

DANSK NEFROLOGISK SELSKAB

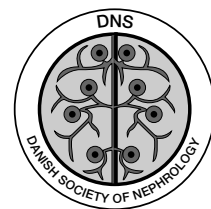


*Landsregister for patienter
i aktiv behandling for
kronisk nyresvigt
Rapport for Danmark 2000*

*Danish National Registry
Report on Dialysis and
Transplantation in Denmark 2000*

The Danish Society of Nephrology

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Forord

Aktiv behandling for kronisk nyresvigt omfatter dialyse og nyretransplantation. Formålet med Dansk Nefrologisk Selskabs Landsregister (DNSL) er at indhente demografiske oplysninger om patienter i disse behandlingsformer og præsentere analyser heraf. I 1993 udkom den første rapport, som dækkede perioden fra 1/1-90 til 1/1-93. Siden er rapporteringen foregået årligt.

Registret blev oprindeligt skabt som et privat register tilhørende Dansk Nefrologisk Selskab (DNS). De lovmæssige og organisatoriske forhold i forbindelse hermed er beskrevet grundigt i forordet til den første rapport.

DNS har fundet det hensigtsmæssigt at ændre registrets status fra et privat register til en offentlig klinisk database. Herigennem er der skabt mulighed for offentlig finansiering af driften, og Københavns amt har fra 1/1-2000 påtaget sig værtsskabet. Samtidig har Sundhedsstyrelsen godkendt registret som en egentlig klinisk database og finansieret en tiltrængt fornyelse af de tekniske faciliteter. For at opnå Sundhedsstyrelsens godkendelse har det bl.a. været nødvendigt at øge antallet af registrerede parametre. Udformningen af den nye database er udført af firmaet Uni-C i samarbejde med repræsentanter fra DNS (Tom Buur og Hans Løkkegaard).

Registrets officielle navn er nu: Den landsdækkende kliniske database for patienter i aktiv behandling for kronisk nyresvigt. Registret ejes af og er hjemmehørende i Københavns Amt og som noget nyt er den registeransvarlige derfor ansvarlig overfor Københavns Amt.

I praksis er de organisatoriske forhold stort set uforandrede. DNS bevarer sin indflydelse på indholdet af den årlige rapport gennem DNS's registerudvalg, hvis formand er den til enhver tid siddende formand for DNS. Fast medlem af udvalget er den registeransvarlige, som formelt har ansvaret for datasikkerhed over for såvel DNS som Københavns Amt. Udvalgets øvrige medlemmer har hidtil bestået af læger med speciel interesse for registrering og med en passende geografisk spredning. Reviderede regler for drift og registerudvalgets sammensætning er under udarbejdelse.

Den nye udgave af den landsdækkende kliniske database er et Windows-baseret program med de tekniske fordele, den moderne teknik muliggør. Indledningsvis har vi bevaret den hidtidige organisation med indtastning af data på de enkelte centre og årlig tilførsel af data centralt via diskette. Den tekniske udformning tillader anvendelse af Internettet, og det er planen at skifte til en sådan løsning, når teknikken tillader sikker overførsel og opbevaring af data i dette medium.

Registret indeholder nu data på 7219 patienter, som 1/1 – 90 enten var eller siden er påbegyndt behandling. Rapporteringen er som tidligere indledt med indtastning af data på de nefrologiske centre, og der er god grund til at takke de mange, som har været involveret i dette betydelige arbejde.

I 1997 lykkedes det at etablere samarbejde med Scandiatransplant og Cancerregistret. Der er siden udvekslet data mellem DNSL og nævnte registre to gange, sidst februar-marts 1999. I 1997 muliggjorde dataudvekslingen en analyse af vævstypernes betydning for de sidste 8 års nyretransplantation. I 1998 resulterede samarbejdet med Cancerregistret i den første analyse af cancerudviklingen i Danmark inden for denne patientgruppe. Samarbejdet med de to registre er planlagt at fortsætte.

Prognostiske vurderinger til brug for den videre udbygning af behandlingsfaciliteter er et af registrets vigtigste opgaver. Det er nødvendigt konstant at overvåge ændringer i incidens og dødelighed. Tidligere års prognostiske vurderinger er fulgt op i dette års rapport.

Aktuelle analyser af patient- og nyregraftoverlevelse er et vigtigt led i en klinisk databases funktion. De tjener til konstant overvågning og kvalitetssikring af etablerede behandlingsformer. På grund af tekniske problemer i forbindelse med udtræk fra den nye database er overlevelsesstatistikken udskudt til næste års rapport.

Dette års udgave indeholder en række nye parakliniske parametre beregnet til at vurdere kvaliteten af de forskellige terapeutiske tiltag. Indtil videre er antallet af parakliniske parametre dog beskedent. Således vil det også forblive, indtil den moderne teknik tillader automatisk overførsel af laboratorieresultater fra sygehusenes EDB-systemer - en udvikling, som må formodes at accelerere de nærmeste år. Disse parametre vil med tiden være værdifulde værktøjer til at sikre en ensartet god behandlingskvalitet i Danmark.

November 2001

Tom Buur

Hans Løkkegaard
Registeransvarlig
National koordinator

Preface

The Danish Registry on Regular Dialysis and Transplantation was founded in 1990, and since then all patients actively treated for end-stage renal disease (ESRD) have been registered – now including 7219 patients. Data is input using identical software programs in all renal centres, and once yearly data are sent to a central database. Here the material is checked for errors, and appropriate corrections are made in dialogue with the reporting centres. Finally, a national report is prepared, and data are transferred to the registry maintained by the European Dialysis and Transplant Association (EDTA), the Danish Cancer Registry and Scandiatransplant.

Data exchange with the Danish Cancer Registry and Scandiatransplant was started in 1997. In 1998 this collaboration resulted in a report concerning the influence of tissue typing on graft survival in Denmark since 1990. Moreover, in 1999 the first report on development of cancer in Danish ESRD patients was published.

The registry was founded and is maintained by the Danish Society of Nephrology (DNS). Reports are published annually.

November 2001

Tom Buur

Hans Løkkegaard
National Co-ordinator

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Fig. 1. Renal centres in Denmark 2000

Renal Centres and Population in Denmark

Transpl. Centre	County	Dialysis center	Population
Skejby	Århus	Skejby	637122
	Nordjylland	Aalborg	494153
	Ringkøbing	Holstebro	272857
	Viborg	Viborg	233186
	Total Skejby		1637318
Odense	Fyn	Odense	471974
	Ribe	Esbjerg	224345
	Sønderjylland	Sønderborg	253482
	Vejle	Fredericia	347542
	Total Odense		1307343
Herlev	Københavns amt	Herlev	
	Total Herlev		613444
Rigshospitalet RH	Bornholm	Rønne	44337
	Frederiksberg	RH	90327
	Frederiksborg	Hillerød	365306
	Færøerne	RH	43751
	Grønland	RH	56124
	København	RH	495699
	Roskilde	Roskilde	231559
	Storstrøm	Nykøbing F	259106
	Vestsjælland	Holbæk	295086
	Total RH		1881295
Total population 01.01.2000			5439400

Table 1. Population and renal centres in Denmark as of 010100.
Statistical Yearbook 2000

Prevalence of ESRD 1991 - 2000

Patients on dialysis or with a functioning graft

Treatment	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
CAPD	341	342	380	384	389	379	406	410	471	453
APD	13	10	18	29	32	42	56	59	70	99
Center-IPD	29	26	23	21	21	18	13	11	11	14
Home-IPD	1	2	1	2	1	17	13	12	7	3
Center-HD	612	626	717	777	892	978	1058	1160	1297	1544
Lim. Care	37	38	42	43	52	62	56	65	62	84
Home-HD	21	17	16	17	15	13	9	7	9	10
In dialysis	1054	1061	1197	1273	1407	1509	1606	1724	1927	2207
Home	376	371	415	432	442	451	484	488	557	565
PD	355	354	399	415	427	438	475	481	548	555
HD	21	17	16	17	15	13	9	7	9	10
Center	678	690	782	841	965	1058	1127	1236	1370	1642
Transpl.	925	1012	1084	1139	1172	1232	1255	1268	1331	1442
In treatment	1979	2073	2281	2412	2579	2741	2861	2992	3258	3655

Table 2. Patients in therapy for ESRD 1991 - 2000. The number of patients on dialysis has increased steadily from 1991 through 2000. In 2000 the prevalence in Denmark of patients on dialysis and with a functioning renal graft was 409 and 265 per million inhabitants, respectively.

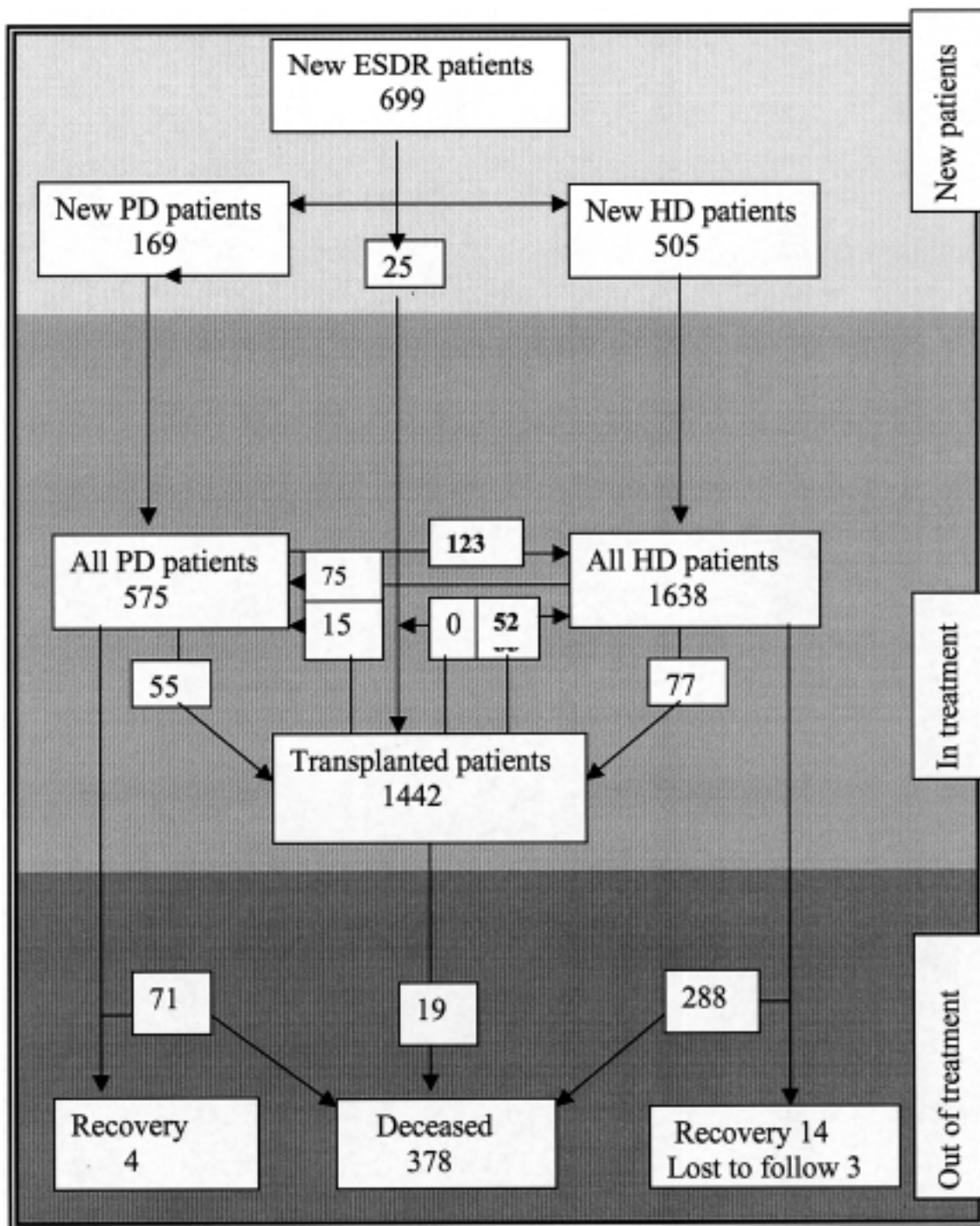


Fig. 2. Changes in the number of patients treated for ESRD during 2000 – status as of 31.12.00. 699 patients started treatment (HD,PD,RAT) in 2000. At the end of the year 2213 patients were on dialysis and 1442 had a functioning renal allograft.

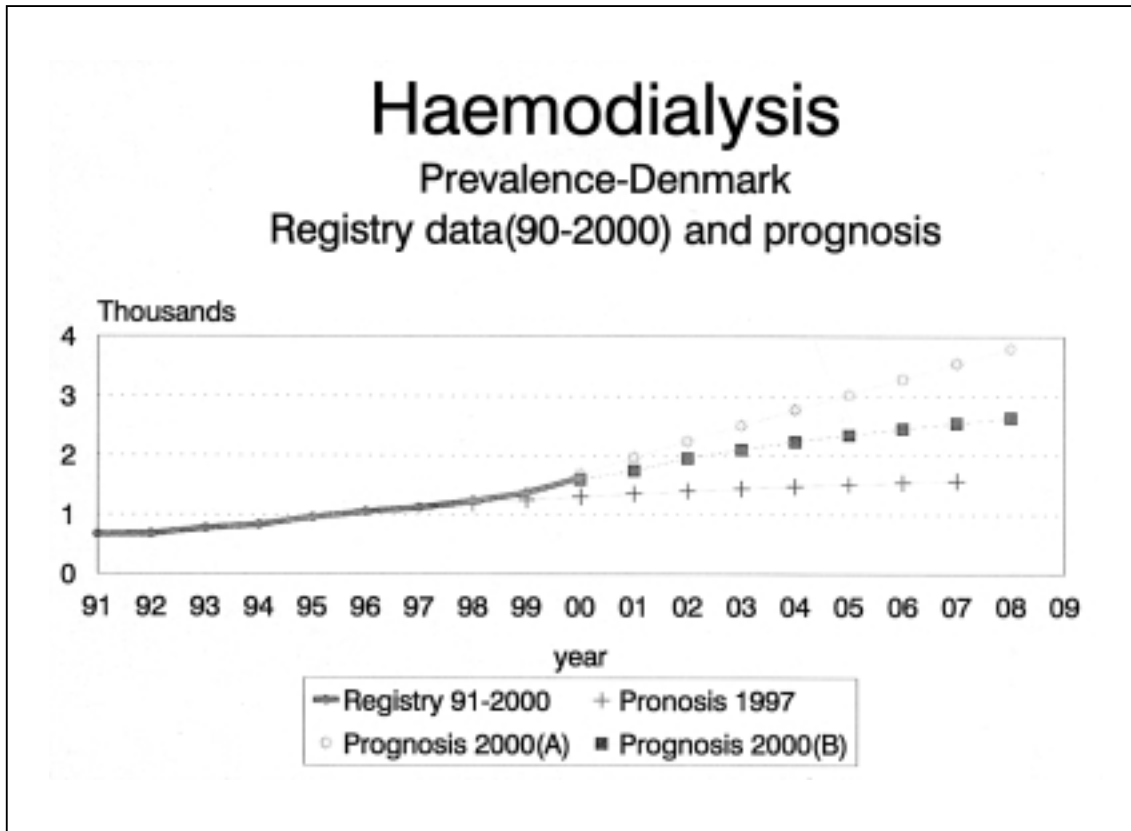


Fig. 3

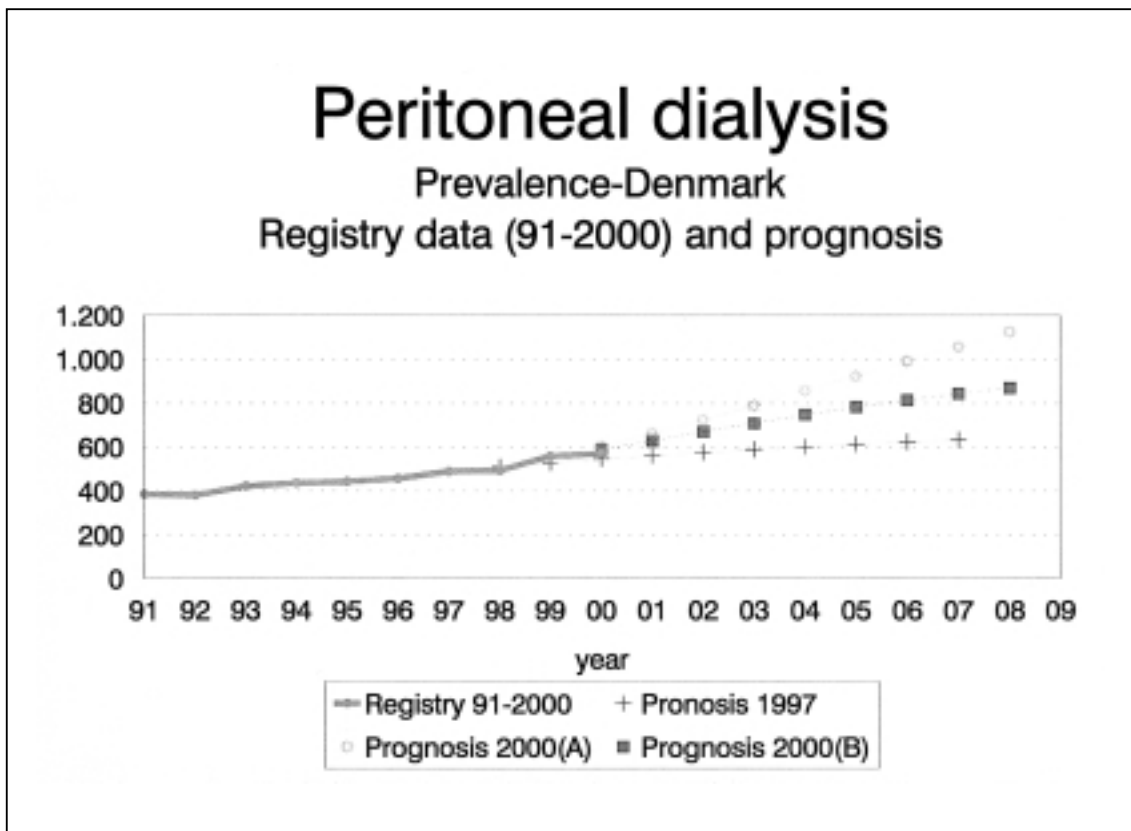


Fig. 4

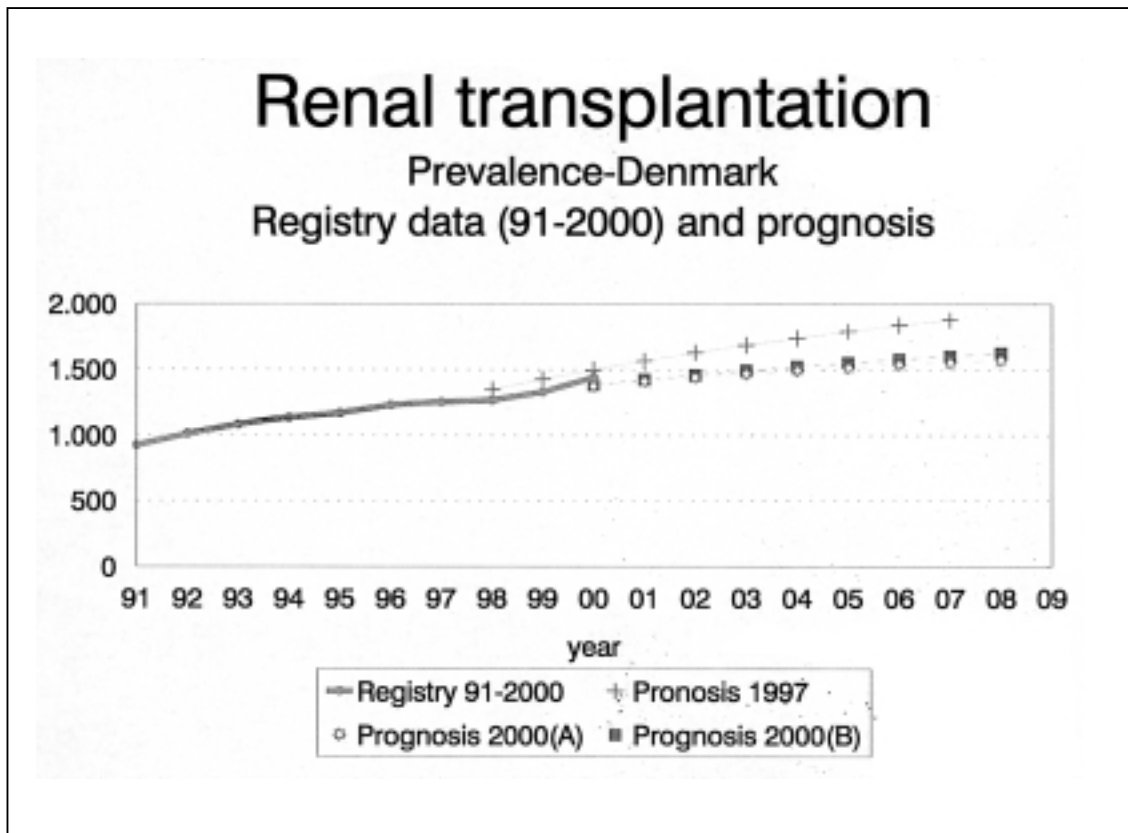


Fig. 5

Figure 3, 4 and 5. Prognostic calculations concerning the number of haemodialysis- (HD) peritonealdialysis- (PD) and transplanted (TX) patients. The calculations are based on data from 1990 – 99 (Vestergaard P., see scientific contribution (4,6,7)).

Three different prognoses are shown:

- a. The first calculation was made in 1997 and shows the prognosis from 1998 to 2007. This calculation was based on the assumption that the prognosis could be calculated from average values of earlier data (1990-97). When this assumption was questioned, two new models were introduced.
- b. Prognosis 2000A assumes an increasing incidence based on average values from the last three years and mortality from the same period.
- c. Prognosis 2000B is based on average figures from the last three years without further increase in incidence and change in mortality.

For further discussion see Peter Vestergaard's report (7). The incidence and mortality rate is difficult to predict. Repeated calculations are necessary in the future.

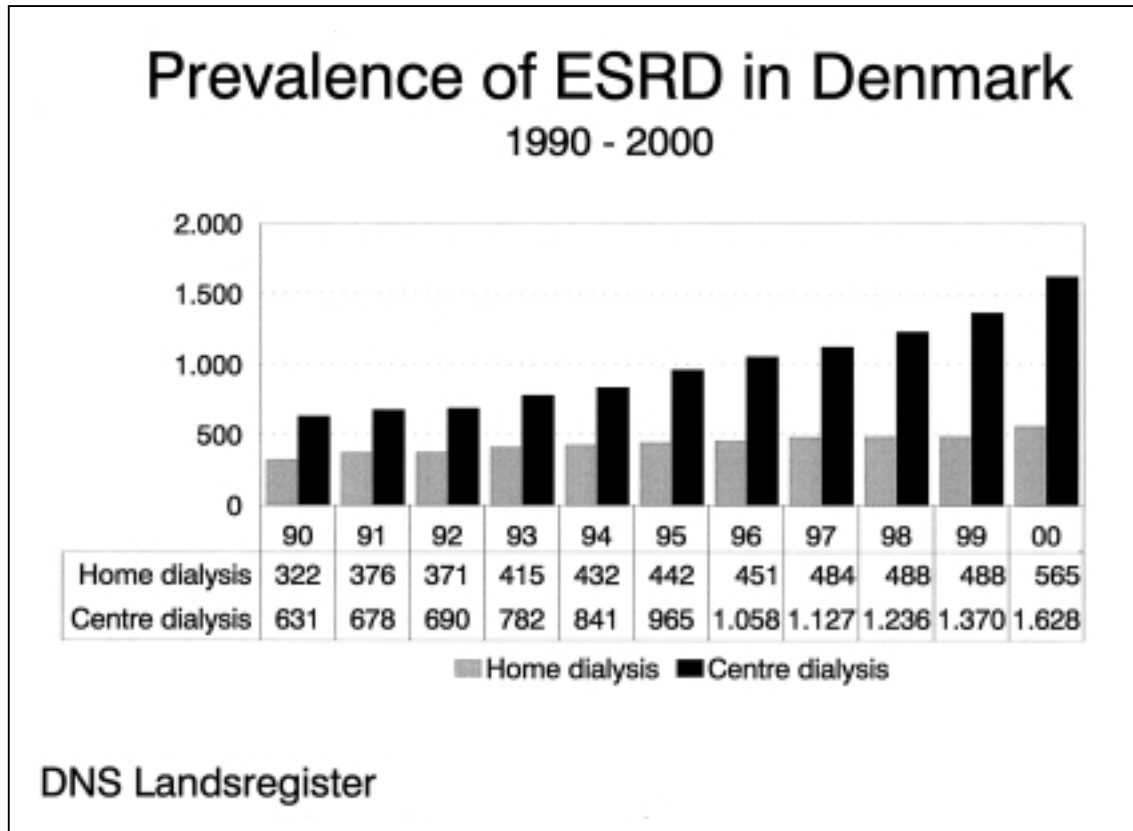


Fig. 6

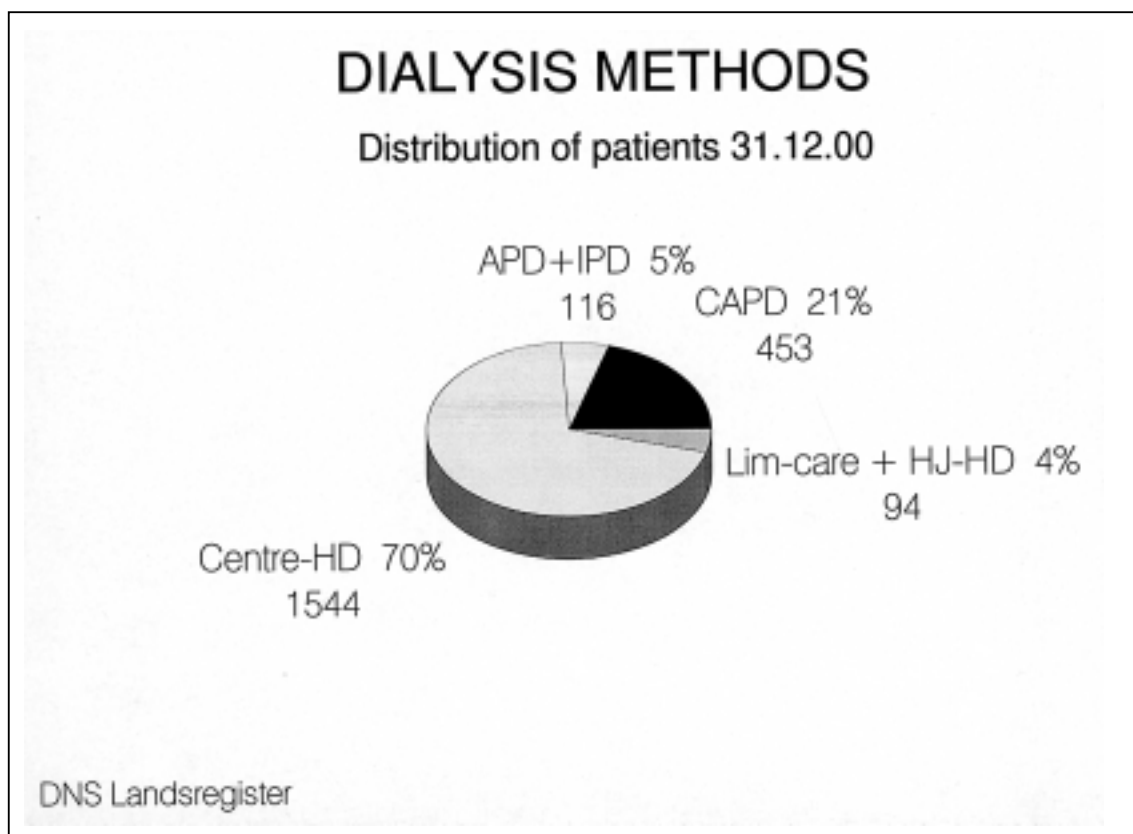


Fig. 7

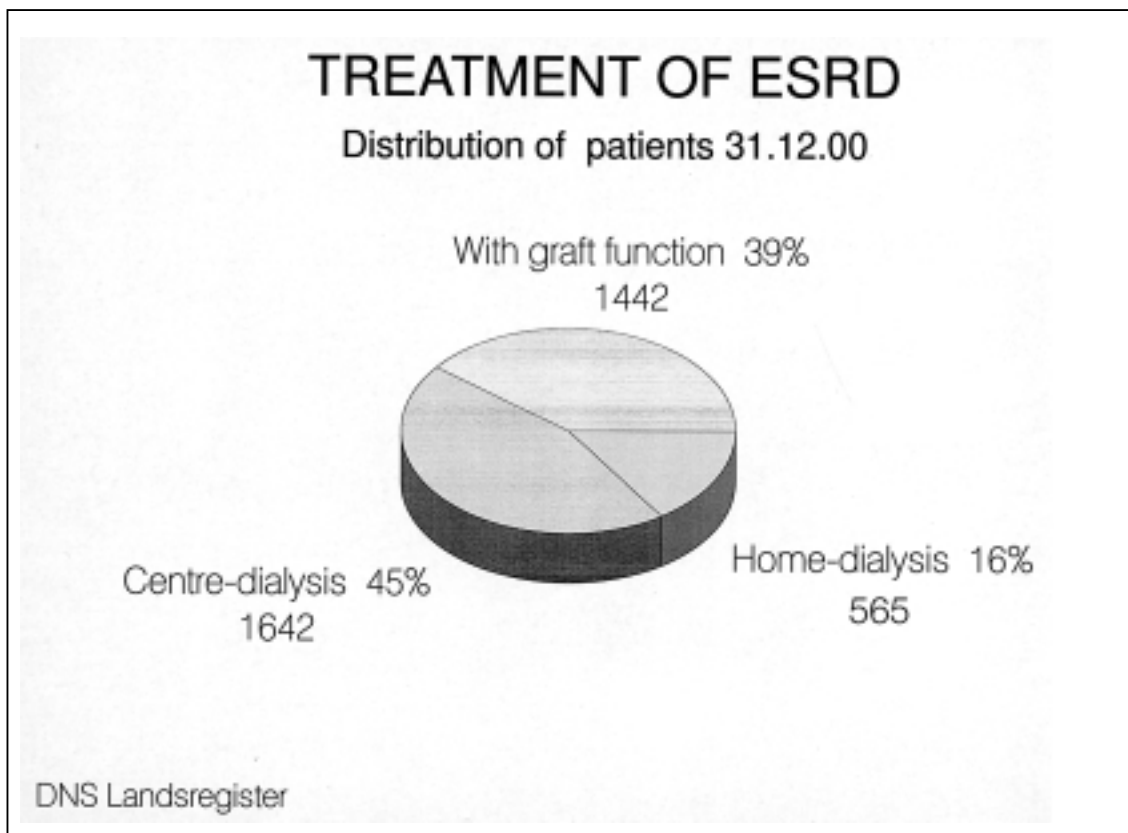


Fig. 8

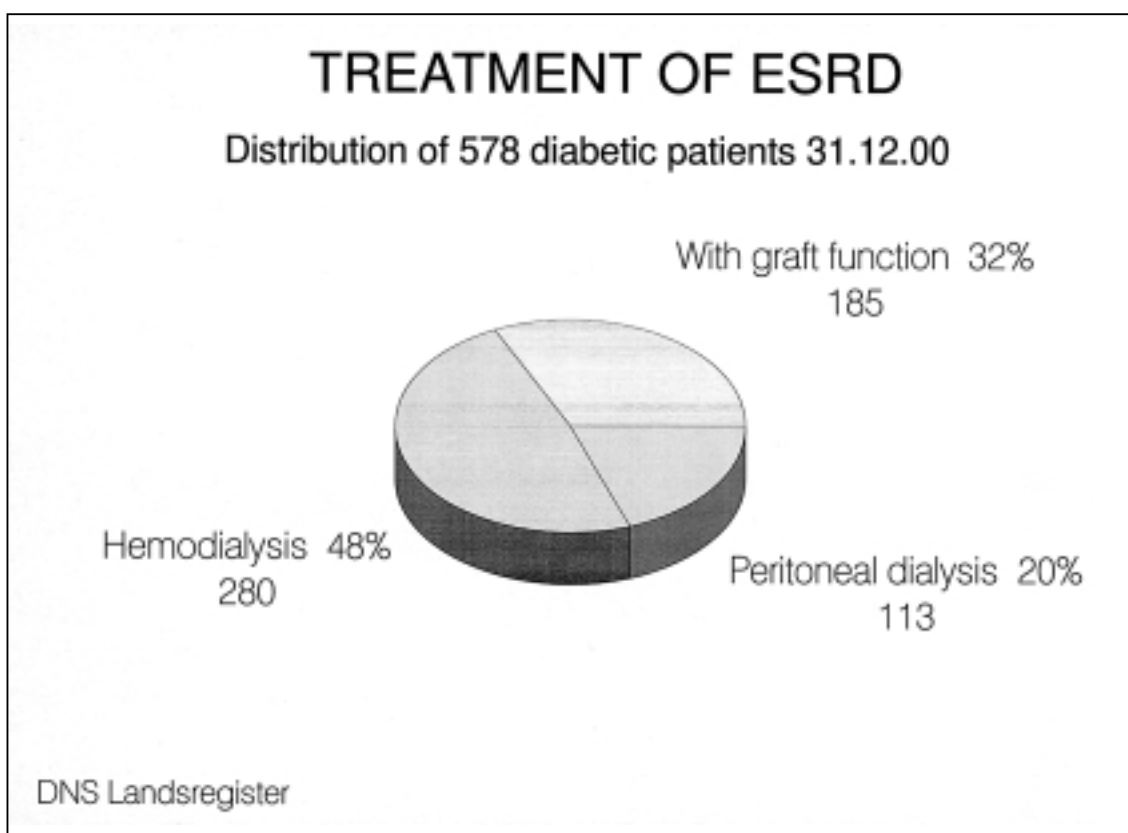


Fig. 9

Incidence of ESRD

Centre	1990		1991		1992		1993		1994		1995		1996		1997		1998		1999		2000	
	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.
Esbjerg	10	46	6	27	15	68	25	114	13	59	13	57	17	77	19	85	17	76	32	143	33	147
Fredericia	14	42	21	63	17	51	26	79	25	75	29	86	26	77	31	91	33	96	42	122	56	162
Herlev	45	75	39	65	36	60	39	65	50	83	40	66	54	89	66	108	62	102	75	123	47	77
Hillerød																						
Holbæk					1	3			2	7	2	7	22	76	35	120	24	82	24	82	40	137
Holstebro	10	37	11	37	13	48	19	71	21	78	28	104	28	104	17	62	24	88	29	107	30	110
Hvidovre	33	60	48	87	39	71	59	107	43	78	49	88	68	121								
Odense	45	98	52	73	39	55	42	59	55	118	55	118	31	66	51	108	43	91	59	125	47	100
Rigshosp.	70	56	87	69	110	87	124	109	115	153	119	114	103	136	97	90	177	137	183	141	218	168
Roskilde							12	54	15	68	13	58	12	57	17	75	37	162	21	92	23	101
Rønne															1	22	6	136	5	111	2	45
Skejby	54	90	49	81	39	65	66	110	47	77	73	118	45	73	74	118	73	117	79	125	103	163
Sønderbg.											14	56	28	111	28	110	24	95	28	110	18	71
Viborg	19	83	18	78	13	56	26	113	26	113	25	109	19	85	25	107	19	82	22	94	22	94
Ålborg	30	62	34	69	38	77	54	111	32	66	48	98	56	114	41	85	48	98	54	110	60	122
Denmark	330	63	365	70	360	69	492	94	445	86	508	97	510	98	539	100	587	104	653	121	699	129

Table 3. New patients (number per million per year) 1990 – 2000 in the renal centres. The incidence in Denmark was rather stable from 1996 - 98 - about 100. In 1999 the incidence has increased to 121 and in 2000 the incidence was 129. Incidence in 1999 in Finland = 90, in Norway = 90 and Sweden = 120. The patients in Hillerød were transferred from Rigshospitalet in 2000 and therefore included in data from Rigshospitalet.

Age distribution 1990 - 2000

Year	00-19	20-29	30-39	40-49	50-59	60-69	70-79	>=80	%>=60
1990	2	11	7	24	18	25	12	0	37
1991	3	7	9	17	23	25	16	0	41
1992	5	5	13	16	24	21	15	1	37
1993	3	5	9	17	21	26	19	1	46
1994	2	7	14	14	20	24	18	1	43
1995	3	8	9	16	17	26	20	1	47
1996	2	6	9	13	18	26	24	2	52
1997	2	5	10	12	22	24	23	2	49
1998	3	4	7	14	20	22	26	4	52
1999	1	4	9	12	17	27	24	6	57
2000	2	3	8	12	20	24	24	7	55
Population	24	16	14	15	11	9	7	5	21

Table 4. Percentage age distribution of patients starting treatment for ESRD 1990-2000
For comparison the age distribution of the Danish population is also indicated.

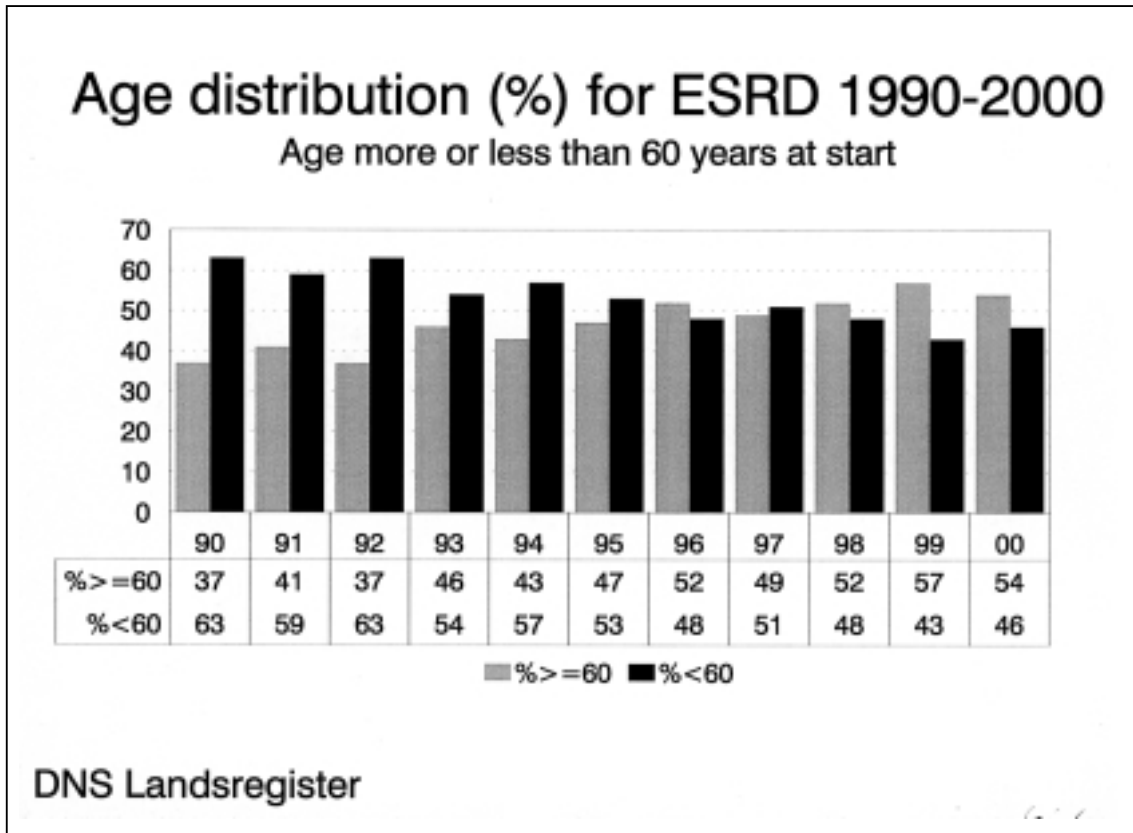


Fig. 10

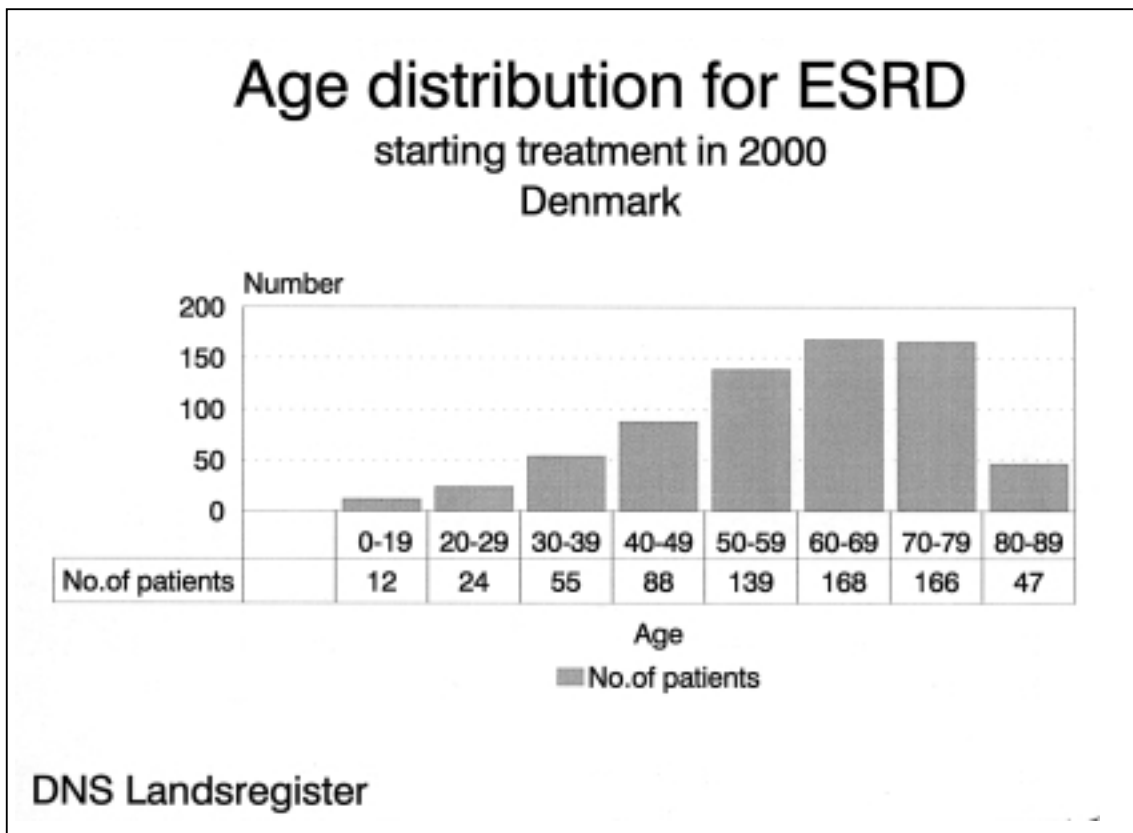


Fig. 11

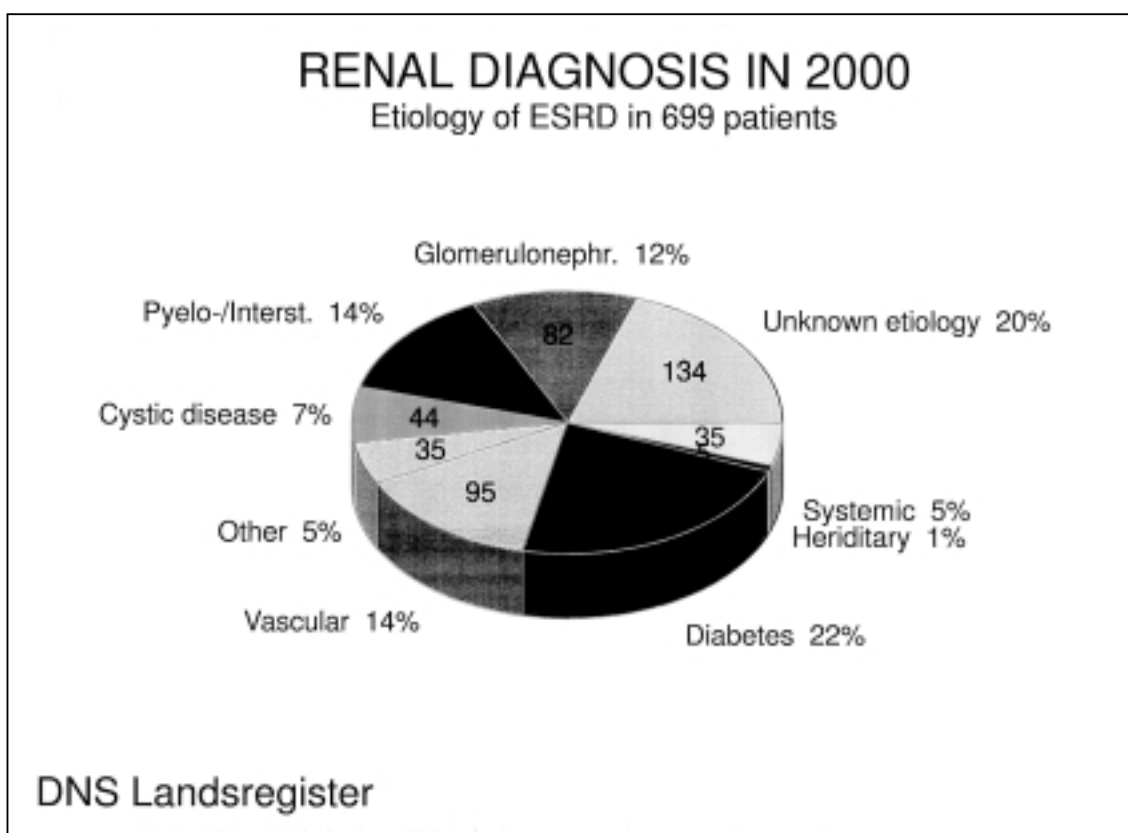
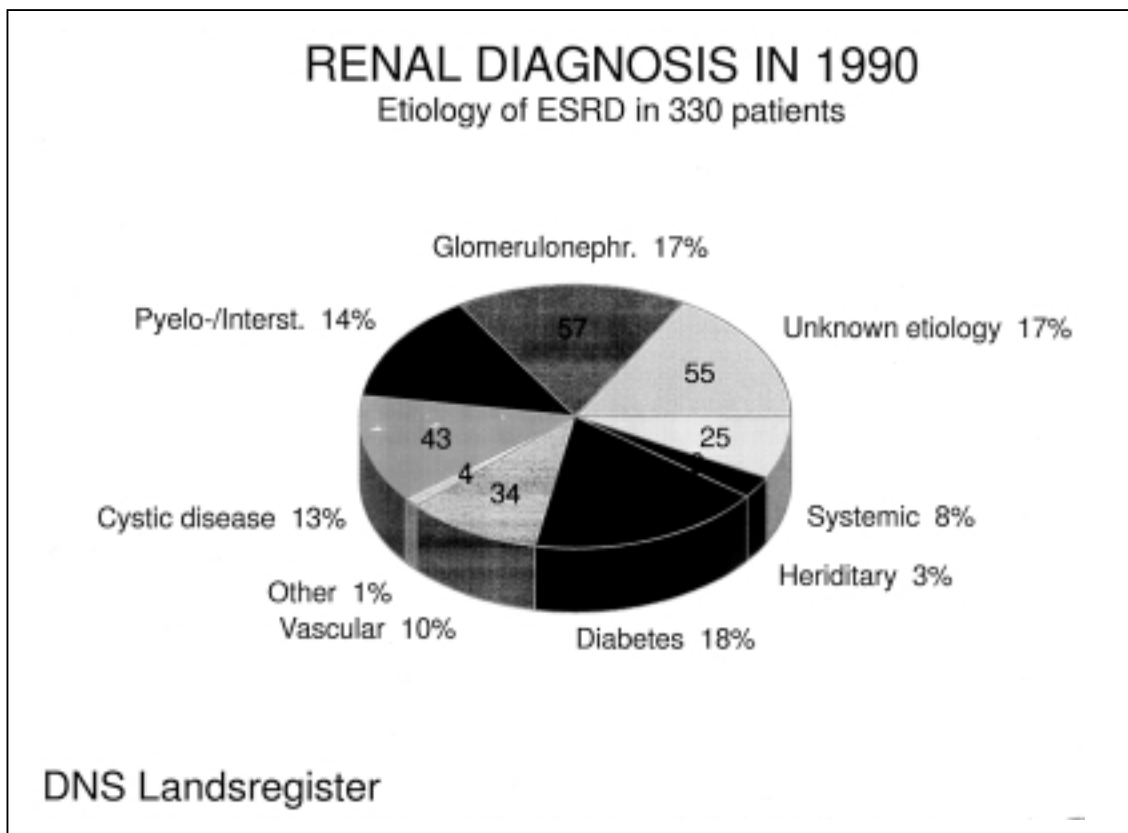


Fig. 12

Renal Diagnoses 2000

Year	0-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	All
Renal diagnosis									
ESRD, unknown causes	2	0	7	7	18	22	37	17	134
Glomerulonephritis	3	6	6	15	24	14	8	1	82
Pyelo/interst. Nephritis	3	1	6	8	10	20	26	6	92
Cystic renal disease	0	1	2	12	13	5	10	2	44
Alport disease	0	0	0	0	0	1	0	0	3
Other hereditary disease	1	0	1	0	0	0	0	0	2
Renal hypoplasia	2	0	1	0	2	0	0	0	3
Renal vascular disease	0	1	3	3	14	24	30	6	95
Renal vasculitis	0	0	0	1	0	3	8	0	16
Diabetes (IDDM)	0	0	13	24	20	14	6	2	77
Diabetes (NIDDM)	0	0	0	4	6	13	13	7	73
Systemic disease	1	0	3	3	4	10	9	0	43
Other renal diseases	0	1	1	2	4	6	6	5	35
Sum	12	24	55	88	139	168	166	46	699

Table 5. Renal diagnosis in 699 patients starting treatment for ESRD in 2000. The patients are stratified according to age.

Renal Diagnoses 1990 - 2000

Renal diagnosis	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	SUM
ESRD, unknown causes	55	61	62	81	76	82	103	110	105	131	134	1000
Glomerulonephritis	57	68	67	81	69	82	74	72	85	99	82	836
Pyelo/interst. Nephritis	45	59	57	76	59	67	58	72	81	78	92	744
Cystic renal disease	43	33	30	47	34	43	37	40	45	47	44	443
Alport disease	4	3	2	2	2	1	4	2	1	0	3	24
Other hereditary disease	4	3	2	4	1	6	2	4	4	3	2	35
Renal hypoplasia	1	6	1	6	4	4	1	3	6	3	3	38
Renal vascular disease	34	44	36	57	60	68	58	58	79	85	95	674
Renal vasculitis	5	3	0	6	10	13	17	15	12	16	16	113
Diabetes (IDDM)	52	53	63	76	69	73	73	65	79	95	77	775
Diabetes (NIDDM)	6	13	9	23	24	40	41	43	37	50	73	359
Systemic disease	20	13	26	18	24	22	33	34	32	36	43	301
Other renal diseases	4	6	5	15	13	7	9	21	21	10	35	146
Sum	330	365	360	492	445	508	510	539	587	653	699	5488

Table 6. Renal diagnoses in patients starting treatment 1990 - 2000.

Measures of quality of dialysis

Measures of quality of peritoneal dialysis 2000					
		Kt/V	Hb mmol/l	P-Albumin g/l	P-Creatinine µmol/l
CAPD	Mean	2.3	7.3	35	751
	Range	2.0-2.6	7.1-7.9	32-37	675-865
	Number	270	345	342	344
APD	Mean	2.3	7.5	38	794
	Range	1.4-2.6	6.0-8.0	33-39	702-1050
	Number	77	91	92	91

Table 7. Selected parameters measuring PD quality. The table shows average values for Denmark as a whole. Range means centre with lowest average – centre with highest average. Number of measurements are given.

Measures of quality of haemodialysis 2000					
		Kt/V	Hb mmol/l	P-Albumin g/l	P-Creatinine µmol/l
Centre HD	Mean	1.4	7.0	38	736
	Range	1.2-1.5	6.4-7.5	32-46	657-866
	Number	885	1136	1131	1132
Lim. Care HD	Mean	1.3	7.3	39	893
	Range	1.3-1.53	6.9-7.5	35-41	809-1013
	Number	25	57	57	57
Home HD	Mean	1.8	7.7	44	783
	Range	1.2-2.2	7.2-8.4	38-48	544-1138
	Number	4	7	7	6

Table 8. Selected parameters measuring HD quality. The table shows average values for Denmark as a whole, the range (centre with lowest average – centre with highest average) and number of measurements are given.

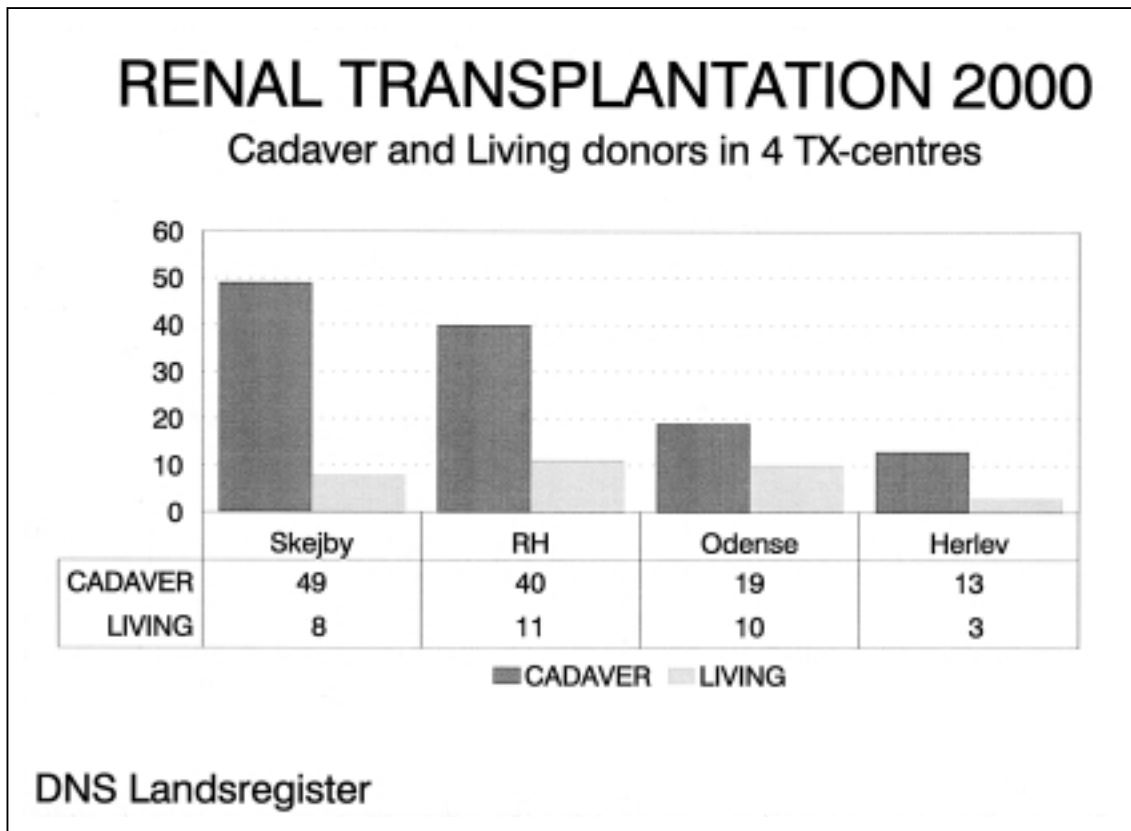


Fig. 13

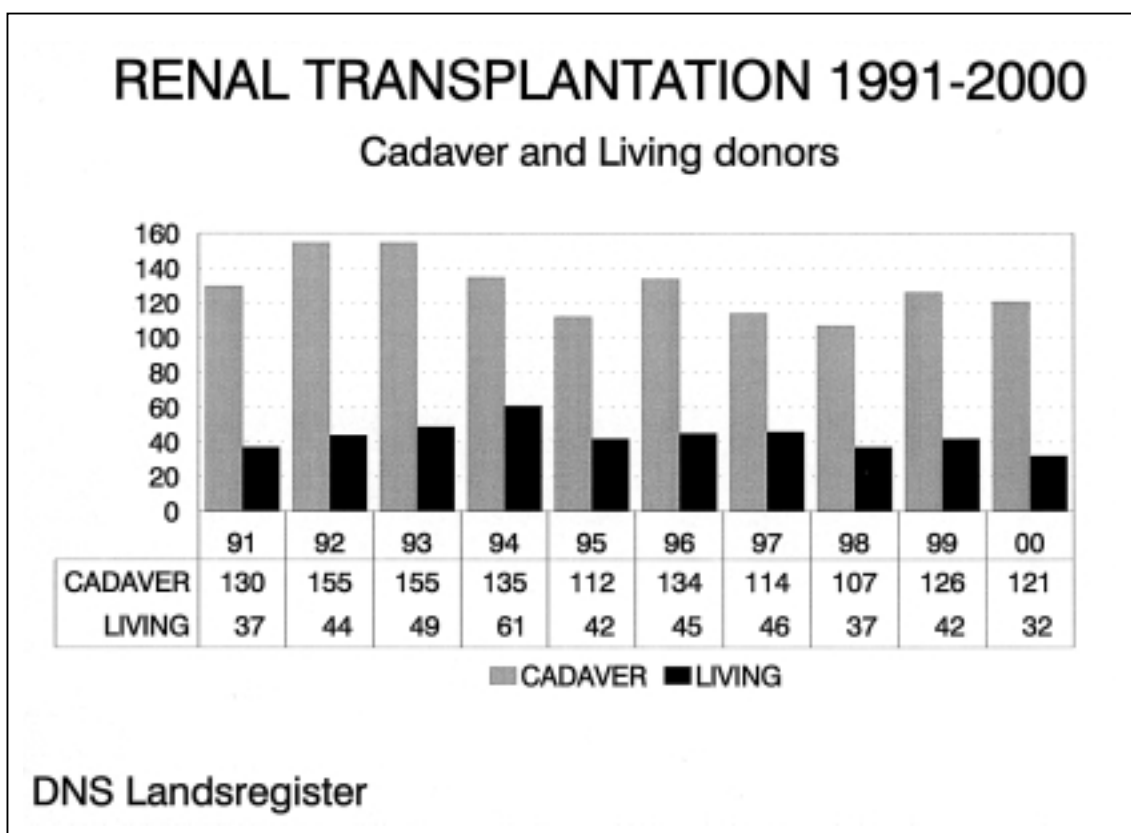


Fig. 14

Renal transplantation 1991 - 2000

Renal transplantation 1991 - 2000									
	Cadaver kidney				Living donor kidney				
Year	1	2	3	4	1	2	3	4	Sum
1991	98	25	7	0	25	9	1	2	167
1992	115	32	7	1	33	8	3	0	199
1993	121	25	9	0	39	7	3	0	204
1994	98	26	7	4	53	6	1	1	196
1995	94	10	8	0	35	6	1	0	154
1996	105	22	7	0	44	1	0	0	179
1997	89	19	5	1	42	3	0	1	160
1998	78	23	4	2	36	1	0	0	144
1999	96	19	10	1	37	5	0	0	168
2000	98	17	7	0	27	5	0	0	153

Table 9. Renal transplantations 1991 – 2000, stratified according to source of donor organ, transplantation number (1-4) and year of transplantation.

Renal transplantation 2000

Renal transplantation 2000									
	Cadaver kidney				Living donor kidney				
Center	1	2	3	4	1	2	3	4	Sum
Skejby	37	7	5	0	7	1	0	0	57
RH	36	3	1	0	11	0	0	0	51
Odense	12	6	1	0	6	4	0	0	29
Herlev	13	0	0	0	3	0	0	0	16
Total	98	16	7	0	27	5	0	0	153

Table 10. Renal transplantations 2000, stratified according to source of organ donor organ, transplantation number (1-4) and transplantation center.

Livingdonor - relation between donor and recipient

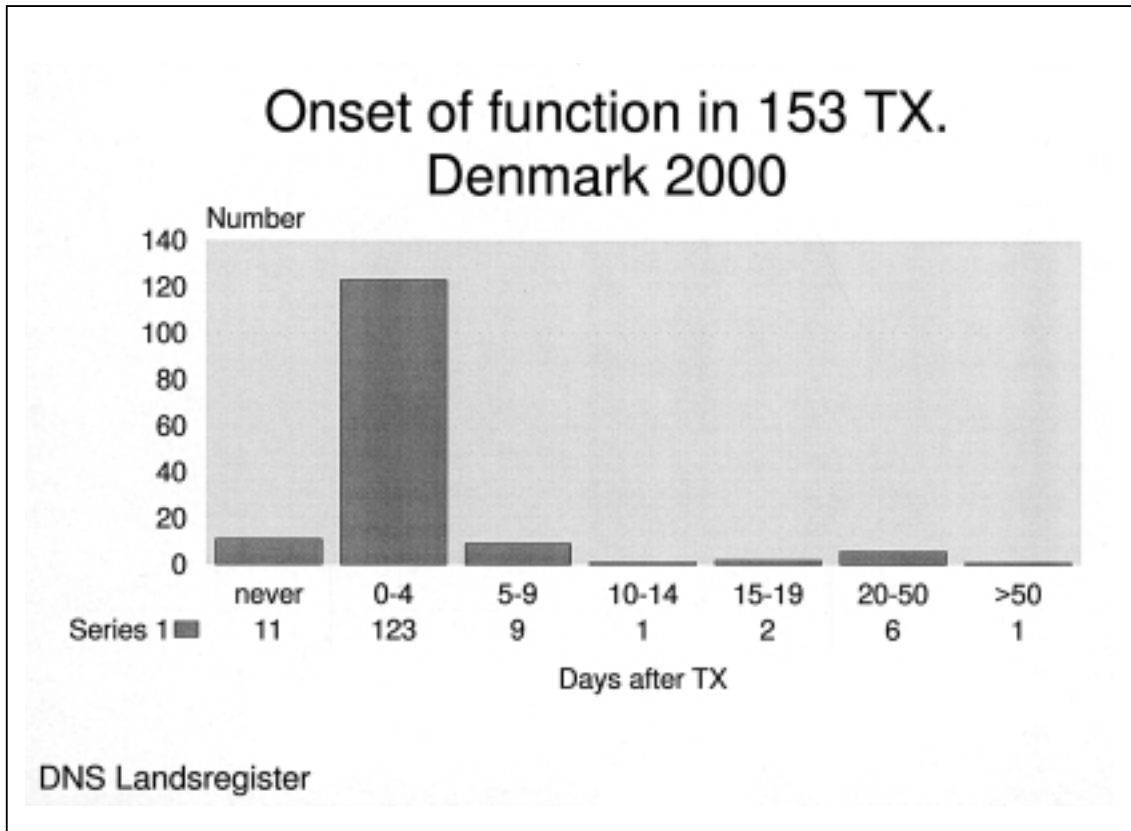
Year	Parents	Siblings				Other related	Unre- lated	Sum
		Shared haplotypes			Ident. Twins			
		2	1	0				
1991	16	12	8	0	0	1	0	37
1992	27	6	4	1	0	4	2	44
1993	20	10	7	1	1	7	3	49
1994	31	10	12	2	1	3	2	61
1995	26	4	4	0	0	5	3	42
1996	29	3	6	2	1	1	3	45
1997	26	12	6	0	1	0	1	46
1998	17	8	10	0	0	0	2	37
1999	26	2	4	2	0	5	3	42
2000	18	5	5	0	0	1	3	32

Table 11. Transplantation with living donor kidneys 1991 – 2000. Stratified according to donor-recipient relationship and year of trans-plantation.

Transplantation follow-up centres

Center	No	Center	No.
Esbjerg	8	Rigshosp.	446
Fredericia	1	Roskilde	28
Herlev	241	Rønne	0
Holbæk	19	Sønderb.	2
Holstebro	47	Viborg	57
Nykøbing F	0	Aalborg	117
Odense	213	Aarhus	263

Table 12. The distribution of ambulatory follow up of 1442 Danish renal transplant patients in 14 nephrological centres. It can be seen that most ne-prological centres are involved in the controlling of stable renal transplant pa-tients. The four transplantation centres are marked.



Renal Transplantation 2000 - Never functioning grafts

Thromb./no function eller rejektion	No funct. 311200
7	4

Fig. 15. Onset of function in 153 transplantations in 2000. The reasons for non-functioning kidneys are given

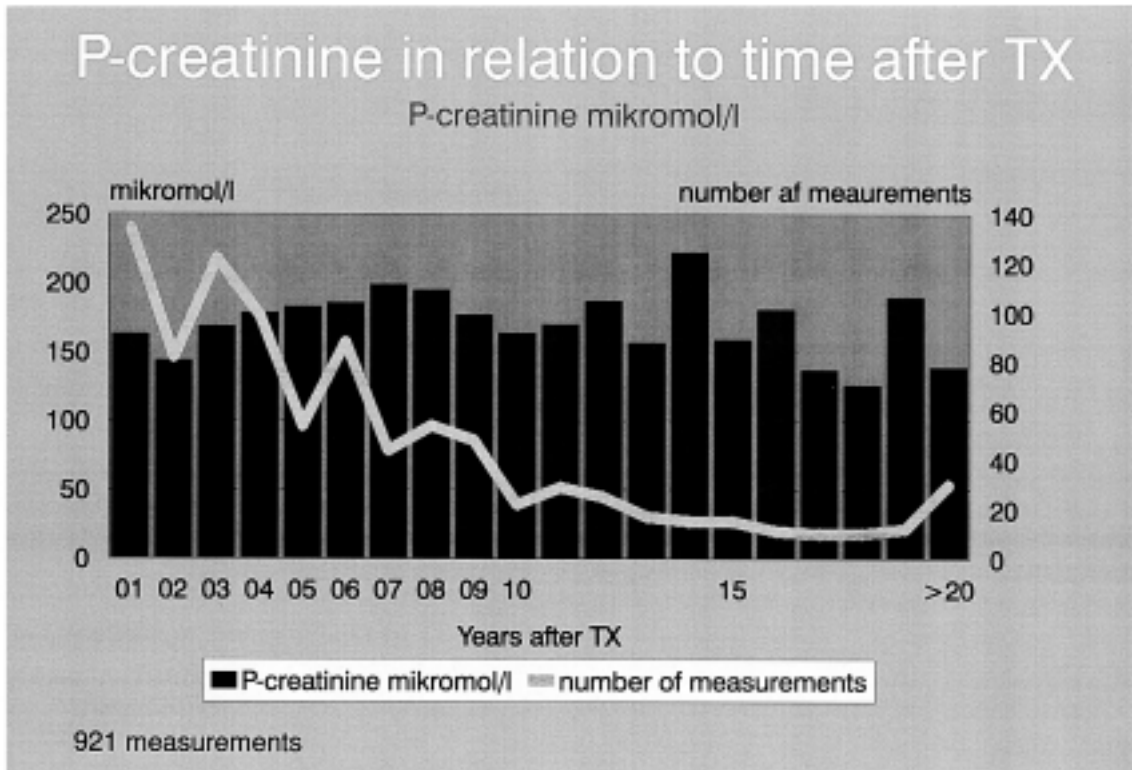


Fig. 16

In 921 cases P-creatinine was measured at varying times after transplantation. Mean values and number of measurements from 1 to >20 years after transplantation are given.

Causes of death 2000				
	Hemodialysis	P-dialysis	Renal-Tx	Sum
Cardiac	99	36	8	143
Vascular	37	20	3	50
Infection	55	11	5	71
Malignancy	23	4	2	29
Other causes	74	10	1	85
Sum	288	70	19	378

Table 13. Causes of death in 378 patients who died in 2000. Cardiac includes acute myocardial infarction, hyper- and hypokalaemia, hypertensive heart failure, fluid overload and cardiac arrest of unknown cause. Vascular causes includes mainly cerebrovascular disease. Infection includes all bacterial and viral diseases.

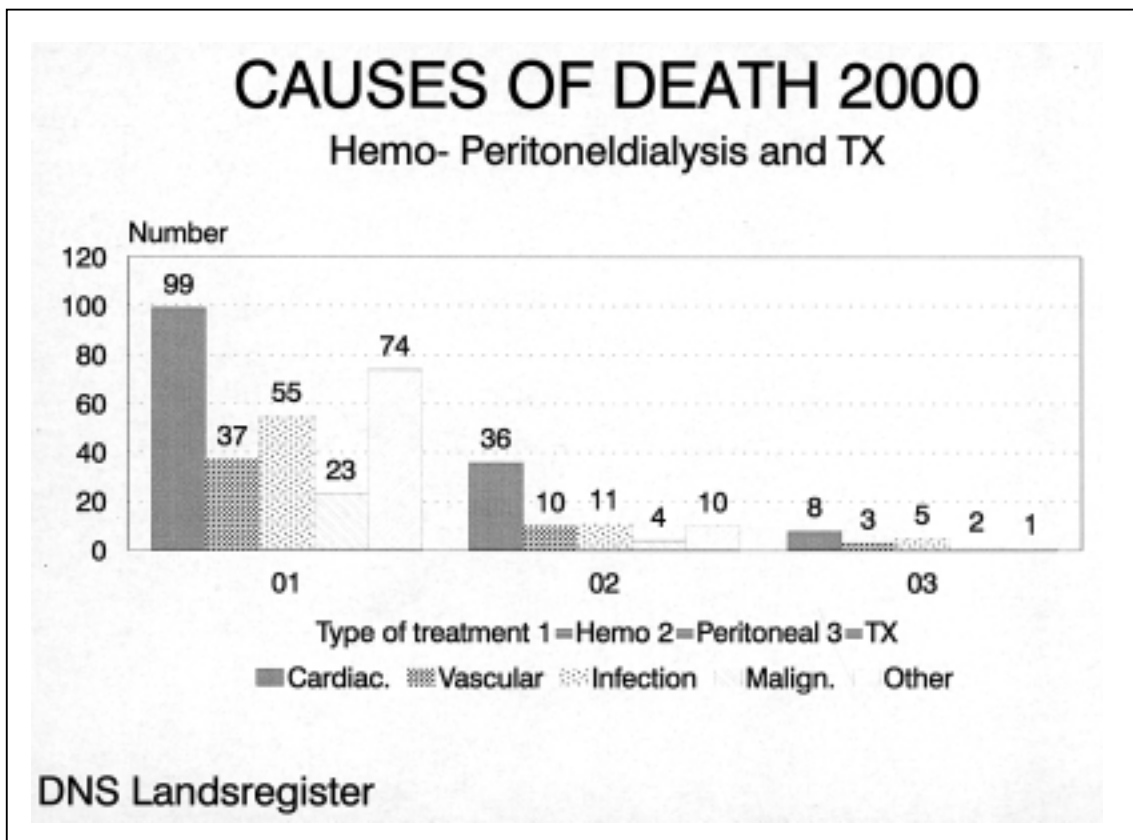
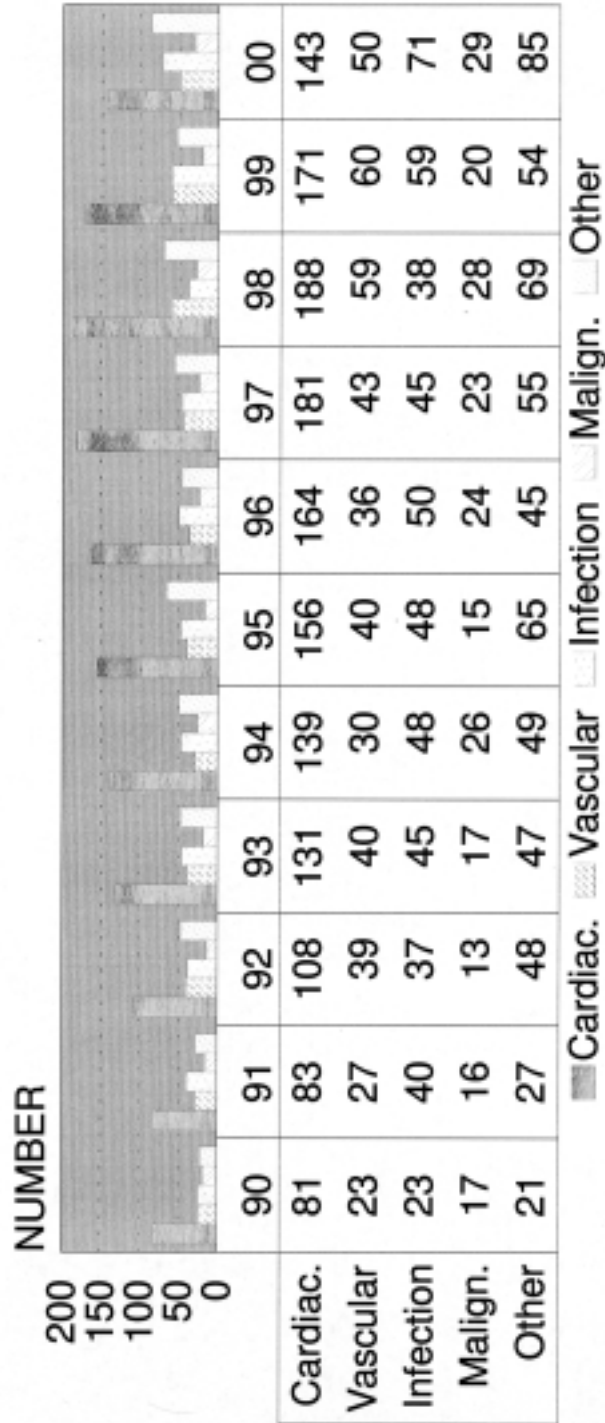


Figure 17. Causes of death in 378 patients who died in 2000.

CAUSES OF DEATH

1990-2000
Denmark



DNS Landsregister

Fig.18

Death rate 2000

Hemodialysis:

New patients starting HD in 2000	=	505
Patients continuing HD from 1999	=	1368
<hr/>		
Dead	=	288
Number of patients alive 311200	=	1638
<hr/>		
Total HD patients for calculation	=	1926

Death rate = 14.9%

Peritoneal dialysis:

New patients starting PD in 2000	=	169
Patients continuing PD from 1999	=	559
<hr/>		
Dead	=	70
Number of patients alive 311200	=	575
<hr/>		
Total PD - patients for calculation	=	645

Death rate = 10.8%

Renal transplantation:

New patients transplanted in 2000	=	153
TX-patients continuing from 1999	=	1331
<hr/>		
Dead	=	19
Patients alive 311200	=	1442
<hr/>		
Total TX-patients for calculations	=	1461

Death rate = 1.3%

Comments: The death rate includes death from patients starting treatment in 2000, patients transferred from other treatments and those who continued from 1999.

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