ANNUAL REPORT 1999

The Norwegian Renal Registry

(Norsk Nefrologiregister)

This report will also be available on:
http://pc-33-85.his.no/Nyreforening/Uremiregisteret/1999.html

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Preface

The Norwegian Renal Registry (Norsk Nefrologiregister) was formally constituted in 1994 as a collaboration between The Norwegian Renal Association (Norsk Nyremedisinsk Forening) and The National Hospital (Rikshospitalet), with the latter as the formal owner. National data on renal replacement therapy (RRT) had been collected within The Renal Association since 1980 in a less formalised manner, and the transplant centre had data on transplanted patients since the sixties. Further, Norwegian renal units had reported to the ERA/EDTA-registry since the late sixties.
According to its statutes, The Norwegian Renal Registry shall combine the handling of data for all these purposes. It shall present national statistical reports and form a basis for research. Reports for 1995 and 1996 (in Norwegian) and 1997 and 1998 (in English) have been distributed, the latter two have also been made available on Internet.

National organisation and policy

Norway has 4.445 mill. inhabitants (Jan.1999) and 19 counties with populations ranging from 74000 to 502000. Each county, except one, has a central renal unit and some have additional unit(s) run in close contact with the central unit. There is only one transplant centre (two in 1963-83). Pre-transplant work-up, as well as post-transplant follow-up beyond 3 months, is handled by the county-centres.
Transplantation has always been considered the treatment of choice, if possible with a living related donor. Since 1984, also spouse donors have been used. Acceptance criteria for transplantation have been wide, strict age limits have not been applied. Over time, an increasing number of non-transplantable patients have also been offered life-long dialysis.

Incidence and prevalence calculations in this report are based on the national population data from Jan.1999, although this in some instances may be slightly misleading since population changes have not been uniform in all counties during the period.

Incidence figures for 1999

During 1999 a total of 395 new patients (in 1998: 401) entered renal replacement therapy (RRT), i.e. 88.9 per mill. inhabitants.
A majority of 68.0% were males and 32.0% females. Median age at start was 63.5 years, mean 59.7 years, ranging from three months up to 88 years.

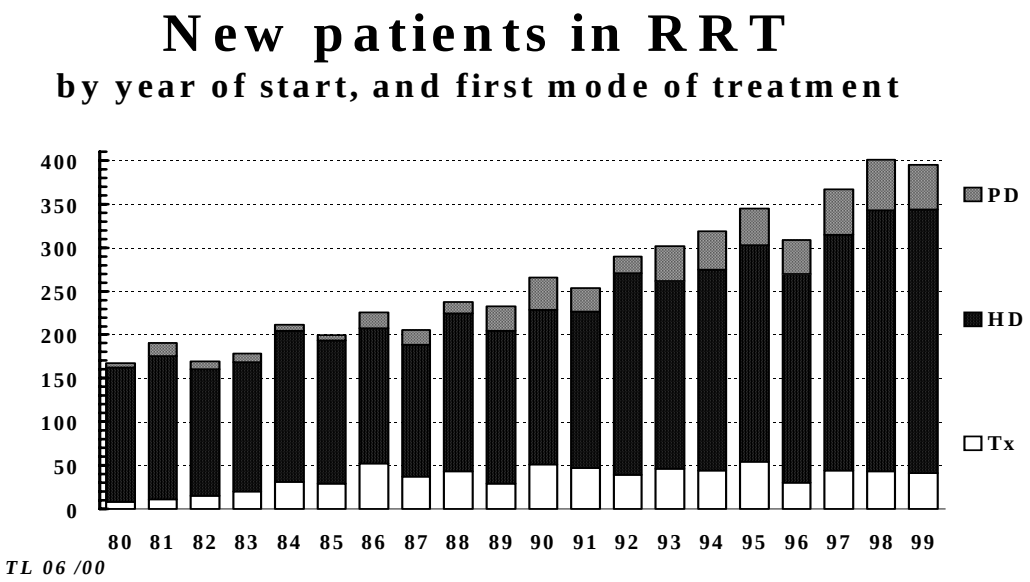
Tabulated by first mode of treatment, and age at start of treatment:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	0	7	17	25	41	52	89	72	303	76.7
PD	2	0	2	3	10	12	10	12	51	12.9
TX	2	1	14	7	10	6	1	0	41	10.4
Total	4	8	33	35	61	70	100	84	395	100
in %	1.0	2.0	8.4	8.9	15.4	17.7	25.3	21.3	100	

Among the PD-patients, 41 were registered with CAPD as first mode of treatment, 9 with CCPD/APD and one with IPD as first treatment.
At start of treatment, 280 (70.9%) were considered by their nephrologist to be a potential candidate for transplantation, while 115 (29.1%) were accepted for life-long dialysis (constituting 34% of those starting with HD and 22% of those starting PD).

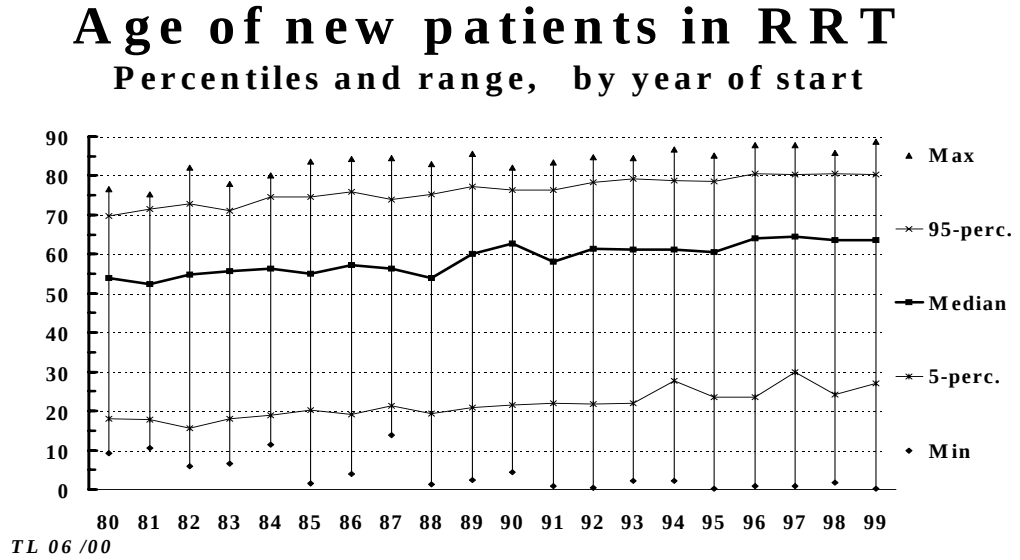
Among patients starting dialysis in 1999, 21% were previously unknown to the renal unit when they presented with terminal renal failure, 49% were known and started RRT as planned, while 30% were known but had a hastened RRT-start.

Incidence data: Changes 1980-1999



It appears from the figure that the incidence is still rising, during the nineties the mean yearly increase has been 5.9%.

Incidence data: Age at start



Since registration started in 1980 there has been a continuous shift in patient age. Both the maximum and the median age at start of RRT have increased. Also the 5-percentile and 95-percentile values (i.e. including the majority of patients) have increased with a similar number of years. At the same time, it appears that even younger children have been included. The number of children below 15 years has not changed during the period - it has ranged from two to eight per year.

Incidence data: Primary renal disease

	1980-84	1985-89	1990-94	1995-98	1999
Glomerulonephritis	34%	36%	31%	25%	23%
Pyelo/interstitial nephr.	16%	14%	11%	12%	10%
Polycystic diseases	10%	9%	9%	10%	5%
Diabetic nephropathy	13%	12%	12%	11%	12%
Amyloidosis	7%	6%	6%	4%	3%
Vascular/hypertensive	5%	8%	18%	22%	31%
Immunological	4%	5%	4%	6%	5%
Kidney tumour	1%	1%	1%	1%	1%
Myelomatosis	3%	2%	1%	3%	1%
Other defined	4%	4%	4%	2%	5%
Unknown	3%	3%	3%	4%	4%
N:	912	1106	1419	1421	395

The main change over time has been an increase of vascular/hypertensive nephropathy and a relative reduction of glomerulonephritis and pyelonephritis/interstitial nephritis. Whether this only reflects changed coding practice or a true shift is not known.

Diabetic nephropathy has contributed 10-14% per year. During most of the period no sub-classification has been registered. In 1999, 25 were registered as having Type I, 21 as Type II diabetes while in one patient diabetes was due to pancreatectomy. In addition 30 patients with other types of primary renal disease were recorded having diabetes as a co-morbid factor (1 Type I and 29 Type II), thus 20% of new patients were diabetics.

Cardiovascular disease is often present at start of RRT. Symptomatic heart disease was reported in 145; five out of these had a previous heart transplant. Cerebrovascular disease was reported in 40 and peripheral arteriosclerotic disease in 72 patients.

Prevalence data: Status by 31.dec. 1999.

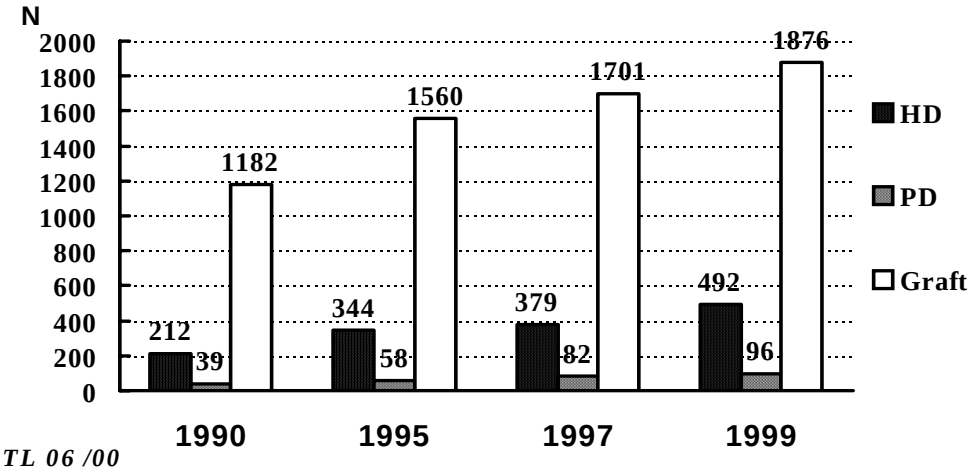
By the end of 1999, 2464 patients in Norway received renal replacement therapy, i.e. 554.3 per million inhabitants. This represents an increase of 146 patients or 6.3% since 1998.
Gender: 63.5% males and 36.5% females.
Median age by the end of the year was 54.4 years, mean 53.6 years and range 0.6-89 years.

Tabulated by last mode of treatment, and age by end of 1999:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	2	13	24	39	68	77	145	124	492	20.0
PD	1	1	3	14	14	20	22	21	96	3.9
TX	23	67	234	321	459	405	272	95	1876	76.1
Total	26	81	261	374	541	502	439	240	2464	100
In %	1.1	3.3	10.6	15.2	22.0	20.4	17.8	9.7	100	

Renal replacement therapy in Norway

Prevalence of treatment modes in 1990, -95, -97 and -99.



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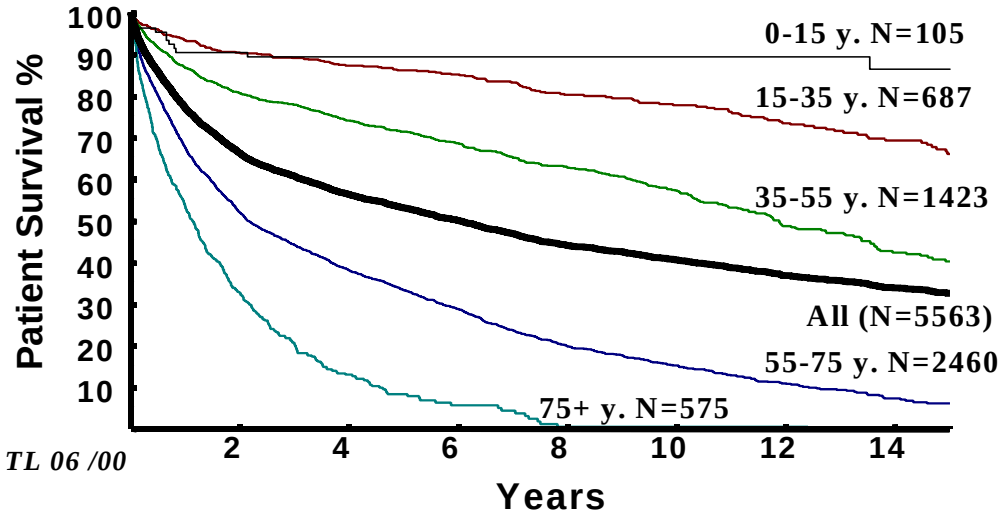
Patient survival on RRT:

Patient survival by June 2000 was calculated by Kaplan-Meier method for all patients starting RRT in the period 1980-99. As expected, the survival declined with increasing patient age. Among the youngest, all were considered potential graft recipients and 92% actually had got a graft, in the oldest age group 23% were considered potential recipients, but only 6% had received a graft.

Age-related survival on RRT.

All new pats. 1980-99, by age at start of RRT.



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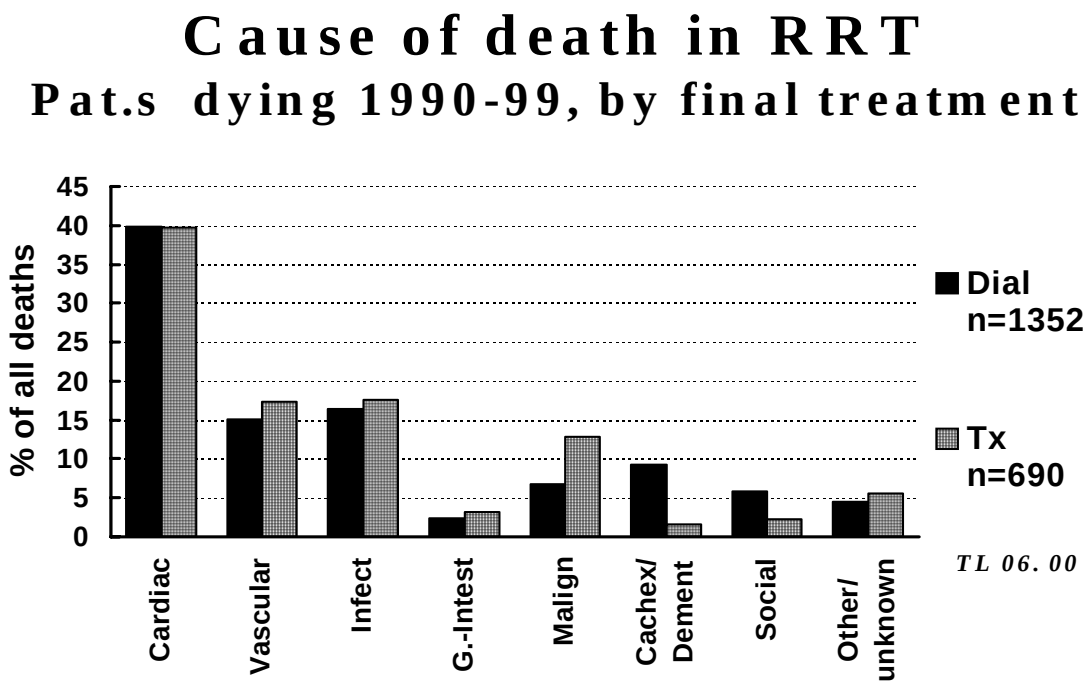
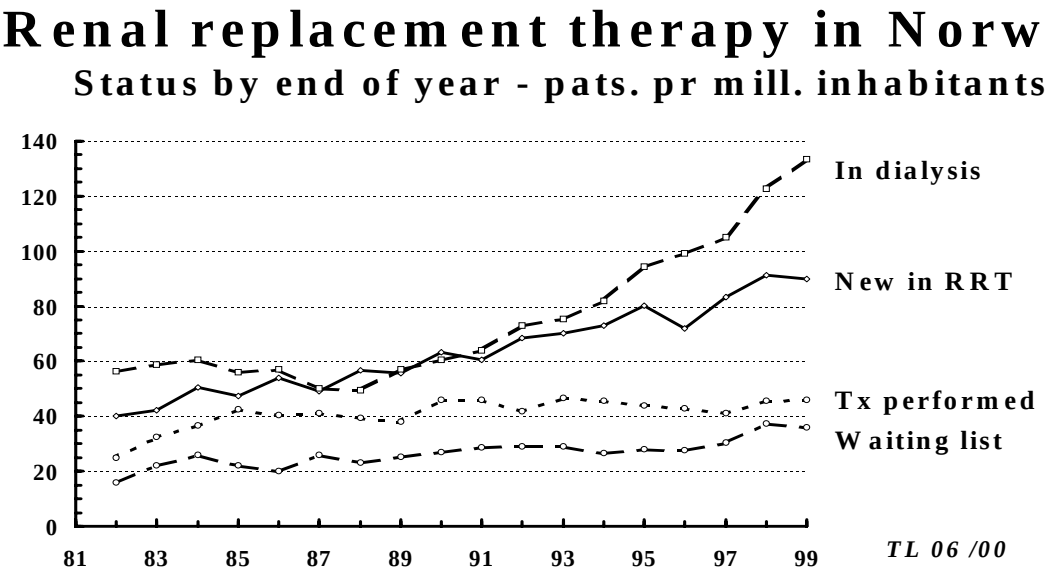
Death in RRT in 1999:

A total of 241 patients in renal replacement therapy died during 1999, i.e. 8.9% out of the 2713 persons at risk. Among these, 68% were males and 32% females. Median age at death was 73 years, mean 68.6 years and the range 7-88 years. Median time from start of RRT until death was 19 months, with a range spanning from one day to 26 years.
The final mode of treatment was HD for 156 patients and PD for 18, while 67 died with a more or less well-functioning graft. Four died within two months after graft loss, thus 71 deaths were termed 'TX-related'.
As in previous years, cardiac (39%) complications were the most frequent causes of death, followed by infections (18%), vascular complications (16%) and malignant tumours (9%).



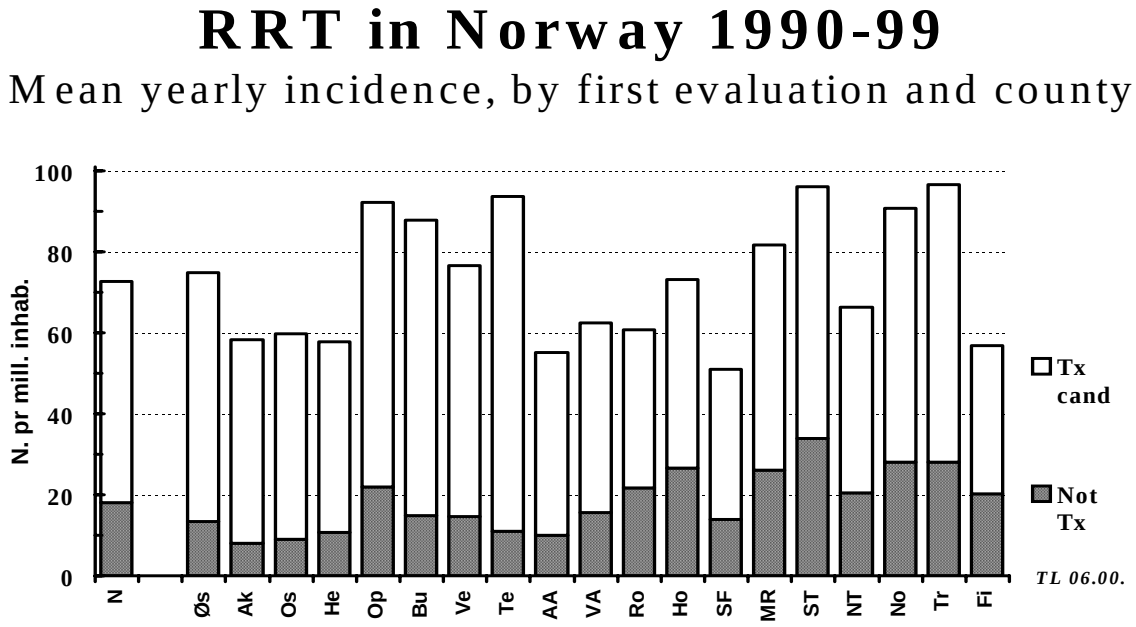
Transplantation and waiting lists:

A total of 204 renal transplants were performed at The National Hospital (Rikshospitalet) in 1999- i.e. 45.9 per million inhabitants. In 82 (40%) the graft came from a living related or spouse donor. 188 (92%) were first grafts.
By end 1999, 159 patients (35.8 per mill.) were on the active waiting list for a necro-kidney. This represented a decrease of 7 patients (4%) since 1998. Among those waiting by Dec.31, median time on the list was 7 months. 45% had waited less than 6 months, 69% less than one year and 92% less than two years. The 122 recipients given a necro-kidney in 1999 had a median waiting time of 11 months and a maximum of 78 months at the time of grafting. Among the 588 patients in dialysis treatment by Dec.31, 213 (36%) were for various reasons not considered candidates for a new renal graft.
A detailed analysis of renal graft survival and HLA-matching effects was printed in *Rev Immunogenetics 1999:1:343-350 (Leivestad T & al.).*



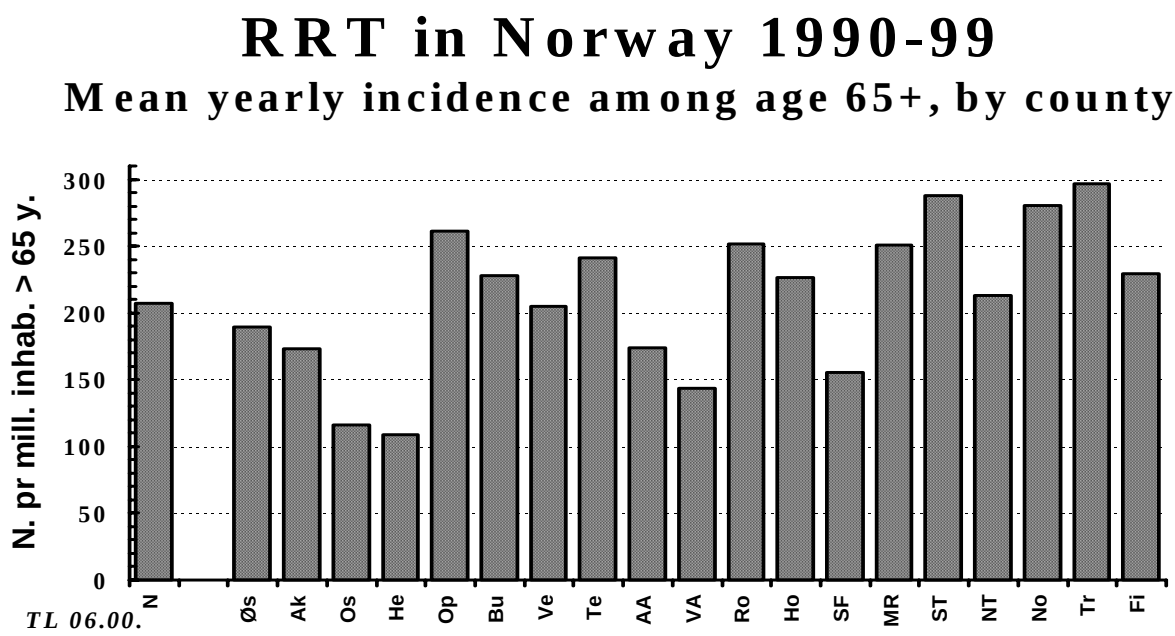
Regional differences within Norway

Incidence:
During all the years since data collection was started, the number of patients reported has differed substantially between centres, also after correction for population size. Further, the proportion of new patients not considered transplantable has varied. To illustrate this, patients were grouped by county of domicile at RRT-start, and incidence data were calculated as a yearly mean for the ten-year period 1990-99.



As appears the incidence of RRT-start varied from 51 to 97 pr. million and year. In general, counties with the highest incidence also reported the highest proportion of non-transplantable patients. This proportion varied from 12% to 36%, with a national (N) mean of 25%.

Last year we reported that the proportions of elderly patients accepted for RRT seemed to vary considerably between the counties. Based on official population statistics (Jan. 1999), the mean yearly incidence of RRT-start among all citizens above the age of 65 in the respective counties, as well as the national mean, was calculated.



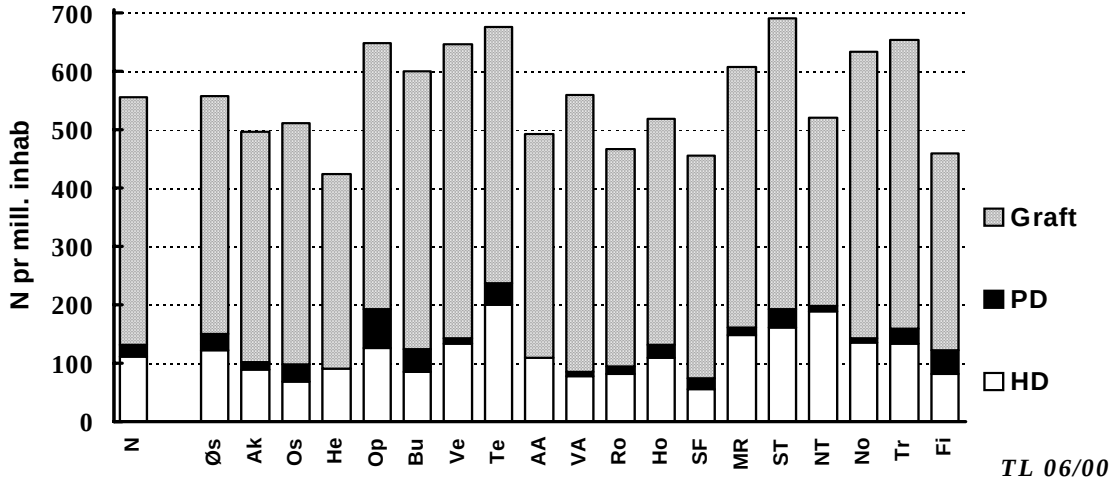
Considerable variations of incidence were seen. Among possible explanations are geographically different attitudes towards treatment among the public or the professionals, or different incidence of terminal renal failure. Distance seems not to be a factor; the most urbanised counties do not have a higher incidence.

The proportion of the new patients in 1999 who first presented in the renal unit with a terminal renal failure varied considerably between counties – from less than 5% and up to 50%. This would indicate that in most counties there might be a need for improved co-operation within the health service.
Identification and evaluation of transplant candidates in pre-terminal phase could facilitate pre-emptive transplantation, thereby reducing the need for dialysis. In the period 1990-99, approx. 18% of those considered potential candidates for transplantation at start of RRT were grafted without preceding dialysis (‘pre-emptive’). The corresponding figures for each centre varied from a low 8% to a high 36%, indicating that in many counties there may be a considerable potential for improvements.

Prevalence:
Again, the data (fig. on next page) demonstrate great differences between the counties. In all counties the majority of patients have a functioning graft, constituting from 62% to 85% of the total RRT-population. The dialysis prevalence ranges from 74 to 237 per mill. inhabitants in the counties, indicating great differences in workloads and costs. In some counties, two out of three dialysis patients are not considered candidates for a new graft, in others this applies only to 10-15%. But counties with high dialysis prevalence do not necessarily have a high prevalence of ‘non-transplantable’.

RRT in Norway by end of 1999

Prevalence, by treatment mode and county



Peritoneal dialysis is used by a minority of Norwegian patients. Only 13% of new patients started with PD as first mode of treatment, giving an incidence of 11 per mill. The national prevalence was 22 per mill. The Swedish 1999-figures show that 28% of all new RRT-patients (33 per mill.) started with PD; the prevalence by the end of 1999 was 81 per mill. In Denmark 25% of all new patients in 1999 (31 per mill.) started with PD, the prevalence of PD was 104 per mill.

In four of the Norwegian counties no patient received PD as first treatment mode in 1999. At the end of the year, PD was not applied at all in two counties. Even the highest county prevalence of 66 per mill. is relatively low. Contrary to what might have been expected, PD is not more widespread in counties with the longest travel distances.

Future development:

The data indicate a that the number of RRT-patients will continue to increase in the coming years. Unless a corresponding rise in kidney donation (living and necro-donors) is achieved, the number of patients in dialysis will rise and they will constitute an increasing proportion of the RRT-population.

Compared to the Swedish and Danish RRT-incidence (respectively 120 and 121 per million in 1999) and prevalence (respectively 693 and 604 per million), Norwegian numbers still are low. There are no clear reasons for such a difference between these nations that are so similar in most respects. Therefore, the Norwegian health service needs to prepare for accommodating a significantly increased number of RRT-patients in the near future.

Report completed 30.06.2000
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