DANSK NEFROLOGISK SELSKAB

Landsregister for patienter
i aktiv behandling for
kronisk nyresvigt
Rapport for Danmark 2004

Danish National Registry
Report on Dialysis and
Transplantation in Denmark 2004

The Danish Society of Nephrology

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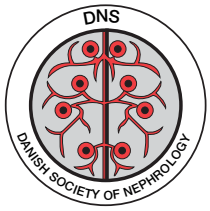

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Forord

Aktiv behandling af kronisk nyresvigt omfatter dialyse og nyretransplantation. Formålet med Dansk Nefrologisk Selskabs Landsregister (DNSL) er at indhente relevante kliniske og para-kliniske oplysninger om disse patienter og videregive en vurdering heraf. I 1993 udkom den første rapport, som omfattede perioden fra 1/1-90 til 1/1-93. Siden er rapporteringen foregået årligt.

Registrets officielle navn er: *Den landsdækkende kliniske database for patienter i aktiv behandling for kronisk nyresvigt.* Registret ejes af og er hjemmehørende i Københavns Amt.

DNS er ansvarlig for indsamling af talmaterialet og behandling af de indsamlede data. Dette organiseres af et *registerudvalg* nedsat af DNS. Formanden 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 består af læger med speciel interesse for registrering og epidemiologisk forskning.

Udvalgets nuværende medlemmer er:

Overlæge *Hans Dieperink*. Formand for registerudvalget. Er ansvarlig for dets funktion og tilfredsstillende relationer til DNS bestyrelse og medlemmer.
Overlæge *Tom Buur* med speciel interesse for registrering af hæmodialyse.
Overlæge *James Heaf* med speciel interesse for P-dialyse.
Overlæge *Hans Løkkegaard*. Registeransvarlig og ansvarlig for drift, kontakt med ansvarlige myndigheder, kontakt til andre registre (Scandiatransplant, Nordiske uræmiregistre, Cancerregister, ERA-EDTA), Datakonsulenter (Uni-C) og endelig udformning af den årlige rapport.
Overlæge *Niels Løkkegaard* med speciel interesse for Hæmodialyse.
Overlæge *Melvin Madsen* med speciel interesse for nyretransplantationer.

Den landsdækkende kliniske database er et Windows-baseret program med de tekniske fordele, den moderne teknik muliggør. Dette program anvendes i år for femte gang. De tekniske problemer i forbindelse med den nye teknik er nu overstået og *Uni-C* takkes i den forbindelse for godt samarbejde. Fremstilling af relevante udtræk er indenfor det sidste år muliggjort ved fremstilling af en *udtræksgenerator*, som tillader fremstilling af udtræk fra både den centrale og decentrale database. Forhåbentlig bidrager dette initiativ til en øget anvendelse af data.

Vi har bevaret den oprindelige organisation med indtastning af data på de enkelte centre og årlig tilførsel af data centralt via diskette. Den tekniske udformning af databasen tillader anvendelse af Internettet og Uni-C har foreslået en løsning, som vil tillade direkte indtastning på nettet. Denne løsning vil indebære betydelige fordele af både teknisk og organisatorisk art. Vi har derfor marts 2005 ansøgt Amtsrådsforeningen om midler til etablering af denne løsning.

Registret indeholder nu data på 10077 patienter, som 1/1 - 90 enten var eller siden er påbegyndt behandling. Der ydes på de nefrologiske afdelinger en betydelig indsats med indtastning af data 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 - sidst i 2005. Scandiatransplant sender én gang årligt vævstyper til DNSL og modtager til gengæld resultater om patientforløb fra DNSL. Fra Cancerregistret, som nu er placeret i Sundhedsstyrelsen, overføres resultater cancerdiagnoser - sidst april 2005. DNS har påbegyndt et samarbejde med onkologerne på KAS-Herlev og i Kræftens Bekæmpelse om en analyse hos patienter i aktiv behandling for terminal nyreinsufficiens. I dette års udgave er vist en tabel som indledningsvis kvantiterer problemet. En nøjere analyse nåede ikke at blive færdiggjort, men vil blive publiceret senere på året.

Endelig fortsætter samarbejdet med *ERA-EDTA registret*, som hvert år modtager data via DNSL. I år er der etableret et direkte samarbejde mellem ERA-EDTA og DNSL med henblik på at øge antallet af registrerede parametre. Problemerne med tilstrækkeligt kvalificeret dataindput er afgørende for en registrerings succes. Svaret på dette er bl. a. automatisk overførsel af data fra de elektroniske medier, hvor datakilden findes. ERA-EDTA har april 2005 indsendt en ansøgning til EU om etablering og finansiering af en række arbejdsgrupper, som skal muliggøre analyse og kvalitetssikring indenfor et udvidet sæt af data. Såfremt ansøgningen accepteres, vil DNSL deltage i et pilotprojekt om dataekstraktion. Indledningsvis starter det i samarbejde med IT-afdelingen i Københavns amt. Senere tillader erfaringerne forhåbentlig, at snitfladeproblemerne kan gøres universelle og anvendes indenfor hele DNSL's område.

Et samarbejde med *danske nyrepatologers* registrering af nyrelidelser er under udarbejdelse og nært forestående.

Også i år er rapporten delt i en *basisdel*, som viser en række væsentlige demografiske data og nogle tillæg, som mere går i dybden med specielle emner. De specielle emner omfatter i år en analyse af indlæggelsesstatistik, DNSL's forhold til ERA-EDTA samt indledende analyse af cancerdiagnoser. Registrering af patientdød har vist sig at være et svagt punkt i registreringen. Vi har derfor valgt hvert år at samkøre registrets data med CPR-registret. Denne usikkerhed skulle hermed være elimineret.

May 2005

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 10077 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 (ERA-EDTA) and Scandiatransplant.

Data exchange with the Danish Cancer Registry and Scandiatransplant was started in 1997. In 1998 and 2004 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. This year cancer data are updated to 01-01-2004 and a new report started.
The registry was founded and is maintained by the Danish Society of Nephrology (DNS). Reports are published annually.

May 2005

Hans Løkkegaard
National Co-ordinator

Indholdsfortegnelse
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Dialyse/Dialysis

Nyretransplantation /Renal Transplantation

Dødsårsager/Causes of death

Tillæg /Supplement

Fig. 1 Renal centres in Denmark 2005

Renal Centres and Population in Denmark

Transpl. Centre	County	Dialysis center	Population
Skejby	Århus	Skejby	653472
	Nordjylland	Aalborg	495669
	Ringkøbing	Holstebro	274830
	Viborg	Viborg	234659
	Total Skejby		1655863
Odense	Fyn	Odense	475082
	Ribe	Esbjerg	224595
	Sønderjylland	Sønderborg	252936
	Vejle	Fredericia	355691
	Total Odense		1308304
Herlev	Københavns amt	Herlev	
	Total Herlev		618407
Rigshospitalet RH	Bornholm	Rønne	43774
	Frederiksberg	RH	91721
	Frederiksborg	Hillerød	373688
	Færørerne	RH	48228
	Grønland	RH	56854
	København	RH	501664
	Roskilde	Roskilde	237089
	Storstrøm	Nykøbing F	261884
	Vestsjælland	Holbæk	302479
	Total RH		**1917381**
Total population 01.01.2004			**5497759**

Table 1. Population and renal centres in Denmark as of 01.01.2004. Statistical Yearbook 2004

Prevalence of ESRD 1991 - 2004

Patients on dialysis or with a functioning graft

Treatment	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
CAPD	336	329	362	366	372	359	384	380	412	363	351	303	305	287
APD	12	10	16	29	33	45	66	78	112	161	246	279	319	328
Center-IPD	35	27	29	18	18	13	10	8	8	8	4		4	2
PD + HD									2	7	5	10	8	6
Home-IPD	1	2	1	0	5	15	12	11	6	3	1	1	1	1
Center-HD	608	623	711	764	854	936	1043	1165	1280	1438	1562	1681	1683	1736
Lim. Care	37	38	42	43	52	62	57	68	64	73	72	61	76	76
Home-HD	21	17	16	17	15	13	9	7	9	11	14	24	33	52
In dialysis	**1050**	**1046**	**1177**	**1237**	**1349**	**1443**	**1581**	**1717**	**1895**	**2071**	**2260**	**2359**	**2429**	**2488**
Home	370	358	395	412	425	432	471	476	543	552	622	617	666	674
PD	349	341	379	395	410	419	462	469	532	534	603	583	625	616
HD	21	17	16	17	15	13	9	7	9	11	14	24	33	52
PD+HD									2	7	5	10	8	6
Center	680	688	782	825	924	1011	1110	1241	1352	1519	1638	1742	1763	1814
Transpl.	**927**	**1005**	**1073**	**1137**	**1154**	**1218**	**1230**	**1257**	**1308**	**1346**	**1387**	**1469**	**1558**	**1649**
In treat-ment	**1977**	**2051**	**2250**	**2374**	**2503**	**2661**	**2811**	**2974**	**3203**	**3417**	**3647**	**3828**	**3987**	**4137**

Table 2. Treatment modalities for ESRD 1991- 2004. The number of patients on dialysis has increased steadily from 1991 through 2004. APD is now the most frequent used method in peritoneal dialysis. Home-HD has increased significantly since 1998.

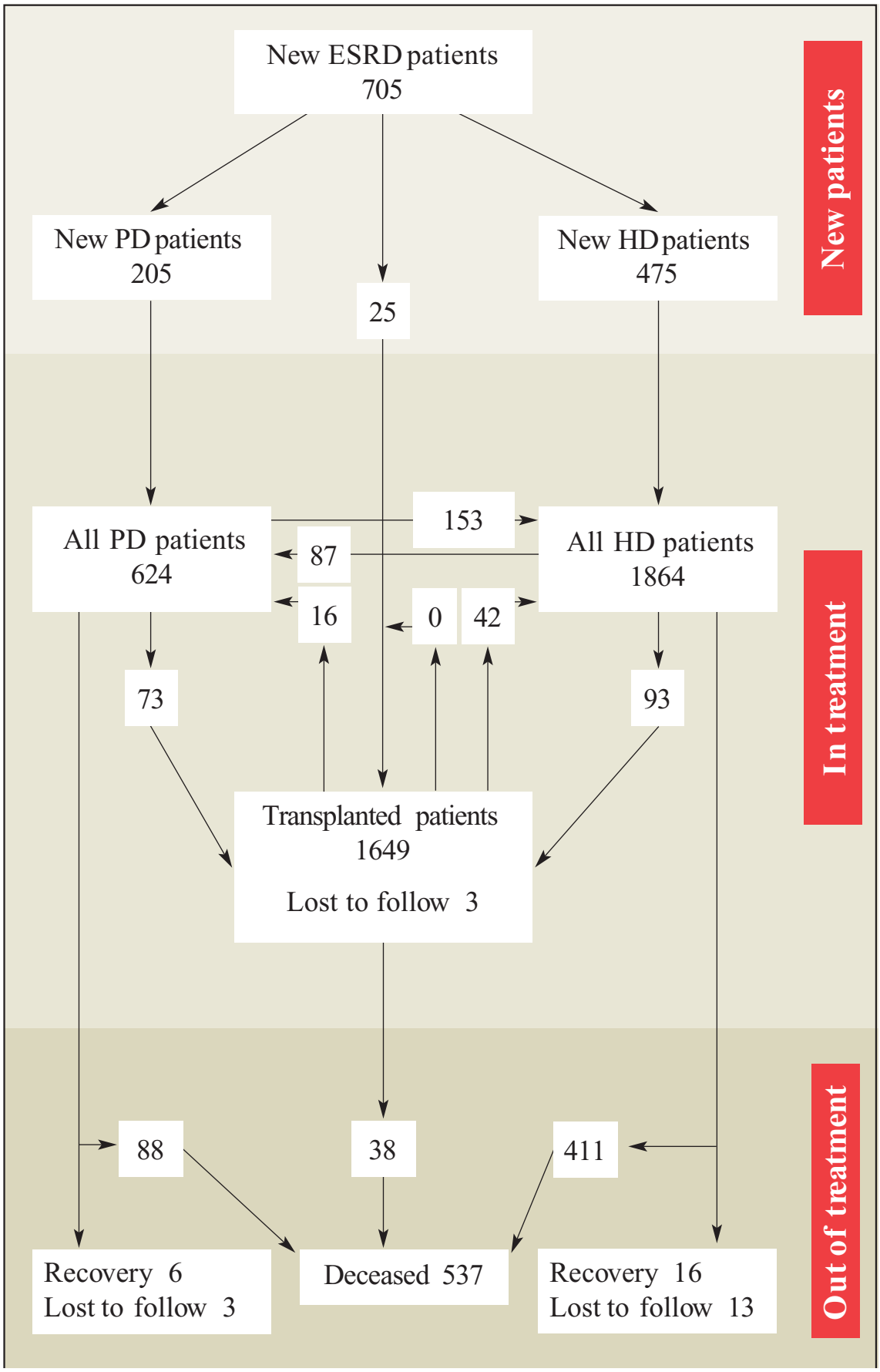


Fig. 2. Changes in the number of patients treated for ESRD during 2004 – status as of 31.12.04. 705 patients started treatment (HD, PD, RAT) in 2004. At the end of the year 2488 patients were on dialysis and 1649 had a functioning renal allograft.

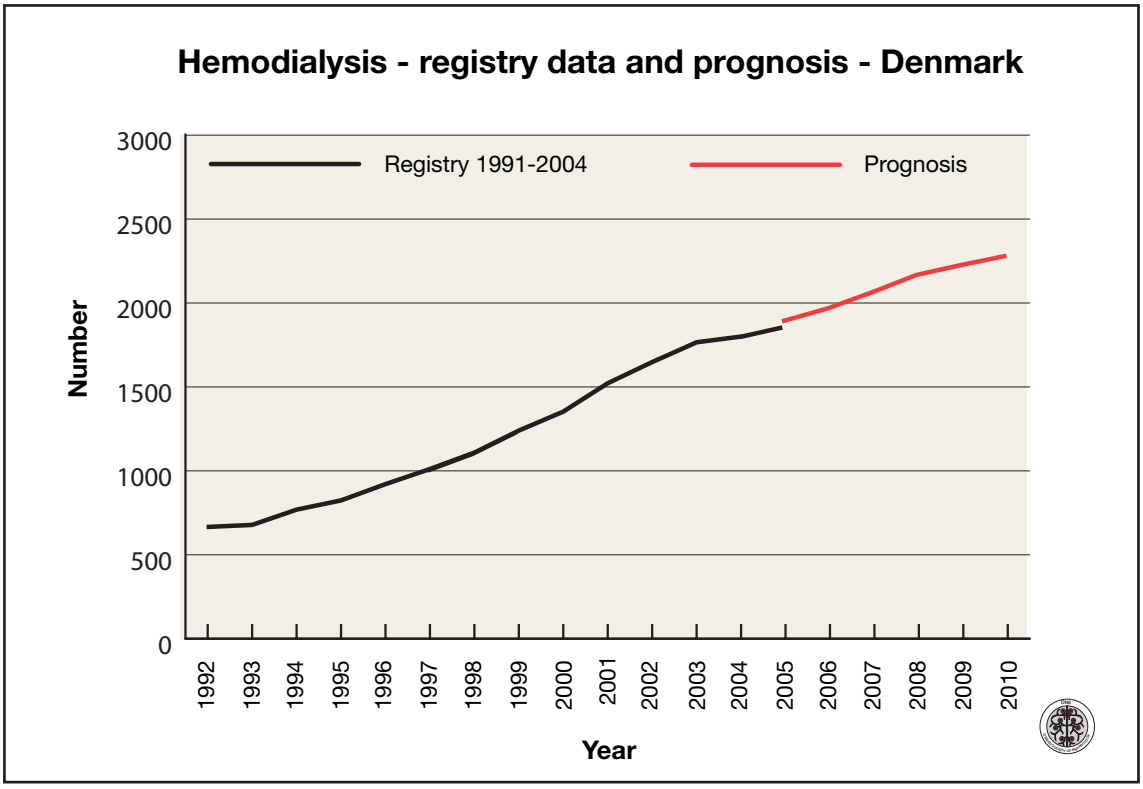

Hemodialysis - registry data and prognosis - Denmark
Registry 1991-2004
Prognosis
Number
3000
2500
2000
1500
1000
500
0
1992
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010
Year

Fig. 3

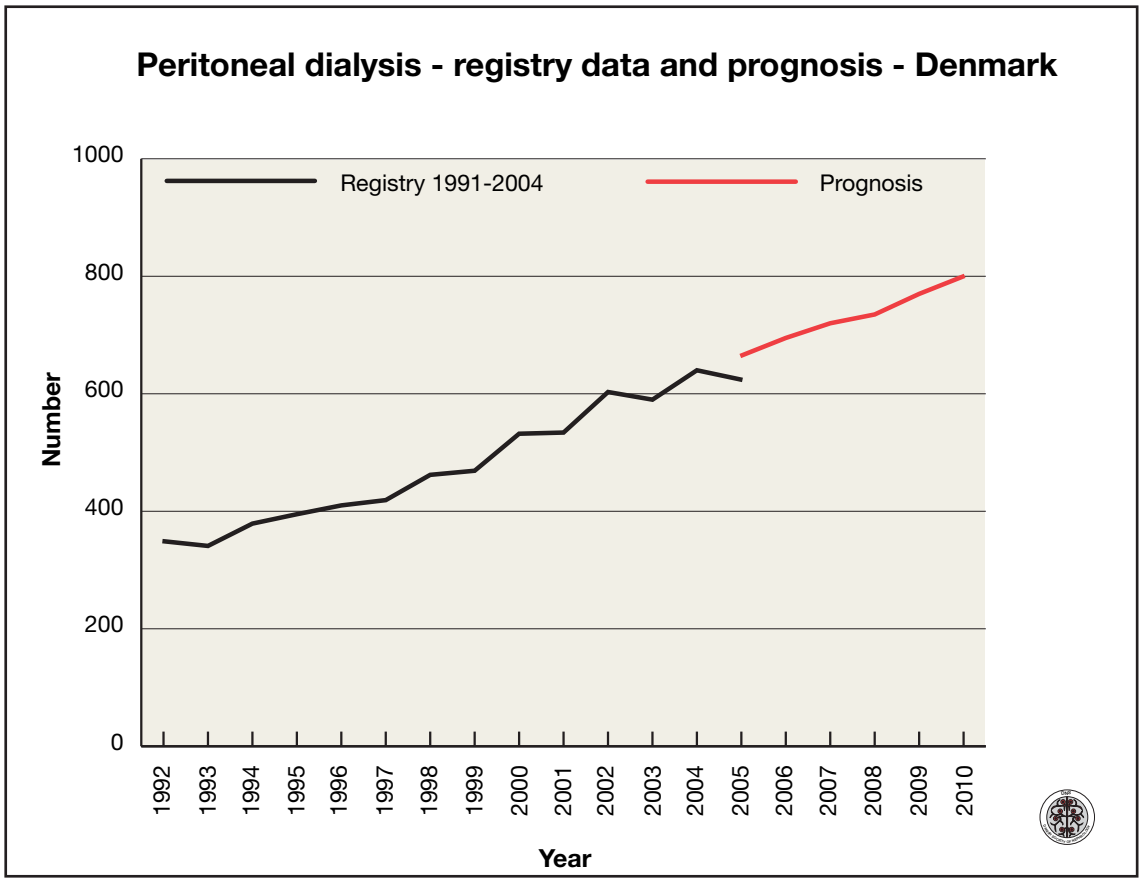

Peritoneal dialysis - registry data and prognosis - Denmark
Registry 1991-2004
Prognosis
Number
1000
800
600
400
200
0
1992
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010
Year

Fig. 4

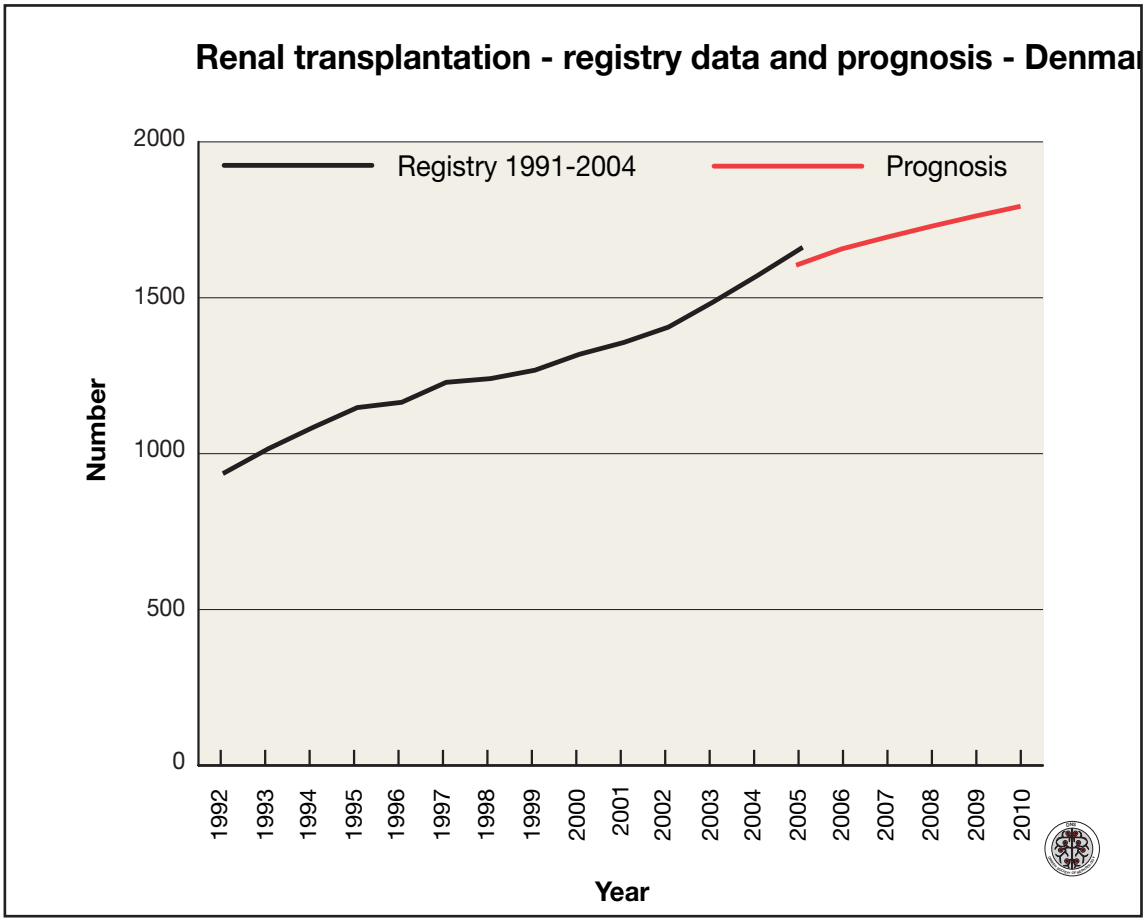


Fig. 5

Fig. 3, 4 and 5. Prognostic calculations concerning the number of hemodialysis (HD), peritoneal dialysis (PD) and transplanted patients from 01.01.2005 to 01.01.2010.The calculations are based on data from 1991 – 2004.

The Prognosis is based on the assumption, that the incidence has reached a stable maximum, and that mortality is unchanged. During the last 4 years the incidence has been stable - 130 per million inhabitants. Death rate also unchanged. See table 15.
For further details see Peter Vestergaard: Prognosis for dialysis and kidney transplant activity in Denmark (DNS landsregister 2003).

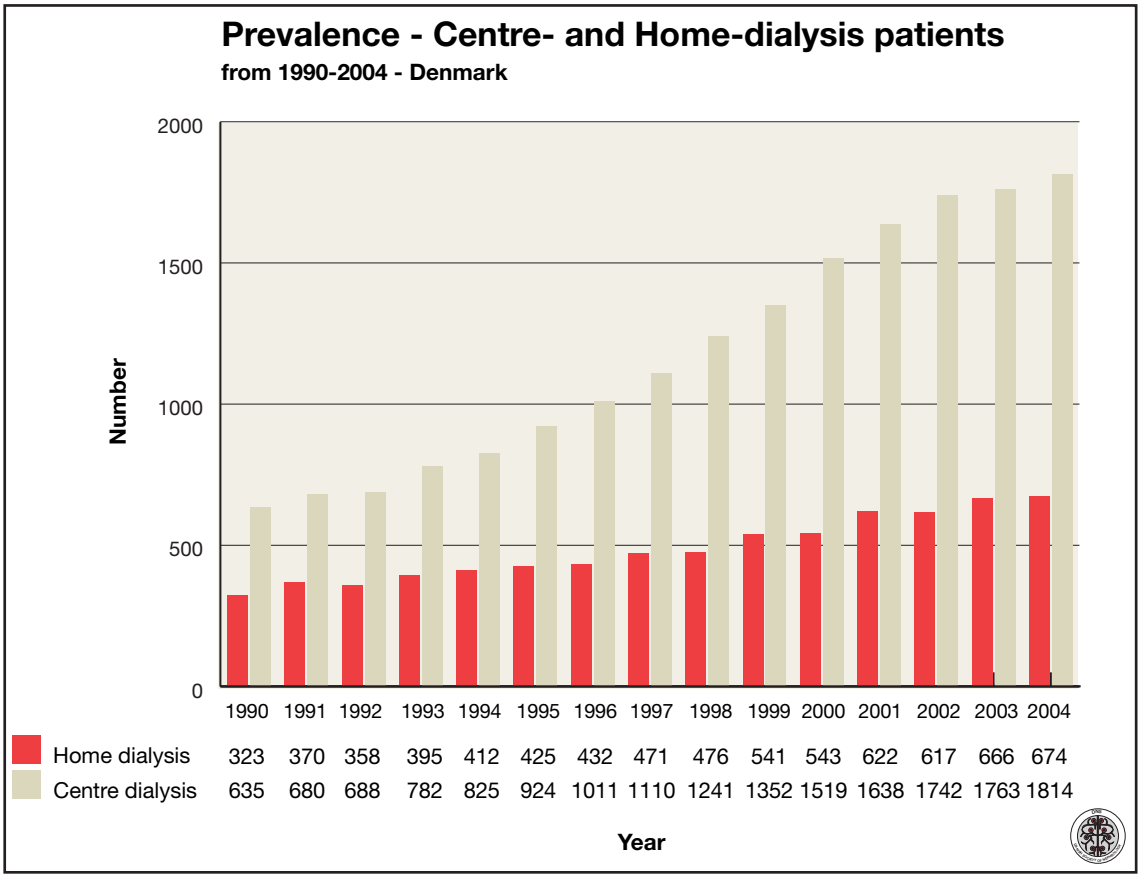


Fig. 6

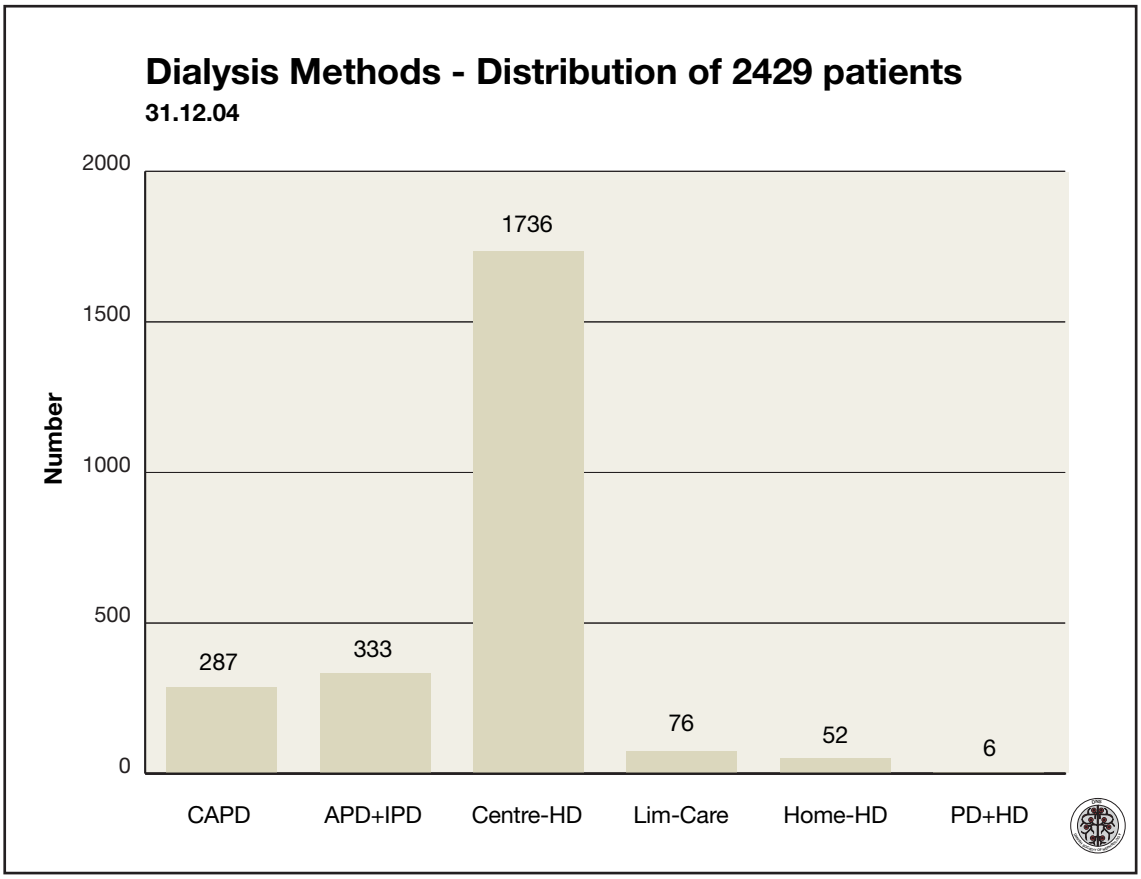


Fig. 7 Dialysis methods used in 2004

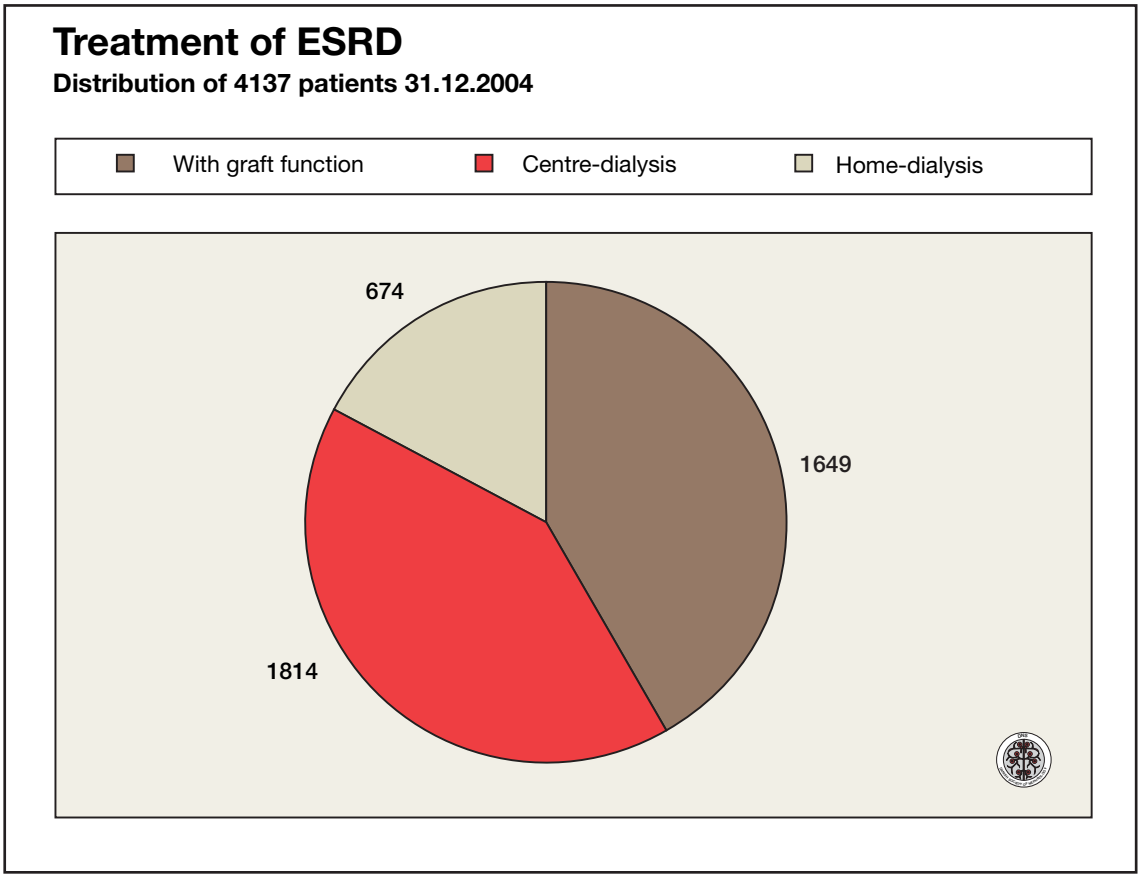

Treatment of ESRD
Distribution of 4137 patients 31.12.2004
With graft function
Centre-dialysis
Home-dialysis
674
1649
1814

Fig. 8.

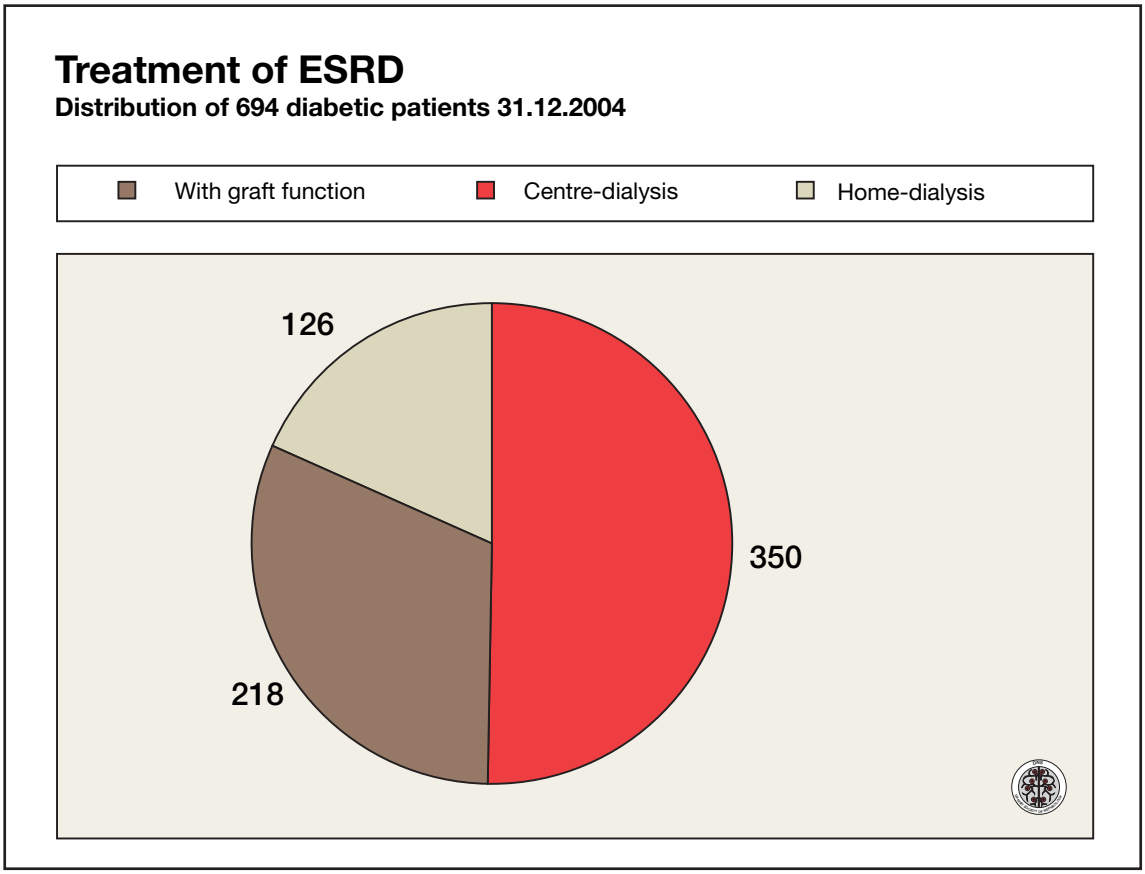

Treatment of ESRD
Distribution of 694 diabetic patients 31.12.2004
With graft function
Centre-dialysis
Home-dialysis
126
350
218

Fig. 9.

Incidence of ESRD

Centre	1990		1991		1992		1993		1994		1995		1996		1997		1998		1999		2000		2001		2002		2003		2004	
	No.	Inc.	No.	Inc.	No.	Inc.	No.	Inc.	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	36	160	25	111	22	98	27	120
Fredericia	14	42	21	63	17	51	26	79	25	75	29	86	26	77	31	91	33	96	42	122	56	162	43	123	39	111	47	135	51	143
Herlev	45	75	39	65	36	60	39	65	50	83	40	66	54	89	66	108	62	102	75	123	47	77	67	109	76	123	78	127	96	155
Hillerød																							41	112	38	103	46	126	66	176
Holbæk					1	3			2	7	2	7	22	76	35	120	24	82	24	82	40	137	40	136	38	127	35	118	28	93
Holstebro	10	37	11	37	13	48	19	71	21	78	28	104	28	104	17	62	24	88	29	107	30	110	41	150	26	95	25	92	35	127
Hvidovre	33	60	48	87	39	71	59	107	43	78	49	88	68	121																
Nykøbing F																									9	RH	6	RH	3	RH
Odense	45	98	52	73	39	55	42	59	55	118	55	118	31	66	51	108	43	91	59	125	47	100	67	142	52	110	81	171	56	118
Rigshosp.	70	56	87	69	110	87	124	109	115	153	119	114	103	136	97	90	177	137	183	141	218	168	142	150	154	163	137	136	100	108
Roskilde							12	54	15	68	13	58	12	57	17	75	37	162	21	92	23	101	28	121	24	102	12	52	29	122
Rønne															1	22	6	136	5	111	2	45	1	23		RH		RH	5	RH
Skejby	54	90	49	81	39	65	66	110	47	77	73	118	45	73	74	118	73	117	79	125	103	163	114	179	102	158	114	179	102	156
Sønderbg.											14	56	28	111	28	110	24	95	28	110	18	71	30	118	30	118	25	99	23	91
Viborg	19	83	18	78	13	56	26	113	26	113	25	109	19	85	25	107	19	82	22	94	22	94	32	137	29	124	28	120	29	124
Ålborg	30	62	34	69	38	77	54	111	32	66	48	98	56	114	41	85	48	98	54	110	60	122	71	144	56	113	46	93	55	111
Denmark	**330**	**63**	**365**	**70**	**360**	**69**	**492**	**94**	**445**	**86**	**508**	**97**	**510**	**98**	**539**	**100**	**587**	**104**	**653**	**121**	**699**	**129**	**753**	**138**	**698**	**128**	**702**	**129**	**705**	**131**

Table 3. New patients (number per million per year) 1990 – 2004 in the renal centres. The incidence in Denmark was rather stable from 1995 - 98 - about 100. Since then the incidence has increased and is now about 130 – stable during the last 5 years.

Age distribution 1990 - 2004

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
2001	2	3	5	9	19	26	27	8	61
2002	2	2	7	9	15	26	30	9	65
2003	1	5	5	11	16	26	28	8	62
2004	3	3	5	12	16	26	25	10	61
Population	4	16	14	15	11	9	7	5	21

Table 4. Percentage age distribution of patients starting treatment for ESRD 1990-2004
For comparison the age distribution of the Danish population is also indicated.

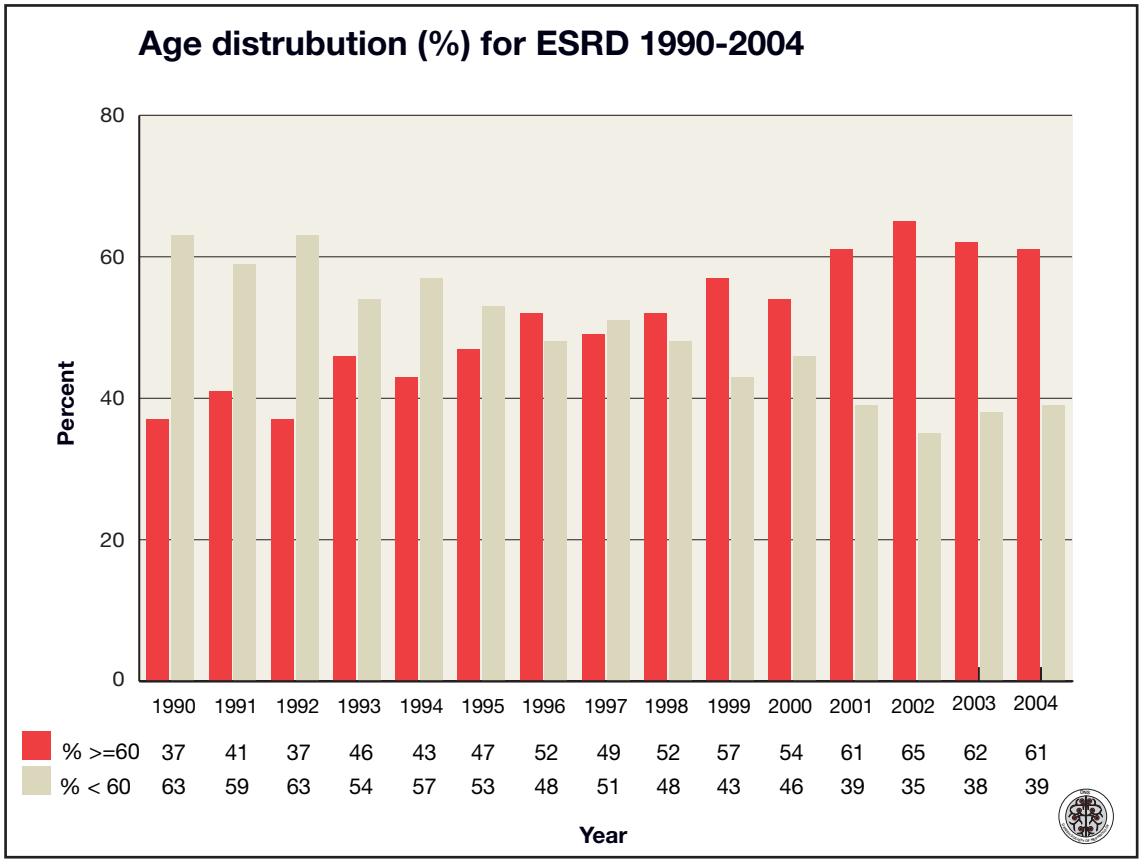

Age distrubution (%) for ESRD 1990-2004
Percent
80
60
40
20
0
1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004
% >=60 37 41 37 46 43 47 52 49 52 57 54 61 65 62 61
% < 60 63 59 63 54 57 53 48 51 48 43 46 39 35 38 39
Year

Fig. 10

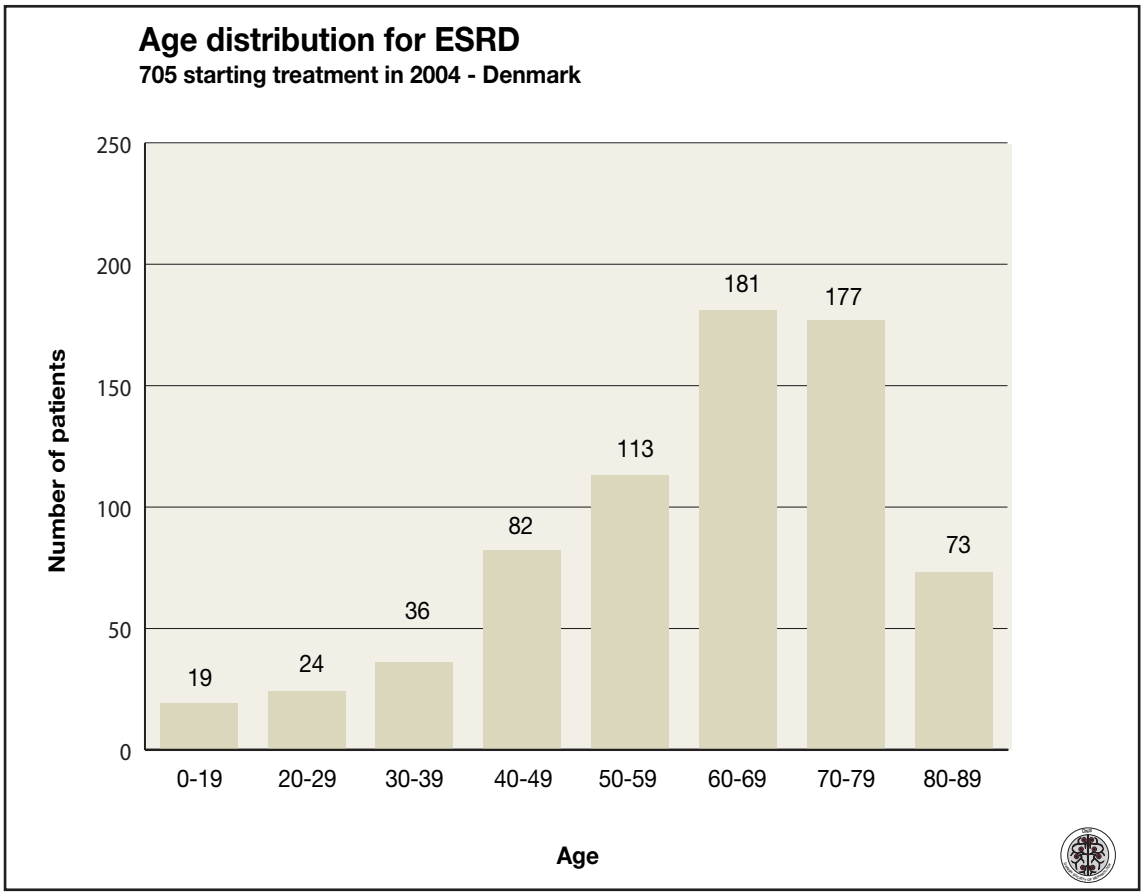

Age distribution for ESRD
705 starting treatment in 2004 - Denmark
Number of patients
250
200
150
100
50
0
19
24
36
82
113
181
177
73
0-19
20-29
30-39
40-49
50-59
60-69
70-79
80-89
Age

Fig. 11

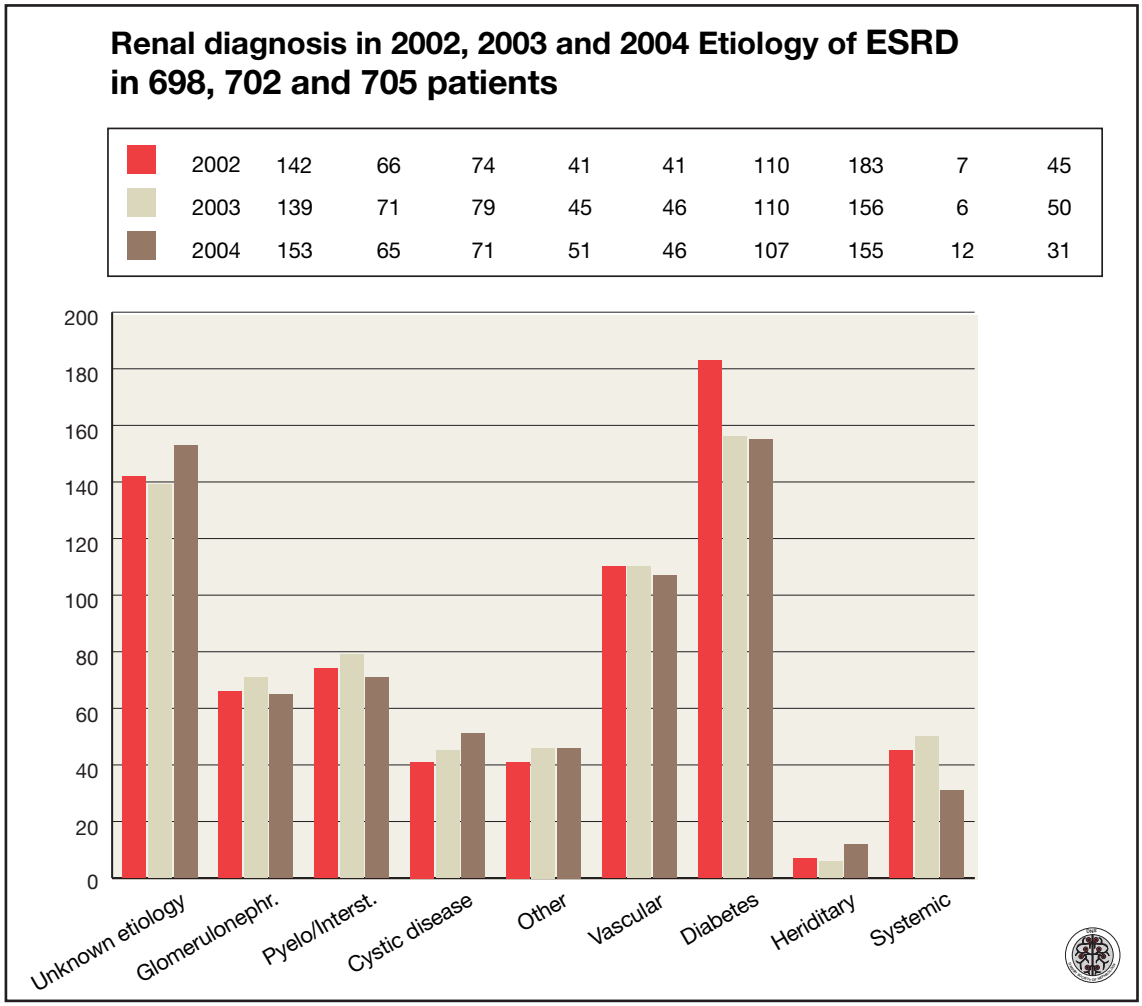


Fig. 12

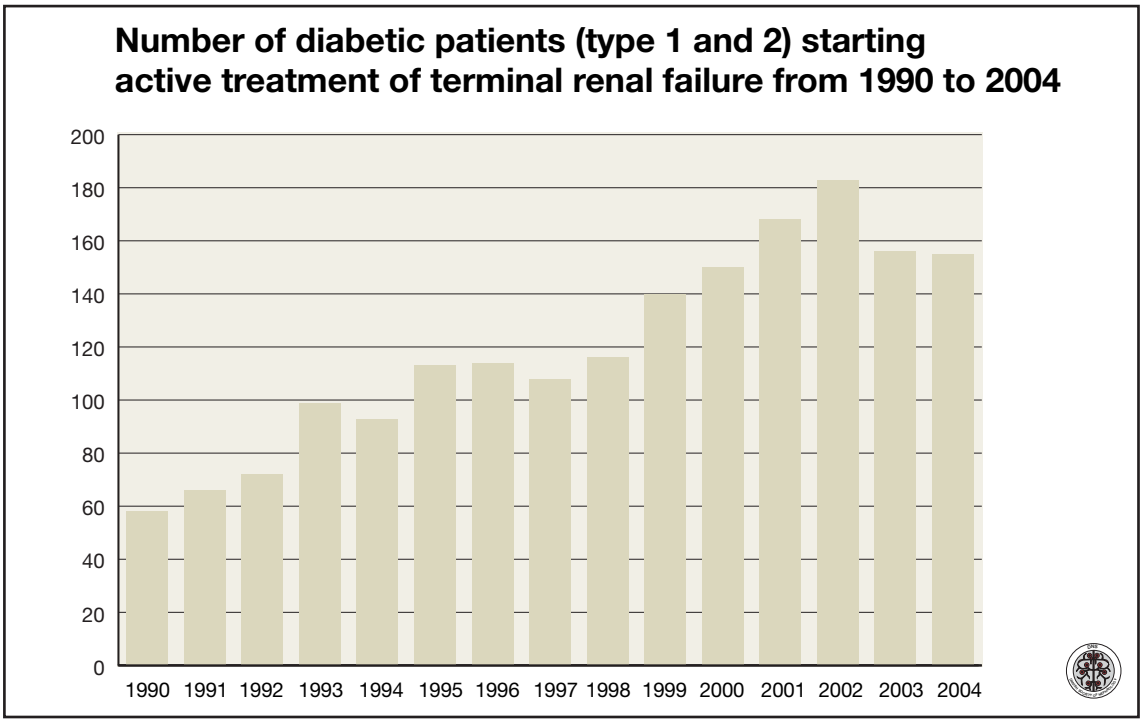


Fig. 13. Number of diabetic patients (type 1 and 2) starting active treatment of terminal renal failure from 1990 to 2004

Renal Diagnoses 2004

Age Renal diagnosis	0-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	All
ESRD,unknown causes	1	4	3	12	21	37	54	21	153
Glomerulonephritis	3	8	7	14	11	12	4	6	65
Pyelo/interst. Nephritis	3	4	4	6	7	17	19	11	71
Cystic renal disease	1	1	0	3	17	14	11	4	51
Alport disease	1	1	0	1	0	1	0	0	4
Other heriditary disease	4	1	1	0	0	0	0	0	6
Renal hypoplasia	2	0	0	0	0	0	0	0	2
Renal vascular disease	1	2	5	10	12	26	37	14	107
Renal vasculitis	0	1	0	1	3	2	5	2	14
Diabetes (IDDM)	1	2	12	26	19	14	6	1	79
Diabetes (NIDDM)	0	0	0	3	9	32	23	9	76
Systemic disease	1	1	1	3	8	11	4	2	31
Other renal diseases	1	1	3	3	6	15	14	3	46
Sum	**19**	**24**	**36**	**82**	**113**	**181**	**177**	**73**	**705**

Table 5. Renal diagnosis in patients starting treatment for ESRD in 2004. The patients are stratified according to age.

Renal Diagnoses 1990 - 2004

Year Renal diagnosis	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	SUM
ESRD,unknown causes	55	61	62	81	76	82	103	110	105	131	134	136	142	139	153	1570
Glomerulonephritis	57	68	67	81	69	82	74	72	85	99	82	86	66	71	65	1124
Pyelo/interst. Nephritis	45	59	57	76	59	67	58	72	81	78	92	83	74	79	71	1051
Cystic renal disease	43	33	30	47	34	43	37	40	45	47	44	53	41	45	51	633
Alport disease	4	3	2	2	2	1	4	2	1	0	3	2	3	2	4	35
Other heriditary disease	4	3	2	4	1	6	2	4	4	3	2	6	2	0	6	49
Renal hypoplasia	1	6	1	6	4	4	1	3	6	3	3	5	2	4	2	51
Renal vascular disease	34	44	36	57	60	68	58	58	79	85	95	95	110	110	107	1096
Renal vasculitis	5	3	0	6	10	13	17	15	12	16	16	12	13	18	14	170
Diabetes (IDDM)	52	53	63	76	69	73	73	65	79	95	77	85	85	74	79	1098
Diabetes (NIDDM)	6	13	9	23	24	40	41	43	37	50	73	83	98	82	76	698
Systemic disease	20	13	26	18	24	22	33	34	32	36	43	39	32	32	31	435
Other renal diseases	4	6	5	15	13	7	9	21	21	10	35	68	30	46	46	336
Sum	**330**	**365**	**360**	**492**	**445**	**508**	**510**	**539**	**587**	**653**	**699**	**753**	**698**	**702**	**705**	**8346**

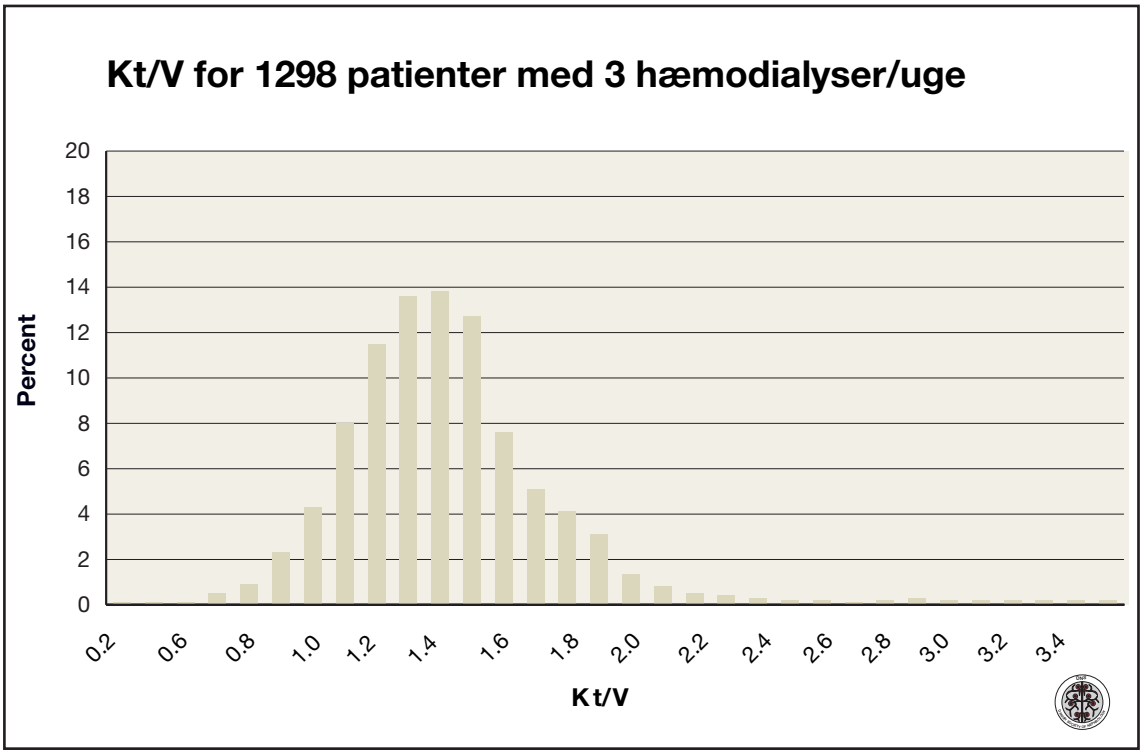
Table 6. Renal diagnoses in patients starting treatment 1990 - 2004.

Hemodialysis – quality control

Data for årets sidste Kt/V-måling fra 1466 hæmodialysepatienter

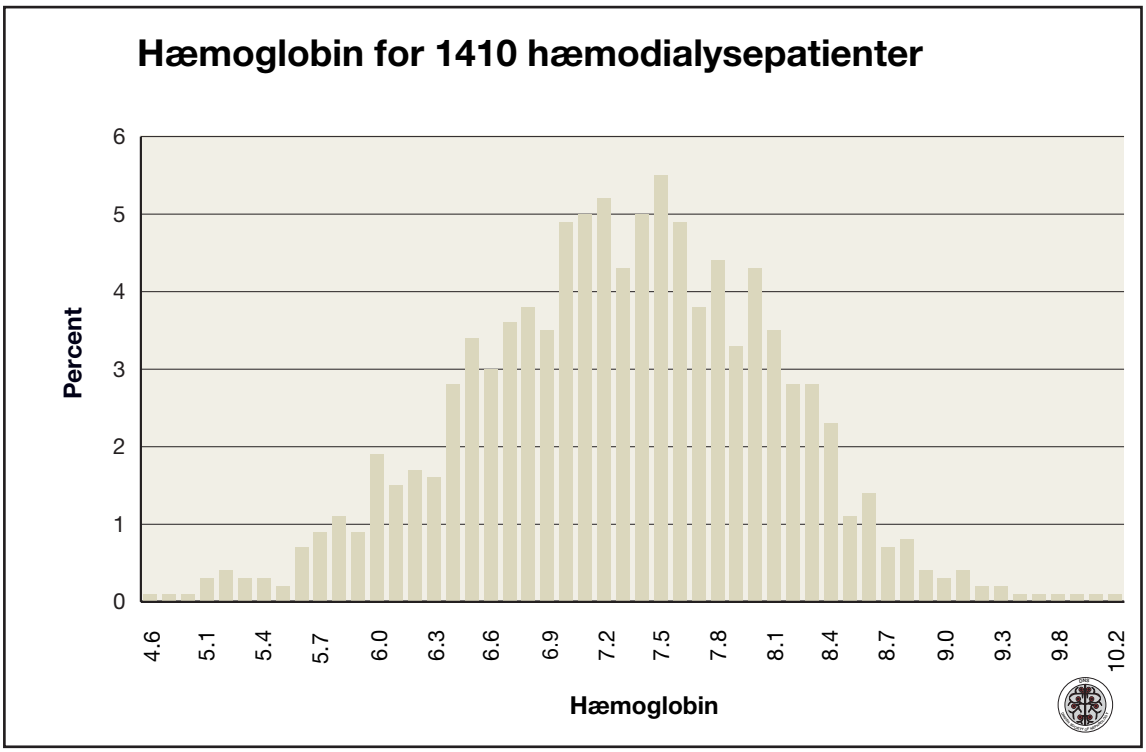
Dialyser/uge	1	2	3	4	5	7
Antal patienter	7	113	1298	35	12	1
Kt/V gennemsnit	2,06	1,99	1,64	1,34	1,59	1,50

Table 7 shows average values for Kt/V in patients treated with 1-7 dialysis per week. Most patients are dialyses 3 times a week. Year=2004



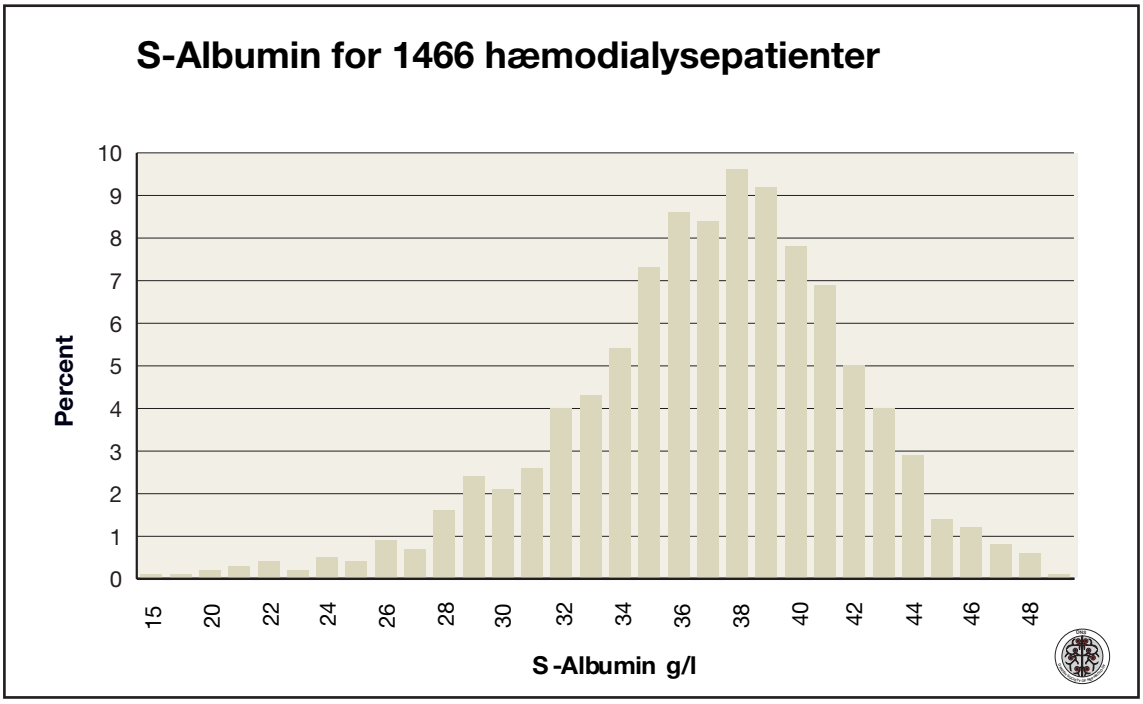
Kt/V ≥ 1,2 var opnået for 72% (68% af mændene og 81% af kvinderne).

Fig. 14 shows Kt/V in 1298 patients with 3 hemodialysis per week. Kt/V >= 1.2 was found in 72% (men 68%, women 81%). Year=2004



82% havde hæmoglobin ≥ 6,5 mmol/l (83% af mændene og 79% af kvinderne).

Fig. 15 shows hemoglobin in 1410 HD patients. Hemoglobin >= 6.5 was found in 82% (men 83%, women 79%). Year=2004



66% havde S-Albumin ≥ 35 g/l (67% af mændene og 66% af kvinderne).

Fig. 16 shows S-albumin in 1466 HD patients. 66% had S-albumin >= 35g/l (men 67%, women 66%). Year=2004

Renal Transplantation 2004

	Cadaver kidney				Living donor kidney		
	transplantation nummer				transplantation nummer		
Center	1	2	3	4	1	2	***Sum***
Herlev	19	3	1	0	7	2	32
Odense	19	8	0	2	8	0	37
Rigshospitalet	35	3	1	0	12	4	55
Skejby	39	5	1	0	18	1	64
Total	112	19	3	2	45	7	188

Table 8. Renal transplantations 2004, stratified according to source of donor organ, transplantation number (1-4) and transplantation center

Renal transplantation 1991–2004

Renal transplantation 1991 - 2004									
	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	16	7	0	27	5	0	0	153
2001	95	23	4	0	33	6	1	0	162
2002	102	26	3	1	38	1	0	0	171
2003	98	27	4	0	44	0	3	0	176
2004	112	19	3	2	45	7	0	0	188

Table 9. Renal transplantations 1991 – 2004, stratified according to source of donor organ, transplantation number (1-4) and year of transplantation.

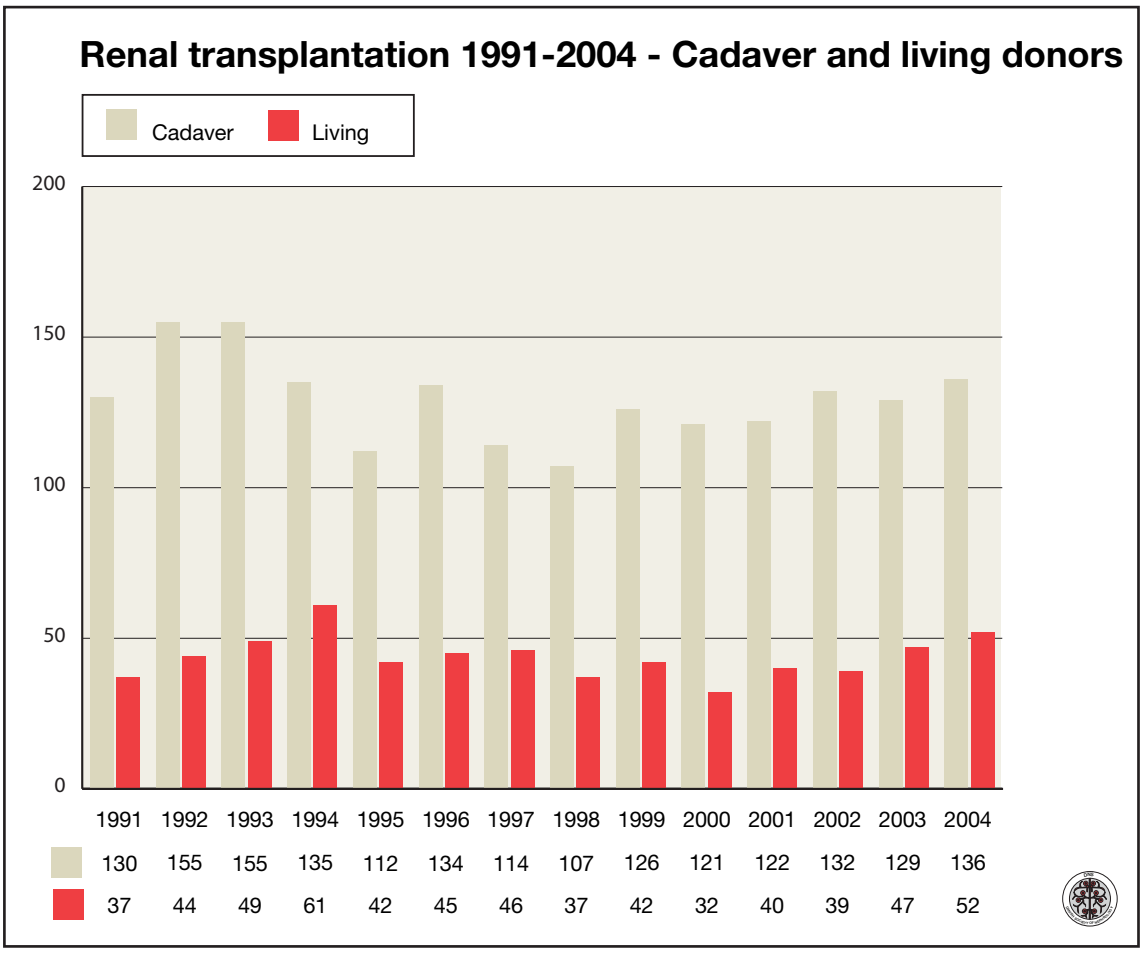

Renal transplantation 1991-2004 - Cadaver and living donors
Cadaver
Living
200
150
100
50
0
1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004
130 155 155 135 112 134 114 107 126 121 122 132 129 136
37 44 49 61 42 45 46 37 42 32 40 39 47 52

Fig. 17

Living donor-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
2001	13	4	11	2	0	5	5	40
2002	23	4	4	0	0	2	6	39
2003	22	2	6	2	0	6	9	47
2004	30	5	3	1	0	5	8	52

Table 10. Transplantation with living donor kidneys 1991 - 2004. Stratified according to donor-recipient relationship and year of transplantation.

Transplantation follow-up centres in 2004

Center	No	Center	No.
Esbjerg	7	Rigshospitalet	475
Fredericia	50	Roskilde	30
Herlev	258	Rønne	0
Hillerød	1		
Holbæk	12	Sønderb.	2
Holstebro	63	Viborg	66
Nykøbing F	0	Aalborg	114
Odense	261	Skejby	310

Table 11. The distribution of ambulatory follow up of 1649 Danish renal transplant patients in 15 nephrological centres. It can be seen that most nephrological centres are involved in controlling stable renal transplant patients. The four transplantation centres are marked.

Transplantation in foreign countries

Year	Number	No. Different Centres
1990	1	1
1991	1	1
1992	0	
1993	3	2
1994	1	1
1995	1	1
1996	0	
1997	2	2
1998	4	2
1999	4	4
2000	3	3
2001	4	3
2002	2	2
2003	7	4
2004	6	3
Total number	39	I alt fra 10 forskellige centre

Table 12 shows, that 39 patients dialysed in 10 different Danish centres, have received kidney transplantation in other countries during a period of 14 years.

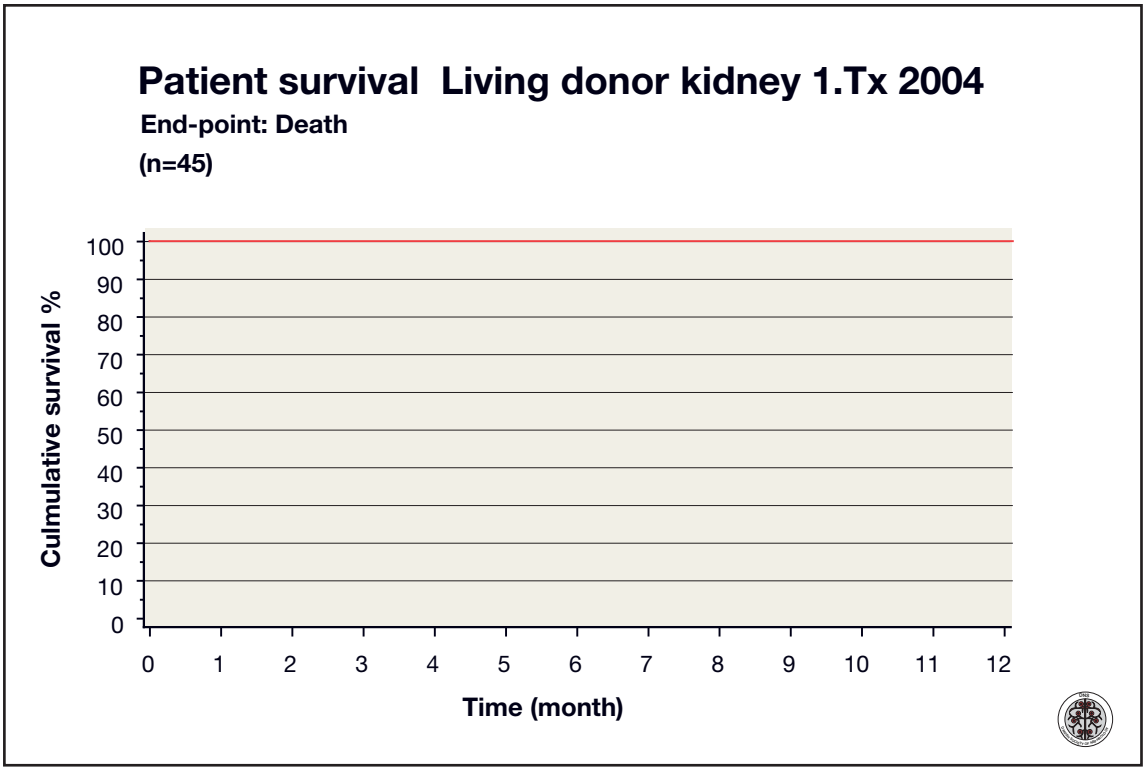

Patient survival Living donor kidney 1.Tx 2004
End-point: Death
(n=45)
Culmulative survival %
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12
Time (month)

Fig. 18.

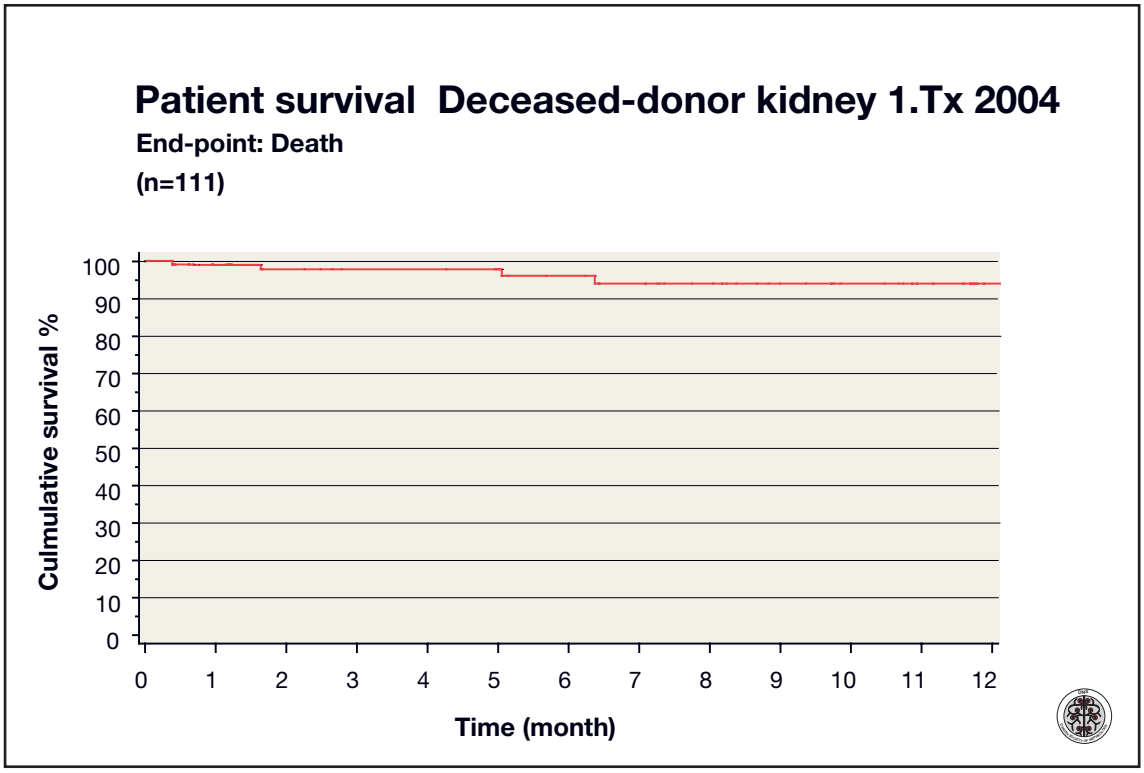

Patient survival Deceased-donor kidney 1.Tx 2004
End-point: Death
(n=111)
Culmulative survival %
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12
Time (month)

Fig. 19.

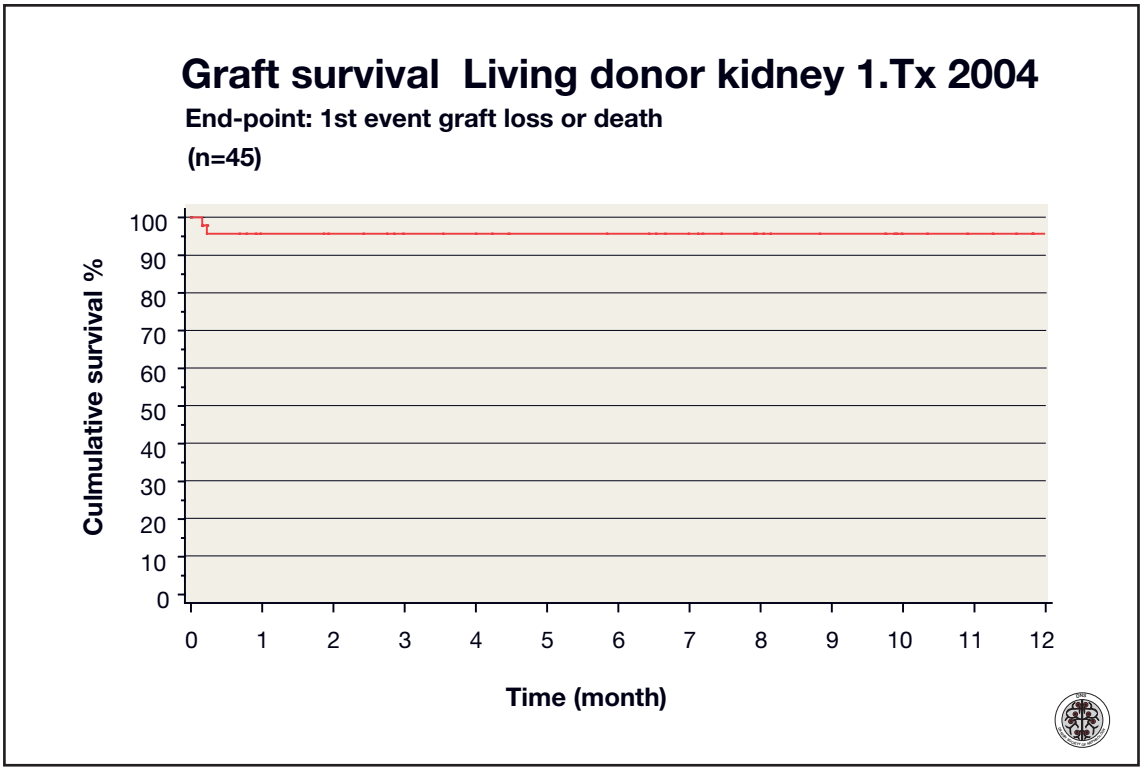

Graft survival Living donor kidney 1.Tx 2004
End-point: 1st event graft loss or death
(n=45)
Culmulative survival %
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12
Time (month)

Fig. 20

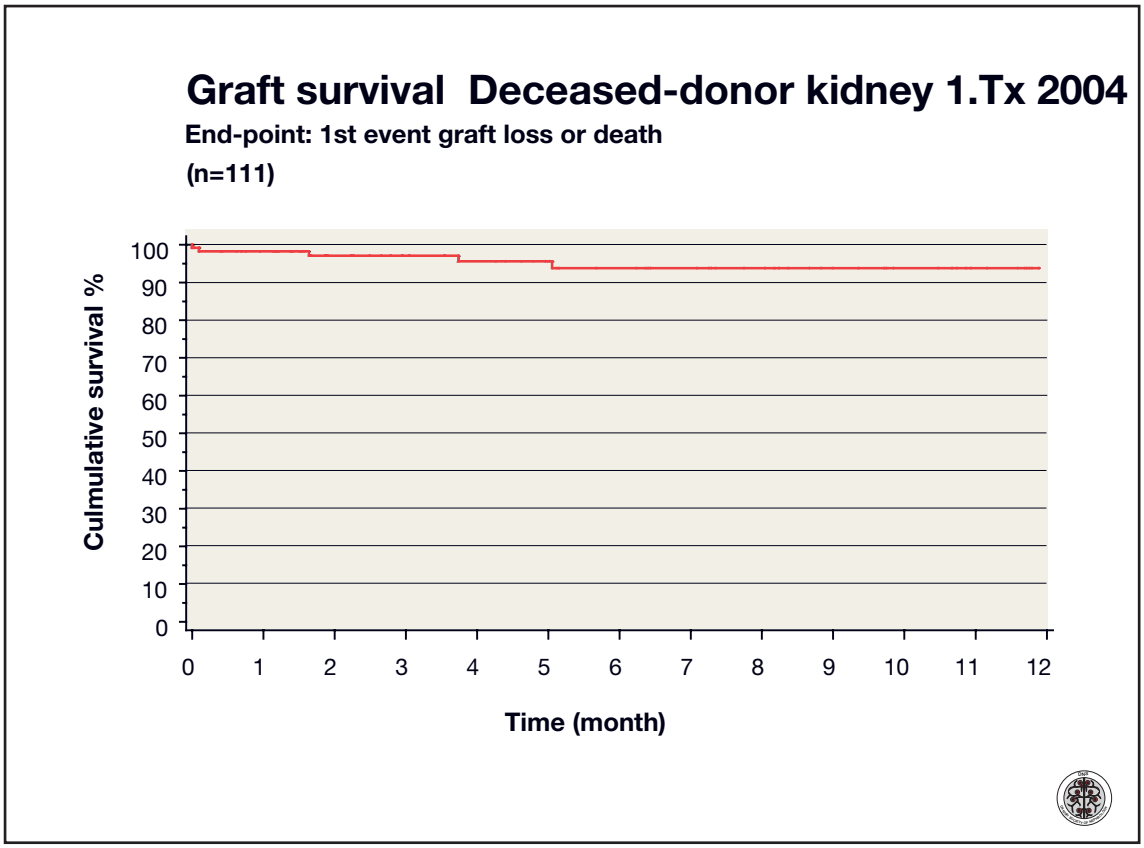

Graft survival Deceased-donor kidney 1.Tx 2004
End-point: 1st event graft loss or death
(n=111)
Culmulative survival %
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12
Time (month)

Fig. 21

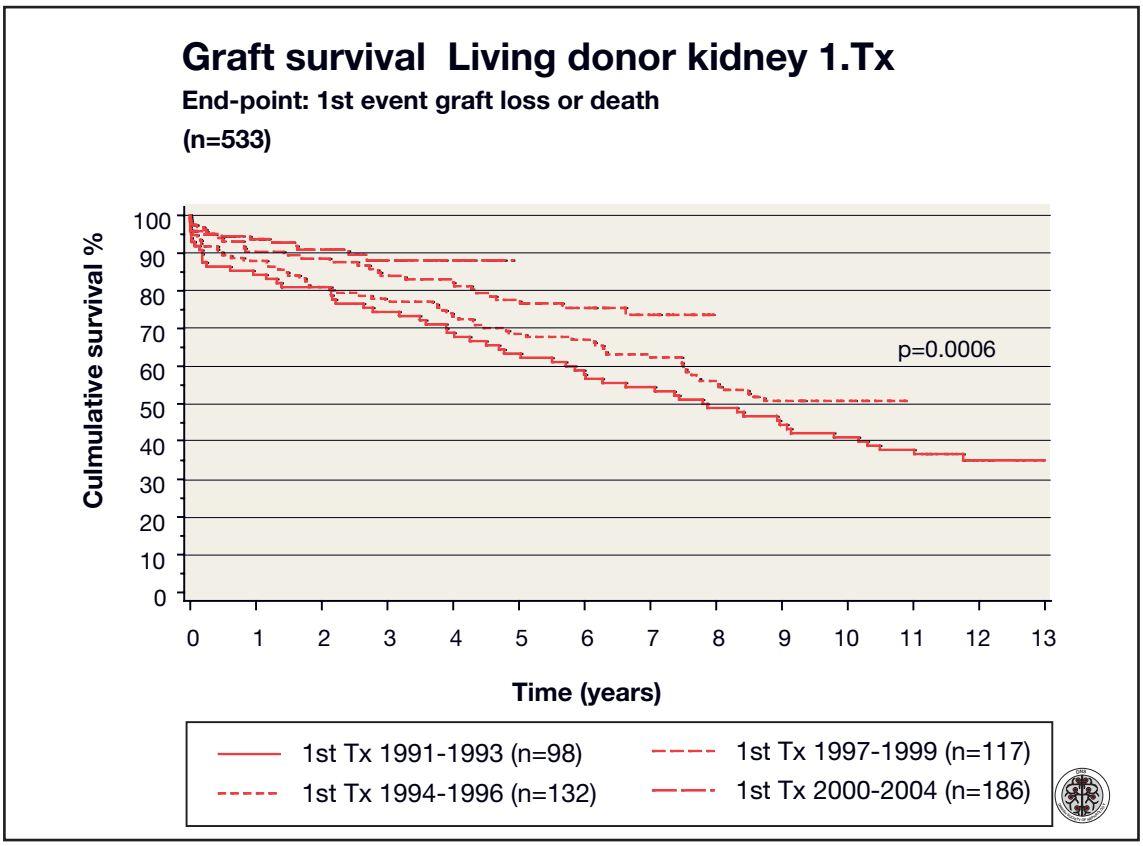

Graft survival Living donor kidney 1.Tx
End-point: 1st event graft loss or death
(n=533)
Culmulative survival %
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12 13
Time (years)
p=0.0006
1st Tx 1991-1993 (n=98)
1st Tx 1994-1996 (n=132)
1st Tx 1997-1999 (n=117)
1st Tx 2000-2004 (n=186)

Fig. 22.

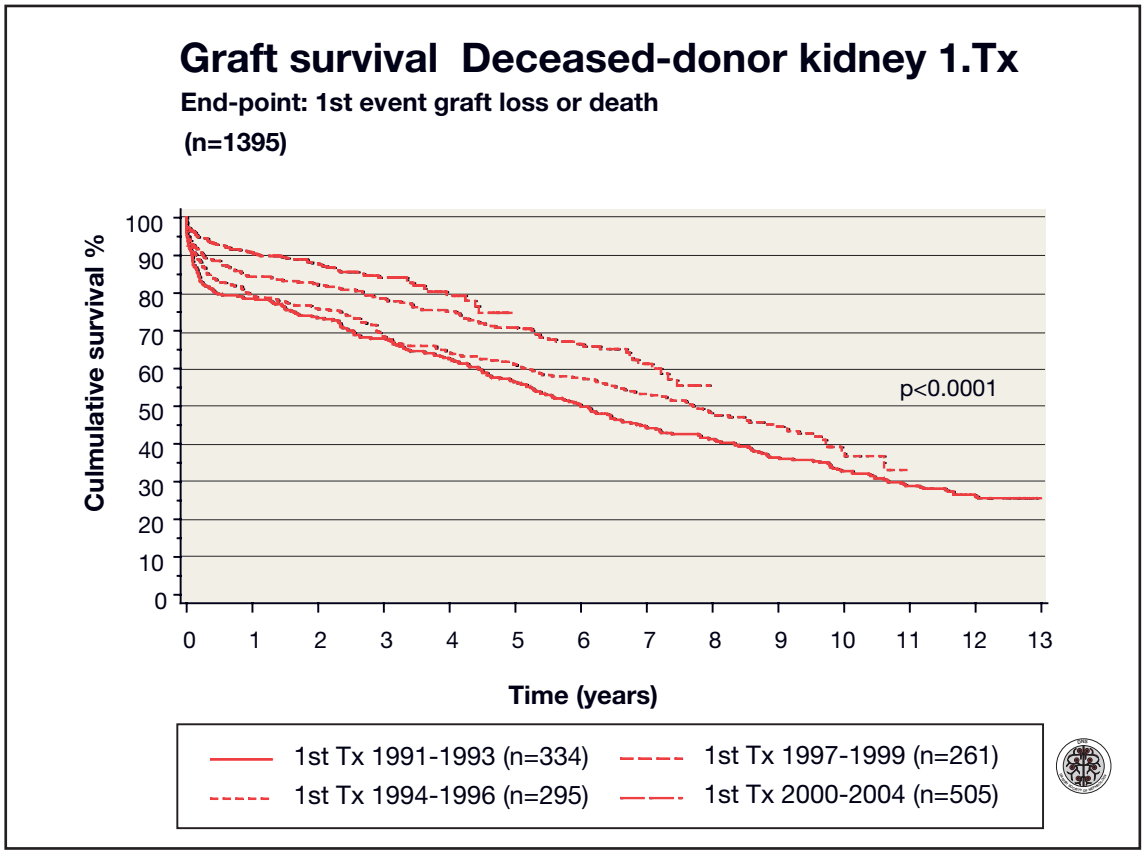

Graft survival Deceased-donor kidney 1.Tx
End-point: 1st event graft loss or death
(n=1395)
Culmulative survival %
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12 13
Time (years)
p<0.0001
1st Tx 1991-1993 (n=334)
1st Tx 1994-1996 (n=295)
1st Tx 1997-1999 (n=261)
1st Tx 2000-2004 (n=505)

Fig. 23.

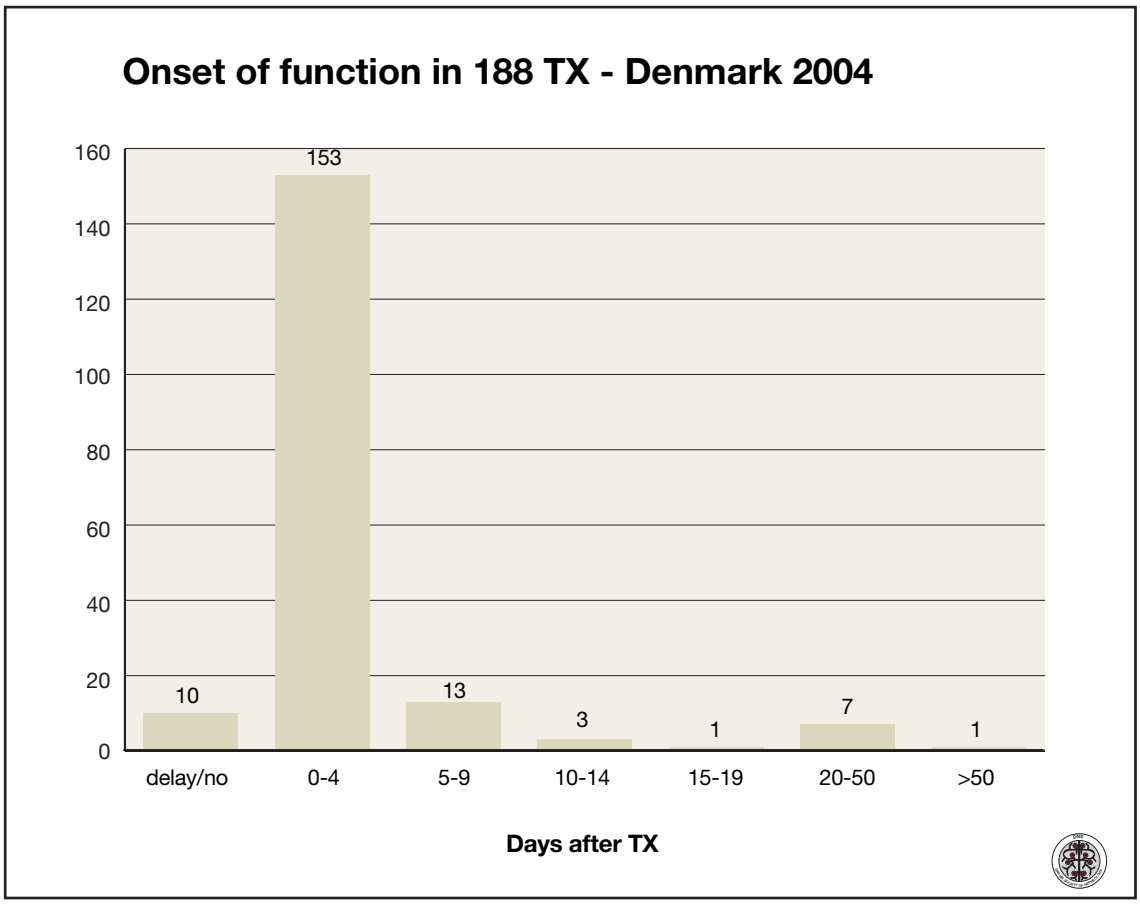


Fig. 24 shows onset of function in 188 patients transplanted in Denmark 2004. Most kidneys functioned within the first week. Ten kidneys didn't function at the end of the year, either due to never functioning (4) or postponed renal function (6).

Causes of death

Causes of death 2004					
	Hemodialysis	P-dialysis	HD+PD	Renal-Tx	Sum
Cardiac	113	33		4	150
Vascular	56	7	1	7	71
Infection	81	22	1	8	112
Malignancy	33	6		8	47
Other causes	128	18		11	157
Sum	411	86	2	38	537

Table 14. Causes of death in 537 patients who died in 2004. 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.

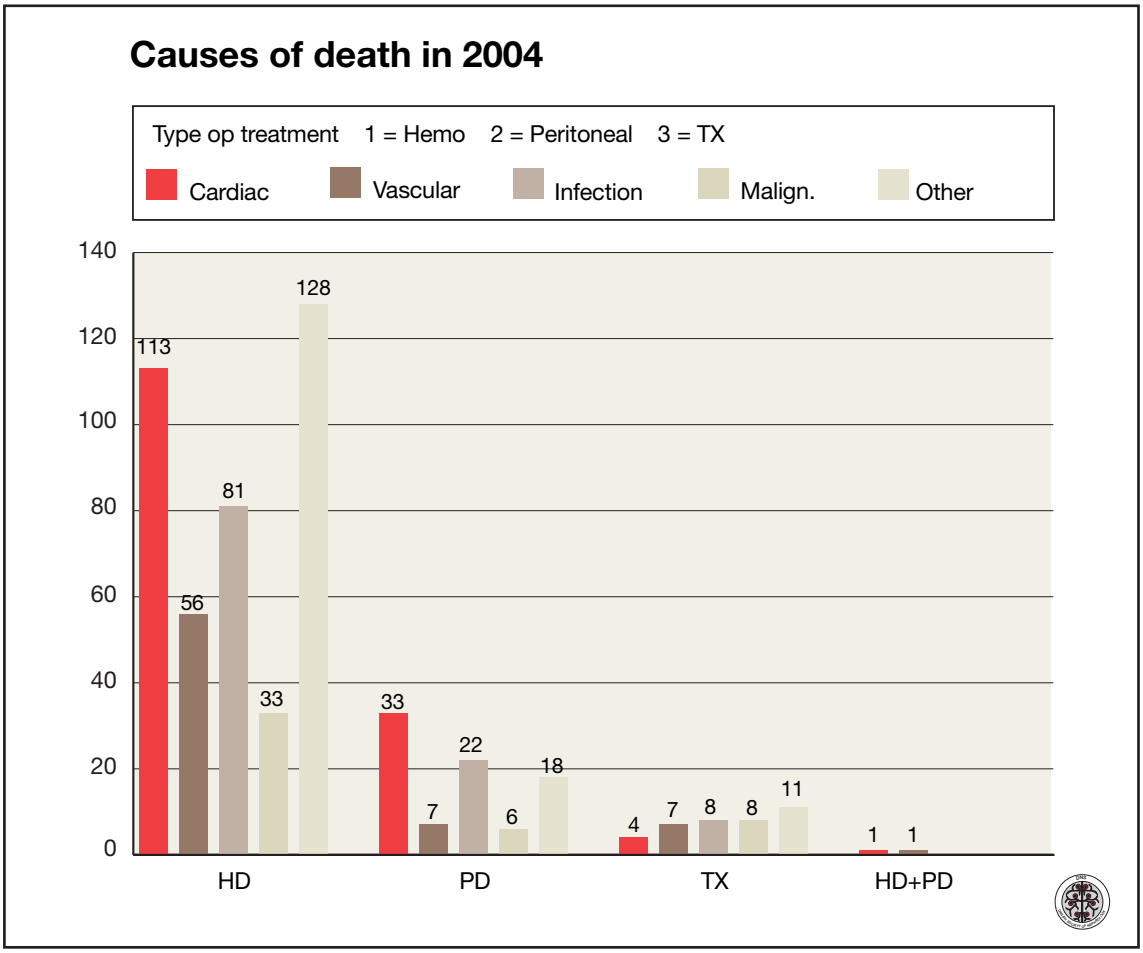


Fig. 25. Causes of death in 537 patients who died during 2004.

Death rate for 2004

Method of calculation:
Death rate = number of death x 100 / Person - years of observation.
All patients included from the start of active treatment.

Hemodialysis:

	Number
Dead	411
Number of patients treated in 2004	2464
Average number of days in treatment	272
Number of person years	1841

Death rate in 100 person years **22,3**

Peritoneal dialysis:

	Number
Dead	88
Number of patients treated in 2004	923
Average number of days in treatment	254
Number of person years	643

Death rate in 100 person years **13,7**

Transplantation:

	Number
Dead	38
Number of patients treated in 2004	1741
Average number of days in treatment	338
Number of person years	1610,7

Death rate in 100 person years **2,4**

Death rate from 1991 - 2004

Year	Hemodialysis	Peritoneal dialysis	Transplantation
	Death rate expressed in number per 100 person years		
1991	20.6	13.4	3.9
1992	22.2	19.6	4.9
1993	26.5	16.0	4.3
1994	23.8	18.6	4.3
1995	27.2	17.8	4.4
1996	25.6	13.6	3.0
1997	24.5	14.9	4.7
1998	24.5	17.8	2.9
1999	23.2	13.8	3.4
2000	25.2	15.4	2.6
2001	23.3	13.5	3.2
2002	23.4	11.9	2.9
2003	22.6	11.4	2.8
2004	22,3	13,7	2,4

Table 15 shows the variation in death rate during the last 14 years expressed in number of death per 100 person years.

Admission Pattern for Danish ESRD Patients 1990 - 2003

Heaf JG. and Løkkegaard H

Introduction

The Danish Nephrology Society National Register was merged with data from the Danish National Patient Register, which contains discharge data for all patient admissions in Denmark since 1977. Only admissions after 1.1.1990, when the DNS register became comprehensive, were included.

9317 patients with ESRD were included, who were admitted 167,217 times after development of ESRD. The admission duration was 6.7 days (range 0-372). Treatment modes were classified as hemodialysis (HD), peritoneal dialysis (PD) or renal transplant (RT). Dialysis treatment duration's of less than 60 days were merged with subsequent longer dialysis courses. (60-day collapsing rule)

Hospital admissions are only a surrogate marker of morbidity. A number of extraneous factors may have altered the results:

1) The change from ICD-8 to ICD-10 disease classification in 1994
2) The introduction of Disease Related Group (DRG) compensation in 2001
3) Possible changes in physician diagnosis habits during the period of observation
4) Changes in admission policy , e.g. the reduction in hospital IPD therapy.

Results and Comments

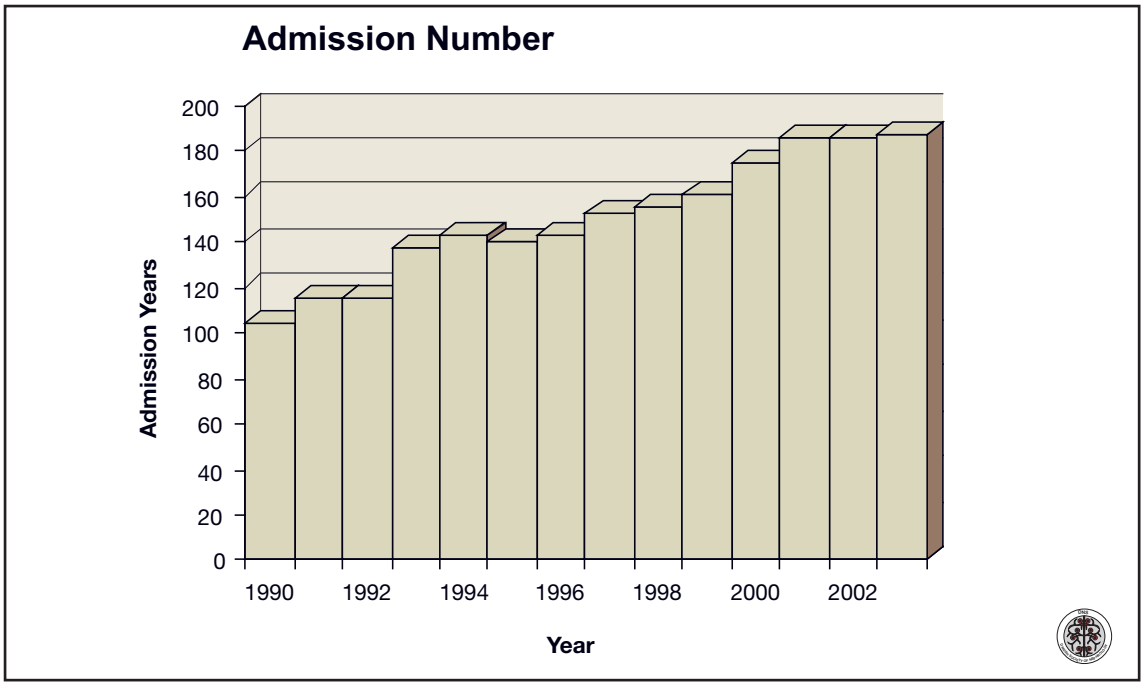


Fig.1. The average number of beds occupied by ESRD patients rose from 105 to 187. The main reason is the increased number of patients in active treatment for ESRD. Prevalence 311290 and 311204 was 1977 and 3987, respectively. As shown in fig. 2 the number of beds required per 100 dialysis patients and 100 transplanted patients is about 6 and 3, respectively. Based on these figures 2500 dialysis patients requires about 150 beds and 1600 transplanted patients about 48 beds.

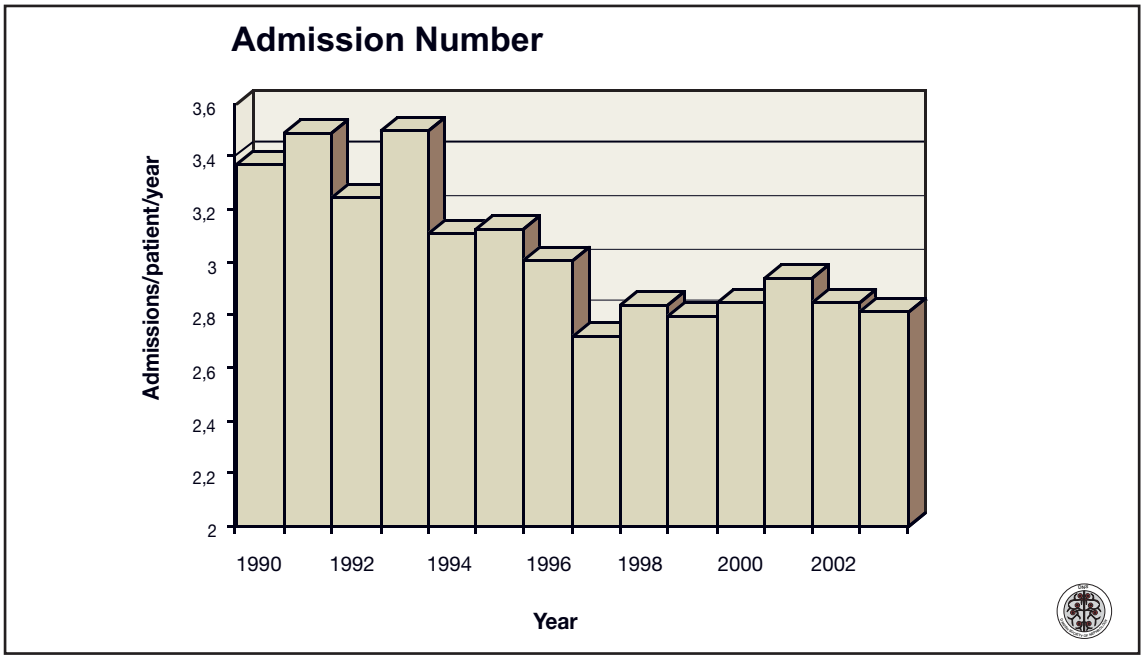


Fig. 2. The average number of admissions fell during the investigation period from 3.4 to 2.8. Since the admission duration was largely unchanged, the number of admission days (AD) shown in this figure fell from 23 to 18 days. Better ambulatory facilities, decentralisation of dialysis treatment and fewer complications in transplantation are most properly responsible for this result.

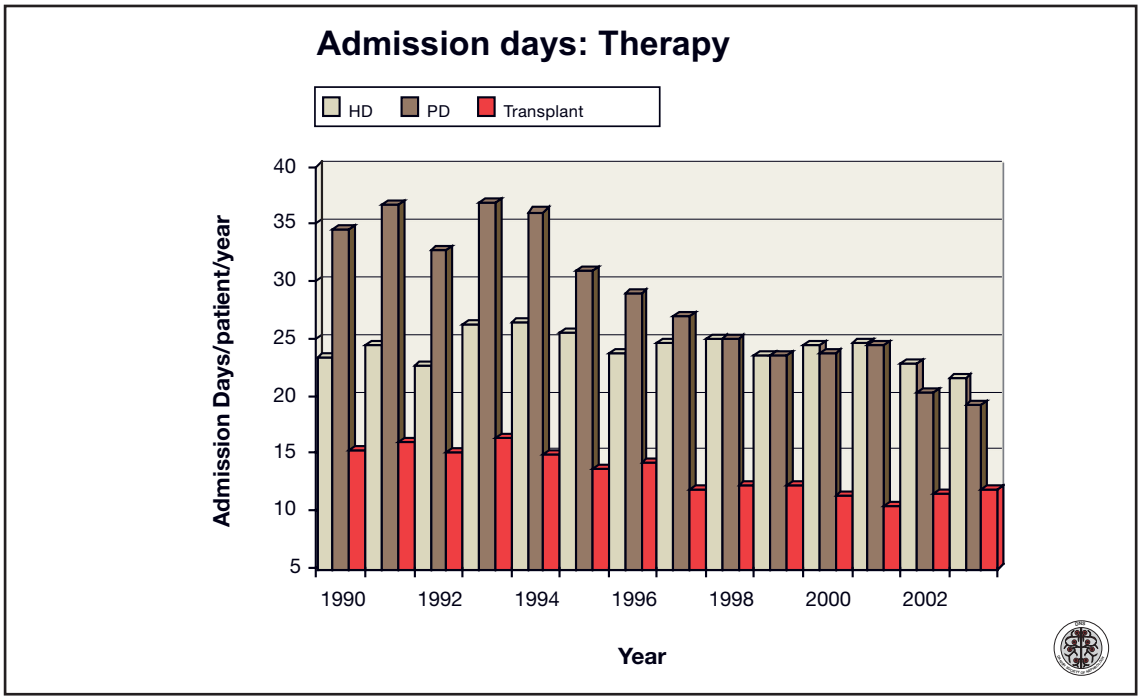


Fig. 3. AD was lowest for RT-patients, falling from 15 to 11 days. HD AD fell from 24 to 22 days and PD from 35 to 19. Thus, at present about 6 beds are required per 100 dialysis patients and 3 beds per 100 transplanted patients.

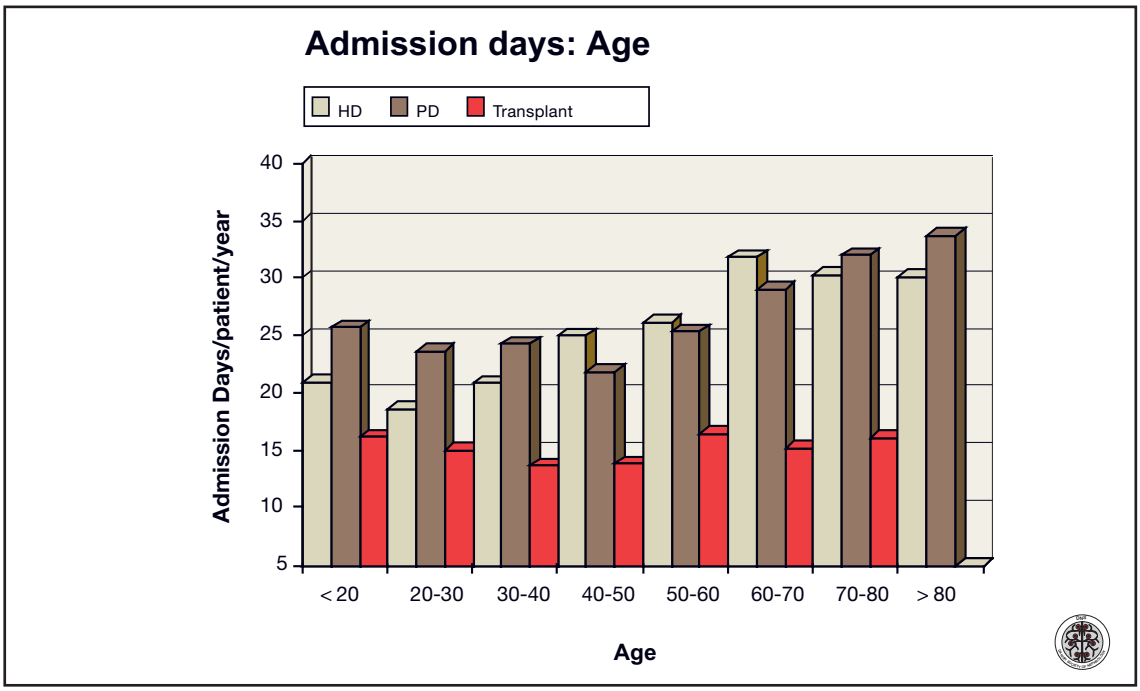


Fig. 4. Elderly dialysis patients required about 10 extra ADs per year, while age had no effect on AD frequency for transplanted patients.

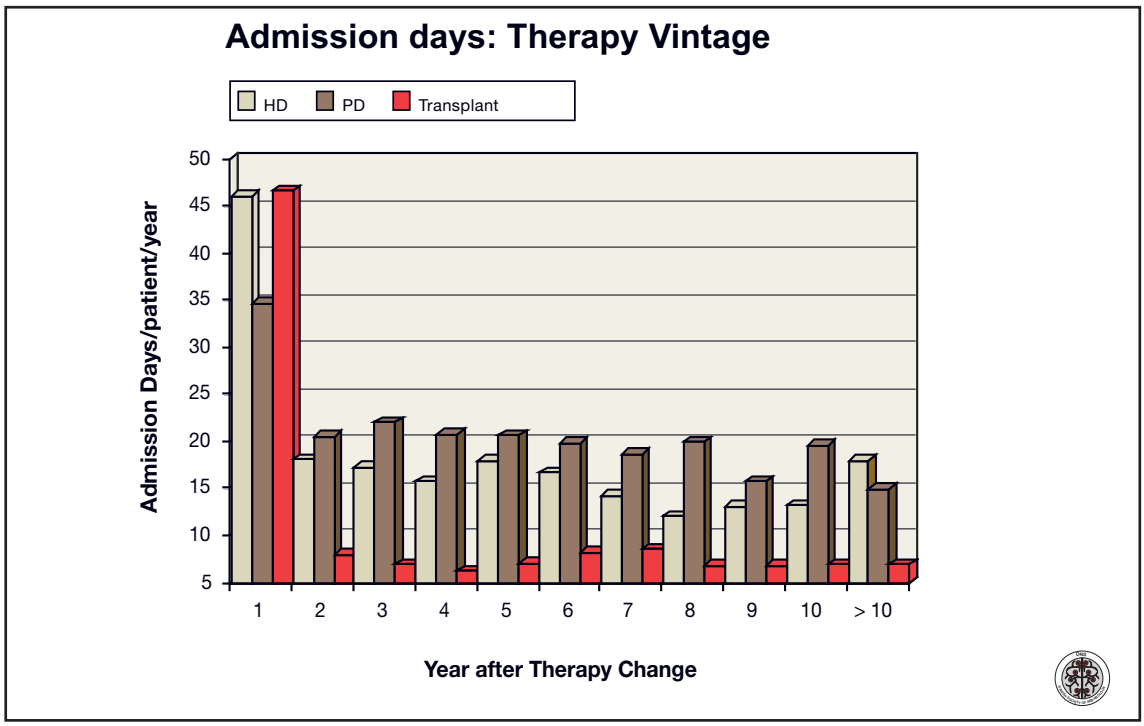


Fig. 5. For all therapies, AD were higher during the first year after therapy initiation, and more or less constant thereafter.

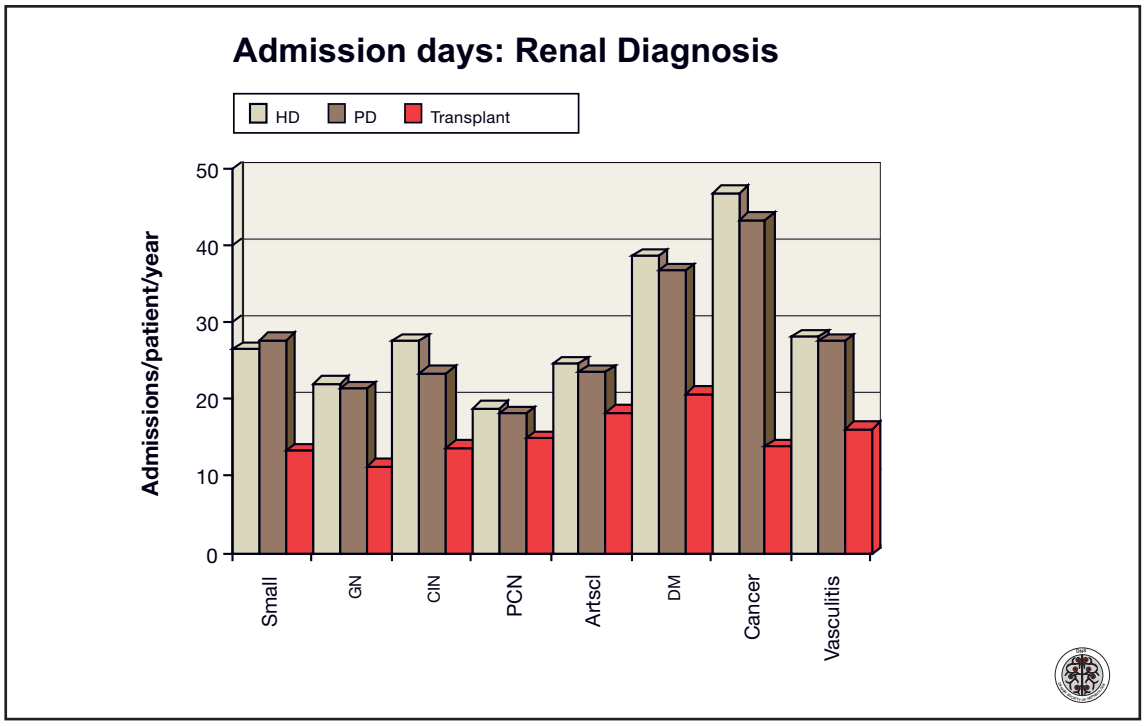


Fig. 6 . AD in relation to renal diagnose. Small = unknown chronic disease, GN = glomerulonephritis, CIN = chronic interstitial nephritis, PCN = polycystic kidney disease, Artscl = atherosclerotic renal daisies, DM = diabetic renal disease, Cancer = renal cancer. Patients with diabetic nephropathy and renal malignancy (including multiple myeloma) had a higher AD, except for RT patients, where renal malignancy had a lower AD, presumable because radical cure has been assured in these patient prior to RT. Surprisingly patients with hypertensive and atherosclerotic renal disease did not have raised AD.

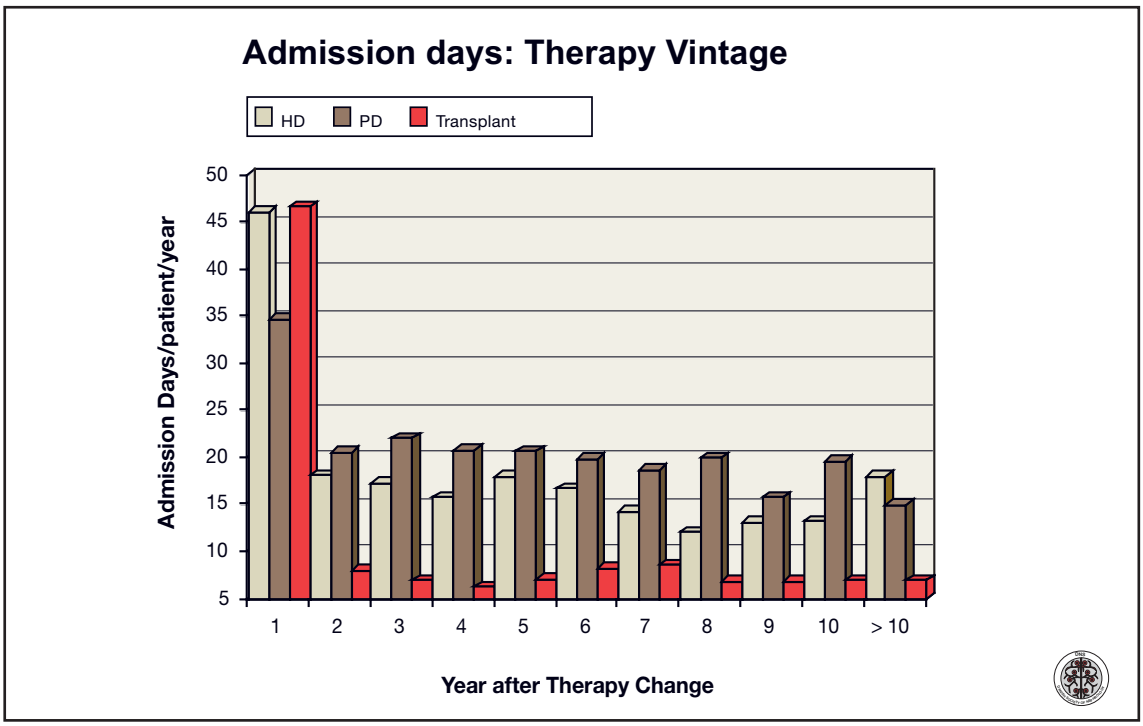


Fig. 7. AD in with osteodystrophy diagnoses. There was no change in osteodystrofy problems.

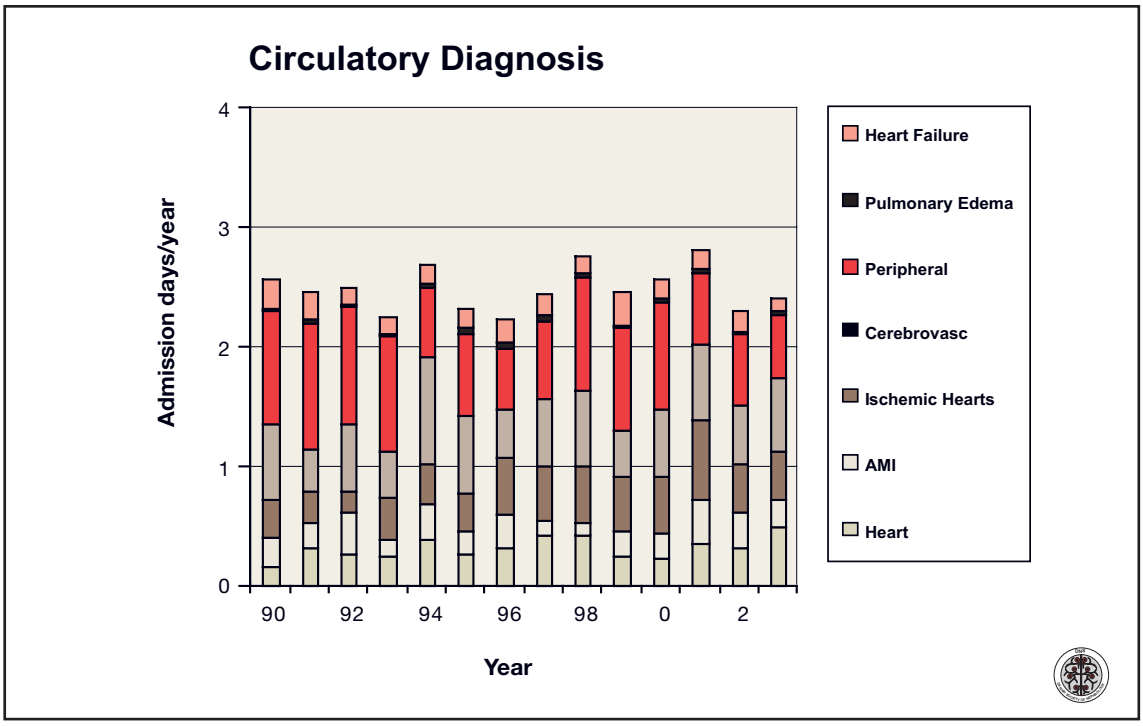


Fig. 8. AD for circulatory disease was unchanged

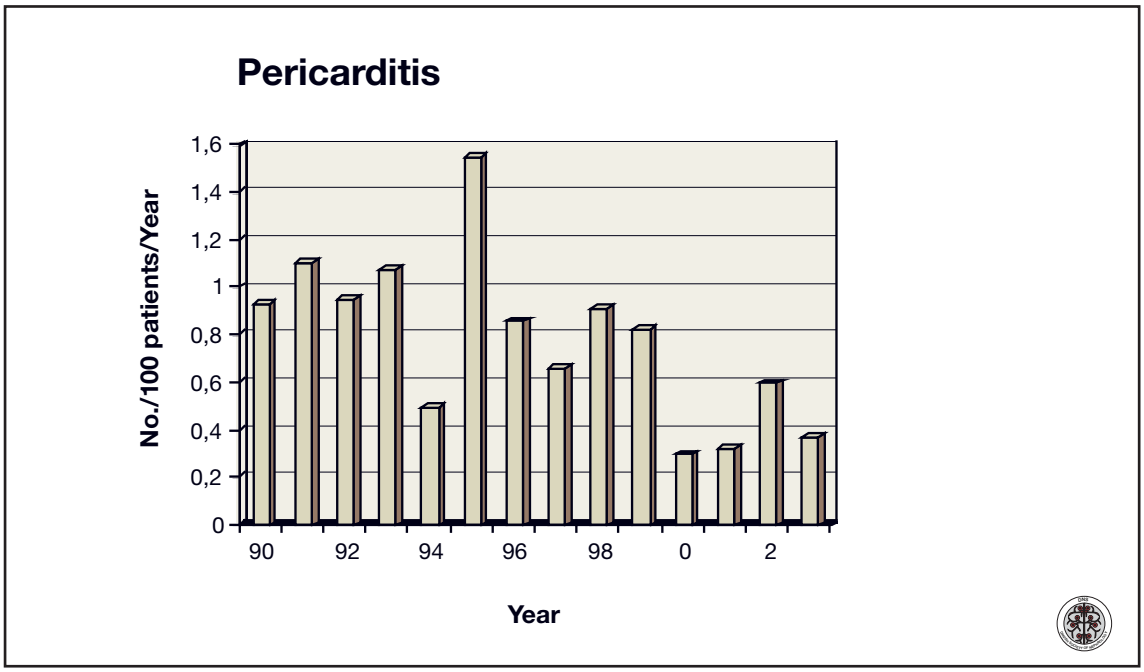


Fig. 9. The incidens of pericarditis fell from 1 to 0.4% per year.

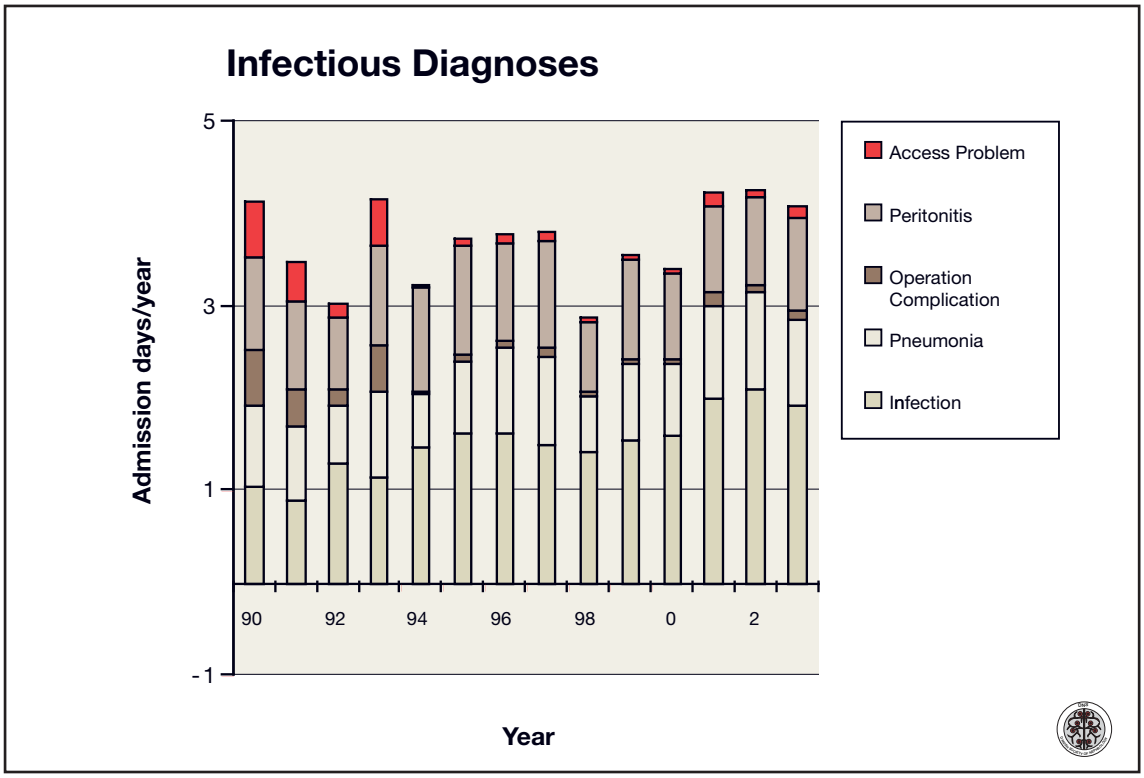


Fig. 10. The AD for all infections was unchanged, but AD for systemic infections (A00-B99) rose 50%. The peritonitis incidence was unchanged during the period at 0.4/year and the peritonitis AD at 2.8/PD patient year. Thus infections remain a major problem in active treatment of ESRD.

In summary - admission patterns for Danish ESRD patients in active treatment have been analysed. Provided a smooth admission and optimal utilisation - at present about 200 beds are required to fulfil the need for hospitalisation, 6 beds per 100 dialysis patients and 3 beds per 100 transplanted patient. Average number of admission days (AD) probably due to better ambulatory facilities, decentralisation of dialysis treatment and fewer complications with transplantation. Elderly dialysis patients required increased hospitalisation, while age had no effect on AD frequency for transplanted patients. For all therapies, AD was higher during the first year after therapy initiation, and more or less constant thereafter. Patients with diabetic nephropathy and renal malignancy (including multiple myeloma) had a higher AD, except for RT patients, where renal malignancy had a lower AD, presumable because radical cure has been assured in these patient prior to RT. Surprisingly patients with hypertensive and atherosclerotic renal disease did not have raised AD. No change I AD was found with osteodystrofy problems and circulatory disease during the investigation period. The incidens of pericarditis fell from 1 to 0.4% per year. The AD for all infections was unchanged, but AD for systemic infections (A00-B99) rose 50%. The peritonitis incidence was unchanged during the period at 0.4 per year and the peritonitis AD at 2.8 per PD patient year. Thus infections remain a major problem in active treatment of ESRD.

Relationer mellem Det Danske Landsregister for patienter i aktiv behandling for kronisk nyresvigt (DNSL) og Det Europæiske Dialyse og Transplantationsregister (ERA-EDTA registre)
Status og fremtidsperspektiver

Hans Løkkegaard

Status

DNSL sender hvert år data til ERA-EDTA-registret, som nu er placeret i Academic Medical Center, University of Amsterdam, Dept. of Medical Informatiks. Managing Director: Dr. Kitty J. Jager. Chairman for ERA-EDTA registry committee: Prof. Carmine Zoccali.
Registret har igennem en årrække været under rekonstruktion. Fra begyndelsen kommunikerede det med de enkelte dialyse- og transplantations-centre, men på grund af den voldsomme stigning i antallet af dialysecentre blev de organisatoriske problemer for overvældende. Man så sig nødsaget til at satse på *input fra nationale eller regionale registre,* som igennem de senere år har været i kraftig vækst. De mange problemer, som de ændrede forhold skabte, skal her forbigås. ERA-EDTA registret fungerer stadig og har siden 1990 modtaget danske data. Danske data fra før 1990 er på grund af manglende kontrol behæftet med så mange fejl, at ingen har haft kræfter og overskud til at justere materialet og inkorporere det i såvel DNSL som ERA-EDTA registret.

ERA-EDTA registrets formål fremgår af fig.1. Man ønsker at rapportere om udviklingen indenfor aktiv behandling af kronisk nyresvigt i Europa, fokusere på internationale forskelle og i et vist omfang skabe arbejdsgrundlag for undersøgelser af mere videnskabelig karakter.

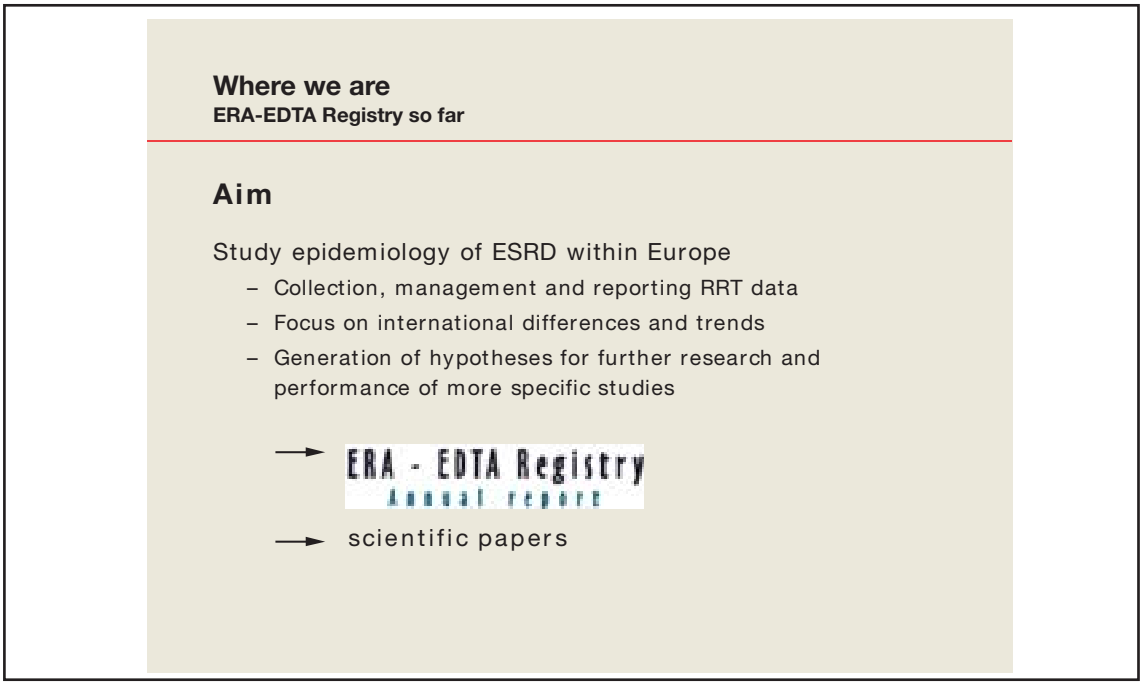


Fig. 1 expresses the aim of the ERA-EDTA registry. Kitty Jager 2005.

Dette sker ved indsamling af data fra så mange Europæiske lande som muligt. Fig. 2 viser en oversigt over de lande og regioner, som på nuværende tidspunkt indsender data. Det fremgår

1. at der indgår et begrænset antal parametre. Dette for at sikre en så omfattende og fuldstændig registrering som muligt. Organisering af et relevant kvalificeret datainput er for øjeblikket et betydeligt problem for alle nationale og regionale registreringer.
2. at registrering til ERA-EDTA foregår på 2 måder. Alle skandinaviske lande, Holland, Belgien, England, Grækenland, Østrig og regionale områder i Italien og Spanien er i stand til at sende individuelle data - dvs. personhenførbare data for patienter der indgår i registreringen. Tyskland, dele af Frankrig, det tidligere Jugoslavien, Rusland og Tyrkiet sender kun aggregerede data i form af f.eks. oplysninger om incidens, antal transplantationer mm.. Nogle lande har magtet at registrere forskellige former for comorbiditet - f.eks. cardiovasculære begivenheder og blodtryksforhøjelse.

Man må konkludere, at de omtalte forhold begrænser mulighederne for en omfattende pålidelig sammenligning landene imellem. Manglende definitioner og ufuldstændige systemer til kodning af en række parametre vanskeliggør yderligere opfyldelse af registrets formål. Videnskabelige tiltag foregår mest ved inddragelse af individuelle centre med specielle interesser og muligheder for supplerende input af data. Indtil videre har de fælles bestræbelserne overvejende resulteret i analyser af incidens og overlevelse.

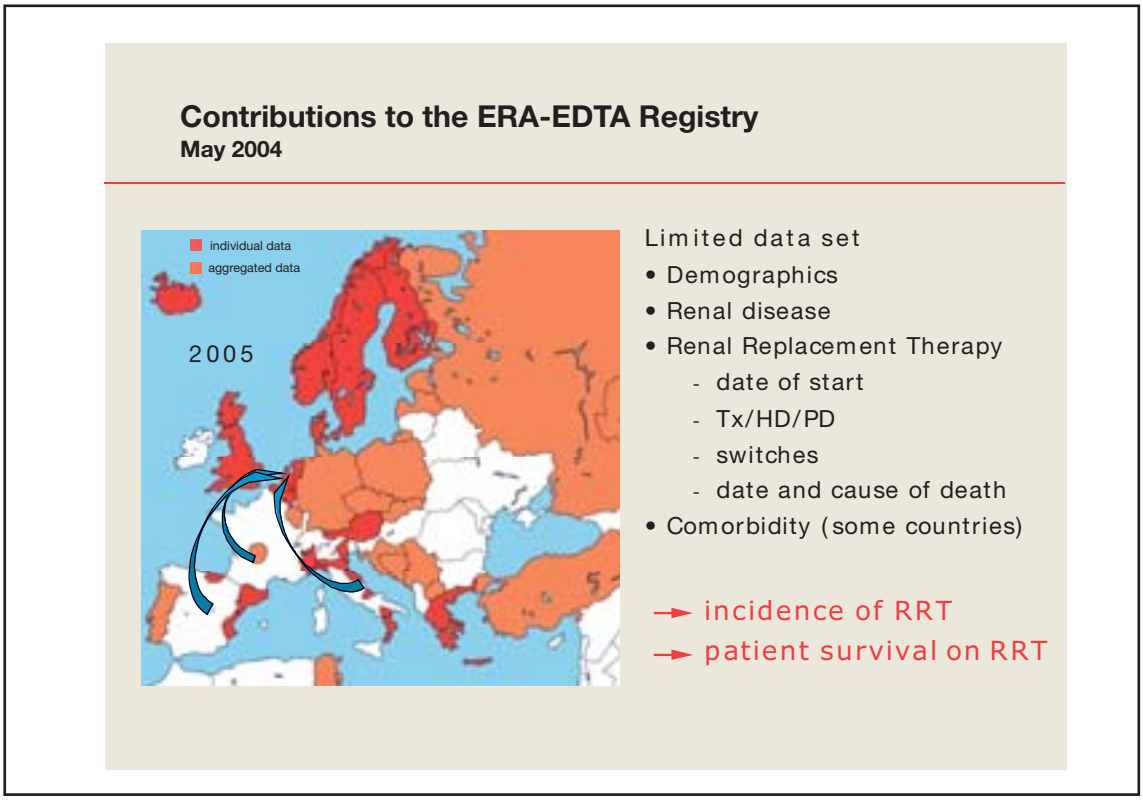


Fig. 2 shows the contributions to the ERA-EDTA Registry May 2004. The contributions are divided in national or regional registries, which sends individual or aggregated data. The dimensions of data set are stated . Kitty Jager 2005.

Incidensen i en række Europæiske lande er angivet i fig. 2. Som anført i DNSL's rapport fra i år har incidensen i Danmark igennem de sidste 5 år ligget konstant omkring ca. 130 per million. Sammenlignet med de øvrige europæiske lande er vi placeret nogenlunde i midten. Da forholdene i Danmark igennem de senere år tillader, at alle som har behov, kan tilbydes aktiv terapi, er der næppe udsigt til større ændringer i incidensen foreløbig. Naturligvis vil forbedrede behandlinger af de primære lidelser (f.eks. diabetes og hypertension) på lidt længere sigt kunne mindske tilgangen til dialyse og transplantation. Man bemærker at incidensen i Finland, Island og Norge er under hundrede og at lande som Belgien og Tyskland har høje incidenstal. Disse forskelle bør underkastes en nøjere analyse.

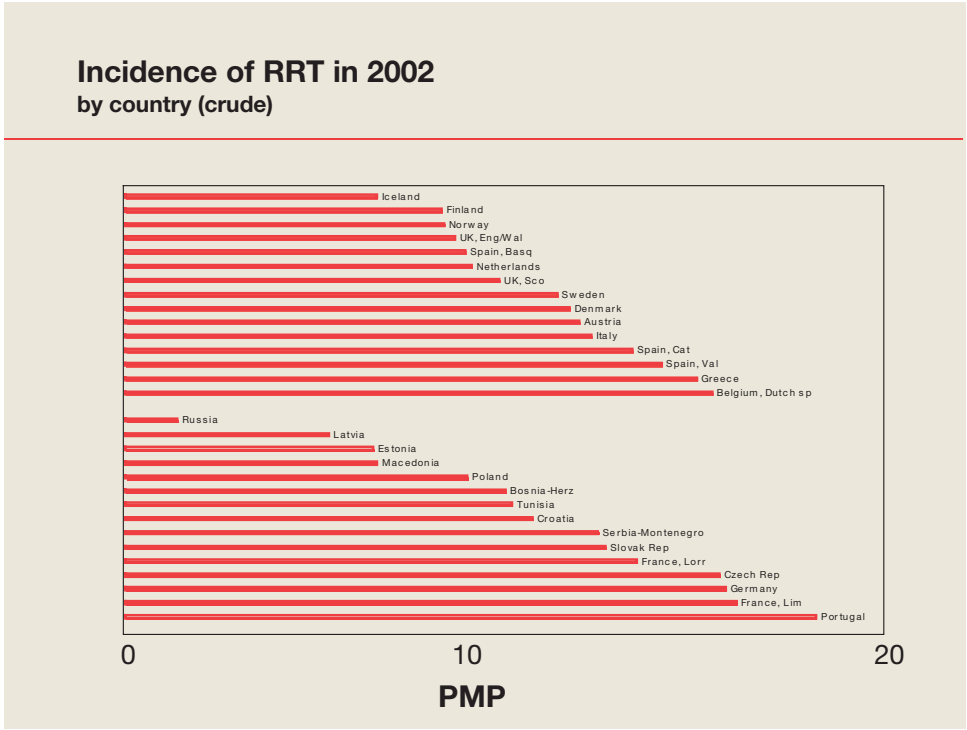


Fig. 3. The incidence of renal replacement therapy (RRT) in different European countries. The results are divided in countries with individual patient data input (upper part) and aggregated data (lower part). In Denmark the incidence during the last 5 years (year 2000 - 2004) is about 130. Three Nordic countries (Finland, Iceland and Norway) have an incidence below 100. The figures of Sweden are close to the Danish. There is considerable dispersion of the results. It is worth mentioning, that Germany, Holland and Belgium have a rather high incidence. Kitty Jager 2005.

I analysen af årsager til de registrerede forskelle viser fig. 4 en række faktorer, som kan tænkes at influere på incidensen. Aldersfordeling i befolkningen, prævalens af den tilgrundliggende sygdom, genetiske faktorer, adgang til nefrologisk ekspertice, sufficient rapportering, andre sygdommes indflydelse på forløbet, sundhedsorganisatoriske forhold og herunder specielt prioritering af økonomien hos ansvarlige myndigheder giver muligheder for variation i antallet af registrerede.

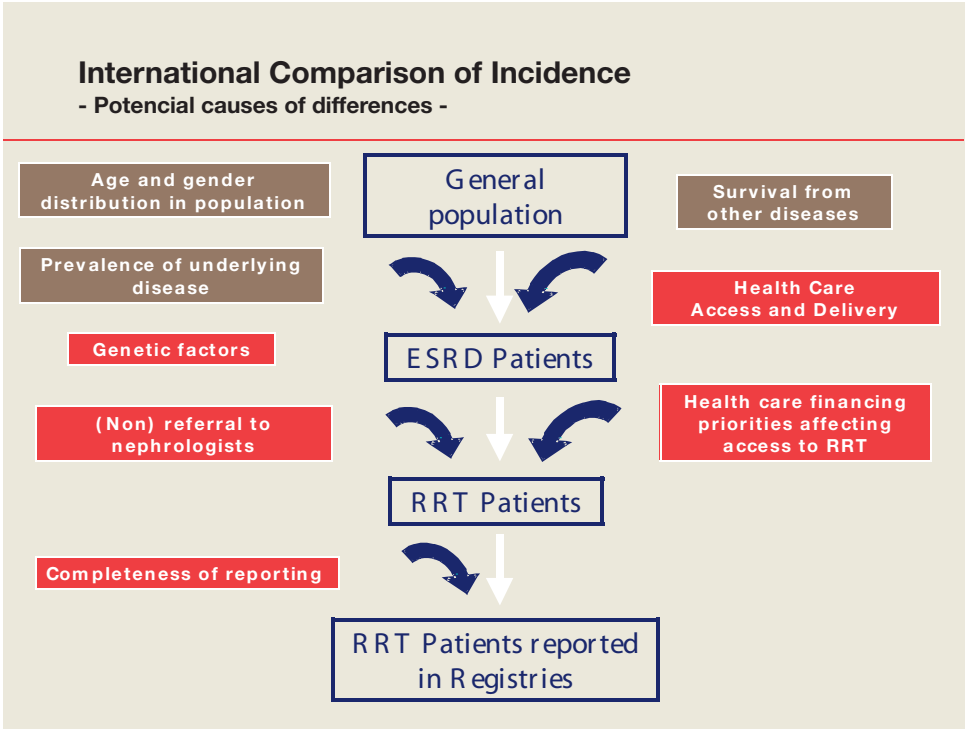


Fig. 4. Potential causes of differences in international comparison of incidence. ESRD = end stage renal disease, RRT = renal replacement therapy. Kitty Jager 2005.

Overlevelsesstatistik er i ERA-EDTA grundigt analyseret for de forskellige behandlingsformer. Sammenlignende overlevelsesstatistik er mulig for lande, som forsyner ERA-EDTA registret med individuelle data. Det drejer sig som omtalt om de skandinaviske lande, UK, Benelux landene, Østrig, Grækenland og vise regioner i Italien og Spanien. En samlet overlevelse for patienter i RRT er vist i fig. 5. Resultaterne er søgt gjort sammenlignelige ved korrektion for alder, køn og diagnose.

En sammenligning mellem Danmark og omtalte lande er vist detaljeret i tabel 1. Det fremgår, at der ikke er den store forskel i resultaterne. Mindre forskelle skal vurderes på baggrund af en række faktorer, som angivet i fig. 6, hvor en række patient- og behandlingsrelaterede faktorer er angivet. Bl. a. alder, køn, nyrelidelse, andre sygdomme, dialysemetode og muligheder for adgang til dialyse og nyretransplantation,

Fremtidsperspektiver

Samarbejdet mellem de nationale registre og ERA-EDTA er en vigtig forudsætning for fælles europæiske holdninger til behandlingstilbud og behandlingskvalitet fremover. Der er derfor både i de nationale registre og ERA-EDTA et stort ønske om større input af relevante data. For at styrke dette arbejdet har ERA-EDTA iværksat et initiativ - QUEST initiativ (QUality European STudy).
Det er et ambitiøst projekt knyttet til Europa Parlamentets vedtagelse af : Community action in the field of public health (Godkendt 23 september 2002) , hvor der blev skabt muligheder for økonomisk støtte til en lang række sundhedsrelaterede initiativer.

ERA-EDTA indkaldte marts 2005 repræsentanter fra nationale og regionale registre til et møde i Toledo for at uddybe de tanker, man fra selskabets side havde gjort sig. Fra Danmark mødte undertegnede i egenskab af at være national koordinator for ERA_EDTA. Kitty Jager gjorde status over registrets arbejde indtil nu og Carmine Zoccali redegjorde for QUEST initiativet og dets muligheder. Man enedes om at søge støtte til etablering af 5 arbejdsgrupper med emnerne anæmi, calcium-fosfor metabolisme, dialyse behov, cardiovasculære risikofaktorer og data ekstraktion. Mødet skulle danne grundlag for en ansøgningen til EU og efterfølgende har der været en hektisk aktivitet for at etablere et realistisk grundlag for ansøgningen, som blev indsendt 15 april 2005.

De danske erfaringer med indsamling af data understreger vanskelighederne ved indtastning af mere end nogle få lettilgængelige konkrete data, som f.eks. renal diagnose og tidspunkter for behandlings start og død. Jeg har derfor understreget nødvendigheden af , at yderligere tilførsel af data vil kræve automatisk overførsel fra andre elektroniske medier f.eks.fra laboratoriesystemet. Jeg har meldt mig i arbejdsgruppen data ekstraktion og deltager i pilotprojekt om programmering af snitflader til kommunikation mellem databaser indenfor sundhedssektoren. Dette er accepteret fra ERA-EDTA's side og indgår i den samlede ansøgning. Projektet involverer én main partner (ERA-EDTA), associated partners (DNS, IT-afdelingen Københavns amt) samt subcontractor (Uni-C). Målet er at muliggøre automatisk dataoverførsel fra så mange systemer som muligt til DNSL's database på landets nefrologiske afdelinger. Såfremt ansøgningen accepteres, er der nedfældet regler for beløbets størrelse og fordeling af udgifter.

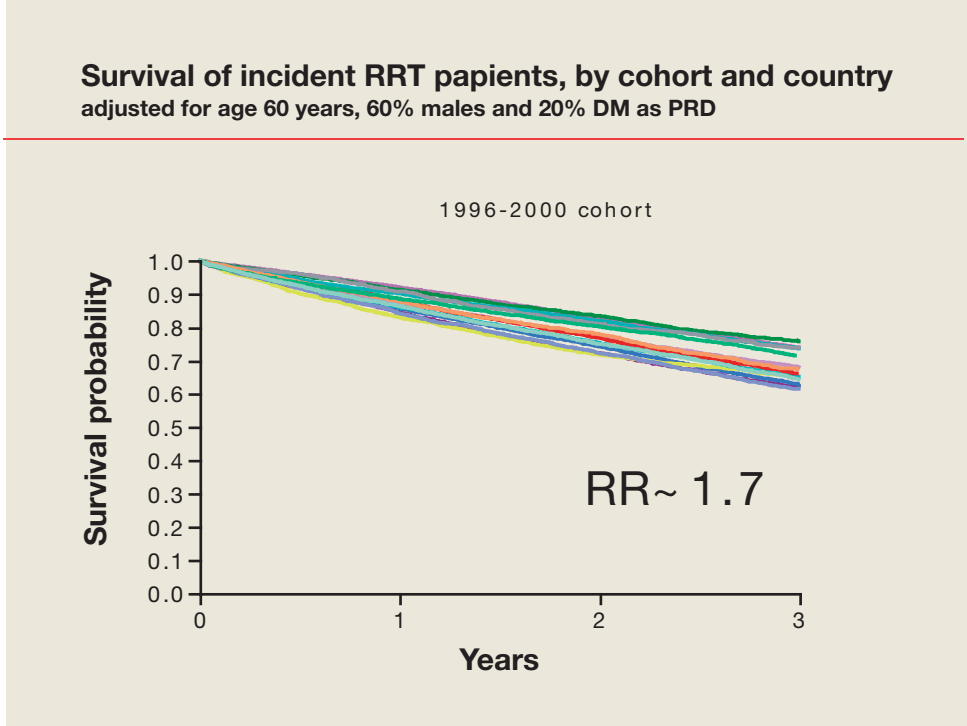


Fig. 5 shows survival of RRT patients in a number of European countries adjusted for age, gender and renal diagnoses. Detailed comparison between results from Denmark and the other countries is shown in table 1

Table A.5.6

90-day, one- and two-year survival probabilities (cohort 1996-2000): Incident RRT patients, adjusted

from day 1 to 90 days, one and two years, adjusted for age, gender and primary diagnosis

	90 day Survival (95% CI)	1 year Survival (95% CI)	2 year Survival (95% CI)
ALL COUNTRIES			
0-19	99,2 (98,6 - 99,8)	96,4 (95,2 - 97,7)	95,4 (94,0 - 96,8)
20-44	98,5 (98,2 - 98,8)	95,0 (94,5 - 95,5)	91,5 (90,8 - 92,1)
45-64	96,1 (95,8 - 96,4)	87,9 (87,5 - 88,4)	79,0 (78,4 - 79,6)
65-74	91,3 (90,9 - 91,7)	76,8 (76,2 - 77,5)	62,3 (61,5 - 63,0)
75+	86,8 (86,2 - 87,5)	66,9 (66,0 - 67,8)	49,0 (48,0 - 49,9)
Male	95,0 (94,8 - 95,2)	85,9 (85,5 - 86,2)	75,8 (75,3 - 76,3)
Female	95,1 (94,8 - 95,3)	86,0 (85,6 - 86,5)	76,6 (76,0 - 77,1)
Diabetes	94,8 (94,5 - 95,2)	82,8 (82,1 - 83,4)	67,8 (66,9 - 68,6)
Hypertension / renal vascular disease	95,0 (94,7 - 95,4)	85,8 (85,2 - 86,4)	76,0 (75,3 - 76,8)
Glomerulonephritis	96,5 (96,1 - 96,9)	90,7 (90,1 - 91,4)	83,7 (82,8 - 84,5)
Other cause	94,4 (94,2 - 94,7)	85,2 (84,8 - 85,6)	76,3 (75,8 - 76,8)
All	95,0 (94,9 - 95,2)	85,9 (85,7 - 86,2)	76,1 (75,7 - 76,5)

	90 day Survival (95% CI)	1 year Survival (95% CI)	2 year Survival (95% CI)
DENMARK			
0-19			
20-44	98,2 (97,1 - 99,3)	93,5 (91,5 - 95,6)	88,2 (85,5 - 91,0)
45-64	95,0 (93,7 - 96,2)	84,5 (82,5 - 86,6)	74,2 (71,7 - 76,7)
65-74	90,1 (88,1 - 92,1)	70,6 (67,5 - 73,7)	54,8 (51,5 - 58,4)
75+	86,6 (83,5 - 89,9)	66,9 (62,6 - 71,5)	46,3 (41,8 - 51,3)
Male	94,8 (93,9 - 95,7)	82,9 (81,4 - 84,5)	71,0 (69,0 - 73,0)
Female	93,5 (92,2 - 94,7)	82,7 (80,7 - 84,7)	71,7 (69,2 - 74,2)
Diabetes	93,5 (91,7 - 95,4)	80,0 (76,9 - 83,2)	63,0 (59,3 - 66,9)
Hypertension / renal vascular disease	94,5 (92,5 - 96,4)	80,1 (76,7 - 83,7)	72,2 (68,3 - 76,3)
Glomerulonephritis	95,1 (92,9 - 97,3)	89,3 (86,2 - 92,6)	80,9 (76,9 - 85,2)
Other cause	94,0 (93,0 - 95,0)	82,4 (80,7 - 84,1)	70,8 (68,7 - 72,9)
All	94,3 (93,5 - 95,0)	82,8 (81,6 - 84,1)	71,2 (69,7 - 72,8)

Table 1. ERA-EDTA calculations comparing patient survival of renal replacement therapy in Denmark with other countries using individual data input to the ERA-EDTA registry. Data adjusted for age, gender and diagnosis. The results should be judged in relation to the statements discussed in fig. 6.

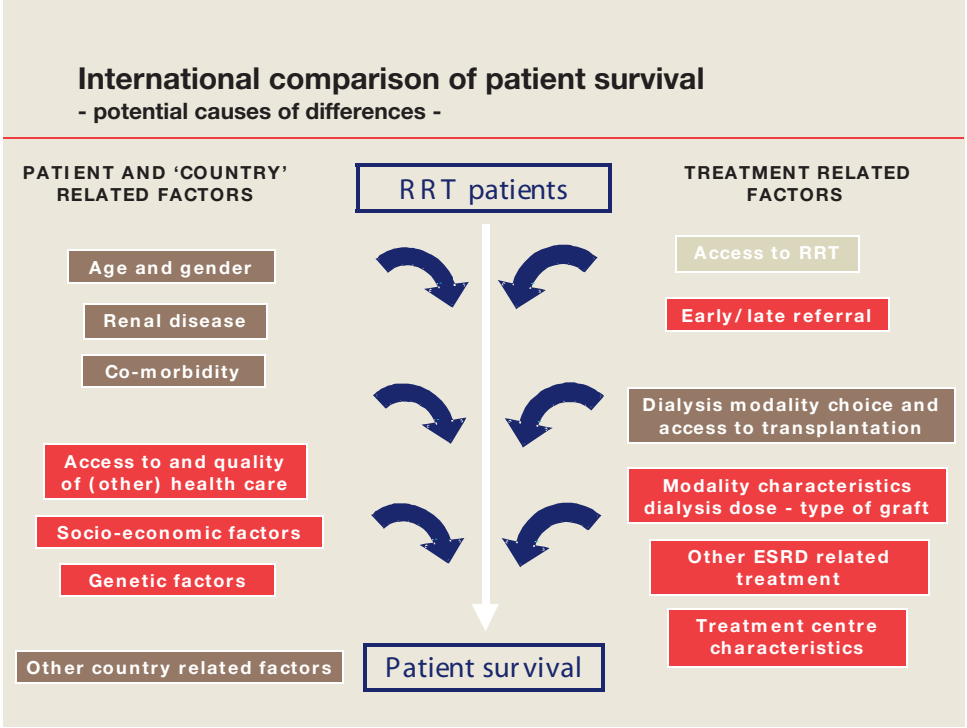


Fig.6. Potential causes of differences in international comparison of patient survival. ESRD = end stage renal disease, RRT = renal replacement therapy. Kitty Jager 2005.

Relation between The Danish National Registry (DNSL) and the European Renal - Dialysis and Transplantation Association (ERA -EDTA registry)

Status and future perspectives

Since 1990 data from the Danish National Registration have been transferred to the ERA-EDTA registry and together with other national/regional registries used to describe e.g. incidence and survival of patients in active treatment for end stage renal disease (ESRD).

The aim and proportions of the ERA-EDTA registration is shown in fig. 1 and furthermore some results are illustrated in fig. 2-6 and table 1. All figures published by the ERA-EDTA registry. An increased interest of qualified analysis of treatment results, have resulted in the so called QUEST initiative from ERA-EDTA , with the aim to enlarge the pool of data and establish working groups to analyse data and bring the results in accordance with international accepted guidelines. Denmark has joined a working group concerned with extraction of data due to the fact, that easy access to and automatic transfer of relevant and well-defined data is a main problem, if the amount of useful data should be enlarged.

The frequency of malignant diseases in patients treated withdialysis and transplantation

Anders Mellemgaard and Hans Løkkegaard

Cancer incidence in the 10.077 patients included in the Danish National Registration for active treatment of chronic renal disease were investigated by linkage to The Danish Cancer Registry. A total of 1090 cancer cases were found in the period from the start of dialysis or transplantation to Dec 31 2003. The total number and distribution by site shown in table 1. Further analysis is in progress for comparison with the cancer risk of the general and the relationship with the different kidney disease groups.

	ICD-9 codes	Name	Number total number
1	1400 - 1470	lips tongue salivary glands mouth palate meso-hypopharynx	15 04 03 04 01 02 29
2	1500 - 1570	esophagus stomach duodenum+small intest. colon, cecum, rectum liver, biliary duct,pancreas	08 12 02 78 23 123
3	1610 - 1627	larynx lung+pleura	07 95 102
4	1700 - 1702	breast	46 46
5	1711 - 1764	cervix+corpus ovary vulva+vagina	47 10 07 64
6	1770	Prostate gland	28 28
7	1781 - 1817	genital urological	06 99 105
8	1903 - 1909 1924	melanoma	23 23
9	1910 - 1919	skin carcinoma	445 445
10	2002 - 2141	lymfosarcoma malig. lymphoma hodgkin multiple myeloma reticulosarcom leukemia	09 11 05 21 03 09 58
11	1940 - 1999	other	67
	1400-2150	Total	1090

Table 1. 1090 cancer diagnosis in 10077 patients after start of active treatment for chronic renal failure.

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