Treatment of End-Stage Organ Failure in Canada

1995 to 2004

(2006 Annual Report)

Canadian Organ Replacement Register

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Acknowledgements

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Report Highlights

End-Stage Renal Disease

- The rate of incident renal replacement therapy rose 41% in Canada, from 112 per million population in 1995 to 158 per million population in 2004.
- At the end of 2004, there were 18,827 patients on dialysis and 12,099 living with a functioning kidney transplant, for a total of 30,924 Canadians with end-stage renal disease registered in CORR.
- In 2004, more than half of the new end-stage renal disease patients (53.2%) initiated renal replacement therapy at age 65 years or older.
- The mortality risk over a 10-year time span was reduced by 10%.
- The number of living donor kidneys for adult patients increased by 88.6% between 1995 and 2004.
- Five-year survival for recipients of living-donor kidneys was 97.5%, compared to 89.1% for those receiving a kidney from a deceased donor.
- The largest mortality risk was found for patients aged 65 years and older, and the second-largest was for those with type 2 diabetes.

End-Stage Liver Disease

- Annually, the number of liver transplants performed on pediatric patients decreased by 44.9% between 1995 and 2004, while the number of liver transplants in those aged 18 years and older increased by 47.5%.
- Less than 2% of liver transplants in Canada were combination transplants.
- The number of patients waiting for a liver transplant grew steadily over the 10 years, with an overall increase of 347%.
- The majority (56%) of patients received their liver transplant after being placed on the waiting list as Status 1 (non-urgent).
- Between 1995 and 2004, the highest five-year survival rate was among those aged 1 to 10 years.

End-Stage Heart Disease

- Between 1995 and 2004, 1,571 patients received a first heart transplant and 58 were retransplanted.
- The number of heart transplants per year decreased by 21%, from a high of 181 in 1995 to a low of 143 in 2004.
- Unadjusted patient survival rates for those with first heart transplants between 1995 and 2004 improved, while the early survival rate (three months) saw a 7.6% decline.
- Those with cardiomyopathy as the cause of end-stage heart disease improved survival at all time points, compared to those with coronary artery disease or congenital heart diseases.
- The proportion of hearts recovered for transplant from deceased donors showed a steady decline over the decade, with an overall relative decline of 28.1%.

End-Stage Lung Disease

- The number of adult lung transplants increased by 64% between 1995 and 2004.
- Bilateral lung transplants accounted for 72.6% of the lung transplants performed in Canada in 2004, which more than doubled between 1995 and 2004.
- Lung transplantation is the only solid organ transplant for which the rate of transplants performed in Canada surpassed that of the rate observed in the United States.
- Despite an 11% increase in the number of donors from whom both lungs were retrieved, the rate of lung recovery from deceased donors was relatively low at 28.3% in 2004.
- There was improved patient survival throughout the decade with the largest improvement seen in one- and five-year survival (14.7% and 11.4% improvement, respectively).

End-Stage Pancreas Disease

- Two-thirds of the 510 pancreas transplants performed in Canada between 1995 and 2004 were simultaneous pancreas–kidney transplants.
- The average age of first pancreas transplant recipients during the decade was 40.1 years.
- The number of patients waiting for a simultaneous pancreas–kidney transplant peaked in 2001 at 172, and then dropped in 2004 to 101.
- After simultaneous pancreas–kidney transplant, patient survival at five years was found to be 92.9%.
- The average age of pancreas donors was relatively low, at 30 years of age.

End-Stage Intestinal Disease

- Intestine transplantation was performed infrequently in Canada, with 36 transplants performed between 1988 and 2004.
- The most commonly reported cause of intestinal failure was a metabolic disorder, a diagnosis that includes short-gut syndrome.
- Two-thirds of the recipients of the intestine-alone procedures, or combined intestine with liver or kidney, were younger than 18 years of age.
- Twelve graft failures were reported between 1988 and 2004.
- Small intestines were recovered for transplantation in less than 1% of all deceased donors in Canada.

Deceased Organ Donation

- There were 4,249 deceased organ donors during the years between 1995 and 2004.
- The mean age of donors increased from 36.8 years in 1995 to 45.0 years in 2004.
- The most frequently observed donor cause of death in 2004 was cerebrovascular accident/stroke.
- The average number of organs transplanted from each deceased donor in 2004 was 3.5.
- The highest number of organs transplanted per donor was in the donor age group of 15 to 39 years, with 4.4 organs per donor.

Diabetes in End-Stage Organ Disease

- Forty percent of all registered end-stage renal failure patients in CORR who initiated treatment between 1995 and 2004 were diagnosed with diabetes.
- Over the decade, the presence of diabetes in new end-stage renal cases climbed from 25% in 1995 to 42% in 2004.
- Diabetes was determined to be the most influential risk factor, among all primary diseases causing end-stage organ failure, in a multivariate adjusted analysis of CORR data.
- Of those new end-stage renal patients with a body mass index (BMI) greater than 30 (defined as obese), 49% had type 2 diabetes and 12% had type 1 disease.
- Diabetic dialysis patients between the ages of 18 and 65 years had a 26.1% lower long-term survival rate compared to those without diabetes.
- For kidney transplant recipients, the largest difference (7%) between diabetic and non-diabetic recipient survival at five years was seen in the 18- to 44-year age group, in favour of non-diabetic patients.

1 Introduction

The Canadian Organ Replacement Register (CORR) is the national information system for renal and extra-renal organ failure and transplantation in Canada, with a mandate to record and analyze the level of activity and outcomes of solid organ transplantation and renal dialysis activities. In various forms, there has been a Canadian register of renal failure statistics since the early 1970s.

The first renal failure registry was started in 1972 under the leadership of Dr. Arthur Shimizu. In 1973, the registry was transferred to Statistics Canada, with the collaboration of The Kidney Foundation of Canada. Its first report was produced in 1974. In the mid-1970s, the Canadian Renal Failure Register, as it was then called, developed more detailed annual reports of dialysis and kidney transplantation activity. The operation of the project faltered briefly in the late 1970s, but was revived in 1980 under a new partnership formed among The Kidney Foundation of Canada, Health Canada and Statistics Canada, with guidance from the Canadian Society of Nephrology, including extensive assistance from Drs. Gerald Posen, John Jeffery and Gerald Arbus.

In 1987, with the support of the Federal/Provincial Advisory Committee on Institutional and Medical Services (ACIMS), the register was expanded to include data on extra-renal organ transplants. The expanded register was originally maintained by the Hospital Medical Records Institute (HMRI). In 1995, CORR became fully integrated with CIHI, which maintains numerous health-related national registries and data holdings.

The mission of CORR is to provide a national database on vital organ replacement therapy in Canada, with the goal of enhancing treatment, research and patient care. Major stakeholders include the Canadian Society of Transplantation, the Canadian Society of Nephrology, the Canadian Association of Transplantation, Health Canada, The Kidney Foundation of Canada and the Canadian Association of Nephrology Nurses and Technologists. The CORR Board of Directors is responsible for providing strategic advice to the register. The Advisory Committee provides advice on analytical issues and reporting. (For a membership list of the Board of Directors and the Advisory Committee as of April 1, 2006, please see Appendix A.)

Data Sources

CORR collects data from hospital dialysis programs, regional transplant programs, organ procurement organizations (OPOs) and kidney dialysis services offered at independent health facilities. For a list of the hospitals and facilities with transplant and dialysis activity reporting to CORR, please refer to Appendix B. CORR receives data on standardized paper forms or spreadsheets. Currently, all data are entered at CIHI by specially trained staff. Data within the database are collected and reported on a calendar-year basis (January 1 to December 31) as is the practice in other international registries reporting on end-stage organ failure, therefore allowing international comparative reporting.

Patients are tracked from their first treatment for end-stage organ failure (dialysis or transplantation) to their death, unless they become lost to follow-up. Only treatments provided in Canada are included in this report. For the purposes of recording continuity of care, however, CORR does capture out-of-country transfers when informed by reporting facilities. Information on organ donors is linked to recipient information. At the present time, CORR does not collect information on patients who have been listed for transplant, but not transplanted.

Since 2002, CIHI has operated CORR in a multi-tier environment using an internet browser. CORR is an Oracle relational database, with over 100 data and code tables included in its architecture. Application services run on IBM AIX.

Data Quality

The collection of patient-level extra-renal transplant data commenced formally on January 1, 1989. These data were collected retrospectively for the years 1981 to 1988 in the *Canadian Organ Replacement Register 1989 Report*. The extent of underreporting of extra-renal transplant activity is unknown. CIHI continues to work with transplant programs to improve the completeness and quality of historical data. Only kidney transplants for patients who had their initial renal replacement therapy on or after January 1, 1981, were originally registered within CORR. As a consequence, not all kidney transplants occurring during the period from 1981 to 1989 are registered in CORR.

While completeness of key data elements has improved over time, one notable problem is that the proportion of unknown values reported for primary diagnosis, cause of death and cause of graft failure exceeds 10% in many cases. Users should consider this when interpreting trends in diagnoses, causes of death and causes of graft failure.

At present, CORR does not collect individual patient data on those wait-listed for transplant. Counts of patients waiting for solid organ transplants are provided on a quarterly basis by 8 of 10 reporting OPOs. The OPOs that contribute wait-list counts are the British Columbia Transplant Society, H.O.P.E. Calgary, H.O.P.E. Edmonton, the Saskatchewan Transplant Program (Saskatoon and Regina), the Manitoba Transplant Program, the Trillium Gift of Life Network (Ontario), Québec-Transplant and the Nova Scotia Multi-Organ Transplant Program (for the Atlantic region). A complete list of OPOs is provided in Appendix C.

Please see Appendix D, CORR Data Quality Documentation: 1995 to 2004, for further detail regarding the completeness and coverage of reporting in CORR.

This Report

This report highlights key data on end-stage organ failure treatments in Canada. Its seven main sections report on:

- renal replacement therapy for ESRD patients (dialysis and renal transplant)
- liver transplantation
- heart transplantation
- lung transplantation
- pancreas transplantation
- intestinal transplantation
- deceased organ donors

There is also a special section in this report focused on providing detailed information on diabetes as it relates to end-stage organ failure.

Data and analysis on renal replacement therapy, transplantation and organ donation in this report cover the decade from 1995 to 2004.

A glossary of the terms used in this report is provided in Appendix E.

Analytical methods used in this report, as well as population figures used for Canada and other countries, are provided in Appendix F.

In addition to this annual summary report, information is available online at www.cihi.ca/corr, in the form of special reports called *CORR inSITES* and semi-annual reports from the OPOs called *E- Statistics on Organ Transplants, Waiting Lists and Donors.* The website also features PowerPoint presentations with summary data.

It is important to note that all data presented in this report are subject to change based on future data submissions or corrections. Analytical conventions used in this report may vary from previously published reports. Discrepancies from previously published reports may reflect database updates and/or differences in analytical approaches.

If you have questions about this report or would like further information, please email CORR at corr@cihi.ca.

2 Renal Replacement Therapy (RRT) for End-Stage Renal Disease (ESRD)

In 1945, Dr. Willem Kolff invented the first artificial kidney machine. Due to limited availability of equipment and difficulty obtaining long-term vascular access for catheters, only patients in acute renal failure were dialyzed. With the invention of the Scribner shunt by Dr. Belding Scribner in 1960, the vascular access problem was largely resolved, and long-term dialysis for those with ESRD became a reality.

2.1 Incident ESRD RRT Patients

2.1.1 Activity

In 2004, there were 92 facilities that registered incident (newly diagnosed) ESRD RRT patients in CORR (Table 1).[i] The vast majority of patients started RRT in hospital-based programs where full renal care services[ii] were delivered. A small number of patients started treatment at two community-based centres in Ontario.

Table 1. Facilities Registering Incident ESRD RRT Patients in CORR for 2004

Province	Full-Care Hospitals* (N)
Alta./N.W.T.	2
B.C.	11
Man.	4
N.B.	4
N.L.	3
N.S./P.E.I.	4
Ont.	31
Que.	31
Sask.	2

* Hospital-based programs with full renal care services.

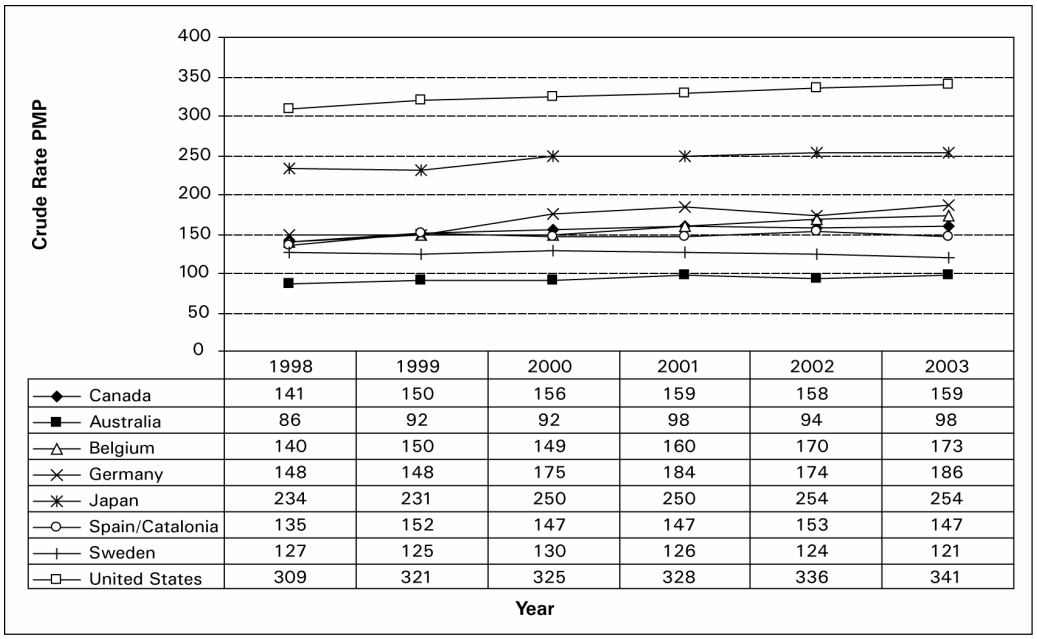
i. The way in which nephrology services are organized in each of the provinces dictates, in part, the way in which centres report to CORR. For example, in Alberta, the Northern and Southern Alberta Renal Programs report as two distinct entities, while in most other provinces, hospitals providing incident treatment to ESRD patients report directly to CORR.

ii. Services provided under the care of nephrologists, which include social work and dietary consultation, as well as inpatient back-up care.

2.1.2 International Comparison

The rate of incident ESRD RRT patients in Canada rose from 112 per million population (PMP) in 1995 to 158 in 2004, a 41% increase. This is in alignment with the increase in ESRD RRT globally, since many registries throughout the world recorded growth in ESRD RRT rates. From 1998 to 2003, the annual rates of incident ESRD RRT patients in Canada were comparable to those in Belgium, Germany and Spain/Catalonia, but higher than those in Sweden and Australia and lower than those in the U.S. and Japan (Figure 1).

Figure 1. Incident ESRD RRT Patients, Selected Countries, 1998 to 2003 (Crude Rate PMP)



	1998	1999	2000	2001	2002	2003
Canada	141	150	156	159	158	159
Australia	86	92	92	98	94	98
Belgium	140	150	149	160	170	173
Germany	148	148	175	184	174	186
Japan	234	231	250	250	254	254
Spain/Catalonia	135	152	147	147	153	147
Sweden	127	125	130	126	124	121
United States	309	321	325	328	336	341

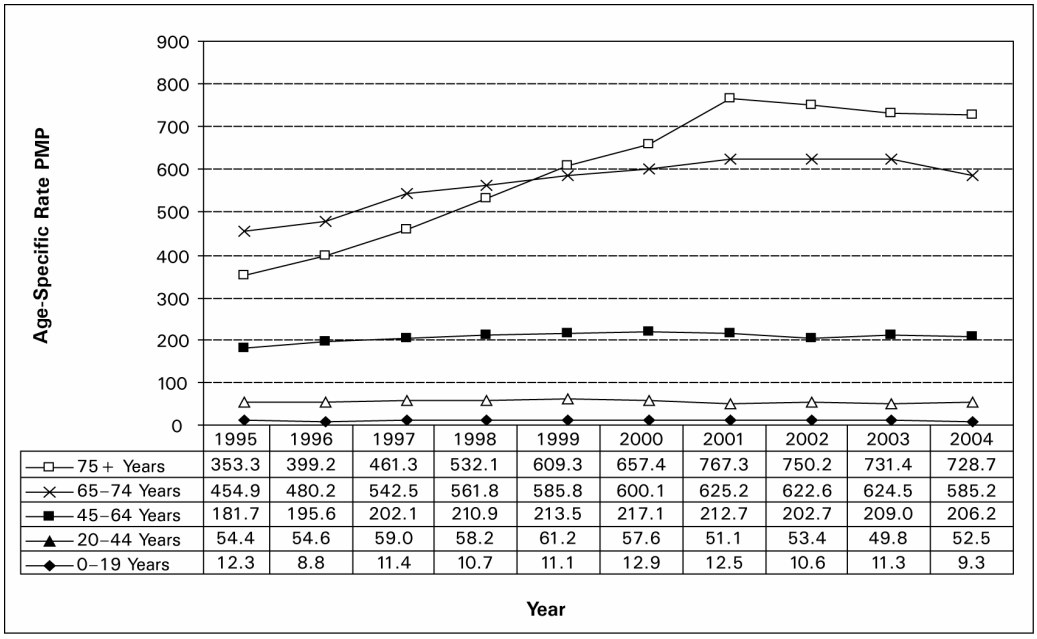
Source of international data: U.S. Renal Data System, *USRDS 2005 Annual Data Report: Atlas of End-Stage Renal Disease in the United States* (Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2005).

2.1.3 Patient Characteristics

When trends in both rates and crude numbers are examined, it must be done within the context and framework of demographic changes in the population over the time of study. During the decade of study (1995 to 2004) the Canadian population changed. Specifically, there were changes in the composition of the Canadian population by age group. For those 19 years of age and younger, the population was relatively stable, with a decrease of less than 1% in the decade under consideration. For the young adult group (20 to 39 years) the Canadian population decreased by 5% during the 10 years of study, while the age group between 40 and 59 years increased by 32%. At the upper end of the age spectrum, the number of Canadians aged 60 years of age and older increased by 17% during the decade.[1]

Considering incident ESRD RRT patients in Canada in terms of age-specific rates, the magnitude and direction of change differed between age groups. There was considerable growth in incident ESRD RRT treatment among patients 75 years of age and older, whose rate more than doubled from 1995 to 2004. For those 65 to 74 years of age, the rate also increased, but to a lesser degree (29%). Those 45 to 64 years of age saw an incremental increase in rates. For the two youngest age groups, rates declined slightly (Figure 2).

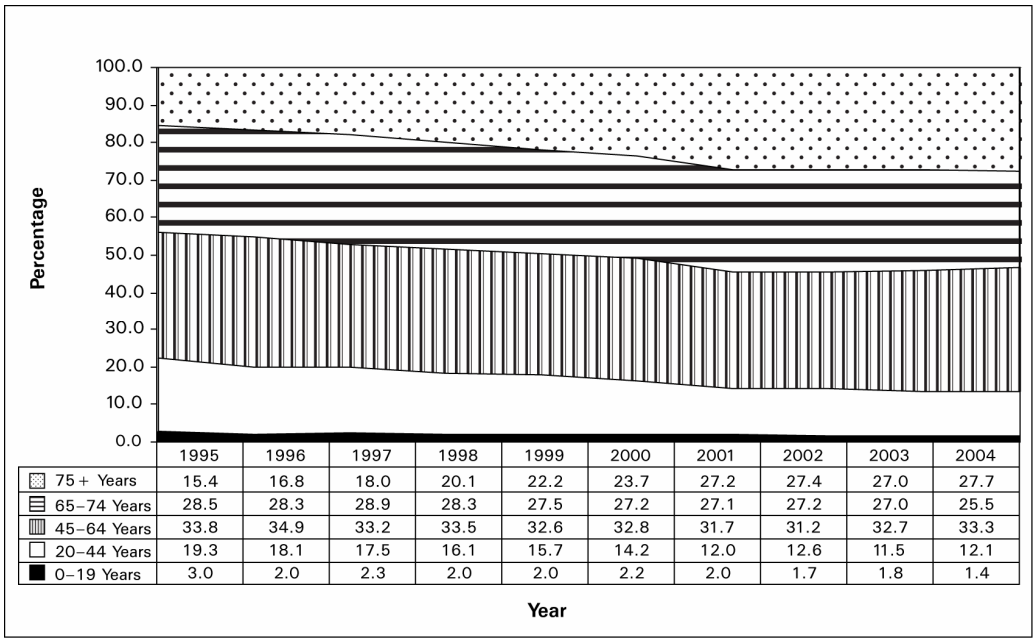
Figure 2. Incident ESRD Patients, Age-Specific Rate PMP, Canada, 1995 to 2004



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
75 + Years	353.3	399.2	461.3	532.1	609.3	657.4	767.3	750.2	731.4	728.7
65–74 Years	454.9	480.2	542.5	561.8	585.8	600.1	625.2	622.6	624.5	585.2
45–64 Years	181.7	195.6	202.1	210.9	213.5	217.1	212.7	202.7	209.0	206.2
20–44 Years	54.4	54.6	59.0	58.2	61.2	57.6	51.1	53.4	49.8	52.5
0–19 Years	12.3	8.8	11.4	10.7	11.1	12.9	12.5	10.6	11.3	9.3

In 2004, more than half of the incident patients (53.2%) initiated RRT treatment at age 65 years or older, 10% more for this age group than in 1995 (Figure 3).

Figure 3. Distribution of Incident ESRD RRT Patients by Age Group, Canada, 1995 to 2004 (Percent)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
75+ Years	15.4	16.8	18.0	20.1	22.2	23.7	27.2	27.4	27.0	27.7
65–74 Years	28.5	28.3	28.9	28.3	27.5	27.2	27.1	27.2	27.0	25.5
45–64 Years	33.8	34.9	33.2	33.5	32.6	32.8	31.7	31.2	32.7	33.3
20–44 Years	19.3	18.1	17.5	16.1	15.7	14.2	12.0	12.6	11.5	12.1
0–19 Years	3.0	2.0	2.3	2.0	2.0	2.2	2.0	1.7	1.8	1.4

When examining age-specific rates of ESRD by province of initial treatment in 2004, considerable variation was observed between provinces (Table 2). The highest rates of treatment for new patients in the pediatric population (from birth to 19 years) were observed in Alberta, the Northwest Territories, the Yukon Territory and Nunavut, at 14.6 PMP. The highest rate for those older than 65 years of age was observed in Newfoundland and Labrador, where a rate of 835.6 PMP was calculated for patients aged 65 to 74 years, and 1,293.2 for patients older than 75 years. In the adult group of 20 to 65 years, normally considered to be the working/career years, the highest rates were observed in Manitoba, with a rate of 77.6 PMP in the 20- to 44-year age group and a considerably higher rate of 340.1 PMP in the 45- to 65-year age group.

Table 2. Incident ESRD Patients, Age-Specific Rate PMP, by Province, 2004

Province of Treatment		Age Group				
		0–19 Years	20–44 Years	45–64 Years	65–74 Years	75+ Years
Alta.*	N	13	68	161	124	96
	PMP	14.6	52.8	204.5	670.6	629.3
B.C.	N	9	84	224	167	178
	PMP	10.0	54.9	201.2	556.6	648.8
Man.	N	3	32	96	41	39
	PMP	9.5	77.6	340.1	528.3	482.9
N.B.	N	2	15	52	43	44
	PMP	11.5	55.8	252.4	799.4	889.2
N.L.	N	0	6	38	31	38
	PMP	0.0	32.6	256.4	835.6	1,293.2
N.S./P.E.I.	N	1	19	61	31	40
	PMP	3.9	50.3	208.9	389.0	560.7
Ont.	N	29	271	658	526	678
	PMP	9.3	58.4	215.1	619.4	927.1
Que.	N	14	97	335	274	251
	PMP	8.1	35.6	162.0	489.2	543.3
Sask.	N	2	25	64	58	41
	PMP	7.3	74.4	270.8	822.4	533.0

* Alberta includes the populations of the Northwest Territories, Yukon and Nunavut.

Hemodialysis (HD) remained the predominant RRT for new ESRD patients in 2004 (Table 3). The majority (78.4%) of incident patients in 2004 started RRT on HD, compared to 68.4% in 1995 (Table 4). Conversely, 19.0% of incident patients in 2004 started on peritoneal dialysis (PD), a reduction from 29.3% in 1995.

There was an increasing number of pre-emptive kidney transplants[iii] performed as RRT in incident ESRD patients during the decade, peaking in 2001 with 139 pre-emptive transplants, and dropping slightly to 134 in 2004. The number of pre-emptive transplants in 2004 represented a 79% increase over 1995 (75 cases).

In terms of the number of patients by age group, there was a 38% increase in the number of incident ESRD patients aged 65 to 74 years from 1995 (941) to 2004 (1,295), and a nearly threefold increase in the number of patients 75 years of age and older (from 509 in 1995 to 1,405 in 2004) (Table 4).

iii. Pre-emptive kidney transplant recipients are patients who have not been treated with dialysis prior to transplantation.

Table 3. Initial Dialysis Treatment, Canada and Provinces, 2004 (Number and Percent)

Treatment Type	Canada	Alta./ N.W.T.	B.C.	Man.	Sask.	Ont.	Que.	N.S./ P.E.I.	N.B.	N.L.
HD*	3,980	362	497	167	145	1,653	820	111	123	102
%	80.5	81.5	77.3	80.7	79.7	78.2	87.0	76.6	78.8	90.3
PD*	965	82	146	40	37	460	122	34	33	11
%	19.5	18.5	22.7	19.3	20.3	21.8	13.0	23.4	21.2	9.7
Total	**4,945**	**444**	**643**	**207**	**182**	**2,113**	**942**	**145**	**156**	**113**

* HD = hemodialysis; PD = periotneal dialysis.

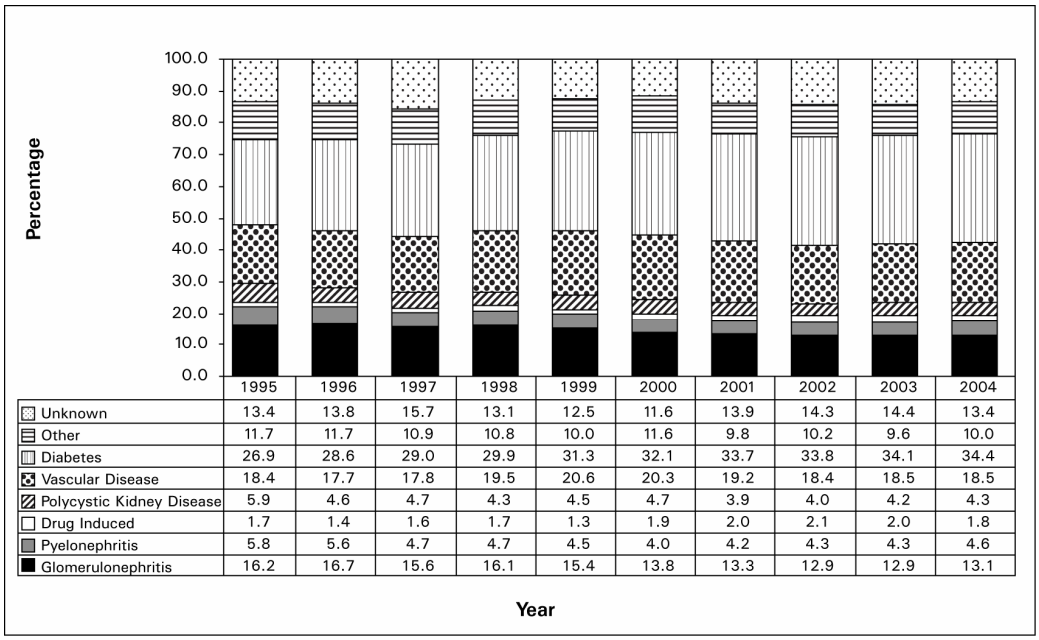
Table 4. Incident ESRD RRT Patients by Year, Age Group and Initial Modality, Canada, 1995 to 2004 (Number)

Age Group	Initial Modality*	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
		N = 3,300	N = 3,535	N = 3,955	N = 4,228	N = 4,540	N = 4,744	N = 4,978	N = 4,987	N = 5,073	N = 5,079
0–19 Years	HD	45	34	52	40	37	46	44	35	41	30
	PD	42	21	28	33	36	34	40	23	29	28
	Pre-emptive	11	6	11	13	15	23	16	26	19	15
20–44 Years	HD	411	394	486	462	471	448	398	436	425	409
	PD	189	198	162	176	180	170	133	147	118	152
	Pre-emptive	36	48	44	44	64	57	68	45	42	56
45–64 Years	HD	748	857	948	1,058	1,117	1,173	1,173	1,190	1,260	1,254
	PD	344	348	326	322	321	334	358	325	342	385
	Pre-emptive	24	31	41	35	42	49	45	41	57	50
65–74 Years	HD	678	756	918	935	993	1,045	1,109	1,120	1,136	1,075
	PD	259	246	221	257	253	240	232	231	226	208
	Pre-emptive	4	1	5	3	5	3	10	3	6	12
75+ Years	HD	375	469	585	720	826	964	1,150	1,190	1,216	1,212
	PD	134	126	128	130	180	158	202	174	156	192
	Pre-emptive	0	0	0	0	0	0	0	0	0	1
Total	**HD**	**2,257**	**2,510**	**2,989**	**3,215**	**3,444**	**3,676**	**3,874**	**3,971**	**4,078**	**3,980**
	PD	**968**	**939**	**865**	**918**	**970**	**936**	**965**	**900**	**871**	**965**
	Pre-emptive	**75**	**86**	**101**	**95**	**126**	**132**	**139**	**115**	**124**	**134**

* HD = hemodialysis; PD = peritoneal dialysis; pre-emptive = pre-emptive kidney transplant.

Diabetic nephropathy was the leading cause of renal failure from 1995 to 2004, and the incidence of this diagnosis increased with each successive year during the decade (Figure 4). A declining trend in the diagnoses of polycystic kidney disease, pyelonephritis and glomerulonephritis as the cause of renal failure in incident patients emerged throughout the decade of observation. The proportion of unknown diagnoses remained stable between 1995 and 2004 at 13.4%.

Figure 4. Distribution of Incident ESRD RRT Patients by Primary Diagnosis Category, Canada, 1995 to 2004 (Percent)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Unknown	13.4	13.8	15.7	13.1	12.5	11.6	13.9	14.3	14.4	13.4
Other	11.7	11.7	10.9	10.8	10.0	11.6	9.8	10.2	9.6	10.0
Diabetes	26.9	28.6	29.0	29.9	31.3	32.1	33.7	33.8	34.1	34.4
Vascular Disease	18.4	17.7	17.8	19.5	20.6	20.3	19.2	18.4	18.5	18.5
Polycystic Kidney Disease	5.9	4.6	4.7	4.3	4.5	4.7	3.9	4.0	4.2	4.3
Drug Induced	1.7	1.4	1.6	1.7	1.3	1.9	2.0	2.1	2.0	1.8
Pyelonephritis	5.8	5.6	4.7	4.7	4.5	4.0	4.2	4.3	4.3	4.6
Glomerulonephritis	16.2	16.7	15.6	16.1	15.4	13.8	13.3	12.9	12.9	13.1

For 23.7% of incident ESRD RRT patients who died between 1995 and 2004, the cause of death was unknown (Table 5). Where the cause was known, cardiac failure was the leading cause of death for all age groups, although social causes (which include treatment withdrawals, treatment refusals and suicides) were a close second overall. When examined by age group, the profile of cause of death differed. In the oldest patient group (75 years of age and older) cardiac deaths were the most prominent, followed by social causes. As a proportion of the number of deaths in each age group, deaths from infections tended to be higher in younger age groups (44 years of age and younger). Accidental deaths, which include incidents related and unrelated to treatment, formed a small proportion of the reported causes of death overall and by age group.

Table 5. Incident ESRD RRT Patients by Age Group* and Cause of Death† 1995 to 2004 (Number and Percent)

Age Group		Cardiac	Social	Infections	Vascular	Gastro-intestinal	Malignancy	Accidental	Other	Unknown	Total
0–19 Years	N	10	8	6	5	4	5	0	7	13	58
	%	17.2	13.8	10.3	8.6	6.9	8.6	0	12.1	22.4	
20–44 Years	N	289	104	127	79	16	46	12	119	272	1,064
	%	27.2	9.8	11.9	7.4	1.5	4.3	1.1	11.2	25.6	
45–64 Years	N	1,769	545	464	352	145	369	34	511	1,335	5,524
	%	32.0	9.9	8.4	6.4	2.6	6.7	0.6	9.3	24.2	
65–74 Years	N	1,947	996	448	522	256	416	33	694	1,639	6,951
	%	28.0	14.3	6.5	7.5	3.7	6.0	0.5	10.0	23.6	
75 + Years	N	1,619	1,272	385	433	213	302	25	753	1,517	6,519
	%	24.8	19.5	5.9	6.6	3.3	4.6	0.4	11.6	23.3	
Total	**N**	**5,634**	**2,925**	**1,430**	**1,391**	**634**	**1,138**	**104**	**2,084**	**4,776**	**20,116**
	%	**28**	**14.5**	**7.1**	**6.9**	**3.2**	**5.7**	**0.5**	**10.4**	**23.7**	

* Age at incident treatment.
† For a breakdown of CORR cause-of-death codes used in this categorization, refer to Appendix F.

There were differences observed in key treatment and patient characteristics for incident dialysis patients for the years 2003 and 2004, depending on the initial province of treatment (Table 6). Newfoundland and Labrador had the lowest proportion of males starting dialysis treatment (53.3%); Ontario had the highest percentage of incident dialysis patients 75 years of age and older (30.8%). The largest proportion of Aboriginal patients was observed in Manitoba (29.4%), followed by Saskatchewan (21.3%). The presence of diabetes among new patients was also highest in these two provinces, at 46.3% and 45.7%, respectively. In B.C., 76.2% of patients started dialysis on HD; HD was the treatment modality in 92.0% and 87.7% of incident patients in Newfoundland and Labrador and Quebec, respectively. Nearly three-quarters of incident dialysis patients had been followed by nephrologists before they began receiving dialysis. This varied from a low of 66.1% in Alberta to a high of 78.1% in Nova Scotia. The proportion of patients diagnosed with glomerulonephritis ranged from a low of 9.0% in Saskatchewan to a high of 14.6% in Alberta. The proportion of patients with vascular disease as the cause of their renal failure was highest in the Atlantic provinces.

As with other chronic diseases, comorbid conditions existing at the time of initial dialysis treatment increased the complexity of patient care.[2, 3] The proportion of incident ESRD patients with co-existing heart disease and peripheral vascular disease was highest in New Brunswick, while the proportion of those with cerebrovascular disease was highest in Nova Scotia (Table 6). Quebec had the highest incidence of chronic lung disease as a comorbidity in ESRD dialysis patients, with one in five incident dialysis patients in the province having that diagnosis. The proportion of patients with malignancies was highest in Nova Scotia and Saskatchewan, at 12.7% in each.

Table 6. Incident Dialysis Patients by Selected Indicators and Initial Province of Treatment, Canada, 2003–2004*

Indicator	Province of Treatment									Total
	Alta./ N.W.T.	B.C.	Man.	N.B.	N.L.	N.S./ P.E.I.	Ont.	Que.	Sask.	
Centres Reporting 2003 (N)	2	11	4	4	3	4	31	31	2	**92**
Centres Reporting 2004 (N)	2	11	4	4	3	4	31	31	2	**92**
Incident Dialysis Patients 2003 (N)	508	599	231	143	98	156	2,071	965	177	**4,948**
Incident Dialysis Patients 2004 (N)	449	642	205	154	113	148	2,117	943	179	**4,950**
% Male	57.8	61.3	56.7	59	53.3	58.1	59.6	61.1	53.7	**59.4**
% Aboriginal†	7.2	3.3	29.4	2.7	1.4	3.0	2.6	1.3	21.3	**4.7**
Median Age (Years)	62	64	59	64	65	64	64	64	63	**63**
% 75+ Years	23.9	28.6	19.1	29.0	29.7	30.6	30.8	25.7	24.9	**28.1**
% HD as Incident Modality	83.3	76.2	81.1	78.0	92.0	77.7	79.8	87.7	80.6	**81.4**
% Followed by Nephrologist Before Starting Dialysis	66.1	74.7	72.3	68.8	68.8	78.1	73.3	66.5	66.9	**71.1**
% Glomerulonephritis as Primary Diagnosis	14.6	11.1	11.9	11.5	10.5	11.5	12.6	13.6	9.0	**12.5**
% Vascular Disease as Primary Diagnosis	12.1	15.4	10.3	23.6	22.5	22.6	21.5	18.6	19.9	**18.8**
% With Diabetes‡	40.7	20.5	46.3	35.7	33.5	33.4	36.3	32.3	45.7	**34.6**
% With Heart Disease§	33.1	28.4	29.3	44.0	37.1	32.7	36.1	36.3	34.6	**34.9**
% With Peripheral Vascular Disease	12.1	15.4	10.3	23.6	22.5	22.6	21.5	18.6	19.9	**18.8**
% With Cerebrovascular Disease	13.7	10.8	16.0	14.3	15.2	19.0	13.5	12.6	14.4	**13.5**
% With Malignancies	9.1	7.8	6.6	11.0	10.0	12.7	10.8	9.1	12.7	**9.9**
% With Chronic Lung Disease	12.7	7.9	4.6	17.7	10.0	11.0	10.6	20.5	15.8	**12.7**

* Information presented is based on patients with reported data.
† Proportion of Aboriginal patients is reported due to the high rate of diabetic nephropathy among Aboriginal Peoples.
‡ Proportion of diabetic patients is based on primary diagnosis and comorbid disease.
§ Heart disease includes patients with one or more of the following: history of angina, previous myocardial infarction, previous coronary artery bypass or previous angioplasty.

2.1.4 Estimated Glomerular Filtration Rate at Initiation of RRT

Estimated glomerular filtration rate (eGFR) is one of the standard biochemical methods of measuring the level of kidney function and of then determining the stage of kidney disease. These data are recorded in CORR and are reported here for the first time. Further exploration of the various formulae and their utilization is planned and future reports will present more in-depth analysis on the role of eGFR.

The eGFR is calculated based on serum creatinine levels in patients. There are two prominent formulae used to calculate an eGFR. Currently, the MDRD (modification of diet in renal disease) equation[4] is used in many programs, along with the Cockcroft-Gault formula.[5] Results based on both formulae are presented in this report.

The Cockcroft-Gault formula is calculated as follows:

- eGFR = (140-age)*initial weight/(0.84*creatinine result) for males
- eGFR = (140-age)*initial weight/(0.84*creatinine result)*0.85 for females

Using the Cockcroft-Gault formula, the average eGFR estimates in ESRD patients in Canada, by province of initial treatment, are presented in Table 7. Overall for Canada, the average eGFR increased from 11.1 ml/minute in 2001 to 12.9 ml/min in 2004. The highest average eGFR from 2001 to 2004 was observed in patients initiating dialysis treatment in Saskatchewan. In contrast, the lowest average eGFR level (below 11 ml/min), was seen in Nova Scotia for all four years.

Table 7. Average eGFR (Cockcroft-Gault Formula) at the Initiation of Dialysis Treatment, by Modality, Canada, 2001 to 2004, (Number and Average)

		Canada	Alta./ N.W.T.	B.C.	Man.	N.B.	N.L.	N.S./P.E.I.	Ont.	Que.	Sask.
2001	N*	4,064.0	332	464	214	128	107	123	1,707	774	215
	Av†	11.1	10.5	11.3	9.9	11.1	13	10.6	11.1	11.2	11.4
2002	N*	4,168.0	356	518	219	124	124	118	1,813	847	161
	Av†	11.3	11.6	11.5	10.8	13.1	11.6	10.3	11.1	11.3	12.3
2003	N*	4,281.0	451	485	193	140	95	136	1,785	823	173
	Av†	12.8	11.9	12.0	11.2	13.2	11.0	9.8	11.6	12.1	12.9
2004	N*	4,409.0	417	538	199	144	109	130	1,860	835	177
	Av†	12.9	12.3	12.3	11.5	13.3	11.0	10.6	11.5	11.4	12.5

* N = Number of patients.
† Av = Average eGFR, or estimated glomerular filtration rate.

The MDRD formula is calculated as follows:

$$eGFR = 32788 * creatinine^{-1.154} * age^{-0.203} * constant$$

Using the MDRD formula, the average eGFR estimates in ESRD patients in Canada by province are presented in Table 8. Overall for Canada, the average eGFR increased from 9.4 ml/min in 2001 to 9.8 ml/min in 2004. The highest average eGFR in 2003 and throughout 2004, at a level greater than 11.2 ml/min, was observed in patients initiating dialysis treatment in New Brunswick (Table 8). The differing results based on these two formulae point to the need for further research and consensus about the most appropriate method to calculate eGFR.

Table 8. Average eGFR (MDRD Formula) at the Initiation of Dialysis Treatment, Canada, 2001 to 2004 (Number and Average)

	Canada	Alta./ N.W.T.	B.C.	Man.	N.B.	N.L.	N.S./ P.E.I.	Ont.	Que.	Sask.
2001 (N)*	4,284	419	556	215	128	107	124	1,714	802	219
Av†	9.4	8.9	9.3	7.7	9.5	10.1	8.9	9.5	9.9	9.3
2002 (N)*	4,440	431	560	219	124	104	120	1,831	888	163
Av†	9.5	9.6	9.8	8.5	10.4	9	8.7	9.6	9.5	9.6
2003 (N)*	4,441	487	536	200	141	95	141	1,812	851	178
Av†	9.9	9.6	10.2	8.4	11.2	9.6	8.4	9.9	10.1	10.1
2004 (N)*	4,562	432	604	206	146	111	137	1,887	861	178
Av†	9.8	9.9	10.1	8.3	11.2	9	8.6	9.8	9.9	9.8

* N = Number of patients.
† Av = Average eGFR, or estimated glomerular filtration rate.

2.1.5 Outcomes

Despite continuing efforts to improve RRT, there was little change in survival benefits associated with RRT over time (1995 to 2004). The five-year survival rates for incident patients on dialysis remained stable at around 40% for the inception cohorts between the years of 1995 and 1999. Although there were likely many factors involved, one of the possible explanations for the stable survival rate is that during this time period there was a change in the profile of patients being initiated on RRT therapy. There was an increase in the frequency with which dialysis treatment was offered to older and more medically frail patients. During the time period under observation for the cohorts between 1995 and 2000, three-month and one-, three- and five-year survival appear to have been slightly better in patients who initiated treatment with PD, compared to those initiating treatment with HD (Table 9).

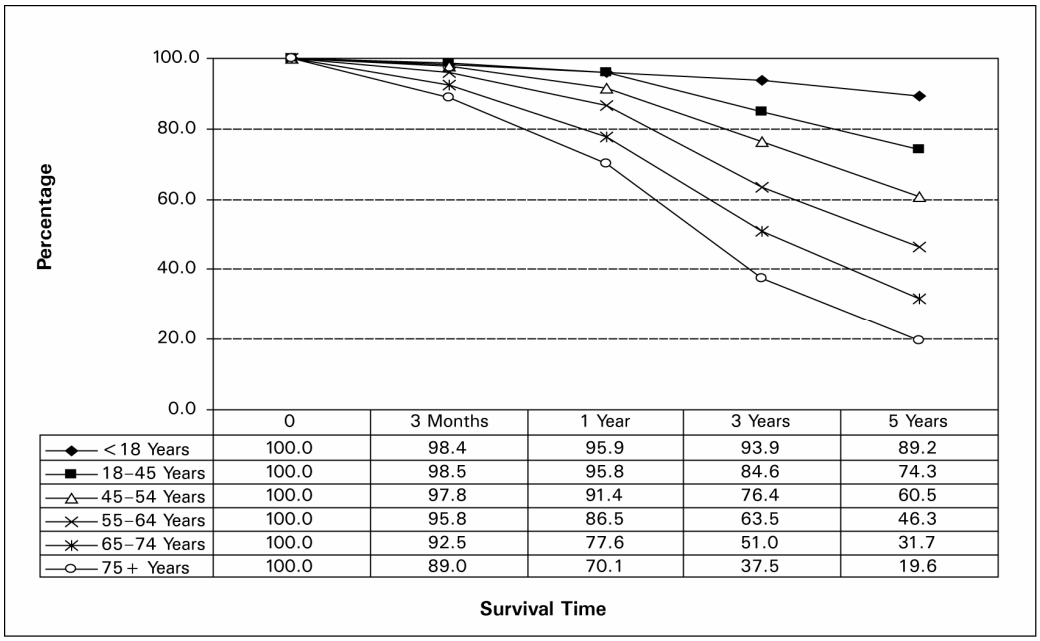
Table 9. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, Canada, 1995 to 1999 (Followed to 2004)

	Survival Time	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
All Dialysis	N	3,225	3,458	3,840	4,133	4,414	4,610	4,839	4,872	4,948	4,950
	3 Months	94.6	94.3	94.2	94.4	94.4	94.2	93.9	94	94.7	94.9
	1 Year	83.3	82.8	83.3	82.9	82.5	82.6	82.5	82.6	84.1	83.8
	3 Years	58.8	58.6	59.5	59.9	58.2	60.6	59.3	55.1		
	5 Years	40.2	39.8	41.6	42.3	40.9	40.3				
HD	N	2,257	2,510	2,989	3,215	3,444	3,651	3,874	3,972	4,077	3,984
	3 Months	93.1	93.4	93.4	93.5	93.4	93.1	93.1	93.2	93.9	94
	1 Year	80.7	80.6	82	81.2	80.8	80.6	80.8	80.8	82.4	81.8
	3 Years	57.5	57.5	58.4	58.4	57.2	58.7	57.9	53		
	5 Years	39.4	38.7	40.6	41.2	39.8	38.7				
PD	N	968	948	865	918	970	959	965	900	871	966
	3 Months	98	96.8	97.1	97.6	93.1	98.2	97.3	97.6	98.4	98.5
	1 Year	89.5	88.8	87.5	88.9	80.6	90.5	89.5	90.7	92	92.4
	3 Years	61.9	61.4	63.3	64.9	58.7	68	65.4	64.2		
	5 Years	42.1	42.8	45	46.1	38.7	47.1				

Note: Patients are censored at the time of their first kidney transplant or when it is determined they are lost to follow-up.

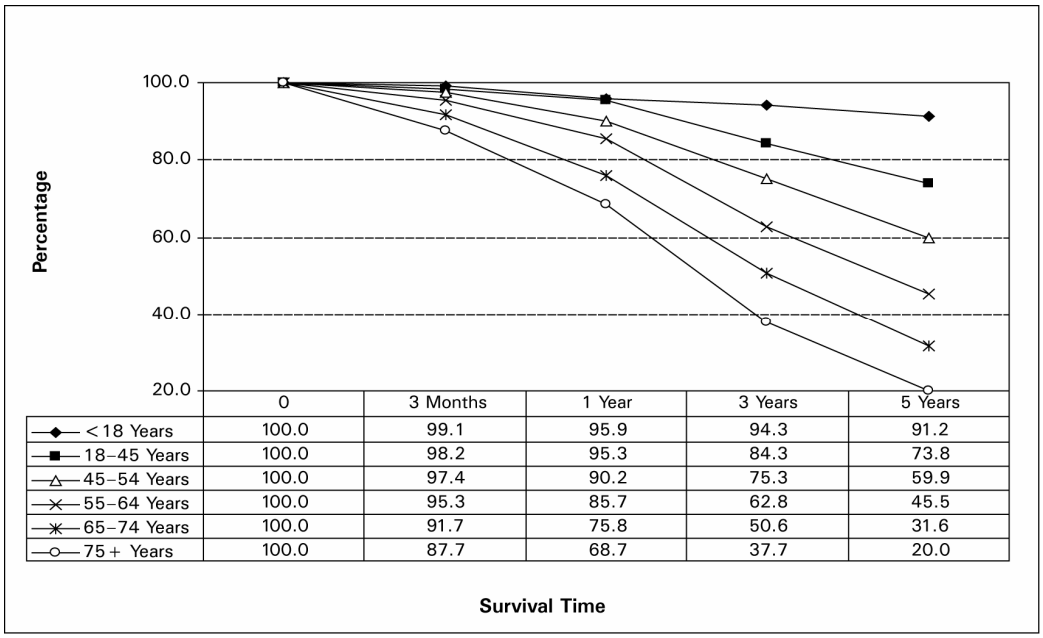
Short-term survival (three months or one year) fluctuated with age and decreased slightly with an increase in age in all dialysis patients regardless of the type of initial treatment (HD or PD) (Figure 5). However, age became a significant factor in the analysis of long-term survival (three- or five-year survival) when a steep decrease in survival was noted with an increase in the patient's age, with the most marked differences existing between those at both ends of the age spectrum. This decrease was marked by a reduction from 89.2% survival at five years in those from birth to 18 years of age to 19.6% survival in those 75 years of age and older (at five years). The survival analysis indicated that patients who initiated treatment with PD between the ages of 18 and 75 years had superior survival compared to their counterpart patients (aged 18 to 75 years) initiating treatment on HD (figures 6 and 7).

Figure 5. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



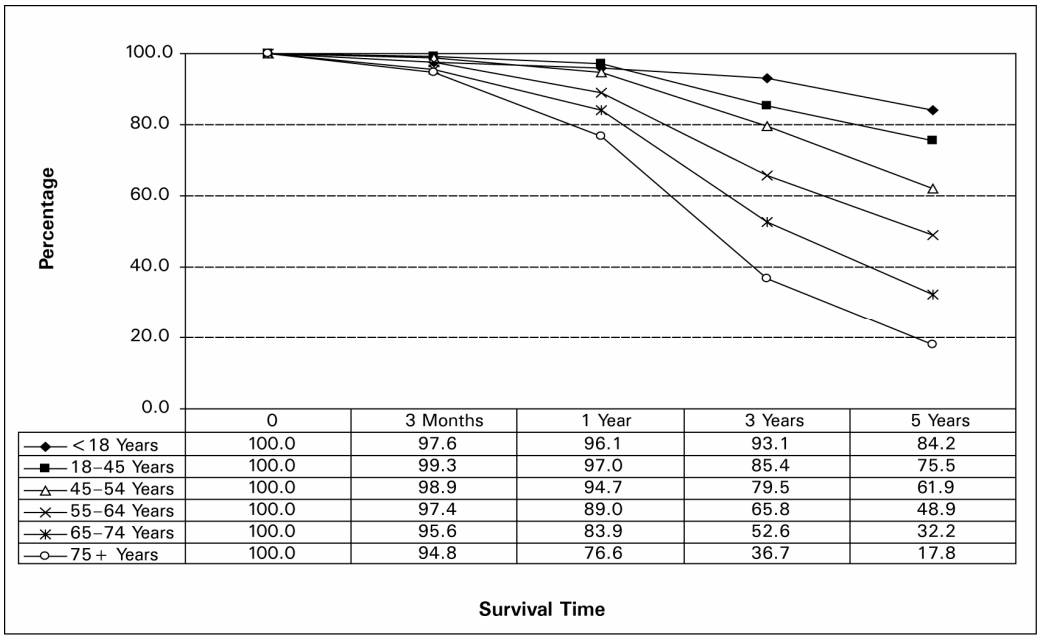
	0	3 Months	1 Year	3 Years	5 Years
< 18 Years	100.0	98.4	95.9	93.9	89.2
18–45 Years	100.0	98.5	95.8	84.6	74.3
45–54 Years	100.0	97.8	91.4	76.4	60.5
55–64 Years	100.0	95.8	86.5	63.5	46.3
65–74 Years	100.0	92.5	77.6	51.0	31.7
75 + Years	100.0	89.0	70.1	37.5	19.6

Figure 6. Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
< 18 Years	100.0	99.1	95.9	94.3	91.2
18–45 Years	100.0	98.2	95.3	84.3	73.8
45–54 Years	100.0	97.4	90.2	75.3	59.9
55–64 Years	100.0	95.3	85.7	62.8	45.5
65–74 Years	100.0	91.7	75.8	50.6	31.6
75 + Years	100.0	87.7	68.7	37.7	20.0

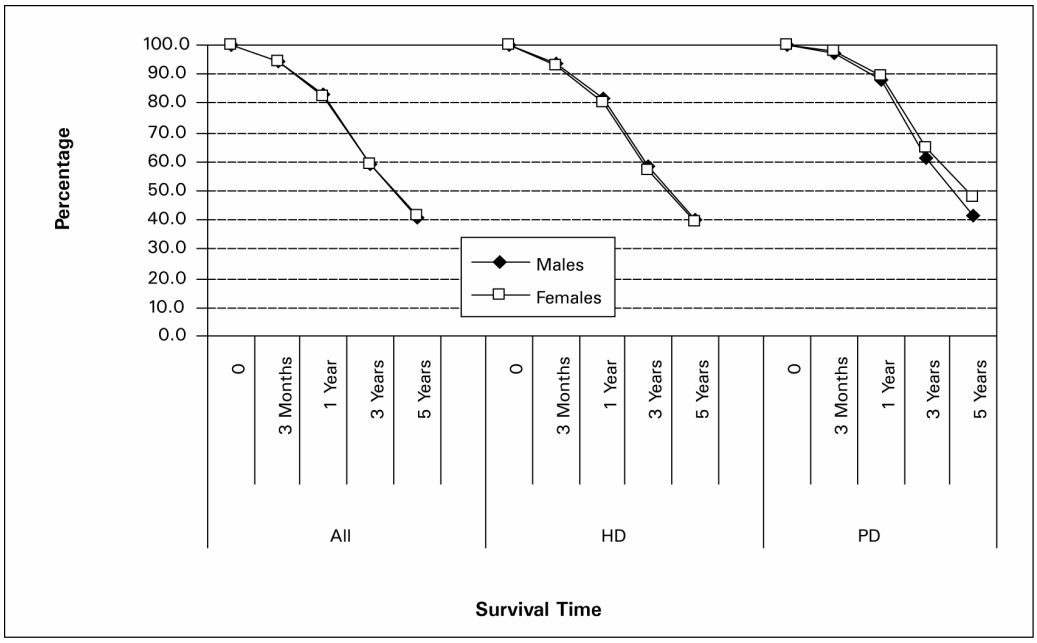
Figure 7. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated With PD, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
< 18 Years	100.0	97.6	96.1	93.1	84.2
18–45 Years	100.0	99.3	97.0	85.4	75.5
45–54 Years	100.0	98.9	94.7	79.5	61.9
55–64 Years	100.0	97.4	89.0	65.8	48.9
65–74 Years	100.0	95.6	83.9	52.6	32.2
75+ Years	100.0	94.8	76.6	36.7	17.8

When the survival rates were compared for females and males starting dialysis treatment, overall, the rates were similar (Figure 8). When examined by treatment modality, for females and males starting treatment on HD, the survival rates were similar. However, differences in five-year survival were seen between males and females when PD was the incident treatment modality, with males demonstrating lower five-year survival rates (40%) when compared to females receiving PD treatment (48%).

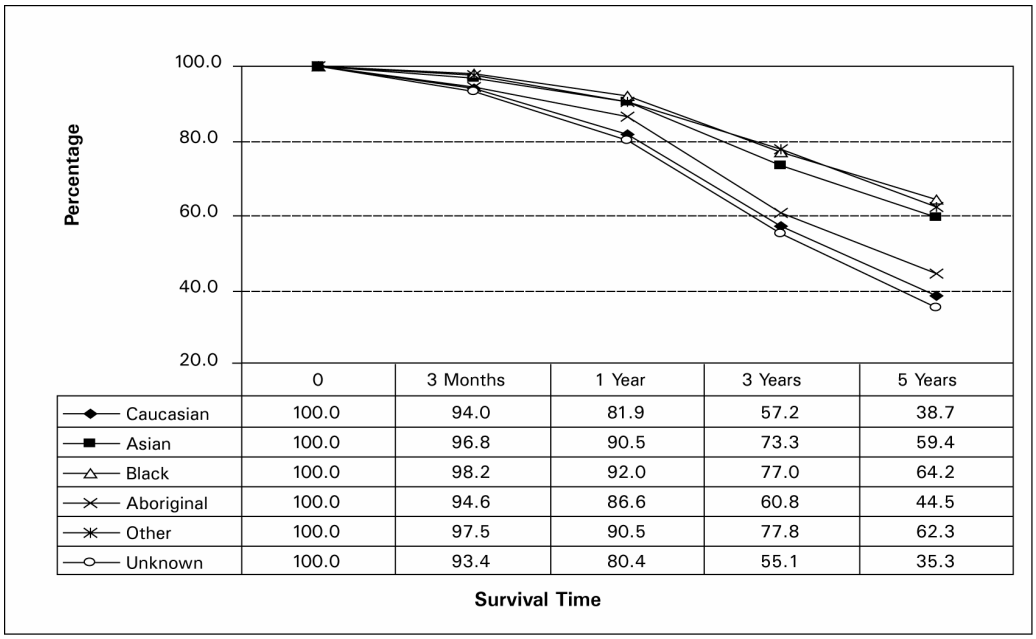
Figure 8. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Treatment Type and Sex, Canada, 1995 to 1999 (Followed to 2004)



Ethnicity and race may be factors in differing mortality rates associated with treatment of ESRD with dialysis. It must be recognized that the factors involved are complex and multi-faceted. When patient race is a variable for analysis of those receiving dialysis treatment in Canada, differences in outcomes are seen, particularly in the survival rate beyond one year. Overall, the five-year survival rate was superior in those patients of Black racial background, followed by those of Asian descent, with those categorized under "other" race (including Filipino, Arabic and Indian), having the third-best five-year survival rate. Caucasians and those among the Aboriginal population had the lowest five-year survival at 38.7% and 44.5%, respectively (Figure 9).

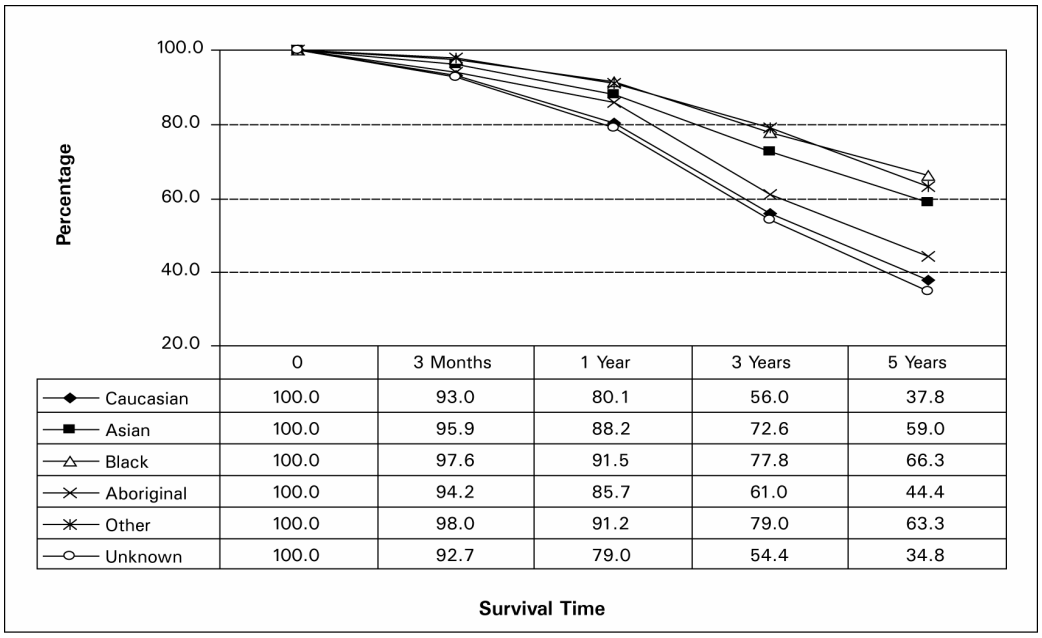
The findings with regard to race and survival are similar for both modalities of dialysis (HD and PD) (figures 10 and 11). These findings are in alignment with those in the published literature with regard to the relationship between race and survival in ESRD.[6, 7] As noted, Canada's Aboriginal People (refers to First Nations, Inuit and Métis) have relatively low five-year survival. Aboriginal People form an important ethnic subpopulation in Canada and it must be recognized that this group of Canadians faces additional challenges in terms of health and health disparities, including a higher incidence of chronic health conditions such as diabetes, heart disease, hypertension, cancer and arthritis.[8, 9, 10] In addition, Canada's Aboriginal population experiences a higher mortality rate (compared to their non-Aboriginal counterparts) due to these conditions, among other causes of death.[11, 12, 13]

Figure 9. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients (All), by Race, Canada, 1995 to 1999 (Followed to 2004)



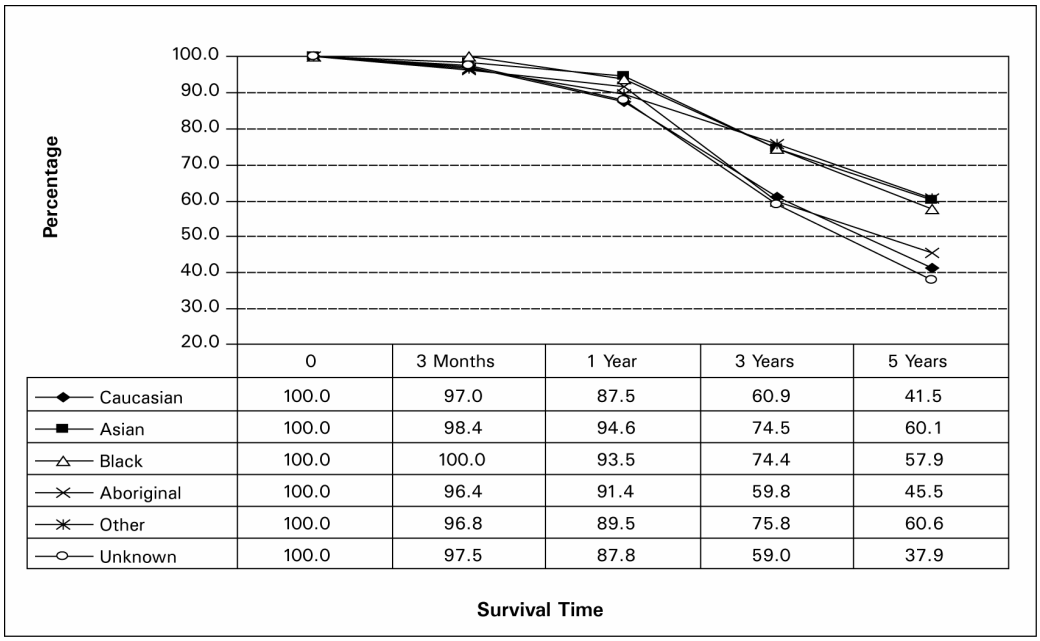
	0	3 Months	1 Year	3 Years	5 Years
Caucasian	100.0	94.0	81.9	57.2	38.7
Asian	100.0	96.8	90.5	73.3	59.4
Black	100.0	98.2	92.0	77.0	64.2
Aboriginal	100.0	94.6	86.6	60.8	44.5
Other	100.0	97.5	90.5	77.8	62.3
Unknown	100.0	93.4	80.4	55.1	35.3

Figure 10. Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Race, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
Caucasian	100.0	93.0	80.1	56.0	37.8
Asian	100.0	95.9	88.2	72.6	59.0
Black	100.0	97.6	91.5	77.8	66.3
Aboriginal	100.0	94.2	85.7	61.0	44.4
Other	100.0	98.0	91.2	79.0	63.3
Unknown	100.0	92.7	79.0	54.4	34.8

Figure 11. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated With PD, by Race, Canada, 1995 to 1999 (Followed to 2004)

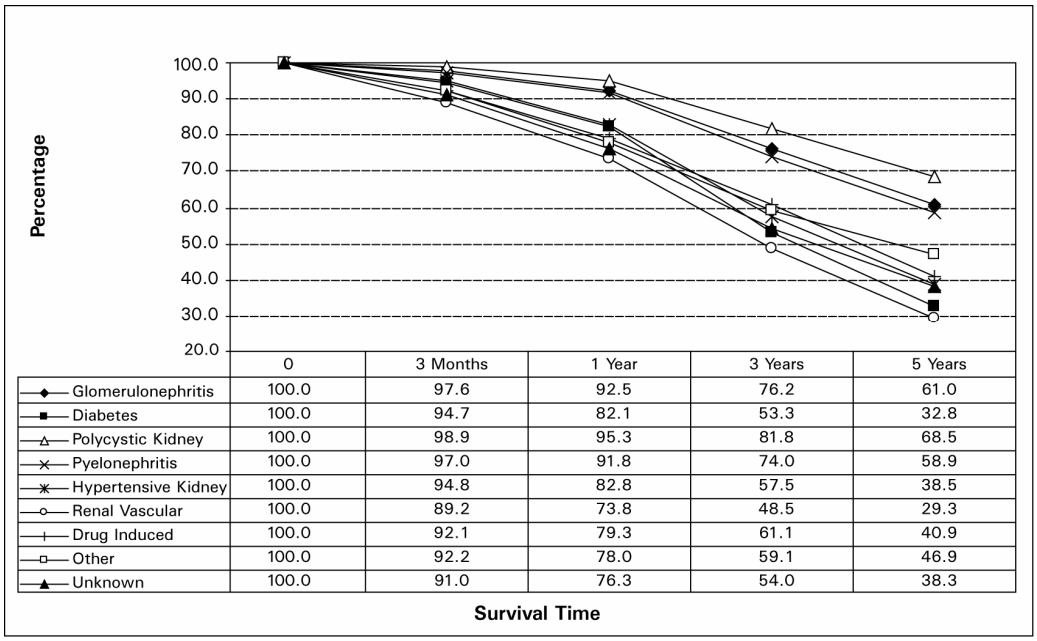


	0	3 Months	1 Year	3 Years	5 Years
Caucasian	100.0	97.0	87.5	60.9	41.5
Asian	100.0	98.4	94.6	74.5	60.1
Black	100.0	100.0	93.5	74.4	57.9
Aboriginal	100.0	96.4	91.4	59.8	45.5
Other	100.0	96.8	89.5	75.8	60.6
Unknown	100.0	97.5	87.8	59.0	37.9

The etiology of renal failure was seen to have an effect on patient survival (figures 12 to 14). In particular, patient survival was compromised with primary diagnoses of renal vascular disease and diabetes, both of which showed relatively poor long-term survival (five-year), at 29.3% (renal vascular disease) and 32.8% (diabetes). Patients whose renal failure was due to polycystic disease, glomerulonephritis and pyelonephritis had improved five-year survival (68.5%, 60.9% and 58.9%, respectively), compared to other etiologies (Figure 12). When diabetes was the primary diagnosis in renal failure, those on PD (34.7% at five years) fared better than those treated with HD (32.2% at five years) (figures 13 and 14). In contrast to the findings regarding differences in treatment modality in patients with diabetes, those with renal vascular disease as the etiology of renal failure appeared to have superior five-year survival on treatment with HD (30.0%) compared to treatment on PD (25.3%) (figures 13 and 14).

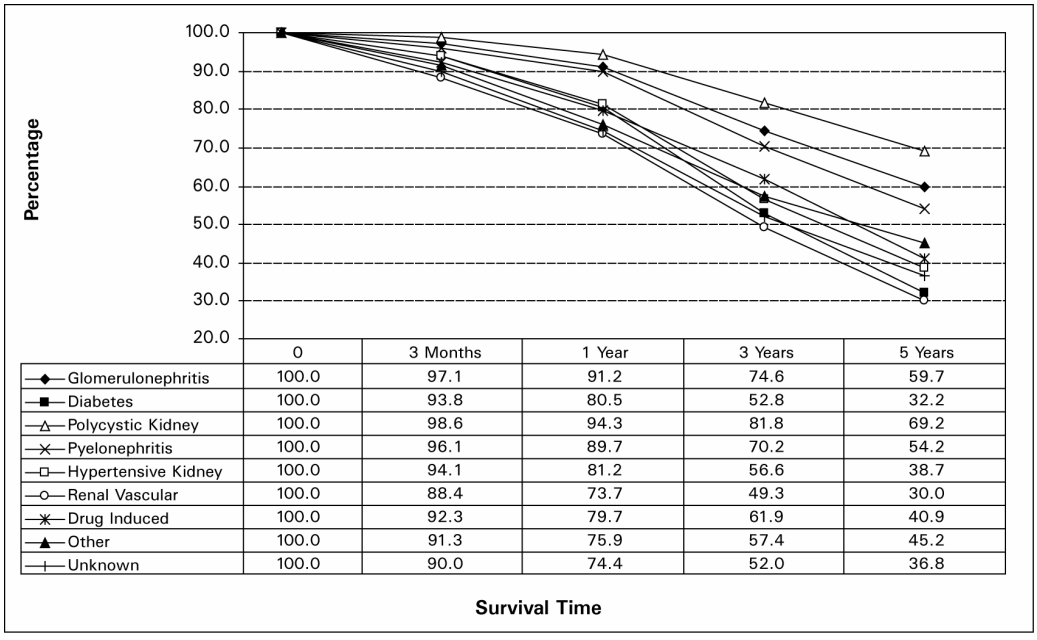
The survival analyses are based on an unadjusted intent-to-treat methodology, and caution must be exercised when interpreting the results.

Figure 12. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Etiology of Renal Failure, Canada, 1995 to 1999 (Followed to 2004)



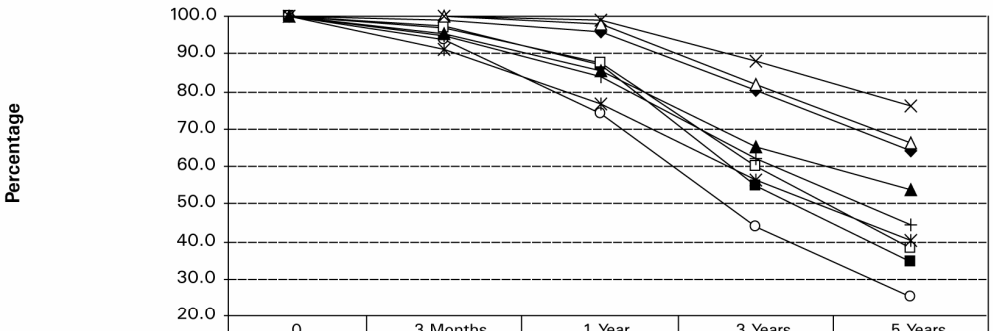
	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	97.6	92.5	76.2	61.0
Diabetes	100.0	94.7	82.1	53.3	32.8
Polycystic Kidney	100.0	98.9	95.3	81.8	68.5
Pyelonephritis	100.0	97.0	91.8	74.0	58.9
Hypertensive Kidney	100.0	94.8	82.8	57.5	38.5
Renal Vascular	100.0	89.2	73.8	48.5	29.3
Drug Induced	100.0	92.1	79.3	61.1	40.9
Other	100.0	92.2	78.0	59.1	46.9
Unknown	100.0	91.0	76.3	54.0	38.3

Figure 13. Unadjusted Three-Month and One-, Three- and Five-Year Survival in HD Patients, by Etiology of Renal Failure, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	97.1	91.2	74.6	59.7
Diabetes	100.0	93.8	80.5	52.8	32.2
Polycystic Kidney	100.0	98.6	94.3	81.8	69.2
Pyelonephritis	100.0	96.1	89.7	70.2	54.2
Hypertensive Kidney	100.0	94.1	81.2	56.6	38.7
Renal Vascular	100.0	88.4	73.7	49.3	30.0
Drug Induced	100.0	92.3	79.7	61.9	40.9
Other	100.0	91.3	75.9	57.4	45.2
Unknown	100.0	90.0	74.4	52.0	36.8

Figure 14. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients Treated With PD, by Etiology of Renal Failure, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	98.8	95.6	80.3	64.2
Diabetes	100.0	97.4	86.9	54.6	34.7
Polycystic Kidney	100.0	100.0	98.2	81.9	66.2
Pyelonephritis	100.0	100.0	99.0	88.2	76.3
Hypertensive Kidney	100.0	96.9	87.4	59.9	38.0
Renal Vascular	100.0	93.5	74.0	43.8	25.3
Drug Induced	100.0	90.9	76.6	56.1	40.1
Other	100.0	95.6	85.4	65.4	54.0
Unknown	100.0	94.9	83.9	62.1	44.5

Survival Time

Survival analysis by multivariate modelling was employed to estimate the effect of several variables simultaneously. In this section the regression modelling was employed using a Cox model. Separate models were fit to "all" dialysis and for each initial treatment modality. Details of the model inputs are found in Appendix F.

Based on the analysis, dialysis patients older than 75 years of age had a mortality risk that was five times greater than that of younger adults (ages 18 to 45 years).

The mortality risk over a 10-year time span was reduced by 10% to 15% for dialysis treatments in Canada ($p < 0.01$). There was a similar, but slightly lower, mortality rate calculated in the model for those treated with HD compared to those receiving PD (Hazard Ratio [HR]: 0.98; confidence interval [CI]: 0.93,1.04) (Figure 15).

Continual ambulatory peritoneal dialysis (CAPD) treatment among PD patients appeared to decrease the risk of mortality (HR: 0.90; CI: 0.82, 0.99) compared to that calculated for automated peritoneal dialysis (APD) treatment (Figure 17).

Diabetes was determined to be the most influential risk factor among all primary diseases causing end-stage organ failure in the multivariate adjusted analysis. When race of dialysis patients was included as a variable in the model, Black and Asian racial backgrounds were predictive of improved survival outcome.

Figure 15. Adjusted Mortality Risk for Dialysis Patients, Canada, 1995 to 1999 (Followed to 2004)

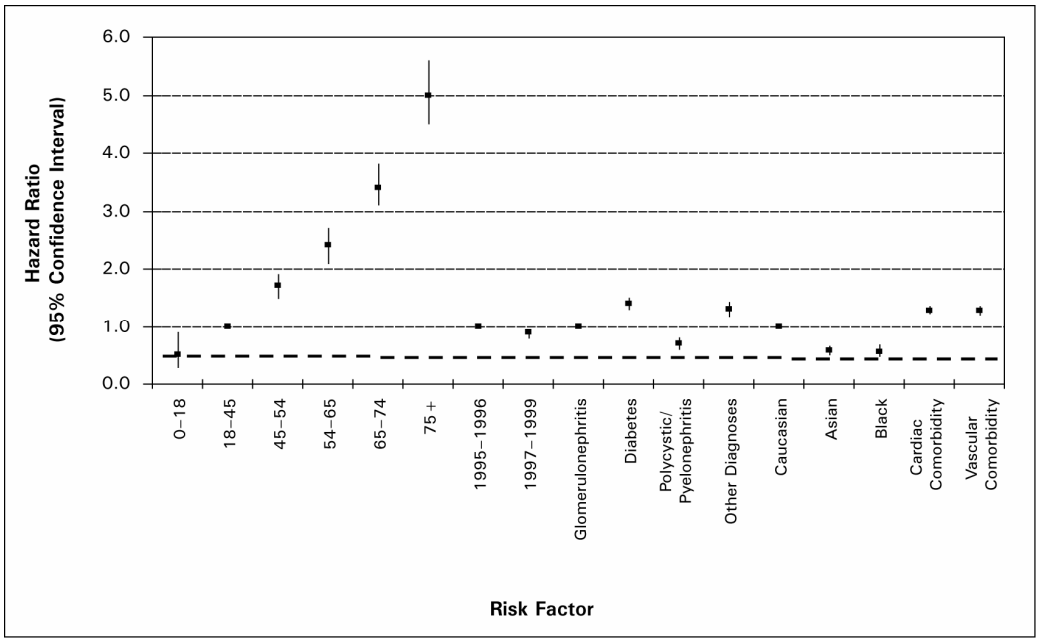


Figure 16. Adjusted Mortality Risk of Patients Who Initiated RRT With HD, Canada, 1995 to 1999 (Followed to 2004)

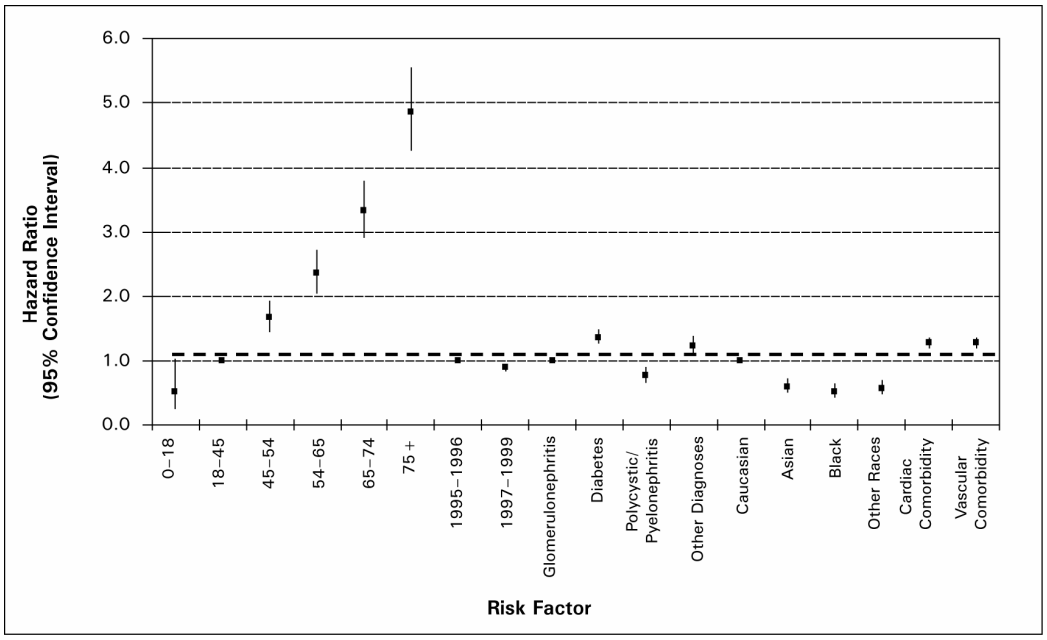
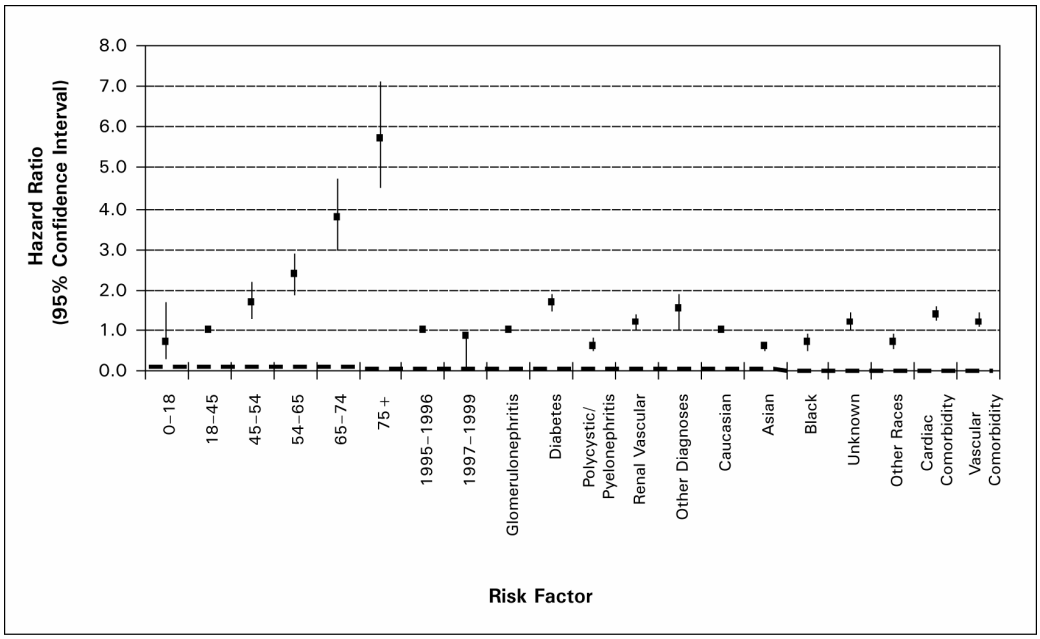


Figure 17. Adjusted Mortality Risk of Patients Who Initiated RRT With PD, Canada, 1995 to 1999 (Followed to 2004)



2.2 Prevalent ESRD RRT Patients (Registered)

One of the measures utilized to assess the growth of an ESRD program is the total patient count at a specified point in time, referred to as prevalence. Prevalence, by definition, is the proportion of people in the entire population who are found to have the cited disease at a certain point in time. The prevalent counts of ESRD patients can be calculated from two data sources: the patient-level data representing registered patients; and a facility survey, which collects aggregate numbers from the facilities representing patients receiving treatment by each facility at the end of each calendar year.

In this section of the report, patient-level data (registered patients) will be used for the analysis of prevalent patient trends and characteristics in Canada.

2.2.1 Activity

At year-end, CIHI gathers counts of patients with functioning transplants as well as patients on dialysis from all reporting centres. There were 18,827 (60.9%) patients who were receiving dialysis and 12,099 (39.1%) living with a functioning kidney transplant on December 31, 2004, for a total of 30,924 Canadians registered in the database with ESRD (Table 10).

2.2.2 Patient Characteristics

Characteristics of prevalent ESRD patients, by age, sex, race and primary diagnosis, are provided in Table 10. In 2004, the largest proportion of prevalent patients, by treatment, was found in the age group of 45 to 64 years at 33.0%, 38.5% and 49.4% for the HD, PD and functioning transplant (TX) groups, respectively. Regardless of age group, male sex was predominant in all three groups of patients (HD: 58.5%, PD: 54.2% and TX: 62.1%). For all prevalent HD, PD and TX patients combined, two-thirds were of Caucasian ethnicity, 6.1% were Asian, 4.3% were noted to be Aboriginal, 3.5% were reported as being Black and 14.3% were of "other" racial origin.

In 2004, diabetic nephropathy accounted for the largest proportion (24.7%) of all prevalent patients followed by patients with glomerulonephritis (22.9%). While a diagnosis of diabetes was most common in patients being treated with HD (31.8%) and PD (29.5%), a diagnosis of glomerulonephritis as the cause of ESRD was more common in patients with a functioning kidney transplant, accounting for 32.5% of transplant patients.

Table 10. Prevalent ESRD Patients at Year-End, by Treatment, Age Group, Sex, Race and Primary Diagnosis, Canada, 2004 (Number and Percentage)

	Number			Percentage of Total		
	HD	PD	TX	HD	PD	TX
Age Group						
0–19 Years	71	58	419	0.5	1.6	3.5
20–44 Years	1,870	617	3,759	12.2	17.4	31.1
45–64 Years	5,043	1,368	5,978	33.0	38.5	49.4
65–74 Years	3,853	850	1,570	25.2	23.9	13.0
75+ Years	4,434	661	373	29.0	18.6	3.1
Sex						
Male	8,939	1,926	7,518	58.5	54.2	62.1
Female	6,332	1,628	4,581	41.5	45.8	37.9
Race						
Caucasian	10,614	2,398	9,184	69.5	67.5	75.9
Asian	910	332	643	6.0	9.3	5.3
Black	673	114	309	4.4	3.2	2.6
Aboriginal	819	163	349	5.4	4.6	2.9
Other	2,255	547	1,614	14.8	15.4	13.3
Diagnosis						
Diabetes	4,863	1,047	1,714	31.8	29.5	14.2
Glomerulonephritis	2,417	723	3,930	15.8	20.3	32.5
Vascular Disease	2,723	575	711	17.8	16.2	5.9
Pyelonephritis	830	186	1,124	5.4	5.2	9.3
Polycystic Kidney Disease	695	193	1,291	4.6	5.4	10.7
Drug Induced	225	31	116	1.5	0.9	1.0
Other	1,419	353	1,708	9.3	9.9	14.1
Unknown	2,099	446	1,505	13.7	12.5	12.4
Total	**15,271**	**3,554**	**12,099**	**49.4**	**11.5**	**39.1**

HD = hemodialysis; PD = peritoneal dialysis; TX = functioning transplant.

When considering the age-specific rates for prevalent ESRD patients in 2004, the highest rate was found among HD patients 75 years of age and older (2,300.2 PMP). Among PD patients, the highest rate was among those 65 to 74 years of age (383.2 PMP), while among living transplanted patients the highest rate was among those 45 to 64 years of age (729.6 PMP) (Table 11). The treatment rates for male patients were higher than the rates for females for all three types of treatments. The largest average annual growth (percent change, 2000 to 2004) was seen for HD, with a 7.4% increase for males and 8.5% for females. The largest annual percent change (31.2%) was observed for patients with kidney transplant who were over 75 years old.

With respect to race/ethnicity, the prevalence of ESRD was 67% higher among Aboriginals compared to non-Aboriginals on HD. However, the rate for kidney transplant was lower at 331.8 PMP, compared to the rate of 379.2 PMP in patients of non-Aboriginal origin.

The number of prevalent ESRD patients with diabetes as their primary diagnosis increased over time. Among those on HD, an average annual increase of 9.3% was observed and among those with a functioning kidney transplant, the average annual increase was found to be 7.8%. The average annual change was smaller among those receiving PD at 2.2% (Table 11).

Table 11. Prevalent Patients at Year-End, by Treatment, Age Groups, Sex, Aboriginal Status, Primary Diagnosis, Canada, 2004 (PMP and Percent Change)

	Rate per Million			Annual Percent Change (2000 to 2004)		
	HD	PD	TX	HD	PD	TX
Age Group						
0–19 Years	9.0	7.3	53.5	-3.1	-4.6	0.8
20–44 Years	158.9	52.5	319.7	1.2	-1.5	0.7
45–64 Years	615.1	167.0	729.6	7.0	2.6	7.3
65–74 Years	1,741.1	383.2	709.5	6.4	0.2	12.9
75+ Years	2,300.2	343.3	193.5	15.3	7.4	31.2
Sex						
Male	565.0	121.7	475.3	7.4	1.9	5.2
Female	392.5	100.9	284.1	8.5	1.6	6.2
Race						
Aboriginal	777.8	155.0	331.8	8.7	1.3	5.3
Non-Aboriginal	466.3	109.4	379.2	12.3	6.8	8.4
Diagnosis						
Diabetes	152.3	32.8	53.7	9.3	2.2	7.8
Glomerulonephritis	75.5	22.6	123.0	4.1	0.2	5.3
Vascular Disease	85.2	18.0	22.3	6.7	0.4	7.1
Pyelonephritis	26.0	5.8	35.2	5.2	-0.8	3.0
Polycystic Kidney	21.8	6.0	40.4	3.8	10.0	5.8
Drug Induced	7.1	1.0	3.6	8.0	-0.8	14.2
Other	44.4	11.0	53.5	5.5	0.2	5.9
Unknown	65.5	13.9	47.1	7.8	6.0	4.3

Age-specific rates PMP in prevalent patients on dialysis increased over time for all age groups except the pediatric group. In 2004, those in the pediatric group had a rate of 16.4 PMP, lower than the rate of 20.9 PMP in 1995 (Table 12). The greatest change, more than twofold, was observed in patients older than 75 years, at a rate of 2,642.5 PMP in 2004, compared to 1,006.3 PMP in 1995.

Table 12. Prevalent ESRD Patients on Dialysis at Year-End, by Age Group, Canada, 1995 to 2004 (Number and Rate PMP)

Age Group		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
0–19 Years	N	166	161	160	163	160	151	159	145	142	129
	PMP	20.9	20.1	20.0	20.3	20.0	18.9	19.9	18.2	18.0	16.4
20–44 Years	N	2,063	2,155	2,274	2,379	2,411	2,437	2,423	2,466	2,490	2,487
	PMP	176.4	183.9	193.7	203.1	206.2	208.5	206.8	209.8	211.9	211.5
45–64 Years	N	3,395	3,681	4,080	4,437	4,834	5,165	5,482	5,762	6,058	6,411
	PMP	552.6	582.5	626.9	661.2	697.3	720.5	739.7	750.7	763.4	782.5
65–74 Years	N	2,584	2,788	3,105	3,361	3,618	3,892	4,153	4,314	4,543	4,703
	PMP	1,249.2	1,334.9	1,472.3	1,580.2	1,694.3	1,813.4	1,921.8	1,983.5	2,074.1	2,125.2
75 + Years	N	1,450	1,689	2,044	2,424	2,841	3,245	3,761	4,282	4,658	5,095
	PMP	1,006.3	1,133.2	1,322.3	1,517.5	1,720.7	1,901.3	2,134.4	2,355.0	2,483.2	2,642.5
Total	**N**	**6,842**	**7,528**	**8,571**	**9,544**	**10,571**	**11,572**	**12,710**	**13,685**	**14,522**	**15,348**
	PMP	**183.7**	**200.2**	**226.1**	**250.0**	**275.3**	**299.3**	**326.0**	**348.0**	**367.0**	**385.6**

There was variation in the sex and age-specific rates for prevalent ESRD patients by province (Table 13). The highest rate for females of all age groups, except for those 75 years of age and older, was observed in Manitoba. Saskatchewan was seen to have the lowest rates for both males and females in the age group of 75 years and older. In contrast, New Brunswick showed the highest rates in the elderly group for both sexes, at 2,299.1 PMP in females 75 years and older and 4,623.2 PMP in males 75 of this age group. The lowest rates for males aged 20 to 44 and 45 to 64 years, and females 20 to 44 and 65 to 74 years, were observed in Nova Scotia.

Table 13. Prevalent ESRD Patients at Year-End, by Age and Sex, Canada and Provinces, 2004 (Number and Rate PMP)

Province of Treatment		Female						Male					
		0–19 Years	20–44 Years	45–64 Years	65–74 Years	≥75 Years	Total	0–19 Years	20–44 Years	45–64 Years	65–74 Years	≥75 Years	Total
Alta.*	N	14	106	221	183	184	708	11	122	328	233	239	**933**
	PMP	32.3	169.1	568.8	1,924.1	2,010.6	432.8	24.0	184.2	822.9	2,594.9	3,915.3	**558.8**
B.C.†	N	6	133	297	232	250	918	9	178	467	320	349	**1,323**
	PMP	12.6	174.0	528.8	1,520.6	1,535.0	433.7	17.9	232.5	846.1	2,170.0	3,131.0	**636.2**
Man.	N	5	90	193	94	73	455	3	88	218	98	77	**484**
	PMP	32.3	446.2	1,360.6	2,299.9	1,453.6	771.9	18.5	418.0	1,552.2	2,668.1	2,520.4	**833.3**
N.B.	N	1	26	72	53	71	223	1	41	82	67	86	**277**
	PMP	11.9	194.7	694.3	1,869.8	2,299.1	586.0	11.2	303.0	801.4	2,633.3	4,623.2	**747.0**
N.L.	N	0	30	50	35	50	165	0	23	76	62	45	**206**
	PMP	0.0	320.6	668.6	1,829.9	2,822.1	627.5	0.0	253.7	1,034.9	3,450.0	3,857.0	**810.8**
N.S.‡	N	2	29	67	54	79	231	1	39	106	80	98	**324**
	PMP	16.1	152.4	452.5	1,300.6	1,766.6	420.6	7.7	208.4	736.6	2,095.3	3,680.9	**616.4**
Ont.	N	19	451	1,084	892	1,015	3,461	31	618	1,621	1,151	1,283	**4,704**
	PMP	12.5	195.5	698.7	1,998.9	2,277.4	551.7	19.5	265.3	1,074.7	2,856.6	4,491.8	**768.7**
Que.	N	14	157	507	416	446	1,540	10	252	807	591	608	**2,268**
	PMP	16.6	117.6	483.7	1,380.7	1,521.4	403.1	11.3	181.4	791.8	2,283.7	3,601.0	**609.3**
Sask.	N	1	60	80	58	60	259	1	44	135	84	82	**346**
	PMP	7.5	361.4	680.7	1,565.4	1,286.5	516.9	7.1	258.6	1,136.1	2,509.4	2,707.4	**700.0**
Canada	**N**	**62**	**1,082**	**2,571**	**2,017**	**2,228**	**7,960**	**67**	**1,405**	**3,840**	**2,686**	**2,867**	**10,865**
	PMP	**16.2**	**186.0**	**621.7**	**1,735.6**	**1,882.7**	**493.5**	**16.7**	**236.5**	**946.5**	**2,556.2**	**3,849.8**	**686.9**

Age was calculated on December 31, 2004.

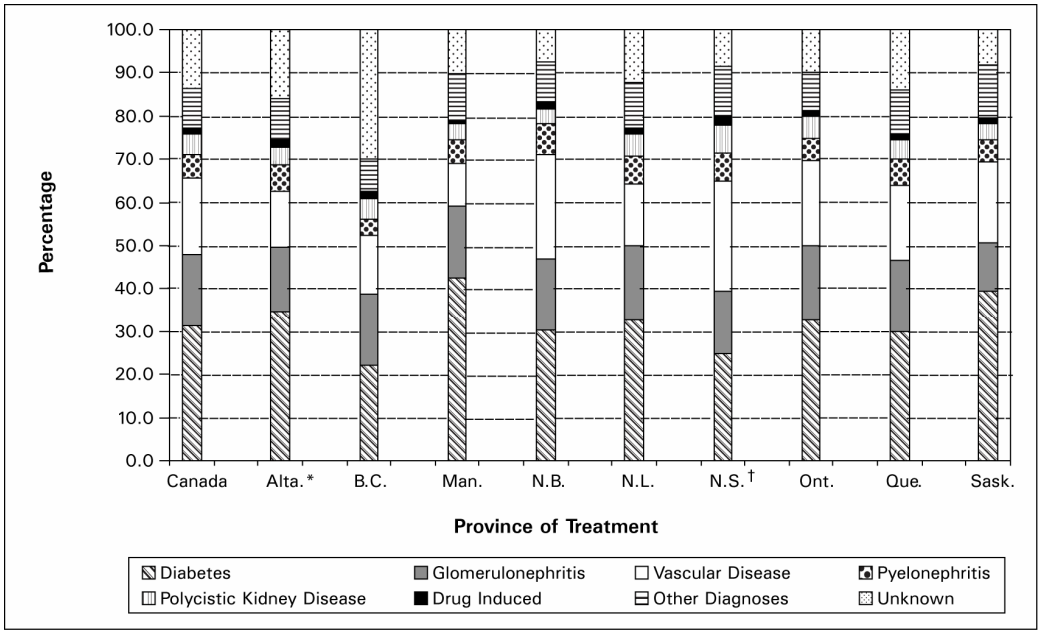
* Alberta includes the populations of the Northwest Territories and Nunavut.

† British Columbia includes the population of the Yukon.

‡ Nova Scotia includes the population of Prince Edward Island.

In 2004, the primary cause of ESRD among prevalent patients varied between provinces.[iv] Diabetes was the most common cause of ESRD among patients on dialysis, accounting for 43.0% of prevalent patients in Manitoba (the largest proportion) and 25.0% in Nova Scotia (the smallest proportion). Renal vascular disease was the second most common cause of prevalent ESRD, and accounted for 17.5% of prevalent ESRD patients nationally, and 25.0% of patients in Nova Scotia and New Brunswick (Figure 18).

Figure 18. Primary Renal Diagnosis in Prevalent Patients on Dialysis, by Province of Treatment, Canada, 2004



* Alberta includes the populations of the Northwest Territories, Yukon and Nunavut.
† Nova Scotia includes the population of Prince Edward Island.

iv. Data for British Columbia are presented, although there is a large proportion of cases with an unknown primary diagnosis, and the data should therefore be used with caution.

2.3 Prevalent ESRD RRT Patients (Facility Profile Data)

As noted in Section 2.2, the prevalent counts of ESRD patients can be calculated from two data sources: the patient-level data representing registered patients; and a facility survey, which collects aggregate numbers from the facilities representing patients receiving treatment by each facility at the end of each calendar year.

In this section of the report, facility-level data (aggregate facility numbers) will be used for the analysis of prevalent patient trends and characteristics in Canada.

At year-end, CIHI gathers counts of patients with functioning transplants and patients on dialysis from all reporting centres. These data are compared against registered patients in the database, and are used as a data quality check. More information on CORR data quality can be found in Appendix D. In this section, these counts are used to illustrate the volume of treated ESRD cases in Canada.[v]

On December 31, 2004, 12,606 patients were reported to be alive with a functioning kidney transplant (Table 14). This represented a 59.0% increase from 1995, and an average increase of 5.9% per year. Transplant patients in Canada, as a proportion of the population, rose from 271.1 PMP in 1995 to 394.6 PMP in 2004, a 46.9% increase. When examining the rate of functioning transplants in patients by province of treatment, it was seen that sizeable variations existed between provinces. The highest rate of patients with a functioning transplant was observed in Newfoundland and Labrador, at 549.3 PMP, and the lowest was seen in Quebec at 342.3 PMP.

v. The *CORR Dialysis Facility Profile* contains counts of all patients living and on dialysis at year-end, including patients who initiated treatment prior to 1981, and who may not be registered in CORR. In addition, it would not be affected by underreporting of deaths as are the patient-level data within CORR. Please see Appendix F for further information.

Table 14. Patients With Functioning Kidney Transplants* at Year-End, by Province of Follow-up, Canada, 1995 to 2004 (Number and Rate PMP)

Province of Treatment		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Alta.	N	804	857	926	1,027	1,137	1,180	1,287	1,331	1,437	1,554
	RPMP	284.0	298.2	316.1	342.6	372.6	380.2	407.8	413.8	440.7	470.1
B.C.	N	1,123	1,140	1,199	1,246	1,282	1,366	1,444	1,511	1,583	1,580
	RPMP	297.3	294.2	303.7	312.8	319.6	338.2	354.1	367.2	381.2	376.5
Man.	N	369	377	382	371	370	387	398	415	438	446
	RPMP	326.8	332.4	336.2	326.1	323.9	337.3	345.7	359.1	377.1	381.1
N.B.	N	209	208	220	220	235	239	266	273	287	293
	RPMP	278.3	276.5	292.3	293.1	313.1	318.4	354.7	363.8	382.2	389.9
N.L.†	N	222	237	237	244	254	264	270	272	279	284
	RPMP	391.2	423.4	430.1	451.9	476.2	500.0	517.3	523.6	538.2	549.3
N.S.‡	N	393	417	455	455	543	606	644	731	803	572
	RPMP	369.8	390.8	425.8	426.1	507.4	566.2	602.4	682.3	748.1	532.2
Ont.	N	2,984	3,201	3,228	3,333	3,675	3,811	3,913	4,238	4,426	4,905
	RPMP	272.5	288.8	287.5	293.2	319.4	326.1	328.9	350.2	361.1	395.8
Que.	N	1,624	1,673	1,784	1,830	1,982	2,158	2,330	2,553	2,601	2,582
	RPMP	224.9	230.9	245.2	250.8	270.6	293.3	315.0	342.9	347.2	342.3
Sask.	N	215	225	232	273	303	319	337	450	384	390
	RPMP	212.0	220.8	227.9	268.3	298.6	316.5	337.0	451.9	386.2	391.8
Total	**N**	**7,943**	**8,335**	**8,663**	**8,999**	**9,781**	**10,330**	**11,159**	**12,046**	**12,517**	**12,606**
	RPMP	**271.1**	**281.5**	**289.7**	**298.4**	**321.7**	**336.6**	**359.7**	**384.0**	**395.4**	**394.6**

* Data are from the year-end *CORR Renal Transplant Facility Profile* and represent point prevalent counts of patients for December 31 of each year.

† Newfoundland and Labrador data for 2002 have been estimated on the basis of the previous year.

‡ Nova Scotia data were calculated from the East Coast cumulative data report by subtracting other provinces.

Patients on HD at 2004 year-end numbered 15,292 (Table 15), while those on PD numbered 3,628 (Table 16), for a total of 18,920 dialysis patients.[vi] The number of patients on HD grew by 139.0% in the decade from 1995 to 2004, with an average annual growth of 13.9%. In contrast, the annual number of patients on PD showed minor variations, with an increase of 5.0% during the decade.

Table 15. Patients on HD* at Year-End, by Province of Treatment, Canada, 1995 to 2004 (Number and Rate PMP)

Province of Treatment		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Alta.	N	498	516	666	770	916	982	1,084	1,199	1,332	1,361
	PMP	175.9	179.5	227.4	256.9	300.2	316.4	343.5	372.7	408.5	411.7
B.C.†	N	672	747	788	921	1,119	1,306	1,258	1,467	1,449	1,522
	PMP	177.9	192.8	199.6	231.2	279.0	323.3	308.5	357.4	349.0	362.7
Man.	N	357	385	444	529	575	617	658	695	716	762
	PMP	316.2	339.4	390.8	465.0	503.3	537.8	573.3	621.3	616.4	651.1
N.B.	N	150	193	199	220	236	264	284	300	328	373
	PMP	199.7	256.5	264.4	293.1	314.4	351.8	378.7	399.8	436.8	496.4
N.L.	N	116	158	138	149	192	216	232	251	273	327
	PMP	204.4	282.2	250.4	276.0	359.9	409.1	444.5	483.2	526.7	632.5
N.S.	N	202	219	278	304	329	332	369	385	467	405
	PMP	190.1	205.2	260.2	284.7	307.4	310.2	345.2	359.3	435.1	376.8
Ont.	N	2,592	2,930	3,498	3,975	4,512	5,031	5,378	5,967	6,369	6,807
	PMP	236.7	264.4	311.5	349.7	392.1	429.6	450.3	485.2	519.6	549.3
Que.	N	1,602	1,720	1,955	2,216	2,409	2,610	2,854	2,914	3,092	3,249
	PMP	221.9	237.3	268.7	303.7	328.9	320.9	374.5	392.4	412.7	430.7
Sask.	N	219	230	284	286	327	355	382	442	485	486
	PMP	215.9	225.7	279.0	281.1	322.3	352.3	381.9	443.8	487.7	488.3
Total	**N**	**6,408**	**7,098**	**8,250**	**9,370**	**10,615**	**11,713**	**12,499**	**13,620**	**14,511**	**15,292**
	PMP	**218.7**	**239.7**	**275.9**	**310.7**	**349.1**	**381.7**	**402.9**	**434.1**	**458.3**	**478.7**

* Data come from the year-end *CORR Hemodialysis Facility Profile* and represent point prevalent counts of patients for December 31 of each year.

† Data are incomplete for two centres in British Columbia. It is estimated that the number of patients missing is approximately 110 on HD.

vi. The difference in numbers of registered patients reported may reflect incomplete reporting of deaths of registered patients.

As a proportion of the population, the rate of patients on HD in Canada showed a more than twofold increase, from 218.7 PMP in 1995 to 478.7 PMP in 2004. When exploring differences in rates for patients on HD by province, there were more noticeable differences observed between provinces in 2004 and more homogeneity in rates reported in 1995. The highest rate of patients on HD treatment was seen in Newfoundland and Labrador, at 632.5 PMP. The lowest rate was reported in B.C., with 362.7 PMP. In contrast to the findings for patients on HD treatment, the rate for the patients undergoing PD decreased over time, from 117.6 PMP in 1995 to 113.6 PMP in 2004 (Table 16). Again, considerable variation existed between provinces. In 2004, the rate of patients on PD was found to be as low as 72.3 PMP in Alberta, and the highest rate was seen in New Brunswick at 240.9 PMP.

Table 16. Patients on PD* at Year-End and Province of Treatment, Canada, 1995 to 2004 (Number and Rate PMP)

Province of Treatment		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Alta.	N	297	315	282	265	217	206	228	235	247	239
	PMP	104.9	109.6	96.3	88.4	71.1	66.4	72.2	73.1	75.8	72.3
B.C.†	N	381	375	377	417	440	443	503	535	590	579
	PMP	100.9	96.8	95.5	104.7	109.7	109.7	123.3	130.2	142.1	138.0
Man.	N	139	136	169	184	206	201	199	200	193	189
	PMP	123.1	119.9	148.7	161.8	180.3	175.2	172.9	173.1	166.2	161.5
N.B.	N	143	144	159	191	185	180	173	156	163	181
	PMP	190.4	191.4	211.3	254.5	246.5	239.8	230.7	207.9	217.1	240.9
N.L.	N	94	89	100	99	100	84	76	66	54	47
	PMP	165.7	159.0	181.5	183.4	187.5	159.1	145.6	127.1	104.2	90.9
N.S.	N	142	159	147	150	147	163	154	156	131	127
	PMP	133.6	149.0	137.6	140.5	137.4	152.3	144.1	145.6	122.0	118.2
Ont.	N	1,425	1,497	1,311	1,194	1,231	1,278	1,318	1,324	1,342	1,490
	PMP	130.1	124.1	116.8	105.0	107.0	105.8	108.2	109.4	109.5	120.2
Que.	N	714	758	813	809	748	741	685	654	614	657
	PMP	92.1	98.2	111.8	110.9	102.1	93.8	88.4	87.8	82.0	87.1
Sask.	N	111	94	88	95	79	85	96	95	110	119
	PMP	109.5	92.2	86.4	93.4	77.9	84.3	96.0	95.4	110.6	119.6
Total	**N**	**3,446**	**3,567**	**3,446**	**3,404**	**3,353**	**3,381**	**3,432**	**3,421**	**3,444**	**3,628**
	PMP	**117.6**	**120.5**	**115.2**	**112.9**	**110.3**	**110.2**	**110.6**	**109.0**	**108.8**	**113.6**

* Data come from the year-end CORR Facility Profiles and represent point prevalent counts of patients for December 31 of each year.

† Data are incomplete for two centres in British Columbia and the number of patients missing is approximately 48 patients on PD.

On December 31, 2004, most HD patients were receiving conventional HD in a full-care hospital setting or independent health facility (Table 17). The proportion of patients receiving HD in a community centre or independent health care facility varied per province, from a high of 33.9% in B.C. to a low of 1.8% in Quebec. Only 2.3% of patients receiving dialysis using HD were being treated in the home setting.

Table 17. Point Prevalent HD Patients,* by Treatment and Province of Treatment, Canada, 2004 (Number and Percent)

Province of Treatment		Full-Care Hospital			Chronic Care†	Community Centre and Independent Health Facility		Home‡	Total
		Conventional	Short Daily	Slow Nocturnal		Conventional	Short Daily		
Alta.§	N	527	0	26	0	776	4	28	**1,361**
	%	38.7	0	1.9	0	29.2	0	2.2	**100**
B.C.	N	946	0	0	0	541	0	35	**1,522**
	%	62.2	0	0	0	33.9	0	1.6	**100**
Man.	N	593	0	0	0	166	0	3	**762**
	%	77.8	0	0	0	22.0	0	0.6	**100**
N.B.	N	321	0	0	0	44	0	8	**373**
	%	86.1	0	0	0	10.7	0	2.3	**100**
N.L.	N	307	0	0	0	20	0	0	**327**
	%	93.9	0	0	0	5.6	0	1.2	**100**
N.S.	N	282	1	0	0	119	0	3	**405**
	%	69.6	0.2	0	0	22.6	0	0.3	**100**
Ont.	N	4,922	85	16	69	1,473	21	221	**6,807**
	%	72.3	1.2	0.5	0.2	13.6	0.3	2.0	**100**
Que.	N	2,958	9	0	0	235	0	47	**3,249**
	%	91.0	0.3	0	0	1.8	0	1.4	**100**
Saskatchewan	N	385	0	0	0	101	0	0	**486**
	%	79.2	0	0	0	18.6	0	0	**100**
Total	**N**	**11,241**	**95**	**42**	**69**	**3,475**	**25**	**345**	**15,292**
	%	**73.5**	**0.6**	**0.3**	**0.5**	**22.7**	**0.2**	**2.3**	**100**

* Data are incomplete for two centres in British Columbia.
† May include conventional or slow nocturnal dialysis.
‡ May include conventional, short daily or slow nocturnal dialysis.
§ Alberta includes the population of the Northwest Territories.

There were a total of 3,332 HD stations in Canadian hospitals and affiliated centres on December 31, 2004 (Table 18). Manitoba had the highest availability of stations for the population (PMP) for treatment, at 150.4 PMP; however, Ontario had the highest ratio of patients treated at each station, at 5.2 per station.

Table 18. Point Prevalent Hospital, Independent Health Facility and Community Centre HD Patients, by Stations and Province of Treatment, Canada, 2004 (Number)

Province of Treatment	Stations† (N)	Patients† (N)	Patients per Stations	Population‡	Stations PMP
Alta.	293	1,361	4.6	3,305,558	88.6
B.C.*	345	1,522	4.4	4,196,383	82.2
Man.	176	762	4.3	1,170,268	150.4
N.B.	100	373	3.7	751,384	133.1
N.L.	74	327	4.4	517,027	143.1
N.S.	117	405	3.5	1,074,824	108.9
Ont.	1,310	6,807	5.2	12,392,721	105.7
Que.	814	3,249	4.0	7,542,760	107.9
Sask.	103	486	4.7	995,391	103.5
Total	**3,332**	**15,292**	**4.6**	**31,946,316**	**104.3**

* Data are incomplete for two centres in British Columbia; the number of patients and the number of stations for B.C. have been calculated based on data from the previous year, which include 118 patients and 48 centres.

† Includes stations located in, and patients being treated at, full-care hospitals, independent health facilities and community centres.

‡ Alberta includes the populations of the Northwest Territories and Nunavut. British Columbia includes the population of the Yukon. Nova Scotia includes the population of Prince Edward Island.

Overall, on December 31, 2004, 47.2% of HD patients received their dialysis through a native AV fistula, although there were observed differences in the distribution of access types by province. The utilization rate of the fistula as the form of access ranged from a low of 42.8% in Saskatchewan to a high of 67.1% in Nova Scotia (Table 19). Permanent (tunnelled) central venous catheters were the second most commonly used access type (36.1%), while for 4.4% of patients, an alternative form of temporary catheter was used.

Table 19. Type of Access for Point Prevalent HD Patients,* by Province of Treatment, Canada, December 31, 2004 (Number and Percent)

Province of Treatment		Native Fistula	Graft		Catheter				Other	Total
			Synthetic Arteriovenous	Saphenous Vein	Permanent Central Venous	Temporary Subclavian Vein	Temporary Internal Jugular Vein	Temporary Femoral Vein		
Alta.	N	616	216	1	409	1	84	0	0	**1,327**
	%	46.4	16.3	0.1	30.8	0.1	6.3	0.0	0.0	**100**
B.C.	N	775	219	13	414	9	13	4	2	**1,449**
	%	53.5	15.1	0.9	28.6	0.6	0.9	0.3	0.1	**100**
Man.	N	436	23	0	242	4	30	2	0	**737**
	%	59.2	3.1	0.0	32.8	0.5	4.1	0.3	0.0	**100**
N.B.	N	143	19	112	83	2	4	0	0	**363**
	%	39.4	5.2	30.9	22.9	0.6	1.1	0.0	0.0	**100**
N.L.	N	194	25	0	122	0	0	0	0	**341**
	%	56.9	7.3	0.0	35.8	0.0	0.0	0.0	0.0	**100**
N.S.	N	273	8	1	22	8	93	2	0	**407**
	%	67.1	2.0	0.2	5.4	2.0	22.9	0.5	0.0	**100**
Ont.	N	3,059	652	8	2,828	284	43	14	25	**6,913**
	%	44.2	9.4	0.1	40.9	4.1	0.6	0.2	0.4	**100**
Que.	N	1,567	333	71	1,269	29	36	6	70	**3,381**
	%	46.3	9.8	2.1	37.5	0.9	1.1	0.2	2.1	**100**
Sask.	N	202	101	0	165	0	4	0	0	**472**
	%	42.8	21.4	0.0	35.0	0.0	0.8	0.0	0.0	**100**
Total	**N**	**7,265**	**1,596**	**206**	**5,554**	**337**	**307**	**28**	**97**	**15,390**
	%	**47.2**	**10.4**	**1.3**	**36.1**	**2.2**	**2.0**	**0.2**	**0.6**	**100**

* Ninety-eight patients were reported with more than one type of access.

Of the PD patients in Canada in 2004, 97.2% were receiving continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD) at home, with the larger proportion of patients on home-based APD at 51.6%, compared to 45.6% of patients on home-delivered CAPD (Table 20). Significant differences were observed among the provinces in the distribution of patients on home CAPD and home APD. The largest proportion of patients on APD (63.2%) was observed in B.C., while the largest proportion of patients on CAPD (69.5%) was observed in Alberta.

Table 20. Point Prevalent Peritoneal Dialysis Patients, by Type of Treatment and Province of Treatment, Canada, 2004 (Number and Percent)

Province of Treatment		Home CAPD	Home APD	Chronic Care CAPD*	Chronic Care APD	Hospital CAPD†	Hospital APD*	Combined PD and HD	Total
Alta.	N	166	66	6	0	1	0	0	**239**
	%	69.5	27.6	2.5	0.0	0.4	0.0	0.0	**100**
B.C.	N	197	366	0	7	0	4	5	**579**
	%	34.0	63.2	0.0	1.2	0.0	0.7	0.9	**100**
Man.	N	50	139	0	0	0	0	0	**189**
	%	26.5	73.5	0.0	0.0	0.0	0.0	0.0	**100**
N.B.	N	117	62	2	0	0	0	0	**181**
	%	64.6	34.3	1.1	0.0	0.0	0.0	0.0	**100**
N.L.	N	28	18	0	0	0	0	1	**47**
	%	59.6	38.3	0.0	0.0	0.0	0.0	2.1	**100**
N.S.	N	85	41	0	0	0	0	1	**127**
	%	66.9	32.3	0.0	0.0	0.0	0.0	0.8	**100**
Ont.	N	578	857	10	11	8	4	22	**1,490**
	%	38.8	57.5	0.7	0.7	0.5	0.3	1.5	**100**
Que.	N	349	296	2	0	6	0	4	**657**
	%	53.1	45.1	0.3	0.0	0.9	0.0	0.6	**100**
Sask.	N	86	28	0	0	1	2	2	**119**
	%	72.3	23.5	0.0	0.0	0.8	1.7	1.7	**100**
Total	**N**	**1,656**	**1,873**	**20**	**18**	**16**	**10**	**35**	**3,628**
	%	**45.6**	**51.6**	**0.6**	**0.5**	**0.4**	**0.3**	**1.0**	**100**

* Includes total and limited self-care.
† Total care only.

2.4 Kidney Transplantation: Adult Recipients

In 1954, the first kidney transplant was performed by Drs. Murray and Harrison. The groundbreaking operation grafted a kidney from one identical twin to another. It wasn't until the end of the 1950s, however, that deceased-donor kidney transplants were successfully and relatively routinely performed. This "path-finding" work established the foundation for eventual and continuing developments in extra-renal transplantation. Today, kidney transplantation is the most commonly performed solid organ transplant in Canada.

2.4.1 Activity

In 2004, there were 23 active kidney transplant programs in Canada operating in seven provinces: B.C. (3 programs), Alberta (2 programs), Saskatchewan (1 program), Manitoba (1 program), Ontario (7 programs), Quebec (7 programs) and Nova Scotia (2 programs). Among patients 18 years of age and older, there were 9,902 kidney transplant procedures registered in CORR between 1995 and 2004. An additional 599 kidney transplant procedures involved pediatric recipients during the same time. The details on pediatric recipients are provided in Section 2.5. There were 325 simultaneous kidney–pancreas (SPK) transplants during this period. SPK transplants are described more fully in Section 2.6, and are excluded from the data and analysis provided in this section.

In the decade of observation, 9,902 kidney transplant procedures were performed among adult recipients in Canada (Table 21). Retransplants comprised 11.2% of the kidney transplants performed. A small number of kidney combination transplants were performed each year, mostly kidney–liver transplants. A total of 8,719 patients received a first kidney transplant between 1995 and 2004, with 64.4% of these first grafts utilizing deceased-donor kidneys.

Table 21. Kidney Transplants,* by Year, Donor Type and Retransplants, Adult Recipients, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Kidney Only First Grafts, Deceased Donor	586	574	570	540	528	618	559	532	565	541	**5,613**
Kidney Only First Grafts, Living Donor	195	225	254	317	338	333	359	350	362	373	**3,106**
Kidney Combinations First Grafts, Deceased Donors	9	6	12	4	7	7	10	7	8	3	**73**
Retransplants	121	124	113	112	118	113	113	114	87	95	**1,110**
Total	**911**	**929**	**949**	**973**	**991**	**1,071**	**1,041**	**1,003**	**1,022**	**1,012**	**9,902**

* Excludes simultaneous kidney–pancreas transplants (see Section 2.6).

Over the decade, the number of adult deceased-donor kidney transplants declined in Nova Scotia, Manitoba, Ontario, B.C. and Saskatchewan (Table 20). Manitoba saw the largest percent decline, with a 61.1% reduction in deceased-donor kidney transplant procedures between 1995 and 2004. Nova Scotia's deceased-donor kidney transplants decreased by 31.4% over the decade. There was a 44.1% decline in B.C. over the decade between 1995 and 2004; however, for 2003 and 2004, the number remained stable. Although the number (225) of deceased-donor kidney transplants in Ontario was 5.0% fewer in 2004 than it was in 1995, there was an upward movement beginning after 2001, with a 23.6% increase between 2001 and 2004. In 2004, Ontario transplant surgeons performed the largest number of deceased-donor kidney transplants in Canada (36.8%), followed by Quebec with 199 cases, representing 32.6% of all renal transplants performed in 2004. Of note, the numbers of deceased-donor transplants for adult recipients in Alberta and Quebec were greater in 2004 than they were in 1995 (Table 22).

Table 22. Deceased-Donor Kidney Transplants,* by Year and Province of Treatment, Adult Recipients, Canada, 1995 to 2004 (Number)

Province of Treatment	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Alta.	63	86	91	77	73	86	84	80	63	68	**771**
B.C.	93	88	77	50	64	57	59	44	52	52	**636**
Man.	36	34	17	14	14	31	12	17	18	14	**207**
N.S.	51	47	86	35	62	77	70	64	50	35	**577**
Ont.	237	227	220	242	178	222	182	199	194	225	**2,126**
Que.	189	178	153	167	196	210	209	188	224	199	**1,913**
Sask.	22	9	16	36	35	20	28	20	29	18	**233**
Total	**691**	**669**	**660**	**621**	**622**	**703**	**644**	**612**	**630**	**611**	**6,463**

* Excludes simultaneous kidney–pancreas transplants (see Section 6).

Canada's capacity to maintain a level of approximately 1,000 kidney transplants annually over the last four years of the decade for adult recipients was largely fuelled by a steady rise in living-donor kidney transplants (Table 23). While the data hinted at a levelling off of living-donor numbers between 2001 and 2003, in 2004, the number of living-donor organs for adult patients increased to 398 in Canada, a 88.6% increase over 1995. In 2004, the majority of all Canadian adult living-donor kidney transplants were performed in Ontario (42.0%), followed by B.C. with 19.0%.

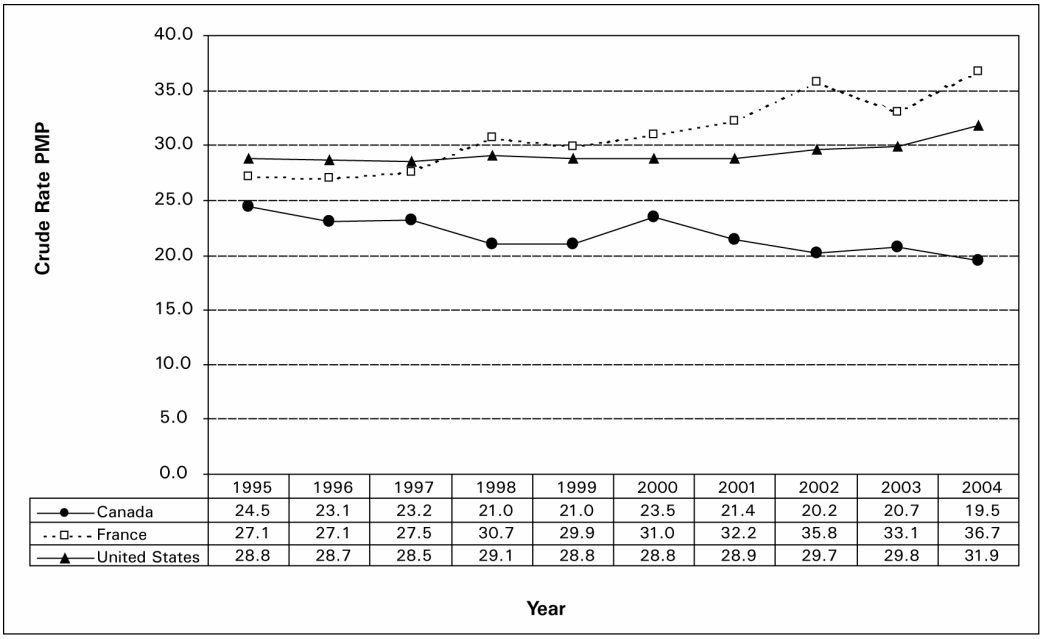
Table 23. Living-Donor Kidney Transplants, by Year and Province of Treatment, Adult Recipients, Canada, 1995 to 2004 (Number)

Province of Treatment	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Alta.	30	31	32	58	50	39	51	49	54	64	**458**
B.C.	27	34	36	39	72	81	83	77	69	76	**594**
Man.	11	8	9	6	16	11	13	21	19	13	**127**
N.S.	22	29	38	38	38	40	34	27	26	23	**315**
Ont.	97	125	130	151	144	157	154	157	158	167	**1,440**
Que.	20	14	15	29	26	25	45	40	48	41	**303**
Sask.	4	13	17	27	16	8	8	14	10	14	**131**
Total	**211**	**254**	**277**	**348**	**362**	**361**	**388**	**385**	**384**	**398**	**3,368**

2.4.2 International Comparison

The deceased-donor kidney transplantation rate PMP,[vii] a crude rate that excludes SPK transplants and includes patients of all ages, declined over the decade in Canada from 24.5 PMP in 1995 to 19.5 PMP in 2004. During the same time period, the rates in the U.S. and in France increased to 31.9 PMP and 36.7 PMP, respectively (from 28.8 and 27.1, respectively) (Figure 19).

Figure 19. Deceased-Donor Kidney Transplants, Canada, France and the United States, 1995 to 2004 (Crude Rate PMP)



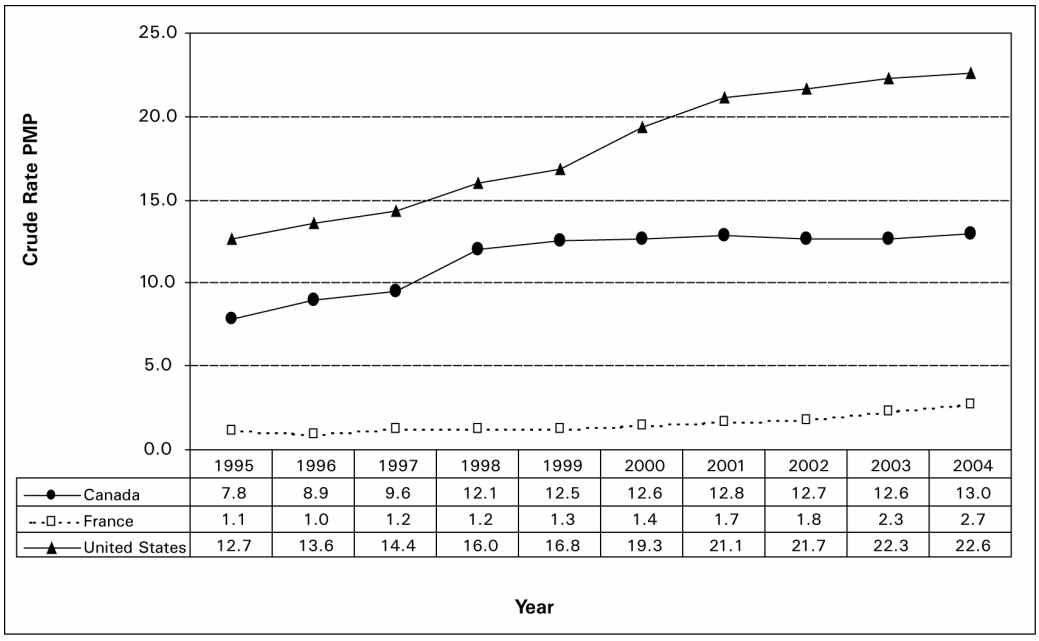
	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Canada	24.5	23.1	23.2	21.0	21.0	23.5	21.4	20.2	20.7	19.5
France	27.1	27.1	27.5	30.7	29.9	31.0	32.2	35.8	33.1	36.7
United States	28.8	28.7	28.5	29.1	28.8	28.8	28.9	29.7	29.8	31.9

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France (2004)* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2005). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2005 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1995–2004* (Richmond, VA: United Network for Organ Sharing, 2005).

vii. The use of rate PMP to calculate donor rates is a less-than-optimal measure. However, it is the current standard used internationally and so is required in this instance to perform international comparative analyses.

In terms of living-donor kidney transplant rates, there are distinct differences between Canada, France and the U.S. Over the decade, the living-donor rates in Canada were up to seven times higher than those seen in France. In 2004, the living-donor rate in Canada (13 PMP) was five times greater than that in France. In contrast, the rate in Canada was 57.5% of the rate in the U.S., where a rate of 22.6 PMP was reported in 2004 (Figure 20). The rate in Canada for living kidney donors remained fairly stable between 1998 and 2004 (12.1 to 13.0), while the rate in the U.S. increased consistently during these years, from 16.0 PMP to 22.6 PMP.

Figure 20. Living-Donor Kidney Transplants, Canada, France and United States, 1995 to 2004 (Crude Rate PMP)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Canada	7.8	8.9	9.6	12.1	12.5	12.6	12.8	12.7	12.6	13.0
France	1.1	1.0	1.2	1.2	1.3	1.4	1.7	1.8	2.3	2.7
United States	12.7	13.6	14.4	16.0	16.8	19.3	21.1	21.7	22.3	22.6

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France (2004)* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2005). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2005 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1995–2004* (Richmond, VA: United Network for Organ Sharing, 2005).

2.4.3 Recipient Characteristics

Three of every five adult kidney transplant recipients were males, regardless of whether the transplant involved a living- or deceased-donor kidney (Table 24). However, between 2003 and 2004, the proportion of male recipients of deceased-donor kidneys decreased by 3.4%, and those of living-donor organs decreased by 9.6%. Among patients who received first kidney grafts, the proportion of recipients with diabetes who received kidneys from living donors during the period of observation decreased (23.4% in 1995 to 19.9% in 2004). For those recipients receiving kidneys from deceased donors, the proportion of those with diabetes rose slightly in the 10 years of study.

The literature notes that the number of patients referred for transplantation who are both older and who have complex comorbidities is increasing.[14] Within CORR, the average age of recipients gradually increased over the decade. The age of deceased–organ donor recipients rose over the decade to 51.2 years (from 45.8 years) and that for living-donor recipients rose to 44.9 years (from 41.1 years).

Table 24. Adult Kidney Transplant Recipients, Selected Characteristics, First Graft, Canada, 1995 to 2004 (Percent)

Donor Type	Characteristic	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Deceased	% Male	66.3	68.3	64.9	67.0	58.5	62.3	64.0	63.5	63.9	61.7
	Average Age (SD*)	45.8	47.0	47.6	47.6	47.7	48.4	50.1	51.0	50.6	51.2
		13.1	12.8	13.0	13.3	13.1	12.3	13.1	13.6	12.9	13.4
	% 60+ Years	17.1	21.0	20.9	23.1	21.4	22.9	28.4	31.7	28.6	32.9
	% Diabetic†	18.9	15.2	17.1	16.9	18.4	16.5	16.5	17.3	22.8	19.1
Living	% Male	57.4	63.6	63.4	63.0	61.5	62.1	55.8	59.3	63.5	57.4
	Average Age (SD*)	41.1	42.1	40.8	43.5	42.8	43.2	42.8	43.8	46.7	44.9
		12.2	12.4	12.1	12.7	13.1	13.0	13.3	13.6	12.9	13.3
	% 60+ Years	9.4	10.4	7.5	13.9	12.5	11.2	14.1	16.1	19.7	15.9
	% Diabetic†	23.4	17.2	16.2	20.4	18.3	16.5	16.7	17.6	22.0	19.9

* SD = standard deviation.

† Determination of diabetic status is based on primary diagnosis and comorbidity data at time of incident dialysis treatment and/or initial kidney transplant.

For the most recent years, 2003 and 2004, glomerulonephritis was the most frequent cause of kidney failure cited in 560 adult kidney transplant recipients, regardless of age, followed by diabetic nephropathy, with 329 adult recipients reported with this diagnosis (Table 25). Polycystic kidney disease was the third-leading cause of kidney failure resulting in transplant in 131 recipients aged 40 to 59 years. Diabetic nephropathy was the second most frequent cause of kidney failure for the 40- to 59-year age group and was reported in 191 recipients. A diagnosis of diabetic nephropathy was also the second-leading cause of kidney failure for those 60 years of age and older (94 recipients).

Table 25. Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Adult Recipients, First Graft, Canada, 2003 to 2004 (Number)

Primary Renal Diagnosis Category	Age Group			Total
	18–39 Years	40–59 Years	60+ Years	
Glomerulonephritis	164	274	122	**560**
Pyelonephritis	45	57	23	**125**
Drug Induced	6	15	12	**33**
Polycystic Kidney Disease	17	131	48	**196**
Hypertension/Other Vascular	24	59	65	**148**
Diabetic Nephropathy	44	191	94	**329**
Other	80	87	42	**209**
Unknown/Not Reported	53	85	54	**192**
Total Diagnoses	**433**	**899**	**460**	**1,792**
Total Patients	**428**	**889**	**460**	**1,777**

* Based on patients with first grafts. Both diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table.

2.4.4 Waiting List and Waiting Times

A change in the definition of pediatric patients from "birth to 14 years" to "birth to 17 years" was implemented in 2002. As anticipated, this change affected the trend line for the adult kidney transplant waiting list, since fewer patients met the definition of "adult" under the new definition (Table 26).

Table 26. Adult Kidney Transplant Waiting List on December 31, Canada, 1994 to 2004 (Number)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
>14 Years	1,808	2,069	2,331	2,341	2,541	2,760	2,989	2,978			
>17 Years									2,927	2,845	2,840

For the most recent three-year period, 2002 to 2004, patients receiving a kidney transplant in B.C. had the longest waits for deceased-donor transplants, with half of the patients waiting for more than five years (Table 27). The shortest median wait time, of just under two years, was reported in Saskatchewan. As a proportion of all kidney transplants performed in a province, pre-emptive transplants for adult recipients were most frequently performed in Manitoba (20.6%) and seen least frequently in Quebec (10.8%).

Table 27. Dialysis Duration Prior to First Kidney Transplant, Adult Kidney Transplant Recipients, Canada, 2002 to 2004 (Number)

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.
Recipients (N)	263	251	63	128	732	489	76
Pre-emptive Transplants, Deceased Donor (N)	16	4	1	6	9	31	3
Pre-emptive Transplants, Living Donor (N)	27	30	12	14	76	22	9
Duration on Dialysis (Median Days),* Deceased Donor	972	1,911	1,204	856	1,658	889	649
Duration on Dialysis (Median Days),* Living Donor	365	335	499	162	389	538	455

* In the calculation of median days on dialysis, pre-emptive kidney transplant recipients were given a value of 0 for their wait time.

2.4.5 Outcomes

At five years post-transplant, unadjusted patient survival rates for the single years spanning 1995 to 2004 were greater than 90% for recipients of living-donor kidneys and—for most years—greater than 85% for recipients of deceased-donor kidneys (Table 28).

Table 28. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Canada, 1995 to 1999 (Followed to 2004)

	Survival Time	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Deceased Donor	N	571	571	560	533	514	601	554	524	555	521
	3 Months	98.4	98.8	99.5	98.3	97.6	99.0	99.6	98.4	98.2	99.1
	1 Year	95.9	96.3	98.3	96.1	96.4	98.7	99.3	97.2	96.9	
	3 Years	92.7	94.6	95.7	92.7	94.0	97.2	97.1	92.3		
	5 Years	89.5	90.7	92.8	90.4	89.1					
Living Donor	N	192	221	240	309	328	321	346	329	350	351
	3 Months	100	100	100	99.4	99.1	98.4	100	100	99.7	99.7
	1 Year	98.9	98.6	99.6	99.4	98.5	98.1	99.7	100	99.4	
	3 Years	97.3	97.6	99.1	97.3	98.1	97.5	98.5			
	5 Years	94.0	96.7	98.2	94.8	97.5					

The five-year graft survival rate was over 75% for deceased-donor grafts for the transplants performed between 1995 and 1999, and over 88% for living-donor grafts in the same time period (Table 29).

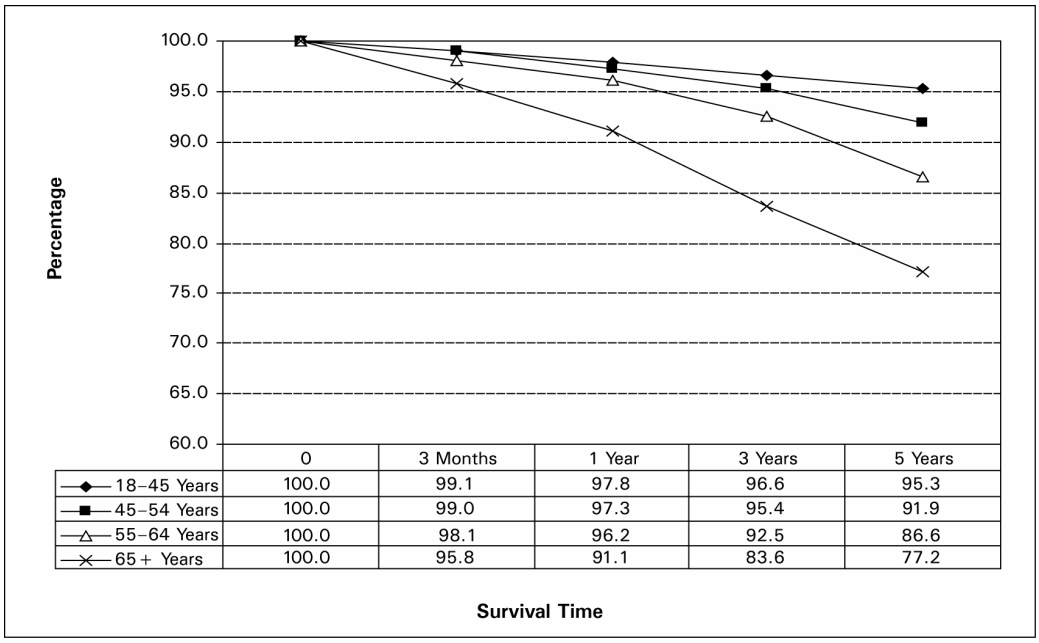
Table 29. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Canada, 1995 to 1999 (Followed to 2004)

	Survival Time	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Deceased Donor	N	586	574	570	540	528	618	559	532	565	541
	3 Months	91.2	94.6	95.3	95.3	94.2	97.0	97.3	94.1	96.2	95.7
	1 Year	87.4	90.2	92.3	91.7	91.2	96.0	95.7	91.6	93.3	
	3 Years	82.4	86.1	86.4	86.2	87.0	92.9	91.6			
	5 Years	76.1	78.7	79.9	79.8	78.5					
Living Donor	N	195	225	254	317	338	333	359	350	362	373
	3 Months	99.0	97.3	97.9	97.7	98.2	96.9	98.0	99.1	98.6	98.7
	1 Year	97.9	94.6	96.2	97.1	96.6	96.3	97.4	98.2	98.0	
	3 Years	95.8	92.3	94.6	92.8	94.5	95.0	94.2			
	5 Years	90.9	89.1	90.3	88.5	91.6					

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

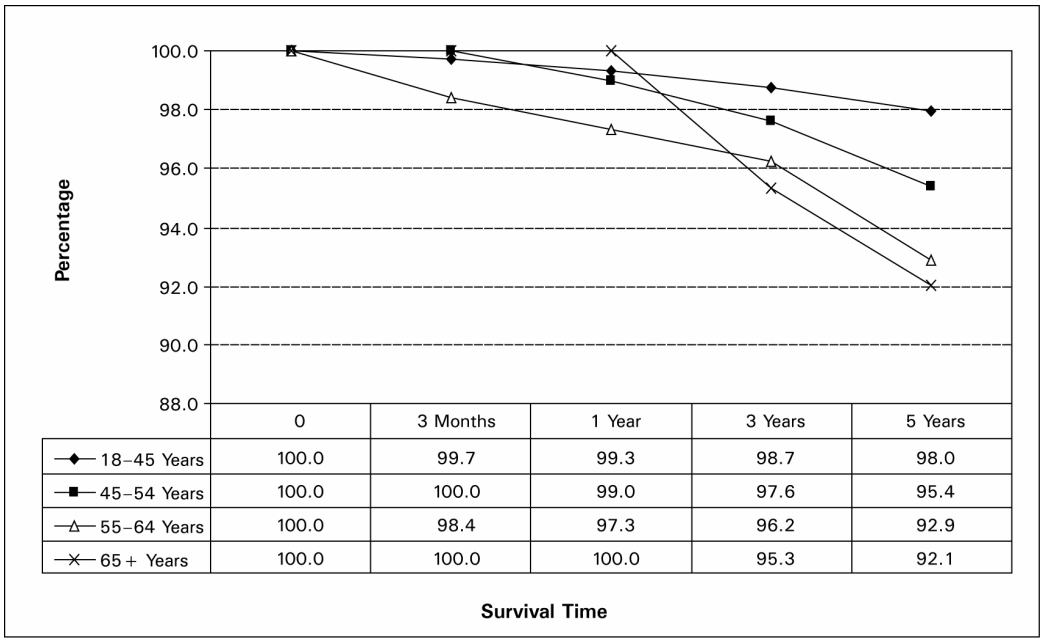
There were notable differences between unadjusted patient survival with living donors, as compared to deceased donors. The most marked differences were seen in long-term survival (defined here as five years) at the upper end of the age continuum. Those in the 65-years-of-age-and-older group, when the transplanted kidney was from a living donor, were observed to have a 14.9% improvement in survival compared to their counterparts receiving a kidney from a deceased donor (figures 21 and 22). The second-largest difference in long-term survival of recipients was seen in those in the 55- to 64-year age group receiving a kidney from a living donor, where a 6.3% improvement was seen in survival at five years compared to those in the same age range receiving a donor kidney from a deceased donor.

Figure 21. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Age at Transplant, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	100.0	99.1	97.8	96.6	95.3
45–54 Years	100.0	99.0	97.3	95.4	91.9
55–64 Years	100.0	98.1	96.2	92.5	86.6
65+ Years	100.0	95.8	91.1	83.6	77.2

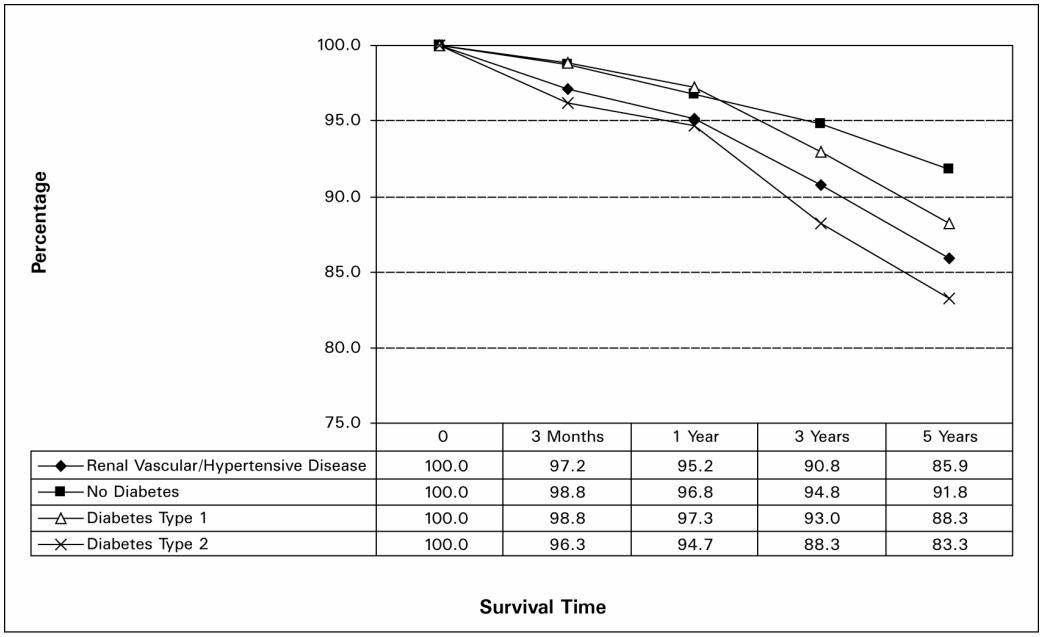
Figure 22. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Age at Transplant, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	100.0	99.7	99.3	98.7	98.0
45–54 Years	100.0	100.0	99.0	97.6	95.4
55–64 Years	100.0	98.4	97.3	96.2	92.9
65+ Years	100.0	100.0	100.0	95.3	92.1

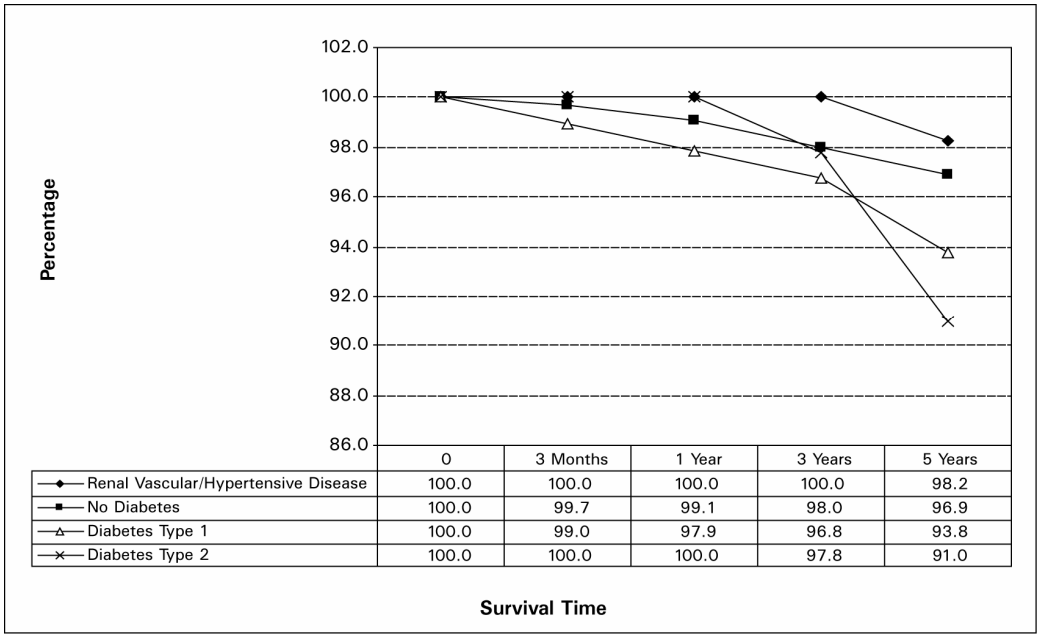
Patient survival after kidney transplantation is affected by the cause of renal failure (figures 23 and 24). Those with type 2 diabetes and a transplanted organ from a deceased donor were found to have the lowest five-year survival rate (83.3%).

Figure 23. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Diagnosis, Canada, 1995 to 1999 (Followed to 2004)



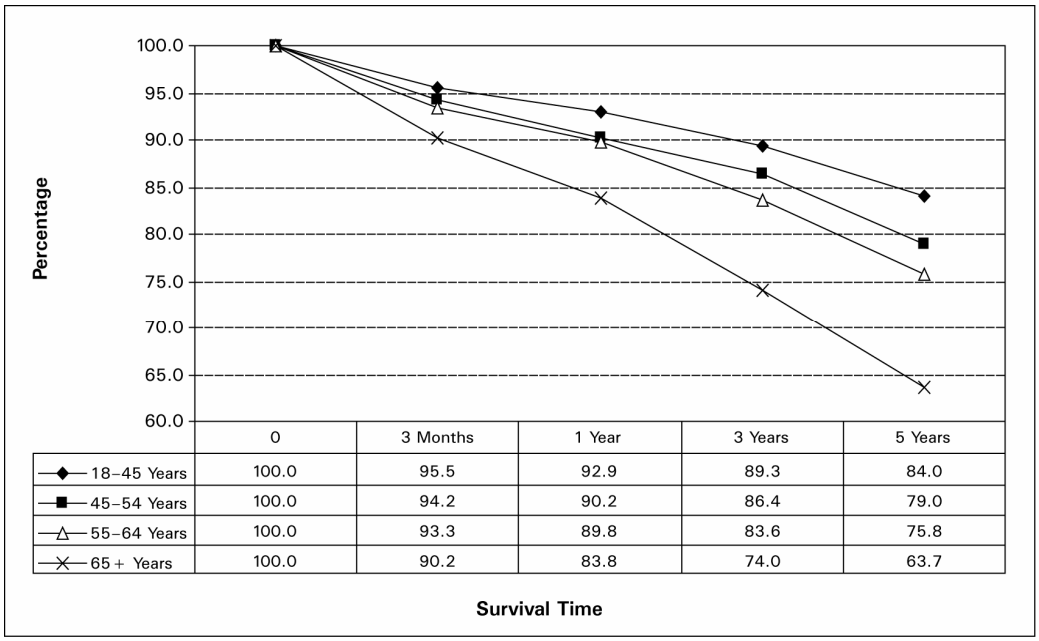
	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/Hypertensive Disease	100.0	97.2	95.2	90.8	85.9
No Diabetes	100.0	98.8	96.8	94.8	91.8
Diabetes Type 1	100.0	98.8	97.3	93.0	88.3
Diabetes Type 2	100.0	96.3	94.7	88.3	83.3

Figure 24. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Diagnosis, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/Hypertensive Disease	100.0	100.0	100.0	100.0	98.2
No Diabetes	100.0	99.7	99.1	98.0	96.9
Diabetes Type 1	100.0	99.0	97.9	96.8	93.8
Diabetes Type 2	100.0	100.0	100.0	97.8	91.0

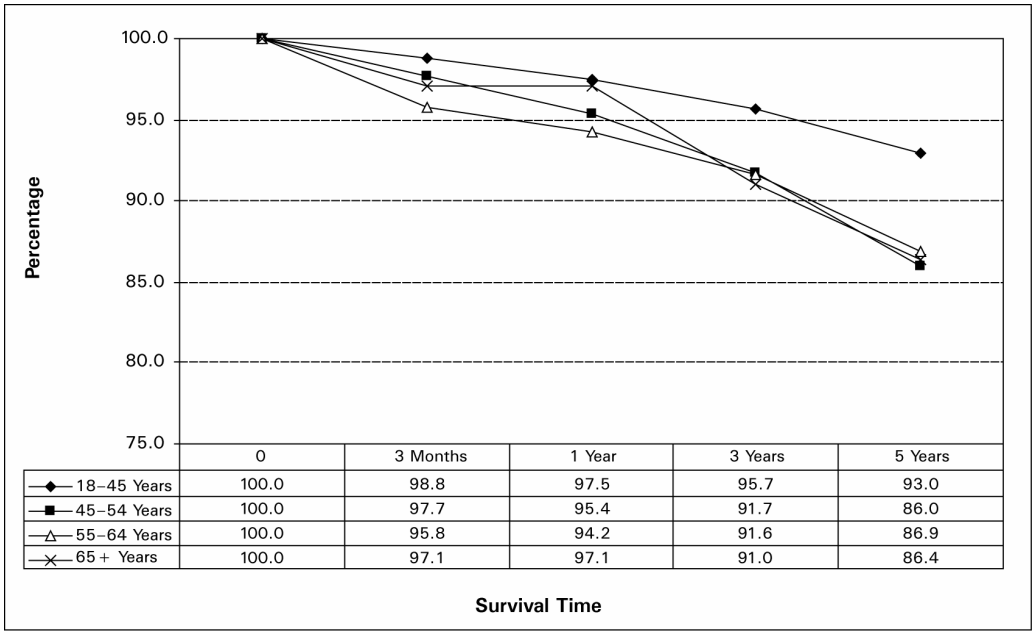
Figure 25. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	100.0	95.5	92.9	89.3	84.0
45–54 Years	100.0	94.2	90.2	86.4	79.0
55–64 Years	100.0	93.3	89.8	83.6	75.8
65+ Years	100.0	90.2	83.8	74.0	63.7

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

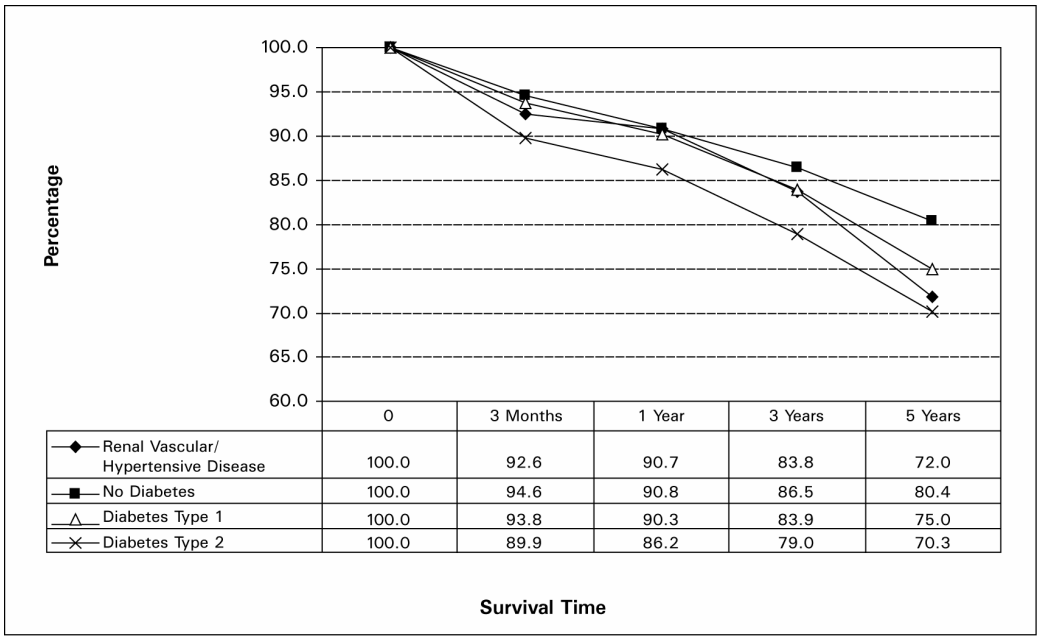
Figure 26. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
18–45 Years	100.0	98.8	97.5	95.7	93.0
45–54 Years	100.0	97.7	95.4	91.7	86.0
55–64 Years	100.0	95.8	94.2	91.6	86.9
65+ Years	100.0	97.1	97.1	91.0	86.4

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

Figure 27. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Deceased Donor, by Primary Diagnosis, Canada, 1995 to 1999 (Followed to 2004)

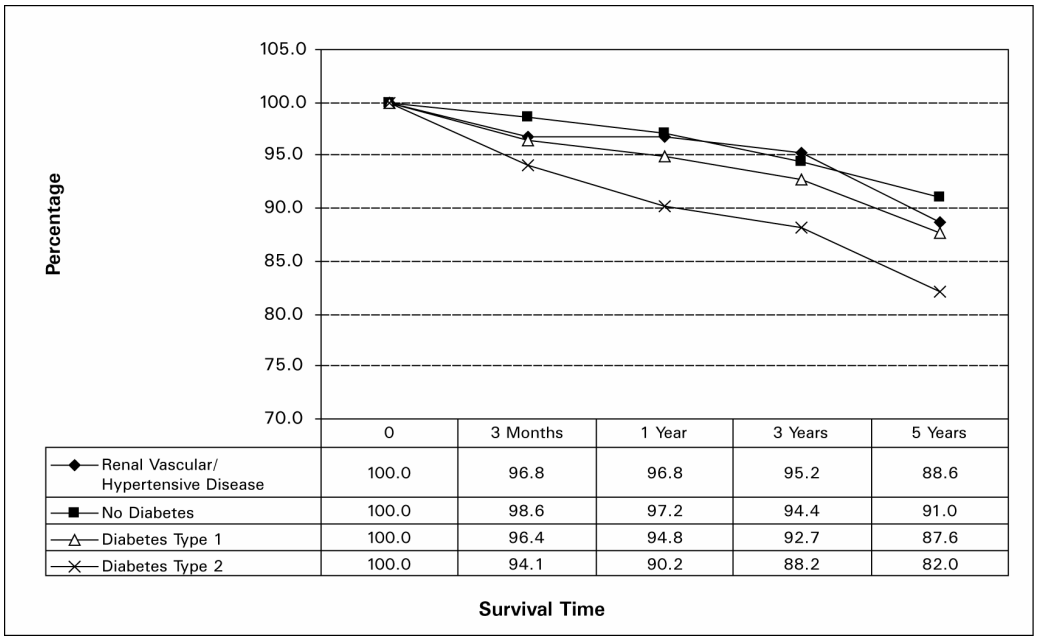


	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/ Hypertensive Disease	100.0	92.6	90.7	83.8	72.0
No Diabetes	100.0	94.6	90.8	86.5	80.4
Diabetes Type 1	100.0	93.8	90.3	83.9	75.0
Diabetes Type 2	100.0	89.9	86.2	79.0	70.3

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

Graft survival was determined to be affected by the etiology of the patient's renal failure. For those with no diabetes, graft survival was superior to the other groups, ranging from 98.6% at three months to 91.0% at five years. The grafts of those with type 2 diabetes had the most compromised status, with graft survival at three months of 94.1%, dropping to 82.0% at five years (Figure 28).

Figure 28. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Adult Kidney Transplant Recipients, First Graft, Living Donor, by Primary Diagnosis, Canada, 1995 to 1999 (Followed to 2004)

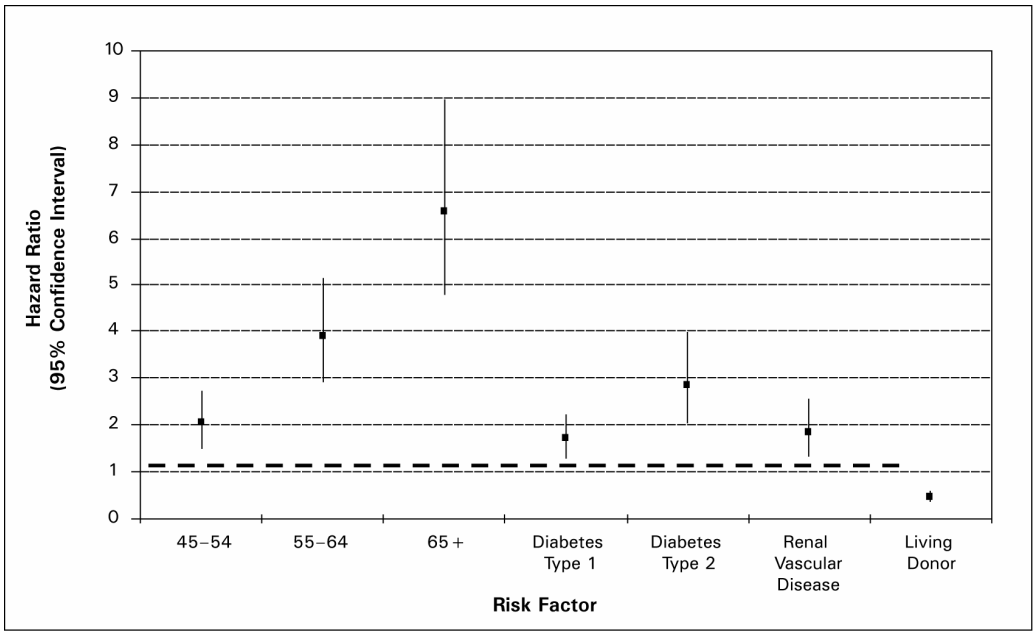


	0	3 Months	1 Year	3 Years	5 Years
Renal Vascular/ Hypertensive Disease	100.0	96.8	96.8	95.2	88.6
No Diabetes	100.0	98.6	97.2	94.4	91.0
Diabetes Type 1	100.0	96.4	94.8	92.7	87.6
Diabetes Type 2	100.0	94.1	90.2	88.2	82.0

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2004). Patients who died with a functioning graft are counted as failed grafts.

Survival analyses were conducted through the use of multivariate modelling techniques, which were developed to estimate the effect of several factors simultaneously on patient survival in kidney transplant recipients. The regression modelling employed a Cox model (see Appendix F). The largest mortality risk of 6.5 (CI: 4.8–8.9) was found for the patients aged 65 and over, and the second largest, of 2.9, was for those patients with type 2 diabetes (CI: 2.1–4.0) (Figure 29).

Figure 29. Cox-Adjusted Mortality Rates for Adult Kidney Transplant Patients, Canada, 1995 to 1999 (Followed to 2004)



2.4.6 Organ Donors

The age of recipients and age of donors showed a correlation (Table 30). The median age of donors ranged between 39, 42 and 46 years for kidney transplant recipients in the 18- to 39-year age group, the 40- to 59-year age group and the 60-years-of-age-and-older group, respectively (Table 30). Almost half of recipients aged 18 to 39 years (47.0%) or 40 to 59 years (48.6%) received a living-donor kidney transplant from a sibling, compared to 13.7% of patients 60 years of age and older who received a living donor kidney from a sibling. The largest number of unrelated donors (31.1%) of all living donors was observed among living donors for recipients in the 40- to 59-year age group.

Table 30. Selected Donor Characteristics, Adult Kidney Transplants, Canada, 1995 to 2004

		Recipient Age Group		
		18–39 Years	40–59 Years	60+ Years
Deceased Donor*	N	1,342	2,804	1,165
	% Male	59.1	59.3	67.4
	Median Age	39	42	46
Living Donor	N	1,186	1,396	407
	% Parent as Donor (N)	28.4 (337)	1.8 (26)	2.7 (11)
	% Sibling as Donor (N)	47.0 (558)	48.6 (679)	13.7 (56)
	% Other Relative as Donor (N)	7.7 (91)	18.4 (256)	56 (228)
	% Unrelated Donor (N)	16.1 (200)	31.1 (433)	27.5 (111)

* Deceased donors will be counted twice if the two kidneys are used for transplantation into different recipients.

2.5 Kidney Transplantation: Pediatric Recipients

While conceptually similar, renal transplantation in children and youth differs in several aspects from transplantation in adults. Etiology of disease, pre-transplant and surgical considerations and measures of outcome can differ in the pediatric population. This section focuses on the incidence and etiology of ESRD leading to transplant in the pediatric population, as well as the outcomes as measured by graft and patient survival.[15]

2.5.1 Activity

In 2002, the age range for pediatric patients in CORR was changed from "birth to 14 years" to "birth to 17 years" in an effort to more accurately capture patients who would be considered pediatric according to the health care delivery system throughout Canada.

In the decade from 1995 to 2004, eight centres provided kidney transplants to pediatric renal failure patients in Canada. Pediatric kidney transplant centres included Halifax, Montréal, Toronto, Winnipeg, Saskatoon, Edmonton, Calgary and Vancouver. The annual number of pediatric kidney transplant procedures ranged from 40 to 78 throughout the decade of observation, with an overall total of 599 procedures (Table 31). During this decade, 578 pediatric recipients received first grafts. There was no increase in the rate of pediatric kidney transplantation over the 10-year period.

Table 31. Kidney Transplants* by Year, Donor Type and Retransplants, Pediatric Recipients, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
First Grafts, Deceased Donor	43	20	42	19	31	33	18	28	27	19	**280**
First Grafts, Living Donor	24	18	26	28	30	44	27	36	28	37	**298**
Retransplants	1	2	0	3	3	1	1	2	3	5	**21**
Total	**68**	**40**	**68**	**50**	**64**	**78**	**46**	**66**	**58**	**61**	**599**

* Includes kidney-combination transplants.

When examining age subgroups in pediatric recipients, the majority of pediatric kidney transplant recipients (70.3%) were aged 11 to 17 years at the time of their transplant (Table 32), while the smallest age group for kidney transplant recipients was those from birth to age 4. Provincial statistics on the distribution of pediatric kidney transplant procedures within the age groups, defined at the time of the kidney transplant procedure, revealed that the largest proportion of patients 0 to 4 years of age was found in Nova Scotia (14.0%), followed closely by B.C. (13.0%). For pediatric patients in the age group of 5 to 10 years, the largest proportion was found in Manitoba (38.8%), and for those aged 11 to 17 years, the largest proportion was reported in Quebec (77.6%). Throughout the decade from 1995 to 2004, a total of 345 pediatric kidney transplants (57.6%) were performed in Ontario and Quebec combined (Table 32).

Table 32. Pediatric Kidney Transplants* by Age Group and Province of Treatment, Canada, 1995 to 2004 (Number and Percent)

Age Group at Transplant		Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
0–4 Years	N	3	9	0	7	21	7	0	**70**
	%	4.0	13.0	0.0	14.0	10.6	4.8	0.0	**11.7**
5–10 Years	N	20	16	19	9	41	26	0	**131**
	%	26.7	23.2	38.8	18.0	20.7	17.7	0.0	**21.8**
11–17 Years	N	52	44	30	34	136	114	11	**421**
	%	69.3	63.8	61.2	68.0	68.7	77.6	100.0	**70.3**
Total	**N**	**75**	**69**	**49**	**50**	**198**	**147**	**11**	**599**
	%	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

* Includes kidney-combination transplants.

From a national perspective, during the 10 years, the number of living-donor kidney (306) outnumbered the number of deceased-donor kidney (293) transplantations in the Canadian pediatric population. However, there were observed differences between provinces in the pattern of donation for pediatric recipients. For all provinces with the exception of B.C. and Quebec, living-donor organs comprised the majority of pediatric kidney transplants. The number of deceased-donor procedures surpassed the living-donor kidney transplants among pediatric recipients in B.C. (64.2%) and Quebec (62.9%) (Table 33).

Table 33. Pediatric Kidney Transplants* by Donor Type and Province of Treatment, Canada, 1995 to 2004 (Number and Percent)

Donor Type		Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Deceased	N	30	42	21	17	86	93	4	**293**
	%	39.4	64.2	45.1	40.7	49	62.9	44.4	**48.9**
Living	N	45	27	28	33	112	54	7	**306**
	%	60.6	35.8	54.9	59.3	51	37.1	66.6	**51.1**
Total	**N**	**75**	**69**	**49**	**50**	**198**	**147**	**11**	**599**
	%	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

* Includes kidney-combination transplants.

2.5.2 Recipient Characteristics

Among pediatric kidney transplant recipients for the years 1995 to 2004, there were slightly more males (53.0%) than females, although the proportion of males was higher among patients from birth to 4 years of age (68.0%). This differs from adult kidney transplant recipients, where three of every five (62.3%) were males, regardless of whether the transplanted kidney was from a deceased or living donor.

When looking at the cause of renal failure among pediatric transplants in Canada, the range of causes is wide and differs substantially from adult kidney transplant recipients. In pediatric patients, the predominant causes of renal failure included various congenital diseases, which were largely related to the patient's age (Table 34). The most frequent cause of renal failure observed in pediatric kidney transplant recipients of all ages was congenital disease, specifically dysplasia/hypoplasia (101). One in four kidney transplant recipients under 11 years of age was reported to have renal failure caused by dysplasia/ hypoplasia. Other diseases, such as cystinosis, glomerulonephritis and focal sclerosis, played a larger role in the pediatric kidney failure of patients aged 11 years of age and older.

Table 34. Kidney Transplant Recipients* by Age Group and Primary Renal Diagnosis Category, Pediatric Recipients, First Graft, Canada, 1995 to 2004 (Number)

Primary Renal Diagnosis Category	Age Group			Total
	0–4 Years	5–10 Years	11–17 Years	
Alport's Syndrome	0	3	11	**14**
Cystinosis	0	7	29	**36**
Dysplasia/Hypoplasia	10	31	60	**101**
Posterior Urethral Valves	5	6	14	**25**
Obstructive Uropathy	4	8	26	**38**
Vesico-Ureteric Reflux	0	3	20	**23**
Polycystic Kidneys	3	7	19	**29**
Nephronophthisis	0	2	17	**19**
Other Congenital/Hereditary	8	11	21	**40**
Other Pyelonephritis	0	2	11	**13**
Glomerulonephritis	5	10	58	**73**
Focal Sclerosis	2	17	21	**40**
Autoimmune Disease	0	2	18	**20**
Moschowitz Syndrome	0	9	15	**24**
Other	2	8	17	**27**
Unknown	3	1	50	**54**
Total	**42**	**127**	**407**	**576**

* Based on patients with first grafts. Diagnoses provided at incident dialysis treatment and subsequent diagnoses at time of kidney transplant are included in this table. Three patients had a diagnosis in more than one category.

When analyzing the number of pediatric kidney transplants by province in the observed decade, it was noted that children and youth from all provinces received transplants. The lowest average rate of transplantation was found in Newfoundland and Labrador, at 6.6 per million pediatric population, while the highest rate was observed in Saskatchewan at 13.2 per million pediatric population (Table 35).

Table 35. Pediatric Kidney Transplant Recipients* by Year and Province of Residence, First Graft, Canada, 1995 to 2004 (Number and Average Rate† per Million Pediatric Population‡)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total	Average Rate PM Pediatric Population‡
Alb.§	6	7	11	9	5	8	2	7	3	7	**65**	8.6
B.C. and Y.T.	9	4	6	7	7	8	3	9	10	4	**67**	7.4
Man.	3	0	1	6	2	6	5	4	4	2	**33**	11.4
N.B.	1	5	3	0	0	2	0	0	1	1	**13**	7.8
N.L.	4	1	0	0	3	0	0	0	0	0	**8**	6.6
N.S. and P.E.I.	2	2	3	4	5	4	3	3	2	0	**28**	11.6
Ont.	18	9	22	11	22	25	22	21	12	22	**184**	6.7
Qc	20	10	20	7	11	18	8	13	22	14	**143**	8.9
Sask.	4	0	2	2	6	6	2	7	0	6	**35**	13.2
Total	**67**	**38**	**68**	**46**	**61**	**77**	**45**	**64**	**54**	**56**	**576**	**8.0**

* Includes kidney-combination transplants. Excludes one patient for whom residence was unknown.
† Crude rate.
‡ Pediatric population used to compute rates is provided in Appendix F.
§ Alberta includes the populations of the Northwest Territories and Nunavut.

2.5.3 Waiting List and Waiting Times

In 2002, the age range for pediatric patients in CORR was changed from "birth to 14 years" to "birth to 17 years." Despite this increase in the age range defined as pediatric within the register, the waiting list for kidney transplantation declined over time to 32 cases in 2004 compared to 57 in 1995, although given the change in definition, an increase in the number of pediatric patients on the wait list would not have been surprising (Table 36). This consistent reduction in the number of individuals listed for transplant is in alignment with the pattern seen in adult kidney transplant recipients. There were three deaths of pediatric patients who were waiting for a kidney transplant recorded from 1995 to 2004.

Table 36. Pediatric* Kidney Transplant Waiting List on December 31, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
< 15 Years	57	59	42	44	48	38	36			
< 18 Years								36	30	32

* From 1995 to 2001, pediatric recipients were defined as patients under the age of 15. In 2002, this definition was changed to patients under the age of 18.

The duration of time on dialysis provides a marker for the waiting time for kidney transplant in most kidney failure patients on dialysis. When examining the time on dialysis prior to transplant, the median number of days on dialysis prior to first kidney transplant was much shorter for pediatric recipients who had a living-donor graft (264 days) as compared to recipients receiving a deceased-donor graft (586 days) in 2004 (Table 37). While this pattern was consistent with that seen in adult recipients (shorter wait times for those receiving living-donor organs), the average median time waiting for transplant differed considerably. In 2004, the wait for adult deceased donor recipients was twice as long as that seen for pediatric patients, and 32.0% longer for living-donor transplant. When looking at the trends over time, the median number of days on dialysis for recipients of a deceased-donor graft increased from 354 days in 1995 to the highest observed value of 586 days in 2004. The median number of days on dialysis for recipients of a living-donor graft jumped substantially to 264 days in 2004 after a decreasing trend over time, with the lowest wait of 87 days seen in 2003. This represents a threefold increase in the time that pediatric recipients of a living-donor kidney waited between 2003 and 2004.

Table 37. Dialysis Duration Prior to First Kidney Transplant, Pediatric Kidney Transplant Recipients, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Recipients (N)	67	38	68	47	61	77	45	64	55	56
Pre-emptive Transplants, Deceased Donor (N)	6	1	3	1	3	5	2	7	7	3
Pre-emptive Transplants, Living Donor (N)	5	5	7	11	10	15	12	16	12	12
Duration on Dialysis (Median Days),* Deceased Donor	354	425	525	453	593	425	291	384	427	586
Duration on Dialysis (Median Days),* Living Donor	275	339	427	281	447	245	195	183	219	390

* In the calculation of median days on dialysis, pre-emptive kidney transplant recipients were given a value of 0 for their wait time.

2.5.4 Outcomes

Unadjusted five-year patient survival for pediatric kidney transplant recipients exceeded 94% for all years that were examined (Table 38). There was little difference in patient survival observed when living-donor recipients were compared to deceased-donor recipients. For transplants utilizing deceased donors, the recipients had a five-year survival ranging from 94.4% to 100%, and for living donors, at five years, 95.7% to 100% of recipients had survived.

Unadjusted five-year graft survival, although somewhat lower than patient survival, was in the 85.0% to 91.0% range for the patients receiving kidney transplant from 1995 to 1999 (tables 38 and 39). Living-donor grafts fared better (83.3% to 93.3%) than deceased-donor grafts (74.3% to 90.1%) in the years between 1995 and 1999, but were variable from year to year (Table 39). The rate of graft survival observed in the pediatric population was different that that observed in adults, both in the short term (three months) and at five years. With the exception of 1996, graft survival with a deceased donor at five years ranged between 83.7% and 89.8%, as compared to the adult range of 76.1% to 79.9%. The average five-year graft survival with the use of living donors was very similar in pediatric and adult patients. For pediatric recipients, the graft survival from living donors ranged from 83.3% to 93.3%, with an average of 89.0%, compared to that of adult recipients, whose graft survival from living donors ranged from 86.0% to 93.0%.

Table 38. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1995 to 2004

	Survival Time	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Deceased Donor	N	43	20	42	19	31	33	18	28	27	19
	3 Months (%)	100	100	100	100	100	100	94.4	100	100	100
	1 Year (%)	94.9	100	100	100	96.8	100	94.4	100	100	
	3 Years (%)	94.9	100	97.6	100	96.8	100	94.4			
	5 Years (%)	94.9	100	97.6	94.4	96.8					
Living Donor	N	24	18	26	28	30	44	27	36	28	37
	3 Months (%)	100	100	100	100	100	100	100	100	100	100
	1 Year (%)	100	100	100	100	100	100	100	100	100	
	3 Years (%)	95.7	95.7	100	100	100	97.7	100			
	5 Years (%)	95.7	95.7	100	96.2	100					

Table 39. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Pediatric Kidney Transplant Recipients, First Graft, Canada, 1995 to 2004

	Survival Time	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Deceased Donor	N	43	20	42	19	31	33	18	28	27	19
	3 Months	97.6	95.0	100	100	100	100	94.4	100	100	100
	1 Year	92.6	95.0	95.1	100	96.8	100	88.9	100	96.3	
	3 Years	92.6	79.6	90.1	89.5	93.5	93.8	88.9			
	5 Years	89.8	74.3	90.1	84.2	83.7	88.0				
Living Donor	N	24	18	26	28	30	44	27	36	28	37
	3 Months	100	94.4	100	100	96.7	97.7	100	97.2	100	100
	1 Year	100	94.4	96.2	100	96.7	97.7	100	97.2	100	
	3 Years	95.7	88.9	88.5	96.3	93.3	93.1	96.3			
	5 Years	91.0	83.3	84.6	92.5	93.3	88.9				

* Graft survival is computed from first kidney transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

2.5.5 Organ Donors

The age of deceased organ donors for pediatric kidney recipients ranged from 1 to 69 years. When exploring donor and recipient age, a positive correlation was observed between the median deceased-donor age and recipient age. The highest median donor age (23.5 years) for transplanted kidneys was found among the oldest pediatric recipient group of 11 years and older, while the median ages of deceased donors for recipients aged 0 to 4 years and 5 to 10 years were 12 and 19 years, respectively.

During the decade of observation, the most frequently reported living-donor relationship for pediatric living-donor kidney transplants were parents in 80.5% (240 out of 298) of cases (Table 40). The number of unrelated living-donor kidney transplantations was largest (29) in the oldest pediatric age group. The proportion of unrelated donors and other relatives was the second-highest living-donor group, representing 8.3%, 10.0% and 14.3% in the age groups 0 to 4 years, 5 to 10 years and 11 to 17 years, respectively. The smallest proportion of living donations to pediatric kidney recipients was from siblings, with none in the 0- to 14-year-old recipients, 5.0% in the 5- to 10-year age group, and 7.9% in the 11-to 17-year-old recipients. This is in contrast to what is observed in the pattern of living donors for adult recipients, where sibling donations are the most prevalent relationship in recipients aged 18 to 59 years.

Table 40. Selected Donor Characteristics, Pediatric Kidney Transplants, Canada, 1995 to 2004

		Recipient Age Group		
		0–4 Years	5–10 Years	11–17 Years
Deceased Donor*	N	10	66	204
	% Male	70	57.6	46.5
	Median Age	12	19	23.5
Living Donor	N	36	60	202
	% Parent as Donor (N)	91.6% (33)	85.0% (51)	77.0% (156)
	% Sibling as Donor (N)	0.0 (0)	5.0% (3)	7.9% (16)
	% Other Relative/ Unrelated Donor (N)	8.3% (3)	10% (6)	14.3% (29)

* Deceased donors will be counted twice if both kidneys were used for transplantation into different recipients.

3 Liver Transplantation

An exciting era in transplant medicine began in 1963 when Dr. Thomas Starzl performed the first human liver transplant in Denver, Colorado. In 1970, Dr. Pierre Daloze performed the first liver transplant in Canada, in Montréal, Quebec. The introduction of advances in immunosuppression resulted in dramatically enhanced survival for transplant recipients. In addition, improvements in organ preservation and surgical techniques beginning in the 1980s have worked together to continue to improve graft and patient survival. The advances in the area are such that liver transplantation is now considered the optimal form of therapy for end-stage liver disease.

The science of liver transplantation underwent a paradigm shift in 1989 when the first living-donor liver transplant was performed at the University of Chicago. The London Health Sciences Centre was the site of the first living-donor parent-to-child liver transplant in Canada in 1993, followed by the first living-donor adult-to-adult liver transplant in Canada in 1999.

3.1 Activity

In 2004, there were nine active surgical liver transplant programs in Canada, which operated in B.C. (one program), Alberta (one program), Ontario (three programs), Quebec (three programs) and Nova Scotia (one program). Most patients from Saskatchewan were treated in Alberta, while most patients from Manitoba were treated in Ontario. Between May 2001 and December 2004, the London Health Sciences Liver Program performed the transplants for the Atlantic program's patients. However, the Atlantic liver program resumed liver transplant surgeries in December 2004.

Pediatric liver transplants were performed at the Hôpital Sainte-Justine (Montréal), the Hospital for Sick Children (Toronto) and the University of Alberta (Edmonton). As of December 31, 2004, there were five living-donor liver transplant programs operating in Canada (in B.C., Alberta and Ontario).

Of the 3,768 liver transplants registered in CORR between 1995 and 2004, 3,433 recipients received first liver transplants (Table 41). Liver transplants in pediatric recipients accounted for 10.9% of liver transplants performed in Canada during the decade, although the annual number of first liver transplants performed on pediatric patients decreased by 44.9% from 1995 to 2004. In contrast, the annual number of first liver transplants in those 18 years of age and older increased by 47.5% between 1995 and 2004. The number of recipients receiving livers from living donors increased from none in 1995 to 54 in 2004. A total of 207 living-donor transplants of livers were performed in Canada during the decade under study. During the 10 years, there were 335 retransplants performed, with the majority of those undertaken in recipients 18 years of age and older (82.4%).

Table 41. Liver Transplants by Year, Donor Type, Age Group and Retransplants, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
First Graft <18 Years, Deceased Donor	49	33	27	24	39	30	20	25	33	15	**295**
First Graft <18 Years, Living Donor	0	1	0	3	6	6	13	10	6	12	**57**
Retransplants <18 Years	8	6	9	5	13	4	4	3	4	3	**59**
First Graft 18+ Years, Deceased Donor	244	288	279	281	300	336	293	290	302	318	**2,931**
First Graft 18+ Years, Living Donor	0	0	0	0	3	13	31	32	29	42	**150**
Retransplants 18+ Years	24	28	35	29	23	20	33	26	31	27	**276**
Total	**325**	**356**	**350**	**342**	**384**	**409**	**394**	**386**	**405**	**417**	**3,768**

Combination transplants with liver are rare in Canada, with less than 2% of the liver transplants performed between 1995 and 2004 being combination transplants. Of the combination transplants performed, the vast majority (83.8%) were liver–kidney transplants (Table 42). Liver–small bowel or other liver combinations were performed sporadically and seldom throughout the period of study.

Table 42. Liver Transplants by Combination Transplants, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Liver Only	319	351	340	338	378	403	383	381	399	414	**3,706**
Liver–Kidney	6	5	8	4	5	4	9	3	5	3	**52**
Liver–Small Bowel	0	0	1	0	1	1	1	1	1	0	**6**
Other Combination*	0	0	1	0	0	1	1	1	0	0	**4**
Total	**325**	**356**	**350**	**342**	**384**	**409**	**394**	**386**	**405**	**417**	**3,768**

* Excludes multivisceral transplants (see Section 7).

The decade spanning 1995 to 2004 saw the majority of liver transplants being performed in the province of Ontario (45.2%), followed by Quebec (26.5%) and Alberta (15.7%) (Table 43).

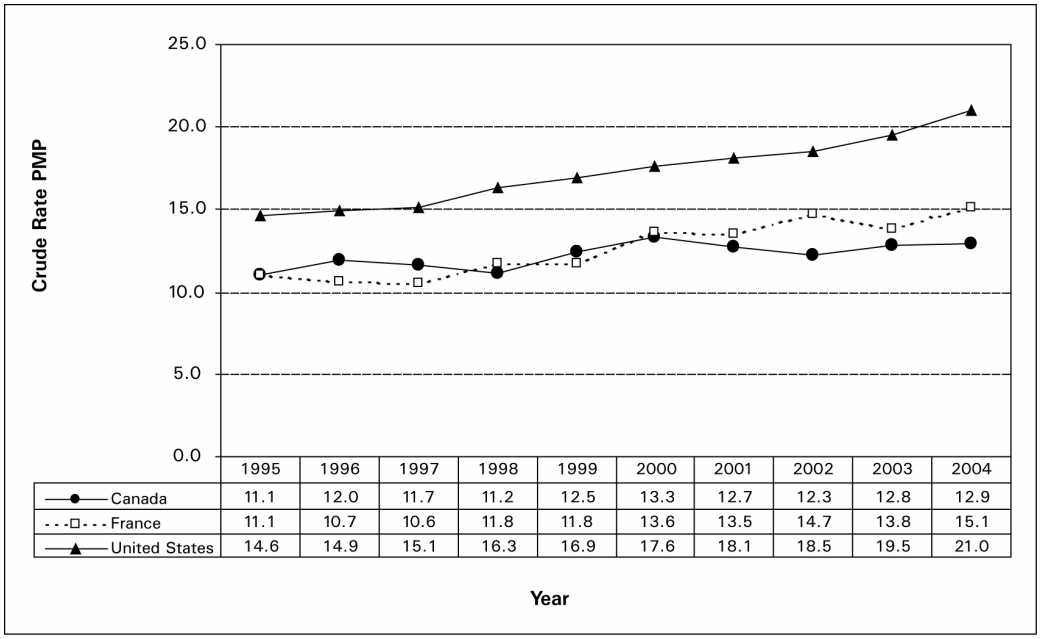
Table 43. Liver Transplants by Year and Province of Treatment, Canada, 1995 to 2004 (Number)

Province of Treatment	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Alta.	38	42	56	55	69	65	63	69	64	71	**592**
B.C.	23	33	38	24	32	34	39	34	35	36	**328**
N.S.	17	17	21	18	29	26	16	0	0	1	**145**
Ont.	161	169	150	155	142	173	176	184	193	202	**1,705**
Que.	86	95	85	90	112	111	100	99	113	107	**998**
Total	**325**	**356**	**350**	**342**	**384**	**409**	**394**	**386**	**405**	**417**	**3,768**

3.2 International Comparison

The crude rate PMP for liver transplantation in Canada remained fairly stable, from a high of 13.3 PMP in 2000 to 12.9 PMP in 2004, and was lower than that seen in the U.S. and France (Figure 30). Between 1995 and 2004, the rate increased by 1.8 PMP in Canada. This situation differed substantially in the U.S., where the rate saw a steady increase each year, for a total increase of 6.4 PMP over the decade, from 14.6 to 21.0 PMP. Between 1995 and 2000, the rates in Canada and France were quite similar, but beginning in 2001 a divergence began to appear, when France's rate continued to increase, while Canada's rate remained consistent.

Figure 30. Liver Transplants, Canada, France and the United States, 1995 to 2004 (Crude Rate PMP)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Canada	11.1	12.0	11.7	11.2	12.5	13.3	12.7	12.3	12.8	12.9
France	11.1	10.7	10.6	11.8	11.8	13.6	13.5	14.7	13.8	15.1
United States	14.6	14.9	15.1	16.3	16.9	17.6	18.1	18.5	19.5	21.0

Data source for France : l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France (2004)* (Paris : l'Établissement français des Greffes, Agence de la biomédecine, 2005). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1995–2004* (Richmond, VA: United Network for Organ Sharing, 2005).

3.3 Recipient Characteristics

Between 1995 and 2004, the average age of liver transplant recipients ranged between 43 and 48 years. Overall, more males (54.8%) received first liver grafts in these years than females, but the male-to-female ratio differed between age groups (Table 44), with those between the ages of 35 and 59 years having the highest proportion of males (65.6%). In contrast, for the age group of less than one year, there were more female liver transplant recipients (57.6%). For those recipients 10 years of age and younger, biliary atresia was the predominant cause of end-stage liver failure. For those in the age groups of 11 to 34 years, where specific diagnoses were recorded, "other hepatitis" was the primary diagnosis. For recipients aged 35 years and older, where specific diagnoses were recorded, hepatitis C, alcoholic cirrhosis and cancer were the major causes of end-stage liver failure cited during the decade.

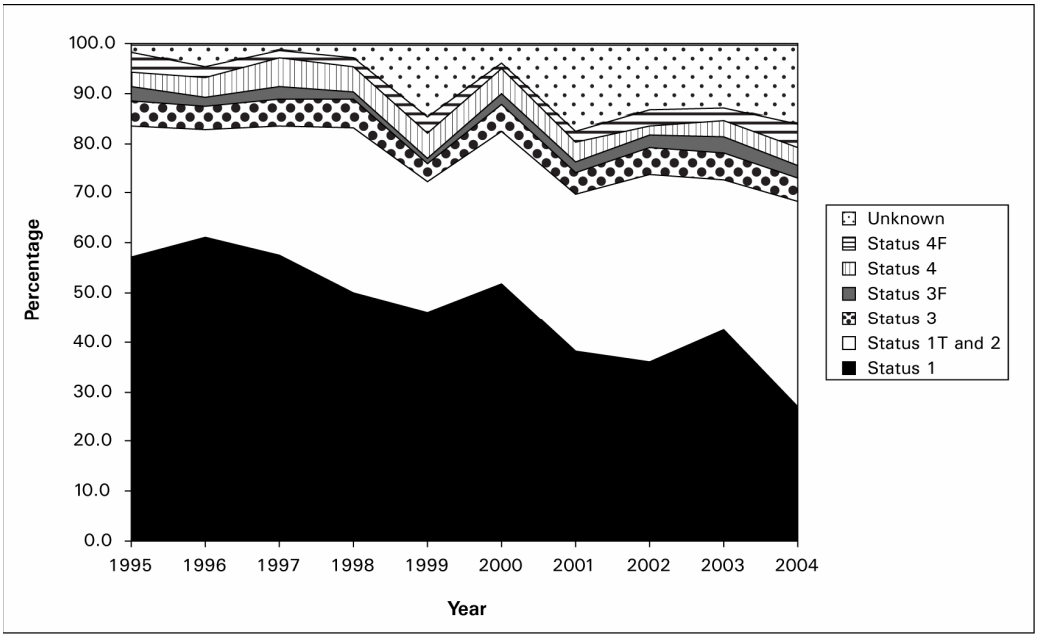
Table 44. Distribution of Primary Diagnoses for Liver Transplant Recipients, First Grafts by Age Group, Canada, 1995 to 2004 (Percent)

Age Group	N	% Male	Primary Diagnosis Category*									
			Primary Biliary Atresia	Hepatitis C	Hepatitis B	Other Hepatitis	Alcoholic Cirrhosis	Cryptogenic Cirrhosis	Cancer	Metabolic Disorders	Unknown/ Missing	Other
<1 Years	172	42.4	62.4	0.6	0	6.4	0	1.2	2.9	5.8	2.9	17.9
1–10 Years	98	55.1	28.0	1.0	0	7.0	0	0	11.0	13.0	7.0	33.0
11–17 Years	82	53.7	4.7	2.3	1.2	20.9	0	2.3	4.7	4.7	7.0	52.3
18–34 Years	282	51.4	0	3.3	7.3	16.7	1.3	4.3	3.0	7.7	3.7	52.7
35–59 Years	2,088	65.6	0.3	27.4	7.2	4.5	18.2	4.9	7.9	2.7	2.0	24.9
60+ Years	711	60.6	0.2	19.6	6.9	4.1	16.3	10.1	13.8	3.8	1.0	24.1

* Up to four diagnoses may be reported per recipient.

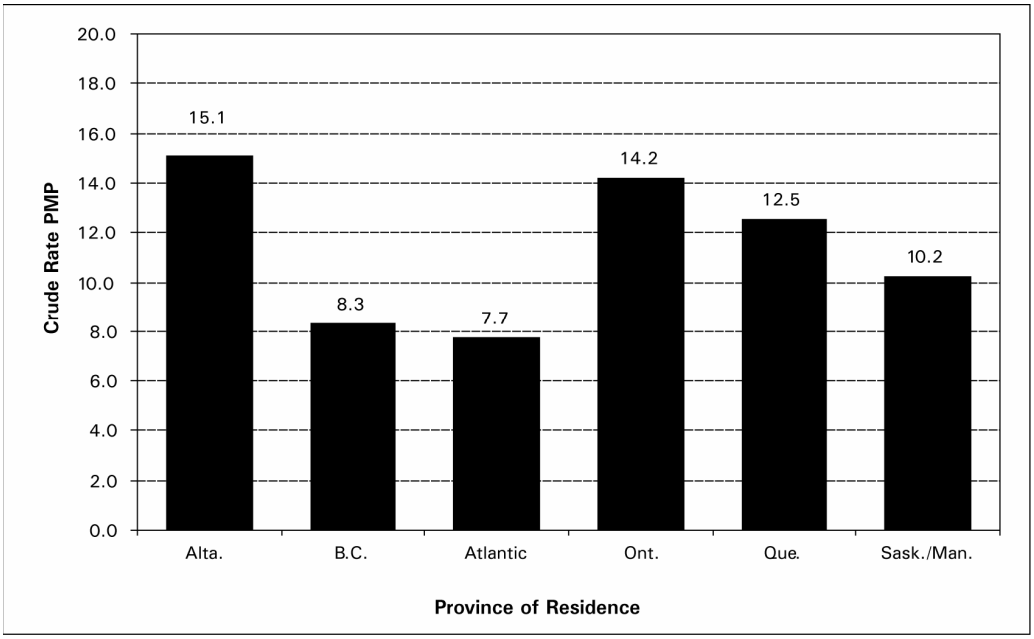
There was little change over the decade in terms of the distribution of patient medical status at the time of transplantation (Figure 31). More than 70% of liver transplant recipients receiving a first graft were considered non-urgent; that is, they had a status of 1 (at home), 1T (with tumour) or 2 (hospitalized) at the time of receiving their transplant.

Figure 31. Distribution of Liver Transplants by Medical Status at Transplant, Canada, 1995 to 2004



There was variation between the crude rates PMP when examined by patients' province of residence for 2004 (Figure 32). The rates for Alberta were the highest (15.1 PMP) followed closely by Ontario (14.2 PMP). The lowest crude rate was seen in the Atlantic region, with a rate of 7.7 PMP. It is important to note that crude rates do not take into consideration potential provincial differences in the prevalence of end-stage liver failure.

Figure 32. Liver Transplant Recipients by Province of Residence, Canada, 2004 (Crude Rate PMP)



Note: Data from Saskatchewan and Manitoba were combined due to small numbers.

3.4 Waiting List and Waiting Times

On December 31, 2004, there were 667 people waiting for a liver transplant in Canada (Table 45). The number of patients waiting for a liver transplant grew steadily over the 10 years, with an overall increase of 347% over that time. The increase was seen in both pediatric and adult patients, although the largest increase was seen in the adult group (18 years and older).

Table 45. Liver Transplant Waiting List, on December 31, Canada, 1995 to 2004

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
<18 Years	23	22	24	26	20	27	36	31	30	37	**253**
18+ Years	126	231	206	260	298	311	418	528	539	630	**3,421**
Total	**149**	**209**	**230**	**286**	**318**	**338**	**454**	**559**	**569**	**667**	**3,674**

A total of 571 patients died while waiting for a liver transplant between 1995 and 2004. Most of the deaths were in those 18 years of age and older (Table 46). The number of deaths of patients on the waiting list under the age of 18 years fluctuated from year to year, demonstrating no real trend. For adult patients, there was an upward trend in deaths on the waiting list over the decade of observation, with slightly fewer in 2004 than in 2003.

Table 46. Deaths Among Patients Waiting for a Liver Transplant, Canada, 1995 to 2004

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
<18 Years	1	1	3	9	7	5	1	4	6	8	**45**
18+ Years	19	22	39	21	63	46	56	78	94	88	**526**
Total	**20**	**23**	**42**	**30**	**70**	**51**	**57**	**82**	**100**	**96**	**571**

The median wait times showed that over the most recent three-year period in the decade studied (2002 to 2004), for deceased-donor liver transplant recipients of first grafts, those listed as urgent had the shortest wait times (Table 47). For non-urgent patients (Status 1, 1T or 2), patients in blood group O had the longest median wait times. For Status 3 patients (in the intensive care unit), patients with blood type B had the longest median wait, and those with type A blood had the shortest median wait.

Table 47. Wait Time From Listing to Transplant for Deceased-Donor Liver Transplant Recipients, First Grafts, Canada, 2002 to 2004

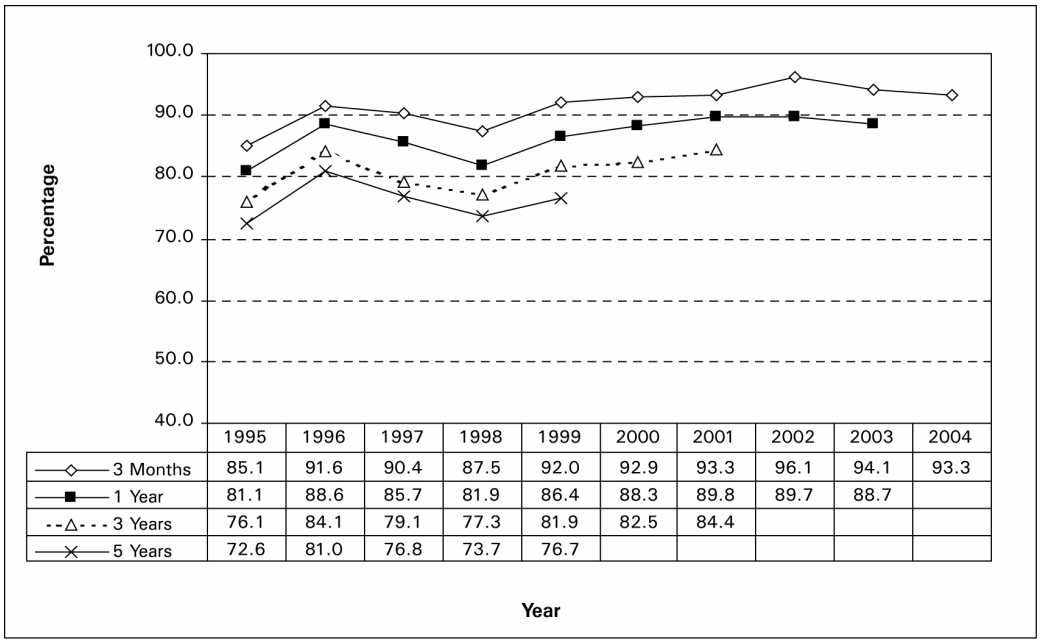
Medical Status as Listing	Blood Group	Wait (in days)			
		N	Min.	Max.	Median
Status 1	A	273	1	1,325	195.0
	AB	40	1	357	51.5
	B	68	21	1,251	310.5
	O	228	6	1,747	332.0
	U	1	535	535	535.0
Status 1T/2	A	103	2	716	33.0
	AB	11	4	368	42.0
	B	31	1	568	55.0
	O	102	0	1,119	106.0
Status 3	A	6	1	50	21.0
	B	4	2	91	30.5
	O	13	2	252	24.0
Status 3F/4/4F	A	41	0	19	1.0
	AB	4	1	3	1.5
	B	9	1	147	3.0
	O	19	0	31	3.0
	U	1	1	1	1.0

Note: Calculated on the basis of actual wait times. Outliers are not excluded.

3.5 Outcomes

Unadjusted patient survival rates for those with deceased-donor liver transplants (first grafts) showed incremental improvements between 1995 and 2002. For 2003 and 2004, however, the proportion of those surviving at three months and one year declined slightly during this time period (Figure 33).

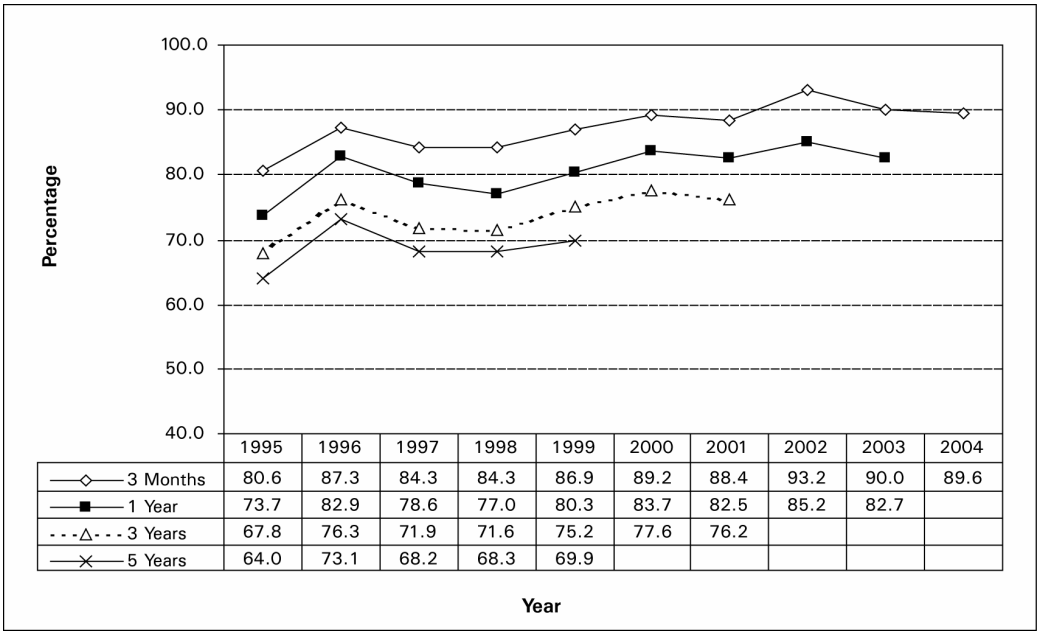
Figure 33. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased-Donor Liver Transplant Recipients, First Graft, Canada, 1995 to 2004



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
3 Months	85.1	91.6	90.4	87.5	92.0	92.9	93.3	96.1	94.1	93.3
1 Year	81.1	88.6	85.7	81.9	86.4	88.3	89.8	89.7	88.7	
3 Years	76.1	84.1	79.1	77.3	81.9	82.5	84.4			
5 Years	72.6	81.0	76.8	73.7	76.7					

Similar to the trend that was observed in patient survival after a first liver transplant, graft survival rates showed an incremental increase until 2002, after which time (2003 and 2004) the three-month and one-year graft survival rates began to decrease slightly (Figure 34).

Figure 34. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Deceased-Donor Liver Transplant Recipients, First Graft, Canada, 1995 to 2004

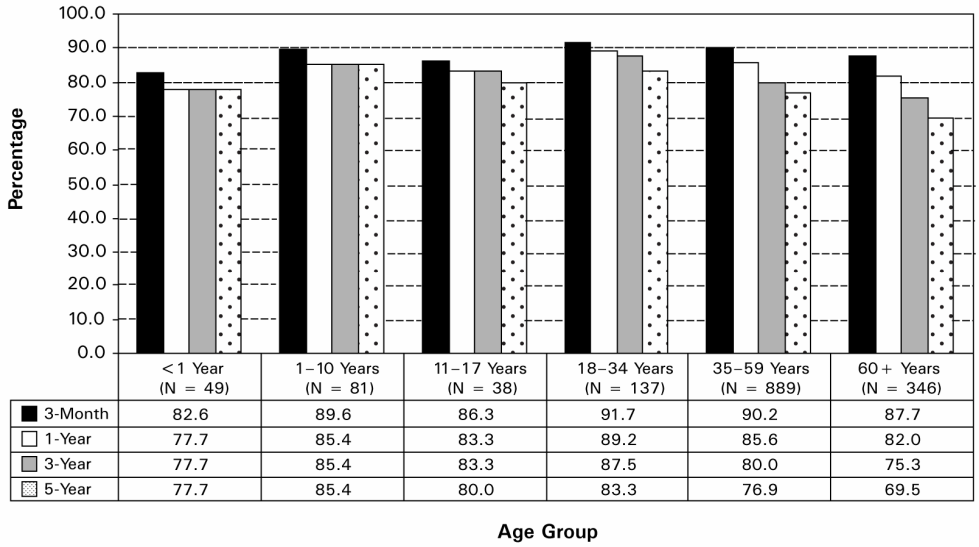


	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
3 Months	80.6	87.3	84.3	84.3	86.9	89.2	88.4	93.2	90.0	89.6
1 Year	73.7	82.9	78.6	77.0	80.3	83.7	82.5	85.2	82.7	
3 Years	67.8	76.3	71.9	71.6	75.2	77.6	76.2			
5 Years	64.0	73.1	68.2	68.3	69.9					

* Graft survival is computed from first liver transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

Unadjusted patient survival by age group for the period between 1995 and 1999 showed the highest survival rates at three months and one and three years post-transplant for recipients aged 18 to 34 years (Figure 35). Long-term survival (at five years) was the highest in those aged 1 to 10 years. Five-year survival was lowest among the oldest liver transplant recipient group (that is, those aged 60 and older).

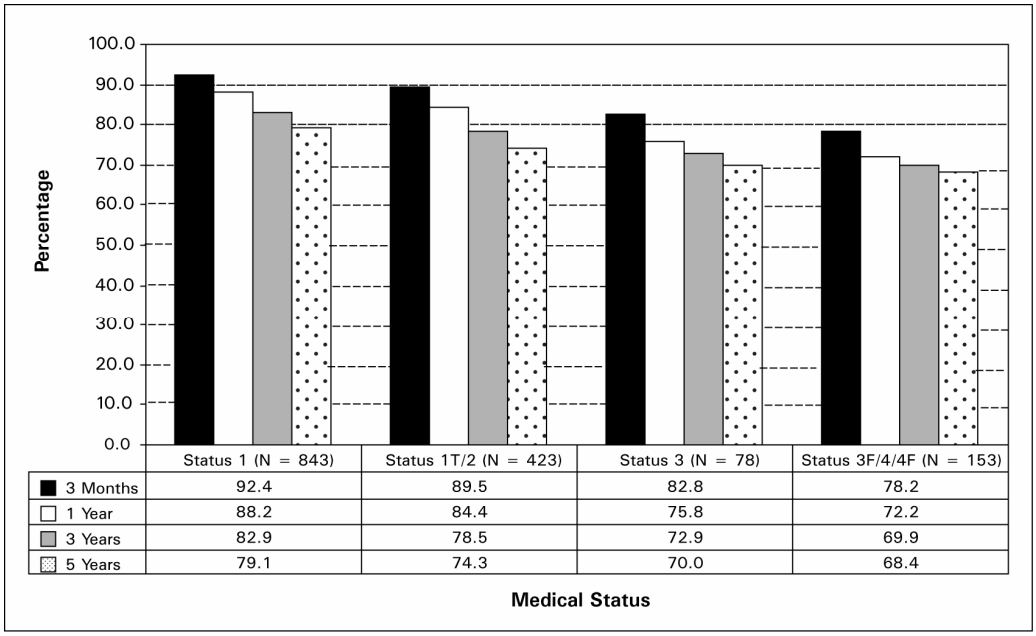
Figure 35. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased-Donor Liver Transplant Recipients by Age Group, First Graft, Canada, 1995 to 1999



	<1 Year (N = 49)	1–10 Years (N = 81)	11–17 Years (N = 38)	18–34 Years (N = 137)	35–59 Years (N = 889)	60+ Years (N = 346)
3-Month	82.6	89.6	86.3	91.7	90.2	87.7
1-Year	77.7	85.4	83.3	89.2	85.6	82.0
3-Year	77.7	85.4	83.3	87.5	80.0	75.3
5-Year	77.7	85.4	80.0	83.3	76.9	69.5

Unadjusted patient survival for deceased-donor liver transplant recipients who received their first liver transplant between 1995 and 1999 clearly demonstrated that medical status at the time of transplant was related to outcome. Recipients with an urgent medical status (3F, 4 or 4F) had lower survival rates at all four follow-up time points compared to patients who received their liver transplant when determined to be non-urgent in status (Figure 36). The best survival at all four time points measured was seen in those patients who received their transplant when determined to be Status 1 (non-urgent). The majority of patients (56%) received their liver transplant when listed as Status 1.

Figure 36. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Deceased-Donor Liver Transplant Recipients, by Medical Status at Transplant, First Graft, Canada, 1995 to 1999



	Status 1 (N = 843)	Status 1T/2 (N = 423)	Status 3 (N = 78)	Status 3F/4/4F (N = 153)
3 Months	92.4	89.5	82.8	78.2
1 Year	88.2	84.4	75.8	72.2
3 Years	82.9	78.5	72.9	69.9
5 Years	79.1	74.3	70.0	68.4

3.6 Organ Donors

The majority of liver donors were male (55.8%). The average age of domestic liver donors was 44.7 years (standard deviation, 17.8), ranging from newborns to patients 86 years old. There was little change in the age of donors over the decade. Additional information about deceased organ donors is provided in Section 8.

Recovery of donor livers used for transplantation from deceased organ donors ranged from 76.2% in 1995 to a high of 87.1% in 1999 (Table 48). The recovery of livers for transplant reached 86.3% in 2004. After a drop in recovery in 2000 from the previous year, the rates showed a consistent, albeit modest, increasing trend in the years following. This increasing trend over the decade occurred in tandem with the maturation of liver transplant programs across Canada.

Table 48. Proportion of Livers Transplanted From Deceased Donors, Canada, 1995 to 2004 (Percent)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Recovery Rate	76.2	84.0	80.9	80.6	87.1	81.1	81.4	83.6	85.8	86.3

Donor livers were shared among programs on the basis of patients' medical urgency. Donor livers from Saskatchewan were typically provided to the Edmonton program, while donor livers from Manitoba were provided to the London program (Ontario). For the period of 2002 to 2004, liver transplant recipients from the Atlantic provinces received their transplants in London, and donor livers were brought into London for these patients. When looking at the ways in which livers were used among recipients who were listed as non-urgent at the time of their wait-listing, the majority of livers originated from the OPO within the province of the transplant program (Table 49).

Table 49. Origin and Destination of Transplanted Livers for Recipients Who Were Listed as Status 1, 1T, 2 or 3, Canada, 2002 to 2004*

Location of OPO	Treated Province					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
	N	N	N	N	N	N
Alta.	111	1	0	3	1	**116**
B.C.	4	65	0	2	3	**74**
Man.	2	0	0	19	0	**21**
N.B.	0	0	0	26	3	**29**
N.L.	1	1	1	18	1	**22**
N.S.	1	0	0	22	2	**25**
Ont.	4	4	0	323	6	**337**
Que.	8	1	0	24	261	**294**
Sask.	30	1	0	2	0	**33**
U.S.	1	0	0	0	0	**1**
Total	**162**	**73**	**1**	**439**	**277**	**952**

* Shaded cells show where local organs were used for transplantation.

More extensive sharing of livers was evident in situations where patients were wait-listed when they were medically urgent (Status 3F, 4 or 4F) (Table 50). The highest numbers of shared organs originated in Ontario and Quebec.

Table 50. Origin and Destination of Transplanted Livers for Recipients Who Were Listed as Status 3F, 4 or 4F, Canada, 2002 to 2004*

Province of OPO	Treated Province				Total
	Alta.	B.C.	Ont.	Que.	
	N	N	N	N	N
Alta.	3	3	3	1	**10**
B.C.	1	1	1	2	**5**
Man.	0	0	2	0	**2**
N.B.	2	0	0	2	**4**
N.L.	1	0	0	0	**1**
N.S.	0	0	0	1	**1**
Ont.	4	7	20	11	**42**
Que.	5	5	12	19	**41**
Sask.	0	0	2	0	**2**
Total	**16**	**16**	**40**	**36**	**108**

* Shaded cells show where local organs were used for transplantation.

4 Heart Transplantation[viii]

With the advent of pioneering techniques for successful heart transplant procedures in the 1950s, world attention was focused on heart transplantation. The first human heart transplant was performed in 1967 by Dr. Christian Barnard in Capetown, South Africa. The low one-year patient survival for heart transplant recipients at the time, however, resulted in dwindling enthusiasm for heart transplantation.[16] The discovery and introduction of the drug cyclosporin to clinical transplantation in the early 1980s resulted in the beginning of substantial improvement in patient survival rates. It was at this juncture that heart transplantation came to be seen as a mainstream treatment for end-stage heart failure.

4.1 Activity

During the decade of 1995 to 2004, 1,629 heart transplants were registered in CORR (Table 51). Included in this total were 18 heart combination transplants, of which 16 were heart–kidney. The number of children under the age of 1 year fluctuated from year to year, with the highest number recorded in 2004 (14). The number of heart transplants in children 1 to 10 years of age also fluctuated between 7 and 10 per year, with the exception of two years with lower numbers (1996 with 6 and 2003 with 4). The majority of heart transplants were performed on those 35 to 59 years of age (52.6%), with those aged 60 and older forming the second-largest age group to receive heart transplants in Canada during this decade (20.9%).

The number of heart transplants performed in Canada decreased from a high of 181 in 1995 to a low of 143 in 2004 (21.0% decrease).

In total, through the decade, 1,571 patients received a first heart transplant, while 58 were retransplanted.

viii. For the purpose of this report, heart–lung transplants are included in Section 5, Lung Transplantation, given that the same data elements are collected for heart–lung and lung transplants.

Table 51. Heart Transplants by Year, Age Group and Retransplants, Canada, 1995 to 2004 (Number)

Age Group	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
First Graft <1 Year	4	3	5	2	9	10	10	5	6	14	**68**
First Graft 1 to 10 Years	8	6	8	7	10	8	8	8	4	7	**74**
First Graft 11 to 17 Years	11	9	7	7	7	8	9	8	10	9	**85**
First Graft 18 to 34 Years	22	14	12	6	12	17	19	15	16	13	**146**
First Graft 35 to 59 Years	96	90	100	105	83	80	71	84	82	66	**857**
First Graft 60+ Years	35	38	25	21	40	38	40	41	33	30	**341**
Retransplants	5	7	6	6	5	12	4	3	6	4	**58**
Total	**181**	**167**	**163**	**154**	**166**	**173**	**161**	**164**	**157**	**143**	**1,629**

Heart transplant procedures are highly specialized and require multidisciplinary and complex care pre- and post-operatively. In Canada, during the 10 years between 1995 and 2004, heart transplants were performed in a relatively small number of hospitals (10). Heart transplant programs existed in the Canadian cities of Halifax, Montréal, Quebec City, Toronto, London, Ottawa, Edmonton and Vancouver. Infant and child heart transplants were performed at the Hospital for Sick Children (Toronto), the Hôpital Sainte-Justine (Montréal), Montréal Children's Hospital and the University of Alberta Hospital (Edmonton). The heart programs located in Ontario (40.9%), Quebec (25.5%) and Alberta (18.4%) performed a combined total proportion of 85% of the heart transplants performed in Canada during this period (Table 52).

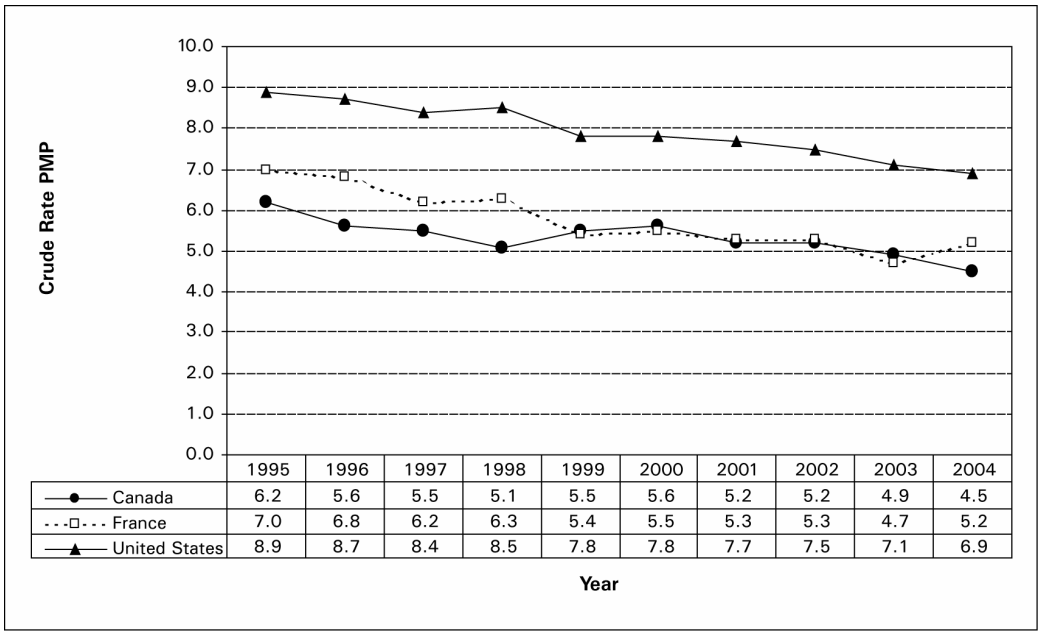
Table 52. Heart Transplants by Year and Province of Treatment, Canada, 1995 to 2004 (Number)

Province of Treatment	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Alta.	21	23	24	32	29	41	42	39	21	28	**300**
B.C.	14	18	20	14	16	11	14	21	18	14	**160**
N.S.	9	6	11	9	9	13	8	6	8	9	**88**
Ont.	86	83	64	63	74	64	58	55	63	56	**666**
Que.	51	37	44	36	38	44	39	43	47	36	**415**
Total	**181**	**167**	**163**	**154**	**166**	**173**	**161**	**164**	**157**	**143**	**1,629**

4.2 International Comparison

Canada's heart transplantation rate was lower than that of the U.S., but similar to France's for the years 1999 to 2003. There was a slight divergence in 2004, with France exceeding Canada's rate for heart transplantation (Figure 37). Heart transplantation was on the decline in Canada and the U.S. between 1995 and 2004. Like in the U.S. and Canada, heart transplantation was on the decline in France between 1995 and 2003, but saw an upswing in 2004.

Figure 37. Heart Transplants, Canada, France and the United States, 1995 to 2004 (Crude Rate PMP)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Canada	6.2	5.6	5.5	5.1	5.5	5.6	5.2	5.2	4.9	4.5
France	7.0	6.8	6.2	6.3	5.4	5.5	5.3	5.3	4.7	5.2
United States	8.9	8.7	8.4	8.5	7.8	7.8	7.7	7.5	7.1	6.9

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France (2004)* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2005). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2005 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1995–2004* (Richmond, VA: United Network for Organ Sharing, 2005).

4.3 Recipient Characteristics

The mean age of heart transplant recipients fluctuated slightly throughout the decade spanning 1995 to 2004, with the mean age ranging from 41 to 45 years. Male recipients outnumbered females in all age groups, with the largest proportion of males seen in the 60-years-and-older age group (86.2% male), and the lowest proportion of males in the 1-to 10-year age group (58.3%) (Table 53). Congenital diseases and unspecified cardiomyopathy were the most frequently observed diagnoses for patients 17 years of age and younger. For those 18 to 34 years of age, the leading diagnosis reported was dilated cardiomyopathy or cardiomyopathy of unspecified origin.

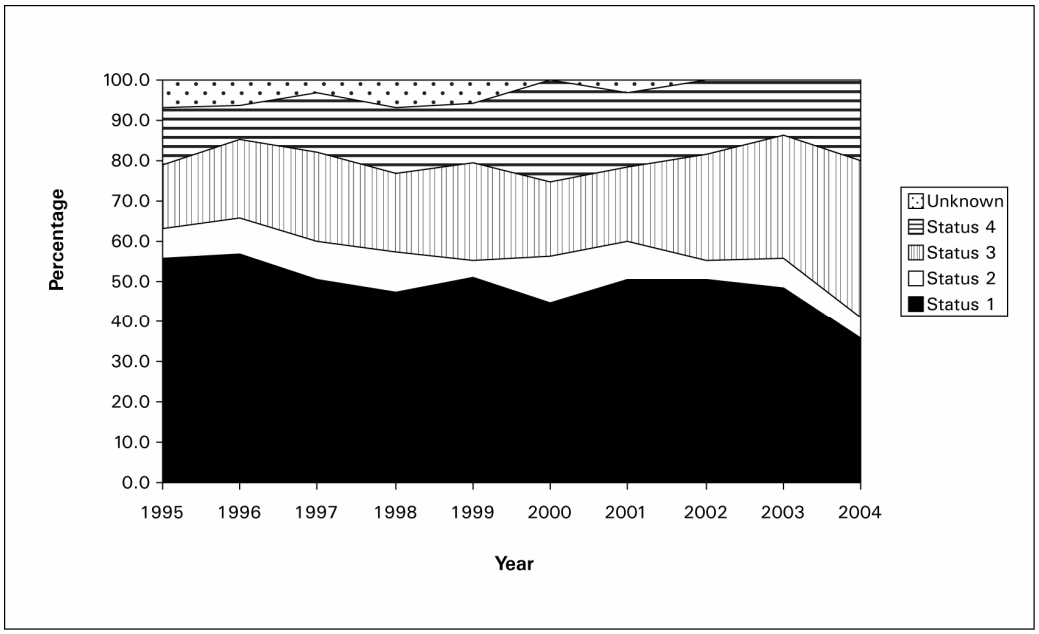
Table 53. Heart Transplant Recipients, First Grafts, by Age Group, Sex and Distribution of Primary Diagnosis Category, Canada, 1995 to 2004

	Total	% Male	Congenital	Cardio-myopathy Unspecified	Dilated Cardio-myopathy	Idiopathic Cardio-myopathy	Ischemic Cardio-myopathy (Coronary Heart Disease)	Unknown/ Missing	Other
<1 Year	**82**	59.8	62.2	17.1	6.1	1.2	1.2	1.2.	13.3
1–10 Years	**6**	58.3	38.3	16.7	11.7	1.7	1.7	8.3	21.7
11–17 Years	**85**	61.1	28.7	29.9	14.9	4.6	1.1	4.6	16.1
18–34 Years	**146**	67.8	12.7	16.7	20.0	11.3	6.0	2.0	31.3
35–59 Years	**857**	78.4	1.5	10.7	14.9	10.0	44.1	2.5	15.5
60+ Years	**341**	86.2	0.3	10.3	12.6	4.0	61.3	2.3	7.8
Total	**1,571**	**76.4**	**8.4**	**12.8**	**13.4**	**8.0**	**39.7**	**2.7**	**15.0**

For heart transplant recipients 35 years and older, the most frequently reported diagnosis was coronary heart disease. In the age group of 60 years of age and older, 61.3% were diagnosed with coronary artery disease as the primary diagnosis leading to a need for heart transplant.

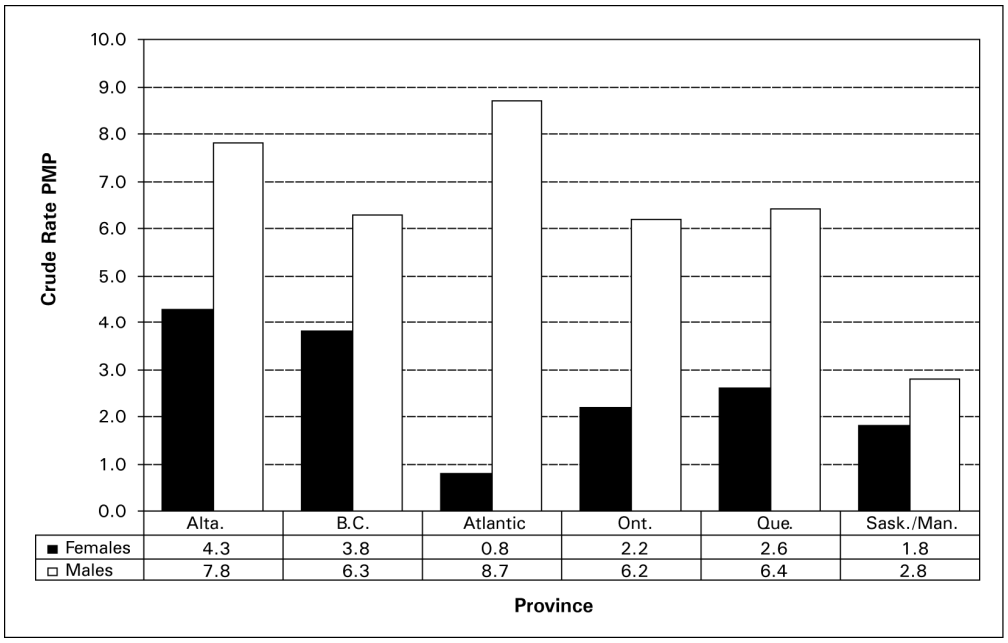
Each person placed on the waiting list for a transplant is categorized according to medical status, with Status 1 and 2 patients being classified as non-urgent. Patients in this category may be at home or in hospital. Status 3A, 3B and 4 patients are seen as urgently requiring transplant. Status 3A and 3B patients may be in the intensive care unit (ICU) or requiring inotropic support. Status 4 patients at listing are the most urgent and are in the ICU, with ventilator support. Examination of the distribution of heart transplant recipients by medical status over time between 1995 and 2004 revealed an increasing proportion of patients who were in the ICU and receiving inotropic support (Status 3) (Figure 38). No clear trend, over time, appeared for the other medical statuses.

Figure 38. Distribution of Heart Transplants by Medical Status* at Transplant, Canada, 1995 to 2004



Over the decade under consideration, the heart transplant rates for females, by province of residence, began to change. When the decade was assessed at the end of 2003, the rate PMP for females ranged between 1.8 and 2.9 in each of the provinces, showing very little provincial variation. When the assessment incorporated 2004 data, both the rates for female heart transplant recipients had risen overall, and the variation between provinces had increased (Figure 39). The rates for female heart transplant recipients ranged from a low of 0.8 PMP in the Atlantic region to 4.3 PMP in Alberta. Conversely, for male recipients, the highest rate was seen in Atlantic Canada, with a rate of 8.7 PMP. Overall, for males, the rates were fairly similar (6.4 to 8.7), with the exception of Saskatchewan, which had the lowest rate for males at 2.8 PMP. These analyses of rates did not take into consideration potential provincial differences in the prevalence of end-stage heart failure.

Figure 39. Heart Transplant Recipients by Province of Residence, Canada, 2004 (Sex-Specific Crude Rate PMP)



	Alta.	B.C.	Atlantic	Ont.	Que.	Sask./Man.
■ Females	4.3	3.8	0.8	2.2	2.6	1.8
□ Males	7.8	6.3	8.7	6.2	6.4	2.8

Note: Data from Saskatchewan and Manitoba are combined due to small numbers.

4.4 Waiting List and Waiting Times

The number of Canadians on the waiting list for heart transplantation fluctuated year to year between 1995 and 2004 (Table 54). While there were fluctuations, there was an overall increase of 27.6% in the number of people waiting for the procedure in the decade. The number of people who died while waiting ranged from 26 to 41 per year, with an annual average of 32 patients over the 10 years.

Table 54. Heart Transplant Waiting List on December 31, Canada, 1995 to 2004

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
< 18 Years	--	--	9	21	13	9	13	13	37	6
18 + Years	--	--	88	99	88	80	112	90	94	119
Total	**98**	**96**	**97**	**120**	**101**	**89**	**125**	**103**	**131**	**125**
Number Died	41	29	28	28	41	30	34	35	30	26

The median wait times for people requiring first heart transplants, over the three-year period between 2002 and 2004, showed that those with an urgent need for a transplant in fact had the shortest wait times (Table 55). Recipients within the blood group O had the longest waits within the medical status groups 1, 2, 3A and 3B. However, for those in Status 4, recipients with blood group B had the longest wait for an organ.

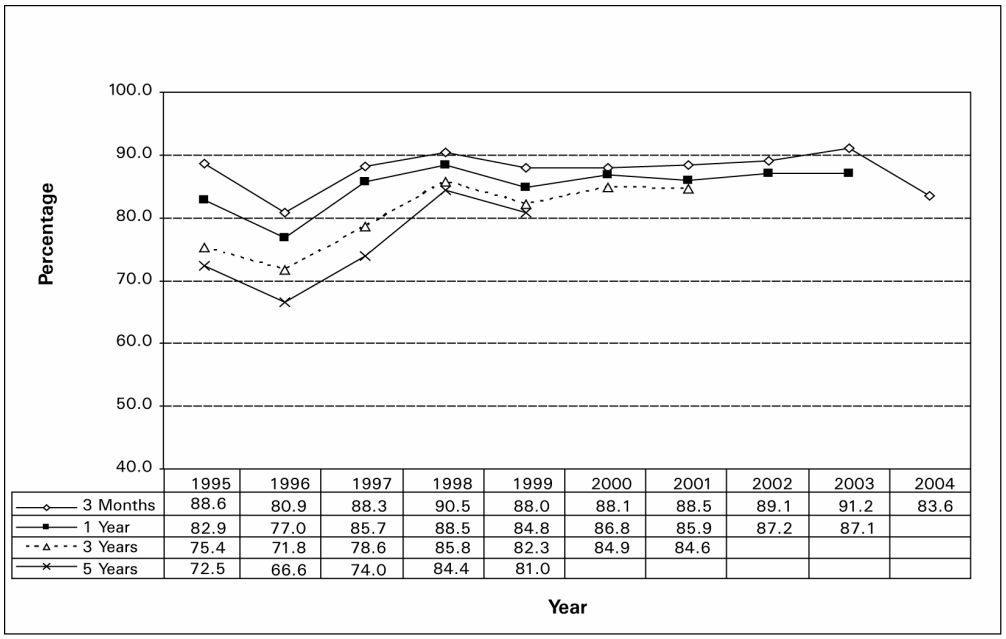
Table 55. Wait Time (Days) From Listing to Transplant for Deceased-Donor Heart Transplant Recipients, First Grafts, Canada, 2002 to 2004

Medical Status at Listing	Blood Group	Wait (in days)			
		N	Min.	Max.	Median
Status 1 (at home) and 2 (hospitalized)	A	127	0	739	89.0
	AB	17	7	176	55.0
	B	37	0	580	82.0
	O	83	0	1,380	247.0
	U	1	51	51	51.0
Status 3A and 3B (ICU or inotropic support required)	A	51	1	365	23.0
	AB	9	0	129	4.0
	B	15	1	283	42.0
	O	35	0	693	62.0
	U	1	12	12	12.0
Status 4 (ICU with mechanical/ ventilator support) and in utero	A	22	1	137	12.0
	AB	9	1	96	5.0
	B	5	1	77	40.0
	O	27	0	146	12.0

4.5 Outcomes

In general, the unadjusted patient survival rates for those with first heart grafts over the period between 1995 and 2003 improved. However, the early survival (three-month) rate for first-time heart transplant recipients saw a decline between 2003 and 2004 of 7.6% (from 91.2 to 83.6) (Figure 40).

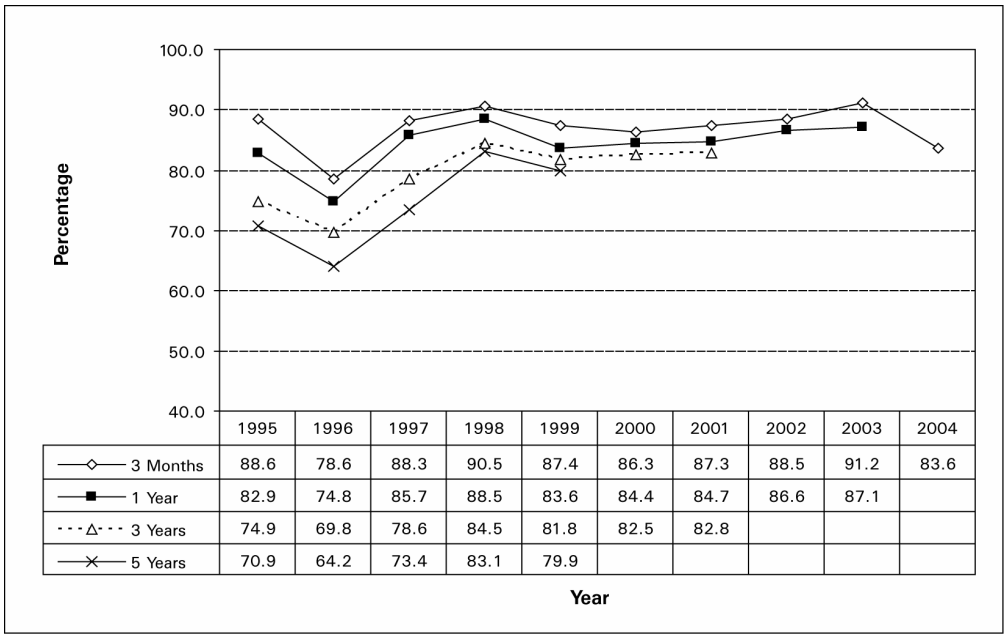
Figure 40. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients, First Graft, Canada, 1995 to 2004



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
3 Months	88.6	80.9	88.3	90.5	88.0	88.1	88.5	89.1	91.2	83.6
1 Year	82.9	77.0	85.7	88.5	84.8	86.8	85.9	87.2	87.1	
3 Years	75.4	71.8	78.6	85.8	82.3	84.9	84.6			
5 Years	72.5	66.6	74.0	84.4	81.0					

Graft survival for heart transplants showed similar trends as seen in patient survival over the decade of study, with improving survival over time, and a drop in three-month survival between 2003 and 2004 (Figure 41).

Figure 41. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Heart Transplant Recipients, First Graft, Canada, 1995 to 2004

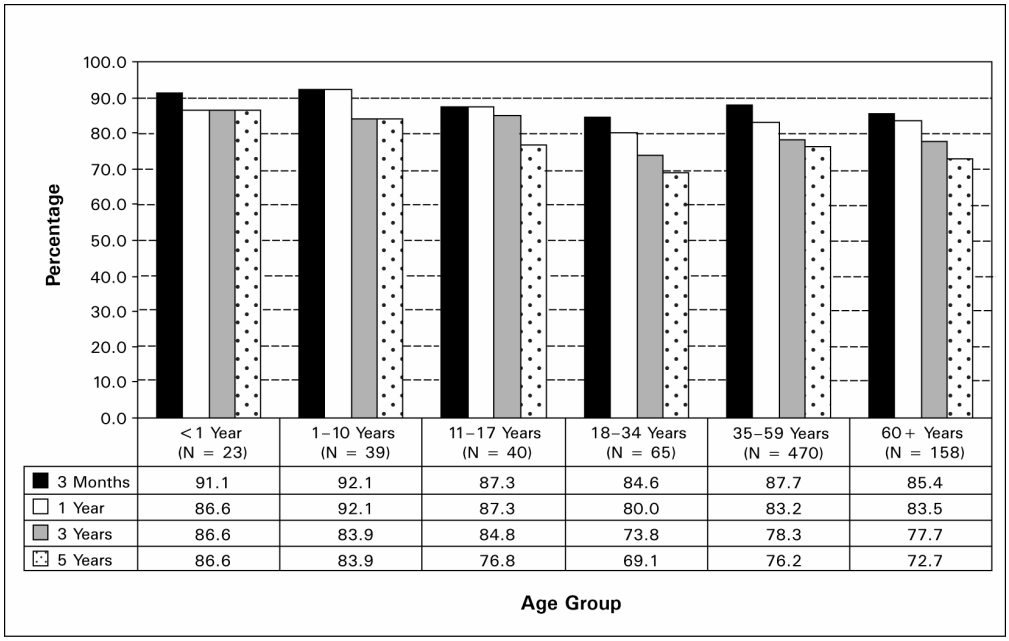


	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
3 Months	88.6	78.6	88.3	90.5	87.4	86.3	87.3	88.5	91.2	83.6
1 Year	82.9	74.8	85.7	88.5	83.6	84.4	84.7	86.6	87.1	
3 Years	74.9	69.8	78.6	84.5	81.8	82.5	82.8			
5 Years	70.9	64.2	73.4	83.1	79.9					

* Graft survival is computed from first heart transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

When examined by age group, patient survival rates at first transplant vary somewhat (Figure 42). Patients in the 1- to 10-year age group have the highest survival rate, at three months and one year (92.1% each). However, both the three-year and five-year survival rates were found to be highest in those under 1 year of age at the time of first transplant (86.6% each). It is important to note that the three pediatric age groups used in this analysis (1995 to 1999) involve small numbers of patients.

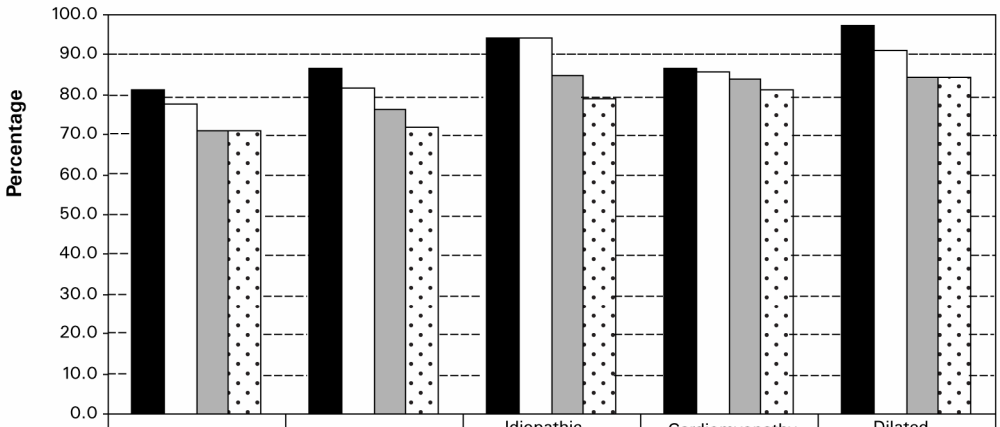
Figure 42. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients, by Age Group, First Graft, Canada, 1995 to 1999



	< 1 Year (N = 23)	1–10 Years (N = 39)	11–17 Years (N = 40)	18–34 Years (N = 65)	35–59 Years (N = 470)	60+ Years (N = 158)
3 Months	91.1	92.1	87.3	84.6	87.7	85.4
1 Year	86.6	92.1	87.3	80.0	83.2	83.5
3 Years	86.6	83.9	84.8	73.8	78.3	77.7
5 Years	86.6	83.9	76.8	69.1	76.2	72.7

When the analysis considers the etiology of end-stage heart failure, those heart transplant recipients with cardiomyopathy as the causal diagnosis of heart failure had improved survival at three months, one year, three years and five years, compared to those with either coronary artery disease or congenital heart diseases (Figure 43). The poorest unadjusted patient survival was observed at three years and five years post-transplant among those with the diagnosis of a congenital heart disease (71.0%).

Figure 43. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients, by Primary Diagnosis, First Graft, Canada, 1995 to 1999

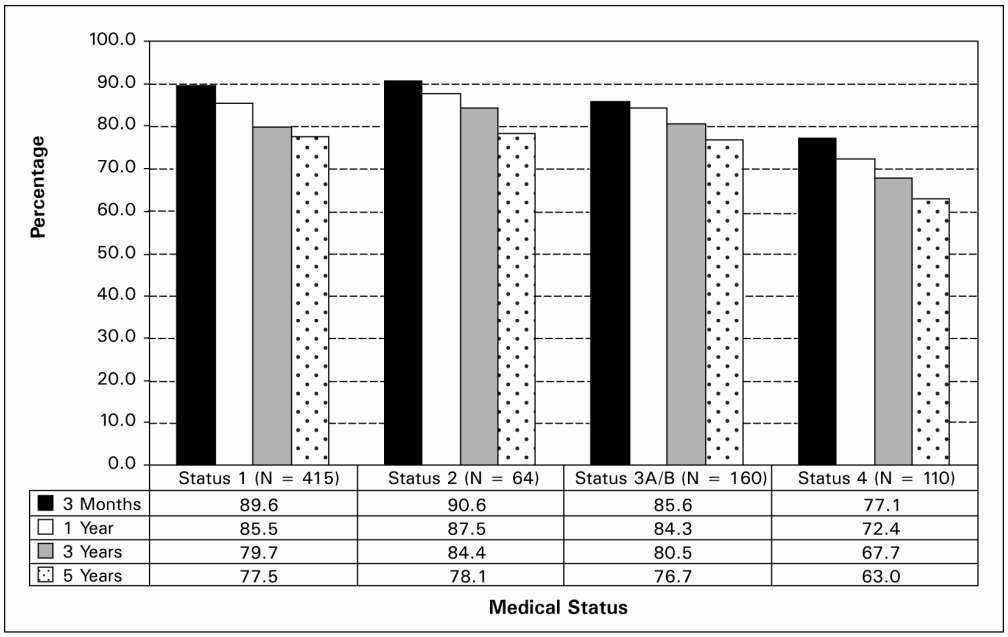


	Congenital (N = 60)	Coronary Artery Disease (N = 354)	Idiopathic Cardiomyopathy (N = 53)	Cardiomyopathy — Unspecified (N = 114)	Dilated Cardiomyopathy (N = 77)
3 Months	81.4	86.4	94.3	86.7	97.4
1 Year	77.9	81.9	94.3	85.8	90.9
3 Years	71.0	76.2	84.9	84.0	84.4
5 Years	71.0	71.9	79.2	81.3	84.4

Medical status at the time of transplant was seen to be an important factor in patient outcome in the analyses. Consistently, at all time points, those in the Status 4 category at transplant had the poorest survival. Similarly, consistently at all time points, those in Status 2 had the best survival rates.[ix] For short-term survival (three months and one year) those assigned to Status 2 had the highest survival rate (90.6% and 87.5%, respectively), while the lowest (at 77.1% and 72.4%, respectively) were seen in Status 4 recipients. Three-year survival varied considerably from a low of 67.7% for Status 4 patients, to a high of 84.4 for Status 2. The analysis of long-term survival, at five years, demonstrated Status 2 recipients to have the best survival rates at 78.1%, followed closely by Status 3 at 76.7% and status 1 at 77.5%. Those determined to be Status 4 at operation had a 63.0% survival rate at five years (Figure 44).

ix. Note that the Status 2 group used in this analysis (1995 to 1999) involved a small number of patients, relative to the other groups.

Figure 44. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Heart Transplant Recipients, by Medical Status at Transplant, First Graft, Canada, 1995 to 1999



4.6 Organ Donors[x]

Recovery of hearts used for heart and heart–lung transplantation reached the lowest rate in the most recent year of analysis (2004), with a recovery rate of 30.5%. The proportion of hearts recovered for transplant from deceased donors showed a steady decline between 1995 and 2004, with an overall relative decline of 28.1% during the decade (Table 56).

Table 56. Proportion of Hearts Transplanted From Deceased Donors, Canada, 1995 to 2004 (Percent)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Organ Recovery Rate	42.4	38.9	37.5	36.5	37.6	34.0	34.5	35.3	34.0	30.5

In Canada, donor hearts are shared across provinces, based on the urgency of a patient's medical need for the organ. Donor hearts from Saskatchewan are typically provided to the Edmonton program, while donor hearts from Manitoba are provided to the London program. In terms of medical status, 60.9% (282) of those listed for heart transplant in 2002 to 2004 were deemed to be Status 1 or 2, while the remainder (181), were listed as Status 3A, 3B and 4 (tables 57 and 58).

x. For details related to heart–lung donors, please refer to Section 5. The remainder of this section excludes donated heart–lungs.

When examining the ways in which hearts were utilized among recipients who were listed as non-urgent (medical Status 1 and 2) at the time of their wait-listing, the Halifax heart transplant program used only hearts recovered from donors at facilities in the Atlantic provinces (Table 57). The Atlantic provinces shared proportionately more organs to programs in provinces outside the region than it received from other parts of Canada. The U.S. sent 22 hearts for transplant to Canada over the decade, with 13.6% of hearts used by the Vancouver and Edmonton programs coming from donors in the U.S. The Halifax program is the only program not to have utilized donated hearts from the U.S.

Table 57. Origin and Destination of Transplanted Hearts for Recipients Who Were Listed as Non-Urgent (Status 1 and 2), Canada, 2002 to 2004*

Retrieval Location	Treated Province					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
	N	N	N	N	N	N
Alta.	26	9	0	2	0	**37**
B.C.	3	27	0	0	0	**30**
Man.	1	0	0	5	0	**6**
N.B.	0	0	9	3	2	**14**
N.L.	0	0	6	1	0	**7**
N.S.	0	0	1	2	2	**5**
Ont.	3	0	0	84	2	**89**
Que.	0	0	0	5	60	**65**
Sask.	5	2	0	0	0	**7**
U.S.	8	4	0	7	3	**22**
Total	**46**	**42**	**16**	**109**	**69**	**282**

* Shaded cells show local organs used for transplantation.

While donor heart organs are shared throughout the continuum of medical status from 1 through 4, the most extensive sharing of organs was seen for patients who were placed on the wait list for transplant when they were in the ICU and deemed to be urgently requiring transplant (Table 58). In Canada, the province of Ontario was most reliant on donor hearts from the U.S., utilizing American donor organs for 20.6% of its urgent heart transplant recipients.

Table 58. Origin and Destination of Transplanted Hearts for Recipients Who Were Listed as Urgent (Status 3A, 3B or 4), Canada, 2002 to 2004 (Number)

Location of OPO	Treated Province					Total
	Alta.	B.C.	N.S.	Ont.	Que.	
Alta.	23	1	0	6	1	**31**
B.C.	0	5	0	2	1	**8**
Man.	0	1	0	3	0	**4**
N.B.	0	0	4	0	0	**4**
N.L.	0	0	0	1	1	**2**
N.S.	0	0	1	1	2	**4**
Ont.	5	0	2	33	8	**48**
Que.	0	2	0	4	42	**48**
Sask.	7	0	0	0	0	**7**
U.S.	7	2	0	13	3	**25**
Total	**42**	**11**	**7**	**63**	**58**	**181**

The average age of domestic heart donors between 1995 and 2004 remained virtually unchanged at 35 years. As the decade progressed, there was a small increase in the number of infant hearts utilized toward the end of the 10 years. Overall, there were fewer female domestic heart donors than male (36.8% female). The proportion of donors who died as a result of motor vehicle collisions declined over the course of the decade, likely reflecting the implementation of effective vehicle safety and injury-prevention strategies. The proportion of donors who died in motor vehicle collisions dropped by 5.7% between 1995 to 1996 and 2003 to 2004. While the overall trend in the decade was that of a reduction, the proportion of donor hearts related to motor vehicle collisions rose 3.0% in the last year (between 2003 and 2004). While motor vehicle collisions declined as a cause of death associated with heart donors, the proportion dying from other causes of trauma climbed steadily throughout the decade, with a 7.9% increase between 1995 to 1996 and 2003 to 2004. Decreases were also seen in CVA/stroke, anoxia/hypoxia and gunshot as causes of death in donors (Table 59).

Table 59. Cause of Death Among Donors of Transplanted Hearts, Canada, 1995 to 1996 and 2003 to 2004

	1995 to 1996		2003 to 2004	
	N	%	N	%
Cerebrovascular Accident/Stroke	136	39.7	102	37.6
Motor Vehicle Collision	99	28.9	63	23.2
Other Trauma	44	12.8	56	20.7
Other	20	5.8	22	8.1
Anoxia/Hypoxia	21	6.1	10	3.7
Gunshot	19	5.5	9	3.3
Unknown	4	1.2	9	3.3
Total	**343**	**100.0**	**271**	**100.0**

5 Lung Transplantation

In 1963, the first human lung transplant was performed by Dr. James Hardy at the University of Mississippi. The transplant recipient was a patient with an isolated lung malignancy, and he lived for 18 days after the transplant. Between 1963 and 1980, only a small number of lung transplants were performed around the world and there was no long-term survival for any of the patients during this era. The introduction of cyclosporin in the early 1980s began to change the landscape for lung transplantation.

Canada made a dramatic mark on the lung transplant landscape with the first single lung transplant operation, performed by the Toronto Thoracic Surgical Group under the leadership of Dr. Joel Cooper in 1983. Dr. Cooper continued to make strides in lung transplant history, performing the first successful bilateral lung transplant in 1986. The first "successful" heart–lung transplant was performed in 1981 at Stanford University. Since that time, results have continued to improve for several reasons: better organ-preservation techniques; improved pre- and peri-operative care, including better follow-up for medical management of recipients; and advances in immunosuppression.

5.1 Activity

The decade between 1995 and 2004 saw both an increase in the numbers of lung transplants being performed annually in Canada, and an improvement in outcomes. Lung transplantation procedures in Canada were performed in 10 facilities throughout the time period: the Montréal General Hospital, Royal Victoria Hospital, Notre-Dame Hospital (Montréal), Hospital for Sick Children (Toronto), The University Health Network (Toronto General Hospital), London Health Sciences Centre, the Health Sciences Centre (Winnipeg), the University of Alberta Hospital (Edmonton), Vancouver General Hospital and Health Sciences Centre and B.C. Children's Hospital (Vancouver). The Montréal General Hospital and Royal Victoria Hospital (now both part of the McGill University Health Centre in Montréal) Lung Transplant programs ended in the fall of 1997 and the London Health Sciences Centre program ended in the spring of 2003.

During the period of study, 1,069 lung transplants were registered in CORR (Table 60). The annual number of lung transplants performed increased by 69% from 1995 to 2004.

Table 60. Lung Transplants by Year, Age Group and Retransplants, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
First Graft 18+ Years	78	67	86	75	85	121	121	130	112	128	**1,003**
First Graft <18 Years	1	4	4	4	5	2	4	5	2	3	**34**
Retransplants	1	5	3	4	2	2	3	4	4	4	**32**
Total	**80**	**76**	**93**	**83**	**92**	**125**	**128**	**139**	**118**	**135**	**1,069**

The Toronto Lung Transplant Program, which includes lung transplant surgeries performed at the University Health Network sites (Hospital for Sick Children and the Toronto Hospital), performed 30.4% (325) of all lung transplant procedures during the 10 years. Notre Dame Hospital and the University of Alberta Hospital each performed 19.7% of all procedures (211 each).

In Canada, for each of the years of study, bilateral lung transplants were the leading type of lung transplant performed, with the number of procedures more than doubling between 1995 and 2004 (Table 61). Bilateral procedures represented 65.0% of the total volume of lung transplant procedures performed in Canada over the decade, accounting for 72.6% of the procedures in 2004. The number of heart–lung transplants performed, while remaining a relatively small annual number throughout the decade, dwindled to only three procedures in 2004. The Winnipeg transplant program pioneered the first living-donor lobar lung transplant in Canada in 1999. From then until 2004, an additional 10 procedures were performed, with 4 of those in 2004.

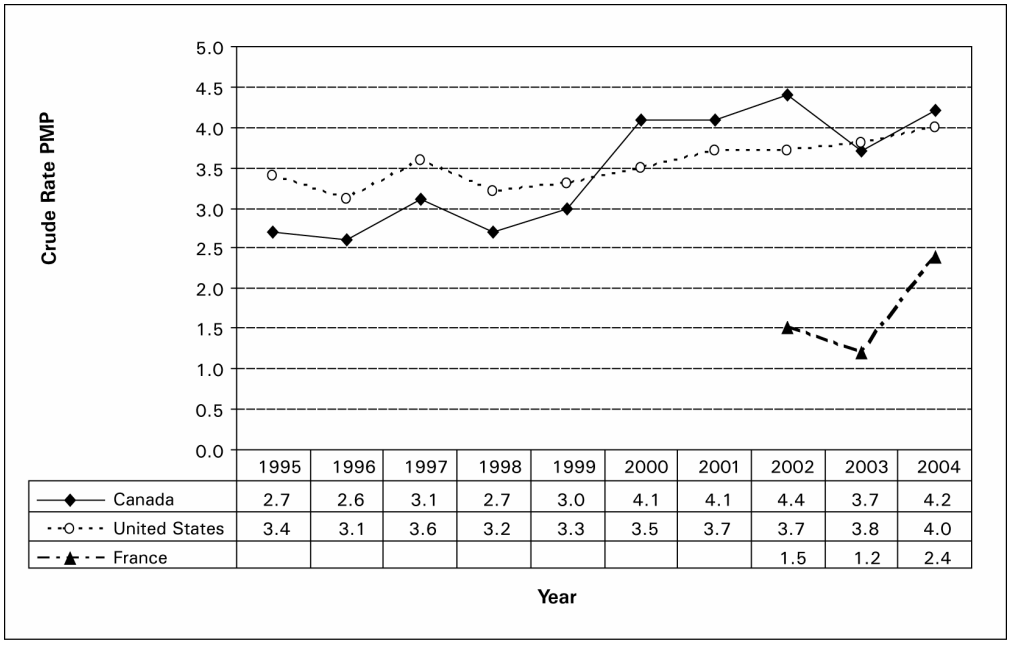
Table 61. Lung Transplants by Transplant Type, Canada, 1995 to 2004 (Number)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Bilateral Lung	45	43	52	46	55	85	82	96	95	98	697
Single Lung	27	29	34	30	30	34	39	36	21	30	310
Living-Donor Lobar	0	0	0	0	2	2	4	0	0	4	12
Heart–Lung	8	4	7	7	5	4	3	7	2	3	50
Total	**80**	**76**	**93**	**83**	**92**	**125**	**128**	**139**	**118**	**135**	**1,069**

5.2 International Comparison

The advances in lung transplantation in Canada during the 10 years studied resulted in the Canadian rate for lung transplantation surpassing the rate observed in the U.S., beginning in the year 2000 (Figure 45). The Canadian rate peaked in 2002, dipped slightly in 2003, but then climbed again to surpass the U.S. rate in 2004. Among all solid organ transplantations, lung transplantation is unique in that it is the only procedure for which Canadian rates have not been consistently below those reported in the U.S. While the rate of lung transplantation in France is relatively low—compared to Canada and the U.S.—between 2003 and 2004 a substantial rate increase was recorded.

Figure 45. Lung Transplants, Canada and the United States, 1995 to 2004, France, 2002 to 2004 (Crude Rate PMP)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Canada	2.7	2.6	3.1	2.7	3.0	4.1	4.1	4.4	3.7	4.2
United States	3.4	3.1	3.6	3.2	3.3	3.5	3.7	3.7	3.8	4.0
France								1.5	1.2	2.4

Data source for France: l'Établissement français des Greffes, *Rapport d'activité et Bilan des activités de prélèvement et de greffe en France (2004)* (Paris: l'Établissement français des Greffes, Agence de la biomédecine, 2005). Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2005 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1995–2004* (Richmond, VA: United Network for Organ Sharing, 2005).

5.3 Recipient Characteristics

The number of adult lung transplants performed in Canada (18 years of age and older) increased by 64% (from 78 in 1995 to 128 in 2004). There was a fairly even split between sexes, with males receiving 537 (53.5%) of the lung transplants in the decade. The number of lung transplants performed annually in those adults 50 years of age and under remained fairly stable, with 50 in 1995 and 54 in 2004. However, in the recipients aged 50 years and older, there was a steadily increasing annual number of lung transplants performed, from a low of 28 in 1995 to a high of 74 in 2004. This finding was in keeping with the observation that the mean age for lung transplant recipients increased over time, from 42.7 years in 1995 to 49.5 years in 2004.

The etiology of lung or heart–lung failures differed for each type of transplant. The diagnostic grouping of congenital diseases (46.8%) and primary pulmonary hypertension (19.1%) were the two most commonly reported causes in heart–lung recipients, emphysema/chronic obstructive pulmonary disease (COPD) (50.6%) and idiopathic pulmonary fibrosis (21.3%) were the most frequently reported causes in single-lung recipients, while cystic fibrosis (32.0%) and emphysema/COPD (18.9%) were most often noted as the etiology of failure for the double-lung transplant recipients (Table 62).

Table 62. Distribution of Primary Diagnoses for All Lung Transplant Recipients, First Grafts, Canada, 1995 to 2004

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	13	1.9	1	0.3	22	46.8
Alpha 1 Antitrypsin Deficiency	60	8.7	25	8.1	1	2.1
Cystic Fibrosis	220	32.0	7	2.3	4	8.5
Emphysema/COPD*	130	18.9	157	50.6	4	8.5
Idiopathic Pulmonary Fibrosis	116	16.9	66	21.3	1	2.1
Primary Pulmonary Hypertension	36	5.2	6	1.9	9	19.1
Unknown	10	1.5	5	1.6	1	2.1
Other	102	14.8	43	13.9	5	10.6
Total	**687**	**100.0**	**310**	**100.0**	**47**	**100.0**

* More than one diagnosis can be reported for a patient.

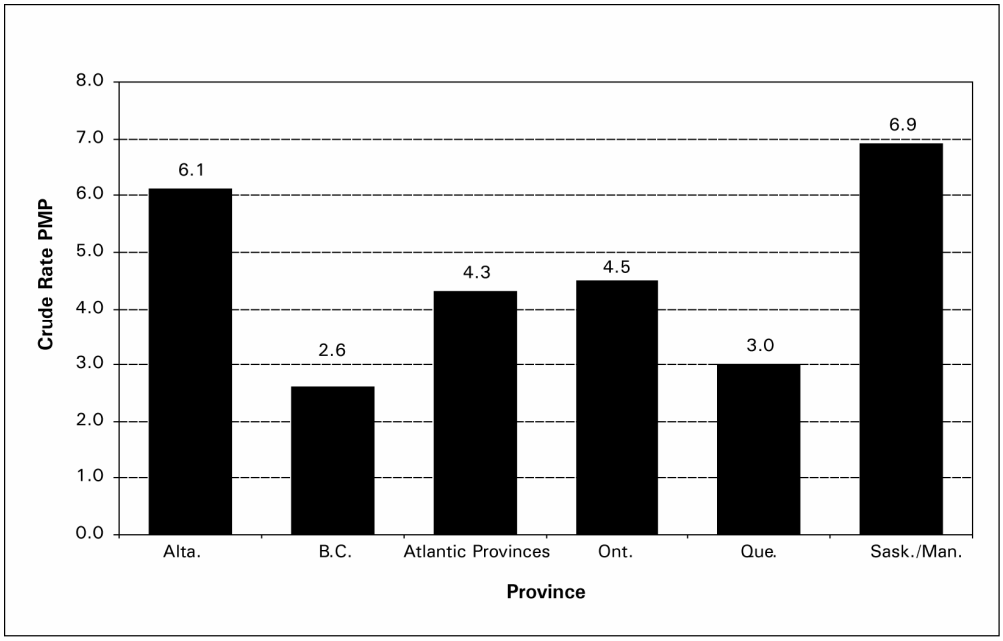
Between 1995 and 2004, there were 34 pediatric recipients, ranging in age from 8 to 17 years at the time of their initial transplant. There was an even split between the sexes for recipients (50% each). Twenty-eight pediatric patients received bilateral lung transplants, with 21 of those having cystic fibrosis as the etiology of end-stage disease necessitating transplant (Table 63).

Table 63. Lung Diagnosis for Pediatric Patients, Canada, 1995 to 2004

	Bilateral Lung		Single Lung		Heart–Lung	
	N	%	N	%	N	%
Congenital	0	0	0	0	2	100.0
Cystic Fibrosis	21	75.0	0	0	0	0
Emphysema/COPD	0	0	1	25.0	0	0
Primary Pulmonary Hypertension	2	7.1	2	50.0	0	0
Other	5	17.9	1	25.0	0	0
Total	**28**	**100.0**	**4**	**100.0**	**2**	**100.0**

Rates of transplant by province of residence demonstrated Saskatchewan and Manitoba to have the highest rate at 6.9 PMP, followed by Alberta with 6.1 PMP. B.C. was seen to have the lowest rate of lung transplant for the decade, with 2.6 PMP (Figure 46).

Figure 46. Lung Transplant Recipients by Province of Residence, Canada, 1995 to 2004 (Crude Rate PMP)



5.4 Waiting List and Waiting Times

The lung transplant waiting list fluctuated from year to year, with an overall decrease between 1995 and 2004, from 195 people waiting in 1995 to 181 people waiting in 2004. Within the wait list, the number of those waiting for a bilateral lung transplant nearly doubled from 83 on the list in 1995 to 155 in 2004 (Table 64). In parallel with the increase in people waiting for a bilateral transplant, the number waiting for a single-lung transplant dramatically decreased from 98 to 22 in the decade.

Table 64. Lung Transplant Waiting List on December 31, Canada, 1995 to 2004

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Bilateral Lung	83	19	44	66	93	108	125	88	131	155
Single Lung	98	66	60	61	64	58	25	50	29	22
Heart–Lung	14	14	15	15	11	11	13	12	12	4
Total	**195**	**99**	**119**	**142**	**168**	**177**	**163**	**150**	**172**	**181**

A total of 267 patients died while waiting for a lung transplant in Canada between 1995 and 2004, for an average of 27 deaths per year during this time. Adult single and bilateral lung transplant (including heart–lung) recipients receiving their first lung transplant in 2004 (125) waited a median of 173 days (range: 0 to 2,542 days) (Table 65). Not surprisingly, duration of time on the waiting list was influenced by patients' medical status at the time of listing, with Status 2 (defined as rapidly deteriorating) patients (37) having a median wait time of 96 days (range: 3 to 565 days). This wait time more than doubled from 2003 to 2004, when there was a median wait of 38 days reported for Status 2 patients. For those listed as Status 1 (defined as stable) (70) the median wait time was 266.5 days (range: 0 to 1,968 days). The wait for Status 1 patients decreased from 2003 (320 days in 2003) to 2004. Status 0 (defined as on hold/inactive) included a small number of patients (18). The Status 0 patients had a wide range of wait times, from 0 to 2,542 days, with a median of 158.5 days.

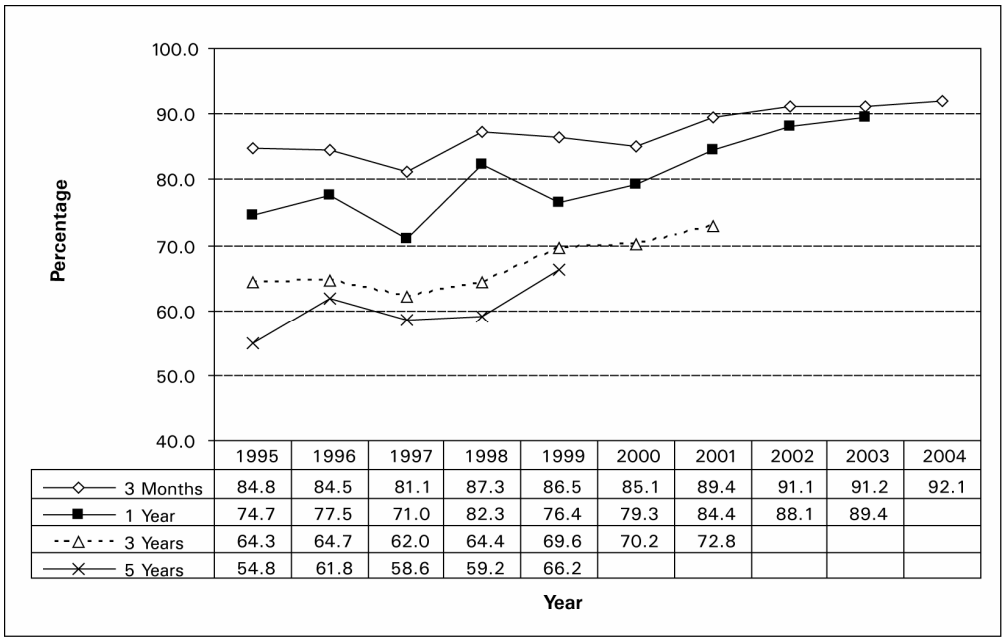
Table 65. Wait Time From Listing to Transplant for Deceased-Donor Adult Lung Transplant Recipients, First Grafts, Canada, 2004

Medical Status at Listing	Wait Time			
	N	Min.	Max.	Median
Status 0	18	0	2,542	158.5
Status 1	70	0	1,968	266.5
Status 2	37	3	565	96.0
Total	**125**	**0**	**2,542**	**173.0**

5.5 Outcomes

There was improved patient survival throughout the decade in both short- and long-term survival for Canadian lung transplant patients (Figure 47). The largest improvements were seen in the one-year (14.7% improvement over 1995) and five-year (11.4% improvement) survival for lung transplant recipients, while the most modest improvement was seen in the shortest-term survival, measured at three months post-transplant (7.3%).

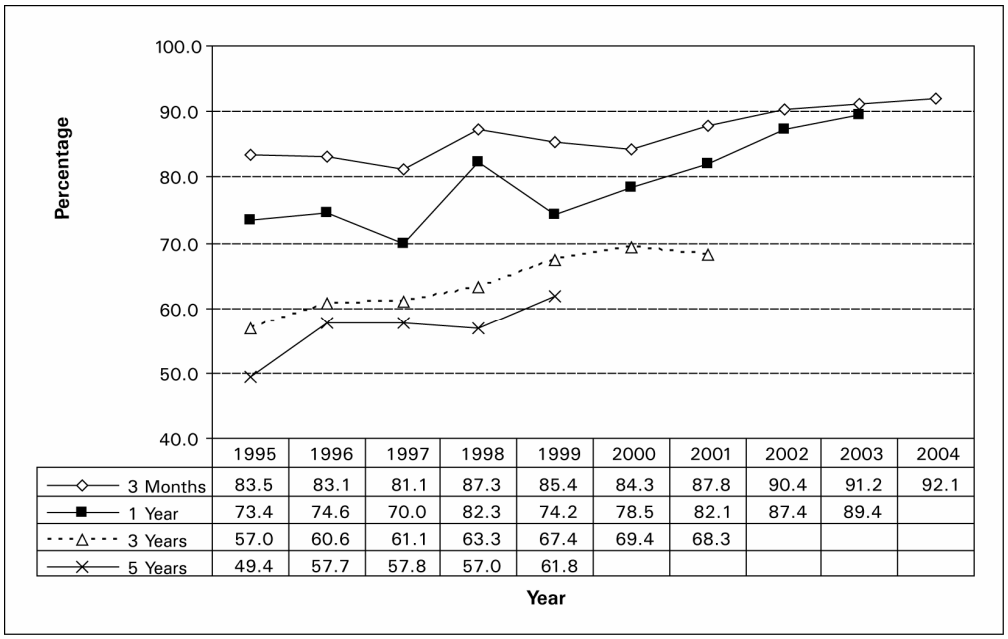
Figure 47. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 1995 to 2004



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
3 Months	84.8	84.5	81.1	87.3	86.5	85.1	89.4	91.1	91.2	92.1
1 Year	74.7	77.5	71.0	82.3	76.4	79.3	84.4	88.1	89.4	
3 Years	64.3	64.7	62.0	64.4	69.6	70.2	72.8			
5 Years	54.8	61.8	58.6	59.2	66.2					

In alignment with the improved patient survival outcomes over the decade, there were similar trends in terms of graft survival over the same time period (Figure 48). Improvement was seen at all time points of measurement. Not surprisingly, the smallest gains were seen in the short-term graft survival, with an improvement of 8.6% over 10 years. The largest improvements in lung transplant graft survival were seen in the one-year graft survival numbers, with a 16% improvement.

Figure 48. Unadjusted Three-Month and One-, Three- and Five-Year Graft Survival* for Lung Transplant Recipients, First Graft, Deceased-Donor Lungs, Canada, 1995 to 2004

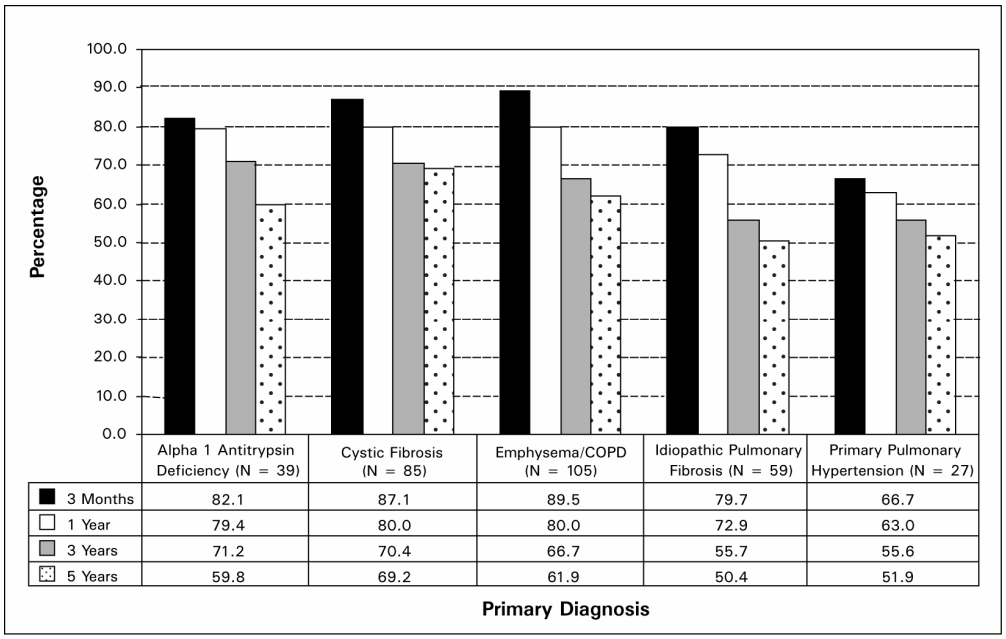


	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
3 Months	83.5	83.1	81.1	87.3	85.4	84.3	87.8	90.4	91.2	92.1
1 Year	73.4	74.6	70.0	82.3	74.2	78.5	82.1	87.4	89.4	
3 Years	57.0	60.6	61.1	63.3	67.4	69.4	68.3			
5 Years	49.4	57.7	57.8	57.0	61.8					

* Graft survival is computed from first lung transplant date to first graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

Analysis was performed using the diagnosis associated with patient lung failure as the test variable. For patients receiving their first lung graft between 1995 and 1999, survival was lowest at the short-term measures of three months and one year for those with a diagnosis of pulmonary hypertension, at 66.7% and 63.0%, respectively, for both time points (Figure 49). However, the role of primary diagnosis in longer-term survival shifted at the three- and five-year marks, for which patient survival was lowest for patients with a primary diagnosis of idiopathic pulmonary fibrosis (55.7% and 50.4%, respectively). The highest patient survival at all time points measured, except at the three-year mark, was observed in those with a diagnosis of cystic fibrosis. These results were consistent with those reported by the International Society of Heart and Lung Transplantation.[17, 18]

Figure 49. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival for Lung Transplant Recipients by Primary Diagnosis, First Graft, Deceased-Donor Lungs, Canada, 1995 to 1999

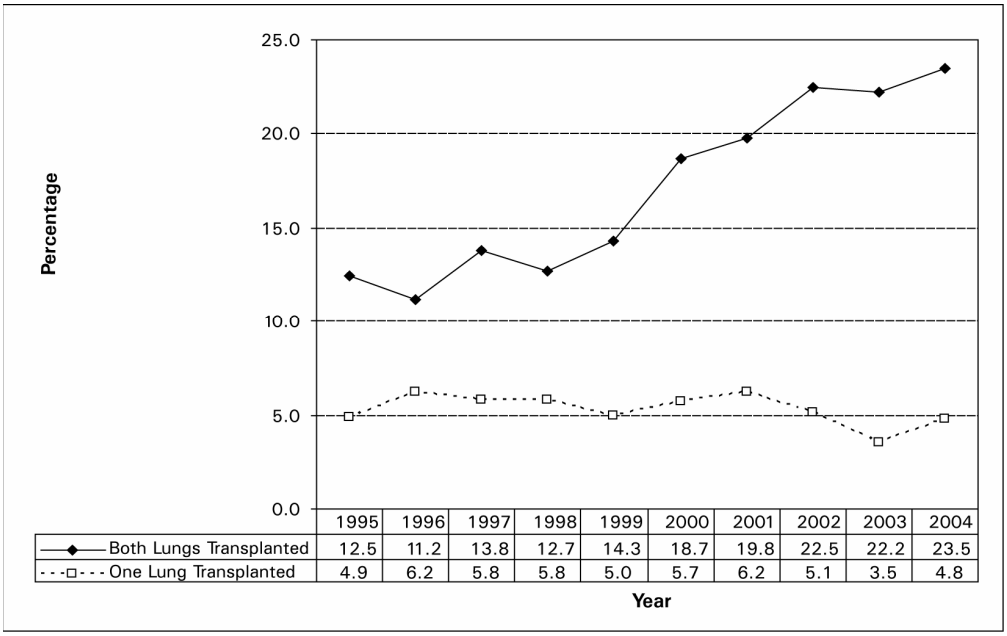


	Alpha 1 Antitrypsin Deficiency (N = 39)	Cystic Fibrosis (N = 85)	Emphysema/COPD (N = 105)	Idiopathic Pulmonary Fibrosis (N = 59)	Primary Pulmonary Hypertension (N = 27)
3 Months	82.1	87.1	89.5	79.7	66.7
1 Year	79.4	80.0	80.0	72.9	63.0
3 Years	71.2	70.4	66.7	55.7	55.6
5 Years	59.8	69.2	61.9	50.4	51.9

5.6 Organ Donors

The recovery of lungs used for transplantation in Canada demonstrated a distinct pattern of activity throughout the decade. While the recovery of single lungs for transplant remained virtually constant through the 10-year span (4.9% in 1995 to 4.8% in 2004), there was a considerable growth in the recovery of both organs between 1995 and 2004 (Figure 50). This growth is of the magnitude of 11% during the time frame. The peak in bilateral retrieval of lungs in the 10 years was seen in 2004, at 23.5%. The growth in recovery of bilateral organs mirrored an increase seen in bilateral lung transplants throughout the decade. It is important to note, however, that despite this encouraging growth, even in 2004, the year with the highest rate of lung recovery, one or both lungs were recovered in only 28.3% of all deceased donors.

Figure 50. Proportion of Lungs Transplanted From Deceased Donors, Canada, 1995 to 2004 (Percentage)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Both Lungs Transplanted	12.5	11.2	13.8	12.7	14.3	18.7	19.8	22.5	22.2	23.5
One Lung Transplanted	4.9	6.2	5.8	5.8	5.0	5.7	6.2	5.1	3.5	4.8

There is no nationally applied algorithm for the sharing of donor lungs across Canada. In most provinces, lungs used by transplant programs were recovered from the provincial procurement programs in that province (Table 66). The Edmonton lung transplant program (Alberta) continued to utilize the highest proportion of lungs from OPOs in the U.S. In contrast, Quebec transplant programs were most likely to transplant lungs recovered from donors identified by Québec-Transplant. The Quebec transplant programs also shared the highest number of organs with other lung transplant programs across Canada.

Table 66. Origin and Destination of Transplanted Lungs, Canada, 2002 to 2004*

Retrieval Location	Province of Treatment					Total
	Alta.	B.C.	Man.	Ont.	Que.	
	N	N	N	N	N	N
Alta.	42	4	4	0	0	**50**
B.C.	10	15	1	0	0	**26**
Man.	0	0	11	0	0	**11**
N.B.	0	0	0	10	0	**10**
N.L.	0	0	0	6	0	**6**
N.S.	0	0	0	4	0	**4**
Ont.	3	1	6	128	4	**142**
Que.	2	0	0	23	71	**96**
Sask.	12	0	2	0	0	**14**
U.S.	21	1	0	7	0	**29**
Total	**90**	**21**	**24**	**178**	**75**	**388**

* Shaded cells show local organs used for transplantation.

As previously noted, deceased donors were observed to have increased in age over the decade reported on. The sex distribution and age characteristics of deceased lung donors varied according to the use of the organs for transplantation (Table 67). The only donated lungs for which the donor was more likely to be female were those organs used for heart–lung transplant. Where both lungs were transplanted into the same recipient, there was a fairly even distribution of male (50.9%) and female donors. The heart–lung donors were also the youngest in average age (30.9 years), compared to the oldest average age donor group, comprising those donors whose two lungs were utilized for transplant into different recipients (40.2 years).

Table 67. Deceased Lung Donors by Lungs Used for Transplantation, Donor Sex and Age Statistics, Canada, 1995 to 2004

	% Male	Mean Age (Years)	Standard Deviation	Min.	Max.
Both Lungs, Different Recipients	50.8	40.2	14.9	12	62
Both Lungs, Same Recipient	50.9	38.1	15.8	5	77
One Lung	58.4	35.9	13.4	14	65
Heart–Lung	41.2	30.9	12.8	10	62

As noted in Section 8, causes of death for donors changed over time, with an increase in the number of donor organs transplanted after death caused by cerebrovascular accidents and strokes. There was a concomitant decrease in the number of organs from donors whose death was caused by motor vehicle collisions. When examined by the mode of use of the lungs for transplant, there were differences observed in the cause of donor death (Table 68). The smallest proportion of organs utilized in each of the transplant uses were when death was caused by gunshot or "other" causes. Notably, heart–lung donors had proportionately fewer deaths from cerebrovascular accidents and strokes than those in the other utilization groups.

Table 68. Deceased Lung Donors, by Lungs Used for Transplantation and Donor Cause of Death, Canada, 1995 to 2004

Cause of Death	Both Lungs, Different Recipients		Both Lungs, Same Recipient		One Lung		Heart–Lung	
	N	%	N	%	N	%	N	%
Anoxia/Hypoxia	7	11	37	5	11	7	3	6
Cerebrovascular Accident/Stroke	39	60	356	53	74	46	20	39
Other Trauma	7	11	76	11	21	13	6	12
Motor Vehicle Collision	4	6	146	22	46	29	17	33
Other	3	5	28	4	4	2	2	4
Gunshot	4	6	23	3	4	2	2	4
Unknown	1	2	10	1	1	1	1	2
Total	**65**	**100**	**676**	**100**	**161**	**100**	**51**	**100**

6 Pancreas Transplantation

ESRD patients with underlying diabetes have two serious conditions, each of which requires a different treatment. For kidney failure, patients need renal replacement therapy and for diabetes, a therapy to regulate glycemia is required. Kidney–pancreas transplantation is a procedure developed to treat both conditions, offering possible improvement in long-term survival relative to dialysis and restoring normal glycemia regulation.[19] Pancreas transplantation offers the type 1 diabetic recipient the prospect of complete insulin independence and the stabilization or amelioration of some diabetes-related complications.[20] While novel therapies such as the insulin pump and islet cell transplants have received considerable attention, pancreas transplantation is currently the only diabetic therapy that provides stable long-term normoglycemia with normal or near-normal glucose tolerance while avoiding hypoglycemic episodes.[21, 22] Despite being a viable treatment for almost 40 years, kidney–pancreas transplantation continues to be underutilized.[23]

Pancreatic transplantation is a procedure reserved for patients who have difficulty maintaining control of insulin levels through other medical means.[24] Drs. Richard Lillehei and William Kelly performed the first simultaneous kidney–pancreas transplant in 1966 at the University of Minnesota. The first pancreas-only transplant, again by Dr. Lillehei in Minneapolis, occurred in 1968. In the early years of the procedure, rates of graft and patient survival were low. The introduction of cyclosporin and anti-T-cell agents, new surgical techniques and refined patient selection criteria all contributed to improved surgical results. Since 1966 it has evolved from an experimental alternative to standard of care, in particular for ESRD patients on dialysis, with diabetes.[25, 26]

Conceptually, three types of pancreas transplant related to recipient indications have been defined. The most common are simultaneous pancreas–kidney transplantation (SPK) for recipients with ESRD. Less commonly, pancreas transplants are performed after a kidney transplant (usually a live-donor kidney transplant) (PAK) or alone, for early complications of hypoglycemia unawareness (PTA).

6.1 Activity

As of December 31, 2004, more than 23,000 pancreas transplants had been reported to the International Pancreas Registry, with more than 17,000 of these having been performed in the U.S. and almost 6,000 from countries outside the U.S.[27]

There were 510 pancreas transplants registered in CORR between 1995 and 2004 (Table 69). Over two-thirds of these transplant procedures involved SPK transplantation (367), less than 6% were performed as pancreas transplantations alone (26) and in 117 patients, the pancreas was transplanted after a kidney transplant (PAK). Five transplants involved second pancreas grafts. A total of 510 patients received their first pancreas grafts during this decade.

Table 69. Pancreas Transplants by Year, Canada, 1995 to 2004 (Number)

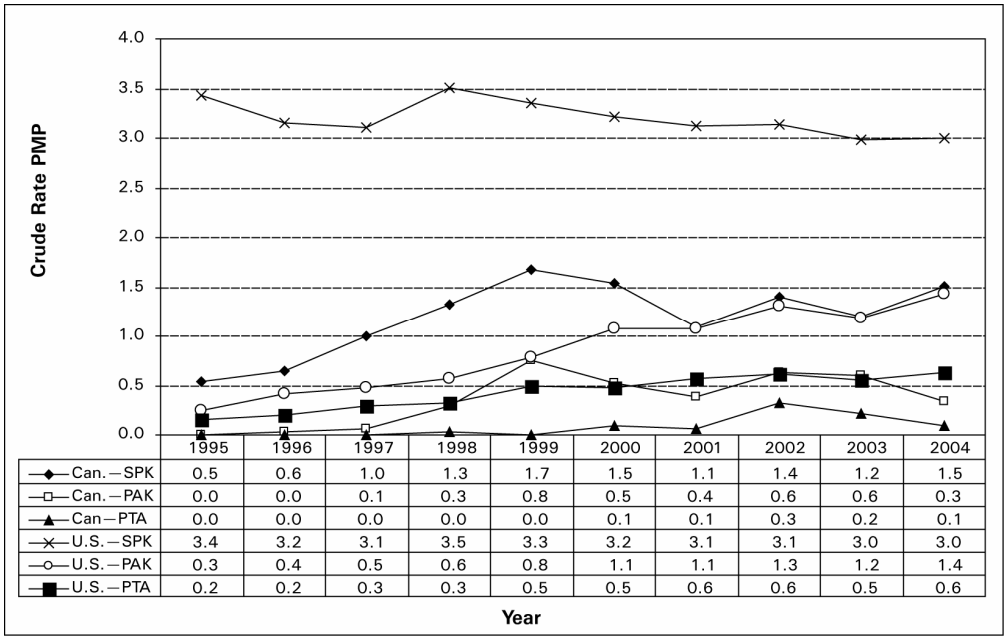
	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Simultaneous Pancreas—Kidney (SPK)	16	19	30	40	51	47	34	44	38	48	**367**
Pancreas After Kidney (PAK)	1	2	4	9	23	16	12	20	19	11	**117**
Pancreas Transplant Alone (PTA)	0	0	0	1	0	3	2	10	7	3	**26**
Total	**17**	**21**	**34**	**50**	**74**	**66**	**48**	**74**	**64**	**62**	**510**

Pancreas transplant programs existed in five provinces during the period from 1995 to 2004: Nova Scotia, Quebec, Ontario, Alberta and B.C. For 2002 and 2004, pancreas transplants for residents of the Atlantic provinces were performed in either Quebec or Ontario. The Quebec and Ontario programs performed the majority of pancreas surgeries over the decade—170 in the Quebec and 156 in Ontario—accounting for 64% of all pancreas transplants performed. When looking at the type of pancreas transplantation, in Quebec, 62.0% of the pancreas transplants were PAK or PTA transplants, in contrast to the other treatment provinces, where between 80% and 90% of transplants were SPKs.

6.2 International Comparison

In Canada, the transplant rate has, in general, lagged behind that of the U.S. and some European countries. SPK, PAK and PTA transplant rates in Canada were lower than rates in the U.S. over the decade (Figure 51). The overall pancreas transplant rate of 5 PMP in the U.S. in 2004 compared with a 1.9 PMP rate in Canada. The proportions of each pancreas transplant procedure were similar in both countries at 71.9% (SPK), 22.9% (PAK) and 5.1% (PTA) in Canada, compared to the U.S. reporting proportions of 71% (SPK), 19% (PAK) and 10% (PTA).

Figure 51. Pancreas Transplants by Type, Canada and the United States, 1995 to 2004 (Crude Rate PMP)



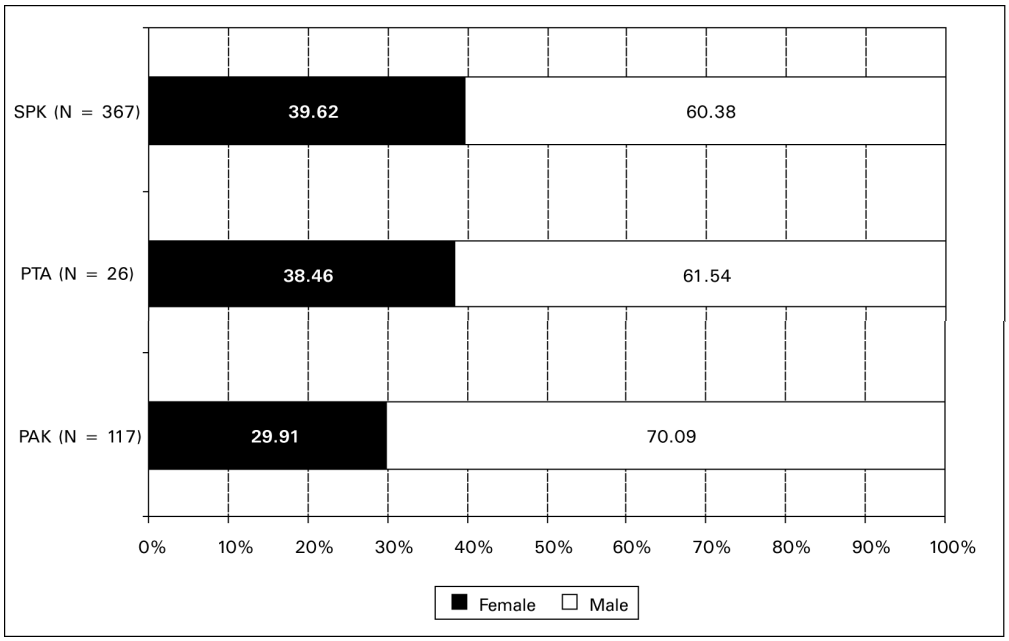
	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Can.—SPK	0.5	0.6	1.0	1.3	1.7	1.5	1.1	1.4	1.2	1.5
Can.—PAK	0.0	0.0	0.1	0.3	0.8	0.5	0.4	0.6	0.6	0.3
Can—PTA	0.0	0.0	0.0	0.0	0.0	0.1	0.1	0.3	0.2	0.1
U.S.—SPK	3.4	3.2	3.1	3.5	3.3	3.2	3.1	3.1	3.0	3.0
U.S.—PAK	0.3	0.4	0.5	0.6	0.8	1.1	1.1	1.3	1.2	1.4
U.S.—PTA	0.2	0.2	0.3	0.3	0.5	0.5	0.6	0.6	0.5	0.6

Data source for the U.S.: Department of Health and Human Services (Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation), United Network for Organ Sharing and University Renal Research and Education Association, *2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1995–2004* (Richmond, VA: United Network for Organ Sharing, 2005).

6.3 Recipient Characteristics

The average age of recipients of first pancreas grafts during the decade was 40.1 years (standard deviation: 7.6; age range: 19 to 75 years). While more males received a pancreas transplant, the sex distribution varied by transplant type (Figure 52).

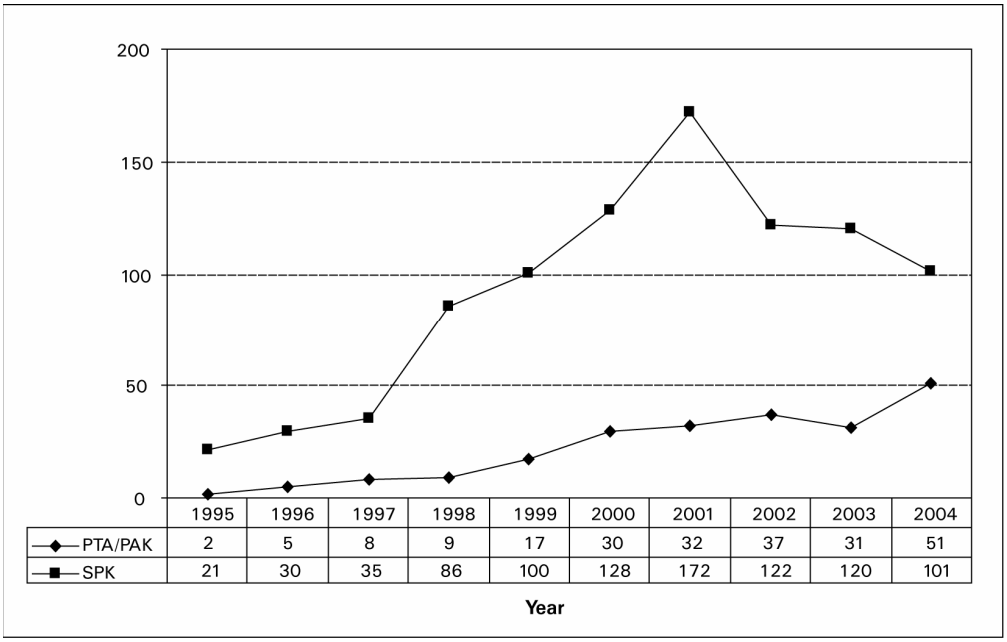
Figure 52. Pancreas Transplant Recipients by Type and Recipient Sex, First Grafts, Canada, 1995 to 2004 (Percent)



6.4 Waiting List and Waiting Times

The number of patients waiting for an SPK transplant at year-end spiked in 2001 to 172 cases and then tapered off in years 2003 and 2004 to 101 (Figure 53). The number of patients waiting for a PTA/PAK transplant increased to 51 in 2004. Deaths on the waiting list for a pancreas or SPK transplant are rare; there were 18 deaths over the decade.

Figure 53. Pancreas and Pancreas–Kidney Transplant Waiting List on December 31, Canada, 1995 to 2004 (Number)



	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
PTA/PAK	2	5	8	9	17	30	32	37	31	51
SPK	21	30	35	86	100	128	172	122	120	101

6.5 Outcomes

Because of the small annual number of PTA and PAK transplants for the years 1995 to 1999, unadjusted patient and graft survival rates were examined only for SPK recipients who received a first transplant in the first five years of the decade (156). Patient survival was 92.9% at five years, and graft survival was considerably lower at five years, at 86.4% (Table 70).

Table 70. Unadjusted Three-Month and One-, Three- and Five-Year Patient and Pancreas Graft Survival Rates, First SPK Grafts, Canada, 1995 to 1999 (Percent)

	90 Days	1 Year	3 Years	5 Years
Patient Survival	98.0	96.7	93.5	92.9
Pancreas Graft Survival*	96.1	95.4	90.9	86.4

* Graft survival is computed from first SPK transplant date to first pancreas graft failure date, death date or end of observation (December 31, 2004). In this analysis, patients who died with a functioning graft are counted as failed grafts.

6.6 Organ Donors

The capture of recovery rates of donor pancreata are imprecise in CORR, and no mechanism currently exists to comprehensively track islet cell transplants.

Sharing of pancreata for the purposes of solid organ transplantation was minimal from 2001 to 2003. For 94% of SPK transplants and 90% of PAK and PTA transplants, the OPO and transplant program were in the same province.

The majority of pancreas donors were males who had died from cerebrovascular accidents/strokes or head traumas caused by involvement in motor vehicle collisions or other circumstances (Table 71). The average age of pancreas donors was similar for simultaneous (SPK) and single pancreas procedures (PAK/PTA), at 30 years of age, and lower than the average age of recipients (40 years).

Table 71. Pancreas Donor Characteristics by Transplant Type, Canada, 1995 to 2004

	PAK and PTA (N = 141)	SPK (N = 363)
% Male	64.5	63.4
Average Age (SD)*	28.7 (11.5)	30.2 (11.4)
Age Range	10–53	3–57
% Died From Cerebrovascular Accident/Stroke	49.1	38.3
% Died From Motor Vehicle Collision	22.7	29.5
% Died From Other Head Trauma	17	18.2

* SD = Standard Deviation.

7 Intestinal Transplantation[xi]

Intestinal transplantation was first attempted in humans during the 1960s. Early intestinal transplant patients died from technical complications, rejection or infection. At the time, intravenous feeding through total parenteral nutrition (TPN) therapy was not yet available. A new era in intestinal transplantation began in the mid-1980s, with the first successful multivisceral transplant performed in Pittsburgh in 1987; the first successful small bowel segment performed in Cologne, Germany in 1988; the first successful liver–bowel in London, Canada in 1988; and the first successful total small bowel in Paris, France in 1989.

The advent of tacrolimus in 1990 saw the emergence of intestinal transplantation as a viable treatment for intestinal failure. Despite recent advances, intestinal transplantation is a therapeutic option only for patients with intestinal failure whose condition continues to decline in spite of TPN; it is not yet an alternative for patients who are doing well on TPN.

7.1 Activity

In 2004, there were four active intestine transplant programs at the following hospitals: the Toronto General Hospital—University Health Network; the Hospital for Sick Children; the London Health Sciences Centre—University Campus; and the University of Alberta Hospital—Capital Health. Patients from across Canada were listed at one of these transplant programs.

From the inception of the Canadian register to 2004, there were 36 intestinal transplants registered among 35 recipients (one patient required a retransplant). The transplants occurred between 1988 and 2004, and included 9 multivisceral, 11 isolated small intestine, 13 liver–small intestine, 2 kidney–small intestine and 1 liver–kidney–small intestine transplants. Nearly two-thirds (22 out of 36) of these transplants were performed in London, Ontario. Two-thirds of the recipients of the solitary small intestine procedures or combined small intestine with liver or kidney were younger than 18 years of age (Table 72). However, cluster transplant, including a small intestine, liver, pancreas and stomach transplant (also known as multivisceral transplant), was more likely to be provided to patients over 18 years of age. All of the intestinal transplants reported were performed with organs from deceased donors.

xi. The information on intestinal transplantation is restricted in content by the small number of intestinal transplants and by data completeness issues. In this section, the time period of observation differs from the remainder of the report in that it is expanded to include the years between 1988 and 2004.

Table 72. Intestinal Transplants by Transplant Period and Age Group, Canada, 1988 to 2004 (Number)

Type of Graft	1988 to 1993		1994 to 1998		1999 to 2004		Total	
	<18 Years	18+ Years	<18 Years	18+ Years	<18 Years	18+ Years	<18 Years	18+ Years
Multivisceral (N = 8)	0	2	1	0	1	4	**2**	**7**
Isolated Small Intestine (N = 11)	1	0	5	2	2	1	**8**	**3**
Liver–Small Intestine (N = 13)	1	4	2	1	5	0	**8**	**5**
Kidney–Small Intestine (N = 2)	0	1	0	1	0	0	**0**	**2**
Liver–Kidney–Small Intestine (N = 1)	0	0	0	0	1	0	**1**	**0**
Total (N = 35)	**2**	**7**	**8**	**4**	**9**	**5**	**19**	**17**

7.2 International Comparison

In 2004, 154 intestinal transplants were performed in the U.S.,[28] compared to only 1 in Canada.

7.3 Recipient Characteristics

For the years between 1988 and 2004, the underlying cause of intestinal failure was reported in 30 (83.3%) of the cases. The most frequently reported underlying condition was a metabolic disorder (14 cases), a diagnosis that includes short-gut syndrome.

7.4 Waiting List and Waiting Times

Waiting list data for intestinal transplantation and deaths among patients listed are reported as "other" organ combinations and are therefore considered to be incomplete. Various ways to improve reporting are currently being investigated, with the goal of achieving more comprehensive information.

7.5 Outcomes

Twelve graft failures were reported from 1988 to 2004. Causes of graft failure, however, were specified for only three patients. Eighteen patients died between 1998 and 2004; among them 40% had a cause of death reported as chronic renal failure. Cause of death was unknown for six patients.

7.6 Organ Donors

Small bowels were recovered for transplantation in less than 1% of all deceased donors in Canada. Within CORR, donor information was available for 34 of the 36 intestinal transplants. Donor age data were available for 34 of the 37 donors. There were 7 donors aged 1 year or younger, 15 were aged 1 to 17 years and 13 were recorded as being 18 years of age and older. Twenty-one donors were female. Twenty of the donors (60%) were identified by the Ontario OPOs.

Cause of death was available for 34 of the 37 donors. Of these, where cause of death was noted, 11 died as a result of head injuries sustained from motor vehicle collisions and another 11 died from cerebrovascular accidents/strokes.

8 Deceased Organ Donors

The 10 OPOs in Canada all submit data to CORR regarding deceased organ donors identified and secured within provincial hospitals. Donors are attributed to the OPO that recovers the donor organs, regardless of where the organs may be transplanted (that is, another province). In Canada, deceased organ donors are defined as donors from whom at least one organ was recovered and transplanted. This definition is more conservative than that used by the United Network of Organ Sharing (UNOS), which includes donors whose organs were recovered, but not transplanted. This is an important distinction when making comparisons of deceased-donor rates between countries. The characteristics of deceased organ donors in terms of organs donated are discussed in the organ-specific sections of this report.

Rate PMP, as a measure of organ donation activity, is less than optimal and its role as an accurate reflection of organ donation activity has been much debated. Calculating a rate using a denominator that reflects the number of potential donors would be a more desired method. Unfortunately, Canada does not yet have a national information system from which the number of potential donors from each province can be reliably identified. Medical chart reviews done at individual hospitals and the much broader work conducted by the Collège des médicins du Québec[29] suggest that there is room to improve Canada's deceased organ donor rates.

The number of deceased organ donors in Canada changed very little between 1995 and 2004 (Table 73).[xii] Dramatic annual fluctuations were found in the number of donors in provinces with populations under 2 million.

Table 73. Deceased Organ Donors, Canada and OPO Province, 1995 to 2004 (Number)

OPO Province	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	Total
Alta.	35	53	52	49	54	55	54	54	38	56	**500**
B.C.	52	48	49	36	41	38	37	30	39	31	**401**
Man.*	24	27	18	15	9	20	9	11	12	7	**152**
N.B.*	13	7	13	11	17	11	17	11	12	10	**122**
N.L.*	5	6	8	3	4	15	15	15	10	5	**86**
N.S.*	15	11	27	9	12	19	9	11	11	9	**133**
Ont.	153	150	154	152	133	165	128	137	142	153	**1,467**
Que.	117	113	95	120	131	135	135	126	142	137	**1,251**
Sask.*	11	4	13	22	19	13	16	13	17	9	**137**
Total	**425**	**419**	**429**	**417**	**420**	**471**	**420**	**408**	**423**	**417**	**4,249**

* Denotes provinces with populations of less than 2 million.

xii. In this section, donor data refer to donors registered within the CORR from whom at least one organ has been used for transplantation. This may differ slightly from aggregate annual counts provided by OPOs.

Socio-demographic factors, such as Canada's aging population and a marked reduction in fatal motor vehicle collisions, have affected the number and characteristics of deceased donors. The mean age of donors in 1995 was 36.8 years, while in 2004 it had risen to 45.0 years. For the period from 1995 to 2004, the oldest average age for donors was in Quebec (47.6 years) and the youngest average age was reported in New Brunswick (33.8 years). The youngest average age overall for deceased donors in the database (25.4 years) was recorded for organs imported from the U.S. (Table 74).

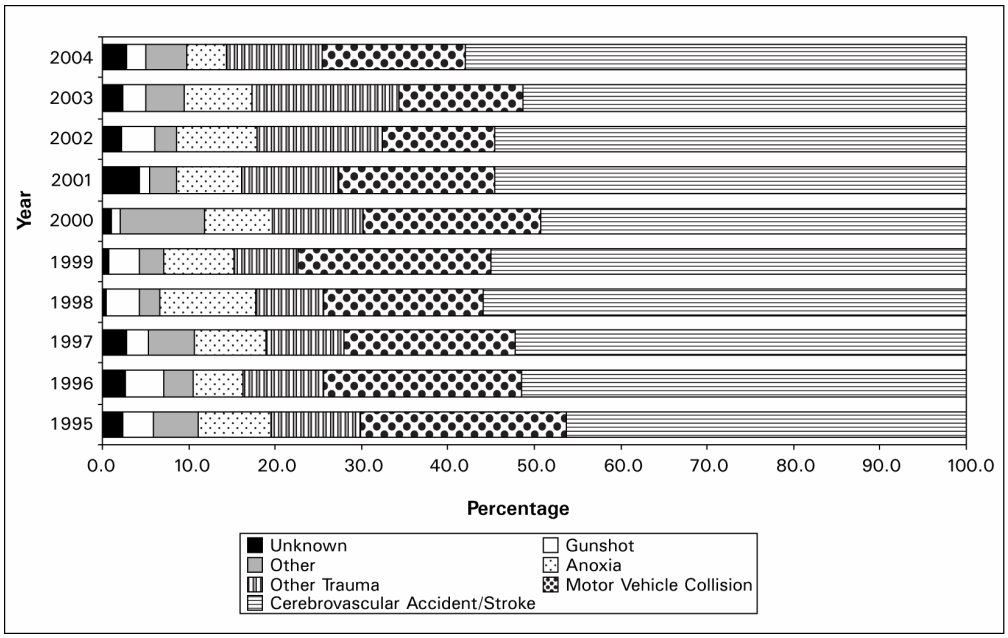
Table 74. Deceased Organ Donors by Age, OPO Location, 1995 to 2004

	Calgary, Alta.	Edmonton, Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.	U.S.	Total
Age Range (Years)	<1–85	<1–70	<1–68	<1–72	8–65	4–71	<1–71	<1–86	2–88	1–86	<1–68	**0–88**
Median Age (Years)	36.0	38.0	44.5	41.0	35.0	44.5	46.0	45.0	49.0	42.0	20.0	**45.0**
Mean Age in Years (SD*)	36.8 (19.9)	35.6 (17.1)	40.6 (16.7)	37.6 (18.8)	33.8 (14.9)	46.2 (15.4)	42.6 (18.8)	44.1 (17.6)	47.6 (18.4)	39.1 (19.0)	25.4 (20.8)	**42.3 (18.9)**

* SD = Standard deviation.

In keeping with the socio-demographic changes in Canadian society and the success of injury-prevention programs in the country, the distribution of causes of death for donors changed over the decade. In 2004, the most frequently observed donor cause of death was cerebrovascular accident/stroke (57%), with a declining proportion of donor deaths due to head injuries sustained from motor vehicle collisions (17%). In 1995, these figures were 54% and 30%, respectively.

Figure 54. Deceased Organ Donors by Cause of Death, Canada, 1995 to 2004 (Percent)



There was some minor fluctuation in the number of organs transplanted from each deceased donor over the years of the study (Table 75). The peak occurred in 2003, with 3.6 organs per donor being used for transplantation. However, the number in 2004 returned to 3.5, a small increase from the 3.4 recorded in 1995. The highest number of organs transplanted per donor was in the donor age group of 15 to 39 years, with 4.4 organs per donor. The smallest number of organs transplanted per donor was seen in the less-than-1-year age group, from whom one organ per donor was transplanted in 2004.

Table 75. Organs Donated per Deceased Donor* by Age Group, Canada, 1995 to 2004

Age Group	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
<1 Year	0.0	0.0	1.0	1.0	2.0	1.2	1.7	1.0	2.0	1.0
1–14 Years	2.9	3.3	3.2	3.0	3.5	3.0	2.5	2.7	3.2	2.9
15–39 Years	3.8	3.7	3.8	4.2	4.2	4.1	4.3	4.0	4.2	4.4
40–54 Years	3.5	3.5	3.5	3.2	3.6	3.4	3.5	3.7	3.8	3.6
55–69 Years	2.8	2.7	2.7	2.5	2.7	2.7	2.9	3.0	3.0	2.9
70+ Years	1.4	1.2	1.3	1.4	2.1	1.5	1.7	2.0	2.1	1.9
Total	**3.4**	**3.4**	**3.4**	**3.3**	**3.5**	**3.4**	**3.4**	**3.5**	**3.6**	**3.5**

* Organ count divided by number of donors per age group. Includes pancreata used for islet cells and organs exported to the U.S. Excludes donors whose age is missing (less than 0.3% of the data.)

9 Focus on Diabetes in End-Stage Organ Disease in Canada

9.1 Overview

Diabetes is an important public health problem throughout much of the developed world, and was cited by the World Health Organization (WHO) as one of four specific chronic diseases (chronic obstructive pulmonary disease, heart disease, certain cancers and diabetes) that presented major and preventable health hazards.[30] The WHO estimated that in 2000, there were 171 million people with diabetes worldwide, and by 2030 this figure is expected to more than double, to reach a total of 366 million.[31] The projected growth will be the result of a combination of factors, including an increasing global population, aging, obesity, lifestyle factors and poor nutrition.

Diabetes is currently the seventh-leading cause of death in Canada.[32] The National Community Health Survey conducted by Statistics Canada demonstrated that about 1.3 million Canadians, aged 12 years and older (5% of the Canadian population), reported that they have been diagnosed with diabetes.[33] The Canadian Community Health Survey identified advancing age, family history, sedentary lifestyle and excess weight as factors associated with the development of diabetes.[34]

This chapter provides further information to enhance the understanding of diabetes as a coexisting condition in patients with end-stage organ diseases in Canada, most specifically those with ESRD.

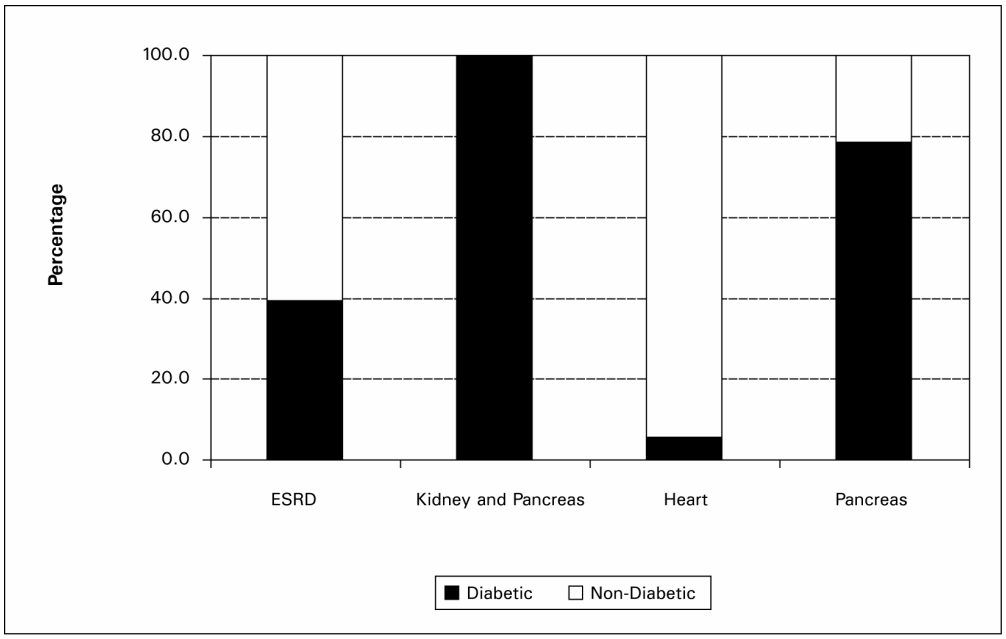
9.2 End-Stage Organ Disease and Diabetes in CORR: 1995 to 2004

Kidney failure is a well recognized complication of diabetes. Diabetes is the fastest growing cause of ESRD, and the leading cause of ESRD globally.[35] In Canada, 40% of all registered ESRD patients in CORR who initiated treatment between 1995 and 2004 were diagnosed with diabetes.

In patients who received whole or partial pancreas transplantation, 80% were diabetic, while the remaining 20% had diagnoses that were related to chronic pancreatitis and pancreatic tumours, or were unknown. In about 5% of heart transplants, diabetes was observed as a coexisting condition (Figure 55). Of note, SPK transplantation is offered as the treatment of choice for those with type 1 diabetes when these individuals have kidney failure; and therefore, 100% of SPK recipients have diabetes.

Comprehensive information on diabetes as a comorbid condition for Canadian patients who received lung or liver transplant was not collected in CORR, and so cannot currently be reported on.

Figure 55. Proportion of Diabetic Patients With End-Stage Organ Disease in Canada, 1995 to 2004

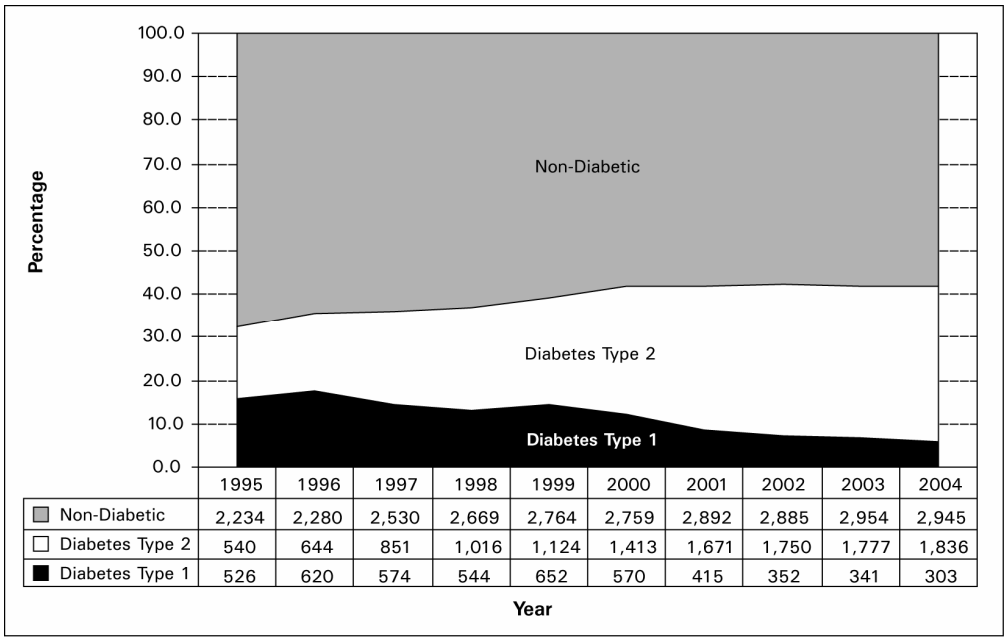


9.3 Diabetes and ESRD

Over the decade (1995 to 2004) the presence of diabetes in new ESRD cases reported to CORR climbed from 25% in 1995 to 42% in 2004, correlating with an increase of diabetes diagnosed in the Canadian population overall (Figure 56). Between 1995 and 2004, this represented more than 17,000 new kidney failure patients with diabetes who were diagnosed with, or had, diabetes as a comorbid condition at the time of renal failure diagnosis.

The number of prevalent ESRD patients with diabetes as their primary diagnosis increased over time. Among those on HD, an average annual increase of 9.3% was observed (between 2000 and 2004). The average annual increase was smaller among those receiving PD, at 2.2% (Table 11).

Figure 56. Proportion of Incident ESRD Patients With a Diagnosis of Diabetes, Canada, 1995 to 2004

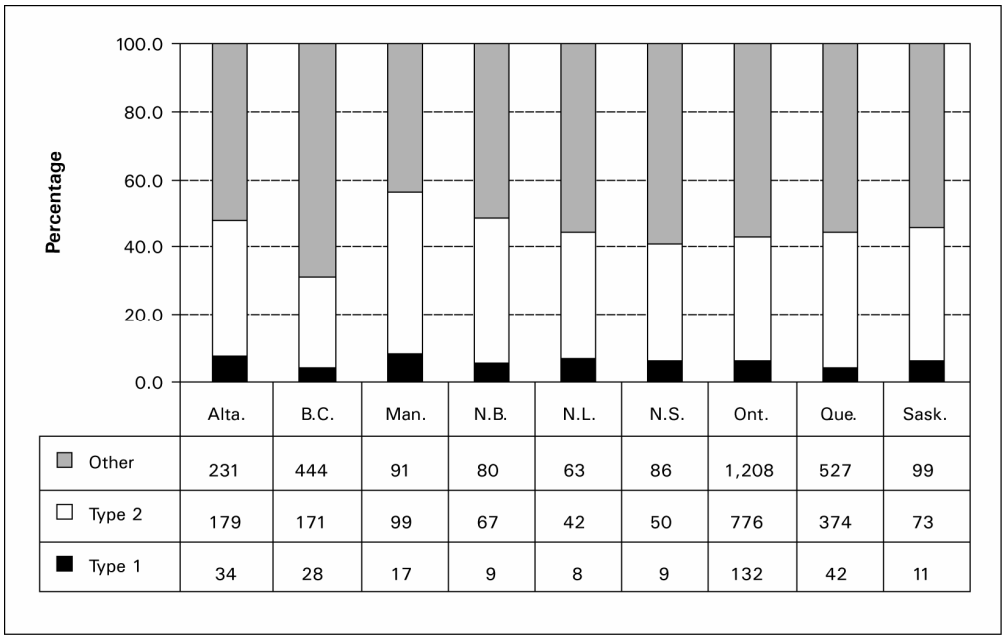


	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Non-Diabetic	2,234	2,280	2,530	2,669	2,764	2,759	2,892	2,885	2,954	2,945
Diabetes Type 2	540	644	851	1,016	1,124	1,413	1,671	1,750	1,777	1,836
Diabetes Type 1	526	620	574	544	652	570	415	352	341	303

The rates of diabetes in ESRD patients in Canada varied between provinces. In 2004, the highest rate was observed in Manitoba, at 55% overall and 8% for type 1 diabetes. Nova Scotia had the lowest rate of coexisting diabetes in ESRD patients, at 41%. The highest rate of type 1 diabetes in association with ESRD was seen in Alberta (7.6%), while the lowest rates were found in Quebec (4.4%) (Figure 57). Rates in the province of B.C. were omitted in this analysis due to concerns about under-reporting.

Of note, while the number of people receiving treatment for ESRD with diabetes increased by 32% between 1995 and 2004, the number of ESRD patients with type 1 diabetes declined by 42%, from 526 in 1995 to a 10-year low of 303 in 2004. The significant increase in diabetes in the ESRD population overall was therefore related to those with type 2 disease, with a more than threefold increase over the decade (540 to 1,836).

Figure 57. Proportion of ESRD Patients With Diabetes, by Province of Treatment, Canada, 2004



	Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.
Other	231	444	91	80	63	86	1,208	527	99
Type 2	179	171	99	67	42	50	776	374	73
Type 1	34	28	17	9	8	9	132	42	11

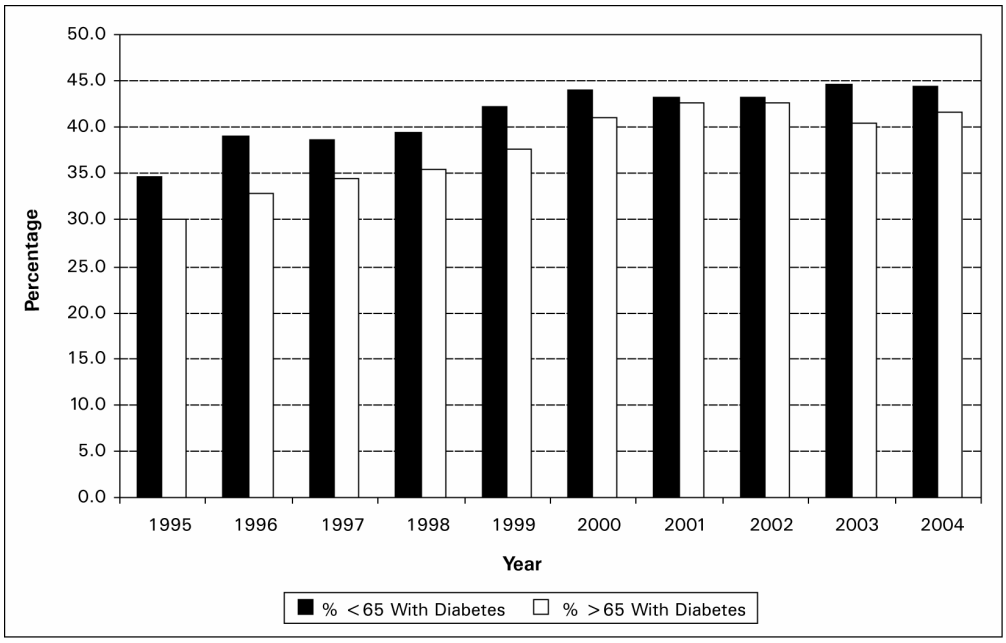
* B.C. numbers are underestimated, since diagnosis was unavailable in 35% of the reported cases for 2004.

9.4 Patient Characteristics

When examined by age groups, the increase in diabetes in new ESRD patients was most pronounced among patients 65 years of age and older. When a multivariate model was employed to examine survival in dialysis patients, diabetes was found to be the single-most influential factor in outcome for this group. A continuing year-to-year increase of the diagnosis of diabetes in the 65-years-of-age-and-older age group was most evident until 2002, at which time a degree of stabilization appeared to occur. In 2004, 41.5% of patients in the 65-years-and-older age group were diagnosed with diabetes, up from 30% in 1995.

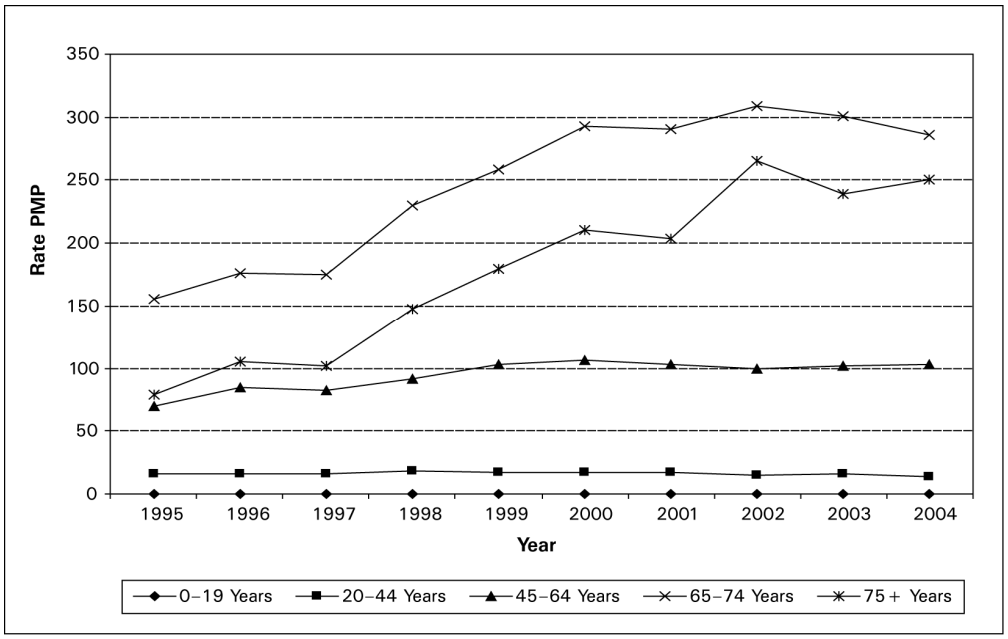
When exploring the relationships between diabetes and ESRD it is helpful to understand the problem in the context of the Canadian population. Analysis of age-specific rates of diabetes in ESRD (PMP) reveal that the rate for those over 65 years of age increased constantly over time until 2002, at which time a degree of stabilization was observed (Figure 58).

Figure 58. Proportion of New ESRD Patients With Diagnosis of Diabetes, by Age Group, Canada, 1995 to 2004



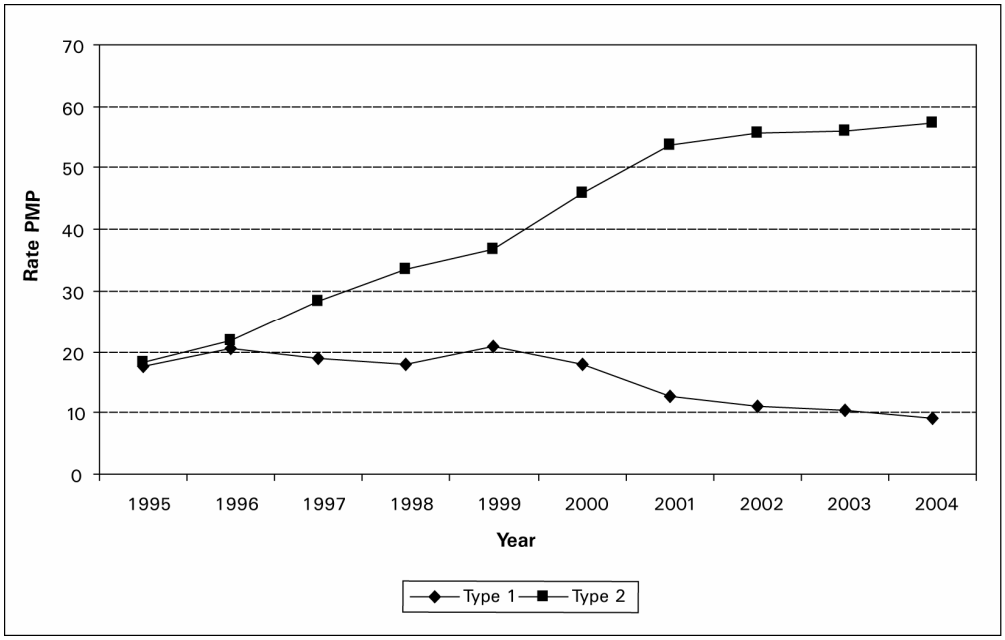
Within this age group, the greatest increase was seen in those over 75 years, at a rate of 250 PMP in 2004, which was three times greater than the rate in 1995 (79 PMP).

Figure 59. Age-Specific Rates of Diabetes in ESRD Patients, Canada, 1995 to 2004 (Rate PMP)



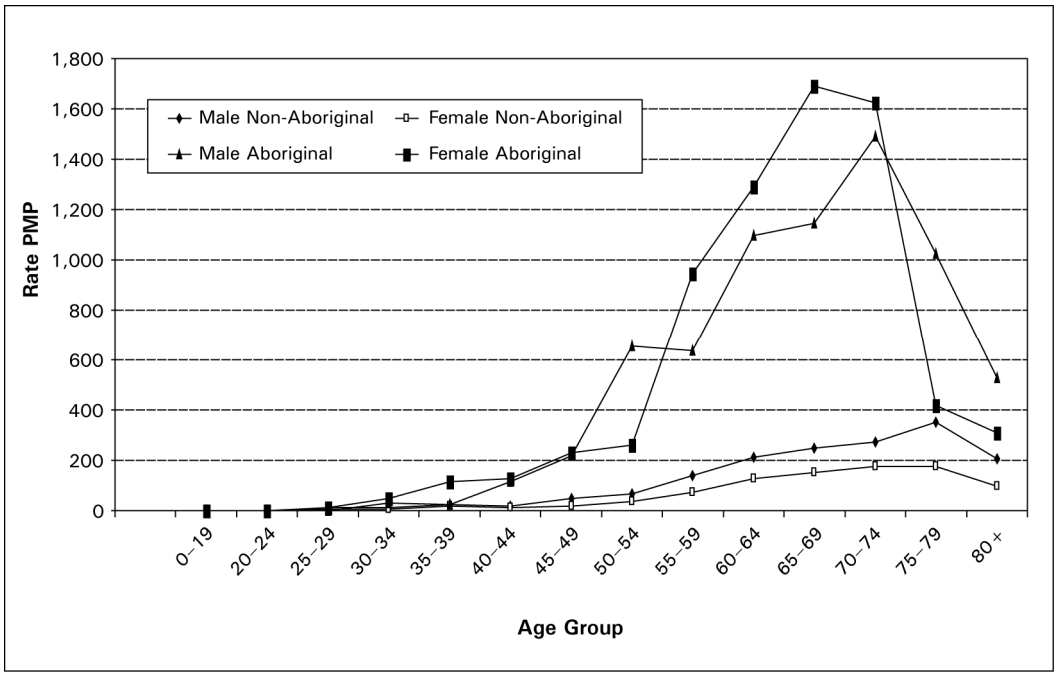
The increasing frequency of diabetes in the population was largely related to an increase in type 2 diabetes. There was a substantial increase in the rate of type 2 diabetes in Canada[36] and in the U.S.[37] The data reported here mirror the increase in type 2 diabetes observed in the Canadian population overall, with a significant increase in type 2 diabetes in ESRD patients in Canada. The rate of 57.3 PMP observed in 2004 was seen to be three times greater than that reported in 1995. The rate of increase in diabetes as a cause of ESRD appears to have stabilized after 2002 (Figure 60).

Figure 60. Type 1 and Type 2 Diabetes in ESRD, Canada, 1995 to 2004 (Rate PMP)



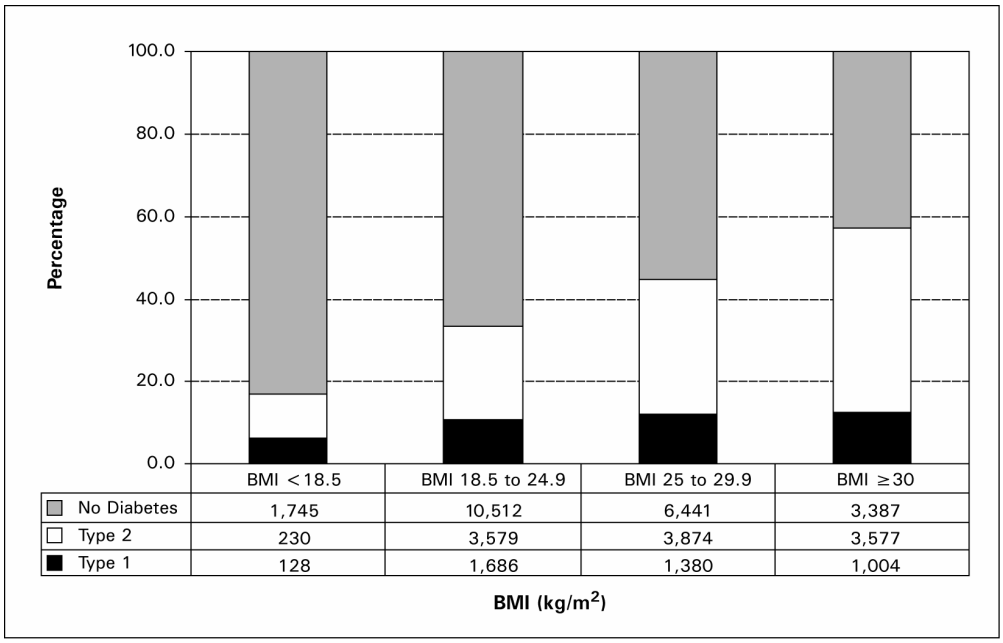
Health Canada reports that the Aboriginal population of Canada has a risk for the development of diabetes, primarily type 2, that is three to five times greater than non-Aboriginal Canadians.[38] In 2004, diabetes in Aboriginal Canadians with ESRD showed elevated rates, up to eight times greater in males over the age of 50 years and in females between 56 and 70 years (Figure 61).

Figure 61. Diabetes in ESRD, by Aboriginal Status, Sex and Age Group, Canada, 2004 (Rate PMP)



There is a growing body of evidence pointing to unhealthy weight as a factor in the development of diabetes.[39] In general, an increase in the prevalence of obesity in those who are initiating dialysis is seen as a factor in the growth of the overall ESRD population, both because of improved survival associated with obesity in dialysis patients and because of a decreased likelihood of transplantation.[40] In ESRD patients newly diagnosed with type 2 diabetes between 1995 and 2004, 49% had a BMI greater than or equal to 30. During the same time period, an additional 12% of newly diagnosed ESRD patients had coexisting type 1 diabetes (Figure 62).

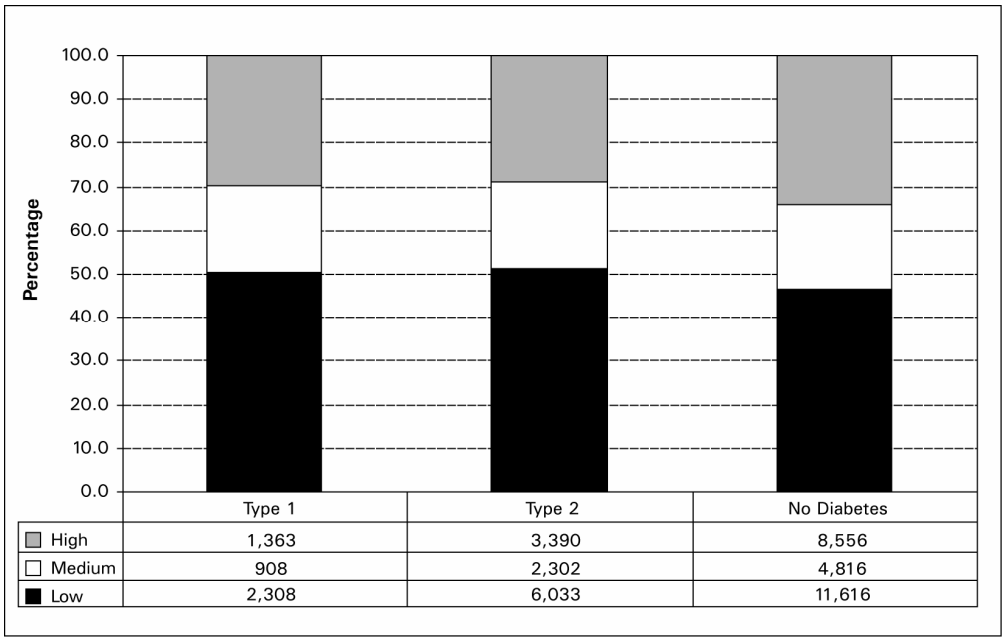
Figure 62. Diabetes and BMI in New ESRD Patients, Canada, 1995 to 2004 (Percent)



	BMI < 18.5	BMI 18.5 to 24.9	BMI 25 to 29.9	BMI ≥ 30
No Diabetes	1,745	10,512	6,441	3,387
Type 2	230	3,579	3,874	3,577
Type 1	128	1,686	1,380	1,004

A suboptimal socio-economic status has been identified as a risk factor for renal failure, independently and in combination with elevated blood pressure.[41, 42] The prevalence of diabetes itself is inversely correlated to socio-economic status in Canada.[43] To examine this phenomenon for the CORR patient population, patient data were linked to the postal code conversion files (PCCF)[44] at the initial treatment in order to get an estimate of the economic status in Canadian ESRD patients with diabetes. For 51% of those with type 2 diabetes, socio-economic status was assessed to be in the low range, compared to 46% in ESRD patients with no diagnosis of diabetes (Figure 63).

Figure 63. Socio-Economic Status and Diabetes, ESRD Patients, Canada, 1995 to 2004 (Percent)



	Type 1	Type 2	No Diabetes
High	1,363	3,390	8,556
Medium	908	2,302	4,816
Low	2,308	6,033	11,616

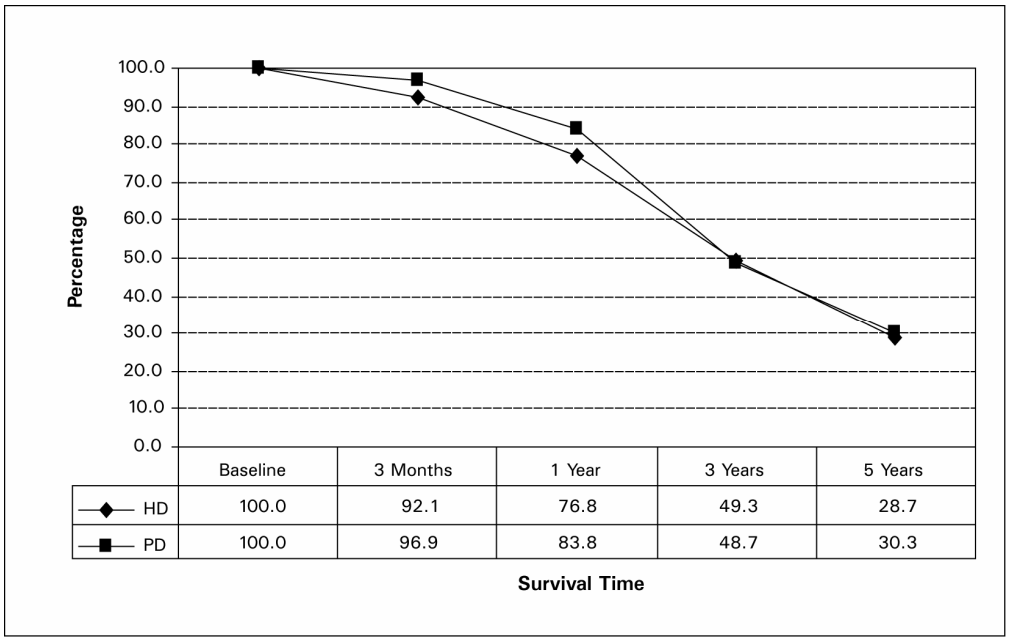
9.5 Outcomes in Dialysis Patients With Diabetes

Diabetes was the most common cause of ESRD among patients on dialysis, accounting for 43.0% of prevalent patients in Manitoba (the largest proportion) and 25.0% in Nova Scotia (the smallest proportion).

The etiology of renal failure was seen to have an effect on patient survival (figures 12 to 14). In particular, patient survival was compromised with primary diagnoses of renal vascular disease and diabetes, both of which showed relatively poor long-term survival (five-year) of 29% (for renal vascular disease) and 32% (for diabetes). Diabetes was determined to be the most influential risk factor among all primary diseases causing end-stage organ failure in the multivariate adjusted analysis of CORR data.

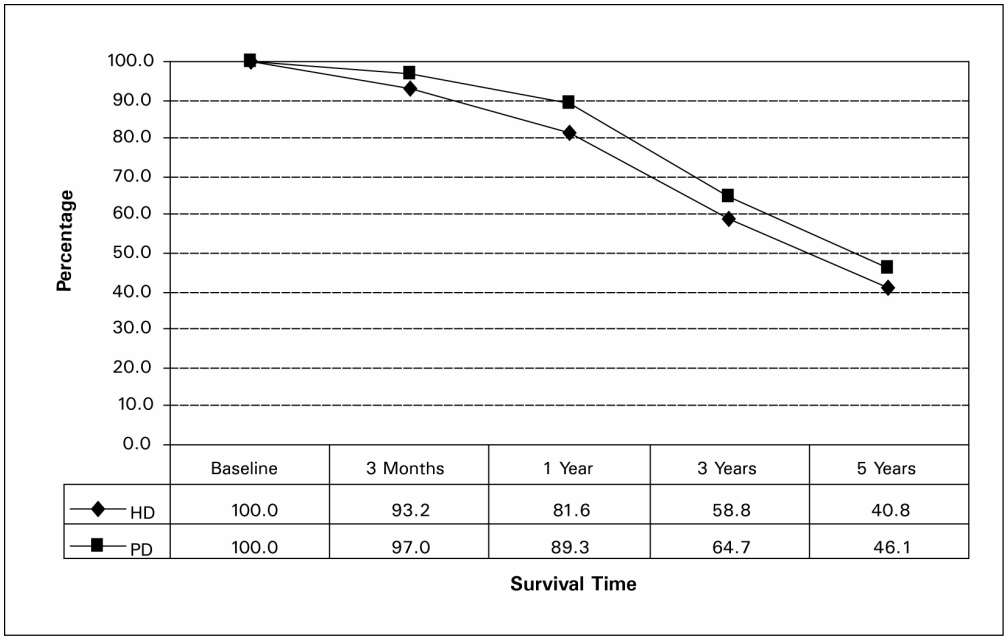
When modality of treatment (HD versus PD) was examined there was some advantage seen in the PD group with improved short-term and long-term survival. The most marked difference was seen at one year (Figure 64). However, when comparing those with diabetes and without diabetes by treatment modality there are considerable differences. At five years, ESRD patient survival on PD with diabetes was 30.3%, while that for those without diabetes was 46.1% (figures 64 and 65). When HD was the treatment modality, there was a 28.7% survival at five years for those with diabetes, compared to 40.8% without diabetes.

Figure 64. Unadjusted Survival at Three Months and One, Three and Five Years in Patients With Diabetes, by Initial Treatment Modality, Canada, 1995 to 1999 (Followed to 2004)



	Baseline	3 Months	1 Year	3 Years	5 Years
HD	100.0	92.1	76.8	49.3	28.7
PD	100.0	96.9	83.8	48.7	30.3

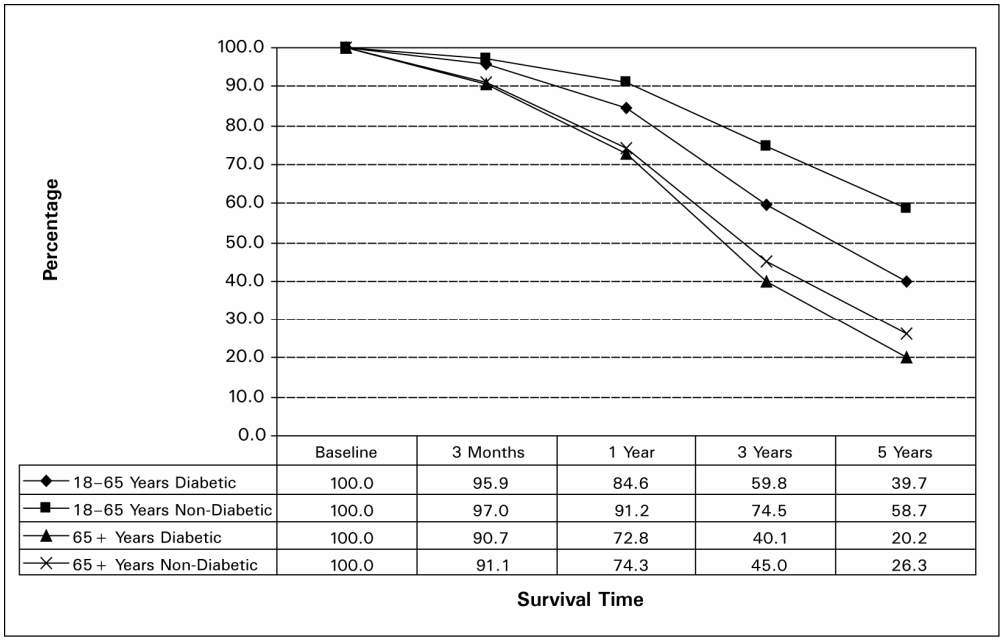
Figure 65. Unadjusted Survival at Three Months and One, Three and Five Years in Patients Without Diabetes, by Initial Treatment Modality, Canada, 1995 to 1999 (Followed to 2004)



	Baseline	3 Months	1 Year	3 Years	5 Years
HD	100.0	93.2	81.6	58.8	40.8
PD	100.0	97.0	89.3	64.7	46.1

When age and diabetic status were considered in the analysis, more marked differences were seen. Diabetic ESRD patients between the ages of 18 and 65 showed a 19.0% lower five-year survival rate compared to those without diabetes (Figure 66). A smaller difference in long-term survival was seen between diabetic and non-diabetic ESRD patients 65 years of age and older, with a 6.1% difference between the two groups.

Figure 66. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Patients on Dialysis With and Without Diabetes, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



	Baseline	3 Months	1 Year	3 Years	5 Years
18–65 Years Diabetic	100.0	95.9	84.6	59.8	39.7
18–65 Years Non-Diabetic	100.0	97.0	91.2	74.5	58.7
65+ Years Diabetic	100.0	90.7	72.8	40.1	20.2
65+ Years Non-Diabetic	100.0	91.1	74.3	45.0	26.3

9.6 Outcomes in Renal Transplant Recipients With Diabetes

Diabetes as the primary cause of ESRD continued to climb in Canada. Among those with a functioning kidney transplant, the average annual increase in those with diabetes as the cause of ESRD was 7.8% between 1995 and 2004. Among patients who received first kidney grafts, the proportion of recipients with diabetes who received kidneys from living donors decreased (23.4% in 1995 to 19.9% in 2004). For those recipients receiving kidneys from deceased donors, the proportion of those with diabetes rose slightly in the 10 years of study.

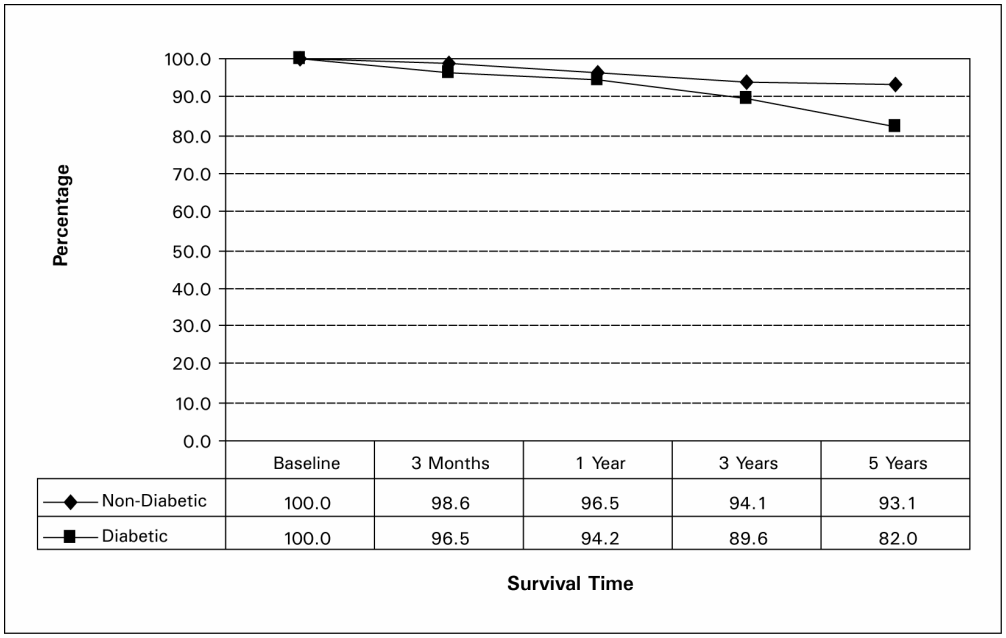
9.6.1 Graft Survival

There are differences seen in graft survival between those with and without diabetes. Graft survival was superior in people without diabetes, ranging from 98.6% at three months to 93.1% at five years. The grafts of those with type 2 diabetes had the most compromised outcome status, with graft survival at three months of 94.1%, dropping to 82.0% at five years (Figure 67).

9.6.2 Patient Survival

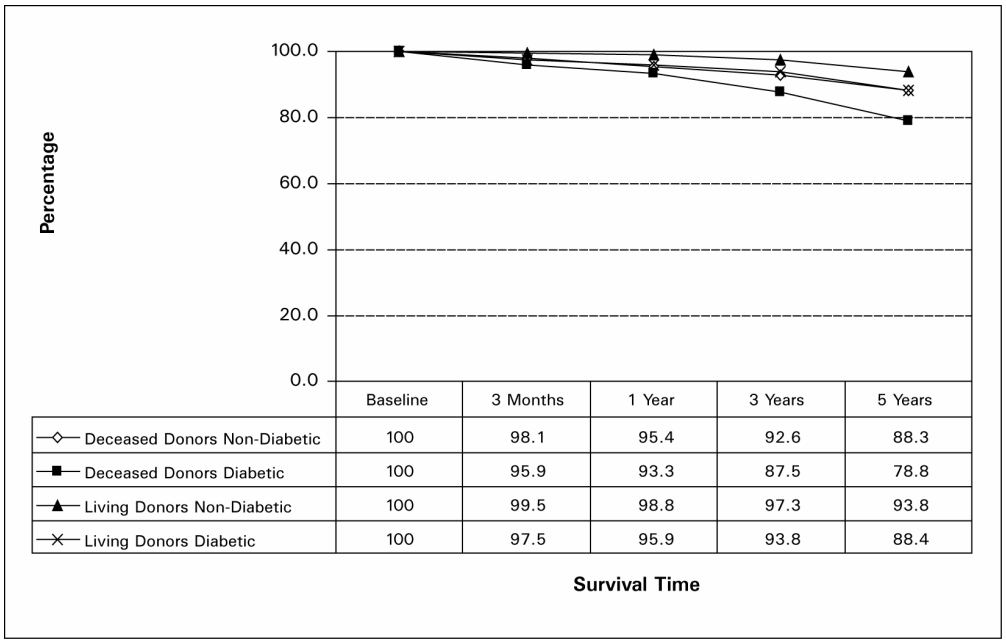
When comparing five-year patient survival between diabetic and non-diabetic kidney transplant recipients overall, there was an 11.1% decreased survival at five years for those with diabetes (Figure 67). There was a 9.5% decreased survival for diabetic recipients when the kidney was donated by a deceased donor and a 5.4% reduced five-year survival when the donated kidney was transplanted from a living donor, compared to non-diabetic recipients. Five-year survival was poorest in diabetic recipients transplanted with deceased-donor organs (78.8%) (Figure 68).

Figure 67. Unadjusted Three-Month, One-, Three- and Five-Year Patient Survival, Kidney Transplant Recipients With and Without Diabetes, Canada, 1995 to 1999 (Followed to 2004)



	Baseline	3 Months	1 Year	3 Years	5 Years
Non-Diabetic	100.0	98.6	96.5	94.1	93.1
Diabetic	100.0	96.5	94.2	89.6	82.0

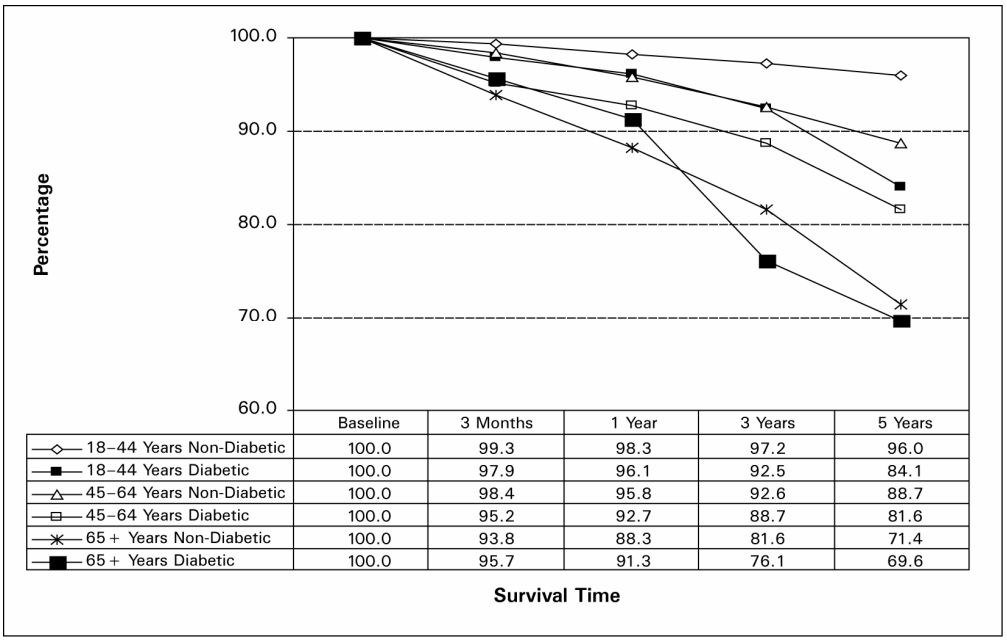
Figure 68. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival, Kidney Transplant Recipients With and Without Diabetes, by Donor Type, Canada, 1995 to 1999 (Followed to 2004)



	Baseline	3 Months	1 Year	3 Years	5 Years
Deceased Donors Non-Diabetic	100	98.1	95.4	92.6	88.3
Deceased Donors Diabetic	100	95.9	93.3	87.5	78.8
Living Donors Non-Diabetic	100	99.5	98.8	97.3	93.8
Living Donors Diabetic	100	97.5	95.9	93.8	88.4

Age was a factor in outcome for kidney transplant recipients with diabetes. Patient survival was most compromised in diabetic patients aged 65 years and older (69.6%), compared to 71.4% for non-diabetic recipients in the same age group. The largest difference (11.9%) between diabetic and non-diabetic recipient survival at five years was seen in the 18- to 44-year age group, with non-diabetic recipients living longer (Figure 69).

Figure 69. Unadjusted Three-Month and One-, Three- and Five-Year Patient Survival in Kidney Transplant Recipients With and Without Diabetes, by Age Group, Canada, 1995 to 1999 (Followed to 2004)



	Baseline	3 Months	1 Year	3 Years	5 Years
18–44 Years Non-Diabetic	100.0	99.3	98.3	97.2	96.0
18–44 Years Diabetic	100.0	97.9	96.1	92.5	84.1
45–64 Years Non-Diabetic	100.0	98.4	95.8	92.6	88.7
45–64 Years Diabetic	100.0	95.2	92.7	88.7	81.6
65 + Years Non-Diabetic	100.0	93.8	88.3	81.6	71.4
65 + Years Diabetic	100.0	95.7	91.3	76.1	69.6

9.7 Conclusion

Diabetes is a large, growing global public health concern. Its many complications, including a reduced health-related quality of life[45] and high mortality rate, have serious consequences for individuals, families and the health care system. Due to the chronic nature of the disease, and the degree of complications associated with it, diabetes is an expensive disease to treat, both in economic and humanistic costs. In end-stage organ failure, particularly ESRD, diabetes plays a pivotal role. As such, diabetes presents a public health challenge for those designing and providing care for the growing population of Canadians affected by diabetes.

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Appendix A

Canadian Organ Replacement Register (CORR) Board of Directors and Members of the Advisory Committee

CORR Board of Directors (April 1, 2006)

Dr. Joanne Kappel, Canadian Society of Nephrology (CSN), Chair/President

Dr. Stanley Fenton, Canadian Society of Nephrology (CSN), Past President

Dr. John Gill, Canadian Society of Transplantation (CST)/CSN, Vice-President

Mr. Peter Hoult, Kidney Foundation of Canada (Secretary/Treasurer)

Dr. Marie-Josée Clermont, (CSN)

Ms. Janet Egan (PHAC)

Mr. Greg Kalyta, Canadian Association of Transplantation (CAT)

Dr. Vivian McAlister,(CST)

Dr. Louise Moist, (CSN)

Dr. Rosalie Starzomski, Canadian Association of Nephrology Nurses and Technicians (CANNT)

Dr. Charles Poirier (QST)

Dr. Semeena Iqbal (QSN)

Dr. Paul Sohi (CSN)

In March of 2006, the Board of Directors voted to alter the constitution to include one additional Board seat, to be assigned to a representative of the Canadian Council on Donation and Transplantation (CCDT).

CORR Advisory Committee (April 1, 2005)

Dr. John Gill—Kidney Transplantation (British Columbia), Chair

Dr. Stanley Fenton—Nephrology (Ontario)

Dr. Joanne Kappel—Nephrology (Saskatchewan)

Dr. Vivian McAlister—Liver Transplantation (Ontario)

Dr. Louise Moist—Nephrology (Ontario)

Dr. Beth Foster—Pediatric Nephrology (Quebec)

Dr. Jean-François Légaré—Heart Transplantation (Quebec)

Dr. Brenda Hemmelgarn—Nephrology (Alberta)

Dr. Blydt-Hansen—Pediatric Nephrology (Manitoba)

Mr. Greg Kalyta, Canadian Association of Transplantation

Dr. Tammy Keough-Ryan—Kidney Transplantation (Nova Scotia)

Dr. Steven Paraskevas—Pancreas Transplantation (Quebec)

Ms. Jan Emerton, Canadian Association of Transplantation

Appendix B

Canadian Transplant Hospitals and Canadian Hospitals and Independent Health Facilities Providing Dialysis to Chronic Renal Failure Patients as Reported to CORR

Independent health facilities are noted with an asterisk (*).

Hospital/Facility	Type of Transplants Performed in 2004								Dialysis Programs in 2004			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney –Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Northwest Territories												
*Stanton Territorial Health Authority									X			
British Columbia												
B.C. Children's	X								X		X	X
Kelowna General									X	X	X	X
Kootenay-Boundary Regional									X	X	X	X
Penticton Regional									X		X	X
Prince George Regional									X	X	X	X
Royal Columbian									X		X	X
Royal Inland									X	X	X	X
Royal Jubilee									X	X	X	X
St. Paul's	X		X						X		X	X
Surrey Memorial									X			
Vancouver	X	X			X		X	X	X		X	X
Alberta												
Foothills Medical	X						X		X	X	X	X
University of Alberta	X	X	X	X	X	X	X	X	X	X	X	X
Saskatchewan												
Regina General									X		X	X
St. Paul's	X								X		X	X
Manitoba												
Brandon Regional									X			
Health Sciences	X				X				X	X		
Seven Oaks General									X			
St. Boniface General									X		X	X
Ontario												
*Bayshore Dialysis Clinic—Brockville									X			
*Bayshore Dialysis Clinic—Stoney Creek									X			
*Brantford General									X			
Children's Hospital of Eastern Ontario									X		X	
*Cornwall Dialysis Clinic									X			
Credit Valley									X	X	X	X

Hospital/Facility	Type of Transplants Performed in 2004								Dialysis Programs in 2004			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney –Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
*Dialysis Mgmt. Clinics Inc.—Pickering									X			
*Dialysis Mgmt. Clinics Inc.—Markham									X			
*Dialysis Mgmt. Clinics Inc.—Peterborough									X			
Grand River									X		X	X
Halton Healthcare Services									X			
Hamilton Health Services Corp. McMaster Children's											X	X
Hospital for Sick Children	X	X	X			X			X	X	X	X
Hotel Dieu Health Sciences									X	X	X	X
Hôtel-Dieu Grace									X		X	X
Humber River Regional									X	X	X	X
Kingston General	X								X	X	X	X
Lakeridge Health Corp. Whitby									X	X	X	X
LHSC—University and South Street	X	X	X		X	X			X			
LHSC—Westminster									X	X	X	X
North Bay General									X			
Orillia Soldiers'' Memorial									X		X	X
*Ottawa–Carleton Dialysis Clinic									X			
Ottawa Hospital	X								X	X	X	X
Peterborough Regional Health									X		X	X
Renfrew Victoria									X			
Sault Area Hospitals Plummer Memorial									X		X	X
Scarborough—General Division									X		X	X
*Sheppard Centre									X			
St. Joseph's (Hamilton)	X								X	X	X	X
St. Joseph's (Toronto)									X		X	X
St. Michael's	X								X	X	X	X
Sudbury Regional Laurentian Site									X	X	X	X
Sunnybrook and Women's College									X	X	X	X
*Sussex Centre									X			
Thunder Bay Regional McKellar Site									X		X	X
Timmins and District									X		X	X
Toronto East General									X			

Hospital/Facility	Type of Transplants Performed in 2004								Dialysis Programs in 2004			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney –Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Toronto General—University Health Network	X	X	X	X	X	X	X		X	X	X	X
University of Ottawa Heart Institute			X									
York Central									X		X	X
Quebec												
Aurores Boréales											X	
CHUS—Fleurimont	X								X		X	X
C.H. de Granby									X			
C.H. de Verdun									X		X	X
Chicoutimi									X		X	
CHUM—Hôtel-Dieu									X			
*C.H. de la région de l'amiante									X			
CHUM—Notre-Dame	X			X	X		X		X	X	X	X
CHUM—St-Luc		X							X		X	X
C.H. Des Vallées de l'Outaouais Pavillon. de Hull									X		X	X
C.H. régional de Trois-Rivières—Pavillon St. Joseph									X		X	X
CHUQ—Hôtel-Dieu	X								X	X	X	X
C.H régional de Lanaudière									X		X	
C.H. régional de Rimouski									X		X	X
C.H. régional du Suroît									X		X	X
C.H. de Santé Val-D'Or									X		X	X
Charles Lemoyne									X		X	X
Haut-Richelieu									X		X	X
Hôtel-Dieu d'Arthabaska									X			
Hôtel-Dieu de Lévis									X		X	X
Hôtel-Dieu de Saint-Jérôme									X		X	X
Hôtel-Dieu de Sorel									X		X	X
Institut de Cardiologie de Montréal			X									
Lakeshore									X			
Laval			X						X	X	X	X
Maisonneuve-Rosemont	X								X	X	X	X
Montréal Children's—McGill	X								X		X	X
Montréal General—McGill									X	X	X	X
Royal Victoria—McGill	X	X	X	X			X		X		X	X
Sacré Coeur de Montréal									X		X	X
*Sainte-Croix									X		X	

Hospital/Facility	Type of Transplants Performed in 2004								Dialysis Programs in 2004			
	Kidney	Liver	Heart	Heart–Lung	Lung	Intestine/ Multivisceral	Pancreas/Kidney –Pancreas	Islet Cell	HD	Home HD Training	PD	Home PD Training
Sainte-Justine	X	X	X						X		X	X
Sir Mortimer B. Davis Hospital— Jewish General									X		X	X
St. Mary's									X		X	X
Nova Scotia												
Cape Breton Regional									X		X	X
IWK Grace Health	X								X		X	X
Queen Elizabeth II	X	x	X						X	X	X	X
Yarmouth Regional									X			
New Brunswick												
Chaleur Regional									X			
Edmundston									X	X	X	X
Georges L. Dumont									X	X	X	X
Saint John Regional									X	X	X	X
Newfoundland and Labrador												
Central Nfld. Regional									X			
St. John's Health Sciences									X	X	X	X
Western Memorial Regional									X			

Appendix C

Canadian Organ Procurement Organizations

British Columbia
British Columbia Transplant Society (BCTS)
555 West 12th Avenue
3rd Floor, West Tower
Vancouver, British Columbia V5Z 3X7
www.transplant.bc.ca

Alberta
HOPE Program—Calgary
Foothills Medical Centre
1403 29th Street North West
Calgary, Alberta T2N 2T9
www.crha-health.ab.ca/hlthconn/items/orgtiss.htm

HOPE Program—Edmonton
University of Alberta Hospital
8440 112th Street
Edmonton, Alberta T6G 2B7

Saskatchewan
The Saskatchewan Transplant Program
Provincial Office
St. Paul's Hospital
1702 20th Street West
Saskatoon, Saskatchewan S7M 0Z9

The Saskatchewan Transplant Program
Regina Office
Regina General Hospital
1440 14th Avenue
Regina, Saskatchewan S4P 0W5

Manitoba
Transplant Manitoba
Gift of Life Program
Health Sciences Centre
820 Sherbrooke Street, Room GE441
Winnipeg, Manitoba R3A 1R9

Ontario
Trillium Gift of Life Network
155 University Avenue, Suite 1440
Toronto, Ontario M5H 3B7
www.giftoflife.on.ca

Quebec
Québec-Transplant
Siège Social/Head Office
4200 St-Laurent Boulevard, suite 1111
Montréal, Quebec H2W 2R2
www.quebec-tranpslant.qc.ca

Québec-Transplant
Bureau de Quebec
2700 Jean-Pierre Street
Québec, Quebec G2C 1S9

Nova Scotia
Multi-Organ Transplant Program
Queen Elizabeth II Health Sciences Centre
Mackenzie Building
5788 University Avenue
Halifax, Nova Scotia B3H 1V7
www.cdha.nshealth.ca/transplantservices/

New Brunswick
Multiple Organ Retrieval and Exchange Program
Health and Wellness Hospital Services Branch
PO Box 5100
Fredericton, New Brunswick E3B 5G8
www.gnb.ca/0217/organ-e.asp

Newfoundland and Labrador
Organ Procurement and Exchange
of Newfoundland and Labrador (O.P.E.N. Program)
Health Sciences Centre
300 Prince Phillip Parkway
St. John's, Newfoundland and Labrador A1B 3V6

Treatment of End-Stage Organ Failure in Canada

1995 to 2004

(2006 Annual Report)

Canadian Organ Replacement Register

Canadian Institute for Health Information
Institut canadien d'information sur la santé

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Appendix D

CORR Data Quality Documentation: 1995 to 2004

The information in this appendix should be used in conjunction with the information presented in Section 1 of this report, Appendix E—Glossary and Commonly Used Acronyms and Appendix F—Analytical Methods. Documentation is just one part of the comprehensive data quality program operating at CIHI. Users who require additional information are encouraged to contact CORR at corr@cihi.ca.

Database Description

The Canadian Organ Replacement Register (CORR) is the national information system for organ failure, transplantation, organ donation and renal dialysis, with a mandate to record and analyze the level of activity and outcome of vital organ transplantation and dialysis activities. It is a longitudinal database, following recipients with end-stage organ failure from their first treatment to their deaths. The national scope of CORR has been useful in informing health care policy vis-à-vis the decline in organ donation across Canada, the rise in end-stage renal disease and the evolution of organ transplantation from experimental to mainstream treatment. For a brief history of the database, please refer to Section 1 of this report.

Data Sources and Methodology

Target Population: All patients who have received an extra-renal organ transplant and all chronic renal failure patients who have initiated renal replacement therapy since January 1, 1981, form CORR's target population. CORR does not contain information on (1) patients who have been determined to have acute, but not chronic, renal failure; (2) recipients of tissue transplants; (3) patients who were listed for but did not receive a vital organ transplant; or (4) potential organ donors (that is, deceased donors who met the criteria for donation but from whom no organs were used for transplantation).

CORR's frame (that is, the entities that would be expected to contribute data to CORR, given its mandate) includes all the dialysis programs treating chronic renal failure patients and all the vital organ transplant programs within Canada. Data are received either directly or indirectly from these programs. Tables D1 and D2 below identify the number of dialysis programs in 2004 and transplant programs in 2004, respectively, that participated in CORR directly or through a regional or provincial registry or organ procurement program.

Table D1. Dialysis Programs Within CORR Frame by Province, 2004

	Alta.	B.C.	Man.	N.B.	N.L.	N.W.T.	N.S.	Ont.	Que.	Sask.	Total
Full-Care Dialysis Programs	2	11	4	4	3	0	4	31	31	2	**92**
Affiliated Community Centres	24	14	11	2	1	0	15	37	10	6	**117**
Independent Health Care Facilities Offering Hemodialysis	0	0	0	0	0	1	0	10	2	0	**13**

Table D2. Transplant Programs Within CORR Frame by Province, 2004

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Kidney	2	3	1	1	7	7	1	**22**
Liver	1	1	0	1	3	3	0	**9**
Heart/Heart–Lung	1	1	0	1	4	5	0	**12**
Lung	1	1	1	0	2	1	0	**6**
Pancreas/Kidney–Pancreas	2	1	0	0	1	2	0	**6**
Intestine/Multivisceral	1	0	0	0	3	0	0	**4**

Frame maintenance procedures have been in place for several years. CORR staff are informed by provincial sources of new dialysis hospitals and generally follow the Discharge Abstract Database (DAD) in terms of assigning facility identifiers (that is, a province code from 1 to 9, along with a four-digit identifier). Unique facility identifiers are assigned to hospitals in Quebec, satellite centres and organ procurement organizations (OPOs) using a consistent notation system. All facility identifiers are identified in the *CORR Directory of Participating Dialysis Centres, Transplant Centres and Organ Procurement Organizations in Canada*, which is published annually. In addition, a formal review process was undertaken in April and May of 2002 to formally verify CORR's frame.

Data Sources: CORR comprises retrospectively collected demographic, clinical and outcome-related data. Data are currently received via paper forms or spreadsheets. Standardized forms are used for the purposes of paper collection, which detail the data elements and the domain values. These forms, and the accompanying instruction manuals, also guide spreadsheet submissions. Specially trained staff enter all the data received.

The CORR data model consists of 119 relational tables: 34 data tables; 68 code tables; 3 population tables derived from Statistics Canada; and 14 system tables. The data tables contain information on 579 data elements. One of these variables is derived (MELD_SCORE) and five are system-generated (RECIPIENT_ID, RECIPIENT_TREATMENT_ID, DONOR_ID, COMMUNITY_CENTRE_ID, ORGAN_FAILURE_CAUSE_ID). Twelve data elements are used either alone or in combination to link the various tables.

Within CORR, data elements are classified as mandatory, conditionally mandatory or optional. Mandatory elements must be submitted and entered (for example, *recipient name*, *birth date*, *treatment code*), whereas conditionally mandatory elements are entered only if other specific conditions are satisfied (for example, *date of death* must be entered if a *cause of death* is given). Prior to 2001, mandatory items within CORR were limited to 19 data elements. Since 2001, major changes have occurred with CORR. Data providers are encouraged to submit information on all data elements, although it should be emphasized that reporting to CORR is not provincially or nationally mandated.

The types of data captured, as well as the points of data capture within CORR, are summarized in Table D3. Changes in patients' treatment status are tracked and treatment outcomes are recorded. Information on organ donors is also collected. Facility-level data on clinical practices and policies are collected from dialysis hospitals and independent health facilities. Counts of patients waiting for a transplant are collected from OPOs.

Table D3. Types of Data Captured and Points of Data Capture in CORR

Dialysis Recipients	Transplant Recipients	Donors	Dialysis Hospital Programs	Hospital Transplant Programs Following Kidney Transplant Recipients	Transplant Waiting List Statistics
When initiate dialysis ⬇ When: • transfer to another program • change treatment modalities • have a kidney transplant • withdraw from dialysis • recover kidney function • die ⬇ Annually, on October 31 (survey with voluntary participation)	When transplanted ⬇ When: • transfer to another program for follow-up • graft fails • retransplanted • die • for liver transplant recipients only—annual follow-up to record recurrent hepatitis B, hepatitis C and liver tumour(s)	When organ(s) retrieved for purposes of transplantation—Deceased Donor Profile and Living Donor Profile	At year-end—hemodialysis facility profile; peritoneal dialysis facility profile	At year-end—renal transplant facility profile	Counts of patients waiting for transplants at each of the transplant programs; reported on a semi-annual basis by the OPOs.

Table D4 outlines the data supply chain for CORR.

Table D4. CORR Data Supply Chain

Province of Treatment	Dialysis Recipients	Organ Transplant Recipients	Deceased Organ Donors	Living Organ Donors	Waiting List Statistics
Alta.	Southern Alberta Renal Program (Calgary) and Northern Alberta Renal Program (Edmonton)	Hospital transplant programs	HOPE Calgary, HOPE Edmonton	Hospital transplant programs	HOPE Calgary, HOPE Edmonton
B.C.	B.C. Renal Agency, Hospital Dialysis Programs	B.C. Transplant Society	B.C. Transplant Society	B.C. Transplant Society	B.C. Transplant Society
Man.	Hospital dialysis programs	Hospital transplant program	Transplant Manitoba—Gift of Life Program	Hospital transplant program	Transplant Manitoba—Gift of Life Program
N.B.	Hospital dialysis programs		Multiple Organ Retrieval and Exchange Program		
N.L.	Hospital dialysis programs		O.P.E.N. Program		
N.W.T.	Hospital dialysis program				
N.S.	Hospital dialysis programs	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program	Multi-Organ Transplant Program
Ont.	Hospital dialysis programs, Toronto Region Dialysis Registry	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network	Trillium Gift of Life Network
Que.	Hospital dialysis programs	Hospital transplant programs	Québec-Transplant	Hospital transplant programs	Québec-Transplant
Sask.	Hospital dialysis programs	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program	Saskatchewan Transplant Program

Error Detection: All dialysis and transplant programs and the OPOs are provided with coding instruction manuals, which provide definitions and descriptions of each data element contained in CORR and information on how to appropriately record data. Other measures designed to help improve the consistency and quality of the data submissions include providing telephone support, conducting site visits and sending written instructions and feedback.

The data entry flow is designed to enhance error detection. On the transplant side, data relating to organ donors is entered first, followed by transplant recipient data. This facilitates identification of transplant recipient–donor links and dialysis recipients who go on to have transplants. On the dialysis side, treatment information must be entered in chronological order. This helps to identify problematic submissions (for example, inconsistent submissions regarding a patient's status).

Upon completion of data entry, reporting centres are forwarded standardized audit reports for the purposes of verification. Changes noted by centres are made in the database. Quality assurance staff may also liaise with a reporting centre prior to data entry when visual scans of the returned forms reveal problems or when problems in the data have been identified through the course of analysts' work on ad hoc requests and research projects.

In 2001, the data entry application underwent a complete redesign. CORR was converted from a Microsoft SQL server two-tier client/server architecture running on a Windows NT platform to an Oracle database with a multi-tier client/server architecture. Within the new web-based application, a number of new hard and soft edits were introduced in order to:

- reduce entry of duplicate records (for example, matching algorithm used to reduce double entry of patient records);
- improve consistency of data (for example, logic checks to ensure entry of treatments in a chronological sequence);
- minimize entry of incorrect data (for example, drop-down menus used to minimize the opportunities for incorrect domain values to be inputted; entry of dates in the format (YYYY-MON-DD) to prevent the juxtaposition of day and month during data entry); and
- improve data completeness (for example, mandatory data elements cannot be bypassed; some data elements are auto-populated; conditionally mandatory data elements are triggered on/off, based on responses to other data elements).

In some cases where data elements are optional (for example, recipient height and weight), the new application employs soft edits, which alert data entry personnel to potential entry errors.

Imputation: No imputed data are stored in CORR.

Quality Evaluation: CIHI's *Data Quality Framework*, which was implemented in 2000–2001, is based on a similar framework used at Statistics Canada and provides a common strategy for assessing data quality across CIHI databases and registries along five general dimensions:

- **Accuracy:** how well information within a database reflects what was supposed to be collected
- **Comparability:** the extent to which a database can be properly integrated into the entire health information system at CIHI
- **Timeliness:** whether the data are available for user needs within a reasonable time period

- **Usability:** how easily the storage and documentation of data allow one to make intelligent use of the data
- **Relevance:** incorporates all of the above dimensions to some degree, but focuses specifically on value and adaptability

The framework implementation is part of the larger quality cycle in which problems are identified, addressed, documented and reviewed on a regular basis. Each CIHI data holding is evaluated for each annual release of data.

Data Accuracy

Coverage: There are no known coverage errors within CORR. The program is aware of all hospitals that should report. Hospitals not included in the frame do not report to CORR. An analysis of transplant procedures as captured in the Hospital Morbidity Database (HMDB) for the calendar years 1995 to 2000 confirms the transplant hospitals within CORR.

Duplicate patient records have been identified and eliminated in the database for pre-2001 data. The new application introduced in 2001 has a matching algorithm in place that prevents duplicate entry of patients.

Unit Non-Response: Because CORR is updated continually, unit non-response is addressed on an ongoing basis. Those centres that have failed to report to CORR in a timely and complete way are identified and staff work with them to improve reporting. Strategies to improve reporting include telephone support and on-site support, where needed. Trending of incident dialysis patients and cross-checking of aggregate-level data sources with patient-level data are two main analytical approaches used to evaluate unit non-response. In this section, unit non-response is described for the data used in this report.

(1) Prevalent ESRD Cases

Prevalent ESRD cases were incompletely reported for the period from 1995 to 2004. Hemodialysis facility profiles, from which the count of prevalent hemodialysis patients is obtained, were not provided by Montréal General Hospital (Que.) for 2000; Hôpital Charles-LeMoyne (Que.) for 2000; Hôpital du Haut-Richelieu (Que.) for 2001; and Royal Inland Hospital (B.C.) for 2002. Peritoneal dialysis facility profiles, from which the count of prevalent peritoneal dialysis patients is obtained, were not provided by Montréal General Hospital (Que.) for 2000 and 2001; Hôpital Charles-LeMoyne (Que.) for 2000; Hôpital du Haut-Richelieu (Que.) for 2001; and Royal Inland Hospital (B.C.) for 2002. In addition, there was suspected under-reporting on the peritoneal dialysis facility profiles for Wellesley Hospital (Ont.) for 1996; St. Joseph's Health Care System (Hamilton, Ont.) for 2000 and 2001; and Hôpital Fleurimont (Que.) for 1995 and 1996. Renal facility profiles, from which the count of functioning kidney transplants was obtained, were not provided by the Health Science Centre, Health Care Corporation of St. John's (N.L.) for 2002. For 2001, The Ottawa Hospital (Ont.) under-reported by an estimated 148 functioning kidney transplants. Data were adjusted for the unit non-response and under-reporting in Section 2.3 of this report.

(2) Incident End-Stage Renal Disease (ESRD) Cases

In terms of unit non-response for incident ESRD cases, under-reporting of incident ESRD cases is estimated to be 69 cases from Quebec in 2001, 115 cases from Quebec in 2002 and 15 cases from Nova Scotia in 2002. Chronic under-reporting of incident cases is more difficult to ascertain.

(3) Kidney Transplants

Since the 1990s, patient-level data submitted by hospitals and OPOs are reconciled with aggregate-level counts received from OPOs, which are received in advance of patient-level data submissions. In addition, the *Renal Transplant Facility Profile* provides another check of the kidney transplant data. Table D5 presents a comparison of these sources, and the respective transplant counts per province for the period from 1995 to 2004, and shows that the patient-level data are higher than the OPO aggregate counts, but lower than the counts provided on the *Renal Transplant Facility Profile*. This may suggest some under-reporting of kidney transplants within CORR.

Table D5. Comparison of Counts of Kidney Transplants* by Data Source, 1995 to 2004 (Number)

	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Sask.	Total
Patient-Level Data Within CORR	1,304	1,299	383	942	3,764	2,363	375	**10,395**
Aggregate Counts Provided in *Renal Transplant Facility Profile*	1,427	1,374	379	1,031	3,909	2,305	361	**10,786**
Aggregate Counts Provided by OPOs at Year-End	1,306	1,306	364	1,006	3,713	2,235	360	**10,290**

* Includes SKP and other kidney combination transplants.

(4) Extra-Renal Transplants

For the extra-renal transplants for the period from 1995 to 2004, the transplants registered in the database were compared against the aggregate counts reported by the OPOs. The results are provided in Table D6, and suggest that no under-reporting of transplant procedures was observed in the last decade.

Table D6. Comparison of Counts of Extra-Renal Transplants* by Data Source, 1995 to 2004 (Number)

Organ Type	Data Source†	Alta.	B.C.	Man.	N.S.	Ont.	Que.	Total
Liver	CORR registration	592	328	na	145	1,705	998	**3,768**
	OPO count	590	326	na	139	1,656	971	**3,682**
Heart	CORR registration	300	160	na	88	666	415	**1,629**
	OPO count	299	157	na	86	695	412	**1,649**
Heart–Lung	CORR registration	10	4	na	na	20	16	**50**
	OPO count	10	4	na	na	19	17	**50**
Lung	CORR registration	202	80	82	na	447	209	**1,020**
	OPO count	198	80	79	na	448	213	**1,018**
SKP	CORR registration	85	64	na	34	141	42	**366**
	OPO count	90	52	na	34	134	34	**344**
PTA/PAK	CORR registration	14	4	na	7	14	104	**143**
	OPO count	16	4	na	8	15	102	**145**
Intestine/Multivisceral	CORR registration	3	na	na	na	20	na	**23**
	OPO count	1	na	na	na	10	na	**11**

* Includes combination transplants; combination transplants are counted under their respective organ types.
† CORR registration = patient-level data within CORR; OPO count = aggregate count provided by OPOs at year-end.

(5) Donors

A comparison of donors registered in CORR contrasted with donor numbers reported by OPOs at year-end is provided in Table D7. This table suggests that no under-reporting of donors has been observed in CORR; however, the under-reporting by OPOs of 30 cases occurred in 2004. Overall, the number of donors collected by CORR between 1995 and 2004 was greater by 20 donors than initially reported by OPOs.

Table D7.Comparison of Deceased and Living Donors Registered in CORR and Reported by OPOs, 1995 to 2004 (Number)

Year	Registered in CORR			Reported by OPOs		
	Deceased Donors	Living Donors	Total Donors	Deceased Donors	Living Donors	Total Donors
1995	423	230	**653**	437	230	**667**
1996	418	269	**687**	420	265	**685**
1997	426	288	**714**	429	283	**712**
1998	415	369	**784**	415	368	**783**
1999	420	393	**813**	421	392	**813**
2000	472	409	**881**	471	409	**880**
2001	416	448	**864**	420	447	**867**
2002	407	441	**848**	405	440	**845**
2003	421	438	**859**	428	431	**859**
2004	440	474	**914**	414	468	**882**
Total	**4,258**	**3,759**	**8,017**	**4,260**	**3,733**	**7,993**

Item Non-Response: Overall, item non-response has improved over time, particularly since 1997. There are, however, some significant province-specific item non-response issues.

Table D8 presents a summary of the proportion of records with null and unknown values on key mandatory data elements within CORR for transplant recipients of first grafts for the period from 1995 to 2004, and for donors for the same period. Rates of non-response/unknowns greater than 10% are shaded.

Table D8. Non-Response/Unknown Values for Key Analytical Data Elements Related to Donors and Transplant Recipients* in CORR, 1995 to 2004

Data Type	Data Element	Percentage of Non-Response/Unknowns									
		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Deceased Donor	Age	0.5	0.2	0.5	0.00	0.7	0.0	0.0	0.0	0.0	0.0
	Sex	0.0	0.0	0.0	0.0	0.5	0.2	0.0	0.2	0.2	0.2
	Blood Type	1.4	1.2	0.2	0.0	0.5	0.0	0.2	0.0	0.0	3.0
	Race/Ethnic Origin	7.2	10.9	13.9	5.5	11.9	20.9	25.4	3.6	22.1	32.1
	Province of Residence (not formally collected until 2001)	60.6	78.7	80.4	88.8	83.7	87.1	0.0	0.0	0.0	0.0
	Cause of Death	2.6	2.6	2.8	0.5	0.7	1.0	4.8	3.8	2.5	3.2
Living Donor	Age	43.9	49.1	26.9	9.2	25.7	1.5	0.0	0.0	0.0	0.0
	Sex	1.7	1.1	48.4	4.9	20.1	0.5	0.9	0.2	0.0	0.0
	Blood Type	4.4	3.0	1.4	6.5	24.9	0.7	0.7	6.8	7.3	12.7
	Province of Residence (not formally collected until 2001)	99.1	98.9	98.9	99.7	98.0	99.0	0.2	0.2	0.5	1.3
Transplant Recipients	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	14.8	14.0	13.6	12.1	13.5	14.4	18.7	16.6	19.9	21.4
	Blood Type	9.2	11.3	7.8	2.2	3.6	1.4	3.2	2.6	3.3	2.8
	Residential Postal Code	5.7	6.3	3.0	2.7	2.9	1.4	0.7	0.6	3.2	3.2
	Cause of Death (deceased recipients only)	25.7	24.2	25.1	22.5	23.2	23.5	20.8	21.2	25.9	14.3
	Diagnosis (heart, liver, lung transplants)	0.9	7.7	1.1	0.7	2.2	1.8	1.7	0.8	5.4	2.1
	Medical Status at Listing (heart, liver, lung transplants)	13.3	9.9	11.1	5.8	12.3	3.7	8.7	1.1	2.8	0.9
	Medical Status at Transplant (heart, liver, lung transplants)	3.1	5.0	5.4	2.6	6.6	0.0	1.7	0.5	0.3	0.0
	Cause of Graft Failure (transplants with failed grafts)	30.1	33.1	34.2	27.6	32.2	33.2	37.2	35.5	33.9	37.4

* Recipients of first grafts for the period from 1995 to 2004.

Table D9 presents a summary of the proportion of records with null and unknown values on key mandatory data elements within CORR for incident dialysis patients for each year in the period from 1995 to 2004. Table D10 presents the same information stratified by province of treatment. Rates of non-response/unknowns greater than 10% are shaded.

Table D9. Non-Response/Unknown Values for Key Analytical Data Elements Related Incident Dialysis Patients Registered in CORR by Year, 1995 to 2004

Data Type	Data Element	Percentage of Non-Response/Unknowns									
		1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Recipient	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Race/Ethnic Origin	8.8	9.2	12.3	12.8	14.0	14.6	6.7	6.7	7.5	6.0
	Residential Postal Code	2.9	1.2	0.9	1.5	2.7	1.5	1.2	0.6	1.4	1.4
	Diagnosis	13.4	13.9	15.7	13.0	12.5	11.9	13.9	14.6	14.3	13.4
	Cause of Death (deceased recipients only)	18.9	22.1	23.1	21.4	23.1	25.3	24.9	26.9	29.7	21.4
Risk Factors at Start of Dialysis	Angina	9.8	7.5	12.9	7.4	6.3	8.1	7.9	7.2	9.1	8.9
	Coronary Artery Bypass/Angioplasty	34.6	31.0	13.8	7.4	6.3	8.2	7.6	7.7	9.7	8.7
	Pulmonary Edema	10.0	7.8	13.1	7.8	6.4	8.4	7.8	7.6	9.3	9.2
	Myocardial Infarct	10.1	8.2	12.8	7.6	6.2	8.1	7.5	7.4	8.9	9.0
	Diabetes	9.2	6.3	11.5	6.8	5.3	6.5	6.5	5.0	6.6	6.5
	Cerebrovascular Accident	9.8	7.9	13.1	7.4	6.5	8.4	7.1	7.2	8.4	8.6
	Peripheral Vascular Disease	10.1	7.9	13.1	7.5	6.3	8.4	7.9	7.9	9.2	9.3
	Malignancy	10.0	8.0	13.3	7.7	6.8	8.4	9.3	9.1	11.5	10.4
	Chronic Lung Disease	10.4	8.0	13.4	7.8	6.5	8.4	8.1	8.0	9.5	9.5
	Use of Medications for Hypertension	8.9	5.9	11.2	7.1	5.6	7.7	5.6	5.4	6.8	6.9
	Presence of Other Serious Illness	15.6	11.4	18.3	11.1	9.7	11.3	17.0	18.5	19.1	18.9
	Current Smoker	13.7	12.3	16.7	11.1	8.0	9.4	13.2	14.5	13.4	15.3

Table D10. Non-Response/Unknown Values for Key Analytical Data Elements Related Incident Dialysis Patients Registered in CORR by Province of Treatment, 1995 to 2004

Data Type	Data Element	Percentage of Non-Response/Unknowns									
		Alta.	B.C.	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.	Total
Recipient	Sex	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	**0.0**
	Race/Ethnic Origin	12.4	21.9	3.1	4.5	5.1	21.0	9.7	4.5	1.7	**9.7**
	Residential Postal Code	1.0	2.9	7.2	1.1	2.1	1.9	0.7	1.1	0.8	**1.5**
	Diagnosis	15.4	29.3	12.7	7.4	17.2	7.9	10.5	13.0	7.5	**13.7**
	Cause of Death (deceased recipients only)	36.2	50.0	29.2	6.5	16.4	13.7	18.2	20.9	14.4	**23.5**
Risk Factors at Start of Dialysis	Angina	6.3	25.7	10.8	2.6	3.3	4.2	7.0	5.0	2.2	**8.4**
	Coronary Artery Bypass/Angioplasty	11.4	29.1	11.5	7.6	8.9	8.5	11.1	9.0	4.8	**12.3**
	Pulmonary Edema	6.8	26.4	10.3	2.8	4.8	4.7	7.1	5.2	1.8	**8.7**
	Myocardial Infarct	6.3	26.3	10.6	2.5	4.3	5.2	6.8	5.2	1.5	**8.5**
	Diabetes	4.2	25.0	9.5	2.2	3.4	3.1	5.0	3.5	1.1	**6.9**
	Cerebrovascular Accident	6.1	25.9	10.2	2.2	3.8	4.5	6.9	4.6	2.0	**8.3**
	Peripheral Vascular Disease	6.2	26.7	10.3	2.6	4.6	5.1	7.2	5.2	1.9	**8.7**
	Malignancy	7.9	27.7	12.4	3.5	4.5	4.8	7.8	5.7	2.5	**9.4**
	Chronic Lung Disease	7.9	27.7	12.4	3.5	4.5	4.8	7.8	5.7	2.5	**8.9**
	Use of Medications for Hypertension	3.9	23.0	9.9	1.8	3.4	4.0	5.6	4.0	1.2	**7.0**
	Presence of Other Serious Illness	11.8	39.8	14.2	10.3	8.3	8.3	12.9	12.2	4.8	**15.3**
	Current Smoker	12.5	33.4	13.0	7.0	6.7	6.6	9.2	12.2	3.6	**12.8**

Reliability/Response Bias: No formal reliability or linkage studies with other external data sources have been undertaken to assess bias or data reliability. Based on record linkage of transplant records in HMDB, preliminary estimates of overall error (expressed as a percentage of total non-agreement) appear to be in the 5% to 10% range. This linkage was based on data from 1995 to 2000 for provinces other than Quebec and applied to a few core variables, including birth date, sex and health card number.

A complete investigation of the extent and impact of reporting bias has not yet been undertaken, and users are warned that while CORR may contain the most comprehensive national data on treatment for end-stage organ failure at the present time, completeness and accuracy of data are significant issues. Bias is suspected for a number of variables, including death status, cause of death, comorbidities and treatment status. Timely updating of patients' status has not been done in a number of centres, most notably from centres in British Columbia and southern Alberta. Patient and graft survival rates for transplant recipients in Canada continue to be higher than rates reported in other countries, also likely due to under-reporting of failures and deaths.

Deaths on the waiting list, which are provided in the form of counts by OPOs, are likely to be underestimated because high-risk (medically urgent) patients are more likely to receive a transplant, and patients who are withdrawn from the list and subsequently die are not included within the death count, even if their deaths were attributable to lack of medical treatment (that is, organ transplantation).

Recent Database Revisions

In 2000, the database underwent a major review involving a number of expert working groups. Data elements were in some cases eliminated or refined, and new data elements and reporting requirements were added. These changes became effective for reporting year 2001.

The main changes included:

- An expansion of the treatment modalities for dialysis
- Addition of data elements on pre-dialysis contact
- Addition of data elements relating to cardiac function and inotrope use on the deceased-donor profile
- Creation of a standardized form on living donors
- Addition of a follow-up survey of all dialysis recipients, designed to capture information on the ways in which current treatment corresponds to the *Clinical Practice Guidelines of the Canadian Society of Nephrology for the Treatment of Recipients with Chronic Renal Failure*
- Refinement of the dialysis and renal facility profiles
- Addition of data elements pertaining to liver tumours in liver transplant recipients
- Addition of a follow-up questionnaire for all liver transplant recipients with diagnoses of hepatitis B, hepatitis C or liver tumours
- Addition of comorbidities for transplant recipients and donors
- Addition of data elements relating to transplant procedures

A new data model was created, which was designed to improve the flexibility of the database for analysis and facilitate the accommodation of future changes.

Appendix E

Glossary and Commonly Used Acronyms

Diabetes: A disease caused by the lack of insulin in the body or the body's inability to properly use normal amounts of insulin.

- *Type 1:* Occurs when the pancreas no longer produces any or produces very little insulin. The body needs insulin to use sugar for energy. Approximately 10% of people with diabetes have type 1 diabetes.

- *Type 2:* Occurs when the pancreas does not produce enough insulin or when the body does not use the insulin that is produced effectively. Approximately 90% of people with diabetes have type 2.

Commonly Used Acronyms

APD: automated peritoneal dialysis

CAPD: continuous ambulatory peritoneal dialysis

COPD: chronic obstructive pulmonary disease

CORR: Canadian Organ Replacement Register

CSN: Canadian Society of Nephrology

CST: Canadian Society of Transplantation

ESRD: end-stage renal disease

HD: hemodialysis

ICU: intensive care unit

OPO: organ procurement organization

PAK: pancreas after kidney transplantation

PD: peritoneal dialysis

PMP: per million population

PTA: pancreas transplant alone (isolated pancreas transplantation)

RRT: renal replacement therapy

SD: standard deviation

SKP: simultaneous kidney–pancreas transplantation

Dialysis: A type of renal replacement therapy, whereby the blood is cleaned and wastes and excess water are removed from the body. Sometimes dialysis is a temporary treatment. However, when the loss of kidney function is permanent, as in end-stage renal disease, dialysis must be continued on a regular basis. The only other treatment for kidney failure is kidney transplantation. There are two kinds of dialysis: hemodialysis and peritoneal dialysis.

- *Hemodialysis:* The blood is cleaned by being passed through a machine that contains a dialyser. The dialyser has two spaces separated by a thin membrane. Blood passes on one side of the membrane and dialysis fluid passes on the other. The wastes and excess water pass from the blood through the membrane into the dialysis fluid, which is then discarded. The cleaned blood is returned to the bloodstream.

- *Peritoneal dialysis:* The peritoneal cavity inside the abdomen is filled with dialysis fluid, which enters the body through a permanently implanted catheter. Excess water and wastes pass from the blood through the lining of the peritoneal cavity (the peritoneum) into the dialysis fluid. This fluid is then drained from the body and discarded. In most cases, this treatment can be performed without assistance from hospital personnel.

End-stage renal disease (ESRD): A condition in which the kidneys are permanently impaired and can no longer function normally to maintain life.

Graft survival: Graft survival refers to whether an organ is still functioning at a certain time after transplantation. The four time points used in this report are three months, one year, three years and five years.

Median waiting time: This statistic reports the middle waiting time value for recipients of an extra-renal transplant. It means that half the recipients waited less than this value, and the remaining half waited more than the value. CORR does not have patient-level data for patients who were listed for a transplant but did not receive a transplant. Thus, these waiting times provide only a partial picture. For kidney transplant patients, time between first dialysis and first kidney transplant are used.

Medical urgency status codes: Liver, heart and lung patients are assigned a status code at the time of their listing for a transplant. This status code corresponds to their medical condition and how urgently they require transplantation. The status codes are updated regularly until a patient is transplanted. CORR collects the initial listing status and the status at the time of transplant.

New patient: A patient with end-stage renal disease who began renal replacement therapy for the first time (either dialysis or renal transplantation) in the calendar year. Also known as an incident patient (see Section 2.1).

Organ donor: A person who donates one or more organs that are used for transplantation. Organ donors may be deceased or living.

- *Deceased donor:* A person for whom neurological death has been determined, consent has been obtained and organs are offered for transplantation. Neurological determination of death means that there is an irreversible absence of clinical neurological function as determined by definite clinical and/or neuro-imaging evidence. Within CORR, deceased donors are defined as those donors who originated in Canada and who have had at least one solid organ used for transplantation. Solid organs that can be donated after death include the heart, liver, kidneys, pancreata, lungs, intestine and stomach.

- *Living donor:* A donor with a biological (related) and/or emotional (unrelated) relationship to the transplant recipient. Living donors most commonly donate one of their kidneys. A lobe of the liver, a lobe of the lung or a segment of the pancreata or the intestine may also be donated by a living donor. At the time of this report, living pancreas and intestine transplants had not been performed in Canada.

Organ procurement organization (OPO): An organization responsible for coordinating the recovery and distribution of organs from deceased donors in its province or region. Since not all provinces in Canada perform extra-renal transplants, OPOs from across the country coordinate their activities to ensure that those patients on the extra-renal organ transplant waiting lists who most urgently require a transplant are offered a suitable organ first.

Organ transplantation: Surgical procedure that involves transplantation of organs or parts of organs recovered from deceased or living donors to recipients with end-stage organ failure. Organs that can be transplanted include the heart, liver, kidneys, pancreas, lungs, intestine and stomach. The single-organ kidney transplant is the most commonly performed transplant procedure. In rare cases, two or more organs may be transplanted. Organs used in these transplants may be from one or more donors.

- *Combination organ transplantation:* Surgical procedure that involves transplantation of organs or parts of organs to recipients who have more than one organ with end-stage organ failure. The most frequent examples of combination transplants in Canada are kidney–liver and kidney–heart transplants, where patients have end-stage renal failure along with liver or heart failure. Organs used in these transplants are usually from the same donor.

- *Islet cell transplantation:* A medical procedure that involves replacing the insulin-producing cells of the pancreas (islet cells), which are destroyed in people with type 1 diabetes. In Canada, islet cells are retrieved from the pancreas of deceased organ donors, although they may be preserved for a period of time prior to being used for transplantation. Islet cell transplants are currently not captured within CORR.

- *Kidney transplantation:* A procedure during which one or two kidneys from a deceased organ donor or one kidney from a living organ donor are surgically recovered and implanted into a person with end-stage renal disease. Not all persons with end-stage renal disease are candidates for kidney transplantation. Most people with end-stage renal disease receive dialysis prior to a kidney transplant.

- *Multivisceral transplantation:* A rare surgical procedure that involves transplantation of the liver, small intestine, pancreas, stomach and duodenum. (Also known as a cluster transplant.)

- *Pre-emptive kidney transplant:* An organ transplant that includes a kidney, where the patient has not been treated with dialysis prior to the transplant.

Organ transplant waiting list: A list of patients awaiting organ transplantation. Lists are maintained by the OPOs. Information on urgent liver and heart patients is shared across provinces. Each list identifies active and on-hold patients.

- *Active patient:* A patient on the organ transplant waiting list who can receive a transplant at any time.

- *On-hold patient:* A patient on the organ transplant waiting list who cannot receive a transplant for medical or other reasons for a short period of time.

Patient survival: Patient survival refers to whether a transplant recipient is still alive at a certain time after transplantation. The four time points used in this report are three months, one year, three years and five years.

Prevalent patient: A patient who is alive and receiving renal replacement therapy for end-stage renal disease on December 31 of a given year, regardless of date of initiation of treatment. Counts of prevalent patients are obtained from treatment hospitals providing patient status change data and facilities at the year-end *Hemodialysis Facility Profile* and *Peritoneal Facility Profile* (see sections 2.2. and 2.3).

Registered patient: A patient who began renal replacement therapy for end-stage renal disease for the first time in 1981 or thereafter and is registered in CORR. The progress of registered patients is monitored each year (see Section 2.2).

Renal replacement therapy (RRT): Procedures of hemodialysis, peritoneal dialysis and kidney transplantation, which in part temporarily or permanently replace a person's failed kidneys.

Appendix F

Analytical Methods

Age Calculation

The computation of patient age is based on a count of months between birth date and treatment date, which is then divided by 12. This calculation yields a whole number in years. For donors, age is collected in terms of a code (for example, *newborn*, *days*, *months*, *years*) and unit (for example, *2*, *12*, *35*) as birth date is not part of the donor data set. For the purposes of this report, donor age is converted to a year-based whole number.

Cause of Death

In Table 5, the following CORR codes are used for the cause of death categories: cardiac—codes 11, 12, 13, 14, 15, 16, 17, 18; social—codes 50, 51, 52, 53, 54 (includes patients who withdrew from dialysis, but for whom no cause of death or date of death was specified); infections—codes 03, 04, 05, 06, 07, 08, 09, 10, 31, 32, 33, 34, 35, 36, 37, 38, 39, 77; vascular—codes 21, 22, 24, 25, 26, 27, 28, 30, 55, 56, 57; gastrointestinal—codes 02, 20, 23, 29, 62, 68, 70, 72; malignancy—codes 66, 67; accidental—codes 81, 82; other—codes 19, 40, 41, 42, 43, 44, 45, 46, 49, 59, 61, 63, 64, 69, 71, 73, 74, 75, 76, 90, 99; unknown—codes 00, 47, 48. This categorization varies slightly from previously reported data.

Deceased Organ Donors

Deceased organ donors, as described in Section 8, are defined as donors identified in Canadian hospitals from whom at least one organ was recovered and used for transplantation. A donor is different from a donated organ. Donors described under the organ-specific transplant sections of the report, however, include donors from the United States.

Graft Survival

The SAS® PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) graft survival rates. The graft survival rates were computed for first organ-specific grafts for patients who were transplanted in each year from 1995 to 2004 at four intervals: three months, one year, three years and five years. Patients were followed until graft failure, death (with or without a functioning graft) or the end of observation (December 31, 2004). Five-year graft survival is reported for patients transplanted in years 1995 to 1999; three-year survival for patients transplanted in years 1995 to 2001. For all years, three-month and one-year survival rates are presented.

Incident ESRD RRT Patients

Counts and rates are based on patients registered during a given calendar year (January 1 to December 31). An incident patient must start RRT for ESRD in a Canadian facility. Patients who began RRT for ESRD outside of Canada, but are subsequently treated in Canada, are included in registered and prevalent, but not incident counts.

International Comparisons
Figure 1 is based on selected countries as reported by the U.S. Renal Data System. Figures 19 (kidney transplant), 30 (liver transplant) and 37 (heart transplant) compare crude transplant rates for Canada with those for France and the United States. These two countries are used because of the fact that data from these countries were readily available for the entire reporting period used in this report, because of Canada's geographic proximity to the United States and its parallel development in terms of transplantation advances, and because of the close cultural ties of Quebec to France. Figures 46 (lung transplant) and 51 (pancreas transplants) compared Canada transplant rates to the United States only.

Organ Recovery Rates
Organ recovery rates (deceased) described in the report are based on organs recovered and transplanted from deceased donors identified in Canadian hospitals.

Patient Survival
The SAS® PROC LIFETEST method (also known as actuarial survival) is used in the calculation of unadjusted (crude) patient survival rates. For figures 5 to 14 and 21 to 24, patient survival was computed for RRT recipients who started dialysis between the years 1995 and 1999 and followed to 2004 at four intervals: three months, one year, three years and five years. Patients were followed to their first kidney transplant, or until they were lost to follow-up, recovered function, died or the end of observation (December 31, 2004).

For dialysis and transplant patient survival trend analyses, patients starting dialysis or receiving first grafts between 1995 and 2004 were followed for the same four time periods until their deaths, they were lost to follow-up or the end of the observation (December 31, 2004). In addition, patient survival rates for specific patient cohorts receiving liver, heart, lung or pancreas transplants during the period from 1995 to 1999 are also provided. The latter method was used so that each patient in the cohort would have a minimum five-year follow-up period. Titles of the figures/tables identify the cohort used in the analysis.

Adjusted Mortality Risk
The adjusted mortality risk analysis (Cox regression) was used to determine whether or not certain risk factors may be influencing survival or failure times in dialysis and kidney transplant patients.

For the Cox regression analysis, the cohort of dialysis and transplant patients starting dialysis or receiving first grafts between 1995 and 1999 was used. The cohort members were followed until second transplant, their death, loss to follow-up or the end of the observation (December 31, 2004).

Hazard ratio with upper and lower confidence intervals are presented in the following tables, which were used for creating figures 15, 16, 17 and 29.

Adjusted Mortality Risk for Dialysis Patients, Canada, 1995 to 1999, Followed to 2004 (N = 11,445), Pertaining to Figure 15 in Text

Risk Factors	Hazard Ratio	UCL*	LCL†
0–18	0.538	0.94	0.31
18–45	Reference	.	.
45–65	1.689	1.92	1.49
54–65	2.379	2.67	2.12
65–74	3.427	3.83	3.07
75+	5.027	5.63	4.49
Males	1.007	1.06	0.96
Hemodialysis	0.984	1.04	0.93
1995–1996	Reference	.	.
1997–1999	0.889	0.94	0.84
Province 1	1.394	1.61	1.21
Province 2	Reference	.	.
Province 3	1.023	1.16	0.90
Province 4	1.137	1.30	1.00
Province 5	1.266	1.41	1.14
Province 6	1.366	1.55	1.21
Province 7	1.014	1.11	0.93
Province 8	1.060	1.15	0.98
Glomerulonephritis	Reference	.	.
Diabetes	1.433	1.53	1.34
Polycystic/ Pyelonephritis	0.731	0.82	0.65
Drug Induced	1.047	1.29	0.85
Renal Vascular	1.044	1.13	0.97
Other	1.286	1.41	1.17
Caucasian	Reference	.	.
Asian	0.583	0.66	0.51
Black	0.563	0.67	0.47
Aboriginal	1.049	1.18	0.93
Unknown	1.060	1.14	0.99
Other	0.613	0.71	0.53
Cardiac Comorbidity	1.287	1.36	1.22
Vascular Comorbidity	1.275	1.35	1.21

* Upper confidence interval
† Lower confidence interval

Adjusted Mortality Risk for HD Patients, Canada, 1995 to 1999, Followed to 2004 (N = 8,741), Pertaining to Figure 16 in Text

Risk Factors	Hazard Ratio	UCL*	LCL†
0–18	0.505	1.02	0.25
18–45	1.000	.	.
45–65	1.673	1.94	1.44
54–65	2.370	2.71	2.07
65–74	3.326	3.78	2.92
75+	4.859	5.54	4.26
Males	0.995	1.05	0.94
1995–1996	Reference	.	.
1997–1999	0.895	0.95	0.84
Province 1	1.459	1.71	1.24
Province 2	Reference	.	.
Province 3	1.022	1.18	0.89
Province 4	1.099	1.29	0.94
Province 5	1.274	1.43	1.14
Province 6	1.335	1.53	1.16
Province 7	1.022	1.13	0.93
Province 8	1.002	1.11	0.91
Glomerulonephritis	Reference	.	.
Diabetes	1.363	1.47	1.27
Polycystic/ Pyelonephritis	0.768	0.87	0.67
Drug Induced	0.988	1.24	0.79
Renal Vascular	1.009	1.10	0.93
Other	1.233	1.37	1.11
Caucasian	Reference	.	.
Asian	0.596	0.70	0.51
Black	0.518	0.64	0.42
Aboriginal	1.028	1.17	0.90
Unknown	1.034	1.12	0.96
Other	0.571	0.69	0.48
Cardiac Comorbidity	1.261	1.34	1.19
Vascular Comorbidity	1.280	1.36	1.20

* Upper confidence interval
† Lower confidence interval

Adjusted Mortality Risk for Patients Treated With PD, Canada, 1995 to 1999, Followed to 2004 (N = 2,731), Pertaining to Figure 17

Risk Factors	Hazard Ratio	UCL*	LCL†
0–18	0.684	1.70	0.28
18–45	1.000	.	.
45–65	1.707	2.19	1.33
54–65	2.383	2.99	1.90
65–74	3.780	4.69	3.04
75+	5.650	7.10	4.49
Males	1.037	1.15	0.93
CAPD Treatment	0.901	0.99	0.82
1995–1996	Reference	.	.
1997–1999	0.865	0.96	0.78
Province 1	1.169	1.63	0.84
Province 2	Reference	.	.
Province 3	1.082	1.41	0.83
Province 4	1.297	1.67	1.01
Province 5	1.249	1.68	0.93
Province 6	1.522	2.06	1.13
Province 7	0.936	1.21	0.72
Province 8	1.248	1.46	1.07
Glomerulonephritis	Reference	.	.
Diabetes	1.685	1.94	1.47
Polycystic/ Pyelonephritis	0.605	0.80	0.46
Drug Induced	1.452	2.54	0.83
Renal Vascular	1.192	1.41	1.01
Other	1.554	1.95	1.24
Caucasian	Reference	.	.
Asian	0.557	0.70	0.45
Black	0.687	0.94	0.50
Aboriginal	1.154	1.57	0.85
Unknown	1.209	1.45	1.01
Other	0.697	0.88	0.55
Cardiac Comorbidity	1.401	1.58	1.24
Vascular Comorbidity	1.255	1.42	1.11

* Upper confidence interval
† Lower confidence interval

Cox Adjusted Mortality Rates for Kidney Adult Transplants Patients, Canada, 1995 to 1999, Followed to 2004, Pertaining to Figure 29

Risk Factors	Hazard Ratio	UCI*	LCI†
Males	1.0	1.2	0.8
18–44	Reference	.	.
45–54	2.036	2.74	1.51
55–64	3.884	5.15	2.93
65+	6.565	8.95	4.82
1995–1996	Reference	.	.
1997–1998	1.0	1.2	0.8
Treatment Province 1	0.735	1.09	0.5
Treatment Province 2	Reference	.	.
Treatment Province 3	1.959	3.03	1.27
Treatment Province 4	1.129	1.76	0.72
Treatment Province 5	1.014	1.37	0.75
No Diabetes	Reference	.	.
Diabetes Type 1	1.7	2.2	1.3
Diabetes Type 2	2.9	4.0	2.1
Renal Vascular Disease	1.8	2.5	1.3
Living Donor	0.5	0.6	0.4

* Upper confidence interval
† Lower confidence interval

Population Estimates Used in Rate Calculations

Rates presented in this report are either crude or age-specific, and not age-standardized.

Crude rate = (number of cases / population) x 1,000,000
Age-specific rate = (number of cases in age group / population of age group) x 1,000,000

All Canadian population estimates are from the Statistics Canada report, Statistics Canada, CANSIM, table 051-0001, and are based on total population figures for July 1. Population estimates for the U.S. and France are total mid-year population estimates from the United States Census Bureau, International Data Base, at www.census.gov/ipc/www/idbnew.html.

Country	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Canada	29,302,091	29,610,757	29,907,172	30,157,082	30,403,878	30,689,035	31,021,251	31,361,611	31,629,677	31,974,400
U.S.	266,557,091	269,667,391	272,911,760	276,115,288	279,294,713	282,338,631	285,023,886	287,675,526	290,342,554	293,656,824
France	58,149,727	58,388,408	58,623,428	58,866,290	59,116,128	59,381,628	59,658,144	59,925,035	60,180,529	60,424,213

Province	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Alta.*	2,800,927	2,842,579	2,897,575	2,966,642	3,020,731	3,072,938	3,125,682	3,184,564	3,224,979	3,274.349
B.C.†	3,807,449	3,905,659	3,980,335	4,014,219	4,042,119	4,069,619	4,108,576	4,145,104	4,177,640	4,227,592
Man.	1,129,146	1,134,188	1,136,137	1,137,515	1,142,491	1,147,373	1,151,285	1,155,492	1,162,776	1,170,268
Atlantic Provinces‡	2,381,021	2,379,283	2,372,144	2,358,209	2,354,163	2,348,928	2,340,937	2,340,843	2,343,970	2,343,235
Ont.	10,949,976	11,083,052	11,228,284	11,367,018	11,506,359	11,685,380	11,897,647	12,096,627	12,238,300	12,392,721
Que.	7,219,446	7,246,896	7,274,630	7,295,973	7,323,308	7,357,029	7,396,990	7,443,491	7,487,169	7,542,760
Sask.	1,1014,126	1,019,100	1,018,067	1,017,506	1,014,707	1,007,767	1,000,134	995,490	994,843	995,391

* Includes Northwest Territories and Nunavut.
† Includes the Yukon.
‡ Includes New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (see breakdown below).

Atlantic Provinces	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
N.B.	750,979	752,312	752,543	750,551	750,611	750,518	749,890	750,183	750,594	751,384
N.L.	567,442	559,807	551,011	539,932	533,409	528,043	521,986	519,270	519,570	517,027
N.S.	928,193	931,413	932,481	931,907	933,847	933,881	932,389	934,392	936,025	936,960
P.E.I.	134,407	135,751	136,109	135,819	136,296	136,486	136,672	136,998	137,781	137,864
Total—Atlantic Provinces	**2,381,021**	**2,379,283**	**2,372,144**	**2,358,209**	**2,354,163**	**2,348,928**	**2,340,937**	**2,340,843**	**2,343,970**	**2,343,235**

For Table 35, the following child population (<18 years) estimates were used.

Province	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Alta.*	766,725	770,292	776,805	785,075	787,012	788,193	787,870	789,420	785,414	795,515
B.C.†	897,046	912,324	922,209	920,129	914,437	907,328	900,396	889,176	876,470	901,012
Man.	293,954	294,295	293,056	291,355	290,694	289,809	288,338	286,374	284,931	289,581
N.B.	179,589	177,305	174,592	171,255	168,464	165,611	162,339	159,210	156,197	166,724
N.L.	142,602	137,203	131,533	125,831	121,353	117,367	112,995	109,188	106,258	120,738
N.S. and P.E.I.	256,210	255,385	252,244	248,322	245,024	241,738	237,535	233,152	228,860	275,740
Ont.	2,652,689	2,687,527	2,709,476	2,731,584	2,744,445	2,766,649	2,793,673	2,805,072	2,793,643	2,745,893
Que.	1,690,171	1,683,129	1,664,663	1,642,069	1,616,863	1,596,734	1,580,565	1,566,619	1,551,727	1,613,809
Sask.	281,640	280,587	277,114	273,975	269,649	264,349	258,241	253,096	249,097	265061
Total	**7,160,626**	**7,198,047**	**7,201,692**	**7,189,595**	**7,157,941**	**7,137,778**	**7,121,952**	**7,091,307**	**7,032,597**	**7,174,073**

* Includes Northwest Territories and Nunavut.
† Includes the Yukon.

Prevalent Patients

Prevalent patient numbers at year-end are based on the patient-level data, which include registering patients with CORR. These are called prevalent-registered patients, while prevalent ESRD patients present facility numbers, which are obtained on year-end when the Facility Profiles are provided by Canadian renal programs. Within these questionnaires, centres are asked to record the number of patients by their modality at year-end. These counts are compared against registered patients within CORR. Over time, the numbers yielded from the Facility Profiles and patient-level data within CORR have become nearly identical to the dialysis counts. Although converging over time, the counts of patients with a functioning kidney transplant from the Facility Profile and the patient-level data are still divergent. As such, the Facility Profiles might continue to provide the most comprehensive picture of the burden of ESRD on the health care system.

Primary Diagnosis

For extra-renal transplant recipients, primary diagnosis is based on the diagnosis made at the time of the patient's first transplant. In some cases, most usually for liver transplant recipients, more than one diagnosis may be recorded. For kidney transplant recipients, primary diagnosis is based on the diagnosis provided at the time of incident dialysis treatment, as well as diagnosis at the time of kidney transplant for non-pre-emptive kidney transplants.

Registered Patients

Registered patients are patients for whom CORR has patient-level information, and the term includes patients who are being treated at a Canadian renal program with dialysis at year-end or who have a functioning kidney transplant at year-end. Prevalent registered patients were presented in Section 2.2. The prevalent number of registered patients in CORR may vary from prevalent counts provided in the annual Facility Profiles for the following reasons: (1) not all patients will be registered in CORR because they may have started treatment prior to January 1, 1981; (2) incident patients have been under-reported by some reporting centres; and (3) deaths are suspected to be under-reported to CORR, potentially inflating numbers of living patients.

Socio-Economic Status (SES) of ESRD Patients

CORR ESRD data were linked with the Statistics Canada Postal Code Conversion (SCPCC) file to obtain the estimate of the socio-economic status for ESRD patients in Canada. In this analysis, the SES was estimated using the neighbourhood income per person equivalent (IPPE). The IPPE is an estimate of household income that is adjusted for the size of the household, based on data provided by the 1996 Canadian Census. Using the IPPE measure, the income groups for the Canadian population are presented by quintiles in the range of 1 to 5 (low, low-middle, middle, middle-upper and high). For the analysis in this report (Section 9), SES was represented by three categories:

a) **Low income**, including the low and low-middle quintiles;

b) **Middle income**, including the middle quintile; and

c) **High income**, including the middle-upper and high quintiles.

Transplant Recipients

Information presented on transplant recipients in this report looks at recipients of first grafts of a specific organ where transplants occurred at a Canadian transplant facility. For example, if a patient has a combination liver–kidney transplant and has no previous transplant history, she would be included as a first graft recipient for both liver (Section 3) and kidney (Section 2). Tables and figures presented in sections 3 to 7, inclusive, refer either to transplant procedures or recipients, with the latter counting patients only one time for their first organ-specific graft. Recipient characteristics and province-specific rates are based on transplant recipients.

Waiting List

Data reported on patients waiting for transplants come from counts provided by provincial and regional OPOs. Patient-level data are not available. For patients waiting for a kidney transplant, the definition of a pediatric patient was changed in 2002 from under the age of 15 to under the age of 18. This definition is now in line with the definition of pediatric patient used for extra-renal transplants.

Waiting Times

Waiting list times are calculated for patients who received extra-renal transplants, and do not include patients who died while waiting, or those patients withdrawn from the list because they became too sick to undergo a transplant. There is currently no national source of information on wait times for all patients listed for transplantation.

For patients who received a kidney transplant, a proxy measure of waiting time (that is, time spent on dialysis pre-transplant) is used. While this approach avoids the problem of incomplete data on waiting list start dates for prospective kidney transplant recipients within CORR, it does not factor in the waiting time for patients who were listed for a kidney transplant, but for whom no transplant occurred. A wait time of 0 is allocated to patients who received a pre-emptive kidney transplant.