

# The Nordic Liver Transplant Registry Annual report 2005

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## **Nordic liver transplant registry - 2005**

As of 31 December 2005 the registry comprises data on 3433 patients of whom 2924 had received a first liver allograft. The registry comprises complete data on all patients listed for liver transplantation during the period 1990-2005; 3221 patients. The remaining 222 patients received a liver allograft prior to 1990. Waiting list data are not available for these patients.

### **Transplantation activity 2005**

The total number of patients receiving a first liver allograft during 2005 was 223. In addition 30 re-transplantations were performed. **The total number of performed liver transplantations was 258. The number of transplantations was slightly lower as compared to 2004.**

Median waiting time (electively listed patients) has increased to 41 days while mean waiting time has increased to 93 days. Median waiting time is stable for blood type O recipients. Both the number of deaths on the waiting list and the number of permanent withdrawals have increased. A total of 19 patients died while waiting for a liver allograft during 2005 and 31 patients were permanently withdrawn.

During 2005 primary sclerosing cholangitis (n=47) followed by alcoholic liver cirrhosis (n=38) and hepatitis C cirrhosis (n=32) 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. In 2005 both mean and median donor age increased for all centres.

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 296 patients were listed for a first liver transplantation in 2005. Of these, 206 received an allograft. Fifteen of the 296 patients died while being active on the waiting list. Twenty-five were permanently withdrawn from the waiting list without receiving a liver allograft. Fifty of the 296 patients were active on the waiting list as of December 31 2005.

### **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 January 31 2006.

### **Future of the registry**

At present, Scandiatransplant is preparing a reorganisation of the registry with a more up-to-date version and an easier way of extracting data and presenting these more continuously. The work is in progress but there will still be some time before the new NLTR-database is implemented.

### **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 Fujisawa, Novartis, Roche and Wyeth, during 2005. 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

A preliminary report has been sent to the contact persons for comments.

The full report is published on internet at:

[www.scandiatransplant.org](http://www.scandiatransplant.org)

Oslo, April 2006

Bjørn Brandsæter

**Eighteen patients underwent transplantation between 1994-1998 in a joint-project between Stockholm and Uppsala.**

## NLTR 2005

### Activity 2005.

**Table 1.**

**Activity during 2005. Total number of transplantations, first transplantations, retransplantations, deaths on the waiting list and permanent withdrawals (irrespective of time of listing).**

Tx centre	Total tx	First liver tx			ReTx	DEA	PW
		CDT	LDT Living related	LDT Domino			
Copenhagen	40	35	1	0	4	1	16
Gothenburg	67	51	3	0	13	2	6
Helsinki	41	38	0	0	3	5	0
Oslo	39	32	0	0	7	6	6
Stockholm	64	53	0	7	4	5	2
Uppsala	7	7	0	0	0	0	1
<b>TOTAL</b>	<b>258</b>	<b>216</b>	<b>4</b>	<b>7</b>	<b>31</b>	<b>19</b>	<b>31</b>

DEA – dead while active on waiting list

PW – permanently withdrawn

CDT – cadaveric donor transplants

LDT - living donor transplants (includes domino liver)

**Table 2.**

**Annual numbers of liver transplantations, 1998-2005**

	2005	2004	2003	2002	2001	2000	1999	1998
Tx no 1	227	240	217	190	192	169	164	175
Tx no 2	29	19	25	21	15	19	16	28
Tx no 3	2	7	5	0	2	3	3	1
Tx no 4	0	2	1	1	0	0	0	0
Tx no 5	0	0	0	1	0	0	0	0
<b>TOTAL</b>	<b>258</b>	<b>268</b>	<b>248</b>	<b>213</b>	<b>209</b>	<b>191</b>	<b>183</b>	<b>204</b>

**Table 3.**

**Annual number of first liver transplantations and retransplantations, 1999-2005.**

	<b>First liver transplantation</b>							<b>Retransplantation*</b>						
	2005	2004	2003	2002	2001	2000	1999	2005	2004	2003	2002	2001	2000	1999
Copenhagen	36	36	36	32	26	20	26	4	6	3	8	6	4	5
Gothenburg	54	60	62	42	50	40	41	13	10	7	11	4	8	5
Helsinki	38	46	40	44	37	28	28	3	4	3	3	1	3	2
Oslo	32	43	31	25	32	25	23	7	2	8	0	5	5	5
Stockholm	60	45	41	44	46	56	46	4	7	9	1	1	4	1
Uppsala	7	11	7	4	1			0	0	1				
<b>TOTAL</b>	<b>227</b>	<b>241</b>	<b>217</b>	<b>191</b>	<b>192</b>	<b>169</b>	<b>164</b>	<b>31</b>	<b>29</b>	<b>31</b>	<b>23</b>	<b>17</b>	<b>24</b>	<b>18</b>

**Comment table 3.**

The number of first liver transplantations has declined while the number of retransplantations is relatively higher compared to 2004.

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

	<b>2005</b>	<b>2004</b>	<b>2003</b>	<b>2002</b>	<b>2001</b>	<b>2000</b>	<b>1999</b>	<b>1998</b>	<b>1997</b>
Primary sclerosing cholangitis	35	42	37	31	37	28	21	24	31
Acute hepatic failure	15	20	26	17	33	16	20	18	24
Hepatitis C cirrhosis	22	26	23	22	10	16	17	17	11
Primary biliary cirrhosis	15	17	17	8	10	18	16	16	14
Metabolic diseases	19	13	9	9	9	11	14	15	6
Alcoholic cirrhosis	26	25	24	29	21	21	13	28	21
Malignant diseases	19	26	17	15	15	17	12	19	9
Autoimmune cirrhosis	12	12	7	10	5	6	10	1	5
Biliary atresia	11	10	9	6	11	7	9	8	3
Hepatitis B cirrhosis	5	10	5	8	4	6	7	5	5
Cryptogenic cirrhosis	8	8	10	5	5	9	4	4	9
Budd-Chiari syndrome	2	2	1	4	5	0	3	5	6
Other cholestatic diseases	0	1	0	2	4	0	1	6	9
Other	38	28	31	22	23	14	17	7	8
<b>Total</b>	<b>227</b>	<b>240</b>	<b>217</b>	<b>190</b>	<b>192</b>	<b>169</b>	<b>164</b>	<b>175</b>	<b>161</b>

\*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.**

PSC is still the leading indication for liver transplantation in the Nordic countries.

**Table 5.**

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

All blood types

	2005	2004	2003	2002	2001	2000	1999	1998	1997
median (days)	41	35	37	52	42	43	30	21	23
mean (days)	93	88	80	89	85	75	55	53	63

Blood type A

	2005	2004	2003	2002	2001	2000	1999	1998	1997
median (days)	38	25	27	26	30	35	19	11	13
mean (days)	77	55	43	64	61	65	31	22	29

Blood type O

	2005	2004	2003	2002	2001	2000	1999	1998	1997
median (days)	60	60	74	102	52	71	73	46	67
mean (days)	125	122	144	118	72	99	102	93	105

**Comment to table 5.**

The waiting time for blood type A has increased. Median waiting time for blood type O is stable.



**Table 6**

Centrewise mean and median waiting times for patients receiving first liver allografts 2000-2005 (excluding highly urgently listed patients).

Blood type A

	<b>CP</b>	<b>GO</b>	<b>HE</b>	<b>OS</b>	<b>ST</b>	<b>UP</b>
Median (days)	42	24	22	22	43	38
Mean (days)	97	57	42	50	72	58

Blood type O

	<b>CP</b>	<b>GO</b>	<b>HE</b>	<b>OS</b>	<b>ST</b>	<b>UP</b>
Median (days)	82	60	41	48	139	71
Mean (days)	160	136	67	99	146	248

**Comment to Table 6.**

There are significant differences in waiting times between centres

**Table 7.**

**Age distribution of patients receiving a first liver allograft, 1998-2005 (age at transplantation).**

<b>age - year</b>	<b>2005</b>	<b>2004</b>	<b>2003</b>	<b>2002</b>	<b>2001</b>	<b>2000</b>	<b>1999</b>	<b>1998</b>
<1	8	10	7	5	10	2	7	6
1-2	1	4	3	0	1	4	2	2
2-10	8	7	5	7	5	2	10	8
11-20	15	11	10	8	6	5	7	4
21-30	12	16	10	16	19	19	7	6
31-40	22	25	28	24	21	14	18	23
41-50	43	68	39	44	40	50	38	48
51-60	77	55	72	63	50	56	50	53
>60	34	44	43	23	40	26	23	23

**Table 8.**

**Recipient age 2000-2005, first liver allograft – according to tx centre (patients < 5 years of age are excluded).**

	<b>Mean age</b>	<b>Median age</b>	<b>Percentage of recipients being &gt; 60 years</b>
Copenhagen	48	50	10.8
Gothenburg	49	51	19.9
Helsinki	48	51	15.5
Oslo	45	47	7.1
Stockholm	49	52	16.5
Uppsala	48	48	23.3

**Table 9.**

**Total number of children under the age of 5 years receiving a first liver allograft (2000-2005).**

	<b>No of recipients &lt; 5 years</b>	<b>Per cent recipients being &lt; 5 years</b>
Copenhagen	11	6%
Gothenburg	13	4%
Helsinki	8	3%
Oslo	18	10%
Stockholm	18	6%

**Comment to Table 9.**

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

**Table 10.**

**Donor age\* (years) – according to centre (2000-2005)  
(first liver allografts)**

	<b>Mean</b>	<b>Median</b>	<b>Per cent donors being &gt; 60 years</b>
Copenhagen	43	45	14%
Gothenburg	46	48	22%
Helsinki	43	46	10%
Oslo	43	47	15%
Stockholm	48	51	28%
Uppsala	52	53	36%

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

**Table 11.**

**Total number of patients accepted to the liver tx waiting list (first acceptance): 296**  
Outcome of patients **listed** during 2005:

	<b>TOTAL</b>	<b>DEA</b>	<b>PW</b>	<b>CDT</b>	<b>LDT</b>	<b>Active</b>
Copenhagen	61	1	13	30	0	17
Gothenburg	74	1	4	57	2	10
Helsinki	47	4	-	40	-	3
Oslo	45	6	5	30	1	3
Stockholm	78	3	2	51	6	16
Uppsala	8	-	1	6	-	1
<b>TOTAL 2005</b>	<b>313</b>	<b>15</b>	<b>25</b>	<b>214</b>	<b>9</b>	<b>50</b>

**Table 12.**

**Diagnoses of patients accepted to the waiting list 1998-2005 (1. acceptance):**

	<b>2005</b>	<b>2004</b>	<b>2003</b>	<b>2002</b>	<b>2001</b>	<b>2000</b>	<b>1999</b>	<b>1998</b>
Acute hepatic failure <sup>®</sup>	<b>29</b>	<b>26</b>	32	24	43	24	28	26
Primary sclerosing cholangitis	<b>47</b>	<b>34</b>	41	35	36	38	27	25
Malignant diseases	<b>23</b>	<b>24</b>	24	19	20	18	21	23
Primary biliary cirrhosis	<b>21</b>	<b>19</b>	18	13	10	16	20	17
Hepatitis C cirrhosis	<b>32</b>	<b>30</b>	25	23	14	20	20	20
Alcoholic cirrhosis	<b>38</b>	<b>35</b>	28	30	27	25	18	30
Metabolic diseases	<b>13</b>	<b>13</b>	12	9	9	11	16	16
Biliary atresia	<b>17</b>	<b>14</b>	7	11	11	11	11	10
Autoimmune cirrhosis*	<b>12</b>	<b>15</b>	8	13	7	7	9	3
Cryptogenic cirrhosis	<b>13</b>	<b>7</b>	9	6	6	8	8	3
Hepatitis B cirrhosis*	<b>5</b>	<b>11</b>	9	7	8	6	7	6
Budd Chiari syndrome*	<b>3</b>	<b>1</b>	2	2	6	0	3	5
Other cholestatic diseases	<b>1</b>	<b>1</b>	1	0	5	2	2	7
Other	<b>42</b>	<b>30</b>	27	23	23	14	23	11
<b>Total</b>	<b>296</b>	<b>258</b>	243	215	225	202	213	202

\*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.

<sup>®</sup>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.**

PSC is still the number one indication for listing for liver transplantation (n=47) and alcoholic cirrhosis is the second most frequent indication (n=38).

**Table 13.****Retransplantation rates 1990-2005**

Comprises data on patients receiving a first liver allograft during 1990-2005. The percentage of patients receiving a second allograft will partially depend on the patient population.

	<b>1. LTX</b>	<b>2.LTX</b>	<b>%- 2.LTX</b>
Copenhagen*	493	61	12.3%
Gothenburg	668	78	11.7%
Helsinki	497	38	7.6%
Oslo	349	47	13.5%
Stockholm	645	56	8.7%
Uppsala	48	2	4.2%

\* including Aarhus

**Table 14.****Retransplantations according to diagnosis – 1990-2005**

	<b>NO. OF 1. LIVER TX</b>	<b>NO OF 2. LIVER TX</b>	<b>TIME (IN DAYS) FROM 1. TO 2. LTX</b>		<b>% OF 2. LTX WITHIN 3 WEEKS</b>
			Mean	Median	
Acute hepatic failure	315	48 (16%)	711	154	35%
Alcoholic cirrhosis	289	19 (6%)	904	578	26%
Autoimmune cirrhosis	106	10 (9%)	465	39	50%
Biliary atresia	126	20 (16%)	383	15	60%
Hepatocellular carcinoma	147	11 (7%)	883	33	27%
Hepatitis C cirrhosis	191	22 (12%)	406	174	18%
PBC	286	22 (8%)	509	178	18%
PSC	406	46 (11%)	828	182	11%

**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 – but most of these retransplantations are late retransplantation.

**Table 15.**

**Distribution of some major diagnoses (patients receiving a 1.liver allograft) – according to centre – 2000-2005**

	<b>Copenhagen</b>	<b>Gothenburg</b>	<b>Helsinki</b>	<b>Oslo</b>	<b>Stockholm</b>	<b>Uppsala</b>
AHF	29	21	45	20	11	2
ALCI	41	43	30	18	14	0
AUCI	5	10	8	11	12	5
BIAT/CODI	12	9	9	16	18	0
BCDI	1	3	3	5	1	1
CRCI/OCCI	13	10	25	10	16	1
MEDI	12	8	2	5	42	1
PBCI	14	22	26	10	15	0
PCYS	7	4	0	5	1	0
PHCC	8	39	7	16	43	6
PHCB	1	18	0	8	10	2
SCCH	20	49	46	49	41	6
HCCA	3	13	14	4	40	3
SECA	0	7	0	1	0	0
OTCA	3	10	3	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 first liver transplantation, 1990-2005.**

<b>COPENHAGEN</b>	<b>GOTHENBURG</b>	<b>HELSINKI</b>	<b>OSLO</b>	<b>STOCKHOLM</b>	<b>UPPSALA</b>
ALCI: 121	PSC: 131	AHF: 124	PSC: 100	MEDI: 104	PSC: 11
AHF: 110	ALCI: 100	PBC: 90	AHF: 60	HCV***: 95	HCV***: 8
PSC: 49	PBC: 75	PSC: 77	BIAT*: 49	PSC: 93	HCC: 7
PBC: 45	HCV***: 69	ALCI: 53	PBC: 40	HCC: 91	AUCI: 6
BIAT*: 36	AHF: 64	BIAT*: 32	ALCI: 30	AHF: 66	MEDI: 4
CRCI*: 34	HCC: 38	HCC: 28	HCV***: 27	PBC: 56	AHF: 4
MEDI: 31	AUCI:32	OCCI: 27	AUCI: 24	BIAT*: 55	HBV: 3

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

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

### Activity 1982-2005

A total of 2924 first liver transplantations and 371 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 and HCC are presented.

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

	<b>1.liver transplants</b>	<b>Retransplants<sup>α</sup></b>	<b>Total number</b>
Helsinki	548	58	606
Stockholm	702*	75	777
Gothenburg	740	103	843
Copenhagen	477	71	548
Oslo	389	59	448
Uppsala	49*	3	52
Aarhus	19	2	21
<b>TOTAL</b>	<b>2924</b>	<b>371</b>	<b>3295</b>

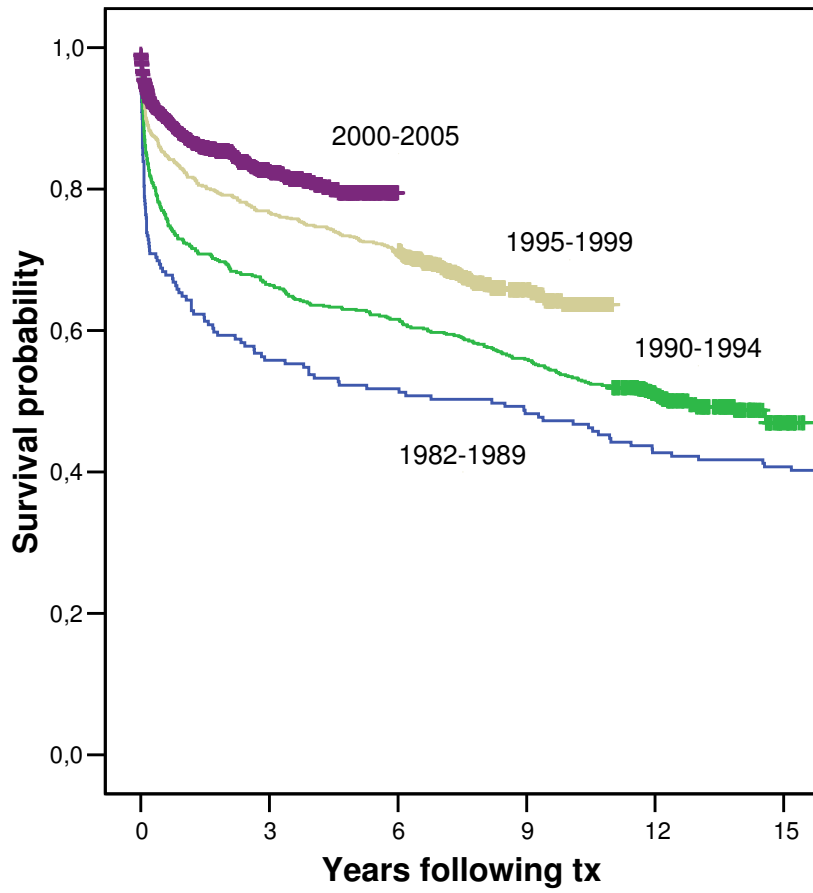
<sup>α</sup> Includes both second, third, fourth and fifth transplantations

\* Patients receiving a liver allograft in Uppsala during the period 1994-1998 are included in both the Stockholm and the Uppsala figures. 18 patients underwent transplantation as Uppsala/Stockholm patients. These 18 patients should be subtracted from the total Stockholm numbers.



**Figure 1.**

**Patient survival according to year of transplantation**

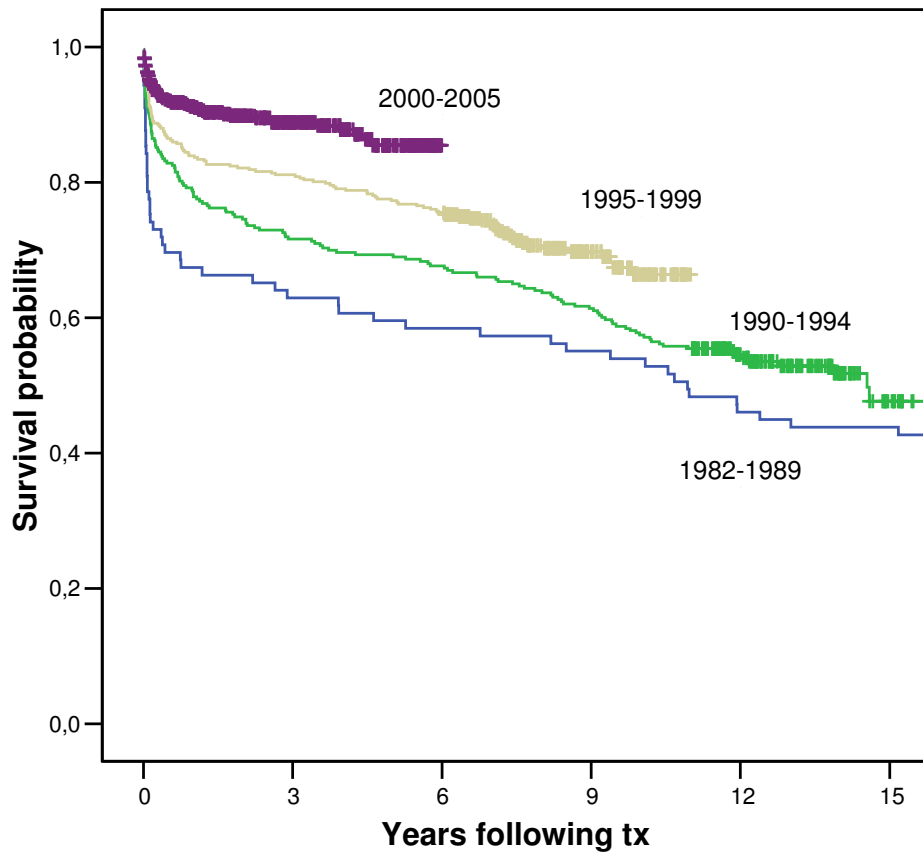


**Figure 1**

**Patient survival according to year of first transplantation**

Figure 2.

**Patient survival, chronic, non-malignant, non-viral liver disease.**



**Figure 2.**  
**Patients survival according to year of transplantation. Chronic, non-malignant, non-viral liver diseases (PBC, PSC, Autoimmune hepatitis, Alcoholic cirrhosis).**

Figure 3.

**Patients survival following transplantation. Fulminant hepatic failure.**

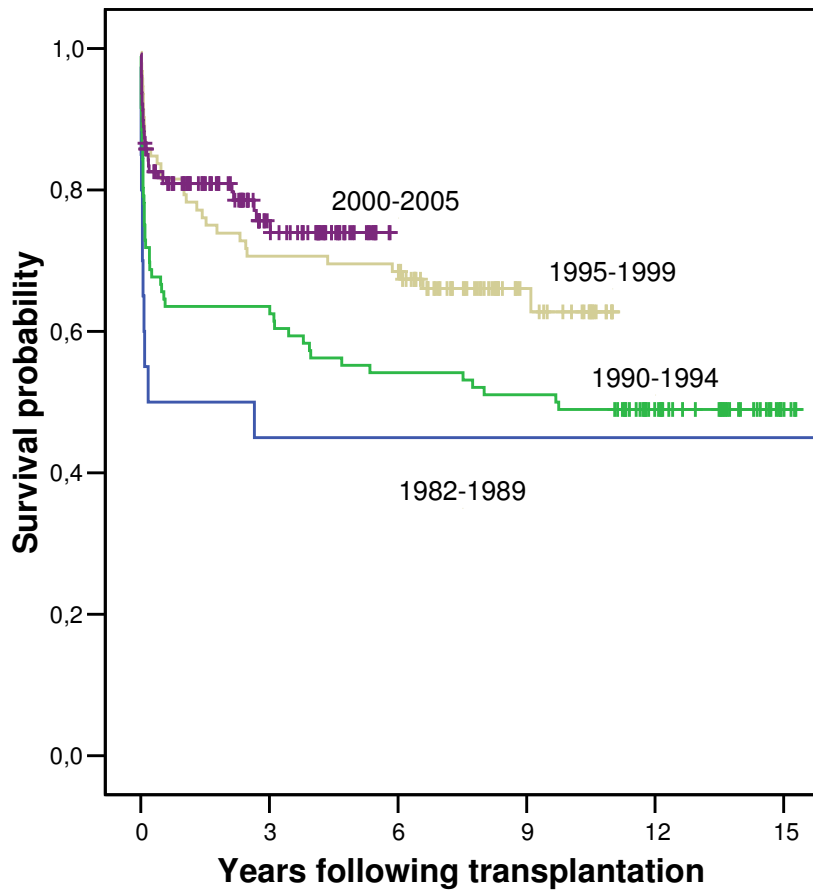


Figure 3.

**Patient survival following liver transplantation according to year of transplantation.**

**Patients with fulminant hepatic failure.**

Figure 4.

**Patient survival according to year of transplantation. HCC as  
transplant indication.**

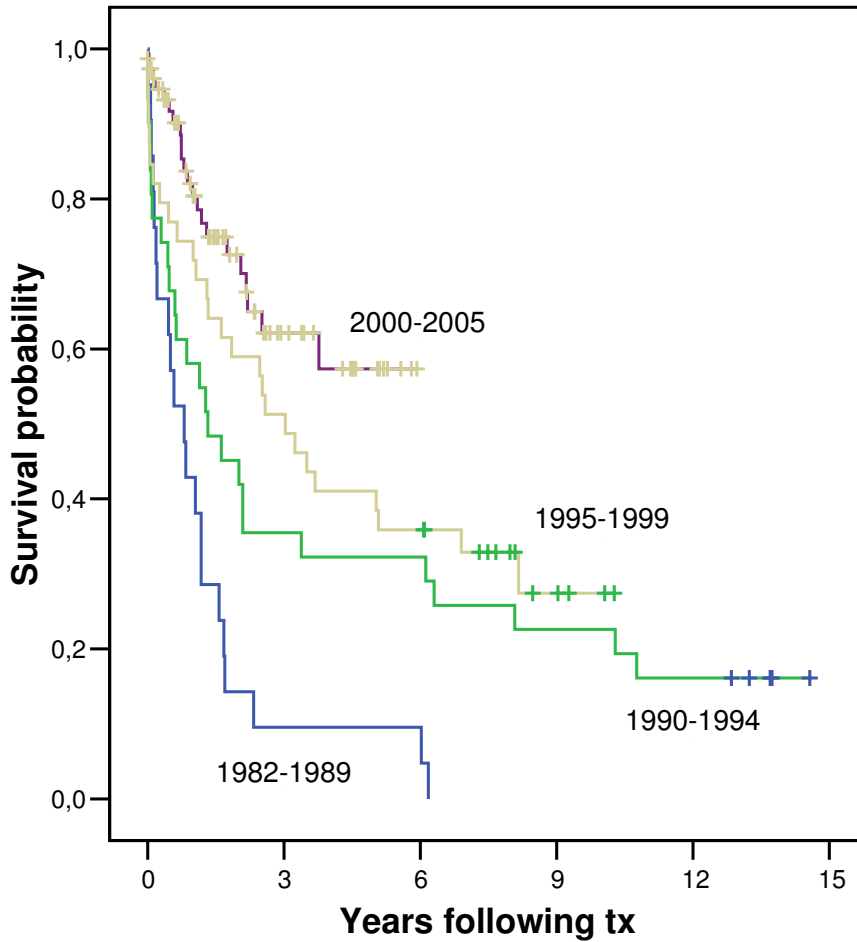


Figure 4.

**Patient survival according to year of transplantation. Hepatocellular carcinoma as  
transplant indication.**

Figure 5.

**Patient survival - PSC as transplant indication.**

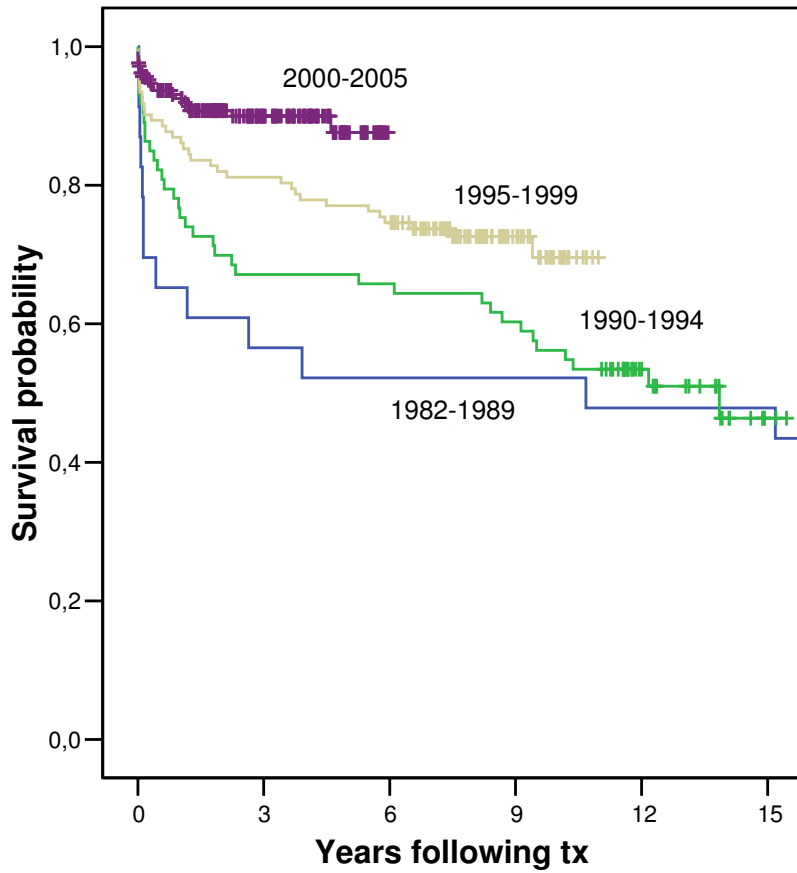


Figure 5.

**Patient survival after liver transplantation for primary sclerosing cholangitis.**