

THE NORDIC LIVER TRANSPLANT REGISTRY ANNUAL REPORT 2004

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Nordic liver transplant registry - 2004

As of 31 December 2004 the registry comprises data on 3116 patients of whom 2687 had received a first liver allograft. The registry comprises complete data on all patients listed for liver transplantation during the period 1990-2004; 2894 patients. The remaining 222 patients received a liver allograft prior to 1990, waiting list data are not available for these patients.

Transplantation activity 2004

The total number of patients receiving a first liver allograft during 2004 was 240. In addition 28 re-transplantations were performed. **The total number of performed liver transplantations was 268. Thus the activity has increased further with by far the highest number of liver transplantations in the Nordic countries ever.**

Median waiting time (electively listed patients) has decreased slightly to 35 days while mean waiting time has increased to 80 days. Median waiting time for blood type 0 recipients has decreased from 72 days in 2003 to 60 days in 2004. The number of deaths on the waiting list has remained stable. A total of 16 patients died while waiting for a liver allograft during 2004.

During 2004 alcoholic liver cirrhosis (n=35), followed by primary sclerosing cholangitis (n=34) and acute hepatic failure (n=26) were the most frequent indications for being listed for a liver transplantation.

Thirty-four recipients (first liver allografts) were above 60 years of age.

Donor age has increased steadily during the nineties, was stable during 2000-2002 but increased to a mean donor age of 48 years in 2003 and remained stable at 48 years in 2004.

Survival rates following liver transplantation are still increasing and are approaching an 85% 1-year survival for patients undergoing transplantation after year 2000.

A total of 260 patients were listed for a first liver transplantation in 2004. Of these, 204 received an allograft. Fourteen of the 260 patients died while being active on the waiting list.

Twenty-four were permanently withdrawn from the waiting list without receiving a liver allograft. Eighteen patients of these 260 were active on the waiting list as of 31 December 2004.

Maintenance of the registry

At present, most centres are relatively up-to-date as concerns the completeness of data in the registry. Data on number of patients, dates of transplantation, diagnosis and status dead/alive are complete.

The results presented in this report are based on the data in the registry as of 15 March 2005.

Acknowledgements - financial support

The maintenance of the software has been performed by Scandiatransplant. We greatly acknowledge the help and support from Niels Grunnet, Melvin Madsen, Christian Mondrup and Frank Pedersen in Aarhus. Without their help and support it would not have been possible to maintain the registry. Without the day-to-day assistance we have received from Christian Mondrup and Frank Pedersen it would not have been possible to tie up a large number of loose ends and develop the registry further.

Transplant nurses and transplant coordinators at the individual centres have made an enormous effort in updating and maintaining the registry. The existence of the registry depends completely on their work and dedication.

The registry received partial financial support from Roche, Fujisawa and Novartis during 2004. This support has been of great help. All financial support has been given without any obligations and the registry has no commitments to any pharmaceutical company.

Organisation and data ownership

It should be emphasised that the registry (software) is the property of Scandiatransplant while the data in the registry is the property of the Nordic Liver Transplantation Group. Utilisation of data should be censored by the latter. The data presented here should not be used without permission from the Nordic Liver Transplantation Group. The contact person for each centre is listed below:

Copenhagen	Preben Kirkegaard
Gothenburg	Styrbjörn Friman
Helsinki	Krister Höckerstedt
Oslo	Aksel Foss
Stockholm	Bo-Göran Ericzon
Uppsala	Frans Duraj

This complete report is distributed to a limited number of persons at each centre; further copies can be delivered on request. A preliminary report has been sent to the contact persons for comments.

The full report is published on internet at:

www.scandiatransplant.org

Oslo, April 2005

Bjørn Brandsæter

NB

Patients listed and receiving liver allografts in Uppsala prior to 2000 are recorded as Stockholm-patients.

Activity 2004.

Table 1.

Activity during 2004 – total number of transplantations, first transplantations, retransplantations, deaths on the waiting list and permanent withdrawals (irrespective of time of listing).

	Total tx	First liver tx			ReTx	DEA	PW
		CDT	LDT				
			Living related	Domino			
Copenhagen	42	35	1	0	6	3	8
Gothenburg	70	52	5	3	10	3	5
Helsinki	50	46	0	0	4	1	3
Oslo	45	43	0	0	2	5	3
Stockholm	50	40	2	2	6	3	4
Uppsala	11	11	0	0	0	1	2
Total	268	227	8	5	28	16	25

DEA – dead while active on waiting list

PW – permanently withdrawn

CDT – cadaveric donor transplants

LDT - living donor transplants (includes domino liver)

Comment to Table 1.

The number of first liver transplantations has continued to increase, while the numbers of retransplantations has shown a slight decline. The activity is high and stable at all centres.

Table 2.**Annual number of liver transplantations, 1997-2004.**

	2004	2003	2002	2001	2000	1999	1998	1997
Tx no 1	240	217	190	192	169	164	175	161
Tx no 2	19	25	21	15	19	16	28	17
Tx no 3	7	5	0	2	3	3	1	0
Tx no 4	2	1	1	0	0	0	0	0
Tx no 5	0	0	1	0	0	0	0	0
Total	268	248	213	209	191	183	204	178

Table 3.

	First liver transplantation							Retransplantations*						
	2004	2003	2002	2001	2000	1999	1998	2004	2003	2002	2001	2000	1999	1998
Copenhagen	36	36	32	26	20	26	37	6	3	8	6	4	5	6
Gothenburg	60	62	42	50	40	41	54	10	7	11	4	8	5	5
Helsinki	46	40	44	37	28	28	33	4	3	3	1	3	2	6
Oslo	43	31	25	32	25	23	19	2	8	0	5	5	5	6
Stockholm	44	41	43	46	56	46	41	6	9	1	1	49	1	6
Uppsala	11	7	4	1				0	1					
Total	238	217	190	192	169	164	175	28	31	23	17	22	18	29

* includes all retransplants - second, third and fourth

Comment to Table 3.

The number of first liver transplantations is the highest ever.

Table 4.**Indication for first liver transplantations according to diagnosis.**

	2004	2003	2002	2001	2000	1999	1998	1997	1996
Primary sclerosing cholangitis	42	37	31	37	28	21	24	31	25
Acute hepatic failure*	20	26	17	33	16	20	18	24	15
Hepatitis C cirrhosis	26	23	22	10	16	17	17	11	5
Primary biliary cirrhosis	17	17	8	10	18	16	16	14	13
Metabolic diseases	13	9	9	9	11	14	15	6	6
Alcoholic cirrhosis	25	24	29	21	21	13	28	21	14
Malignant diseases	26	17	15	15	17	12	19	9	5
Autoimmune cirrhosis*	12	7	10	5	6	10	1	5	9
Biliary atresia	10	9	6	11	7	9	8	3	9
Hepatitis B cirrhosis	10	5	8	4	6	7	5	5	4
Cryptogenic cirrhosis	8	10	5	5	9	4	4	9	6
Budd Chiari syndrome*	2	1	4	5	0	3	5	6	6
Other cholestatic diseases	1	0	2	4	0	1	6	9	9
Other	28	31	22	23	14	17	7	8	19
Total	240	217	190	192	169	164	175	161	141

*Patients with Budd Chiari syndrome, autoimmune hepatitis and HBV may be recorded as acute hepatic failure if listed as urgent, the figures given for Budd Chiari in this table exclude patients listed as acute hepatic failure

Comment to Table 4.

For several years PSC has been the leading indication for liver transplantation in the Nordic countries. Hepatitis C cirrhosis, alcoholic cirrhosis and malignant disease are increasing as transplant indications.

Table 5.

Duration of time on waiting list, patients receiving 1. liver allograft (excluding highly urgently listed patients)

	2004	2003	2002	2001	2000	1999	1998	1997	1996
median (days)	35	37	52	42	43	30	21	23	27
mean (days)	88	80	89	85	75	55	53	63	64

Blood type A

	2004	2003	2002	2001	2000	1999	1998	1997	1996
median (days)	25	27	26	30	35	19	11	13	13
mean (days)	55	43	64	61	65	31	22	29	12

Blood type O.

	2004	2003	2002	2001	2000	1999	1998	1997	1996
median (days)	60	74	102	52	71	73	46	67	63
mean (days)	122	144	118	72	99	102	93	105	112

Comment Table 5.

The medium waiting times, both for blood type A and O, have continued to decrease.

Table 6.

Centrewise mean and median waiting times for patients receiving first liver allografts 2000-2004.

Blood type A

	CP	GO	HE	OS	ST	UP
Median (days)	28	24	15	26	42	21
Mean (days)	67	54	38	37	76	58

Blood type 0

	CP	GO	HE	OS	ST	UP
Median (days)	63	52	37	44	146	74
Mean (days)	132	126	64	86	150	75

Comment to Table 6.

There are significant differences in waiting times between centres. Waiting times in Helsinki are in particular shorter especially compared to Stockholm. This trend has been stable for several years.

Table 7.

Age distribution of patients receiving a first liver allograft, 1997-2004 (age at transplantation).

age - year	2004	2003	2002	2001	2000	1999	1998	1997	1996
<1	10	7	5	10	2	7	6	2	4
1-2	4	3	0	1	4	2	2	6	3
2-10	7	5	7	5	2	10	8	4	6
11-20	11	10	8	6	5	7	4	8	4
21-30	16	10	16	19	19	7	6	12	12
31-40	25	28	24	21	14	18	23	17	14
41-50	68	39	44	40	50	38	48	44	33
51-60	55	72	63	50	56	50	53	42	47
>60	44	43	23	40	26	23	23	24	18

Table 8.

Recipient age 1997-2004, first liver allograft – according to tx centre (patients < 5 years of age are excluded).

	Mean age	Median age	Percentage of recipients being > 60 years
Copenhagen	46	50	13.7
Gothenburg	49	52	23.5
Helsinki	48	50	19.2
Oslo	45	46	7.4
Stockholm	47	50	17
Uppsala	47	50	21.4

Table 9.

Total number of children under the age of 5 years receiving a first liver allograft (1997-2004).

	No of recipients < 5 years	Per cent recipients being < 5 years
Copenhagen	14	6%
Gothenburg	19	5%
Helsinki	13	5%
Oslo	26	12%
Stockholm	19	5%

Comment to Table 9.

The marked difference between Oslo and the other centres is due to a high number of children with cholestatic liver diseases accepted for liver transplantation in Norway.

Table 10.

**Donor age* (years) – according to centre (1997-2004)
(first liver allografts)**

	Mean	Median	Per cent donors being > 60 years
Copenhagen	41.2	44	10%
Gothenburg	45.1	47	19%
Helsinki	41.4	44	8%
Oslo	40.2	44	10%
Stockholm	46.2	50	24%
Uppsala	48.2	50	21%

* donor age is missing in approximately 4% of the cases

Table 11.

Total number of patients accepted to the liver tx waiting list (1. acceptance): 260
Outcome of patients **listed** during 2004:

	TOTAL	DEA	PW	CDT	LDT	Active
Copenhagen	45	3	10	27	0	5
Gothenburg	65	3	5	40	8	7
Helsinki	48	1	3	43	0	1
Oslo	49	5	2	39	0	3
Stockholm	41	2	3	31	3	2
Uppsala	12	0	1	11	0	0
TOTAL 2004	260	14	24	191	11	18

Table 12.**Diagnoses of patients accepted to the waiting list 1997-2004 (1. acceptance):**

	2004	2003	2002	2001	2000	1999	1998	1997
Acute hepatic failure [@]	26	32	24	43	24	28	26	28
Primary sclerosing cholangitis	34	41	35	36	38	27	25	32
Malignant diseases	24	24	19	20	18	21	23	10
Primary biliary cirrhosis	19	18	13	10	16	20	17	17
Hepatitis C cirrhosis	30	25	23	14	20	20	20	11
Alcoholic cirrhosis	35	28	30	27	25	18	30	23
Metabolic diseases	13	12	9	9	11	16	16	5
Biliary atresia	14	7	11	11	11	11	10	4
Autoimmune cirrhosis*	15	8	13	7	7	9	3	4
Cryptogenic cirrhosis	7	9	6	6	8	8	3	7
Hepatitis B cirrhosis*	11	9	7	8	6	7	6	7
Budd Chiari syndrome*	1	2	2	6	0	3	5	2
Other cholestatic diseases	1	1	0	5	2	2	7	6
Other	30	27	23	23	14	23	11	20
Total	258	243	215	225	202	213	202	176

*Patients with autoimmune hepatitis, HBV and Budd Chiari may be recorded as acute hepatic failure if listed as urgent, the figures given for these diagnoses in this table exclude patients listed as acute hepatic failure.

[@]NB A few patients with the diagnosis acute hepatic failure were not listed for a highly urgent liver transplantation, i.e. they were listed for an elective liver transplantation.

Comment to Table 12.

HCV, alcoholic cirrhosis, biliary atresia and autoimmune cirrhosis have all increased as indication for acceptance to the waiting list. Sclerosing cholangitis seems to have reached a plateau.

Table 13.**Retransplantation rates 1990-2004**

Comprises data on patients receiving a first liver allograft during 1990-2004. The percentage of patients receiving a second allograft will partially depend on the patient population.

	1. LTX	2.LTX	%- 2.LTX
Copenhagen*	456	58	13.3%
Gothenburg	613	65	10.6%
Helsinki	458	36	7.9%
Oslo	316	39	12.3%
Stockholm	567	49	8.6%
Uppsala	41	2	4.8%

* including Aarhus

Table 14.

Retransplantations according to diagnosis – 1990-2004

	NO. OF 1. LIVER TX	NO. OF 2. LIVER TX	TIME FROM 1. TO 2. LTX		% OF 2. LTX WITHIN 3 WEEKS
			Mean	Median	
Acute hepatic failure	299	43 (14%)	679	147	42%
Alcoholic cirrhosis	263	14 (5%)	955	644	14%
Autoimmune cirrhosis	93	9 (10%)	502	15	56%
Biliary atresia	115	19 (17%)	372	14	63%
Hepatocellular carcinoma	129	9 (7%)	553	33	33%
Hepatitis C cirrhosis	169	21 (12%)	405	152	19%
Primary biliary cirrhosis	270	21 (8%)	524	200	19%
Prim. scler.cholangitis	372	40 (11%)	583	134	13%

Comment to Table 14.

Children with biliary atresia run a higher risk of needing a second transplantation, the majority of these within a few weeks. Patients with primary sclerosing cholangitis has an increasing need for retransplantations – most of these retransplantations being late retransplantation. Only 14% of patients who underwent liver transplantation for alcoholic cirrhosis underwent retransplantation – probably not because they did not need one but possibly because they were not offered a second transplantation.

Table 15.

Distribution of some major diagnoses (patients receiving a 1.liver allograft) – according to centre – 1997-2004

	Copenhagen	Gothenburg	Helsinki	Oslo	Stockholm	Uppsala
AHF	36	26	63	21	21	3
ALCI	51	63	31	17	19	1
AUCI	8	11	9	8	14	4
BIAT/CODI	14	13	7	23	18	0
BCDI	3	4	7	5	1	1
CRCI/OCCI	23	15	26	11	17	0
MEDI	11	9	6	9	52	0
PBCI	17	27	38	17	19	0
PCYS	9	5	0	6	1	0
PHCC	12	49	5	18	51	8
PHCB	2	27	0	8	12	2
SCCH	25	58	50	58	56	5
HCCA	2	15	18	4	48	2
SECA	0	9	0	1	0	0
OTCA	3	16	4	3	2	0

AHF - acute hepatic failure

ALCI - alcoholic cirrhosis

AUCI - autoimmune hepatitis-cirrhosis

BCDI - Budd Chiari (only chronic cases)

BIAT - biliary atresia

CRCI/OCCI – cryptogenic cirrhosis and cirrhosis other causes

MEDI - metabolic diseases

PBCI - primary biliary cirrhosis

PCYS - polycystic liver disease

PHCC - HCV cirrhosis

PHCB - HBV cirrhosis

SCCH – primary sclerosing cholangitis

HCCA - hepatocellular carcinoma

OTCA - all other cancers including cholangiocarcinoma, other primary hepatic cancers and secondary cancers

Table 16.
Most frequent indications for acceptance to the waiting list for 1. liver transplantation, 1990-2004.

Copenhagen	Gothenburg	Helsinki	Oslo	Stockholm	Uppsala
ALCI 106	SCCH 118	AHF 116	SCCH 91	MEDI 94	SCCH 9
AHF 91	ALCI 93	PBCI 87	AHF 51	SCCH 90	PHCC** 8
PBCI 39	PBCI 70	SCCH 68	BIAT* 46	PHCC** 80	HCCA 7
SCCH 39	PHCC** 62	ALCI 47	ALCI 26	AHF 76	AUCI 5
CRCI 31	AHF 45	HCCA 27	PHCC 21	HCCA 76	AHF 4
MEDI 31	PHCB 36	OCCI 26	AUCI 21	PBCI 51	MEDI 3
BIAT* 31	HCCA 32	BIAT* 25	MEDI 19	BIAT* 48	PHCB 3

*The figure includes patients with biliary atresia and other cholestatic disorders in children (CODI)

**The figure includes only patients with PHCC as a primary diagnosis, patients with other primary diagnosis, e.g. ALCI or HCCA are not included

Activity 1982-2004

A total of 2687 first liver transplantations and 337 retransplantations have been performed since 1982, the distribution among the centres is given below.

Survival curves for the total material, for different time periods and for major diagnostic groups are given. In addition survival curves for a limited number of diagnoses – primary sclerosing cholangitis, fulminant hepatic failure, malignant liver disease in general and HCC in particular are presented.

Table 17.**Total number of first liver transplantations and retransplantations performed per centre**

	1.liver transplants	Retransplants [⊠]	Total number
Helsinki	510	55	565
Stockholm	632*	68	700*
Gothenburg	686	90	774
Copenhagen	441	67	508
Oslo	357	52	409
Uppsala	42*	3	45*
Aarhus	19	2	21
TOTAL	2687	337	3024

⊠ Includes both second, third, fourth and fifth transplantations

***Patients receiving a liver allograft in Uppsala during the period 1994-1998 are included in both the Stockholm and the Uppsala figures.**

Figure 1.

Patient survival according to year of transplantation

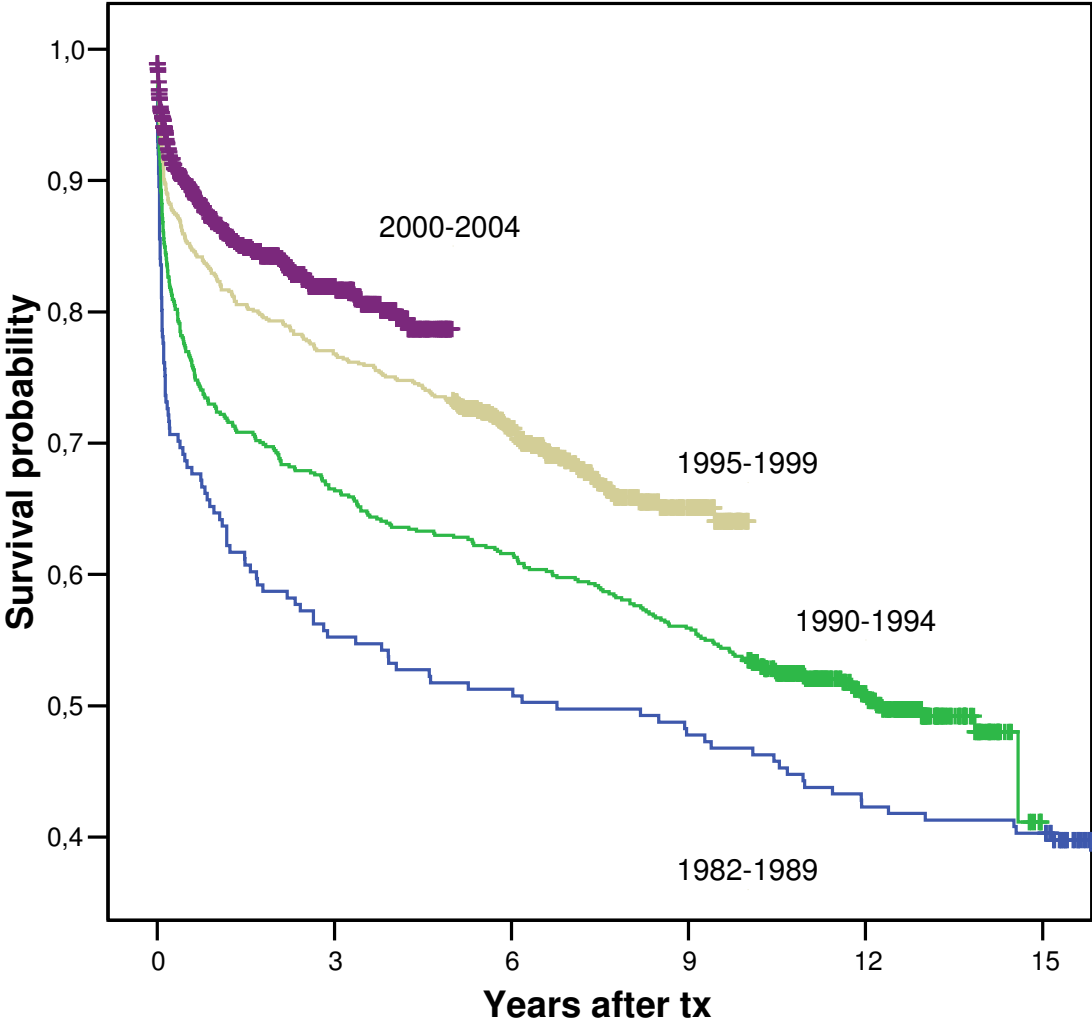


Figure 1.

Patient survival according to year of first transplantation

Figure 2.

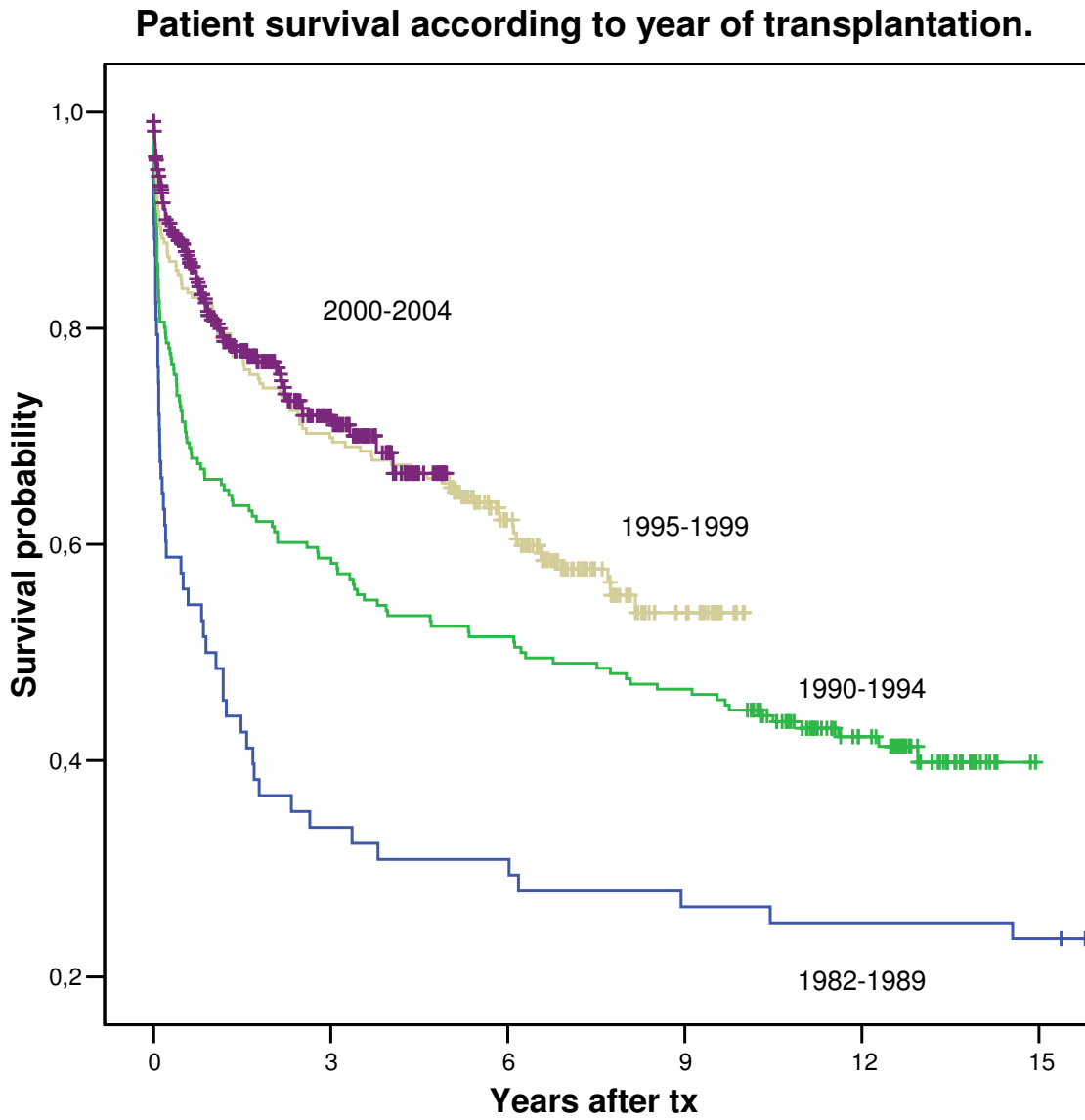


Figure 2.

Patient survival according to year of transplantation. Chronic, non-malignant, non-viral liver disease.

Figure 3.

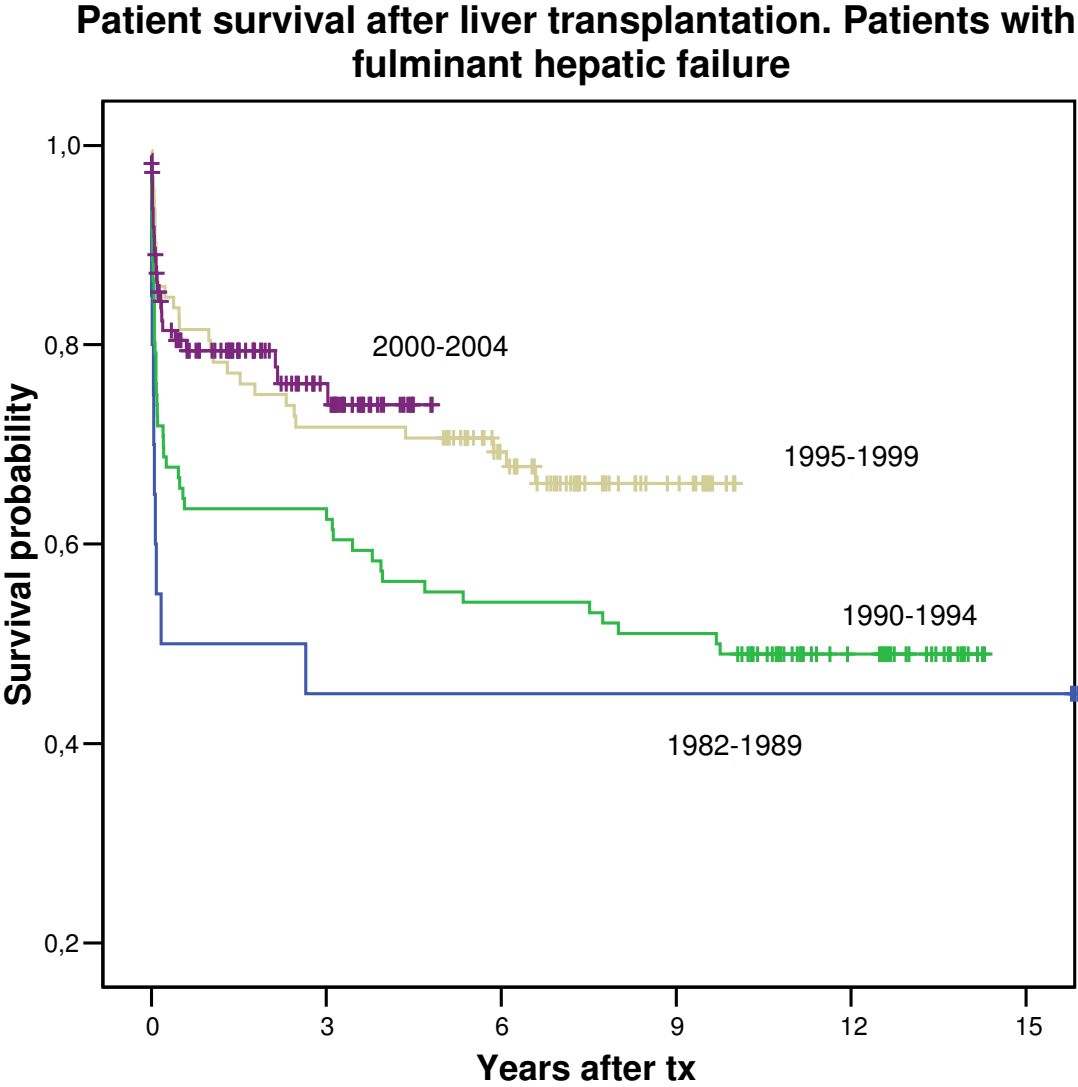


Figure 3.
Patient survival after liver transplantation according to year of transplantation. Patients with fulminant hepatic failure.

Figure 4.

Patient survival according to year of transplantation. Malignant liver disease as transplant indication.

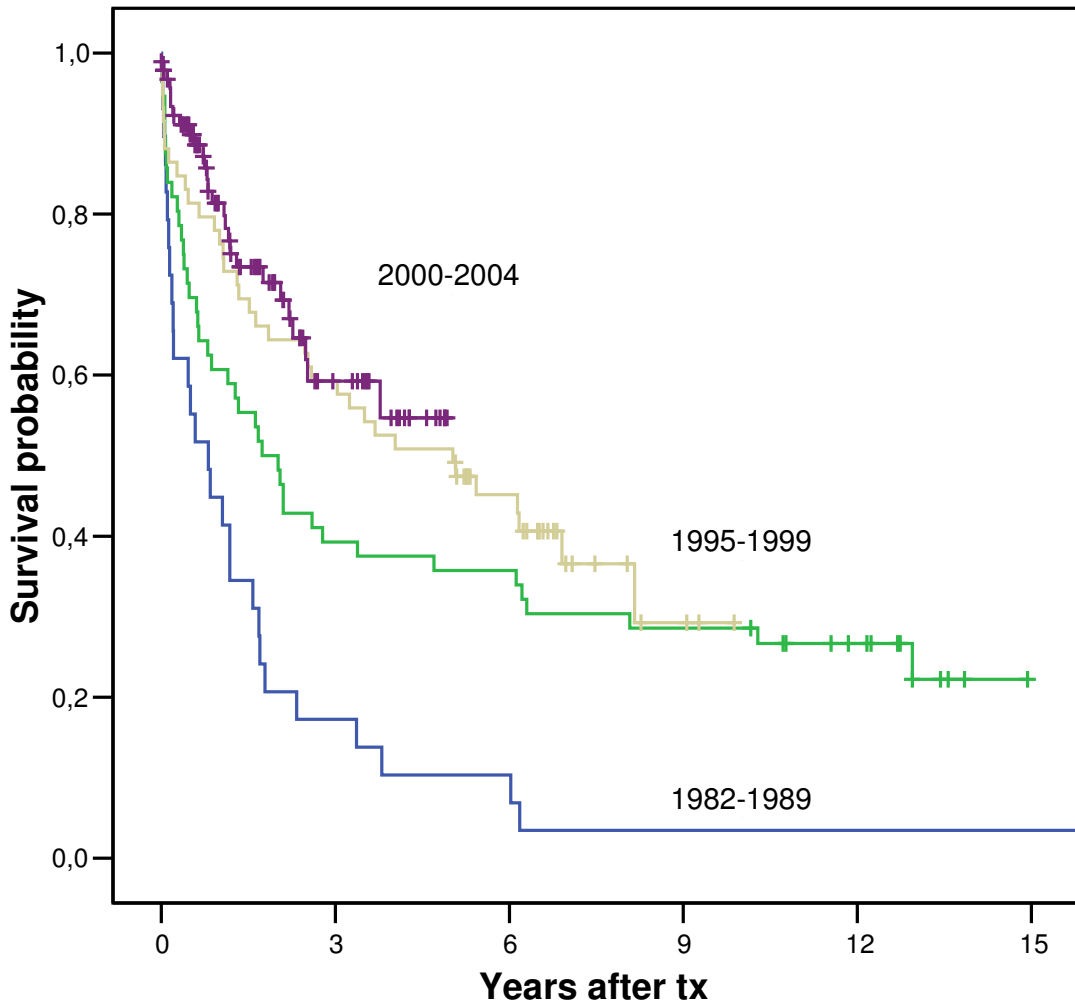


Figure 4.

Patient survival according to year of transplantation for patients with malignant liver disease as transplant indication.

Figure 5.

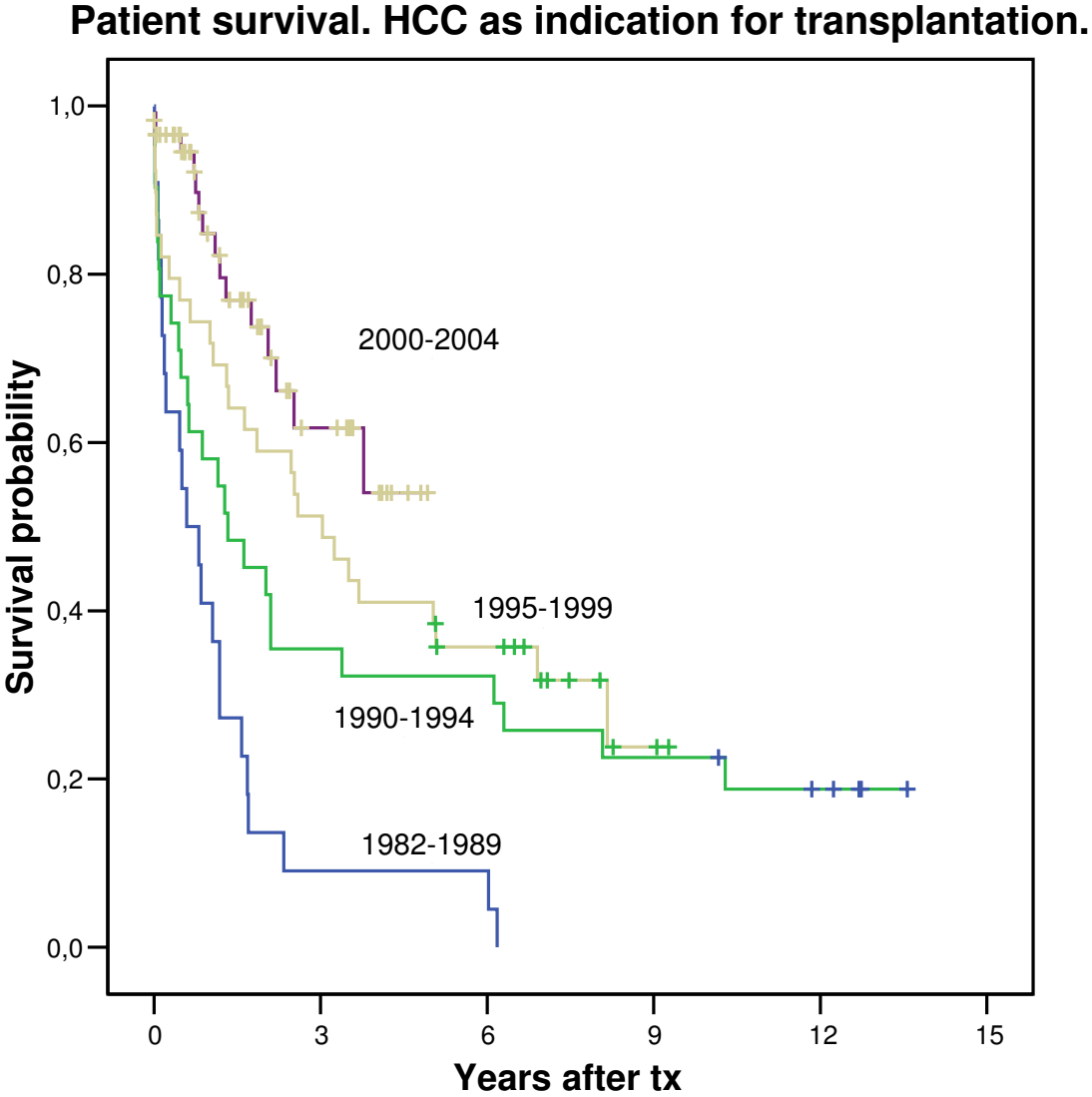


Figure 5.

Patient survival after liver transplantation for patients with hepatocellular carcinoma as transplant indication.

Figure 6.

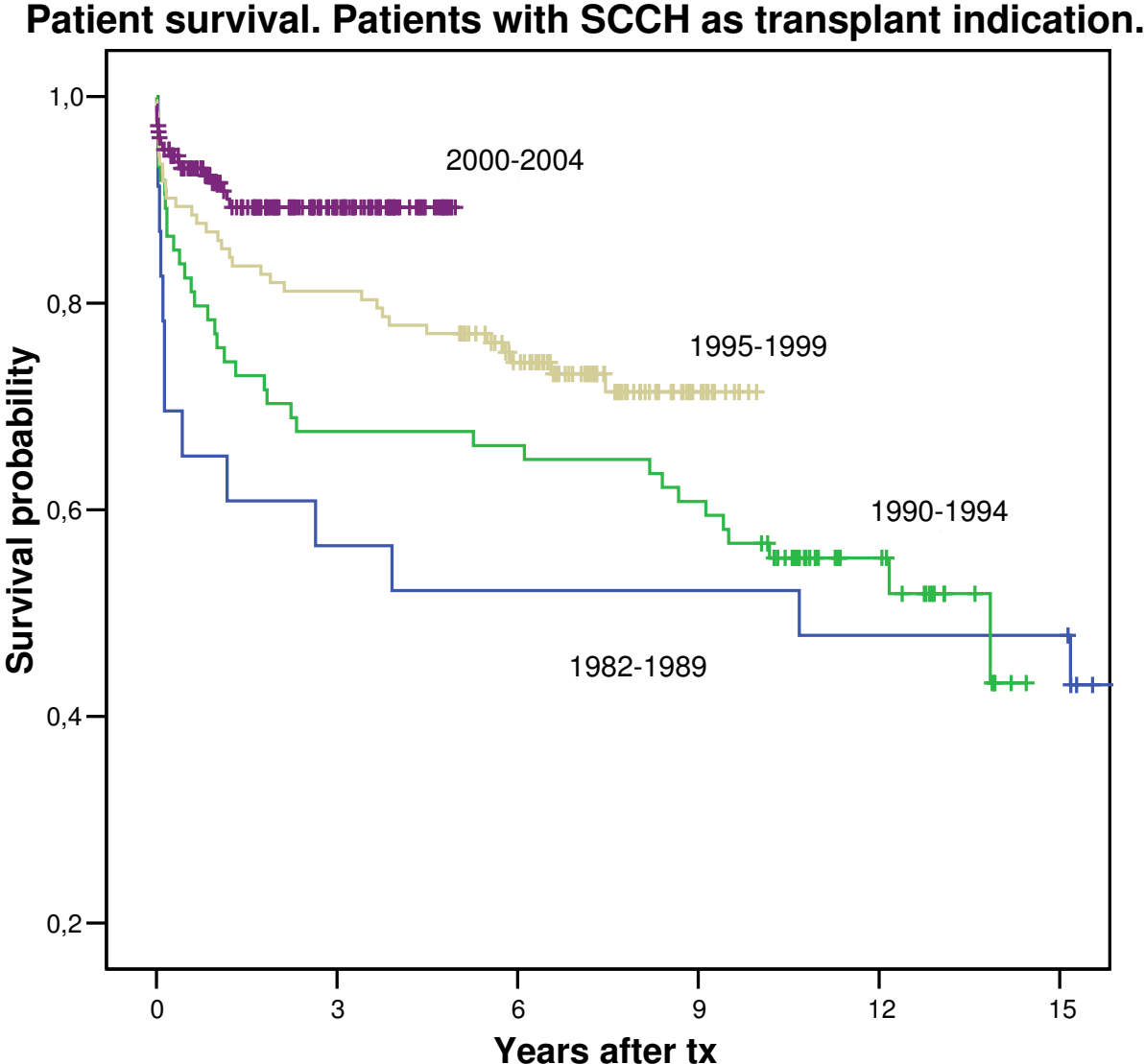


Figure 6.

Patient survival after liver transplantation for primary sclerosing cholangitis.

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