

ORIGINAL ARTICLE

Analysis of the attitudes and motivations of the Spanish population towards organ donation after death

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Summary

Starting with the relevance of the Spanish experience, this study analyses the population's disposition towards organ donation after death by means of a representative survey of the adult Spanish population ($N = 1206$, estimated error $\pm 2.87\%$, $P < 0.05$). Of the participants, 8.1% were declared donors, 59.3% were likely to donate, 14.5% were against donating and 18.1% did not know or did not respond; 87.3% would donate relative's organs if the deceased favoured donation, 50.2% if the deceased's wishes were unknown and 13.1% even if the deceased opposed donation. Among people who were favourable towards donation, the main motives expressed were the will to save other people's lives, solidarity and knowing they might someday need a donation. The most important motives for not donating among participants who were against it were the fear of premature organ extraction, of premature pronouncement of death and of mutilation. Reluctance to donate is associated with low socio-economic and cultural level, advanced age and high religious commitment; it is also associated with a low perception of transplant efficacy, not directly knowing any transplanted people and the lack of qualified information. The results support diverse potentially effective strategies for promoting donation in the general population.

Introduction

Organ transplantation currently depends on the availability of human organs. Their scarcity means that there is a waiting list of almost 63 000 in the European Union [1], and over 100 000 people in the United States [2]. The process of obtaining organs is clearly conditioned by the resources of health services and by health professionals' performance in potential donor identification and management tasks. However, in accordance with the current legislation in Western countries, the generation of organs is ultimately subject to a personal or family decision [3], strongly mediated by psychosocial processes. From these premises, there has been an appeal to complement progress in medical-surgical procedures with psychosocial research [4–6], and to date, an important number of

studies have been developed that have analysed the factors that affect the diverse phases that lead to donation. The existing literature has revealed the crucial importance of the processes that take place at the time of the family decision; however, it has also revealed the influence that both the opinions of the deceased, expressed while still alive, and the relatives' disposition towards donation have on this final decision [7–16]. Therefore, the need to analyse and intervene both in the practices of the professionals involved in the process of organ generation and in the attitudes of the general population has been stressed.

Spain is the country with the highest world rate of donations, having reached a rate of 34.2 deceased organ donors per million person (pmp) in 2008 (the mean of the other European countries attained is 16.9 pmp, the United States 26.3 pmp, Canada 14.6 pmp and Australia

12.1 pmp) [1]. In turn, Spain presents a 17.9% rate of family refusals, in contrast to the known numbers in some countries such as Italy (32.6%) or the United Kingdom (38.1%) [1]. A proactive donor detection programme performed by well-trained transplant coordinators, the introduction of systematic death audits in hospitals and the combination of a positive social atmosphere with adequate economic reimbursement for the hospitals have been cited as key factors for this success [17,18]. Starting with the potential relevance of the Spanish situation for other contexts, the purpose of this study was to analyse the disposition of the general population towards organ donation after death, the underlying motives and to explore its relationship to diverse sociodemographic and informative factors. This would be interesting with an aim to directing the policies of donation promotion within the Spanish context, and to offering useful guidelines to design interventions in other places that start with a lower level of donations.

Materials and methods

Subjects

A random representative sample of the Spanish population, of both genders, fixed on 1206 subjects aged 18 years and above, was used. The sample was computer-designed by means of the stratified cluster-sampling procedure and included, as sampling points, 98 electoral areas belonging to 39 provinces. The selection of primary sampling units (municipalities) was carried out randomly with probability proportional to the population size of each stratum. The secondary units (electoral areas) were chosen in a simple random fashion. The final units (individuals) were randomly selected according to age and gender quotas following standard 'random route' procedures. Sampling error for a confidence level of 95.5% (two sigmas) and $P = Q$ was estimated at $\pm 2.87\%$.

Instrument

The instrument used was the '*Cuestionario de Aspectos Psicosociales de la Donación*' (Questionnaire on Psychosocial Aspects of Donation, CAPD). The previous version – whose design was based on the review of various studies in the field and on interviews with professionals involved in transplant coordination, with representatives of patients' associations and with a wide range of sectors from the general population – had been applied and validated in previous studies [19,20], and was modified and extended for its application in the present study. The CAPD is made up of one open question and 44 closed questions that refer to demographic data, information about organ donation and transplant, intention to donate

one's own and one's relative's organs, reasons for and against donation, and opinions of procedures of request for permission to extract organs and of the distribution of organs. This study presents a summary of the results obtained in the variables considered most relevant.

Procedure

The questionnaire was completed in a personal interview in the subjects' homes by interviewers especially trained for the task. Before the administration of the questionnaire, all participants were informed that this was a study carried out by the Autonomous University of Madrid and they were reassured about the anonymity and confidentiality in the treatment of their responses. Likewise, the lack of any kind of commitment or later request derived from the responses was clarified. All the interviewers were directly supervised and 29.9% of the interviews ($n = 360$) were monitored to ensure that they were performed according to the required conditions.

Data analysis

Descriptive, univariate and multivariate exploratory analysis was performed, applying the procedures of chi-square automatic interaction detection (CHAID) and segmentation analysis, as described below.

Results

Descriptive analysis

Attitude towards donation of one's own organs is positive in a majority of the Spanish population. Although only 8.1% ($n = 98$) of the sample reported being declared organ donors [owning a donor card or having registered as donors in the 'Registro de Últimas Voluntades' (Last Will Register)], 59.3% ($n = 715$) of those interviewed claimed they were not effective declared donors (they have no donor card nor are they registered), but were likely to become one. Another 14.5% ($n = 175$) said, 'I am not a donor, and am not likely to become one'; 17.2% ($n = 207$) responded 'I don't know' and 0.9% ($n = 11$) did not reply. With regard to the intention to donate relatives' organs in the event of their death, a large majority of those interviewed would be likely to donate a relative's organs in those cases in which they knew the deceased had a favourable opinion (87.3%, $n = 1053$), and a small percentage of participants would either refuse permission (5.8%, $n = 70$) or did not know what to respond or did not answer the question (6.9%, $n = 83$). The expressed wishes of the deceased would also prevail if those interviewed knew the deceased was unfavourable towards donation, but to a lesser extent than in the

previous case: 72.4% ($n = 873$) would refuse permission, but 13.1% ($n = 158$) would grant permission, and 14.5% ($n = 175$) did not know what to respond or did not respond in this case. In the case of no knowledge about the relative's will, even though there is a predominance of predisposition to grant permission (50.2%, $n = 606$), a remarkable percentage of subjects would not know what to decide or did not answer (25.9%, $n = 312$) or would refuse permission (23.9%, $n = 288$). Subjects' responses to each of the three situations differed significantly (chi-square = 1751.8, d.f. = 6, $P < 0.001$). In any case, results revealed that only 40.6% ($n = 490$) of the participants have communicated to their family their willingness to donate their own organs.

The perceived influence of different motives for donating and not donating was analysed by means of a four-point scale: (1: 'No influence'; 2: 'Some influence'; 3: 'Quite a lot of influence'; 4: 'A lot of influence'). Individuals who favoured donation (donor card holders, registered donors or people who were likely to donate, $n = 813$) marked the following motives as most influential: 'To save a child's life' (3.79), 'To save other people's

lives' (3.76), 'Solidarity' (3.32), 'The thought that I might need organs from others one day' (3.32), 'To avoid the futile destruction of organs' (2.99) and 'Moral duty' (2.85). Individuals who opposed donation ($n = 175$) stated the following reasons as more influential: 'Fear of the organs being extracted while still alive' (2.47), 'Fear of premature pronouncement of death to extract organs' (2.42), 'Fear of mutilation or deformation of the body' (2.37), 'Desire for a traditional funeral in which the corpse has not been touched' (2.36), 'Refusal to think about things involving death' (2.35) and 'Fear of organs being used improperly or unfairly' (2.35). The individuals who took no previous stance about donating their own organs (responses 'I don't know' or 'no reply', $n = 218$) indicated the following potentially most influential motives to become inclined to donate: 'To save a child's life' (3.59), 'To save other people's lives' (3.54), 'The thought that I might need organs from others one day' (3.16) and 'Solidarity' (2.97). In turn, they indicated the following potentially most influential reasons for not donating: 'I never thought about it' (2.83), 'Fear of premature pronouncement of death to extract organs' (2.57),

Table 1. Relationship of the personal disposition towards donation of one's own organs to sociodemographic variables.

		Disposition towards donation of one's own organs			
		Favourable, <i>n</i> (ASR)	Unfavourable, <i>n</i> (ASR)	DK/DR, <i>n</i> (ASR)	Total, <i>N</i>
Age (chi-square = 63.16, d.f. = 6)*	18–24	103 (1.4)	18 (–0.7)	20 (–1.0)	141
	25–44	379 (4.5)	39 (–5.7)	85 (–0.3)	503
	45–64	215 (–0.5)	52 (0.9)	54 (–0.3)	321
	>64	116 (–6.4)	66 (6.7)	48 (1.6)	230
Occupation (chi-square = 58.7, d.f. = 4)*	Worker/student	552 (6.8)	71 (–6.1)	111 (–2.7)	734
	Unemployed/housework	145 (–3.4)	44 (1.6)	57 (2.7)	246
	Retired	109 (–5.1)	58 (6.1)	39 (0.6)	206
Marital status (chi-square = 21.59, d.f. = 4)*	Single/partner	292 (2.9)	45 (–2.2)	59 (–1.6)	396
	Married	433 (–0.9)	89 (–0.8)	124 (1.8)	646
	Widowed/separated	83 (–2.9)	38 (4.3)	23 (–0.5)	144
Subjective socio-economic level (chi-square = 30.73, d.f. = 4)*	High/medium-high	84 (1.6)	4 (–3.4)	24 (1.2)	112
	Medium	478 (2.5)	85 (–2.1)	109 (–1.1)	672
	Low/medium-low	218 (–3.6)	76 (4.4)	64 (0.4)	358
Income (chi-square = 33.98, d.f. = 2)*	Higher than average	387 (5.7)	48 (–4.3)	71 (–3.0)	506
	Equal to or lower than average	315 (–5.7)	99 (4.3)	111 (3.0)	525
Studies (chi-square = 50.07, d.f. = 4)*	Reads and writes or less	38 (–2.1)	21 (4.1)	8 (–1.2)	67
	Primary	165 (–5.4)	65 (4.4)	66 (2.6)	296
	Secondary or university	606 (6.1)	83 (–6.2)	131 (–1.8)	820
Size of place of residence (chi-square = 20.20, d.f. = 4)*	<2000 inhabitants	51 (–2.1)	19 (1.9)	18 (0.8)	88
	2001–1 000 000 inhabitants	690 (4.4)	132 (–2.2)	152 (–3.3)	974
	>1 000 000 inhabitants	72 (–3.6)	24 (1.2)	37 (3.4)	133
Importance of religion (chi-square = 37.79, d.f. = 2)*	A lot-pretty much	290 (–4.5)	103 (6.1)	82 (–0.1)	475
	Little-not at all	501 (4.5)	61 (–6.1)	119 (0.1)	681

Cells that yield ASR > 1.96 and ASR < –1.96 have, respectively, higher and lower concentration of subjects than expected in the case of absence of relationship between variables ($P < 0.05$).

DK/DR, doesn't know or doesn't reply; ASR, adjusted standardized residuals.

* $P < 0.001$.

Table 2. Relationship of the personal disposition towards donation of one's own organs to informative variables.

		Disposition towards donation of one's own organs			
		Favourable, <i>n</i> (ASR)	Unfavourable, <i>n</i> (ASR)	DK/DR, <i>n</i> (ASR)	Total, <i>N</i>
Among your relatives or acquaintances, have you known anyone who needed a transplant? (chi-square = 15.5, d.f. = 2)*	Yes	196 (3.8)	27 (-1.9)	28 (-2.9)	251
	No	613 (-3.8)	146 (1.9)	177 (2.9)	936
Among your relatives or acquaintances, have you known anyone who received a transplant? (chi-square = 15.8, d.f. = 2)*	Yes	165 (3.8)	23 (-1.6)	21 (-3.1)	209
	No	637 (-3.8)	150 (1.6)	184 (3.1)	971
In topics of organ donation and transplant, you consider your information is: (chi-square = 28.6, d.f. = 4)*	Sufficient	347 (4.6)	42 (-3.9)	65 (-2.1)	454
	Insufficient	438 (-4.6)	120 (3.9)	131 (2.1)	689
In your opinion, in comparison with other alternative treatments, organ transplants are: (chi-square = 52.1, d.f. = 6)*	More efficient	474 (5.9)	57 (-5.4)	95 (-2.3)	626
	Just as efficient	91 (-0.1)	19 (-0.1)	24 (0.1)	134
	Less efficient	12 (-0.8)	7 (2.7)	1 (-1.5)	20
	Don't know	227 (-6.0)	86 (5.0)	87 (2.7)	400
Have you received any information about donation and transplant on TV? (chi-square = 11.9, d.f. = 2)**	Yes	565 (-3.3)	128 (1.6)	162 (2.6)	855
	No	220 (3.3)	32 (-1.6)	35 (-2.6)	287
Have you received any information about donation and transplant from newspapers and books? (chi-square = 9.8, d.f. = 2)**	Yes	208 (2.6)	25 (-2.8)	44 (-0.7)	277
	No	575 (-2.6)	135 (2.8)	153 (0.7)	863

Cells that yield ASR > 1.96 and ASR < -1.96 have, respectively, higher and lower concentration of subjects than expected in the case of absence of relationship between variables ($P < 0.05$).

DK/DR, doesn't know or doesn't reply; ASR, adjusted standardized residuals.

* $P < 0.001$, ** $P < 0.01$.

'Fear of the organs being extracted while still alive' (2.43) and 'I don't know how to do it' (2.4).

Exploratory analysis

To perform the exploratory analysis, we selected as grouping variable the disposition to donate one's own organs, excluding from the analysis the participants ($n = 11$) who did not answer this question. First, univariate analysis was performed with the sociodemographic variables (gender, categorized age, educational level achieved, perceived socio-economic level, professed religion, importance granted to religion, size of place of residence and nationality) and diverse informative variables (means through which they had received information about donation and transplant, appraisal of the information they had about donation and transplant, knowledge of transplanted persons, of donors or of persons who needed a transplant, perception of the cost and efficacy of transplants in comparison with other therapeutic alternatives). To perform this analysis, we used the CHAID algorithm [21]. This algorithm reorganizes the original categories of the 'predicting' variables (in this case, sociodemographic and informative variables) so that the discrimination of the criterion variable

(personal disposition towards donation) is maximized, providing more parsimonious relation structures. In Tables 1 and 2, the results of the sociodemographic and informative variables are presented that had a significant relationship to the disposition towards donation of one's own organs. Besides the absolute frequency of each cell, these tables also include the adjusted standardized residuals (ASR) to identify the cells that have a higher (ASR > 1.96) or lower (ASR < -1.96) than expected concentration of subjects in the case of absence of relationship between variables.

Positive disposition towards donation of one's own organs is higher in certain groups of the population. Among them, the following are noteworthy: individuals between 25 and 44 years, workers and students, single people or people with a common-law partner, people with a medium-to-high perceived economic status or with a higher-than-average income, subjects with secondary or university level studies, individuals residing in towns or cities with between 2001 and one million inhabitants, and subjects who grant little or no importance to religion. Negative disposition towards donation is more pronounced among the following: people older than 64 years, retirees, widowed people, people with a medium-low or low perceived socio-economic level, individuals with an

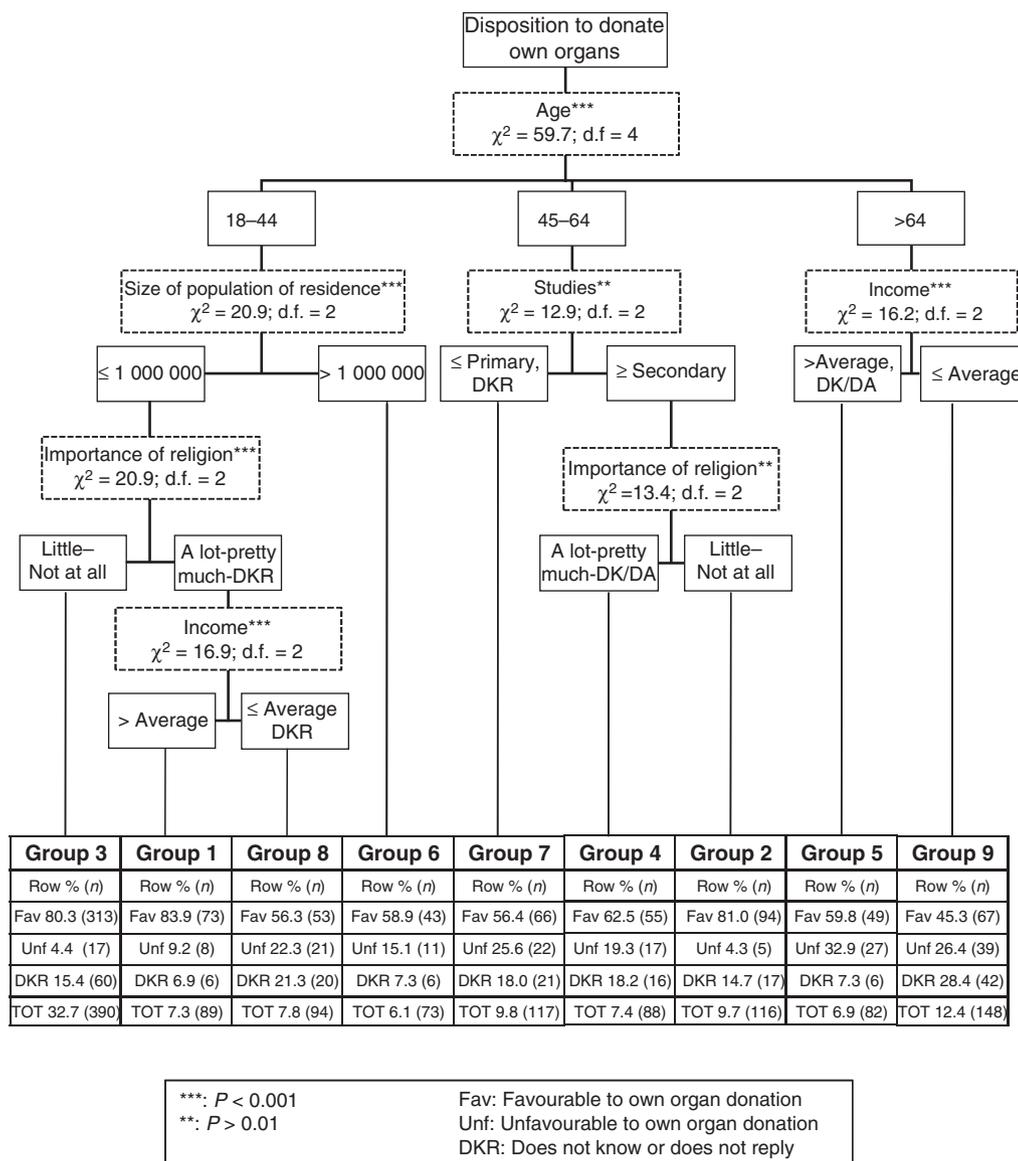


Figure 1 Segmentation analysis of disposition towards donation.

average or less-than-average level of income, people who have only achieved primary studies or less, and people who grant much or very much importance to religion. Those who do not know what stance to take about the donation of their organs are mostly concentrated among housewives and unemployed people, individuals with an average or less-than-average income, those with primary studies and people living in cities with more than one million inhabitants.

There is a higher number of people favourable to donating their organs among the following groups: those who have known someone who needed or received a transplant, people who think they have sufficient information about donation and transplant, those who consider that trans-

plant is more efficient than other alternative treatments, individuals who have not used television as a source of information, and people who rely on newspapers and books as a source of information. There are more people with unfavourable disposition among those who think their information is insufficient, people who either think that transplant is less effective than other alternative treatments or who do not know, and people who have received information by television. The people who do not take up a stance about the donation of their own organs are more concentrated among the following: people who have not known anyone who needed or received a transplant, people who think their information about donation and transplant is insufficient, people who do not know what to think

about the efficacy of transplants and people who have used television as a source of information.

Multivariate analysis

To specifically delimit the sectors of population with differentiated dispositions towards organ donation and, likewise, to assess the discriminant capacity of the diverse sociodemographic variables with regard to disposition towards donation, we used segmentation analysis [21]. This analysis divides the original sample into different groups, using sequentially the predictor variables (sociodemographic variables, in this case) and, as the criterion, the maximization of the differences in the grouping variable (personal disposition to organ donation, in this case). To perform this analysis, we again used the CHAID algorithm from the Answer Tree Program, taking as selection criterion the chi-square statistic (likelihood ratio). Bonferroni's adjustment was applied to correct Type 1 Error [22], allowing the segmentation of the sample only for significance levels lower than 0.05 and specifying a minimum size of 100 subjects for the source nodes and 50 for the final nodes.

In Fig. 1, the final results of the analysis are displayed, showing in detail how the sample was segmented and displaying the characteristics of the nine resulting groups, numbered from 1 to 9 in decreasing order of percentage of positive disposition to donating one's own organs. The variable age had the highest discriminative power among the three categories of disposition to donate and, in each age sector, a different variable discriminated best among them: in the case of people between 18 and 44 years, it was population size; in the case of the age group between 45 and 64 years, it was the educational level; and in the age group over 64 years, the most discriminative variable was the level of income. The discrimination capacity of the importance granted to religion appears later on in some subgroups, as does the level of income.

The sociodemographic variables do not allow us to delimit 'pure groups' of disposition towards donation. However, they do delimit certain groups of population with pronounced tendencies in one or the other direction. On one hand, the three groups with a percentage favourable to donation disposition of higher than 80% (groups 1, 2 and 3), made up by the confluence of diverse sociodemographic characteristics, are noteworthy. On the other hand, in one group of the sample (group 9), consisting of people over 64 years of age with low levels of income, there was less than 50% of people favourable to donation.

Discussion

In this study, we have explored several aspects of the perception and disposition of the adult Spanish population

towards organ donation, obtaining numerous indicators of various stages of the process. The interpretation of the results, however, should take into account the main limitations that are present in opinion surveys. The first is the participants' tendency to respond according to the social climate because of social desirability [23]; the second is the potential distance between participants' responses to certain questions and their real behaviour if the proposed situation actually occurs in real life, and this distance is particularly important when the participants have little prior information or when they have not really considered the issue about which they are being asked [24]. In any case, with this information, it is possible to establish several relevant reflections to orient actions concerning donation promotion.

From a general viewpoint, our results offer percentages that are more favourable towards donation than those provided by the most recent empirical study that has explored this aspect in Spain. Thus, the Special Eurobarometer carried out in 2006 [25] estimated that 56% of the citizens residing in Spain would be prepared to donate their own organs. There are no substantive differences in the procedures of both studies, but there are slight differences in the instruments and population range, which could partially explain this variation. In any event, our study shows an important consistency with the results of other studies carried out in Spain during previous years [26]. The comparison of our results with those obtained in surveys performed in other countries presents some difficulties: first, great diversity of measurements and indicators in the literature; and second, the scarceness of studies with samples that meet the adequate requirements of representativeness at a national level. In any event, taking into account the available works and, according to our results, there is a common pattern to the diverse populational studies carried out in Western countries [27–33], in which a majority favourable to donation is observed with reduced percentages of committed behaviours, such as signing an organ donation card. At this time, no systematic data are available about family permission in different countries that allow comparing rates of family denial and attitudes towards donation in each national context. In any event, the rates of family permission, which exceed 80% in Spain in the last few years, are noteworthy, in view of the levels of positive disposition that do not exceed two-third of the population. This should lead to more systematic analysis of the potential efficiency of the actions specialized in supporting the families and in obtaining consent to improve the rates of donation.

Among the individuals who were favourable to donation, solidarity and reciprocity predominate as motives to donate, revealing that both these arguments can be used

as effective elements to promote donations. The argument of solidarity would work by granting an important social reinforcement to those who show a disposition to donate, especially in contexts where donation is valued by the majority. This argument could be used to promote donation by means of the process called 'positive social labelling,' as has been done in diverse altruistic contexts [34]. By this means, granting in advance by public mass media certain positive characteristics to the population would favour the generation of positive behaviours that are coherent with such characteristics. The argument of reciprocity would work as a result of the existence of an implicit norm that underlines the need to correspond equitably in any exchange between subjects [35]. In the specific case of promotion of donation, it could be used by anticipating the possible situation of need that could affect anyone.

In the cases of reticence towards donation, none of the reasons analysed obtained high scores for the series of people who are opposed to donation. This fact may reveal insufficiently elaborated arguments or stances that would be difficult to express in a social context that provides a high level of support to donation. Therefore, our results do not allow us to advise the use of specific refutational messages to promote donation. However, we recommend continuing to emphasize the aspects of equity, transparency, and institutional and scientific support when transmitting the process of donation and transplant. This would lead to further progress in overcoming some of the more extended fears. Our results, in any event, indicate the potential effectiveness of positive arguments in individuals who are undecided, especially arguments that propose the possibility of helping people, for instance, children, who are in a particularly vulnerable situation. As empirical work in the sphere of experimental social psychology has shown, the clear definition of the recipients of help and the tangible evidence that the recipient of such help depends specifically on the person who is being asked to help increase the probability of altruistic behaviours [36].

With regard to donating relatives' organs, our study clearly reproduces another classic result in the literature, which indicates a tendency towards concordance between the expression of one's will while still alive and the decision taken by the family [8,15,16,19,37–39]. In any case, as also occurs in contexts that encourage donation, there is a higher tendency to respect a person's will when it is favourable. According to our data, in many cases, people have not communicated their will to their family. Therefore, it could be very important to stimulate people who are favourable, so they will communicate their wishes to their families to facilitate the family decision process. This would maximize the probability of family consent and

facilitate the family's decision process, avoiding the appearance of an additional stressor at the difficult moment of crisis caused by a death. This personal communication may be simpler and more direct than the formalization of the donor card, and according to the existing evidence in the studies on family permission [7,12], it may be highly effective.

Examination of sociodemographic characteristics shows that the disposition towards donation varies as a function of the level of social insertion, reflecting a common result in the literature, in which reticence is associated with a lower socio-economic or cultural level [19,24,27,41–43] and more advanced ages [19,27,29,40,41,44]. Actions to promote donation should therefore focus more on the disadvantaged sectors of society, which present higher levels of reticence. Our results also indicate a general relationship between high religious commitment and reticence to donate; however, this general association should be interpreted taking into account its potential variation as a function of different religious creeds [31] and, likewise, in light of their interaction with other sociodemographic variables, as shown by the segmentation analyses. In fact, one of the subgroups with the highest predisposition is made up of people with an important religious commitment. It may therefore be of interest for future studies to explore systematically how other variables can modulate the attitude, towards donation, of people who profess certain religions. This perspective is of special interest because, despite the fact that the great majority of religious doctrines officially support donation, their followers do not necessarily do so [31]. The will to donate also varies as a function of diverse aspects of the available information on the topic, underscoring the perception of efficacy, direct knowledge, and the existence of qualified information as the elements most closely linked to a positive disposition, and also following the general tendencies previously found in this field [29,45,46]. In any case, both the sociodemographic variables and the informative variables considered show moderate discriminant power of the different stances towards donation. Therefore, although epidemiological approaches such as the one developed herein are essential to know the climate of opinion of donation within a certain setting, they should be complemented with studies that explore in more detail the psychosocial processes on which citizens' decisions about donation are based.

Likewise, with a view to promoting an increase in the rates of donation, it is essential to analyse the factors that intervene in the materialization of the dispositions of the population in different rates of consent in each geographical and cultural context. In this sense, it seems necessary to make an effort to generate, at an international level, systematic data collection protocols of the essential factors

that condition donation. This would allow the grounded contrast of the variables that modulate donation in the diverse spheres and facilitate the design of more effective actions concerning promotion of donations.

Authorship

SB, MMJ and SJMC were responsible for empirical work supervision and data analysis. D-GB, VMO and CE defined the goals and contents of this work and contributed to the interpretation of the results. LJS and MJM developed the foundation of the study and synthesized the conclusions. MB and MR acted as advisors throughout the development of the project.

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