecified	137		
oligomeganephronic hypoplasia	36		
segmental renal hypoplasia (Ask-Upmark kidney)	8		
congenital renal dysplasia with or without urinary-tract malformation	120		
syndrome of agenesis of abdominal muscles (Prune-belly syndrome)	18	25	1 (0)
Renal vascular disease	,	37	1.6%
type unspecified	6		
due to malignant hypertension (no primary renal disease)	.5		
due to hypertension (no primary renal disease)	14		
due to polyarteritis	4		
Wegener's granulomatosis	1		
other renal vascular disease, classified	7	242	10.30/
Multisystem disease	0	243	10.2%
diabetes, insulin dependent (Type I)	9		
diabetes, non-insulin dependent (Type II) myelomatosis	3 1		
· ·	-		
amyloid lupus erythematosus	8 19		
Henoch-Schönlein purpura			
Goodpasture's syndrome	56 2		
Haemolytic-uraemic syndrome (Moschcowitz syndrome)			
other multisystem disease	115 30		
Aiscellaneous	30	83	3.4%
nephropathy caused by drugs	10	0.3	3.476
cortical or tubular necrosis	10 19		
nephrocalcinosis and hypercalcaemic nephropathy			
kidney tumour	14 17		
traumatic or surgical loss of kidney			
other identified renal disorders	6		
other mentaled tenal disorders	17		

^{*}Introduced in 1983.

alive on treatment, hospital haemodialysis 41%, home haemodialysis 3%, and CAPD approximately 8%. This distribution was very different according to country, as shown in Table 4, where the proportional contribution of

different forms of therapy at various time intervals is given for France, the Federal Republic of Germany, Italy, the Nordic countries (Denmark, Finland, Norway and Sweden), Spain, and the United Kingdom.

^{**}Introduced in 1984.

Table 7. Proportional distribution of groups of primary renal diseases recorded as cause of end-stage renal failure in patients aged less than 15 years commencing treatment in each of the years 1981-85

Causes of end-stage renal failure in new patients from 1981 to 1985	1981 (%)	1982 (%)	1983 (%)	1984 (%)	1985 (%)
Chronic renal failure, aetiology uncertain	5.9	5.3	6.0	4.8	6.3
Glomerulonephritis	29.7	23.8	25.9	26.4	23.2
Pyelonephritis/interstitial nephritis	22.8	26.1	22.1	27.9	21.8
Hereditary/familial nephropathy	15.9	12.3	18.4	12.9	18.1
Congenital hypoplasia/dysplasia	12.3	13.7	12.8	12.7	15.5
Renal vascular disease	1.4	1.8	2.0	1.3	1.2
Multisystem disease	9.7	14.4	8.6	11.6	7.1
Other	2.1	2.3	4.0	2.2	6.5

Transplantation activity

Transplantation activity in children during 1985 is summarised in Table 5. This shows the graft according to the country where the child was registered on 31 December 1985, and does not necessarily indicate where the transplant was performed. Out of a total of 384 grafts that were reported in 1985, 16% were from a living donor. Among cadaver grafts, 26% were regrafts (40% in the UK) and only 10 (3%) were third grafts; only one fourth graft was reported.

Achievement in transplantation for children was also studied using the Selwood method. There were national differences in the contribution of transplantation to the treatment of children who commenced RRT during the 5 years between 1981 and 1985, as shown in Table 4 and Fig. 2. In Nordic countries, which include Denmark, Finland, Norway and Sweden, over 50% of children had a functioning transplant by 1 year after start of treatment, compared with 10%-20% in France and Italy, 20%-30% in Spain and the Federal Republic of Germany, and over 40% in the United Kingdom. By 2 years, the 50% mark had been passed by the United Kingdom, and by 4 years, this figure had also been reached by the Federal Republic of Germany, France and Spain. In interpreting these data, it is necessary to bear in mind the number of children alive on renal replacement therapy in each country, given in Table 1. The size of the treated paediatric population in some countries may explain the difficulty encountered in achieving early grafting; alternatively, the observed differences may reflect different policies.

Primary Renal Disease

The proportional distribution of causes of end-stage renal failure (ESRF) in children who started renal replacement therapy between 1981 and 1985, as reported to the Registry, is shown in Table 6. Glomerulonephritis and pyelonephritis accounted for approximately 25% each of all primary renal diseases; hereditary and/or familial

nephropathies were responsible for 15.6% of cases of ESRF, followed by congenital hypoplasias and dysplasias (13.5%) and multisystem disease (10.2%). It is worth noting that in only 5.7% of the 2372 children who started RRT from 1981 to 1985 was the aetiology of chronic renal failure considered uncertain; this figure was much smaller than in adults.

When the proportional distribution of different groups of primary renal diseases in each of the 5 years is considered, a definite trend is not seen, except perhaps for glomerulonephritis (Table 7) which accounted for almost 30% of all primary renal diseases in 1981, but for only 23% in 1985, thus confirming the trends already described in the preceeding years. It is not possible to say if this fact reflects a reduction of the incidence of glomerular diseases, a modification in the diagnostic practice, or an increased acceptance of patients with non-glomerular diseases.

Causes of Death

Table 8 shows the causes of death in patients who died on RRT aged less than 15 years during the period 1981–1985. The causes of death have been grouped under several headings. Cause of death uncertain/not determined/unknown, cardiac arrest, cause unknown, as well as cases where a cause of death was not recorded, have been grouped together; they represented a relatively small proportion of the total.

Hyperkalaemia and fluid overload have been considered separately and accounted for half of the known 'cardiac' causes. These latter causes, unfortunately, relate to either non-compliance or poor dialysis strategy; the proportion was much higher than in adult patients (4.9%) and is probably specifically related to the difficulty of dialysis management in children. These data confirm the previous finding that excess weight gain (weight gain between haemodialysis treatments exceeding 8% of body weight at least once a week) is associated with excess mortality [5]. Infection also represented an important cause of death in children on RRT.

Table 8. Proportional distribution of causes of death in patients who died on RRT aged less than 15 years during the years 1981 85. Numbers of patients with each cause of death recorded are also shown

Cause of death on	renal replacement therapy	Deaths	198185
		n	%
Cause of death not	given uncertain/not determined/unknown cardiac arrest, cause unknown	17 16 24	17.5
Cardiac	Myocardial ischaemia and infarction Haemorrhagic pericarditis Hypertensive cardiac failure Other causes of cardiac failure Hypokalaemia	$\left.\begin{array}{c} 2\\11\\19\\20\\3 \end{array}\right\}$	16.9
	Hyperkalaemia Fluid overload	23) 31)	16.6
Vascular	Pulmonary embolus Cerebrovascular accident Haemorrhage from vascular access or dialysis circuit Haemorrhage from ruptured vascular aneurysm Haemorrhage from surgery Other haemorrhage	1 22 1 1 2 4	9.5
Infection	Pulmonary infection (bacterial) Pulmonary infection (viral) Pulmonary infection (fungal) Infection elsewhere Septicaemia Tuberculosis (lung) Generalised viral infection Peritonitis	8 8 1 2 25 1 4 7	17.2
Liver disease	Viral hepatitis Cirrhosis, not viral	1 }	0.6
Gastro-intestinal	Gastrointestinal haemorrhage Mesenteric infarction Pancreatitis Sclerosing (or adhesive) peritoneal disease Perforation of peptic ulcer Perforation of colon	5 1 1 1 1	3.1
Social	Patient refused further treatment Suicide Therapy ceased for any other reason	1 1 5	2.2
Miscellaneous	Uraemia caused by graft failure Bone-marrow depression Cachexia Malignant disease possibly induced by immunosuppressive therapy Malignant disease not induced by immunosuppressive therapy Dementia Other identified causes	5 1 9 2 13 1 17	14.7
Accident	Accident related to treatment Accident unrelated to treatment	3 3}	1.8
Total		326	100

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