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The
Norwegian Renal Registry

(Norsk Nefrologiregister)

This report will also be available on:
http://www.nephro.no/registry.html

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Preface

The Norwegian Renal Registry (Norsk Nefrologiregister) was formally constituted in 1994 as collaboration between The Norwegian Renal Association (Norsk Nyremedisinsk Forening) and Rikshospitalet University Hospital, 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 stored data on transplanted patients since the sixties. Further, Norwegian renal units had reported to the ERA-EDTA-registry since the late sixties.

During the recent years a process of transition from a pure epidemiological registry into a quality-oriented registry has been initiated. Some results from this have appeared in the latest annual reports. With the present way of collecting and processing quality data, they can not be collected in time to be included in the annual report. They will instead be the theme for yearly quality-seminars and for special reports.

National organisation and policy

Norway has 4.660 mill. inhabitants (July 2006) and 19 counties with populations ranging from 73000 to 533000. 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 during 1963-83). Pre-transplant work-up, as well as post-transplant follow-up beyond 3 months, is handled by the county-centres.

The county-centres are responsible for reporting data from day 1 on all patients receiving renal replacement therapy (RRT) for chronic renal failure within their area. Treatment of acute renal failure is not reported unless the failure turns out to be irreversible, in which case the whole treatment period is included. Minor changes of treatment modality, e.g. from HD to HDF or between CAPD and APD, are not reported. Similarly, temporary changes to HD for PD-patients are not reported. At intervals, cross-checking for unreported deaths is performed against official census data.

Transplantation has always been considered the treatment of choice, if possible with a living related donor. Since 1984, also unrelated 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 July 2006, 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 2006

During 2006 a total of 464 new patients (in 2005: 459) entered renal replacement therapy (RRT), i.e. 99.6 per mill. inhabitants.

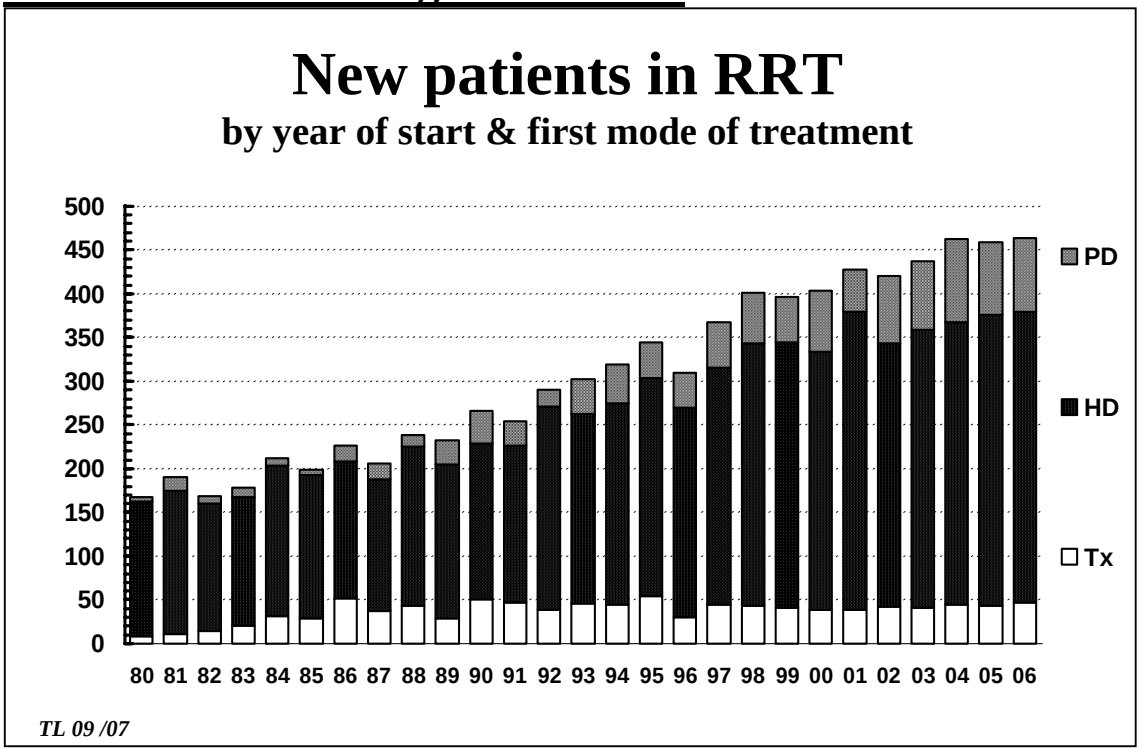
A majority of 66.9 % were males and 33.1 % females. Median age at start was 67.0 years, mean 64.0 years, ranging from 2.9 to 93.3 years.

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

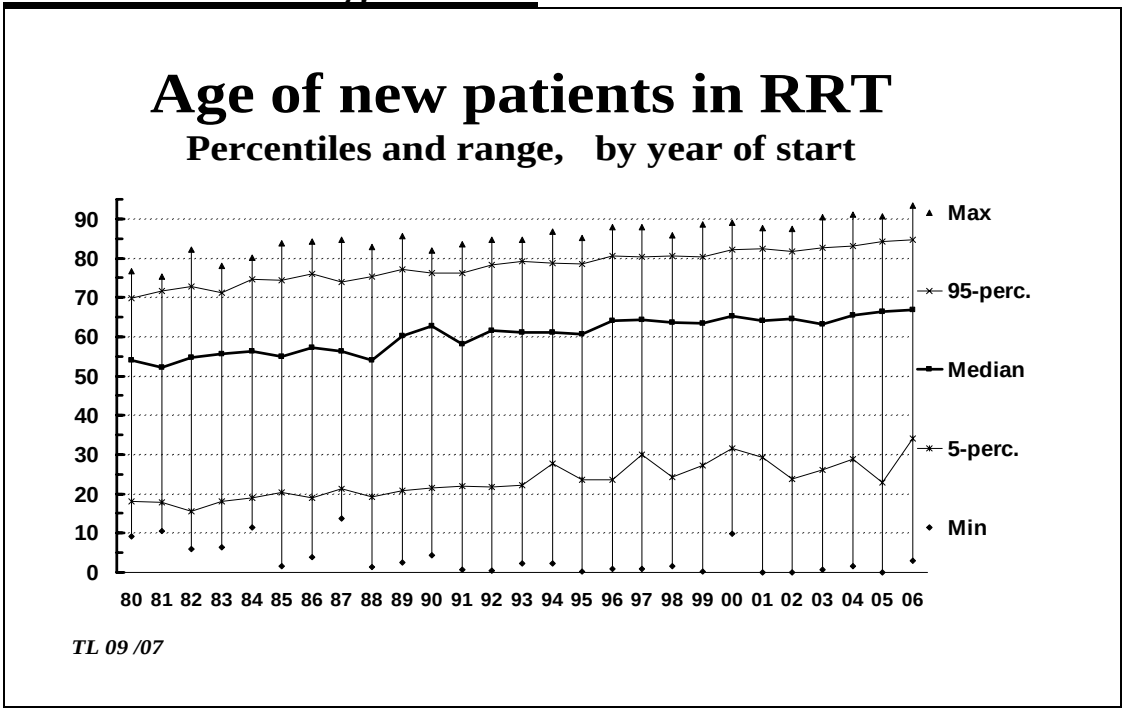
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	1	1	11	22	31	68	83	115	332	71.6
PD	1	2	2	5	9	21	22	23	85	18.3
TX	3	3	3	10	10	8	10	0	47	10.1
Total	5	6	16	37	50	97	115	138	464	100
in %	1.1	1.3	3.4	8.0	10.8	21.1	24.7	29.7	100	

At start of treatment, 288 (62.1 %) were considered by their nephrologist to be a potential candidate for transplantation, while 176 (37.9 %) were accepted for life-long dialysis (constituting 45 % of those starting with HD and 31 % of those starting PD).
Among patients starting dialysis in 2005, 75 % had been under control by the renal unit for at least four months, while 25 % were previously unknown.

Incidence data: Changes 1980-2006



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. But also smaller children have been accepted; the youngest ever started PD in 2005 at age 13 days. Five children below 15 years started RRT in 2006; after the record of 12 in 2005 we seem to be back to the previous range between two and ten per year.

Incidence data: Primary renal disease

	1980-89	1990-94	1995-99	2000-04	2005	2006
Glomerulonephritis	35%	31%	24%	18%	19%	20%
Pyelo/interstitial nephr.	16%	11%	11%	11%	8%	8%
Polycystic diseases	10%	9%	9%	9%	7%	8%
Diabetic nephropathy	13%	12%	11%	15%	13%	16%
Amyloidosis	6%	6%	4%	3%	2%	2%
Vascular/hypertensive	7%	18%	25%	29%	32%	30%
Immune/systemic	5%	4%	5%	4%	3%	5%
Kidney tumour	1%	1%	1%	1%	1%	2%
Myelomatosis	2%	2%	2%	3%	3%	2%
Other defined	4%	4%	3%	4%	6%	1%
Unknown	3%	3%	4%	4%	6%	5%
N:	2019	1418	1817	2149	459	464

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

Diabetic nephropathy has contributed 10-15% per year. Until 1995 sub-classification was not reliably registered. In 2006, 24 were registered as having Type I and 52 as Type II diabetes. In addition 59 patients with other types of primary renal disease were recorded having diabetes as a co-morbid factor (one was Type I and 58 Type II), thus 29% of new patients were diabetics.
The time from onset of diabetes to start of RRT differed considerably. For the 24 with Type I diabetes the mean time was 33.6 years, for the 52 with Type II diabetic nephropathy the mean time was 14.7 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy in mean had 8 years of diabetes duration.

Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 148 (32%); another two had a previous heart transplant. Left ventricular hypertrophy was reported in 106 (23%). Cerebrovascular disease was reported in 56 (12%) and peripheral atherosclerotic disease in 82 patients (18%).

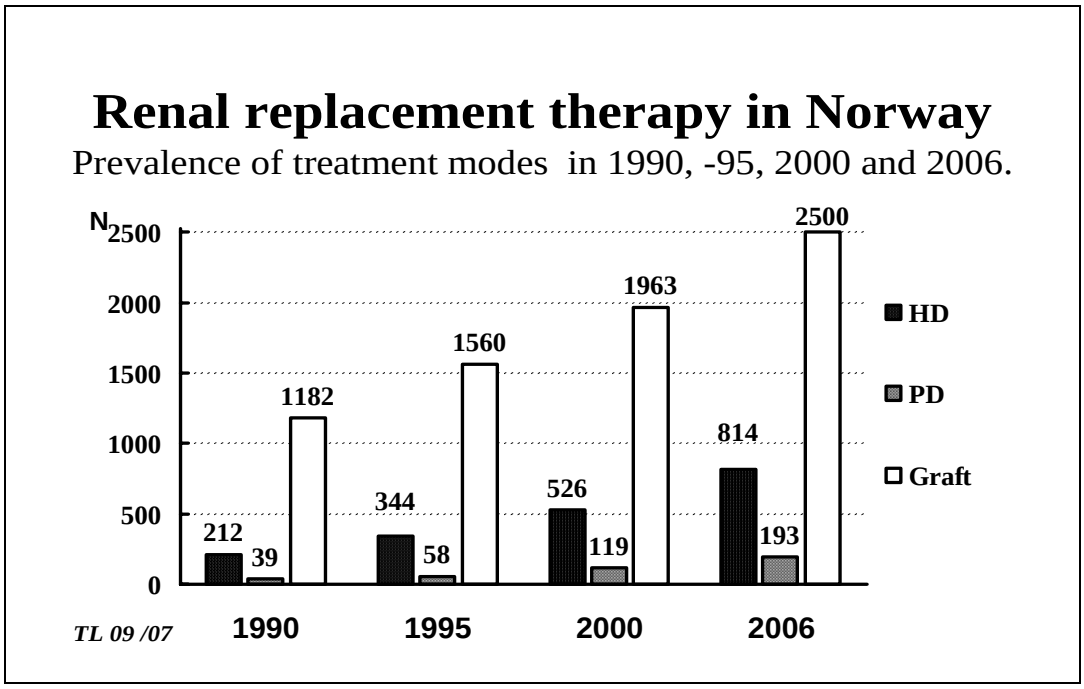
Prevalence data: Status by 31.dec. 2006.

By the end of 2006, 3507 patients in Norway received renal replacement therapy, i.e. 752.5 per million inhabitants. This represents an increase of 124 patients or 3.7 % since 2005.
Gender: 64.3% males and 35.7% females.

Median age by the end of the year was 58.5 years, mean 56.9 years and range 1-93.6 years.

Tabulated by last mode of treatment, and age by end of 2006:

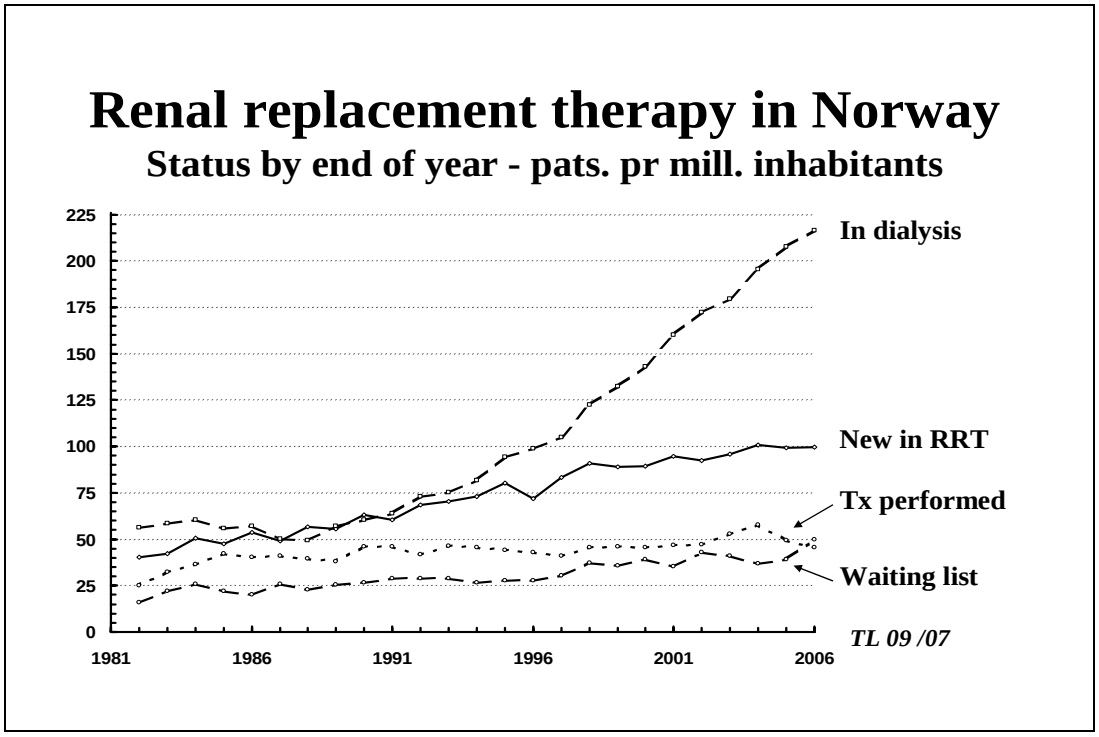
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	3	10	36	65	78	152	171	242	57	814	23.2
PD	0	2	12	16	21	39	38	57	8	193	5.5
TX	42	76	187	403	540	653	433	158	8	2500	71.3
Total	45	88	235	484	639	844	642	457	73	3507	100
In %	1.3	2.5	6.7	13.8	18.2	24.1	18.3	13.0	2.1	100	



Transplantation and waiting lists:

A total of 212 renal transplants were performed at Rikshospitalet University Hospital in 2006, i.e. 45.7 per million inhabitants. In 80 (38%) the graft came from a living donor (LD), 20 of those were biologically unrelated to the recipient (17 were spouses). Among the LD-graft recipients 27 out of 68 first graft recipients were grafted pre-emptively, three out of 12 re-graft recipients did not receive dialysis. 132 patients received a deceased donor (DD) graft, 22 out of the 112 first graft recipients were pre-emptively transplanted (20 %), while two out of 20 had a re-graft without entering dialysis. There were 180 first grafts (68 LD and 112 DD), 28 were second grafts (10 LD, 18 DD), three third grafts (2 LD, 1 DD), and one fifth graft (DD). Simultaneous kidney + pancreas transplantation was performed in six. Among patients with a functioning kidney graft two received one or more doses of isolated Langerhans Islet cells.

In principle, transplantation is offered to all patients considered to profit from it, with no strict upper or lower age limit. The age of the 112 first DD-graft recipients in 2006 ranged from 13 to 82 years, with a mean age of 58.1 y. Out of these, 33 % were above the age of 65 and 8 % were 75 or older. The 68 recipients of a first LD-graft were from 1 to 73 years, mean 44 y. Regraft recipients (n=32) were from 2 to 75 years, mean 46.4 y.



By end 2006, 232 patients (50.0 per mill.) were on the active waiting list for a DD renal graft. This represented an increase of 52 patients (29%) since 2005. Among those waiting by Dec.31, median time on the list was 9 months. 33 % had waited less than 6 months, 60 % less than one year and 15 % more than two years. The 132 recipients given a DD-graft in 2006 had a median waiting time of 9 months and a maximum of 91 months at the time of grafting. Among the 1007 patients in dialysis treatment by Dec.31, 501 (49.8 %) were for various reasons not considered candidates for a new renal graft.

Quality measures in RRT.

A: New patients in 2006 – status at start of RRT.

A total of 464 patients started RRT in 2006. Among the 332 starting haemodialysis, the access was via catheter in 228 patients (69%), while 31% had AV-fistula or graft (1 case) access.

Status at start of RRT	Total (n:464)	HD (n:332)	PD (n:85)	Tx (n:47)
Creatinine (mean)	658 mmol/l	673	672	533
GFR (mean), by MDRD formula	9.0 ml/min	8.6	8.4	12.5
Albumin, mean	35 g/l	34	37	42
Haemoglobin, mean	11.0 g/dl	10.7	11.6	11.9
Haemoglobin - % <11	48 %	57 %	34 %	13 %
ESA use	63 %	60 %	81 %	55 %
Active D vitamin use	59 %	56 %	65 %	68 %
Statin use	50 %	49 %	53 %	45 %
Not on antihypertensive drugs	10 %	12 %	5 %	0
Using >2 antihypertensive drugs	48%	49 %	49 %	40 %

As might be anticipated, pre-emptively transplanted patients had a somewhat lower serum creatinine, thus higher GFR, and a higher haemoglobin and albumin than those starting dialysis.

B: Prevalent RRT patients by end of 2005.

Once a year, the registry collects data on a set of treatment details and quality measures for all patients in RRT. Data for the treatment year 2006 is not completed and will be part of the next annual report. Instead data from 2005 will be shown.
Status data were requested for all dialysis patients who had been on RRT for at least one month by 31.Dec.2005, the return was 100%. Similarly, data were requested for all patients with a functioning graft except those transplanted during September to December 2005. The return rate was above 99%.
HD-access: 48 % of the HD patients had a functioning AV-fistula; additionally 2 % had a graft, while the remaining 48% were dialysed via catheter. In 2004 46 % used catheter, thus there was no improvement in AV-fistula usage. Such data were not collected previously.

Anaemia control: Among prevalent dialysis patients, 23 % were below the target Hgb level of 11 g/l. while 25 % were above the proposed upper limit of 13 g/l. ESA was used by 88 %, including most patients with Hgb > 12. In general, transplanted patients had higher Hgb; only 7 % were using ESA.

	< 9 g/l	9-11 g/l	11-12 g/l	12-13 g/l	13-15 g/l	> 15 g/l
HD	3 %	23 %	24 %	29 %	20 %	2 %
PD	3 %	7 %	24 %	27 %	37 %	3 %
Tx	0.5 %	5 %	14 %	22 %	45 %	15 %

Comparing the dialysis centres, the best one had 80% of their dialysis patients within the range 11-13 g/l, the poorest had less than 40% within that range.

Blood pressure control: A majority of patients use antihypertensive medication; only 23 % of dialysis patients and 21 % of patients with functioning graft do not. Among dialysis patients, 19 % use 3 or more antihypertensive drugs; this is also the case in 15 % of the transplanted.

	BP ≤ 130/80	BP 131-140/81-90	BP > 140 and/or > 90
Dialysis patients	51 %	4 %	45 %
Transplanted patients	66 %	12 %	22 %

Also here a considerable variance between centres could be seen. In the best performing dialysis centre 82% of patients had BP 130/80 or lower, while others only obtained such control in 35%. The fraction of well controlled Tx-patients varied between 84 and 41 %.

Among tx-patients, 42% of those not using calcineurin inhibitors (CNI) were also not taking antihypertensive medication, this applied to 19 % of CNI users. The observed blood pressure in these two groups was similar, even though the CNI-users were significantly younger.

Phosphate control: 87 % of dialysis patients were reported to use phosphate binders, 32% using calcium-containing, 31 % using calcium-free and 24% using a combination of the two. Approximately 60 % had serum phosphate < 1.8 mmol/l.; the control was better among those not using binders. It also seemed that control was poorest among those given the combination.

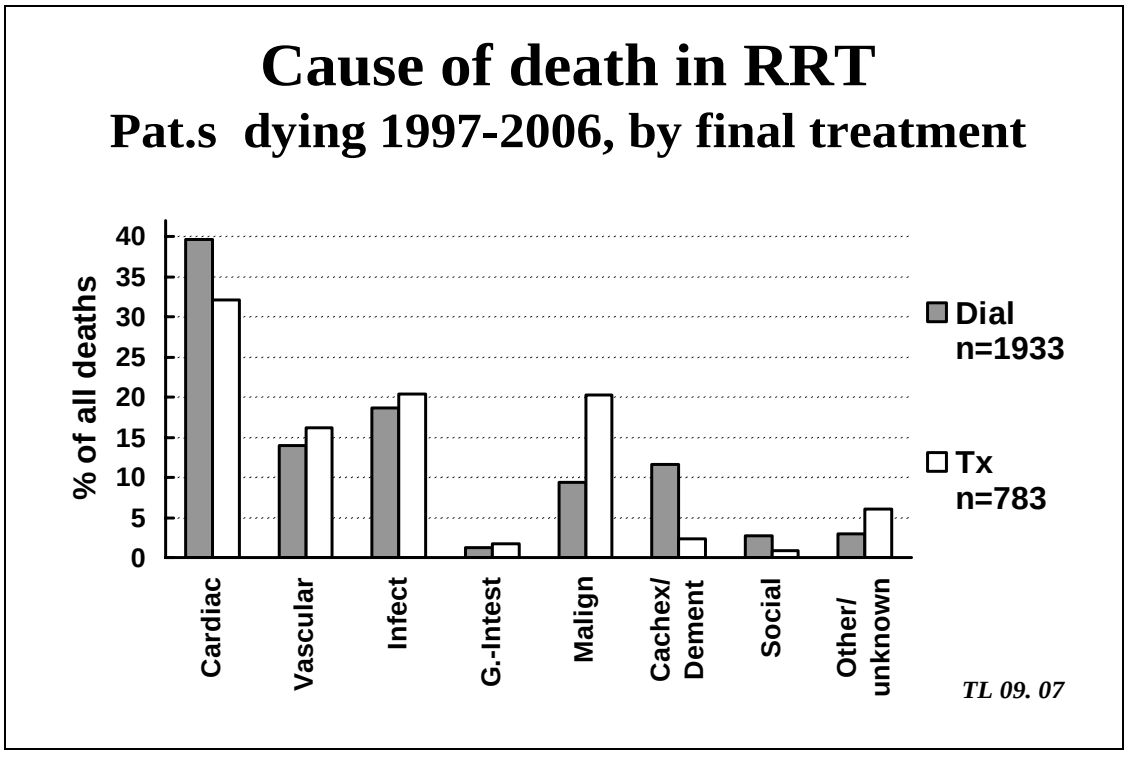
Immunosuppressive drugs: Based on the received 2005-forms, more than 90 % used a calcineurin inhibitor (CNI), near 75% used cyclosporine and 16% tacrolimus. Most also used an anti-proliferative agent, 31% used azathioprine, 42 % used mycophenolate-mofetil (MMF), and 2.5 % used mycophenolic acid (MPA). A minority used an m-TOR inhibitor; approximately 2 % used sirolimus and 2 % evrolimus. Some 2 % were steroid-free, 76 % used

less than 5 mg/day and less than 8% used 10 mg/d or more, most of them were transplanted before 1983 and were without CNI.

Graft function: Using the MDRD formula, GFR was calculated in all (without corrections for the few paediatric recipients). In 1 % GFR was below 15 (stage 5), in 9.9% between 15 and 30 (stage 4), 48.5% were in the range 30-60 (stage 3), 33.7 % were between 60 and 90 (stage 2), while 6.9% had GFR of 90 or greater. There was a different distribution among CNI-users and those not using CNI, mainly consisting of relatively more in stage 2 and fewer in stage 3 among those not using CNI (p: 0.025, Wilcoxon)

Death in RRT:

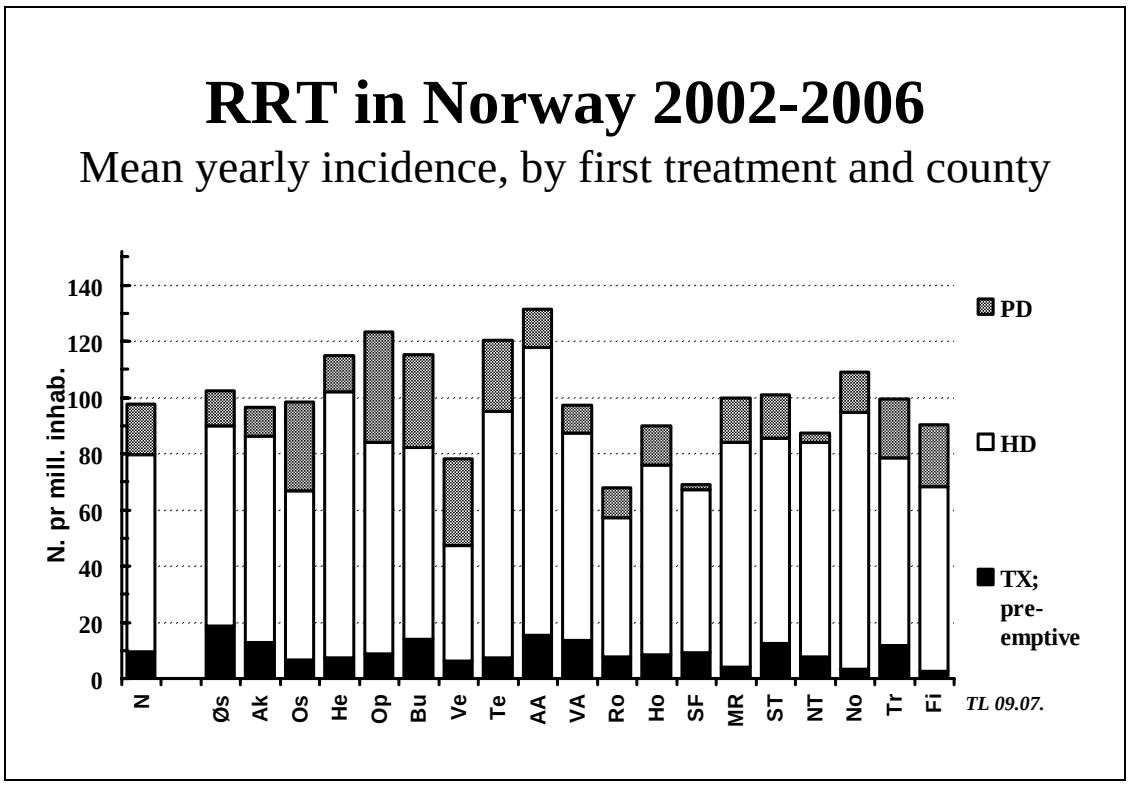
A total of 318 patients in renal replacement therapy died during 2006, i.e. 8.5 % out of the 3747 persons at risk. Among these, 71% were males and 29% females. Median age at death was 75 years, mean 71.8 years, and the range 23-91 years. Median time from start of RRT until death was 35 months, with a range spanning from ten days to 29 years.
The final mode of treatment was HD for 227 patients and PD for 21, while 70 died with a more or less well-functioning graft. Four died within two months after graft loss; thus 74 deaths were termed 'TX-related'. Dialysis treatment was terminated and followed by death in 41 patients, in six of those the patient refused further treatment.
As in previous years, cardiac (36%) complications were the most frequent causes of death, followed by infections (22%), malignant tumours (14%), and vascular complications (13%). The following figure illustrates the cumulated data from the latest ten-year period.



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 first mode of treatment (HD, PD or pre-emptive transplant) for new patients differs considerably. In the following figure, patients were grouped by county of domicile at RRT-start and the incidences were calculated as a yearly mean for the five-year period 2002-2006:



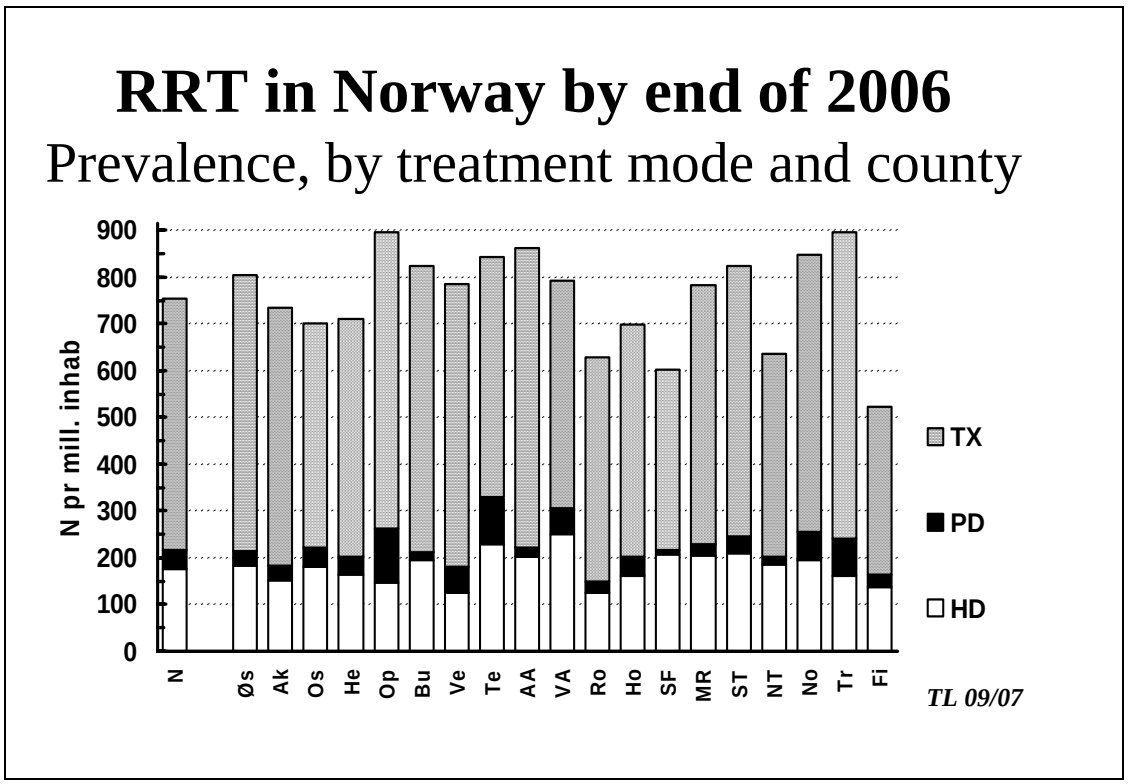
As appears, the mean yearly incidence of RRT-start varied from 68 to 132 pr. million. Compared to last years figure, one may see that Rogaland now has the lowest mean incidence. With the rather small population in most counties, figures may be expected to change from year to year, but over years there has been a lower incidence in the west-coast counties.

Although there is national consensus that pre-emptive transplantation is preferable, this was only achieved in 10 %; in the individual counties this figure ranged from 3 % (Finmark and Nordland) to 18 % (Østfold).
In some counties PD is rarely used, in others up to 40 % of new patients have this as first treatment mode. 72 % received HD as first treatment mode, in the counties this ranged from 52 % to 88 %.

The proportion of the new patients in 2006 who started dialysis without having been known by the renal unit for at least 4 months was 27 %, with wide variations between centres; from 8% in one centre and up to 50 % at highest. In the majority of these cases the diagnosis would imply that renal failure has developed gradually over years. Over the years, these figures seem not to have improved significantly; thus in most counties it seems to be need for improved co-operation within the primary health service in order to achieve more early referrals.

We have previously reported marked centerwise differences in the age distribution of incident patients. In 2006 mean age of new patients in the different counties ranged from 58 to 71 years, i.e. less variation than in 2005. The huge variation in age-specific incidence between counties was latest shown in the 2004 report.

Prevalence:
Again, the data demonstrate great differences between the counties. In all counties the majority of patients have a functioning graft, constituting from 61% to 77% of the total RRT-population. The dialysis prevalence ranges from 150 to 331 per mill. inhabitants in the counties, indicating considerable 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 to 25-30 %. But counties with high dialysis prevalence do not necessarily have a high prevalence of 'non-transplantable' patients.

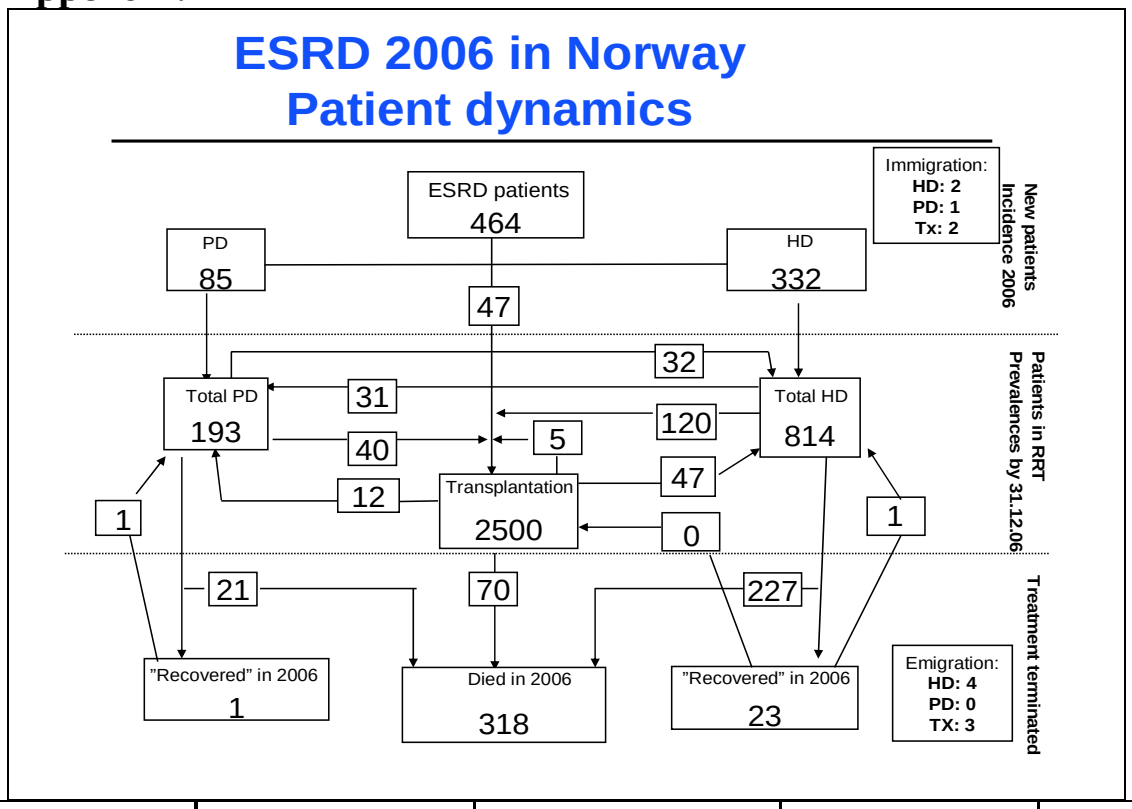


Concluding remarks:

The incidence of chronic renal failure over the last few years seems to have levelled off. With an increased survival rate (see the 2004-report), a markedly increased prevalence of RRT-patients can nevertheless be expected over the coming years. Marked county differences may also indicate that in some areas there still is under-treatment; if so, we can still expect further increased national incidence. The high transplantation rates achieved in the later years may have retarded the yearly increase in dialysis prevalence somewhat. It is not obvious that the supply of organs for transplantation will rise further; in 2006 it fell by 7 % compared to 2005 and it may even decrease further. Thus, the number of patients in dialysis will probably still rise and they will constitute an increasing proportion of the RRT-population.
Comparing our data on the quality of RRT with updated international guidelines, it seems that there still is room for improvement. Registry data will over the coming years be used for comparisons between the centres to a greater extent than has been the case. Hopefully, the registry can in this way be an instrument for improved RRT quality and thus benefit the patients who have consented to have their data included in the registry.

Report completed 17.10.2007
Torbjørn Leivestad M.D.

Appendix:



		New pat in 2006				Pat. in RRT pr 1/1.2007				Dialyses etc in 2006			Died		
	Satellites	HD/HDF	PD	Pre-emptivel	Total	HD/HDF	PD	Graft	Total	HD-sessions	Pl.exch.	Other	Dial.pat.	Tx-pat.	Not tx-candidate
Tromsø	4	13	3	1	17	29	15	108	152	4958	73	0	10	3	22
Harstad		3	0	0	3	9	0	37	46	1253	0	0	2	0	6
Bodø	6	17	6	0	23	41	13	119	173	6583	22	133	8	3	28
Levanger	3	11	1	3	15	24	3	51	78	3181	32	8	12	3	16
Trondheim	4	20	5	1	26	60	10	177	247	9360	260	489	17	5	43
Ålesund	2	18	4	0	22	49	6	126	181	7687	16	0	15	5	39
Førde	1	9	0	2	11	21	1	35	57	2998	63	10	6	1	14
Bergen	1	29	7	4	40	66	18	208	292	9819	165	66	23	6	46
Stord/Hauges.	1	7	3	2	12	23	8	56	87	3818	33	9	6	4	13
Stavanger		12	1	4	17	35	3	158	196	5596	91	51	8	5	15
Kristiansand	1	15	1	2	18	42	9	82	133	6226	25	0	9	3	31
Arendal		9	0	2	11	21	2	63	86	3404	5	45	8	2	15
Skien	1	11	4	1	16	37	17	85	139	6041	22	108	14	4	24
Tønsberg		7	3	2	12	29	9	130	168	4478	92	0	11	5	16
Hønefoss(new)	1					12	0	33	45	1371	0	0			7
Drammen	1	19	5	4	28	36	7	108	151	4665	25	0	17	3	15
Lillehammer	2	10	10	1	21	30	22	109	161	4435	25	0	14	2	28
Elverum		17	2	0	19	27	5	87	119	4473	0	21	11	4	15
Fredrikstad	1	20	3	6	29	48	8	153	209	7504	35	0	11	3	16
AHUS		29	9	4	42	51	13	133	197	7680	0	0	8	2	28
Ullevål		38	17	1	56	98	24	238	360	13953	62	0	27	8	50
RH		18	1	7	26	26	0	204	230	4735	294	72	7	3	14
SUM		***332***	***85***	***47***	***464***	***814***	***193***	***2500***	***3507***	***124218***	*1340*	*1012*	***244***	***74***	***501***
- Pr. mill inh.		*71,2*	*18,2*	*10,1*	*99,6*	*174,7*	*41,4*	*536,4*	*752,5*	*+ 4,9 % from 2005*					*107,5*
% of total		*71,6*	*18,3*	*10,1*	*100*	*23,2*	*5,5*	*71,3*	*100,0*						*49,8*