

Chapter 4: All Patients Receiving Renal Replacement Therapy In 1998

Introduction

This chapter provides information on the demography of the 13,466 patients on the Registry who were alive on 31/12/98 with details of diagnosis and treatment. It also includes the one-year survival rate for patients who were alive on 1/1/98. All 12 units in Scotland (population 5.1 m) are included and the 19 participating units in England and Wales, as detailed in the introduction. However the population served by the units in England and Wales is derived from estimates made by the individual centres; until all units contribute it is important to note that the accuracy of calculations based on population cannot be assured. The prevalence of patients in England and Wales is similar to that in Scotland (table 4.1).

	England & Wales	Scotland	Total
No. of units	19	12	31
No. of patients	10,510	2,956	13,466
Population (m)	19.9* (of 52.2m)	5.1	25.0*
Patients (pmp)	528*	580	539*

* = estimated figures

Table 4.1 Summary of adult patients registered and total population covered

For the transplant units providing a transplant service to other renal units the additional transplant population is not included in the population served. As the Registry grows and covers large contiguous areas, errors due to cross-boundary flow of patients will become insignificant. It will then be possible to estimate prevalence and incidence rates of renal replacement therapy for health authorities and regions using postcodes of individual patients.

Age

The median age for all patients alive on 31/12/98 was 54 years with 26.6% of patients over 65 and 16.8% over 75 years. As might be expected the median age was less for those with working transplants followed by patients on peritoneal dialysis and then haemodialysis (table 4.2). The wide variation in median age of dialysis patients between the different renal units is illustrated in Figure 4.1. It is not possible to say from the currently available information to what extent this is a reflection of differences in when a unit was established, policies on referral / acceptance for treatment, age of local population, funding, or survival rates.

	Median Age			
	Transplants	Peritoneal dialysis	Haemodialysis	All
England & Wales	49	59	62	54
Scotland	46	57	59	52

Table 4.2 Median age and treatment modality

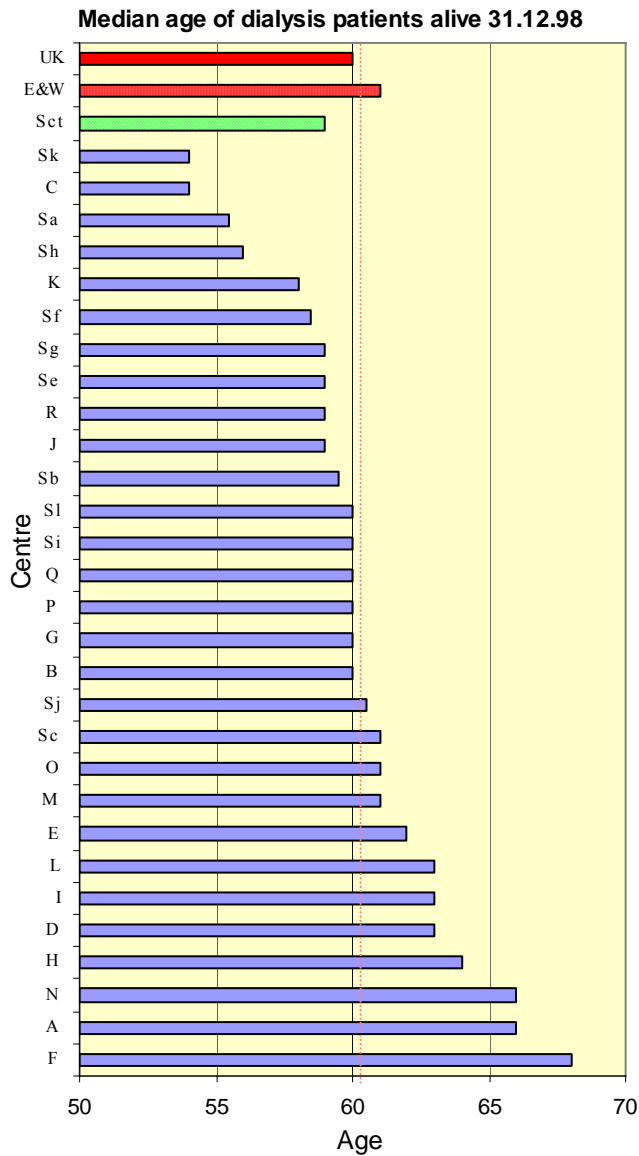


Figure 4.1 Median age of dialysis patients by Centre

Gender

Overall 61% of patients on Renal Replacement Therapy were male (62% in England and Wales; 58% in Scotland). The male preponderance was present in all age groups (Figure 4.2), and was greatest in the oldest group despite the greater proportion of women in the older general population.

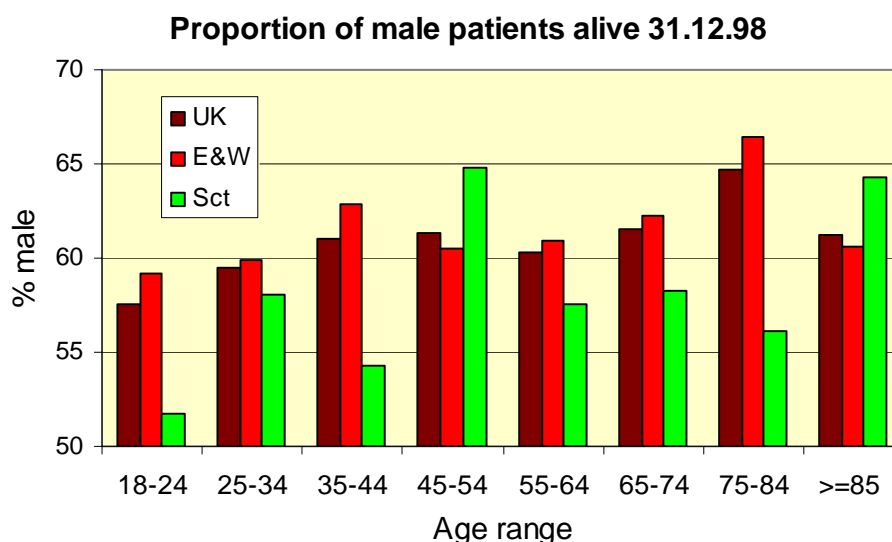


Figure 4.2 Gender distribution by age

Ethnicity

Ethnicity was recorded in 61% of the patients from the contributing Units in England and Wales. Ethnicity information was provided for at least 90% of patients by nine centres whereas in six centres this was either not recorded at all or very rarely. As yet ethnicity has not been requested in the data set for Scotland. The data available demonstrated a wide variation in the percentage of Black and especially of Asian patients (Table 4.3). As Registry coverage becomes more complete, with large contiguous areas covered, it will be possible to relate these figures to the ethnicity of the local population, and hence derive ethnic specific prevalence rates.

	% with data complete	% White	% Black	% Asian	% Chinese	% Other
Plymouth	100	99			1	1
Birmingham	99	77	5	17	1	1
Sheffield	99	94	1	3	1	1
Sunderland	97	99	1	0	0	0
Coventry	96	81	3	16	1	0
Middlesborough	96	96	0	3	0	0
Bristol	95	94	3	2	1	1
Gloucester	91	100	0	0	0	0
Wordsley	90	91	2	6	0	0
Nottingham	89	89	5	6	-	0
Leeds, St James's	83	91	1	7	-	-
Leicester	80	80	2	14	0	3
Carshalton	76	89	5	6	1	-
Cardiff	15	*	-	*	-	-
Exeter	4	*	-	-	-	-
Carlisle	0	-	-	-	-	-
Hull	0	-	-	-	-	-
Oxford	0	-	-	-	-	-
Stevenage	0	-	-	-	-	-
E & W	61	90	2	7	0	1

* - completeness of data returns too small to for reliable estimate.

Table 4.3 Ethnicity

Primary Renal Disease

Details of primary renal disease are shown in Table 4.4. These definitions are based on the original EDTA codes. Outflow obstruction is included in “pyelonephritis”. The category “glomerulonephritis not histological proven” has been included in “aetiology uncertain”. The diagnosis was given in all but 3.4% of patients. Missing information was more common in patients over 65 years (6.0% compared with 3.0% in the younger patients). More of the older patients were categorised as “aetiology uncertain” (33% compared with 23%). The male preponderance was greater in those whose diagnosis was given as hypertension, glomerulonephritis, and reno-vascular disease and not present in pyelonephritis and polycystic kidneys. Diabetic nephropathy contributed a similar proportion to both age groups.

Diagnosis	All patients	Age < 65	Age > 65	M : F ratio	Inter unit range
		On 31/12/98	On 31/12/98		
Aetiology uncertain *	25.2	22.5	32.5	1.75	13-45
Glomerulonephritis**	15.7	18.1	9.4	2.43	8-23
Pyelonephritis	15.5	17.0	11.6	1.09	8-25
Diabetes	9.5	9.7	9.2	1.56	6 –16
Type I	6.8	7.9	4.0	1.57	4-11
Type II	2.7	1.7	5.2	1.54	0- 7
Polycystic Kidney	9.3	9.7	8.1	1.03	4 -14
Hypertension	5.3	4.9	6.3	2.56	1 - 13
Renal Vascular disease	2.6	1.2	6.5	1.96	0 - 7
Not sent	3.4	2.6	5.7	1.81	0 -17
Other	13.5	14.2	10.7	1.30	2 - 20
All Patients Total	13026	9513	3513	1.57	

* - includes patients listed as “glomerulonephritis not biopsy proven”.

** - biopsy proven.

Table 4.4 Primary renal disease in all patients and according to age and gender

Diabetes

Diabetic renal disease was recorded in 9.5% of patients (inter Unit variation 6-16%). Overall, patients with diabetics were the group with the highest proportion treated by peritoneal rather than haemodialysis (Table 4.5).

Proportion of patients on PD by diagnostic category	
Diagnosis	% treated on PD
Diabetes	42.3
Aetiology uncertain *	36.9
Glomerulonephritis	36.8
Polycystic Kidney	33.2
Pyelonephritis	32.2
Hypertension	29.4
Renal Vascular disease	24.1
Other	28.7

* - includes patients listed as “glomerulonephritis not biopsy proven”.

Table 4.5 Proportion of patients on PD by diagnostic category

Of all patients with diabetic nephropathy causing end stage renal failure, 31% had working transplants, 29% were on peritoneal dialysis and 40% on haemodialysis. Further details of patients with diabetic nephropathy in relation to Type I and Type II and age and modality of treatment are shown in Tables 4.6a and 4.6b. It is acknowledged that the categorisation of diabetes may show variation between units, some type II diabetics requiring insulin being included as type I.

4.6a	Type I	Type II	Non-Diabetics
Number	891	350	11,338
M : F ratio	1.6	1.5	1.6
Median Age on 31/12/98	50	65	53
Median Age started ESRF	45	63	45
Median days on treatment	995	598	2,014
% HD	33	57	32
% PD	29	30	16
% transplant	37	13	51

4.6b	Type I	Type II	Non-diabetics	Type I	Type II	Non-diabetics
	< 65	< 65	< 65	≥ 65	≥ 65	≥ 65
Number	752	166		139	184	
% HD	27	46	25	67	67	53
% PD	30	32	14	25	28	22
% transplant	43	22	61	8	5	25

Tables 4.6a and 4.6b Type of diabetes – age, sex ratio, treatment

At all ages diabetics are less likely to have a functioning transplant. This is most marked for type II diabetics, who are also more likely receive haemodialysis than peritoneal dialysis.

Modalities of Treatment

The relationships between age and treatment are shown in Figures 4.3 and 4.4, which emphasise the predominance of transplantation in younger patients and of haemodialysis in the elderly. More patients were treated by haemodialysis than PD in all age groups, but the preference for haemodialysis is more marked with increasing age. This is important for future planning, as the predicted increase in the dialysis population will be mainly in the older age group.

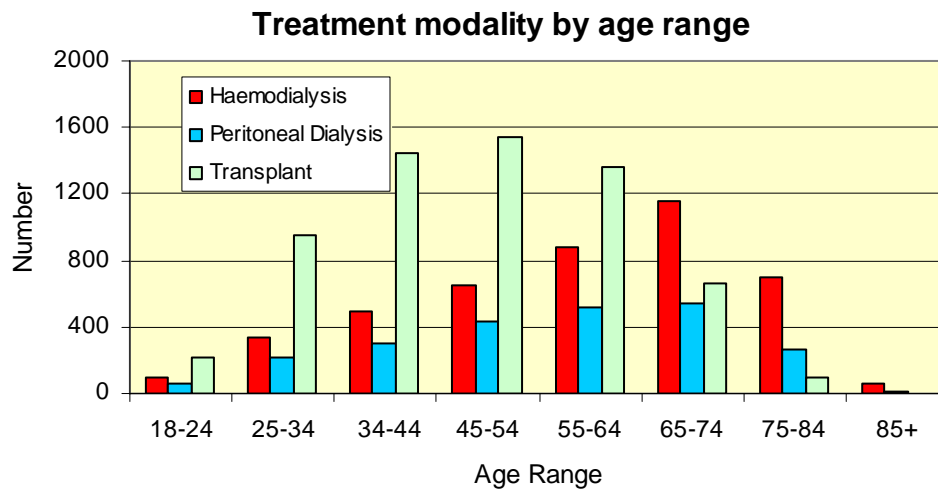


Figure 4.3 The number of patients treated by the three modalities in each age group

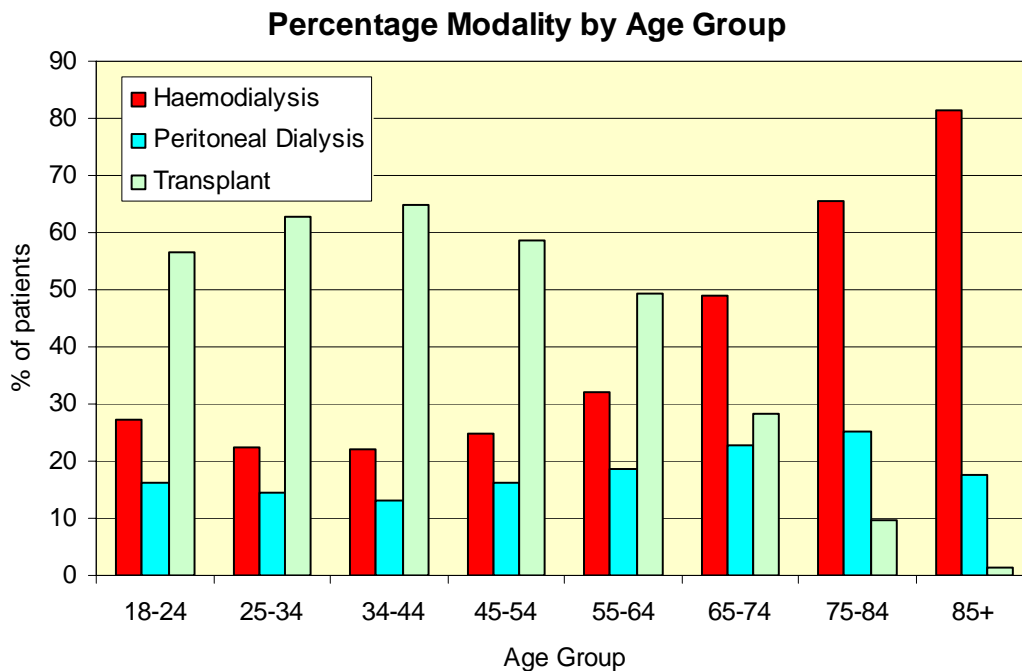


Figure 4.4 For each age group, the percentage of patients on each modality of treatment

The proportion of patients treated by the different types of haemodialysis and peritoneal dialysis is shown in Figure 4.5.

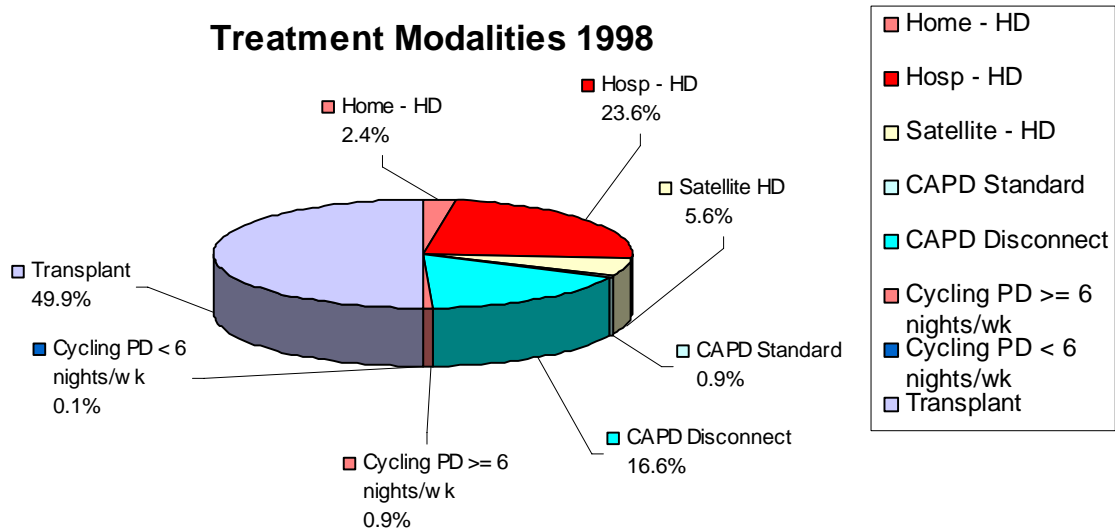


Figure 4.5 Treatment modalities of patients alive 31/12/98

Peritoneal dialysis

Only four centres K, T, F and D, had patients on “standard” CAPD – consisting of 1,4, 5, and 14% of their dialysis patients respectively. In the case of the latter centre this was nearly twice the number on disconnect CAPD.

The frequency of use of cycling PD varies widely. All Scottish units make some use of cycling PD, two centres, Sj and Sf, had more patients on cycling PD than on continuous PD. Sj has 16% of dialysis patients on cycling PD compared with 6% on continuous PD, Sl has 11 compared with 16% on CAPD, and Sh has ten compared with 42%. Of the 19 English units contributing to the Registry only one has a significant use of cycling PD, and eight of the 19 English units do not use this form of therapy.

Peritoneal dialysis modalities

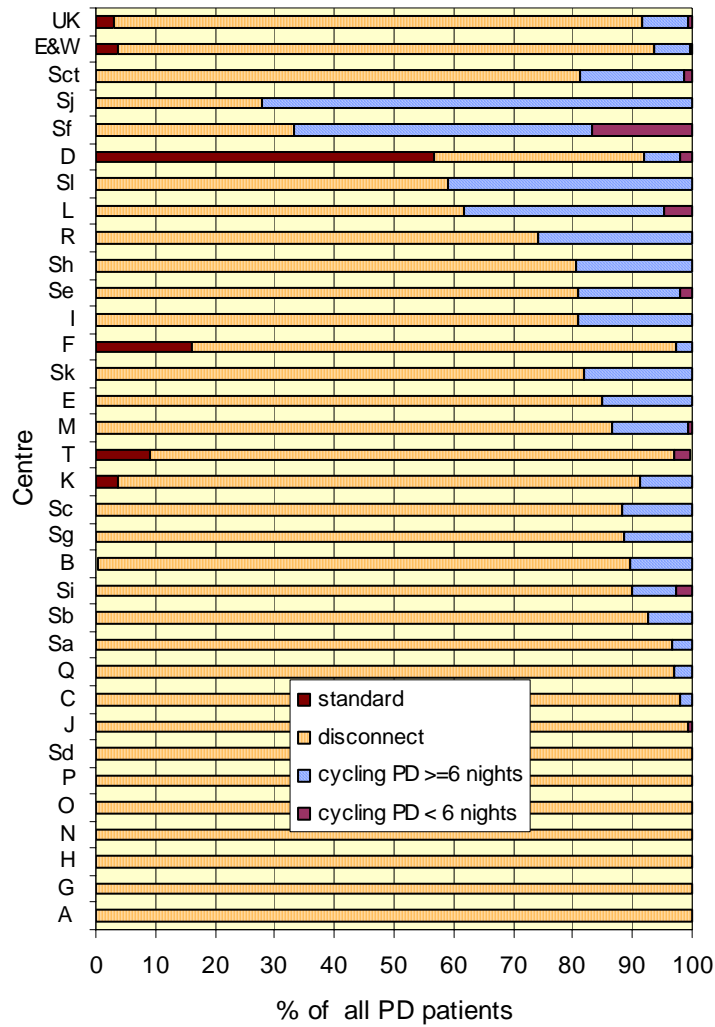
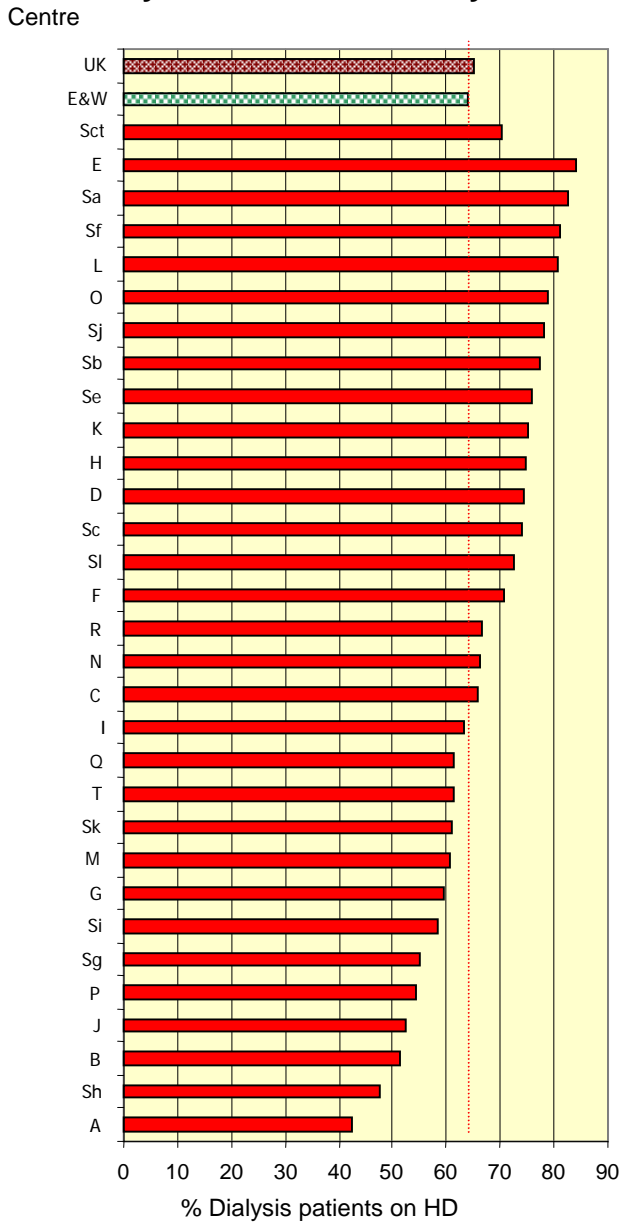


Figure 4.6 Peritoneal dialysis modalities

Haemodialysis

Figure 4.7 shows a wide variation in the proportion of patients treated by haemodialysis (almost two fold) which is not explained by age alone. Figure 4.8 demonstrates the limited role of home haemodialysis in most units, and the importance of satellite units in some.

% Dialysis Patients on HD by centre



% Dialysis Patients on HD by centre and by age

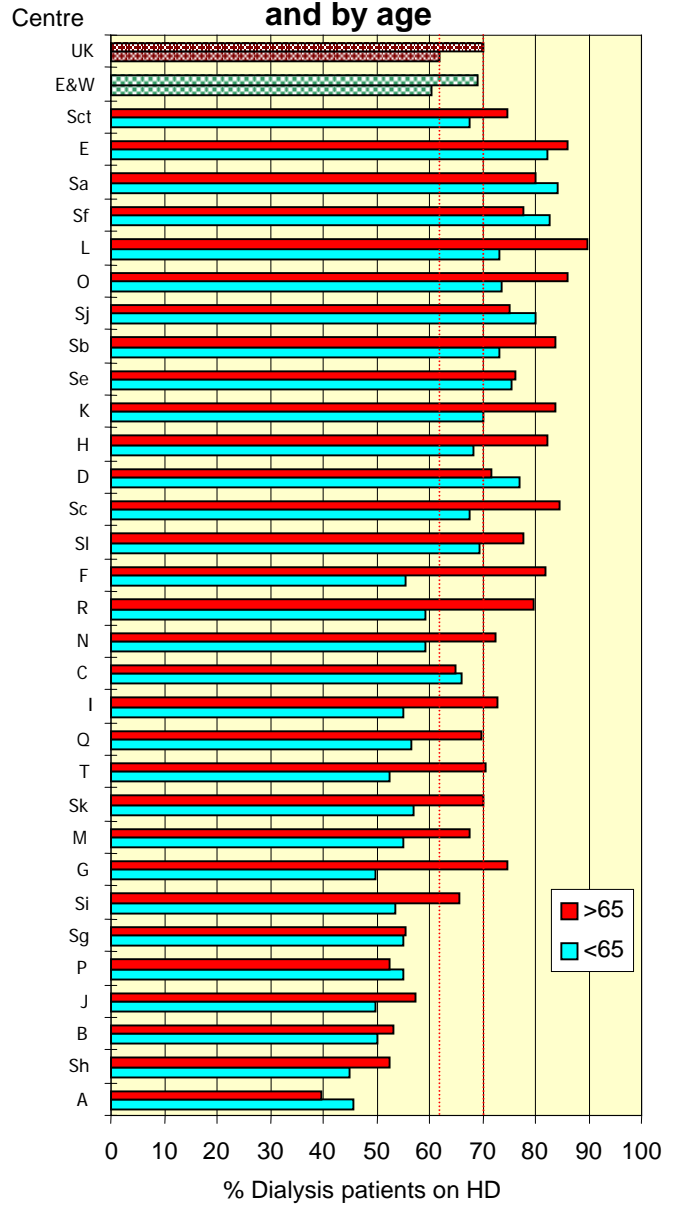


Figure 4.7 Percentage of dialysis patients on HD by centre and by age

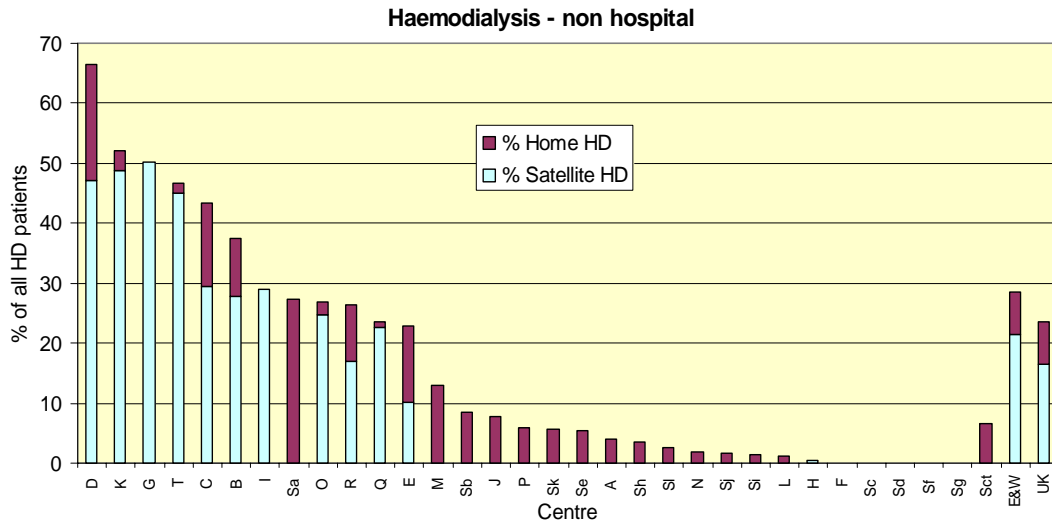


Figure 4.8 Percentage of HD patients on satellite and home HD

Change in treatment modalities 1997 – 98

As there are many more units included in this Registry report than previously figures for the total Registry are not directly comparable with last year. Trends can be identified from the 11 units participating in the Registry throughout 1997-1998. Tables 4.7 and 4.8 show that for these units the proportion of patients with a functioning transplant fell from 49% to 47%. This reflects an increase in the dialysis population rather than a fall in the transplant population. This is due to relatively static rates of transplantation, increasing rates of acceptance for RRT, and the increase in acceptance of older patients and others with more co-morbidity who are not suitable for transplantation. The absolute number of patients with a functioning transplant rose from 2654 to 2808 (2.5 % in 12 months).

	% HD Home	% HD Hospital	% HD Satellite	% HD Total	% PD standard	% PD Disconnect	% PD cycling	% PD Total	% with Transplant
1 st qtr 1997	3.5	22.3	7.9	33.7	1.5	14.9	0.9	17.3	49.0
1 st qtr 1998	3.3	22.8	8.6	34.7	1.5	14.5	1.4	17.4	47.9
4 th qtr 1998	3.1	23.5	9.3	35.9	1.1	14.4	1.5	17.0	47.0

Table 4.7 Proportion of patients with different modalities of RRT 1997 and 1998

	HD Home	HD Hospital	HD Satellite	HD Total	PD standard	PD Disconnect	PD cycling	PD Total	PD Transplant
1 st qtr 1997	187	1206	430	1823	81	807	51	939	2654
4 th qtr 1997	182	1291	479	1952	89	819	70	978	2739
1 st qtr 1998	192	1320	495	2007	87	840	81	1008	2772
4 th qtr 1998	184	1403	558	2145	66	862	88	1016	2808

Table 4.8 Number of patients with different modalities of RRT 1997 and 1998

The number of patients on home haemodialysis is static. There has been an increase in the number of patients treated at hospital and satellite haemodialysis units (a combined annual increase of 9.9%). The overall number of patients on PD has increased through

1997–1998 from 939 to 1016 (3.9 % in 12 months) although the rate of increase slowed during 1998. There was a reduction in the use of Standard CAPD in these centres.

Long term trends

Sequential figures on modalities of renal replacement therapy from the same population are not available. However reviewing data drawn from different sources (table 4.9) it is clear that haemodialysis is increasing as a proportion of total dialysis therapy.

	England		England and Wales			Scotland		
	1991	1995	1996	1997	1998	1991	1996	1998
% on haemodialysis	52	56	64	66	62	49	67	70

Table 4.9 Proportions of dialysis patients on haemodialysis, UK, 1991 – 1999

Survival on renal replacement therapy

The survival data below is for England and Wales only, with Scotland excluded from this analysis because of technical problems which occurred with the data during transfer between systems and was only highlighted during the analysis. The data presented are those on survival during 1998 of those patients alive on renal replacement therapy on 1/1/98. Patients who had been transplanted in the six months before 1/1/98 were excluded because post-operative mortality would distort the survival statistics for each modality.

	No. of patients	No patients died	Death rate (95% CI)	K-M 1 yr survival (95% CI)
Dialysis	4554	706	17.8 (16.5 - 19.1)	83.8% (82.6% - 84.8%)
Transplant	4853	121	2.6 (2.1- 3.1)	97.4% (97.0% - 97.9%)
Censored at dialysis				
Transplant	4853	141	3.0 (2.5 –3.5)	97.1% (96.6% - 97.5%)
Inc. dialysis return				

Table 4.10 Survival during 1998 of patients on RRT on 1/1/98

The analysis was repeated separately for patients aged under 65 on 1/1/1998 and for patients aged 65 or more on 1/1/1998 (table 4.11).

Age on 1/1/1998	No. of patients	No patients died	Death rate (95% CI)	K-M 1 yr survival (95% CI)
< 65	2695	253	10.6 (9.3 – 12.0)	89.9% (88.7% - 91.0%)
≥ 65	1859	453	28.5 (26.0 – 31.3)	75.2% (73.3% - 77.2%)

Table 4.11 Survival during 1998 of dialysis patients by age

At the English and Welsh units there were 35 patients who died in 1998 who were aged less than 35.

The one-year survival of diabetic and non-diabetic patients over 65 (table 4.12) was similar, although the confidence intervals are much wider for the smaller number of diabetic patients. However mortality was higher in diabetic than for non-diabetic patients in those under 65 years. Patients with no primary renal diagnosis have been excluded from the analysis.

Age	Primary Diagnosis	No. of patients	No. patients died	Death rate (95% CI)	K-M 1 yr survival (95% CI)
<65	Diabetic	362	65	21.3 (16.4 - 27.1)	80.5% (76.2% - 84.8%)
	Non-Diabetic	2279	182	8.9 (7.7 - 10.3)	91.4% (90.2% - 92.6%)
≥65	Diabetic	173	44	29.5 (21.5 - 39.6)	74.5% (67.9% - 81.0%)
	Non-Diabetic	1624	374	26.7 (24.1 - 29.6)	76.6% (74.5% - 78.7%)

Table 4.12 Survival during 1998 of dialysis patients by age and diagnosis

Age	No. of patients	No. patients died	Death rate (95% CI)	K-M 1 yr survival (95% CI)
<55	1527	85	6.2 (5.0 - 7.7)	93.9% (92.7% - 95.2%)
55-64	752	97	14.4 (11.7 - 17.5)	86.6% (84.1% - 89.1%)
65-74	979	194	22.9 (19.8 - 26.4)	79.7% (77.1% - 82.2%)
≥75	645	180	32.4 (27.9 - 37.5)	72.0% (68.6% - 75.5%)

Table 4.13 Survival during 1998 of non-diabetic dialysis patients by age

Statistical methodology of mortality analysis

Patients have been classified as ‘Scottish’ or ‘English or Welsh’ according to where they were receiving treatment on the 1/1/1998. Patients who moved from Scotland to England or Wales or vice versa, have therefore not been censored but have been classified according to where they were receiving treatment on the 1/1/1998.

Dialysis patients

$$\frac{\text{the number of deaths on dialysis}}{\text{the number of patient years at risk.}}$$

The mortality rate was defined as :-

It was calculated according to the following rules. Note that the number of patients years at risk is the sum of the number of days each individual patient was at risk of dying divided by 365 (the number of days in a year).

1. For patients who were transplanted, the number of days at risk is censored on the date of transplant i.e. patients are counted as at risk until they have their transplant.
2. For patients who transfer out, and do not transfer back into another Renal Registry Centre, the number of days at risk is censored on the date of transfer out.
3. For patients who transfer out, but transfer back into another Renal Registry centre on transplant, the number of days at risk is censored on the date of transfer out.
4. Patients are not censored if they transfer out, but transfer into another Renal Registry centre on dialysis. Similarly patients are not censored if patients transfer into another Renal Registry centre on 'treatment unknown' as it is assumed if the patient had a transplant then it would be recorded.
5. If patients die on the day of transplant, then the death is not counted, and the number of days at risk is censored on the date of transplant.
6. If a patient transfers out and has a transplant, then the patient is censored on the date of the first event.
7. Patients who died, received a transplant, or transferred out on the 1/1/1998 were included and were counted as being at risk for one day.
8. Patients who stopped treatment have not been censored, even if they did not die within the next few days.
9. The one year survival estimates were calculated using the Kaplan Meier method.

Transplant

The same rules were applied except survival was calculated both censoring at return to dialysis or by not censoring at return to dialysis

Comments

1. Compared with the 1998 Registry report the proportion of the population of the UK covered by the Registry has increased substantially from about 16% to about 43%. It is thus likely that any extrapolations made from Registry data in respect of the whole UK will be more accurate.
2. There were 1229 deaths in England and Wales 1998 compared with 1788 new patients. This leaves 549 additional patients being treated for ESRF, a 5.3% increase. This requires additional financial resources year on year even if the take on rate remains stable.

3. To enable the Registry to provide more meaningful data on prevalence of RRT in relation to local populations renal units will need to provide more complete data on ethnicity.
4. Although a diagnosis was given in most patients it is widely agreed that there is room for discussion of the definition of some categories– especially hypertension, vascular disease, pyelonephritis, outflow obstruction, and glomerulonephritis without biopsy.
5. For the centres on the Registry in 1997, there was an annual increase of **10%** in the number of **haemodialysis** patients, **4%** in **peritoneal dialysis** patients and **2.5%** in **transplant** patients providing an overall **5.3%** increase in the **total** number of patients on renal replacement therapy