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International Collaborative Donor Project[☆]



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ABSTRACT

The International Donor Collaborative Project (PCID) research group was created in 1996 in Spain with the aim of promoting research in the field of organ donation and transplantation, led by Spanish surgeons. During this period they have developed the questionnaires of the PCID, both the attitude towards cadaver and live donation, which are the most used questionnaires in publications in indexed journals. They have been the driving group of stratified studies representative of the populations under study, and of the performance of multivariate statistical analyses in the field of psycho-social research in organ donation and transplantation. The main contributions of the group focus on the analysis of health center professionals and emerging migrant groups. In recent years, studies have been extended to the United States, Latin America (mainly Mexico) and Europe.

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Proyecto colaborativo internacional donante

RESUMEN

El grupo de investigación Proyecto Colaborativo Internacional Donante (PCID) surge en el año 1996 en España con el objetivo de potenciar la investigación en el campo de la donación y el trasplante de órganos, liderado por cirujanos españoles. Durante este período han desarrollado los cuestionarios del PCID, tanto el de actitud hacia la donación de cadáver como de vivo, que son los cuestionarios más utilizados en publicaciones en revistas indexadas. Ha sido el grupo impulsor de estudios estratificados representativos de las poblaciones a estudio y de la realización de análisis estadísticos multivariantes en el campo de las investigaciones psicosociales en la donación y el trasplante de órganos. Las principales aportaciones del grupo se centran en el análisis de los profesionales de centros sanitarios y en grupos emigrantes emergentes. En los últimos años, se han extendido los estudios a Estados Unidos, Latinoamérica (principalmente México) y Europa.

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Organ transplantation has been one of the most spectacular advances made in medicine. It is an example of how modern medicine has progressed extraordinarily thanks to its traits of teamwork, superspecialization and its multi- and interdisciplinary nature. The combination of numerous factors, including the development of various branches of medical and basic sciences as well as technologies, have made transplantations, which were still a distant challenge in the middle of the 20th century, a routine procedure of medical practice today.

The role of surgeons is fundamental to the advancement of transplantation programs, and their work should not be limited only to the surgical part. Surgeons should enhance the overall effects, since, given its peculiarities, transplantation is a therapy that cannot be performed at any time as it requires organ donation. It is a special therapy, with no fixed schedule in most cases that requires special dedication in time and effort.

In this context, essential aspects to increase organ donation rates should be very clear. The first is to have an infrastructure that allows donation to be conducted in all healthcare regions of the country. To this end, Spain has a model developed by the National Transplant Organization (NTO) that has made our country the world leader in donation rates, surpassing the barrier of 40 donors per million inhabitants. This system is known worldwide as the "Spanish model" and is an international point of reference when talking about promoting organ donation.¹ In this model, the hospital transplant coordinator is the cornerstone of the program.

The second aspect is the optimization of donation by promoting multiple-organ donation, donation after cardiac death, living donation and special techniques (split and domino transplantation in liver transplantation, cross-transplantation, etc.). In Spain, these 2 aspects are highly developed and the work of the NTO has been key in this regard.¹

The third aspect is to reduce refusal to donate rates, which continues to be a key factor of donation rates. Thus, between the years 2012 and 2016, 1690 donations were lost due to refusals, representing a loss of 4100 organs that could potentially have been transplanted.² For this purpose, two factors are important. The first is transplant coordination team training, for which the Spanish NTO has developed specific courses² that have been shown to be highly effective. The second is to determine the social reality that surrounds us and to detect groups who are unaware of the significance of donation and require a special approach to obtain organ donation. Hence the importance of psychosocial studies before donation to detect these groups in anticipation, intending to continue improving donation rates. This activity should not be left alone in the hands of transplantation coordinators; the involvement of the rest of the members of the transplant team, including surgeons, is fundamental and will be important in its future progress.

Given this situation, a research group led by surgeons emerged in 1996 with the aim to promote research in the field of organ donation and transplantation, called the Donor Project. The ultimate goal was to increase donation rates by decreasing family refusal rates in cadaver donation and

promoting live donation. The first step was the development of validated tools (opinion-attitude questionnaires), which would allow us to determine these parameters with certain reliability given the non-existence of validated questionnaires and the great heterogeneity of existing ones. In those years, the questionnaires of the International Donor Collaborative Project (PCID) were designed, for both cadaver and live donations, which have been cited in more than 300 publications in indexed journals. In addition, there is a need to provide quality psychosocial studies, with stratification of the samples as well as complete bivariate and multivariate statistical analyses to be representative of the populations studied, because there have been many inadequate and biased psychosocial studies of low methodological quality.

The work chronology of the group has evolved with the needs of the coordinating teams, the appearance of new social groups and the findings of the different studies conducted.

After the initial formative studies in adolescents,^{3,4} the first projects in the general population were done to determine the social groups that are least likely to donate with the intention of creating targeted campaigns to improve their attitude. A population study (n=2000), stratified by age, sex and geographic location, observed that 63% of the population is in favor of donation. The population profile identified as unfavorable towards organ donation is "A person over 50 years of age with primary or lower education, who does not take part in nor wants to take part in prosocial activities, who has fears about cadaver manipulation and who does not understand the concept of brain death." These early studies already show the effectiveness of transplant coordination in obtaining negative rates lower than the percentage of population not in favor of donation.

One of the most interesting aspects derived from this project⁵ was to analyze the important impact that health center professionals have on the attitude of the population towards donation. As shown in Fig. 1, among the population that had received information about donation by medical professionals, 89% were in favor of donating their organs compared to 65% of those who had not. In addition, it was observed that if the information transmitted by the professionals was positive, 93% were in favor; however, if this was not favorable, only 44% were in favor, and it was more difficult to later reverse the negative opinions based on information provided by healthcare professionals.⁶⁻⁸

This fact influenced subsequent lines of research, which focused on hospital physicians, since it would be more effective to assess the situation in this opinion-generating group and their awareness than in any population campaign. The studies showed some data that, although they could be suspected, were surprising. In a sample (n=1262) stratified by work category and department type in Spanish hospitals with transplantation units, only 69% of the respondents were in favor of donating their organs after death,⁹ which is similar to the rate reported in the general population. Moreover, when focusing on the departments related with transplantation (generating units, transplantation units and follow-up units), which at least theoretically must be more informed, a study stratified by department and occupational category (n=309)

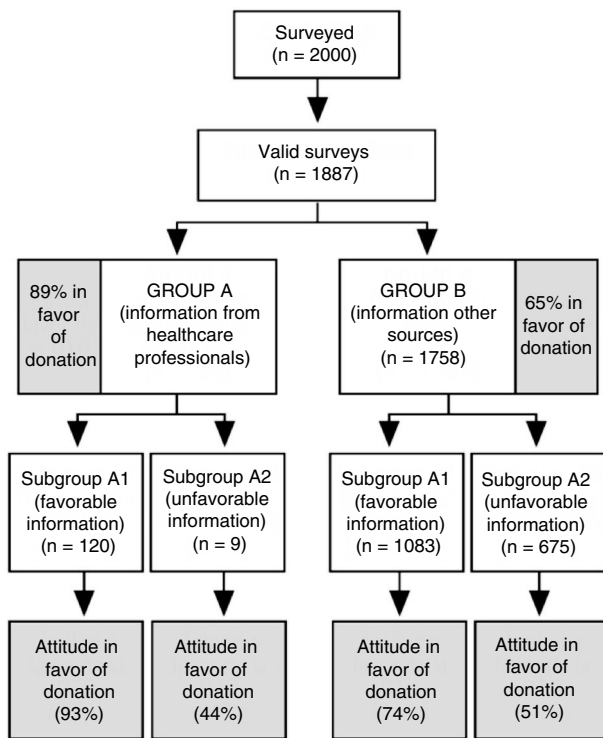


Fig. 1 – Impact of the attitude of the population towards organ donation depending on whether they had received information from medical professionals or other sources.

showed that only 70% were in favor.¹⁰ Again, this result was similar to departments not related with transplantation. In both studies, a very direct relationship with job category was observed.

The study was completed with a project in Primary Care, since it is the first point of contact of the population with the healthcare system and is an important means of communication and promotion of health. In a randomized sample stratified by job category and geographic location, 414 professionals from 32 hospitals were interviewed, and 79% of the respondents were in favor of donation,¹¹ which confirms the great differences between different job categories. All these data show that the professionals of health centers are more in favor when they have less contact with the world of transplantation. Thus, they are more in favor in Primary Care, then in hospital services unrelated to transplantation and, finally, transplant-related units. These differences are accentuated among the staff who have less medical training (nursing assistants, orderlies, etc.). It is possible that the lack of understanding about the subject coupled with their involvement with the donation-transplant process may generate distrust and fear. This situation confirmed that informative activities are essential, especially among hospital staff of non-medical categories (Fig. 2).

During this period, researchers from other countries joined our project, hence the change of name from the Donor Project to the International Donor Collaborative Project, which was established as an association based on Article 22 of the Spanish Constitution and Organic Law 1/2002 of March 22, with tax identification number: G73767428. This has made it

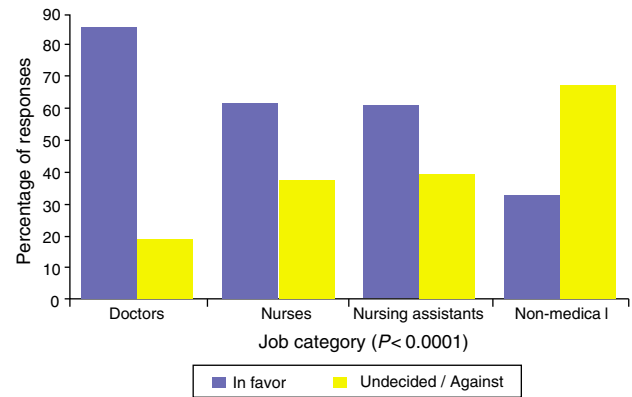


Fig. 2 – Attitude towards donating one's own organs after death among hospital staff, according to work category.

possible to assess whether this situation is repeated in other countries or is specific to Spain, and a joint project between Spain, Cuba, Mexico and Costa Rica confirmed that it is quite widespread.^{12,13}

This has been the basis for the establishment of informative talks, especially in units related with transplantation, so that the different professional categories have the minimum basic information and no rejection is generated due to ignorance. This aspect has been useful, especially for nursing assistants and non-medical personnel. However, in the case of medical professionals (doctors and nurses), it is difficult to modify their attitudes once they have acquired their professional maturity. Therefore, the PCID has proposed to carry out 2 projects at universities during the training period of students in both medicine and nursing.

A nationwide, multicenter study was conducted at 22 medical schools, including 9275 students who were stratified by geographical area and academic year. The results showed that 80% were in favor of organ donation, 2% against and 18% undecided. Interestingly, these results improved progressively with more years of training, so that students in their last year of medical school were 87% in favor.^{14,15} In the nursing school study, 52 centers participated with a total of 9001 respondents, who were likewise stratified, and similar results were obtained to those from the medical students (78% in favor, 2% against and 20% undecided).¹⁶ Both projects concluded that training in organ donation and transplantation should be strengthened in university education in order for medical professionals to have a well-founded favorable attitude, as they are potentially a true opinion-generating group.

In this context, given the lack of guidelines, 2 sets of guidelines were published on organ donation and transplantation (the NTO has recently done so) to serve as the basis for several groups in the presentation of informative talks and to resolve doubts.^{17,18}

One of the fundamental aspects in medicine, and especially in the world of transplantation, where citizen collaboration with organ donations is essential, is to anticipate problems to avoid any impact on donation rates, proposing preventive solutions before they arise. Therefore, the significant increase in the non-native population residing in Spain, all from countries with donation rates much lower than those of Spain, has motivated a detailed analysis of different emerging social

groups. This approach is complex because it involves people with different nationalities, languages, cultures and religions. In Spain, three large groups must be differentiated, corresponding to the population of European, Latin American and African origins, which have been analyzed by the PCID. In these emerging social groups, the primary objectives of these projects are to determine the attitude of the non-native population in Spain towards donation and its structure, analyze the existence of psychosocial variables influencing this attitude, and define population profiles towards organ donation.

Regarding the *European population residing in Spain*, we have distinguished between the 3 largest groups: those of Anglo-Saxon (the most numerous), German and Eastern European origins.

In the Anglo-Saxon population residing in Spain, a stratified sample was obtained according to the nationality of the United Kingdom, obtaining a total of 1700 respondents. Among them, 72% were in favor of donation, 8% against and 20% undecided, with similar data among their different nationalities, shown in Fig. 3.¹⁹ These data are more favorable than those of the native Spanish population. In addition, the NTO data confirm that the donation rates among the resident Anglo-Saxon population in Spain are high. This project presents several methodological peculiarities and highlights

the importance of design and pilot studies. Thus, the pilot study of the project detected that having translated the questionnaire, indicating that the study was for an English-speaking population, led to the non-completion of the questionnaire in the pilot study by the natives of Wales, Scotland, Northern Ireland and the Republic of Ireland, as they do not consider themselves English. Small details that may not seem important can lead to the failure of an expensive project.

As for the population of German origin, the results were very similar to those of the Spanish population, with 65% in favor, 20% undecided and 15% against. This study did detect a series of interesting circumstances, as most subjects were middle-aged or geriatric and only spoke German.²⁰ For this reason, the incorporation of a German-speaking social worker to provide fluent communication should favor good patient-physician relationships and organ donation. This figure has already been established in areas with important German colonies, such as the Levante area of Spain.

Finally, regarding the Eastern European population, the study stratified by different nationalities does show a less sensitized group with a more negative attitude. Only 51% are in favor of organ donation, 24% are against and the remaining 24% are undecided. Like the German population, the main problem is the difficult communication given the different



Fig. 3 – Attitude towards donating one's own organs after death among citizens of the United Kingdom residing in Spain.

Table 1 – Distribution of Latin Americans Surveyed According to their Nationality and Their Attitude Towards Organ Donation; Comparative Macrostudy Between Spain and the State of Florida (USA).

Country	Florida			Spain		
	Estimated residents	Sample obtained	Attitude in favor	Estimated residents	Sample obtained	Attitude in favor
North America	1 129 718	297	–	96 390	84	–
Mexico	1 129 718	297	97 (33%)	96 390	84	54 (64%)
Central America	3 433 912	947	–	149 503	126	–
Cuba	1 542 438	438	120 (28%)	71 234	62	37 (60%)
Puerto Rico	945 550	259	95 (37%)	1150	2	1 (50%)
Nicaragua	305 143	89	20 (23%)	143	0	–
Dominican Republic	275 451	66	30 (46%)	68 769	57	36 (63%)
Honduras	137 302	35	14 (40%)	1348	1	1 (100%)
Guatemala	98 882	23	9 (39%)	1521	1	1 (100%)
El Salvador	67 144	19	9 (47%)	1356	1	1 (100%)
Costa Rica	29 761	8	4 (50%)	1671	1	1 (100%)
Panama	29 741	9	5 (56%)	1633	1	1 (100%)
Other countries	2500	1	1 (100%)	678	0	–
South America	770 543	206	–	1 157 300	1027	–
Colombia	341 414	97	38 (39%)	217 000	178	124 (70%)
Venezuela	122 116	35	15 (43%)	23 850	22	9 (41%)
Peru	102 965	23	7 (30%)	49 600	39	20 (51%)
Ecuador	72 574	19	7 (37%)	513 000	461	271 (59%)
Argentina	67 260	17	7 (41%)	62 900	55	46 (84%)
Chile	25 549	7	3 (43%)	23 650	22	12 (54%)
Uruguay	16 542	4	2 (50%)	19 500	18	12 (67%)
Bolivia	14 938	4	2 (50%)	213 000	206	101 (49%)
Paraguay	3222	0	0	1132	0	0
Brazil	1220	0	0	31 000	24	16 (67%)
Other countries	2743	0	0	2668	0	0
Total	5 334 173	1450	485 (33%)	1 403 193	1237	745 (60%)

Numbers in bold are the sum of all the countries in that region.

languages spoken by this population group. This is a priority group in the promotion of organ donation.

Regarding the Latin American population, it should be noted that this is a large multicultural group that emerges from the miscegenation of Native American populations with the Spanish and Portuguese colonizers. Most of these countries have economic problems and often see emigration as an opportunity for improvement. The two great migratory flows are towards Spain, due to the cultural and linguistic similarities that favors their integration, and towards the United States, due to the geographic proximity and economic power. The PCID, with the collaboration of Spanish researchers and the state of Florida, conducted a macro-study in Spain and another in Florida, stratified by nationality (Table 1), where a previously undetected aspect has been observed. In Spain, the Latin American population presents a similar attitude to the Spanish native population, with 60% in favor of donating their organs.^{21,22} Data from the NTO confirm donation rates in Spain similar to those of Spanish natives. However, in Florida, the attitude is much less favorable, with only 33% in favor of donating their organs.^{23,24} The data in Florida confirm lower donation rates than in the native population.

Emigrants can have a different attitude towards organ donation depending on the country to where one emigrates. Factors such as social integration, access to the public healthcare system, etc., may influence this situation. To investigate this further, there are PCID projects underway in 3

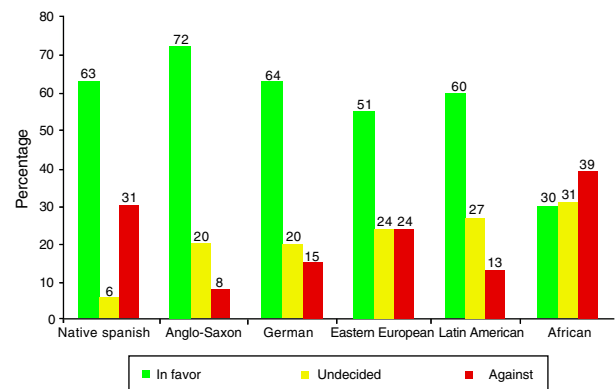


Fig. 4 – Attitude towards donating one's own organs after death among different major population groups residing in Spain; comparative data from the different databases of the International Donor Collaborative Project.

different countries (native country, emigrants to Spain and emigrants to the US) to compare these attitudes towards organ donation.

Last of all, regarding the African population residing in Spain, this macroproject has been started and the preliminary data demonstrate a very unfavorable attitude, where less than 30% would donate their organs after death. This requires a

detailed analysis by nationality, language and religion to be able to draw conclusions in this regard.

Fig. 4 is a graphic representation of the comparison of the different major population groups residing in Spain.

The field of organ donation and transplantation is an unending area of research that requires continuous updating in order to avoid and prevent problems that negatively influence donor rates and, therefore, our transplant activity. The involvement of surgeons is fundamental, given our vision of the donation and transplantation process. Moreover, it is necessary to begin to work with new emerging groups in recent years (such as Asian populations, etc.), promote living donation²⁵⁻³¹ and favor the psychological and social integration of our transplanted patients.^{32,33}

Conflict of Interest

The author has no conflict of interest to declare.

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