



## Multifactorial Snowball Effect in the Reduction of Refusals for Organ Procurement

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### ABSTRACT

Interviewing the family of a possible organ donor is a legal requirement in Spain, but it is the stage at which most potential donors are lost. Multiple factors influence the family's acceptance or rejection of this option, including awareness of the wishes of the deceased, personal preconceived attitudes of family members, as well as issues related to the hospital and its health care personnel, whose attitudes are a key factor in obtaining permission. We examined all 651 donation situations in a single hospital that included a family interview over the last 15 years. Among these 651 cases, 191 families refused donation (29.3%). The rate of donation refusal has fallen from 46.3% to 12.5% over these 15 years. To better understand the evolution of donor characteristics, interviewees, and the setting, we divided the sample into three 5-year periods to analyze key variables collected from the family interviews. The results showed that at the same time as the donor profile has changed, namely, fewer brain trauma cases and more victims of stroke as well as older mean age and more coexistent diseases, there has been an improvement in the factors related to the information and opinion of both the families and the donor about this process. The main reasons for refusal of donation have changed from negation of brain death, religious factors, and the desire to maintain the body intact during the 1990s, to sociocultural reasons in minority ethnic groups, to presumed refusal during life, and to family disagreements during the more recent years.

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**F**AMILY REFUSAL at the hospital interview after confirmation of brain death is currently the main reason for the loss of potential donors. Efforts have been undertaken from several different directions to change this tendency. After reducing the number of possible donors who are lost because of family refusal,<sup>1</sup> the rate of donation in the province of Malaga, Spain has reached 41 donors per million person. Analysis of the social changes, modifications in the attitudes of interviewed family members, and increased information concerning the wishes of the deceased about organ donation are key aspects that must be further examined to understand this problem.

### MATERIALS AND METHODS

We studied the information concerning all possible donations ( $n = 651$ ) that included a family interview over the last 15 years (1990 to 2004) in a single 900-bed hospital with a neurosurgery service and a catchment population approaching one million persons. The percentage of family refusals was calculated by dividing the number of refusals by the total number of families interviewed. To better understand the changes in the attitudes shown by the families, the reports completed by the transplant coordinators after each dona-

tion interview were grouped into three 5-year periods (period 1: 1990 to 1994; period 2: 1995 to 1999; period 3: 2000 to 2004). The main variables studied were related to the donor, the expressed opinion during the life of the deceased, and the attitudes of the interviewed family members. The statistical analysis was performed with the  $\chi^2$  test.

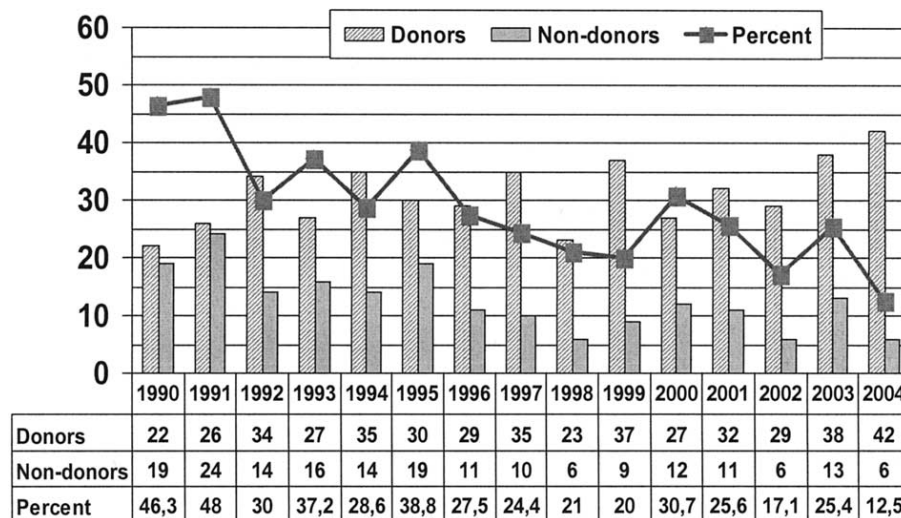
### RESULTS

The total number of possible donors lost because of refusal by the family between 1990 and 2004 was 191 (29.3%). We confirmed a progressive decrease in the loss of donors because of family refusal, namely, from 46.3% in 1990 to 12.5% in 2004 (Fig 1). The loss rates during the 5-year period were: (1) 37.6%; (2) 26.8% and (3) 22.7% ( $\chi^2 =$

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**Fig 1.** Absolute number of effective donors and donors lost due to family refusal, and then percentages of the total number of interviews undertaken each year.

12.2;  $P < .01$ ). During this period of changes not only were there in donor profile (age, cause of death, coexisting conditions), but also in the attitudes of family members attending the interview concerning the wishes of the deceased about organ donation, the possession of a donor card, and conformity with the work of the health care personnel even though they were unable to prevent death. Table 1 summarizes the changes leading to permission or refusal during the interviews concerning some of these variables over the three periods.

## DISCUSSION

A notable increase in the number of organs available for transplant at our center has been achieved by a reduced loss of potential donors due to refusal at the interview of the deceased's family. Analysis and interpretation of factors related to the loss of potential donors due to family refusal are difficult over short-term periods. This study over a 15-year period permitted a wider view of the changes in society, health care professionals, and the interview procedures by transplant coordinators'. The statistical analysis of each 5-year period showed that refusals have fallen in

parallel with increased information and greater confidence in the health care system, which has also seen improvements in the attitudes of its personnel.

The key factors at our hospital improved awareness of family opinions about donation and a slight increase in the number of individuals possessing a donor card. These factors have resulted in an improved inclination of the study population toward donation; thus they should therefore be a basic aim in any type of awareness campaign.<sup>2</sup> Knowing a person who has received a transplanted organ encourages others to donate just as much as or even more than efforts undertaken on an institutional basis. Persons who have received a transplant, their families, and all those on the transplant waiting list should therefore be involved in information campaigns to favor donation.

The main activities concerning social awareness in the province of Malaga during this considerable period of time were related to continuous information campaigns given freely by the local mass media, talks at institutes and schools, further education of teachers about organ donation, information leaflets given out in the 40 largest towns in the province to commemorate Donor's Day, and, with the

**Table 1. Most Notable Characteristics of the Donating and Nondonating Families Over 15 Years (1990–2004)**

	1990–1994		1995–1999		2000–2004		<i>P</i>
	Donors	Nondonors	Donors	Nondonors	Donors	Nondonors	
Donor age (y)*	32.3 ± 17	30.1 ± 14	43.7 ± 15	42.9 ± 12	47.2 ± 14	44.0 ± 15	.01** NS***
Death stroke (%)	40.4	—	46.3	—	61.5	—	.05
Donor card (%)	4.4	—	5.3	—	6.4	—	.05
Talked about donation with family (%)	34.0	21.4	39.2	28.3	51.1	33.6	NA
Know transplanted person (%)	6.1	2.1	8.3	2.6	11.3	3.2	.05
Low or low medium sociocultural level (%)	39.2	65.3	36.7	53.1	32.1	51.0	.01

NA, not applicable.

\*Only 15 years and older.

\*\*Between three periods.

\*\*\*Between each period.

collaboration of transplanted persons and their families, the erection in Malaga of a monument to the donor financed by popular subscription with the help of such events as conferences by nongovernmental organizations.

The number of families who have spontaneously offered to donate, even before brain death has been officially certified, has increased notably over recent years. This improvement is related to confidence in health care personnel and transparency surrounding the key aspects of organ donation, such as brain death, distribution of organs, and benefit to the recipients, as well as perceiving increased ethical standards.

The current interannual refusal rate of 15% is mainly related to minority groups that perceive social separation, immigration, or a low sociocultural level. General information and education is where best to achieve improved attitudes towards donation,<sup>3</sup> although the benefits of these interventions can only be seen over the medium term.

Finally, we should not forget the beneficial snowball effect resulting from increased participation by different

institutions (administration, health care personnel, mass media), who have multiplied their efforts to increase the number of donors to rates that seemed unattainable 15 years ago.<sup>4</sup> Consolidating or even lowering the rates of loss of potential donors due to family refusal is possible, provided that we continue the campaigns within hospitals of social awareness and increase the number of transplant coordinators, who are a key factor in this pursuit.

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