

DECREASE IN REFUSALS TO DONATE IN SPAIN DESPITE NO SUBSTANTIAL CHANGE IN THE POPULATION'S ATTITUDE TOWARDS DONATION

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Summary - Organ donation refusals have progressively decreased in Spain from 25% in 1993 to 15.2% in 2006. Our aim was to analyse whether the general population's attitude towards donation in Spain had changed substantially during this period of time.

A survey was conducted among a representative sample of the population at three different periods, in 1993 (n=1,288), 1999 (n=990) and 2006 (n=1,126), using a specifically designed questionnaire.

No significant changes were observed regarding the population's attitude towards donation of their own organs. Whereas in 1993, 64.5% were willing to become a donor or had a donor card, the corresponding values were 63.9% and 66.5% in 1999 and 2006, respectively. Although there was a significant increase in those who had spoken about donation within the family circle (49.9% in 1999 vs. 57.4% in 2006, $p < 0.05$), there was no significant increase in the degree to which people had communicated their wishes regarding donation (41% vs. 40.7%).

During a thirteen-year period in Spain there have been no substantial changes in the population's general attitude towards donation. This also applies to the amount of communication on that attitude. An improvement in the technique for approaching the relatives may have been decisive for the observed decrease in the rate of refusals.

Introduction

Organ transplantation has become a common lifesaving and life-enhancing procedure, with excellent results. The improved success rates have contributed to a substantial increase in the number of patients awaiting transplantation. However, the number of deceased organ donors and organs available for transplantation has not increased at the same rate. The result is an increasing gap between the number

of patients waiting for a transplant and the number of patients who actually receive a transplant each year¹. Patients deteriorate and even die while waiting for an organ.

Refusals to donate represent one of the most important limitations in the process of deceased organ donation^{2,3}. In relation to the number of families approached, the estimated rate of refusals to donate has been described at 46% in the United States³ and well over 40% in some European countries¹ (Figure 1).

Refusals represent an obstacle for deceased donation, both in countries with presumed consent and with informed consent policies, since no significant differences exist between the two in everyday practice, at least in most European countries⁴. In fact, in many countries with presumed consent, the families are always approached to understand what the wishes of

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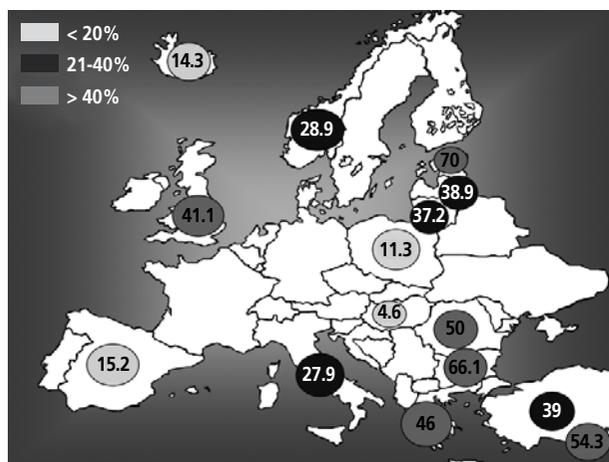


FIGURE 1 - Refusals to organ donation [(number of refusals/number of approached families) x100] in different European countries in the year 2007.

the deceased were on donation and/or to ask for consent to proceed with donation in the event that the wishes of the deceased were unknown. If there is a contradiction between the wishes of the deceased and those of the family, the decision of the latter is usually respected. In fact, this is the case in Spain, which has had a presumed consent policy since 1979, though it is never applied in actual practice^{5,6}.

It is considered that refusals to donate have been highly influenced by the population's attitude towards donation^{7,8,9}. The information the population receives on the subject and the specific characteristics of the population influence this attitude. For instance, several groups within the population have been identified as more reluctant to donate organs, such as minorities and specific ethnic, religious and age groups^{2,10-13}. Another factor that also influences the rate of refusals is the degree to which people have communicated their wishes regarding donation to their relatives^{7,8,9,14}. Lastly, the rate could be highly influenced by the hospital care received and, in particular, the way the interview with the relatives is performed and the manner in which relatives are supported in their time of grief. This is an issue that has not received enough recognition within medical literature¹⁴.

In recent years, a national strategic plan has been developed in Spain to reduce refusals to donate. This plan includes a set of actions aimed at four different targets: the general population, special groups within the population (mass media, minorities, coroners and judges, and others), health care professionals and professionals in charge of approaching the family to request donation.

In the context of this strategy, and in order to generate a positive climate in society towards donation, we have been working closely with the mass media, instead of making significant investments in direct promotional campaigns^{5,6}. Notably, as regards the correct way to approach relatives, great efforts have been made to train all the professionals di-

rectly or indirectly involved in the deceased donation process. Training in this field has not focused exclusively on the request for organ donation, but was placed in the context of a programme aiming to improve communication between health care professionals and relatives of the deceased and to ensure adequate support at the time of mourning.

In parallel to the development of these actions, a slow but progressive decline in refusals to donate has been observed, as shown in Figure 2, and in 2006 refusals to donate decreased to a historical minimum of 15.2%¹⁵. Beyond this, deceased organ donation rates have increased from 21.7 donors pmp in 1993 to 33.7 pmp in 2006, which represents the highest deceased donation rate recorded¹⁵.

The aim of this study was to analyse whether substantial changes have occurred in the general Spanish population regarding the level of information on organ donation and transplantation, attitudes towards donation of their own organs and those of a deceased close family member and the degree to which attitudes towards donation have been discussed within the family circle. This analysis would indirectly help to verify whether the observed decrease in refusals to donate has occurred as a result of a positive change in the previously described issues.

Material and Methods

A survey was conducted on a representative sample of the Spanish peninsular population (15 out of the 17 Spanish regions) of 18 years of age or older at three different periods, in 1993, 1999 and 2006.

Sampling

Samples were selected using the procedure of cluster stratification. Each stratum represented the population of each of the 15 studied regions. The primary sampling units (districts) were selected in a randomised way, proportional to the population of each of the stratum. The secondary units (electoral sections) were selected using a simple randomisation process. The final units (individuals) were selected according to the sex and age rates using the procedure of randomised routes. The sample represented 1,288 individuals (estimated sample error $\pm 2.7\%$ for a confidence level of 95% and $P=Q$) in 1993, 990 (estimated sample error $\pm 3.2\%$ for a confidence level of 95% and $P=Q$) in 1999 and 1,126 individuals (estimated sample error $\pm 2.98\%$ for a confidence level of 95% and $P=Q$) in 2006.

Questionnaire and procedures

A questionnaire was specifically designed for the 1993 survey, as described previously¹⁶. In summary, this questionnaire contains closed questions on socio-demographic data, information on organ donation and transplantation, attitudes

towards donation of own organs as well as organs of a next of kin, reasons to support or not support organ donation and attitudes towards different procedures for requesting organ donation and organ allocation. The questionnaire remained virtually unchanged for the subsequent surveys, apart from the addition of new questions in 1999 and 2006.

The survey was based on an in-house interview administered by professionals who were specifically trained for this task. Prior to the interview, the subjects were informed of the anonymity, confidentiality and independence of their answers, with no acquired commitment derived from their responses.

Statistical analysis

Variables are represented as percentages. Statistical comparisons of the answers to the different questions among the three years were made using the Chi-square test. To address the specific differences between the different option answers, the Z test was applied, with the Bonferroni correction, when applicable. P values <0.05 were considered statistically significant.

Results

The socio-demographic characteristics of the samples are shown in Table 1. In summary, statistically significant changes have occurred over the years regarding the age

distribution of the population. Changes have occurred in almost all of the age strata. Notably, the representation of the population aged 18 to 24 years decreased, while the group aged 65 years or older increased over time. In addition, significant changes were observed regarding the level of studies and the socioeconomic status of the population.

Information on organ donation and transplantation

The evolution of the degree of information on donation and transplantation is shown in Table 2. The perceived degree of information underwent a transient increase over time. A higher percentage of the population acknowledged it had enough information on the topic in 1999 than in the previous and subsequent years. In order to objectively address the population's knowledge, two questions were included in the survey on the cost and efficacy of transplantation when compared to other alternative therapies. Remarkably, more than half of those surveyed did not know or did not answer the question about the cost of transplantation. A low percentage considered transplantation to be less expensive than other alternatives and this percentage was significantly higher in 1999, compared to 1993 and 2006. A high percentage of the population considered transplantation to be more efficacious than other therapies at the three periods, although this percentage was significantly higher in 1999 than in the other two years studied.

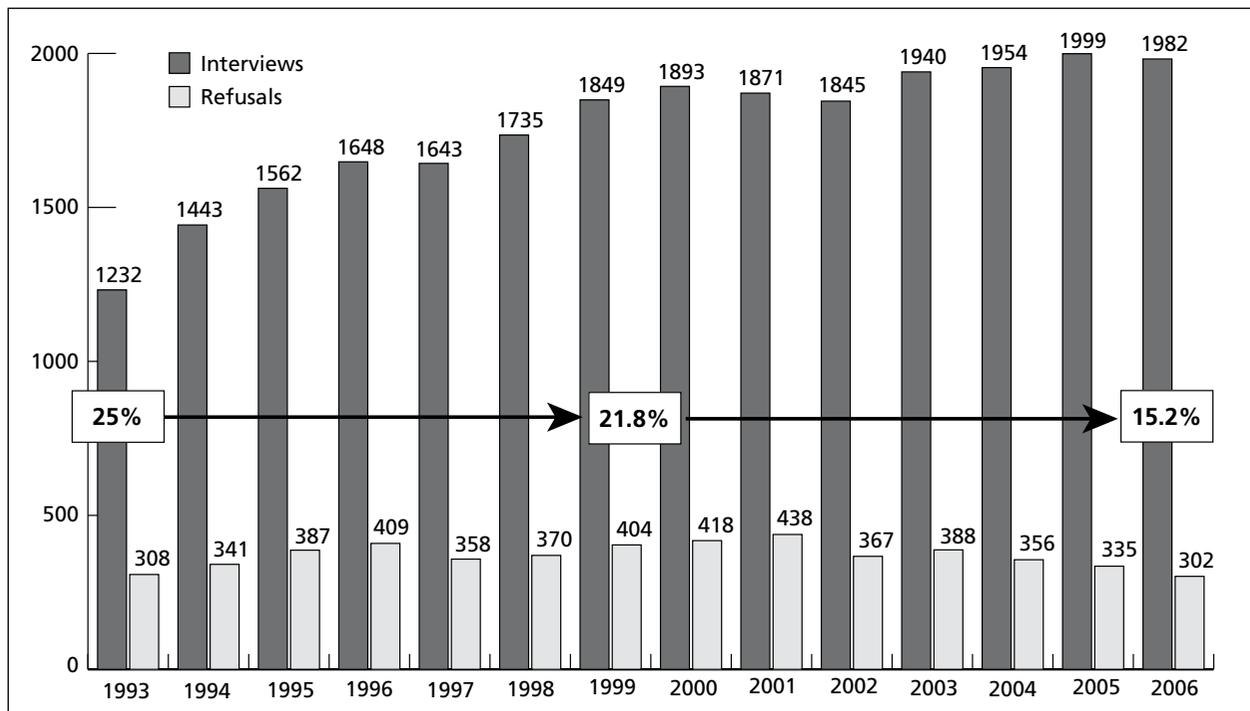


FIGURE 2 - Evolution in the number of families who were approached to request organ donation and the number of refusals to organ donation from 1993 to 2006 in Spain. The rate of refusals to organ donation [(number of refusals/number of approached families) x100] is shown in boxes for the years 1993, 1999 and 2006.

TABLE 1. Demographic and socio-economic characteristics of those surveyed in the years 1993 vs. 1999 vs. 2006				
	1993 (n=1288)	1999 (n=990)	2006 (n=1126)	p
Sex (%Male/Female)	47.6%/ 52.4%	48.1%/ 51.9%	47. 6%/ 52.4%	ns
Age distribution				<0.001
18-24 years	19.9%	16.5%	11.8%	<0.05 ^a
25-34 years	18.8%	17.1%	21.4%	<0.05 ^b
35-44 years	15.9%	16.4%	20.1%	<0.05 ^c
45-54 years	16.0%	17.1%	15.1%	ns
55-64 years	14.9%	16.0%	12.1%	<0.05 ^b
≥ 65 years	14.5%	16.8%	19.5%	<0.05 ^c
Studies				<0.001
Reading-writing	18.1%	18.6%	5.3%	<0.05 ^a
Primary-secondary	62.1%	62.2%	70.1%	<0.05 ^a
Medium-certifications	10.5%	10.2%	12.5%	ns
High-post-graduates	9.2%	9%	12.1%	ns
Socio-economic status				<0.001
High / medium-high	3.2%	4.2%	9.1%	<0.05 ^a
Medium	60.9%	51%	56.2%	<0.05 ^c
Medium-low	26.9%	24.2%	23%	ns
Low	6.6%	12.7%	7.1%	<0.05 ^d

^a 1993 and 1999 vs. 2006
^b 1999 vs. 2006
^c 1993 vs. 2006
^d 1999 vs. 1993 and 2006

TABLE 2. Perceived degree of information on donation and transplantation and knowledge on the cost and efficacy of transplantation, when compared to alternative therapies				
	1993 (n=1288)	1999 (n=990)	2006 (n=1126)	P
Regarding donation and transplantation, the information you have is:				<0.001
Enough	36.6%	48.8%	38.2%	<0.05 ^a
Not enough	58.3%	48%	57.1%	<0.05 ^a
Does not know/answer	5%	3.2%	4.7%	ns
In your opinion, compared to alternative therapies, transplantation is:				< 0.001
More expensive	19.9%	21.4%	21.9%	ns
Equally expensive	11.1%	10.5%	12.3%	ns
Less expensive	13.3%	17%	10%	<0.05 ^b
Does not know/answer	55.7%	51.2%	55.8%	ns
In your opinion, compared to alternative therapies, transplantation is:				< 0.001
More efficacious	56.8%	65.9%	52.2%	<0.05 ^a
Equally efficacious	10.9%	8.7%	11.4%	ns
Less efficacious	2.7%	1.7%	1.8%	ns
Does not know/answer	29.6%	23.8%	34.6%	<0.05 ^c

^a 1999 vs. 1993 and 2006
^b 1993 vs. 2006; 1999 vs. 1993 and 2006
^c 1993 vs. 1999; 2006 vs. 1993 and 2006

To evaluate direct knowledge on transplantation through people who had been involved in the process, three specific items were added to the questionnaire in 1999 and 2006. The percentage of those surveyed who had known someone in need of an organ transplant was 14.2% in 1999 and 20.9% in 2006, and this difference was statistically significant ($p < 0.05$). No significant differences were observed between 1999 and 2006 with regard to the percentage of those surveyed who knew someone who had received a transplant (15% *vs.* 17.8%), or in the percentage that had known someone who had been an organ donor after death (10.7% *vs.* 13.4%).

Attitude towards organ donation

The evolution of personal opinions on organ donors and on the possibility of a close family member becoming an organ donor is shown in Table 3. Although statistically significant differences were observed over the years, the majority of those surveyed expressed an overall very good or good opinion. However, the study performed in 1999 showed more favourable results for both items. As an exception, there was a significant decrease, sustained throughout the years, in the percentage of the population with a very poor opinion on organ donors, a value that remained under 1% in 1999 and 2006.

One of the key items of the survey corresponded to the attitude towards donation of own organs. As can be seen from the answers shown in Figure 3, no statistically significant differences were observed in the answers for the three years studied. Approximately two thirds of the population showed a favourable attitude towards donation of their own organs (had a donor card or were willing to become a donor): 64.5% in 1993, 63.9% in 1999 and 66.5% in 2006. However, a small percentage of the population did have a formal commitment to organ donation (had a donor card).

The attitudes towards allowing organ recovery from a deceased close family member under different degrees of knowledge on the deceased person's wishes about donation were also studied (Table 4). The answers reflect the population's great respect towards the wishes of the deceased. However, there was a progressive decrease over time in the percentage of those surveyed who would not allow recovery if the deceased person was in favour of becoming a donor. In addition, a higher percentage would have allowed recovery in the event that the deceased person was not willing to become a donor in 1999 than in the other two years studied. Finally, there were no significant changes in the answers about allowing organ recovery in the case of not having information on the deceased person's wishes about donation.

Communication within the family circle

Specific items to evaluate the degree of communication within the family circle were added only in the 1999

and 2006 surveys. The percentage of the population that had talked about organ donation within the family circle significantly increased from 49.9% in 1999, to 57.4% in 2006 ($p < 0.05$). In comparison, 49.2% of those surveyed had not talked about organ donation within the family circle in 1999, and this percentage significantly decreased to 42% in 2006 ($p < 0.05$).

In spite of the fact that the issue of transplantation had been more frequently addressed within the family context, the percentage of those surveyed that had communicated their wishes about organ donation to their family did not increase significantly over time (40.7% in 1999 versus 41% in 2006). Accordingly, 57.6% and 56.4% of those surveyed had not informed their families of their wishes regarding organ donation in 1999 and 2006, respectively.

Discussion

Over a 13-year period, a progressive decline in the rate of refusals to donate has been observed in Spain¹⁵. The reason behind this decline could be interpreted, at first glance, as the consequence of having created a more positive attitude among the population towards donation. Another possible explanation would be that the degree of communication regarding donation wishes had increased within the family circle. However, the results of our study failed to demonstrate any of these hypotheses.

First of all, and surprisingly, our study shows that opinions about and attitudes towards donation among the Spanish population, although highly positive throughout the study period, have not improved over time. For instance, although the vast majority of the population had a very good or good opinion about organ donors and about a family member becoming an organ donor, the percentage with a very good opinion on the two issues significantly decreased from 1999 to 2006. In addition, about two thirds of the population were prone to becoming a donor and/or had a donor card at the three studied periods. This fact reflects clear support from our population towards the donation and transplantation system. However, this percentage did not significantly increase during the study period either. Notably, when it came to the point of expressing the attitude towards a deceased close family member becoming a donor, the majority of the population would respect the wishes of the deceased in the three years studied. However, the significant decrease observed in 2006 in the percentage of the population that would allow recovery both when the wishes of the deceased were favourable and when they were not favourable towards donation was remarkable.

Several issues could help to explain the lack of a sustained positive change in the population's opinion about and attitude towards donation over time. Firstly, the perception of

TABLE 3. Opinion on organ donors and on the possibility of a deceased close family member becoming an organ donor				
	1993 (n=1288)	1999 (n=990)	2006 (n=1126)	P
What is your opinion about organ donors?				<0.001
Very good	68.5%	76.5%	68.4%	<0.05 ^a
Good	26.8%	20.7%	27.6%	<0.05 ^a
Indifferent	0.2%	1.8%	2.5%	<0.05 ^b
Poor	0%	0.1%	0.3%	ns
Very poor	3.1%	0.1%	0.4%	<0.05 ^b
Does not know/answer	1.5%	0.8%	0.9%	ns
What would be your opinion about a close family member who becomes a donor?				< 0.001
Very good	-	63%	57%	<0.05 ^c
Good	-	31.9%	34.5%	ns
Indifferent	-	2.5%	2%	ns
Poor	-	0.4%	1.6%	<0.05 ^c
Very poor	-	0.8%	1.4%	ns
Does not know/answer	-	1.5%	3.5%	<0.05 ^c

^a 1999 vs. 1993 and 2006
^b 1993 vs. 1999 and 2006
^c 1999 vs. 2006

TABLE 4. Attitude towards donation of organs from a deceased close family member under different degrees of knowledge on the wishes of the deceased about donation				
	1993 (n=1288)	1999 (n=990)	2006 (n=1126)	P
Would you allow organ recovery from a deceased close family member if you knew s/he was favourable to organ donation?				< 0.001
Yes	93.0%	89.5%	87.0%	<0.05 ^a
No	3.0%	4.2%	6.0%	<0.05 ^b
Does not know/answer	4.0%	6.3%	7.0%	<0.05 ^a
Would you allow organ recovery from a deceased close family member if you knew s/he was not favourable to organ donation?				<0.001
Yes	14.4%	20.0%	12.7%	<0.05 ^a
No	73.4%	63.8%	72.6%	<0.05 ^c
Does not know/answer	12.3%	16.2%	14.7%	<0.05 ^d
Would you allow organ recovery from a deceased close family member if his/her wishes about organ donation were unknown?				ns
Yes	51.6%	51.4%	49.6%	ns
No	24.8%	21.4%	24.4%	ns
Does not know/answer	23.6%	27.2%	25.9%	ns

^a 1993 vs. 1999 and 2006
^b 1993 vs. 2006
^c 1999 vs. 1993 and 2006
^d 1993 vs. 1999

the degree of information on donation and transplantation decreased in 2006 when compared to 1999, returning to a level similar to the one described in 1993. The same behaviour was observed regarding the answers on the cost and efficacy of transplantation, with only a transient increase in the percentage that considered transplantation to be more efficacious and less expensive than other alternative therapies. The decrease in the information and knowledge on donation and transplantation in 2006 may be due to less coverage of the issue in the mass media at that time. Alternatively it could be due to a “normalisation of transplantation” in society. As a result, the Spanish population may have found the information on the topic offered by the media less striking over time. The latter observation may be supported by the finding that, over the years the mass media has become a less important source of information (data not shown).

Secondly, some of the changes in the population’s characteristics may have negatively influenced the attitude and knowledge itself. For instance, the percentage of the population aged over 65 years has increased over time and the advanced age group has been described as more reluctant to donate organs¹¹⁻¹³. In addition, the number of immigrants living in Spain has progressively increased over the years¹⁴. Many of these immigrants belong to cultures and religious groups identified as being less prone to becoming a donor. Unfortunately, information on the country of origin in our samples was only collected for the last year investigated and therefore a comparison regarding this variable was not possible in our study.

Finally, apart from the general attitude towards donation, the other factor that we hypothesise could have influenced the refusal was the degree to which a generally very positive attitude was being communicated within the family circle. It has been shown that the greater the family’s knowledge on the attitude of the deceased towards donation, the more easily a decision can be made^{7,8,9,14}. However, once again, we failed to demonstrate that the degree of communication had increased over time, even though the topic of donation and transplantation seemed to have become more prominent within the family context.

The fact that refusals to donate have decreased over the years in spite of an unchanged, although highly supportive, population’s attitude towards donation and a similar degree of communication of this attitude within the family circle, leads us to conclude that the decrease in refusals to donate may have been highly influenced by the use of a better technique in the approach to the family. This improvement may be related to the efforts made by our system in training professionals to adequately support the relatives in mourning, to establish efficient communication and to carry out an effective interview to request organ donation.

Our study shows that the population’s positive attitude towards donation is necessary but is not enough to decrease refusals to donate and guarantee the success of a deceased donation program. This conclusion can also be derived from recent European Union reports showing that those countries with a better attitude towards donation are not necessarily the ones with lower rates of refusal and higher deceased donation rates¹⁸.

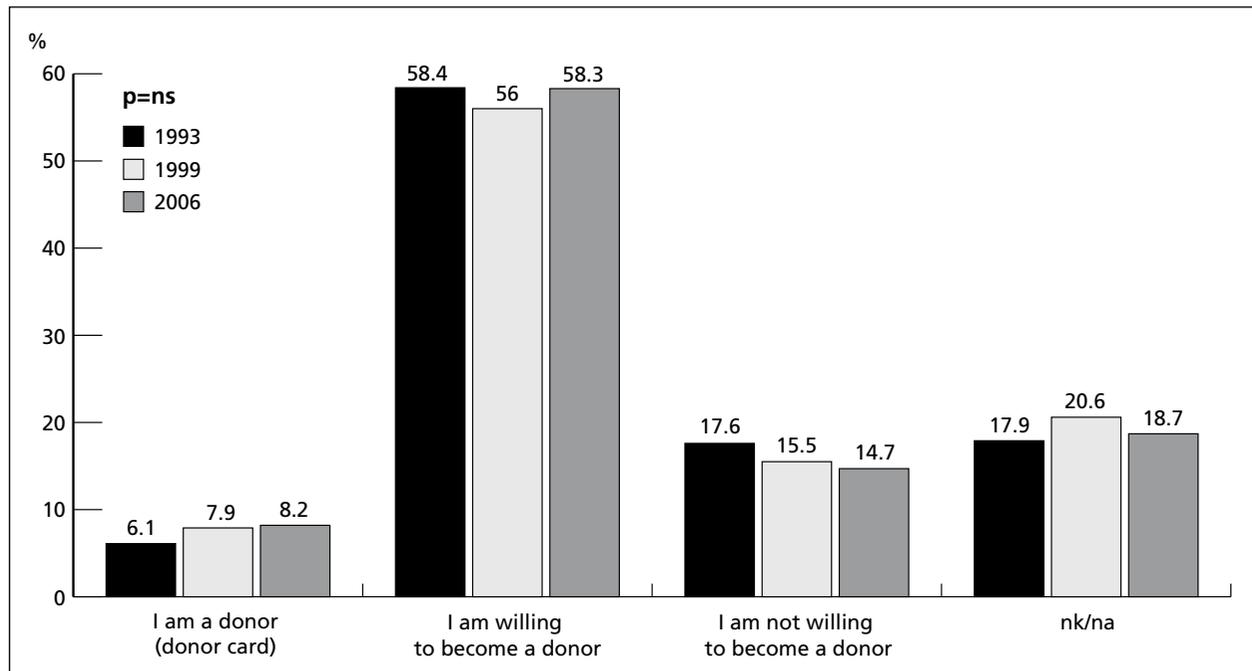


FIGURE 3 - Attitude towards donation of own organs in the 1993, 1999 and 2006 survey.

Decreasing refusals to donate has been addressed through expensive promotional campaigns with little, if any, demonstrated impact on the attitude of the population or the rate of refusals. On the other hand, some have proposed developing legal measures mainly involving the implementation of a policy of presumed consent, which is a change with controversial impact on organ donation rates¹⁹⁻²¹.

Finally, it has been suggested that rewarding the donor's family might be a good way of reducing refusals to donate²², but this measure, apart from very important ethical considerations, may have a very negative effect on the population's opinion on donation and transplantation. In this scenario, where such measures are somehow being balanced by our systems, we believe that even an indirect demonstration of the usefulness of training our professionals in supporting the relatives in their grief and the request for organ donation is of the utmost interest. Training in this field may be one of the key factors to efficiently decrease refusals to donate and increase the availability of donors and organs for transplantation at a time of dramatic shortage.

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