

Heart transplant registry of Catalonia

Statistical report 1984-2000

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Introduction

Catalonia's first heart transplant unit was set up in 1984, in the Hospital de la Santa Creu i Sant Pau. A few years later, in 1991, the Hospital de Bellvitge Prínceps d'Espanya started out its activity in this same field, followed by the Hospital Clínic i Provincial de Barcelona in 1998. These three centres are currently authorised to perform this type of treatment.

The heart transplant registry was started up in 1993, and contains the data on transplants performed in Catalonia since 1984. The data on transplants performed during the 1984-1993 period were compiled retrospectively. The registry has been collecting data periodically and systematically since 1994.

In accordance with its objectives, the registry caters to requests for information from the Catalan Health Service and the Department of Health and Social Security for the planning and management of resources and the purchase of services. The registry is also a source of information that can be accessed by external users, such as health-care professionals, and also attends to requests from other areas. In all cases, the data are issued in accordance with the law in force on the treatment and use of personal data.

The main objective of this document is to disseminate the activity and the characteristics of heart transplants performed in Catalonia from 1984 until 2000, both to professionals directly involved in this treatment and those engaged in health administration.

Evolution of the heart transplant

In Catalonia over the 1984-2000 period, 509 heart transplants were performed on 500 patients. The accumulated transplant rate¹ is 83.6 per million inhabitants (pmp).

In 2000, 65 transplants were performed on 64 patients (one patient received two transplants in the same year), giving an annual transplant rate of 10.7 pmp. According to this indicator, transplant activity in 2000 varied considerably between countries: 8.9 pmp in Spain, 10.9 pmp in Austria, 8.4 pmp in Belgium and Luxembourg, 5.1 pmp in Germany, 2.5 pmp in Holland, 7.9 pmp in the United States and 5.6 pmp in Canada. In any event, these data must be interpreted prudently, taking into account the different factors that have an influence on transplant activity in each country (health system, indication criteria, population structure, etc.)

The annual evolution in the number of transplants has increased continually since 1992, coinciding with the authorisation of a new centre to perform this type of treatment. The figure increased again as of 1997 with the start-up of the third transplant unit (figure 1). In 2000, 7 transplants more than in 1999 were carried out.

Figure 1 Annual evolution in the number of heart transplants. 1984-2000 period.

Of the 500 patients on the registry, 328 (65.6%) were still alive on 31 December 2000, 171 (34.2%) had died and one case was lost to follow-up.

¹ Total number of transplants performed in the period in the authorised centres, regardless of the place of residence of the recipient and the donor source with regard to the population of Catalonia (1996 Census. Institut d'Estadística de Catalunya).

Description of the population

Of the 500 patients who have had a heart transplant, 404 (80.8%) are men and only 96 (19.2%) are women. This distribution is practically the same as for the 1984-1999 period, although the slight increase in women observed in recent years is maintained (21.5% of transplants in the year 2000).

The mean age for patients overall is 49.2 years (49.4 for men and 48.3 for women). In the year 2000 the mean age increased slightly with regard to the previous year, going from 51.6 to 52.5 years (figure 2). In this same year the mean age for men and women is practically the same.

The increase observed over the years is due mainly to the progressive increase in transplants in patients aged above 50 (figure 3). Patients aged between 35 and 64 account for 83.2% of all patients. Men aged between 50 and 64 account for 54% of all men and 44% of all patients. There are 18 patients aged 65 or older; 15 are men, and 6 of these transplants were performed in 2000 (figure 4).

Figure 2 Annual evolution of the mean age of the patients who have had a heart transplant. 1984-2000 period.

Figure 3 Annual evolution of the number of patients who have had a heart transplant, by age group. 1984-2000 period.

Figure 4 Number of patients who have had a heart transplant, by age group and gender. 1984-2000 period.

Of the 500 patients who have had a heart transplant, 450 (90%) live in Catalonia and 50 (10%) in the rest of Spain (basically in the Balearics and Aragon) or abroad. In the year 2000, 62 patients living in Catalonia (96.8%) and 2 (3.2%) from the rest of Spain had a transplant. The trend in recent years towards a reduction in the percentage of transplants in patients that do not live in Catalonia has been maintained.

Table 1 shows the crude rate of cumulative incidence² and prevalence³ of patients who have had a heart transplant, by the health region where they live. The lowest rates are in the Health Regions of Lleida and Tortosa; these regions are geographically furthest away from the centres that perform heart transplants. It should also be remembered that due to the low number of patients in these regions, small variations in activity may modify these rates substantially.

² Cumulative incidence: number of patients that live in Catalonia who had a first heart transplant during the 1984-2000 period (new cases), with regard to the population of each health region and that of Catalonia (1996 Census. Institut d'Estadística de Catalunya), per million of population.

³ Prevalence: number of patients that live in Catalonia who had a first heart transplant and were alive on 31 December 2000 (prevailing cases), with regard to the population of each health region and that of Catalonia (1996 Census. Institut d'Estadística de Catalunya), per million of population.

Table 1 Crude rate of cumulative incidence (1984-2000) and prevalence (31 December 2000) of the first transplants in patients living in Catalonia by the health region where they live.

pmp: per million inhabitants.

In order to minimize the effect of some factors (demographic characteristics, for example) that may cause distortions when comparing crude rates between different communities, the rates of incidence by age and gender are standardized by the indirect method. Thus, figure 5 shows that the standardized rate of incidence⁴ in most regions is around the global rate for Catalonia and those furthest off are still Lleida and Tortosa. The confidence interval of the estimated rate is broader in the regions with fewer cases. Thus, in the case of Tortosa, for example, the rate of incidence is between 0.6 and 59.8 pmp with a 95% probability. The differences between the rates of these two regions and the overall rate for Catalonia are statistically significant, since in neither of these two cases does the confidence interval comprise the value of the rate of Catalonia.

Figure 5 Standardized rate of cumulative incidence of first transplants in patients that live in Catalonia, by the health regions where they live. 1984-2000 period.

CI 95%: confidence interval of 95%.

pmp: per million inhabitants.

⁴ Standardized rate of cumulative incidence by age and gender, by the indirect method: this method consists of applying the specific rates of incidence for each group of age and gender of a standard or reference population to the actual groups of the study populations, in this case the health regions. The reference population used is the overall population of Catalonia (1996 Census. Institut d'Estadística de Catalunya). One of the limitations of this method is that it only allows comparison of the rates for each region to that of Catalonia, but not between regions.

Indications

The indications for heart transplant of the patients on the registry are grouped into the following categories:

- Dilated heart disease
- Ischemic heart disease
- Valvular heart disease
- Other (Congestive cardiomyopathy, Congenital heart disease, Restrictive hypertrophic cardiomyopathy, ...)

The most frequent indication for heart transplant for the 1984-2000 period, for men and women, is dilated heart disease (49.6% of all patients: 45.8% men and 65.6% women), followed by ischemic heart disease (36.8% of all indications). In this case, 94.6% of the patients presenting this indication are men (figure 6).

Figure 6 Number of patients who have had a heart transplant, by indication and gender. 1984-2000 period.

The annual evolution in the number of patients according to the indication shows that dilated heart disease was the most frequent up to 1998. In 1999 and 2000, ischemic heart disease, which had started to increase as of 1997, accounted for the same percentage as dilated heart disease (43.8% of all transplants in 2000, in both cases) (figures 7 and 8). The annual evolution in patients with valvular heart disease or any of the heart diseases of the *others* category, due to their low number, is very heterogeneous.

Figure 7 Annual evolution of the number of patients who have had a heart transplant, per indication. 1984-2000 period.

Figure 8 Annual evolution of the percentage of patients who have had a heart transplant, by indication. 1984-2000 period.

The mean age shows statistically significant differences ($p < 0.0001$) between the different indications (Table 2). The differences are maintained when this variable is analysed separately in men ($p < 0.0001$) and women ($p = 0.004$).

Fifteen percent (15%) of patients with dilated heart disease and 36% of the "Other" category are under the age of 30. In this case, as well as in valvular heart disease, it should be remembered that the low number of cases may affect the mean age.

Table 2 Mean age by indication and gender. 1984-2000 period.

O: Mean age in years

CI 95%: Confidence interval of 95%

Survival

The actuarial method was used to calculate the survival of patients who have had a heart transplant and the level of statistical significance was evaluated between the different curves with the Wilcoxon test. The survival curves were interrupted when the number of cases fell below 10.

On studying overall survival for the 1984-2000 period, it can be seen that patients who have had a heart transplant have a 73.6% survival probability after one year, 70.0% after 3 years, 66.6% after 5 years and 58.5% after 10 years.

It must also be remembered that overall survival is affected by the characteristics of the transplants performed during the early years (low number of cases, a new technique) and other factors of transplants performed in subsequent years (inclusion of patients with a poorer prognosis and older patients). To ensure that the result are as well adapted as possible to the context of each stage, three periods were defined to analyse survival (figure 9). Thus, differences can be observed between the three periods, even though the differences between the second and third are not statistically significant.

Figure 9 Survival of patients who have had a heart transplant. 1984-2000 period.

The different analyses of survival presented below were performed using the data from transplants performed as of 1992, since the current heart transplant behaviour is more adapted to the survival pattern observed in this period.

The survival of patients by gender presents no statistically significant differences ($p=0.6$), even although men have a slightly higher survival rate than women (figure 10).

Figure 10 Survival of patients who have had a heart transplant, by gender. 1992-2000 period.

In view of the low number of patients aged under 15 years (5 cases) who received a transplant after 1992, this group was not included in the by-age survival analysis (figure 11).

The group of patients aged between 15 and 49 years has a better survival than older patients, although this difference is not statistically significant ($p=0.5$), as neither are those observed on comparing age groups to each other (figure 11). The biggest difference (8%) is to be found in survival after three years between patients aged 15 to 49 years and those above 60 years.

The survival of patients according to the indication shows non-statistically significant differences ($p=0.4$). Patients who have had a transplant for dilated heart disease are those who generally speaking have a better survival rate, whereas patients with ischemic heart disease present a worse survival rate (figure 12). The differences between these two groups of patients (6% in the first three months, 8% after one year and 6% after 3 years) ($p=0.08$) and those observed on comparing the other groups of indication to each other are not significant ($p=0.4$).

Figure 11 Survival of patients aged above 15 years who have had a heart transplant, by age group. 1992-2000 period.

Figure 12 Survival of the patients who have had a heart transplant, by indication. 1992-2000 period.

* Number of cases < 10.

Mortality

Of all the patients who had a transplant during the 1984-2000 period, 171 have died (34.9% of the men and 31.3% of the women), representing an overall mortality rate⁵ of 34.2%.

Of the 171 patients who died, 84 (49.1%) did so over the first 30 days post-transplant. This constitutes a mortality rate after 30 days⁶ of 16.8%. This indicator is used to describe mortality associated with the technique or with other factors such as indication or the availability of organs.

17.6% of the men and 13.5% of the women died over the first 30 days post-transplant.

Table 3 Annual evolution of overall mortality rates and mortality after 30 days in patients who have had a heart transplant. 1984-2000 period.

* Does not include follow-up of 4 patients who received the transplant in December 2000.

The evolution of these data shows a decreasing trend, although fluctuations caused by the low number of cases should be taken into account, particularly in the 1984-1990 period. Mortality after 30 days fell for the period in question as well as in the year 2000.

The most frequent causes of death are graft dysfunction, infections and acute rejection (figure 13). These 3 causes account for 60.2% of all deaths.

64.3% of the deaths that take place in the 30 days post-transplant are due to graft dysfunction and infections (figure 14); in the group of patients who died 30 days after the transplant the most frequent causes are infections, acute rejection and malignancies. These three causes account for 52.8% of all deaths after 30 days.

Figure 13 Distribution of the number of deaths, by gender and cause of death. 1984-2000 period.

Figure 14 Distribution of the causes of death, according to the time elapsed as of the transplant. 1984-2000 period.

⁵ Overall mortality: percentage of deaths taking place at any moment over a given period of time in the population of heart transplant patients, it being assumed that almost all the deaths took place for causes directly related to the transplant or heart condition.

⁶ Mortality after 30 days: percentage of deaths taking place in the first 30 days after the transplant, over a given period of time in the population of heart transplant patients, it being assumed that almost all the deaths took place for causes directly related to the transplant or heart condition.

Donation data

Table 4 shows some of the data on heart donation, depending on the origin of the transplanted organ.

21.8% of the organs come from the same hospital where the transplant was carried out, 45.8% from other hospitals in Catalonia and 32.4% from hospitals outside Catalonia.

Mean donor age (29.8 years) shows no differences according to the origin of the organ ($p=0.6$).

On analysing the means of ischemia time according to the origin of the organ, statistically significant differences are observed ($p<0.0001$).

The most frequent cause of death of the donor is craniocerebral injury (60.8% of all causes). Although there are differences according to the source of the organ, they are not statistically significant ($p=0.5$).

Table 4 Specific data on transplants, the organs transplanted and donors. 1984-2000 period.

* In 9 cases information on cold ischemia time is not available