1984-2018

Catalan Heart Transplant Registry

Statistical Report





Catalan Heart Transplant Registry

Statistical Report 1984-2018

Notifying Centres

Hospital Clínic de Barcelona Hospital de la Santa Creu i Sant Pau Hospital Universitari de Bellvitge Hospital Universitari Maternoinfantil Vall d'Hebron

Head of Registry: Organització Catalana de Trasplantaments

Registry Technician: Nuria Trota

Data collection and entry: Eulàlia Roig, Sònia Mirabet, Vicens Brossa (Hospital de la Santa Creu i Sant Pau); José Gonzalez Costello, Josep Roca Elies (Hospital Universitari de Bellvitge); Fèlix Pérez Villa, Maria Angeles Castel, Marta Farrero, Ana García (Hospital Clínic de Barcelona); Dimpna C. Albert, Ferran Gran (Hospital Universitari Maternoinfantil Vall d'Hebron); Nuria Trota, Pedro López (Organització Catalana de Trasplantaments).

Data processing and drafting of the report: Nuria Trota

© Generalitat de Catalunya Departament de Salut

> Edition: Servei Català de la Salut Organització Catalana de Trasplantaments

Barcelona, December 2018

Acknowledgements

The Catalan Transplant Organization (OCATT), which is responsible for the Catalan Heart Transplant Registry, would like to express its appreciation to all the staff members of the centres authorized to perform heart transplants for their contribution to the maintenance of the registry by supplying data and their participation in the preparation of the report through their contributions.

Dr. Jaume Tort i Bardolet Director of OCATT

Address correspondence to:

Nuria Trota Catalan Transplant Organization (OCATT) Edifici Dr. Frederic Duran i Jordà Pg. Taulat 106-116 08005 Barcelona

Email: ntrota@catsalut.cat

http://trasplantaments.gencat.cat

Contents

Introduction	9
Methodological Aspects and Definitions	10
Evolution of Heart Transplants	11
Recipient characteristics	13
Donor characteristics	20
Transplant characteristics	22
Retransplants	25
Survival	27
Mortality	33
Waiting List	37
Heart Transplants in Children	40

Introduction

In 1984, the first heart transplant carried out in Catalonia was performed at Hospital de la Santa Creu i Sant Pau. It was also the first successful heart transplant carried out in Spain. A few years later, in 1991, the Hospital Universitari de Bellvitge began working in this field, and was followed by the Hospital Clínic de Barcelona in 1998. The Hospital Maternoinfantil Vall d'Hebron was authorized to perform heart and heart-lung transplants in 2006 for children and adolescents.

The Heart Transplant Registry was created in 1993 and contains data on the transplants done in Catalonia since 1984. The data on transplants carried out in the 1984-1993 period were gathered retrospectively, but, since 1994, the registry has systematically gathered data as they have become available.

Publishing the registry is one of the objectives of OCATT, as is managing the data of the Registry Advisory Committee, which responds to the information requirements on planning, resource management and the purchase of services of the Catalan Health Service and the Ministry of Health. The registry is also an information source that is accessible to external users, such as healthcare professionals, and responds to the needs of other sectors. In all cases, processing of and access to data is subject to regulations in force on the protection of personal data.

The main aim of this report is to provide information about the activity and characteristics of the heart transplants carried out in Catalonia in 2018, and to describe the evolution of the transplants carried out since 1984. This information is made available to professionals who are directly involved in this treatment, as well as members of the public administration working in the area of healthcare.

Methodological Aspects and Definitions

This report describes the evolution of heart transplants in Catalonia and analyses the characteristics of receivers, donors and transplants, as well as the results obtained.

The Kaplan-Meier method was used to calculate the patient survival rate (time before death). The level of statistical significance of the different curves was evaluated using the Log-rank test. The survival curves break off when the number of cases fell below 10

The probability of receiving a transplantation was calculated bearing in mind the competitive risk model with three events of interest: transplantation, death and removal from the waiting list.

Description of indicators:

Annual transplant rate

The total number of heart transplants carried out during the year at authorized centres, regardless of the place of residence of the receiver, compared with the population of Catalonia (census of 1991, 1996 and, starting in 1997, annual census updates. National Statistics Institute). Expressed per million inhabitants (pmi).

Mortality rate at one month

Percentage of deaths occurring during the 31 days following the heart transplant.

Mortality rate at three months

Percentage of deaths occurring during the 90 days following the heart transplant.

Evolution of Heart Transplants

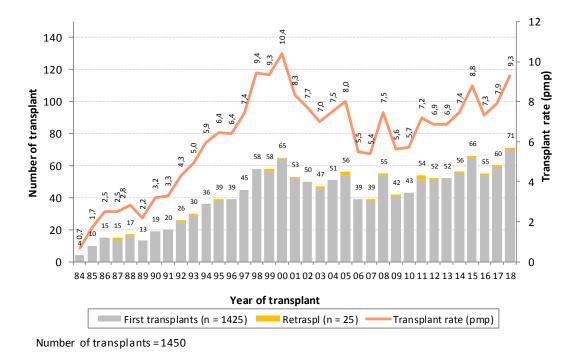
In the 1984-2018 period in Catalonia, 1450 heart transplants were performed: 1425 first transplants and 25 retransplants. These transplants were carried out on 1427 patients; two patients received the first transplant outside Catalonia. 1,4% (20) of the transplants were combined with another organ (Table 1).

Table 1. Number of combined transplants. 1984-2018

	year activity init	n
Heart – pancreas	1988	1
Heart – kidney	1999	14
Heart – lung	2006	2
Heart – liver	2008	3
Total combine	20	

The annual evolution of the number of heart transplants has varied over the years, showing upward trends in 1992 and 1997 (years in which new centres began activity) and until 2000, when the first changes in evolution were registered. In 2018, 71 transplants were performed (Figure 1).

Figure 1. Annual evolution of the number of transplants and annual heart transplant rate. 1984-2018



Because of these changes in trend, the annual rate of heart transplants was also affected and showed a clear upward trend in the 1992-2000 period, but has declined since then. In 2018, the transplant rate was 9.3 per million inhabitants (Figure 1).

The annual heart transplant rate varies considerably between countries. Catalonia shows one of the highest rates of transplant activity (Figure 2). However, these data should be interpreted with caution, bearing in mind different factors that affect transplant activity in each country (the healthcare system, indication criteria, population structure, etc.).

Catalonia Spain 6,9 Germany Austria 7,4 Belgium France Holland 2,2 Italy 3,9 Portugal 3,2 United Kingdom Switzerland Canada 5,2 **United States** 10,5 0 2 6 8 10 12 Transplant rate (per million population)

Figure 2. Heart transplant rate in different countries. 2018

Source: Newsletter Transplant. International Figures on Organ Donation and Transplantation - 2018. 2019. Vol. 24.

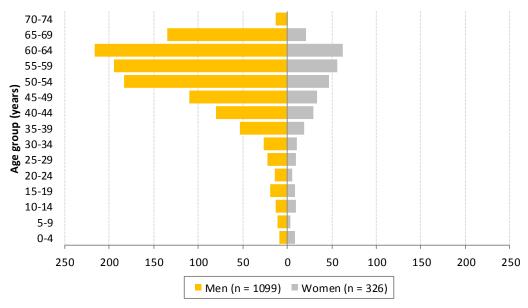
Recipient characteristics

Sex and age

Of the 1425 patients who received transplants (first transplants) in the 1984-2018 period, 1099 (77.1%) were men and 326 (22.9%) were women. In 2018, 52 (74.3%) patients were men and 18 (25.7%) were women.

The mean age of the patients who received their first heart transplant in the 1984-2018 period was 51 (52 for men and 48 for women), the median age was 54 with the range being from age 3 months to 72 years (Figure 3).

Figure 3. Number of patients who received their first heart transplant, by age group and sex. 1984-2018



Number of patients (first transplants) = 1425

In 2018, the mean age was 51 but seven transplants were performed on children under 16 years. Taking into account patients aged 16 or over, the mean age in 2018 was 56 (Figure 4).

In 2018, 30.0% (21) of the patients who received their first transplantation were between 50 and 60 and 37.1% (26) were over 60. In 1997, these percentages were 33.3% (15) and 20.0% (9), respectively (Figure 5).

Globally, 65.1% of patients were 50 or over when they received their first heart transplant. In fact, 52.1% of all patients were men aged 50 or more.

Figure 4. Annual evolution of the mean age of patients receiving their first heart transplant. 1992-2018

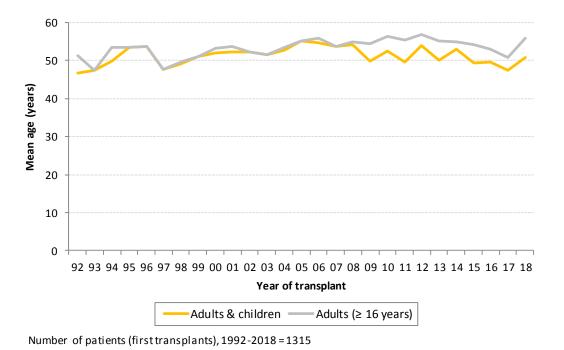
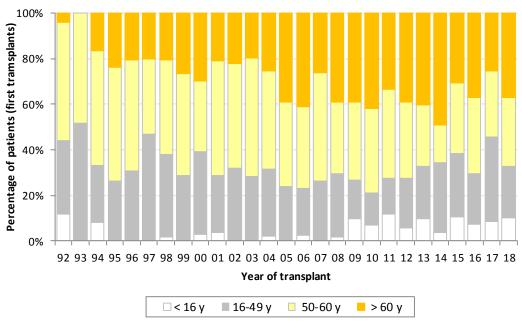


Figure 5. Annual evolution of the percentage of patients who received their first heart transplant, by age group. 1992-2018



Number of patients (first transplants), 1992-2018 = 1315

♦ Place of residence

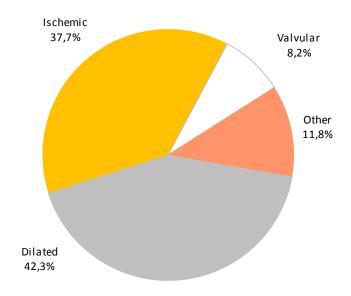
90.1% (n = 1286) of patients receiving transplants were residents of Catalonia, 9.5% (n = 135) were residents of another part of Spain, and 0.4% (n = 6) were foreigners. In general, the patients who were not residents of Catalonia came from the Balearic Islands (n = 88) or the autonomous community of Aragon (n = 15).

♦ Indications

The diseases for which a heart transplant is indicated are arranged in four groups: dilated cardiomyopathy, ischemic cardiomyopathy, valvular cardiomyopathy and the "other" category, which includes restrictive cardiomyopathy, congenital cardiomyopathy and hypertrophic cardiomyopathy.

Dilated cardiomyopathy and ischemic cardiomyopathy have been the two most common indications and represent 42.3% and 37.7%, respectively, of all the heart transplants carried out in Catalonia since 1984 (Figure 6). In the case of men, 44.4% of patients suffered from ischemic cardiomyopathy and 39.8% from dilated cardiomyopathy. In the case of women, the most common indication (50.9%) was dilated cardiomyopathy (Figure 7).

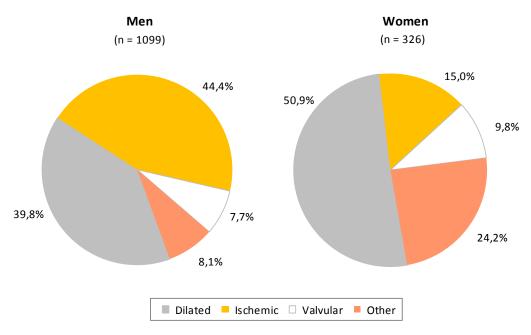
Figure 6. Percentage of patients who received their first heart transplant, by indication. 1984-2018



Number of patients (first transplants) = 1425

Table 2 provides a breakdown of the indications included in the "Other Indications" category.

Figure 7. Percentage of patients who received their first heart transplant, by indication and sex. 1984-2018



Number of patients (first transplants) = 1425

Table 2. Indications included in the "Other Indications" category. 1984-2018

	Men	Women	Global
	n %	n %	n %
Hypertrophic cardiomyopathy	29 (32,69	%) 25 (31,6%)	54 (32,1%)
Restrictive cardiomyopathy	25 (28,19	%) 25 (31,6%)	50 (29,8%)
Congenital disease	29 (32,69	%) 20 (25,3%)	49 (29,2%)
Arrhythmogenic right ventricular dysplasia	5 (5,6%	8 (10,1%)	13 (7,7%)
Sarcoidosis	1 (1,1%	-	1 (0,6%)
Danon disease	-	1 (1,3%)	1 (0,6%)
Total	89 (100%	%) 79 (100%)	168 (100%)

In 2018, 35.7% (n = 25) of the patients with dilated cardiomyopathy, 35.7% (n = 25) with ischemic cardiomyopathy, 8.6% (n = 6) valvular cardiomyopathy and 20.0% (n = 14) with other indications (seven patients with hypertrophic cardiomyopathy, three with restrictive cardiomyopathy, three with congenital disease and one with arrhythmogenic right ventricular dysplasia).

The most common disease has changed over the years. Although dilated cardiomyopathy was the most frequent indication in the early years, the percentages of this disease are now much more similar to those of ischemic cardiomyopathy. At any rate, given the low number of transplants performed annually, it is difficult to assess the slight changes between one year and another (Figures 8 and 9).

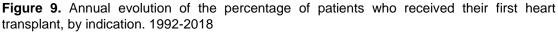
70
60
50
40
30
20
92 93 94 95 96 97 98 99 00 01 02 03 04 05 06 07 08 09 10 11 12 13 14 15 16 17 18

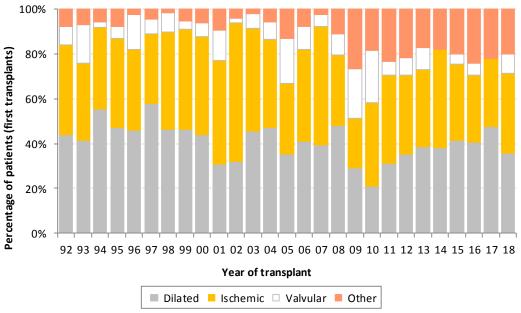
Year of transplant

Dilated Ischemic Valvular Other

Figure 8. Annual evolution of the number of patients who received their first heart transplant, by indication. 1992-2018

Number of patients (first transplants), 1992-2017 = 1315

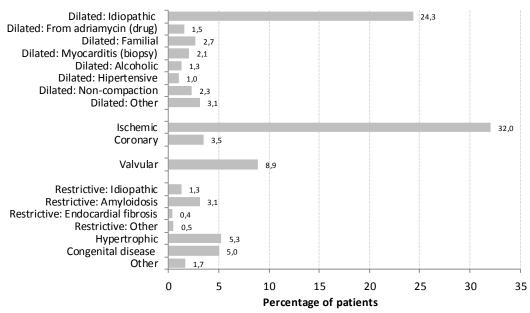




Number of patients (first transplants), 1992-2017 = 1315

In 2004, the registry started using a new system to classify indicated diseases so they could be accounted for more accurately. The most frequent indications in the years from 2004 to 2018 were idiopathic dilated cardiomyopathy, ischemic cardiomyopathy and valvular cardiomyopathy (Figure 10).

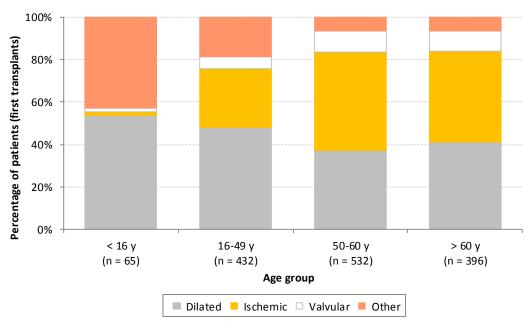
Figure 10. Percentage of patients who received their first heart transplant, by indication. 2004-2018



Number of patients (first transplants) = 777

The most frequent indication in patients younger than 50 years is dilated cardiomyopathy. In patients over 50 years, the percentage of patients with ischemic cardiomyopathy is slightly higher than dilated cardiomyopathy (Figure 11).

Figure 11. Percentage of patients who received their first heart transplant, by indication and age group. 1984-2018



Number of patients (first transplants) = 1425

Statistically significant differences in mean age were observed between the four indications (p < 0.0001): the patients with ischemic cardiomyopathy or valvular cardiomyopathy were older than those who presented with dilated cardiomyopathy (Table 3). The differences between men and women when treated separately were also statistically significant (Table 4).

Table 3. Mean and confidence interval of age, by indication. 1984-2018

	n	mean	IC 95%	range
Dilated cardiomyopathy	603	49	47,7 – 50,2	0 – 72
Ischemic cardiomyopathy	537	55	54,4 - 55,9	1 – 72
Valvular cardiomyopathy	117	55	52,5 - 56,5	7 – 71
Other forms of cardiomyopathy	168	40	36,7 – 42,4	0 – 72
Total	1.425	51	49,9 – 51,4	0 – 72

Table 4. Mean and confidence interval of age, by indication and sex. 1984-2018

		n	mean	IC 95%	range
Dilated	Men	437	49	47,8 – 50,8	0 – 72
cardiomyopathy	Women	166	48	45,6 - 50,6	0 – 69
Ischemic	Men	488	55	54,5 – 56,1	1 – 72
cardiomyopathy	Women	49	54	51 – 56,1	34 – 69
Valvular	Men	85	54	51,8 – 56,5	7 – 71
cardiomyopathy	Women	32	55	51,8 – 59,1	24 – 65
Other forms of	Men	89	41	36,5 – 44,6	1 – 72
cardiomyopathy	Women	79	38	34,4 – 42,5	0 – 67
-	Men	1099	52	50,8 - 52,5	0 – 72
Total	Women	326	47	45,5 – 49,1	0 – 69

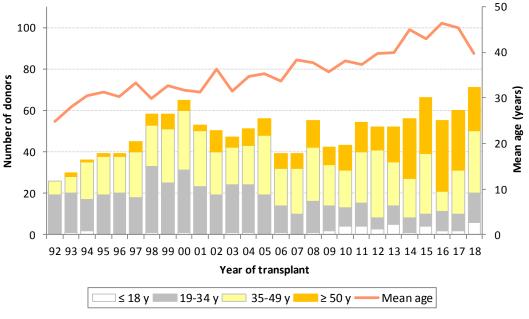
Donor characteristics

Sex and age

Of the 1337 transplants carried out in the 1992-2018 period, 66.8% (n = 893) of the donors were men and 33.2% (n = 444) were women. In 2018, 71.8% (n = 51) were men and 28.2% (n = 20) were women.

The mean age of the donor over the 1984-2018 period was 36, the median age was also 36 and the range was from some months to 74 years (in the 1992-2018 period, the mean age of the donor was 36 and the median age was 37). The mean age has increased over the years, going from 25 in 1992 to 40 in 2018 (Figure 12).

Figure 12. Evolution of the mean age of the donor. 1992-2018



Number of donors = 1337

◆ Cause of death

The most frequent cause of death of the donor was head trauma (HT), which represented 46.9% (n = 680) of all causes, followed by cerebrovascular accident (CVA) / stroke, which represented 41.4% (n = 601) (In the 1992-2018 period, these percentages were 45.1% and 43.0%, respectively).

In keeping with the increase in the age of donors, the number of donors who died from CVA / stroke also increased (Figure 13). In 2018, 36.6% (n = 26) of donors died from head trauma and 46.5% (n = 33) from CVA / stroke.

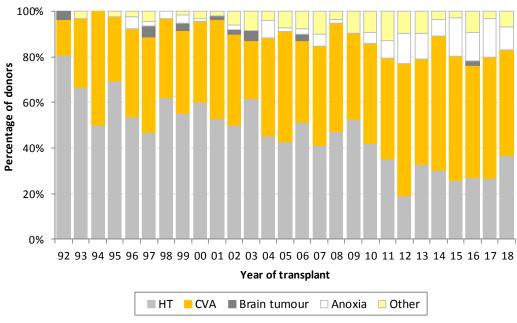


Figure 13. Evolution of the cause of death of donor (%). 1992-2018

Number of donors = 1337

♦ Source of organs

In the 1984-2018 period, 19.8% (n = 287) of the transplanted organs came from the same hospital where the transplant was carried out, 42.9% (n = 622) from other hospitals in Catalonia, and 37.3% (n = 541) from hospitals outside Catalonia. In 2018, 23.9% (n = 17) of the organs came from the same hospital, 23.9% (n = 17) from Catalonia, and 52.1% (n = 37) from outside Catalonia (Figure 14).

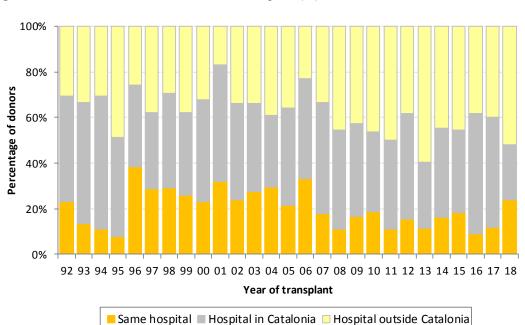


Figure 14. Annual evolution of the source of organs (%). 1992-2018

Number of donors = 1337

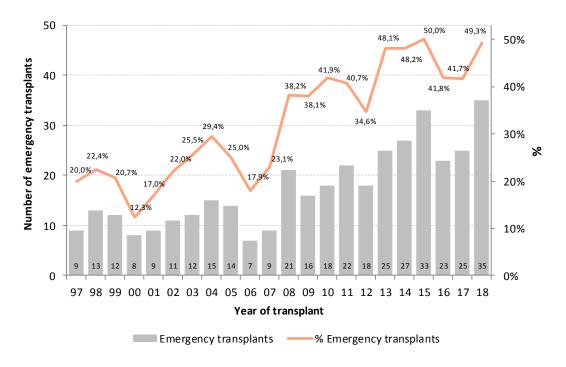
Transplant characteristics

♦ Emergency

Of the 1450 transplants carried out in the 1984-2018 period, 27.7% (401) were emergency. The evolution of the percentage of emergency transplants shows an upward trend (Figure 15).

49.3% (35) of the transplants carried out in 2018 were emergency.

Figure 15. Annual evolution of the number and percentage of emergency transplants. 2000-2018



♦ Assistance device

In keeping with the increase in emergency transplants, the number of patients who received a ventricular assist device prior to transplant also increased (Figure 16). In 2018, 80.0% (28) of the emergency transplanted patients received an assist device: 24 short-term ventricular assist device and four long-term ventricular assist device.

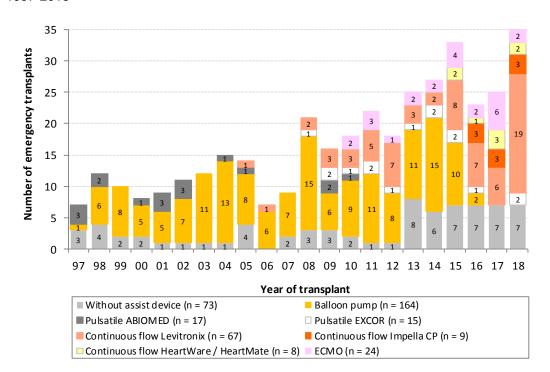


Figure 16. Annual evolution of the ventricular assistance device in emergency transplants. 1997-2018

♦ Ischemia time

The mean ischemia time was 181 minutes. Bearing in mind the source of the organ, the differences observed were statistically significant (p < 0.0001). When the organ came from a hospital outside Catalonia, the mean ischemia time was 74 minutes longer than when the organ came from a hospital in Catalonia (Table 5).

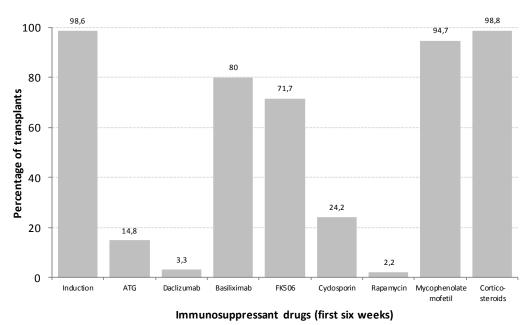
Table 5.	Ischemia time,	in minutes,	in accordance	e with the source	of the organ.	1984-2018
----------	----------------	-------------	---------------	-------------------	---------------	-----------

	Same Hospital	Hospital in Catalonia	Hospital outside Catalonia	Total
	(n = 286)	(n = 619)	(n = 538)	(n = 1443)
Mean	133	159	233	181
Median	127	152,0	235,0	180
Range	50 – 255	64 – 369	80 – 360	50 – 369
95% CI	129,1 – 137	155,6 – 162,7	229,5 - 236,2	178,5 – 184,4

♦ Immunosuppressors

The distribution of immunosuppressors used in the first six weeks after transplant is shown in Figure 17. The overwhelming majority of transplant patients underwent induction immunosuppressive treatment and basiliximab was the drug used most.

Figure 17. Immunosuppressant drugs used in the first six weeks after heart transplant. 2004-2018



Number of transplants = 731

Retransplants

A total of 25 of the 1450 heart transplants (1.7%) carried out in the 1984-2018 period have been retransplanted. Two of these patients received the first transplant outside Catalonia.

The time between one transplantation and the other ranged from 1 day to 20 years ¹. The mean was 6.5 years (the median was 7.5 years). Specifically, 4 patients (17.4%) received a second transplant within the first week after receiving the first, 3 (13.0%) between the first week and three months after receiving the first transplant, 1 (4.3%) between the third month and the first year and 15 (65.2%) after the first year.

Tables 6 and 7 show the main characteristics of the retransplants.

Table 6. Characteristics of the patients who received a retransplantation, by the time elapsed since the first transplantation. 1984-2018

	0 - 3 months	> 3 months
	(n = 7)	(n = 16)
Sex		
Men	5 (71,4%)	13 (81,3%)
Women	2 (28,6%)	3 (18,8%)
Age (years)		
Mean	44	37
Median	42	39,5
Range	35 – 63	15 – 59
Indications		
Dilated cardiomyopathy	2 (28,6%)	10 (62,5%)
Ischemic cardiomyopathy	3 (42,9%)	6 (37,5%)
Valvular cardiomyopathy	-	-
Other forms of cardiomyopathy	2 (28,6%)	-

Of the 7 patients who received a retransplantation in the first three months after the first transplant, four had died (two by infection) at 31 December 2018. Of the 16 patients who received a retransplantation after the third month, 11 had died at 31 December 2018: 2 due to graft vascular disease, 2 due to primary dysfunction of the graft, 2 due to infection and 5 due to other causes.

_

¹ Taking into account the patients who received the transplant and retransplant in Catalonia.

Table 7. Characteristics of the donor and the transplantation (first transplant), by the time elapsed since the first transplantation. 1984-2018

0 - 3 months	> 3 months
(n = 7)	(n = 15)
20	29
23	25
11 – 25	14 – 52
6 (85,7%)	11 (68,8%)
-	3 (18,8%)
1 (14,3%)	2 (12,5%)
144	182
140	160
87 – 230	95 – 300
	(n = 7) 20 23 11 - 25 6 (85,7%) - 1 (14,3%) 144 140

Survival

The survival rate of patients receiving a first heart transplant in Catalonia in the 1984-2018 period was 88% in the first month, 79% in the first year, 74% in the third year, and 71% in the fifth year (Figure 18).

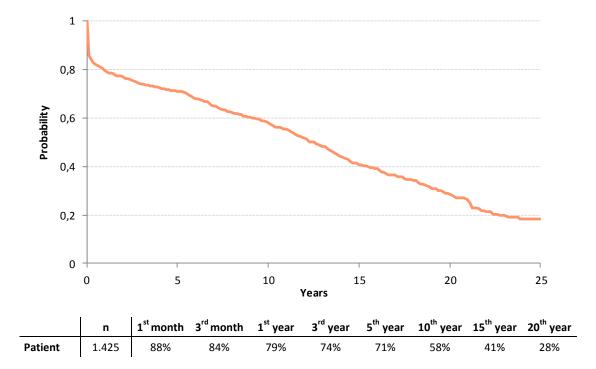


Figure 18. Survival rate of patients receiving a heart transplant. 1984-2018

The overall patient survival rate in the 1984-2018 period was affected by the characteristics of the transplants carried out in the first few years (low number of cases, learning period) and by the factors of the transplants carried out in subsequent years (the inclusion of older patients and patients with a more negative prognosis).

The study by period was divided into six time intervals: 1984-1991, 1992-1996, 1997-2001, 2002-2006, 2007-2011 and 2012-2018. Statistically significant differences were observed between the five periods (p < 0.0001) and between the last two periods (p = 0.008) (Figure 19).

The survival rate percentages were very similar to those of the Spanish and international registries (Table 8).

In order to gain a more up-to-date look at the results, survival rates were prepared with data on the transplants carried out since 1997. In the 1997-2018 period, the patient survival rate was 90% in the first month, 82% in the first year, 76% in the third year, 73% in the fifth year, and 59% in the tenth year.

Probability 0,6 0,4 0,2 1984-1991 1992-1996 1997-2001 p < 0.0001 2002-2006 2007-2011 2012-2018 0 0 2 3 5 6 8 9 10 11 12 13 14 15 Years

Figure 19. Survival rate of patients receiving a heart transplant, by period. 1984-2018

	n	1 st month	1 st year	3 rd year	5 th year	10 th year
1984-1991	110	66%	56%	51%	50%	42%
1992-1996	167	89%	77%	75%	71%	59%
1997-2001	275	87%	80%	73%	69%	56%
2002-2006	240	89%	82%	76%	75%	61%
2007-2011	227	87%	79%	73%	69%	57%
2012-2018	406	94%	85%	80%	77%	-

Table 8. Survival: Data comparing the Catalan (RTCC), Spanish $(RETC)^2$ and international registries $(ISHLT)^3$. 2009-2018

	RTCC	RETC	ISHLT
	(2009-2018)	(2009-2018)	(2010-6/2017)
1 st month	0,92	0,87	0,93
1 st year	0,83	0,78	0,86
5 th year	0,74	0,70	0,75

28

² González-Vílchez F, et al. Registro Español de Trasplante Cardíaco. XXX Informe Oficial de la Sección de Insuficiencia Cardíaca y Trasplante Cardíaco de la Sociedad Española de Cardiología (1984-2018). Rev Esp Cardiol. 2019;72(11):954-962.

³ International Society for Heart and Lung Transplantation (available at: http://www.ishlt.org).

The long-term survival rate was lower for men than women (Figure 20), the differences were statistically significant (p = 0.014).

Figure 20. Survival rate of patients receiving a heart transplant, by sex. 1997-2018

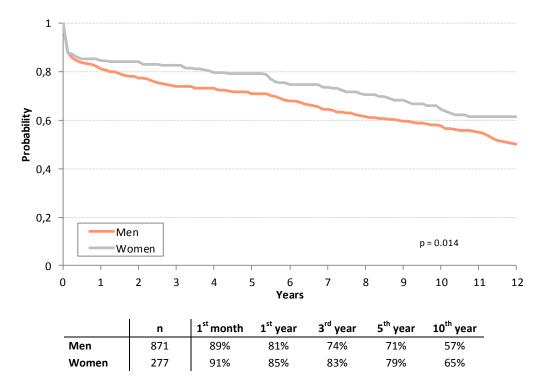
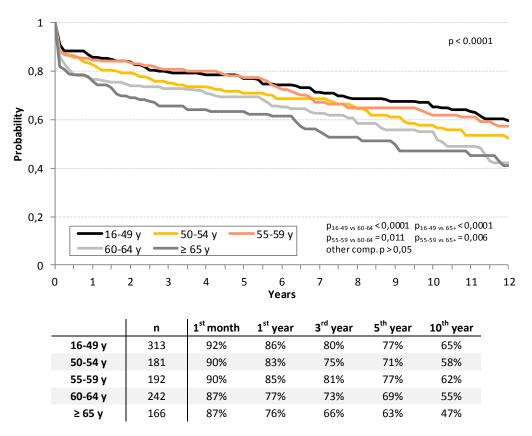


Figure 21. Survival rate of patients age 16 and older receiving their first heart transplant, by age group. 1997-2018



Other

152

93%

Patients over the age of 60 have the lowest survival rate, with statistically significant differences (p < 0.0001) (Figure 21).

Bearing in mind the indicated disease, the patients with ischemic cardiomyopathy, who had the lowest survival rate (Figure 22). The differences between the four diagnostic groups were statistically significant (p < 0.0001) and also the differences between the two most represented diagnostic categories (p < 0.0001).

1 p < 0.0001 0,8 Probability 0,4 0,2 p_{Dilated vs Ischemic} < 0.0001 Dilated Ischemic p_{Ischemic vs Other} = 0.005 Valvular Other other comp. p > 0.050 0 2 3 4 5 6 7 8 9 10 11 12 Years 10th yea<u>r</u> 1st year 3rd year 5th year 1st month n Dilated 458 92% 84% 79% 76% 66% Ischemic 86% 70% 67% 444 78% 51% Valvular 76% 94 89% 84% 81% 60%

Figure 22. Survival rate of patients receiving a heart transplant, by indication. 1997-2018

When the survival rate was analysed based on the time elapsed between the extraction of the organ and the time of the transplant, it was observed that the probability of survival was greater when the ischemia time was less than or equal to four hours (p = 0.002) (Figure 23).

88%

82%

77%

62%

There are statistically significant differences (p = 0.003) in survival rates of patients depending on whether the transplant was an emergency or elective (Figure 24).

Taking into account the different devices used in emergency transplants, the most serious patients have a lower survival rate (Figure 25).

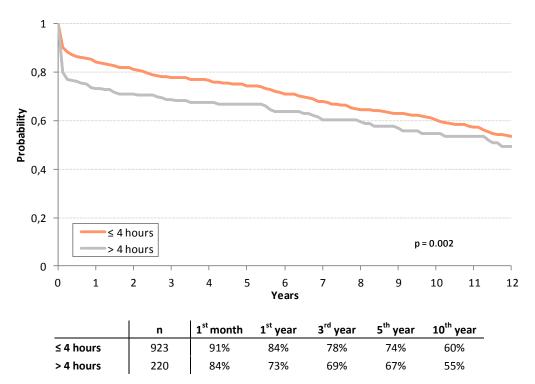


Figure 23. Survival rate of patients receiving a heart transplant, by ischemia time. 1997-2018

Figure 24. Survival rate of patients receiving a heart transplant, by emergency. 1997-2018

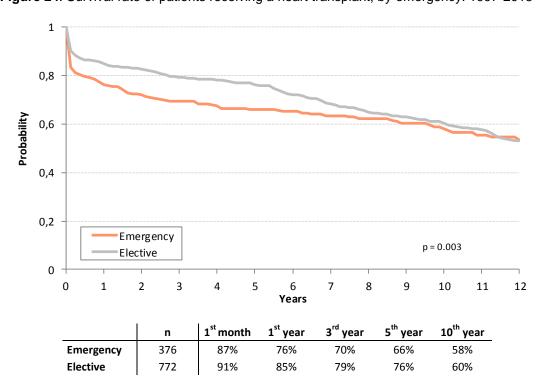
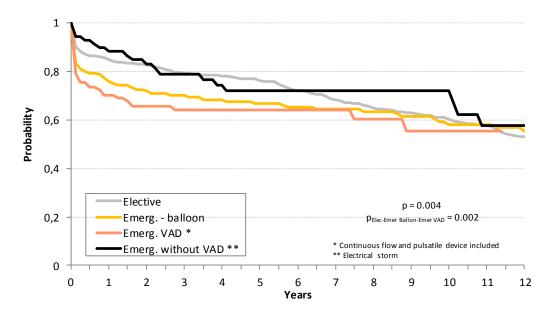


Figure 25. Survival rate of patients receiving a heart transplant, by emergency and ventricular assistance device. 1997-2018



	n	1 st month	1 st year	3 rd year	5 th year	10 th year
Elective	772	91%	85%	79%	76%	60%
Emerg balloon	164	89%	76%	70%	67%	58%
Emerg. VAD	113	82%	70%	64%	64%	55%
Emerg. without VAD	70	96%	88%	79%	72%	72%

Mortality

Of the 1427 patients receiving a transplant in the 1984-2018 period, 735 (51.5%) had died at 31 December 2018, 685 (48.0%) remained alive, and monitoring could not be continued on 7 (0.5%).

The most common causes of death were infection (20.4%), neoplasm (14.8%), primary dysfunction of the graft (13.5%) and graft vascular disease (12.1%). The first three causes alone accounted 50% of all deaths (Figure 26).

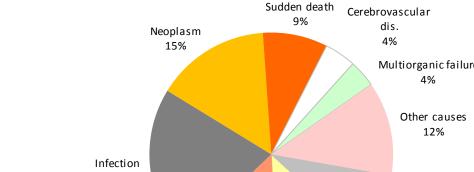
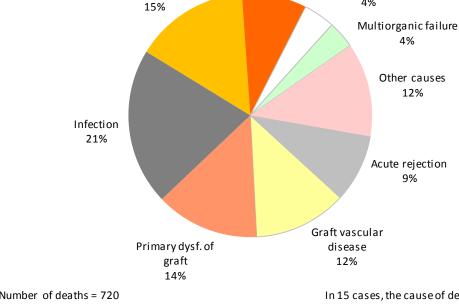


Figure 26. Percentage of deaths, by cause of death. 1984-2018

Number of deaths = 720 In 15 cases, the cause of death was unk



When the sex of the patient was considered, these four causes of death were the same, though the percentages for each sex varied (Figure 27).

In 24.1% of cases, death occurred in the first month after transplantation (Figure 28) and the main cause of death was primary dysfunction of the graft (Figure 29).

The mortality rate at one moth is 12.8% (10.7% in 1997-2018 period and 9.7% in 2002-2018 period). In 2018, the mortality rate at one month was 7.0%, upper than the year before (Figure 30).

Figure 27. Percentage of deaths, by cause of death and sex. 1984-2018

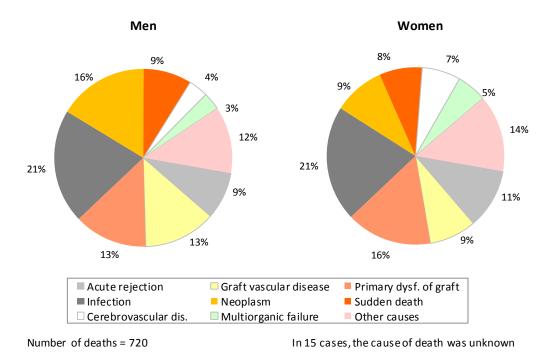
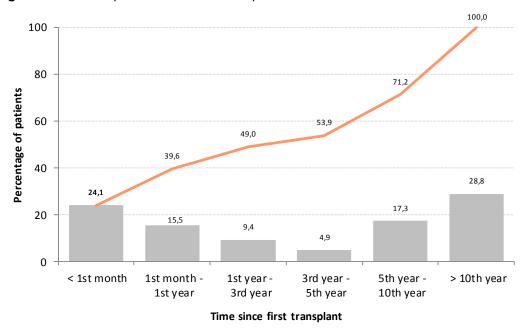


Figure 28. Time elapsed between the transplantation and death. 1984-2018



Number of deaths = 735

Figure 29. Percentage of deaths by cause of death and time elapsed since the transplantation, patients who received a single heart transplant. 1984-2018

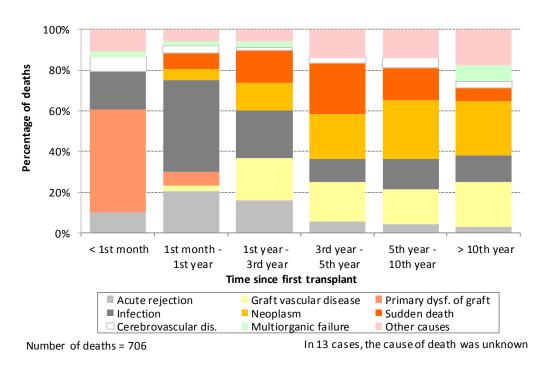
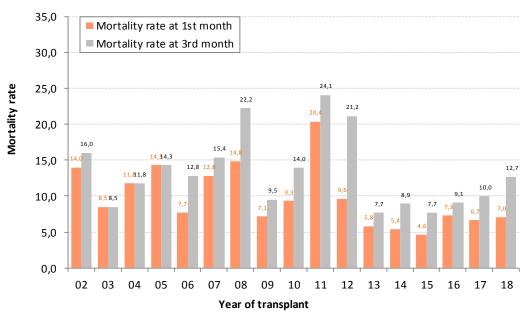


Figure 30. Evolution of the mortality rate at first and third months after the heart transplant. 2002-2018

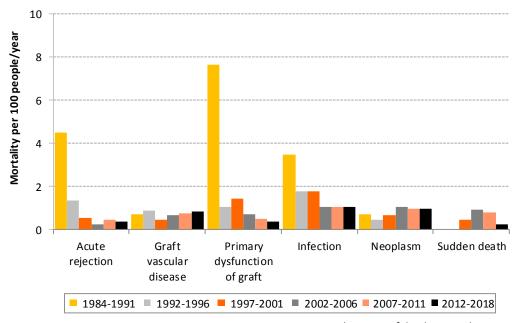


Mortality rate at 1st month, 2002-2018 = 9,7% Mortality rate at 3rd month, 2002-2018 = 13,2%

Mortality was analysed in terms of percentage (per 100 people/year) in relation to the period (year of death). The 1984-1991 period was clearly the one with the highest mortality rate (18.06%), whereas in subsequent periods the mortality rate was less than half the rate of the first period (1992-1996: 7.12%; 1997-2001: 6.25%; 2002-2006: 5.50%; 2007-2011: 6.55%; 2012-2018: 5.20%). Figure 31 shows the

distribution of the cause of death by period, and reflects the drop in mortality due to primary dysfunction of the graft and severe rejection.

Figure 31. Distribution of the cause of death by period, year of death, as a percentage (per 100 people/year). 1984-2018



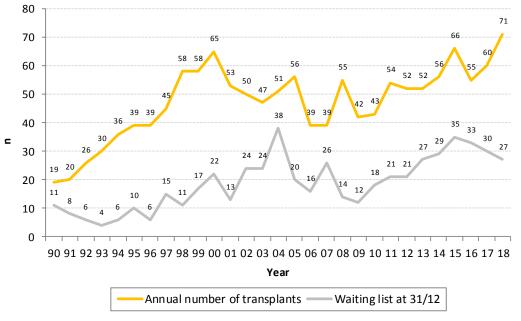
Number of deaths = 720

In 15 cases, the cause of death was unknown

Waiting List

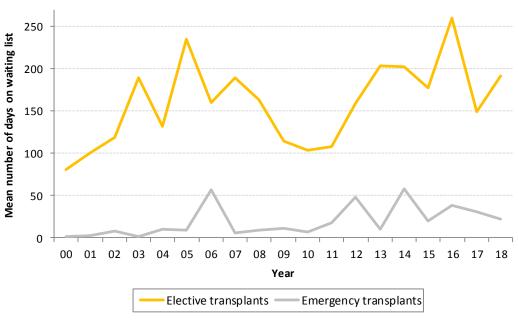
The number of patients on the waiting list at the end of 2018 was lower than in previous years, going from 30 to 27 (Figure 32).

Figure 32. Evolution of the waiting list and the number of heart transplants. 1990-2018



Source: Donor and Transplant Registry

Figure 33. Mean number of days on the waiting list to receive a heart transplant. 2000-2018



Source: Donor and Transplant Registry

In 2018, the mean number of days that a patient was on the waiting list for a heart transplant was 147; 192 days in elective transplants and 22 days in emergency transplants (Figure 33).

In 2018, 78 patients were added to the waiting list. Of the patients taken off the list,4 were removed because their health improved and 1 worsened. The mortality rate of the patients on the waiting list was 6.2% (7). Because of the low number of cases in recent years, the major fluctuations observed should be evaluated with caution (Figure 34).

12 Mortality of patients on waiting list (%) 10,6 10,6 10,5 10.4 10 8.9 8,6 8.3 8,2 8 6.7 6,7 5,6 6 4 2 0 01 02 03 04 05 06 07 08 09 10 11 12 13 14 15 16 17 18 Año % Death % Death + Definitive exclusions

Figure 34. Mortality of patients on the waiting list to receive a heart transplant (%), 2000-2018

Source: Donor and Transplant Registry

In the 2010-2018 period, the probability of receiving a heart transplant in the first six months on the waiting list was 58%; in the first year, it was 73% (Figure 35).

When the probability of receiving a transplant was analysed bearing in mind the patient's blood type, it was observed that patients with blood type A or O have the same probabilities (57% in the first six months and 72% in the first year). Patients with blood type B and AB had higher probabilities, but these probabilities were unreliable due to the low number of cases (Figure 36).

1,0 0,8 0,6 0,4 0,2 0,0 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 Months on waiting list

Figure 35. Probability of receiving a heart transplant. 2010-2018

Source: Donor and Transplant Registry

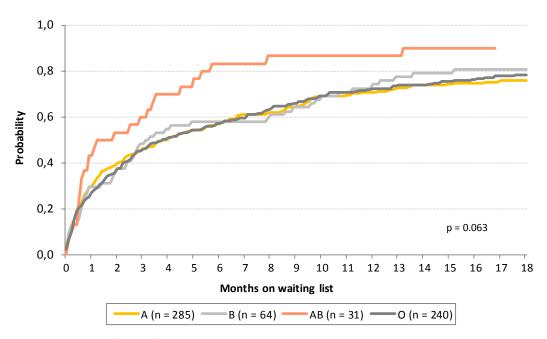


Figure 36. Probability of receiving a heart transplant, by blood type. 2010-2018

Source: Donor and Transplant Registry

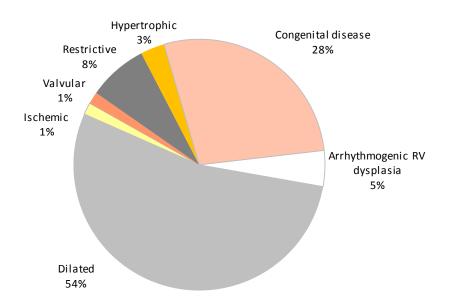
Heart Transplants in Children

Of the 1450 transplants carried out in Catalonia in the 1984-2018 period, 66 were performed on children under 16 years of age (65 first transplants and one retransplant). These transplants were carried out in 66 patients; one patient received the first transplant outside Catalonia. In 2018, 7 transplants were performed.

Of the 65 patients who received heart transplants, 58.5% (38) were men and 41.5% (27) women. The mean age was 9 (median = 9, range = 3 month – 15 years), although 43.1% (28) of patients were 12-15 years.

The two most frequent indications are dilated cardiomyopathy and congenital disease (Figure 37 and 38).

Figure 37. Indications in patients receiving transplants as children (under 16 years of age). 1984-2018



Number of patients (first transplants) = 65

Tables 9 and 10 show the characteristics of the donor and the transplants carried out on children.

Of the 66 patients (under 16 years of age), 17 (25.8%) had died at 31 December 2018.

100% Percentage of patients (first transplants) 80% 60% 40% 20% 0% 12-15 y < 2 y 2-11 y (n = 13) (n = 24)(n = 28)Age group Dilated Ischemic Valvular ■ Restrictive Hypertrophic Congenital disease ☐ Arrhythmogenic RV dysplasia

Figure 38. Indications in patients receiving transplants as children (under 16 years of age) by age group. 1984-2018

Number of patients (first transplants) = 65

Table 9. Characteristics of donors in patients receiving transplants as children (under 16 years of age). 1984-2018

Sex of donor			
Men	34 (51,5%)		
Women	31 (47,0%)		
Missing data	1 (1,5%)		
Donor age (years)			
Mean (± SD)	16 (± 13,0)		
Median	14		
Range	0 – 56		
Cause of donor's death			
НТ	30 (45,5%)		
CVA	12 (18,2%)		
Other	24 (36,4%)		
Source of organ			
Same hospital	13 (19,7%)		
Hospital in Catalonia	10 (15,2%)		
Hospital outside Catalonia	43 (65,2%)		

Table 10. Characteristics of transplants in patients receiving transplants as children (under 16 years of age). 1984-2018

Emergency			
Urgent	40 (60,6%)		
Elective	26 (39,4%)		
Ischemia time (minutes)			
Mean (± SD)	205 (± 57,9)		
Median	213,5		
Range	60 – 340		

