FACULTAD DE MEDICINA

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GRADO EN MEDICINA

TRABAJO FIN DE GRADO

"Estudio sobre la información y sensibilidad sobre la donación de órganos en el ámbito de la Universidad de Cantabria y Hospital Valdecilla".

"Study on information and sensitivity about deceased organ donation in the field of the University of Cantabria and Valdecilla Hospital ".

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INDEX

This research project had been carried out in three different European Universities: Imperial College (London, United Kingdom), Erasmus University (Rotterdam, The Netherlands) and University of Cantabria (Santander, Spain); leaded by Maria Theodosopoulou (Department of Surgery and Cancer, Imperial College, London).

I was given the opportunity to take part in it, working with Professor Casanova who has driven (as the coordinator) the Spanish part. Thus, my version would develop exclusively those results and conclusions arisen from it.

ABSTRACT

Shortage of organs is the biggest challenge in transplantation worldwide. Each day many people die waiting for an organ while public health care costs are burdened at critical levels. Statistics of organ registration numbers and family consent rates in Deceased Organ Donation (DOD) do not seem to dramatically change despite the systematic effort of its social promotion.

This research project was based in the performance of surveys (N=323) in Valdecilla Hospital and Medical School of University of Cantabria in three population groups closely linked to health care field: medical students, administrative staff and kidney-transplanted patients. Furthermore, we complemented the task with focus group interviews from those referred collectives (N=17). Their qualitative data analysis was used to interpret, analyse and better understand survey results.

The findings of this project could lead to the design of DOD specific health literacy campaigns due to its resulting conclusions, taking an overview from the National Transplant Organisation (ONT) website as a core.

KEY WORDS

- Deceased Organ Donation (DOD)
- Transplantation
- “Health literacy campaigns”
- Family consent

ABSTRACT “SPANISH VERSION”

La escasez de órganos es el mayor desafío en la esfera del trasplante a nivel mundial. Cada día muchas personas mueren esperando recibir uno. Las tasas de donación y el consentimiento familiar para la donación de órgano de cadáver no parecen cambiar sustancialmente a pesar del esfuerzo constante en su promoción social.

Este proyecto se basó en la realización de encuestas en el Hospital Valdecilla y la Facultad de Medicina de la Universidad de Cantabria (N = 323) sobre tres colectivos estrechamente vinculados al medio sanitario: estudiantes de medicina, personal administrativo y pacientes renales trasplantados. Además, se llevaron a cabo entrevistas en los grupos referidos (N=17), como una herramienta de apoyo en la interpretación, análisis y compresión de los resultados de la encuesta.

Los hallazgos de este proyecto podrían conducir al diseño de campañas de sensibilización y educación en el área de la donación de órganos del donante cadáver a través de sus conclusiones resultantes, teniendo como base una visión general procedente de la página web de la Organización Nacional de Trasplantes (ONT).

KEY WORDS

- Donación
- Trasplante
- Campañas de sensibilización
- Consentimiento

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INTRODUCTION

A great number of lives are daily-saved due to current innovations in the transplantation field. More and more people are in need of a new organ, which could save their life and improve their wellbeing. At the same time, the number of available organs after sudden death or accident increases, although this rate of supply is not enough to handle the situation: not being able to match a fast-growing global organ demand. Additionally, in those traumatic moments, potential donors' relatives are not always prepared to give consent for the donation of the organs of their next- of-kin.

Throughout campaigns, all around the world, promoting organ donation, awareness on the issue raise through numerous ways, such as advertisements, posters, leaflets, websites, talks and patients' stories. Despite of the valued resources that are invested, still the high family refusal rates and the gap between demand and supply of organs persist.

This study is based in a research project aimed at being a helping tool for understanding those who need to be targeted in means of health literacy programs for deceased organ donation.

The strategic aim of this project is to prepare health literate people in the subject of DOD. The difficulty of its elaboration lies in the meticulous design, efficiently targeting population needs on a lifelong basis.

Structurally, it followed a two-stage research approach. The first one, quantitative, was performed as a questionnaire with the intention to examine the characteristics of pro-donation population, people who are registered organs donors, and people who are not registered; lifelong family patterns in DOD communication; and finally, domain specific health literacy knowledge about DOD. The second and last stage, qualitative, was accomplished by focus group discussions, aspiring to inspect the mindset behind of people, to better comprehend those answers delivered in the survey.

The findings of this project could lead to the design of DOD specific health literacy campaigns due to its resultant conclusions in terms of the definition of an identity profile of registered and non-registered donors, located gaps of knowledge and identified communication patterns that ensure consistency in lifelong learning about DOD.

RESEARCH AIMS

The point of this project is to comprehend health literacy in deceased organ donation (DOD) as part of a lifelong socialisation process towards building the identity of a registered /non-registered organ donor.

The following questions are the ones that have been used as a guide:

- What is the identity profile of a registered/non -registered organ donor?
- What is the DOD knowledge /gap of knowledge profile of a registered /non-registered organ donor?
- Are there any lifelong family communication patterns that identify registered/non-registered organ donors?
- Are there any consistent lifelong patterns in thinking about DOD among registered /non-registered organ donors?

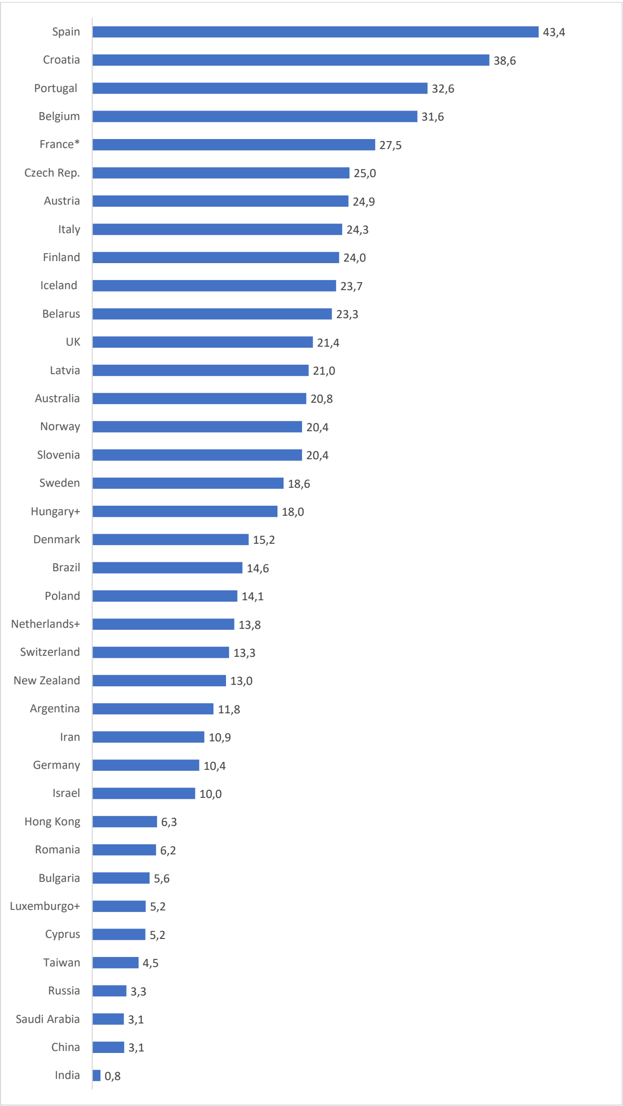
BACKGROUND: PRESENT STATUS IN DECEASED ORGAN DONATION

Transplantation is one of medicine's greatest achievements in history. Continuous medical advancements allow transplants to be lifesaving procedures with high survival rates as well as provide major improvement to the quality of life not only of patients but their families.

ORGAN DONATION RATES

In the last publication of August 2017, regarding the previous year (2016): the data of the International Registry in Organ Donation and Transplantation (IRODAT) shows the organ donation rates in 46 countries worldwide. Spain occupies the lead position, with 43,4 pmp.

WORLDWIDE ACTUAL DECEASED ORGAN DONORS 2016 (pmp)



* 2015
\+ Utilized donor rate

Figure 1: Worldwide Actual Deceased Organ Donors 2016 (IRODAT August 2017)

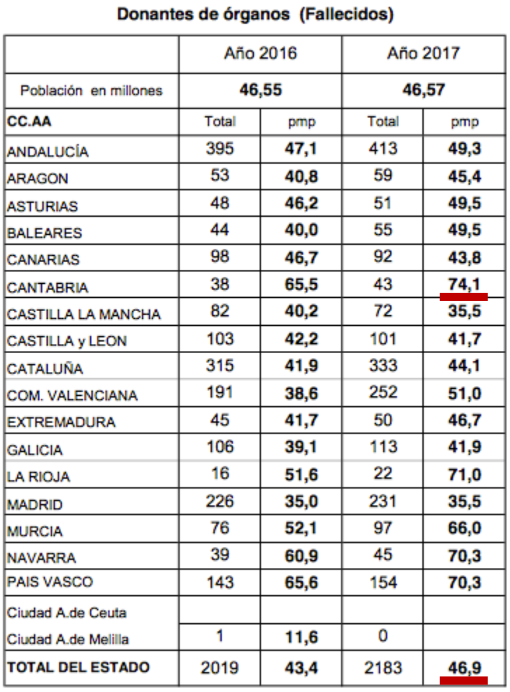
ORGAN DONATION IN CANTABRIA-SPAIN: A BRIEF OVERVIEW.

The practices of organ donation vary highly from one country to another in respect to legislation, process of registering as a donor, technical organisation, public awareness and information. Next, we will delve into ours, Spain.

In recent years, Spain has been regarded as a ‘gold standard’ example of Deceased Organ Donation. Over recent years, donation has been maintained at 33-35pmp and a subsequent average of 85pmp transplantations (Matesanz et al 2011).

Last year (2017), Spain has reached new historical high rates both in the total number of donors (+ 8.1%), with a total of 2,183, and in the solid organ transplants (+ 9.1%), standing at 5,261.

Next figure shows the rating evolution from 2016 to 2017 in the different Autonomic Communities. It shows that Cantabria occupies the first position with 74.1 pmp (the highest ratio all over the world), overcoming the national one (46.9 pmp).



Donantes de órganos (Fallecidos)

	Año 2016		Año 2017	
Población en millones	**46,55**		**46,57**	
CC.AA	Total	pmp	Total	pmp
ANDALUCÍA	395	**47,1**	413	**49,3**
ARAGON	53	**40,8**	59	**45,4**
ASTURIAS	48	**46,2**	51	**49,5**
BALEARES	44	**40,0**	55	**49,5**
CANARIAS	98	**46,7**	92	**43,8**
CANTABRIA	38	**65,5**	43	**74,1**
CASTILLA LA MANCHA	82	**40,2**	72	**35,5**
CASTILLA y LEON	103	**42,2**	101	**41,7**
CATALUÑA	315	**41,9**	333	**44,1**
COM. VALENCIANA	191	**38,6**	252	**51,0**
EXTREMADURA	45	**41,7**	50	**46,7**
GALICIA	106	**39,1**	113	**41,9**
LA RIOJA	16	**51,6**	22	**71,0**
MADRID	226	**35,0**	231	**35,5**
MURCIA	76	**52,1**	97	**66,0**
NAVARRA	39	**60,9**	45	**70,3**
PAIS VASCO	143	**65,6**	154	**70,3**
Ciudad A.de Ceuta				
Ciudad A.de Melilla	1	**11,6**	0	
TOTAL DEL ESTADO	2019	**43,4**	2183	**46,9**

Figure 2. Spanish donor rates by Autonomic Communities (data from 2017)

Regarding the data from the previous table, many countries are seeking to adopt components of the multi-faceted “Spanish Model”, of which Cantabria participates; developing its transplantation activity in its main hospital: “Marqués de Valdecilla”.

“THE SPANISH MODEL”

In 1979, under the ’Spanish Transplantation Law’, Spain adopted the presumed consent or ‘opt out’ policy for deceased organ donation (Bramhall, 2011; Hitchen, 2008). However, family consent is still a factor of paramount importance and the final determinant, considered in standard medical practice, before the procurement of organs.

Despite legislation being an integral supportive component in Spain's success, it only represents part of a wide infrastructure.

The Spanish model of organ donation works at a local, regional and national level to ensure an integrated coordination performed by its National Agency for Organ Donation: the "ONT" (National Transplant Organisation).

The hospital level operates with 170 transplant coordinators (TCs), responsible for identifying potential donors and interacting with family members to obtain consent before procurement of organs proceeds (Matesanz 2007). Most of these TCs are or anesthesiologists or intensive care therapists (like it happens in Valdecilla Hospital). They examine deaths at critical care units, and determinate if a patient fulfils the relevant criteria for DBD (donation after brain death) or DCD (donation after cardiac death) and, in that case, considered as a potential donor. In the regional level, there are 17 coordinators who work together and ensure policy is adhered to and technical issues surrounding procurement and family consent are resolved.

Patients who enter hospital with severe brain injuries are admitted to intensive care for a potential DBD to be diagnosed. This stage is subject to the consent of family members who are first approached by those coordinators. Donors must be screened for neoplasia or infection before procurement. In addition, target organs of potential donors should be as satisfactory preserved as possible to mitigate the risk of rejection by the recipient.

ORGAN SHORTAGE: THE MAIN PROBLEM

One of the major world-wide long-lasting challenges in the transplantation field is the limited shortage of available organs. There is an uninterrupted growing need for organs, which is not matched by the number of available donors.

Despite advances in medicine and technology, and increased awareness of organ donation and transplantation, the gap between supply and demand continues to widen; according to the US Department of Health and Human Services and the Organ Procurement and Transplantation Network (OPTN). Reflexing on the following graphic, the issue that emerges is why this gap exists.

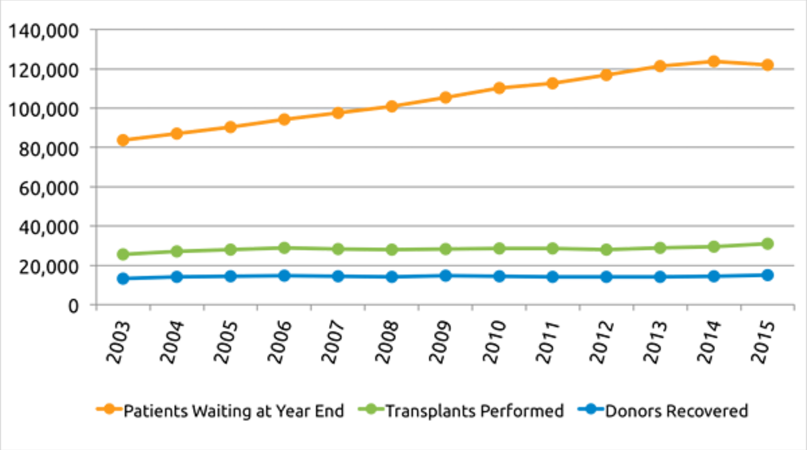


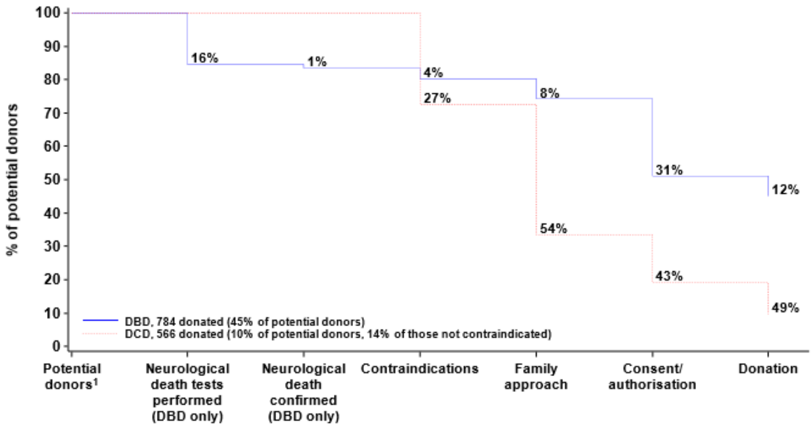
Figure 3: Organ supply and demand by OPTN

ORGAN HARVESTING: AN OBSTACLE RACE

The process to achieving an organ could be defined as an obstacle race that starts from the time of clinical diagnosis of circulatory or brain death and ends to the family consent, as shown in figure 4. But, in fact, this "run" has started long before the clinical diagnosis by a physician but with the wish of the individual about DOD and its communication to his family. Organisation of DOD in each country is also one of the firsts steps of the race.

Along that path to organ donation there are several steps that can make the person lose the potential organ to transplant.

Figure 13.3 **Stages at which potential organ donors lose the opportunity to become actual donors, 1 April 2015 to 31 March 2016**



Potential DBD donor - A patient who meets all four criteria for neurological death testing excluding those for which cardiac arrest occurred despite resuscitation, brain stem reflexes returned, and neonates less than 2 months post term
Potential DCD donor - A patient who had treatment withdrawn and death was anticipated within four hours

Figure 4: NHSBT Potential Actual Donors 2015-2016

Using previous figure as a guide, next pages will go deeper into this topic by focusing on different aspects there underlined: consent legislation, the role of family and communicative aspects related to DOD.

THE DEFAULT CONSENT SYSTEM

As shown before, Spain has a leader position in organ donation rates. This tendency has been consistently maintained throughout the last decades. Due to its success, many countries have tried to follow which is called "the Spanish model": whose key point is the presumed consent legislation. According to this system everybody is considered as a potential donor, unless explicitly 'opts-out'.

Checking the bibliography about this issue, two totally opposite positions are found.

The first one is a study carried out in 15 European countries, examining attitudes and the willingness to donate and give a consent. They found that 82% of the participants who were keen to donate their organs would also be willing to give consent, and that in countries with presumed consent people were keener to donate in relation with participants from countries with informed consent (Mossialos et al (2009)).

On the other hand, the second one upheld that a presumed consent system does not entail improved organ donation rates, as independently of the default system family is involved in the decision of donation and the wishes of the relatives are respected (Gevers et al, 2004).

THE ROLE OF FAMILY IN DOD

The refusal rates are quite high. Families receive, at a short and emotionally loaded time, complex health information. At the same time, they are forced contemplate many relevant ethical religious and cultural traditions in relation to this matter.

Two key aspects would facilitate the family's decision (Frutos et al, 2005): Knowing the wishes of the deceased and an informative approach by specially trained health care professionals that communicate their message in an accurate and sensitive style.

In relation to the first idea just underlined, it is widely-spread that those personal whishes are not usually publicly discussed with other family members. Why does it happen? Deeply exploring the literature on this matter, there are several ideas that come on scene and that are synthetized in the next points:

- People who had recently been exposed to information about DOD and had discussed the issue with their families are more willing to donate (Haustein and Sellers, 2004)

- Families who know that their next-of-kin wanted to donate their organs, tend to be more willing to respect that wish, as opposed to not knowing the patient's wish (Scandroglio et al, 2010).

- People who are knowledgeable about organ donation will usually share this information with other family members and act as sources of information themselves (Volz Wenger and Szuks, 2011)

- The two most common reasons for not discussing organ are presented in the form of social comments such as 'didn't come up in conversation' and 'not happy to talk about my death' (Webb et al, 2015).

Straightaway, according to the second key aspect, it is undoubtedly understood that the final decision of families is highly influenced by the conditions in which they are called to give consent. On a research fundament, the main ideas obtained are following presented:

- The identity of the announcer: 75% families are positive for consent when approached by both Organ Procurement and hospital staff, as opposed to 67% when approached by organ procurement organisation and 9% when approached by hospital staff (Stahler et al, 2014)

- The communication strategy: asking the family to respect the patient’s wishes, instead of asking for permission appears to influence the decision of the family (Christmas et al, 2008).

- Family’s initial response to request for organ donation predicted 91.5% their decision to a high degree (Siminoff et al, 2001)

The figure shows which are the reasons given by the families not to consent.

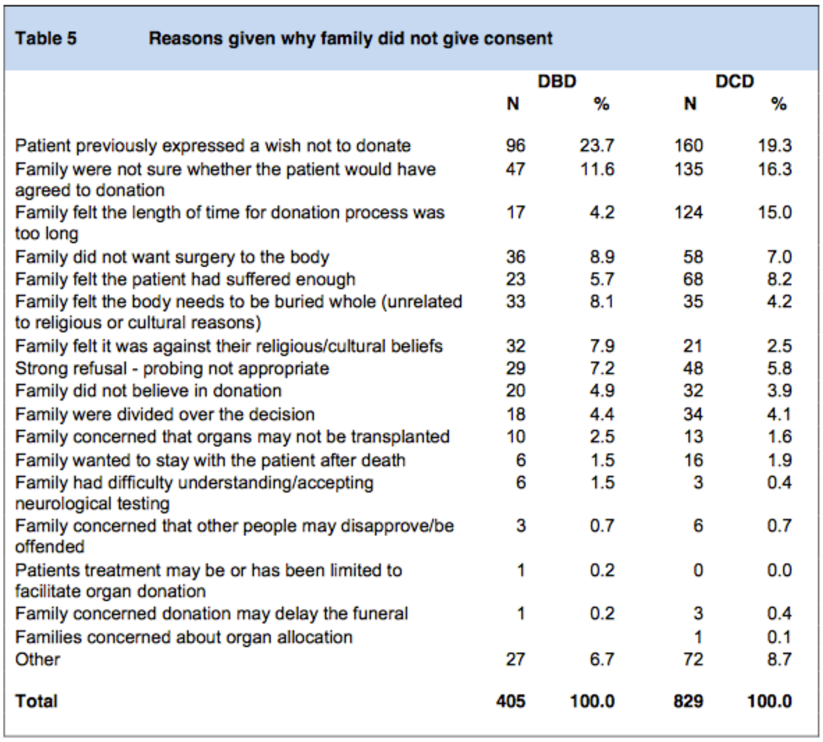


Table 5 **Reasons given why family did not give consent**

	DBD		DCD	
	N	**%**	**N**	**%**
Patient previously expressed a wish not to donate	96	23.7	160	19.3
Family were not sure whether the patient would have agreed to donation	47	11.6	135	16.3
Family felt the length of time for donation process was too long	17	4.2	124	15.0
Family did not want surgery to the body	36	8.9	58	7.0
Family felt the patient had suffered enough	23	5.7	68	8.2
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	33	8.1	35	4.2
Family felt it was against their religious/cultural beliefs	32	7.9	21	2.5
Strong refusal - probing not appropriate	29	7.2	48	5.8
Family did not believe in donation	20	4.9	32	3.9
Family were divided over the decision	18	4.4	34	4.1
Family concerned that organs may not be transplanted	10	2.5	13	1.6
Family wanted to stay with the patient after death	6	1.5	16	1.9
Family had difficulty understanding/accepting neurological testing	6	1.5	3	0.4
Family concerned that other people may disapprove/be offended	3	0.7	6	0.7
Patients treatment may be or has been limited to facilitate organ donation	1	0.2	0	0.0
Family concerned donation may delay the funeral	1	0.2	3	0.4
Families concerned about organ allocation			1	0.1
Other	27	6.7	72	8.7
Total	**405**	**100.0**	**829**	**100.0**

Figure 5: Reasons given why family did not give consent

AGREEMENT OR REFUSAL TO ORGAN DONATION

Not a negative attitude of society towards organ donation is recorded by many studies, even though the previously mentioned problem of organ shortage.

The reasons taken by people to become or not an organ donor is examined in several studies targeting different groups (adolescents, college students, teachers, families who gave or refused consent, healthcare staff and general population), bounding what outlines their unwillingness or refusal to consent to organ donation.

- Knowledge about DOD: Reduced knowledge about DOD, even among university students, is one of the most common difficulties for people who are not willing to donate (Liu et al, 2013)

- Brain death: A concept particularly hard to process. Although Spain has better organ donation rates than other European countries, studies show that brain death is not fully understood (Rios et al, 2013)

- Media: messages released by the media are sometimes conflicting and considered to be myths. Additionally, negative messages have strong impact on people, as they tend to be reminded and serve as an excuse of people's unwillingness to become donors. (Harbaugh et al, 2011; Quick, 2009)

- Religion: Deceased Organ Donation is a complex issue and as such it is obviously not mentioned in official original religious texts; offering several different interpretations. It is also not clear whether their faith supports or not DOD and how compatible are teachings about life after death, sanctity of the body, and burial rituals with the practices of DOD (Oliver et al, 2010).

HEALTH LITERACY ON DOD

WHAT DOES HEALTH LITERACY MEAN?

It could be defined as the understanding of health-related information and it cannot be predicted by the educational level of people. The last European Health Literacy Survey, performed in 2012, shows that it is low or inadequate.

The functional perspective of health literacy is to hold deficits in reading, writing, and arithmetic skills of patients and helping them to better understand medical issues such as instructions on how to take medication, health routines or consent forms.

ONT WEBPAGE

The NTO's webpage is considered, in terms of this research project, the main informative point from Spanish people from where they should obtain health literate on DOD.

This is explained because it provides information on transplants to the general population: up-to-date status of DOD, its promotion based on arguments to support it and how to get the donor card.

Due to what has just been mentioned, this website (online available at http://www.ont.es) was explored and used as a database to treasure the topics that would be included in the survey performed to carry out this project.

METHODS

INTRODUCTION

This project was carried out in three different European universities: United Kingdom, The Netherlands and Spain. To be more precise, it took place in the environment-related to the Hammersmith Hospital-Imperial College (London, UK), Erasmus University (Rotterdam, The Netherlands) and University of Cantabria (Santander, Spain).

There were three target groups of people, all of them close to health care field: medical students, administrative staff and patients (kidney-transplanted).

It was executed in two consecutive-related phases, quantitative and qualitative, respectively.

- The first stage was performed as a survey with the ambition of exploring several aspects related to DOD health literacy among the different before-mentioned collectives, their knowledge and doubts.

- The second stage was performed as focus groups interviews: three for each group, with a total of nine. Its intention was to result as a tool to interpret, infer and comprehend the results obtained by the survey fulfillment.

QUESTIONNAIRE

For the questionnaire to be elaborated, the chief researcher of the project underwent different stages:

1) Literature review as a basis to define the main topics of the survey. As a result, pre-pilot stage was delivered.

2) The pre-pilot questionnaire was clarified in both questions and topics by semi-structured interviews which included a cognitive approach (a total of 12 people participated). The result that emerged was a clarification of the range of questions and answers which would be finally included.

3) Having found the topics of the questionnaire, the next step was to draft questions and answers. A great effort was made to use the most neutral style in the writing, not leading the respondents to any particular answer.

4) Involving 16 participants, a further edition of the questions was performed. Their remarks resulted very useful to find words which were not easily understood, found to be ambiguous or needing further explanations.

5) All the interpretations were incorporated, resulting in the final layout of the questionnaire. It was piloted so that the final comments could be taken into consideration, just before the distribution of the questionnaire. It involved 13 people, whose remarks resulted in the final proof-read of the questionnaire.

The resultant questionnaire consists in a total of 31 questions, clustered in 6 different parts, which are named below:

- A: Personal views about organ donation after death
- B: Talking about organ donation after death
- C: How you have learnt about organ donation after death
- D: How clear is your understanding of organ donation after death
- E: Organ donation after death in Europe
- F: Demographic information

An original sample of the questionnaire is added to the project, as an annex.

The questions of the survey were officially validated by a statistical consultant of Imperial College Office for Statistics and by measuring the agreement of two measurements; the following is an indicative example, in which the agreement between the two measurements for brain death reaches 87.5% and the kappa statistic is 0.714.

The minimum sample size was 259 participants, so that a group test with a 0.05 two-sided significance level has 90% power to detect the difference between the null hypothesis proportion, p0, of 0.50 and the alternative proportion, pA, of 0.60.

The project has been approved by the Medical Education Ethics Committee (MEEC) of Imperial College, the London-Hampstead Research Ethics Committee, and the Joint Research Compliance Office of Imperial College. Additionally, it received ethical authorization in Rotterdam and Santander.

FOCUS GROUP DISCUSSION

The focus groups discussion is a strategy to encourage members of each group to share the development of their own individual and collective thinking with regards to DOD.

The aim was to incite a discussion between the participants upon the main questions set by the researcher instead of following an interview style format.

Before the focus group discussions started, the researcher explained to the participants the purpose of the project and, more specifically, of the discussion, as well as that there were no right or wrong answers. The investigator also clarified the conversation base was meant to be created by participants' individual life experiences, views and suggestions.

The format of running the discussions consisted on prompt or clarifying questions asked by the researcher whenever felt appropriate either for the flow of discussion or to explain and better understand any relevant information considered 'basic knowledge'. Conversational flow was respected as much as possible so that participants could freely discuss and exchange their thoughts, opinions, and experiences.

As planned, the researcher exclusively intervened when discussion was going off topic, during voice overlaps and instances where several topics were raised simultaneously.

The discussions orbited around social, family, religious, personal views and experiences. They helped to show those influences which facilitate or hinder to get knowledge around DOD and factors that influence their decisions on this issue.

In each country, three focus groups were run: one with medical students, one with administrative staff, and one with kidney-transplanted patients. The total size of the focus groups was 51 participants. More specifically, there were a total 17 people in the Spanish focus groups, in which I participated actively.

The medical students chose to speak in English, and I, personally, assisted with translation, as needed on an additional basis. The other two focus groups discussions were run in Spanish, and me, as a native speaker and research partner run them, and similarly carried out the translation, after having written the Spanish script.

During discussion time, I wrote down some notes in order to make sure every detail mentioned was recalled and as a tool to clarify some ideas.

Each discussion lasted about one hour. To warrant accuracy, the transcription of the discussions started almost immediately after they took place. In a following moment, the one from the staff and the patients were translated into English.

Focus group discussions were recorded, always with the consent of the assistants, whose participation was anonymous. Direct quotations from respondents were used, but personal views/comments were anonymized and consequently cannot be attribute to anyone.

RESULTS

FOCUS GROUPS DISCUSSIONS

As referred previously, a total number of 51 people participated in the focus group discussions among the three selected countries. Following the line of my project, just the 17 Spanish participants will be taken into consideration, and, therefore, the results from the Spanish group discussions, exclusively, will be exposed in this chapter.

The ensuing pages show an overview of the themes and subthemes, complemented with quotes from real individual testimonies of each group.

THEMES AND SUB-THEMES

Through the analysis, it became obvious that there were three reoccurring themes brought repeatedly into discussion.

The first theme is **Position**, which is broken down to the sub-themes of

- Views referring to positive, negative, neutral attitudes, views about the body, influences which shaped these views;
- Relevance referring to personal experiences,
- Other donation types referring to their views on other donation options, such as altruistic, live-related, for science;
- Discussion with family referring to sharing their views and decisions with family, knowing their family’s views.

The second theme is **Processes** and it consists of the sub-themes of

- Registering referring to ways of registering, views and suggestions on registering;
- Waiting lists referring to how they work, Consent referring to knowledge of the process, views on the family decision;
- Treatment of donor referring to the medical processes, attitudes about donor;
- Allocation of organs referring to organs and the recipient;
- Legislation referring to perspectives of the national law about DOD, suggestions about possible change, rationale for suggestion.

The third theme is **Communication** and its sub-themes are

- Campaigns referring to messages, advertisements, printed materials, ways of engaging the audience;
- School referring to education through the school system;
- Media referring to television shows, documentaries, films, videos;
- Patients referring to their present and future involvement in awareness about DOD;

- Social media referring to their impact;
- Healthcare professionals referring to how doctors and nurses educate about DOD and suggestions about their future role;
- Religion referring to how religious leaders inform the congregation about DOD and suggestions on how they could be involved.

STUDENTS

POSITION

All the participants were positive about DOD. They understand much more the need of DOD that general population thanks to their studies and had not registered as a donor, as they did not feel it is needed due to the legislation on this issue.

Experiences from the medical school or news in the media had been topics of discussion with their parents. Meeting patients makes them to get concerned about their problem.

- *“I talk about my family and my friends, because they are studying nursing and all agree with the donor organs, because you can help another person with organ that you will not need any more”*

- *“when you are in the hospital and you are practicing, for example I was in intensive care unit but also last year I was at the nephrology and you see many, many transplants that and when you go back to your home and you talk with your parents about every day and the topics, that’s why I start with that topic at home”*

- *“the first time when I talk about this topic with my family there was one day a stand of a foundation, I don’t know what, to convince people to get a donor card, in the street”*

- *“when, sometimes, the news you hear about the importance of numbers of transplants in Spain, so that’s a way to talk about it”*

- *“I think it is necessary, but I know some people might have some problems, with the religion or whatever, but I think it is necessary, and the way they see in the movies”*

- *“For example, gypsy people usually accept organ but they are skeptical about donation”*

- *“it is not fair, some people ‘I do not like to give, but I prefer to accept’”*

- *“in the future, I would like to become donor. Probably I don’t know, the influence of the degree I am studying now, or probably the influence that doctors are, the influence of the family”*

- *“all of them, all of them positive opinions about that, no religious problems”*

- *“the father in my family, he has a donor card, so I don’t have any problems”*

- *“most people in Spain don’t have donor card. I know what to do with my body, it is the responsibility of my family not my responsibility”*

PROCEDURES

They talked about the legislation. Presumed consent was interpreted as a responsibility the family must assume in that final moment.

They also discussed about gaps of knowledge of the public towards procedures, such as who is the recipient of an organ or whether his nomination is possible or not.

- *“people was quite interested in the topic, maybe because they have a lot of”*

- *“questions that were not resolved. I, for example, they thought they can choose the recipient. For example, if I am a donor, I can choose who can receive that organ and I said, ‘no, you can’t be around to'”*

- *“at the end the last decision is in the family. That’s the law in Spain, the law in Spain is very advanced and theoretically all people are in a position to be donors, and this decision, family decision”*

COMMUNICATION

They were positive towards a European campaign for DOD and they called for different ways of achieving it: collaboration of European universities and associations of medical students, organizing events one specific day throughout Europe. They also talked about volunteering of medical students to promote awareness and share their experiences to reach a wider public.

A variety of campaigns about DOD to engage people was discussed: posters, screensavers, volunteering associations, concerts, songs, television marathons, running marathons, popular figures (such as artists or athletes as spokespersons).

The impact of social media was highlighted for reaching people at all places and times. In this way, a platform in a world-known social network was mentioned to be created as a creative tool to touch the youngest.

Engaging points of campaigns about other health issues were underlined and used as good practices that could promote DOD as well.

According to their views, an area of awareness not fully developed is education about DOD from a young age at school. They contemplated it should be seriously considered and stablished from a basis.

- *"I would get the education by the basics, at school, at the level children are learning but introducing it from the beginning, because I have friends who have never listened about organ donation and the answer is the education. And we are in our twenties, it's quite sad"*

- *"One time, I remember one time there was a marathon and all the benefit was for transplantation"*

- *"Volunteer, maybe, for example in the stand of the organisation, somewhere you can donate or you can be involved any question you have with people who are concerned about this. It will help"*

- *"we would organise some activities the same day for, everywhere. For example, the 1st June or the last Sunday of April, a race, or maybe, I don't know, or a concert"*

- *"I think that the best thing is someone who has the problem, but on the other side you need someone that hooks, attracts people"*

- *"for example, in Asturias there is an activity of some people to organise something related to donation, activity like some video, you know, something to increase the knowledge around the society"*

- *"his advertisement, which was really popular for the last years showing young people or something like that. If you don't give your organs to the heaven, give your organs to men. Something like that. We need your organs, don't send your organs to heaven"*

- *"for example, a bombardment of bone marrow transplant ... they made a video with children that were in hospital and they danced and it was very emotional. And they put it on buses and everywhere"*

- *"you know sometimes you share a message and they share it with 10 friends and the idea is to share an organ, and you share it with another friend and you make a chain"*

- *"think the person who can transmit it the best is the patient and the family, the people who need and who have received. To see the need and the result of the process"*

KEY MESSAGES

- ✓ The cooperation between European institutes was suggested as a strategy for European awareness campaigns.

- ✓ Involving people in campaigns through volunteering, fundraising, concerts as a proposed idea to the message of DOD.

- ✓ Campaigns could be more interactive with the public; assisting not only in the provident of information, but also clarify doubts on the issue.

ADMINISTRATIVE STAFF

The discussion with Spanish administrative staff focused a lot on communication issues, and on attitudes about DOD.

POSITION

Positive attitudes were expressed by all the participants of the group. The discussion run precisely around them and the high rates of donations in Spain.

Variations of these rates within the national geography were considered to exist due to the different cultural practices between North and South of Spain, in relation to the body and its conception. Some touched topics during the discussion were: religion, empathy and the evolution in the burial rituals.

- They talked about Catholic people in our country, whose religiosity mind would consider organ donation as a way to help the others; remarking that this attitude was not evident in other catholic countries.

- Other participants of the group assed that willingness to donate is highly related to empathy of the people: putting themselves in the shoes of the others.

- Emotional detachment from the dead body, donating a great importance to the soul was suggested. The change of burial rituals was brought as an example, in the sense that nowadays people accept cremation and the decomposition of the body, unthinkable years ago.

They all felt proud of the Spanish transplantation system, both solidarity of the people, competence of the healthcare specialists and overall structure and organisation of the transplant services, considered as a success in which public trust. It was boundlessly praised as a factor of success and created confidence to the public.

Despite the fact thinking and talking about death, is in general considered a difficult practice. It was claimed that helping others could be felt as a relief for the mourners, hoping their loved one is still live through another person's body.

The personal impact relevance of DOD was also expressed by a participant, whose husband had been transplanted. Based on their individual experience, their relatives and friends became better informed about the organ donation issue.

- *"It's a question of generosity. Religion is generosity and the donation is an act of generosity, it's a culture"*

- *"the body can be used and it will allow another person to live"*

- *“if it is the death of an adult, I do not think so, and the donation is useful, I believe that there is no remorse at any moment.”*

- *“obviously, you don’t love a liver or a heart. You love a child, a person”*

- *“in Spain, little is said about death, talking, then, about donation after death, means talking about death, implicitly.”*

- *“I do not know anyone who has said "I am against organ2 donation”*

- *“donation rates are higher in the North than in the South*

- *I have not had any negative experiences but I have always been clear that you have to help. And that you can do it with your body, facilitating other people survival. I have always been clear. And I have faith. I mean, I am a person of faith and a practitioner. I have always been clear that the body is not a thing to be worshiped that way. The body is transient for me, the soul is the important thing*

- *I am not a religious person and yet, from another point of view, I have come to the same conclusion*

- *Perhaps, our level of empathy, as a country in general, is higher than the level of other countries*

- *my case is a bit special. My spouse has a transplanted organ, so I know the subject quite deeply. I think, maybe more than other people*

PROCEDURES

The default law of consent was not considered to be the reason of the high rates of organ donation. It was expressed that decision to donate organs is personal, and it must be respected by the others. At the same time, family has the responsibility to decide in the final moment (especially, if the deceased did not mention his will during lifetime).

- *“maybe it's not that important ... if we had an education in organ donation, it's*

- *“not as important how they go asking you, because if you are convinced in what you are doing”*

- *“we were making similarities between money. If you need your money, doesn’t matter what your family thinks about it, it’s your decision. Not your family decision. It’s your decision, and they have to respect”*

- *“although the law protects your decision, the family is always asked. What do you think? It can affect the family”*

COMMUNICATION

Discussing on how to create effective campaigns, analysis of target groups' needs was commented to be very relevant. According to them, if messages are more personalized, they could be more relatable and relevant. They considered that a message is more engaging if connected to a real story. From that idea lies the need of patients' participation in campaigns, television and radio programs or scholars' formation.

- *"I think campaigns like these, where you have people in front and explaining things to you"*

- *"First, create the mentality, the social mentality"*

- *"Perhaps the most effective way is to bombard with publicity. All the information that comes through your eyes and ears is more effective. But repeatedly, without a rest. Because the people, we need them to repeat us, to remind us. I mean, it is the most effective"*

- *"if they keep repeating the same message to you, it is very effective, because in the unconscious"*

- *"People who study the market, who know the sensitivity of the people, can determine in what things or matters that population, as a whole, is more empathetic, to act in that sense "*

- *"The wider the campaign, the better, at all levels"*

- *"a very clear example, with a different subject, now that you have reminded me, it is, for example, the refugee issue. We were all, at first, knowing that there were people dying. Actually, the civilian population did not realize the tragedy until the dead child appeared on the beach. The image of Aylan"*

- *"if they are telling you and putting pictures to you like: "Today this girl has survived thanks to the intervention of these teams and things like that", because all this motivates you to act"*

- *"An image impacts more than any word"*

- *"Advertising is very important. It is decisive"*

- *"in Spain, I think, it influenced a lot, at that time, to put a face to the people with transplants"*

- *"it is like a ball that feeds your ego. If they tell us that we are very good at"*

- *"something or that we have enhanced in something that we excel at something; because that even makes us be more inclined to do it"*

- *“It is also another way of acting: on people’ ego”*

- *“USA example. Fire fighters are very dear. And the fire fighters go to the schools, and give the children a fireman's cap. That is, that love to the firefighter is generated. That respect to the fire fighter figure”*

- *“In Spain, there was a long period of time that people who had been transplanted appeared in television, and I think that creates a lot of empathy: "putting a face to this people”*

- *“Frequently, news, like for example “the number of transplants in Spain has increased by a percentage -whichever it was-”, appeared, and there was a person, who had been transplanted, talking. I remember images of patients who were still in the hospital”*

- *“in a school, you are not going to take a child of 6 or 7 years who have been transplanted to give a talk. But a 14-15-year-old-boy who has been transplanted going to a 5-6-year-old-children class... I believe that if they see someone who is very close to them and that can even make jokes that excite the children (like showing the children a scar or something like that)”*

KEY MESSAGES

- ✓ High rates in organ donation are believed to exist due to general trust in the medical system and extended structures of transplantation mechanisms, among other factors.

- ✓ A sense of national pride was shared about the compassion of the people and the medical system.

- ✓ Patients were considered to be a key agent of the campaigns, and, thus, should actively participate to share their experience with the public.

PATIENTS

POSITION

No negative arguments were mentioned. The participants confessed their awareness about DOD existed even before their pathological condition forced them to get knowledge on this issue, but obviously, ever since they were diagnosed, it suited more relevant in their daily lives. From that moment, they became more operating to be better informed.

- *“I have already heard things about donation”*

- *“what was coming out on the news or what I heard and that, but I had never figured out that I would get there”*

- *“I believe that the problem of the concept of donation means changing the concept of death a bit. I mean, it is an end-of-life stage. The donation, more than the one when it dies and is the burial and such or such cremation; A bit of what you think is that it could be a culture change to say that this is part of the end of life, in certain people, in certain circumstances that your organs for donation may be useful”*

- *“what is important is to create the culture that the donation is part of the end of life and that well, and in the end, the families who have donated gives them peace of mind knowing that they have donated and that is worthy for another person”*

- *“I'm sure the families of their own donors, when they think about it, because thanks to my brother, or my father or my ... a lady with a liver transplant, a lady with a kidney and a pancreas are living and those are the things that are difficult to interpret”*

- *“It coincided that, unfortunately, a cousin's son needed a bone marrow transplantation”*

- *“One of my daughters and my brother have become donors”*

- *“I do have several colleagues who in fact had signed up to donate”*

- *“for example, a partner of the husband, he has been always very aware of how I was and that and he said that his son who had dialysis I do not know how many hours and that was suddenly that and that took a lot in that and in the end the donor was the mother. She donated alive”*

- *“Because of that, well, we have always talked about and in relation to what the lady says, you see it on TV”*

- *“The school, because then the children, that is a novelty, then, just after arriving home, the first thing they are going to do is saying that today a doctor came and told us this and this”*

- *“And the children are very intelligent. I saw it, for example, in the case that I told you about my cousin. Well, he was 7 years old and had two younger brothers, but at home, he never hid what was there. His brothers took it very naturally. And it is today, he is missing, unfortunately, but it is one thing, that they took it very naturally”*

PROCEDURES

The procedures of DOD were completely-understood when they were put in the waiting lists.

Family’s final consent requirement was understood to be a major element of DOD in our country.

- *“Spain has it, but it is never applied because it does not make sense. If the family does not want to, what are you going to get with this?”*

- *“In Spain, the law allows everyone to be a donor at the time of death. The law is this way but it is never applied”*

- *“in May it was when I started to do the peritoneal dialysis and on September, the 19th they called to tell me that I was on the waiting list. And in January ... “*

COMMUNICATION

Television was emphasised as a major part of the campaigns because it reaches many people. Also, discussion with friends and colleagues were mentioned as a strategy to involve more people. They said that famous figures could participate in DOD campaigns to help with its promotion.

The participants called for a collaboration between doctors and patients who could inform and educate people in conferences but also on television programs.

They proposed that education on DOD should start at school because they considered children to be enough qualified to understand and accept it. The earlier people get familiarised with the issue, the more willing they would be to become donors in the close future.

They also commented on the opportunity of instructing people that belong to large groups, such as the military or university students.

- *“Where people transplanted from ... for example my case of kidney-pancreas, another case of liver ... Yes, each of a different thing; talking about his experience: before and afterwards.”*

- *“I think that sometimes one, as you see, the person who has been favored by”*

- *“saying so, is always seen, that is spoken positive to another, in this regard. And that I have seen. Many of my colleagues who had previously been transplanted only spoke positively to others”*

- *“The school, because then the children, that is a novelty, then, just after arriving home, the first thing they are going to do is saying that today a doctor came and told us this and this”*

- *“Information through the patients; with a doctor who can explain it and that's good, maybe it also attracts people to get interested into that the television would be fantastic, to be able to make that program of cases that were real, advised by doctors who know about and explain it to the people.”*

- *"if there is a case that catches the attention, the TV does a lot"*

- *"I think the best thing is TV, about a show; Like the ones that are now about hospitals and that. They give real life cases. Well this is the same. Talking about kidney diseases and make it a half hour program or an hour a day. People watch TV a lot."*

- *"Dedicated exclusively to transplants"*

- *"the television would be fantastic, to be able to make that program of cases that were real, advised by doctors who know about and explain it to the people."*

- *"One of the doctors was talking about the processes. It was an exclusive interview with her. She explained how processes were, how they were all things and good."*

- *"some lectures years ago and talked about transplantation for people"*

- *"a conference or something with a doctor attending"*

- *"information through the patients; with a doctor who can explain it and that's good, maybe it also attracts people to get interested into that"*

- *"the television would be fantastic, to be able to make that program of cases that were real, advised by doctors who know about and explain it to the people."*

KEY MESSAGES

- ✓ The cooperation of patients and doctors in explaining and promoting to the public DOD was suggested.

- ✓ Television programs on transplantation were also called to have a relevant role in advertising.

- ✓ Word of mouth, using celebrities, and fundraising were some of the ways to awareness promotion.

- ✓ The need to educate students on DOD from a young age was highlighted and the presentation of patients, even children patients, was suggested as a practical possibility to reach juvenile audiences

QUESTIONAIRE

In this section, the findings of the survey are presented.

A cross-cultural comparative case study design is used to analyse survey data statistics (N=1309), taken from UK, The Netherlands and Spain.

As mentioned before for the group discussion results, only the outcomes of the survey in Spain (N=323) will be taken into contemplation, and therefore, will be exposed in this succeeding.

Results obtained from the questionnaire can be structured in differenced parts:

- Firstly, an overview sample is revealed.
- Then, we will go through the results of the test in these well-defined concepts:
    - The consistency of communication with family and friend
    - Personal view about DOD
    - The knowledge score
    - The profiling of the registered and non-registered.

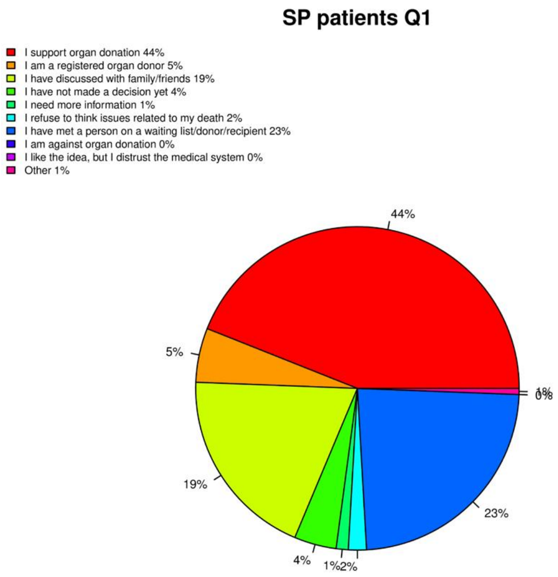
OVERVIEW OF THE SPANISH SAMPLE

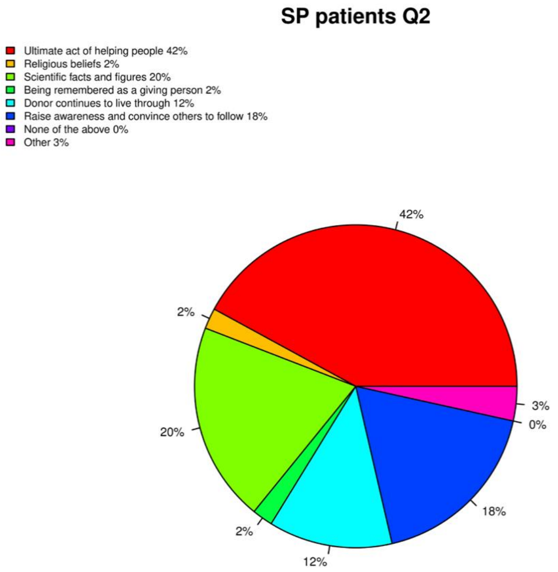
Notions of answers from questions asking about individual interpretation are presented.

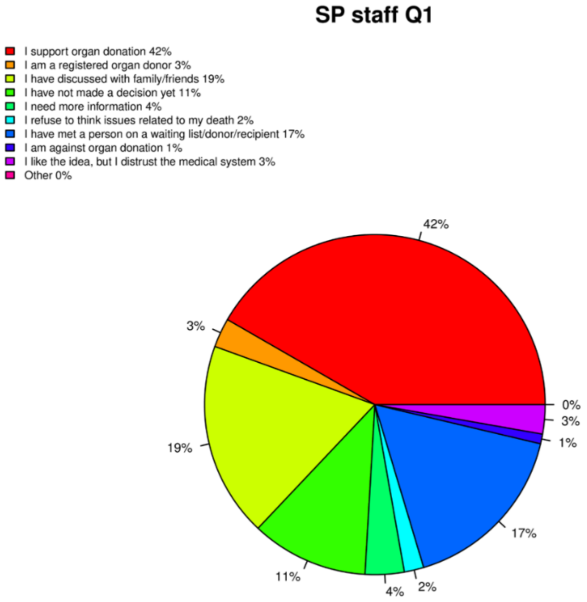
It can be perceived that there is a distinction of the three groups (medical students, patients and administrative staff). As a result, it is presented a graphic for each group for each question (it means, a total of three graphics per question).

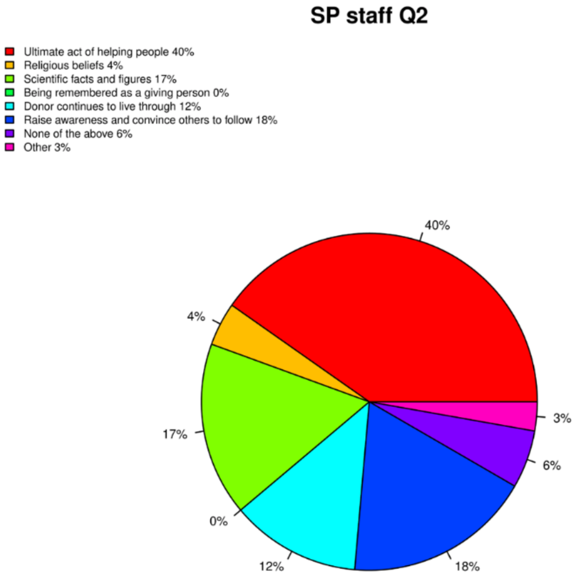
Remarking, over, that it is only referred to the Spanish sample.

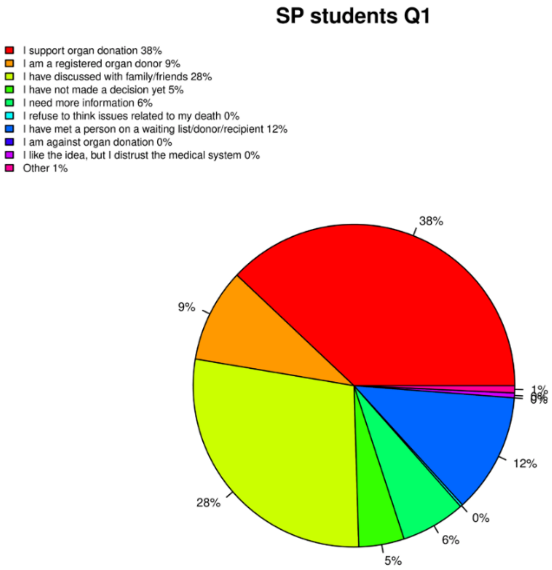
- Q1: positions of the sample regarding DOD
- Q2: reasons for supporting DOD
- Q3: reasons to oppose DOD
- Q4: awareness in other health issues
- Q9: Sources of information about DO

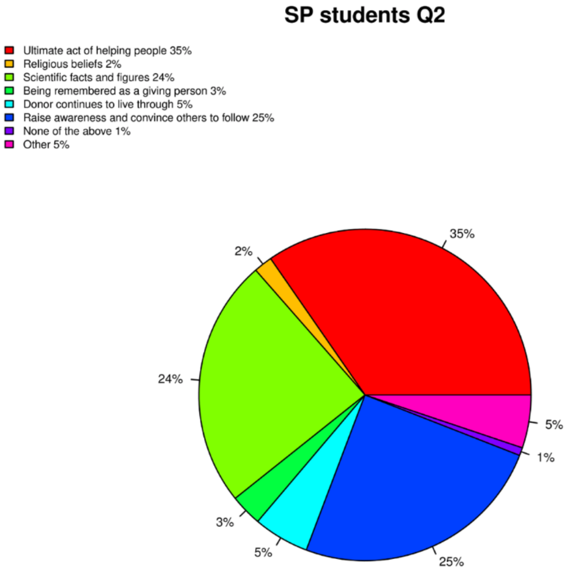

SP patients Q1
I support organ donation 44%
I am a registered organ donor 5%
I have discussed with family/friends 19%
I have not made a decision yet 4%
I need more information 1%
I refuse to think issues related to my death 2%
I have met a person on a waiting list/donor/recipient 23%
I am against organ donation 0%
I like the idea, but I distrust the medical system 0%
Other 1%
44%
5%
1%
0%
19%
23%
4%
1%
2%

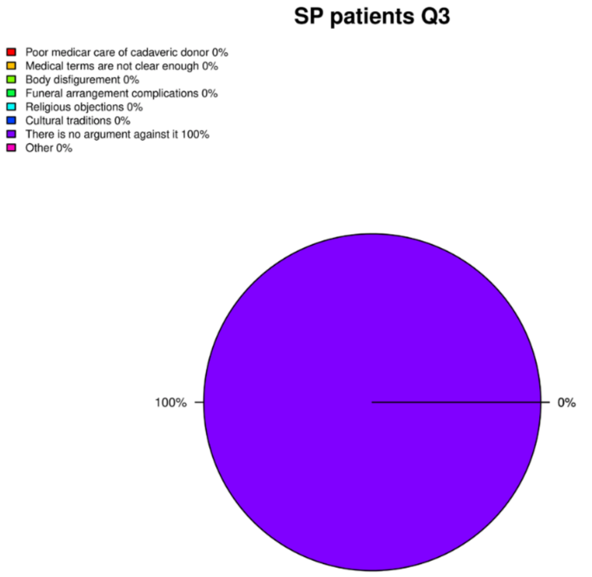

SP patients Q2
Ultimate act of helping people 42%
Religious beliefs 2%
Scientific facts and figures 20%
Being remembered as a giving person 2%
Donor continues to live through 12%
Raise awareness and convince others to follow 18%
None of the above 0%
Other 3%
42%
2%
3%
0%
20%
18%
2%
12%

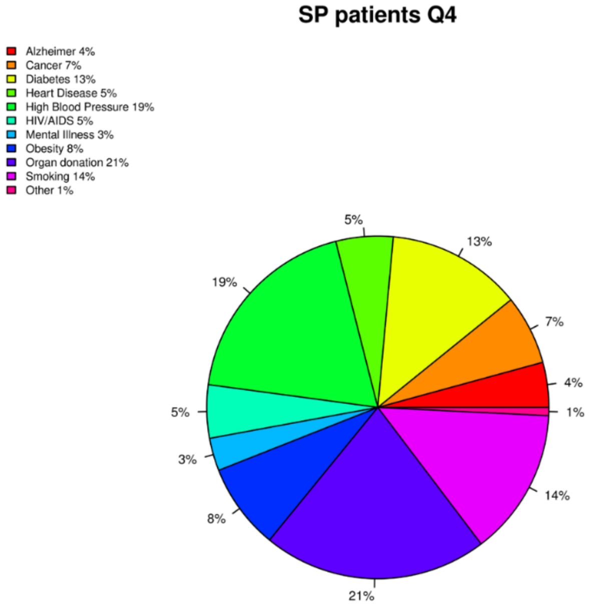

SP staff Q1
I support organ donation 42%
I am a registered organ donor 3%
I have discussed with family/friends 19%
I have not made a decision yet 11%
I need more information 4%
I refuse to think issues related to my death 2%
I have met a person on a waiting list/donor/recipient 17%
I am against organ donation 1%
I like the idea, but I distrust the medical system 3%
Other 0%
42%
3%
0%
3%
1%
19%
17%
11%
4%
2%

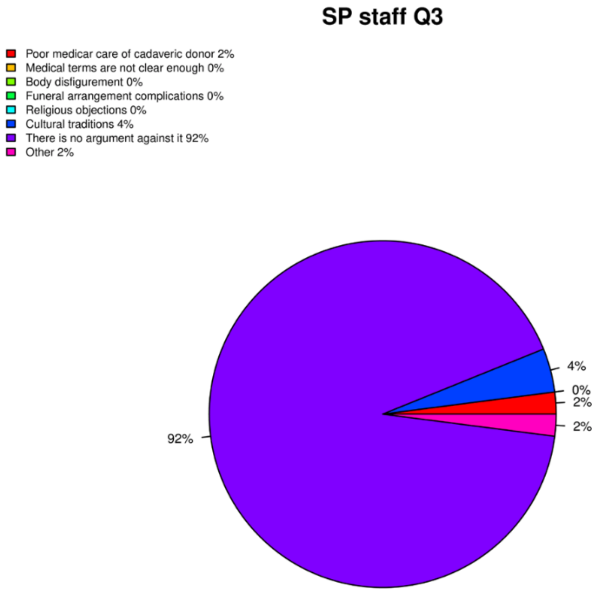

SP staff Q2
Ultimate act of helping people 40%
Religious beliefs 4%
Scientific facts and figures 17%
Being remembered as a giving person 0%
Donor continues to live through 12%
Raise awareness and convince others to follow 18%
None of the above 6%
Other 3%
40%
4%
3%
6%
17%
0%
12%
18%

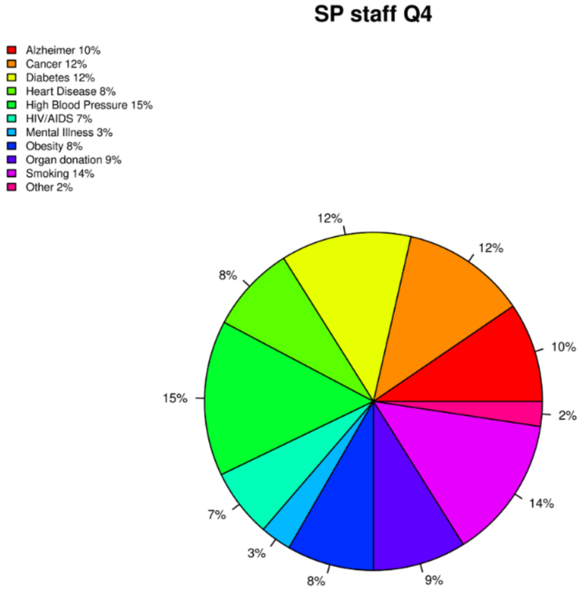

SP students Q1
I support organ donation 38%
I am a registered organ donor 9%
I have discussed with family/friends 28%
I have not made a decision yet 5%
I need more information 6%
I refuse to think issues related to my death 0%
I have met a person on a waiting list/donor/recipient 12%
I am against organ donation 0%
I like the idea, but I distrust the medical system 0%
Other 1%
38%
9%
1%
0%
0%
12%
28%
0%
6%
5%

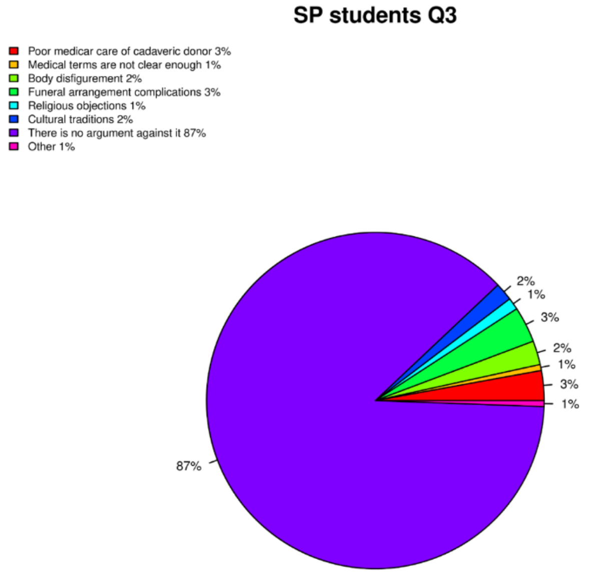

SP students Q2
Ultimate act of helping people 35%
Religious beliefs 2%
Scientific facts and figures 24%
Being remembered as a giving person 3%
Donor continues to live through 5%
Raise awareness and convince others to follow 25%
None of the above 1%
Other 5%
35%
2%
24%
5%
1%
3%
5%
25%

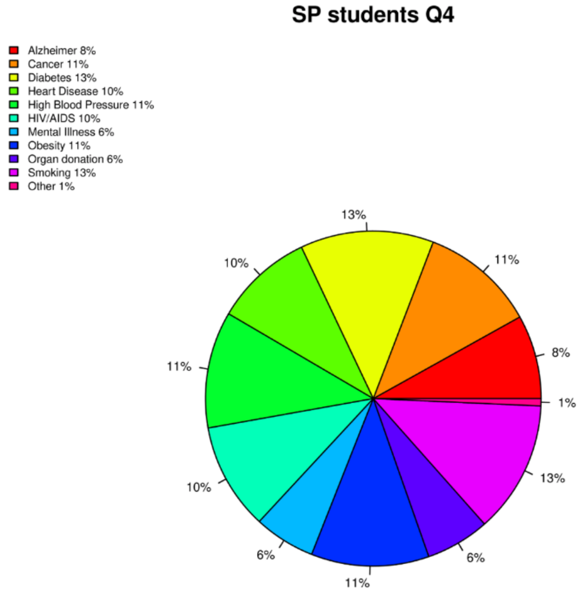

SP patients Q3

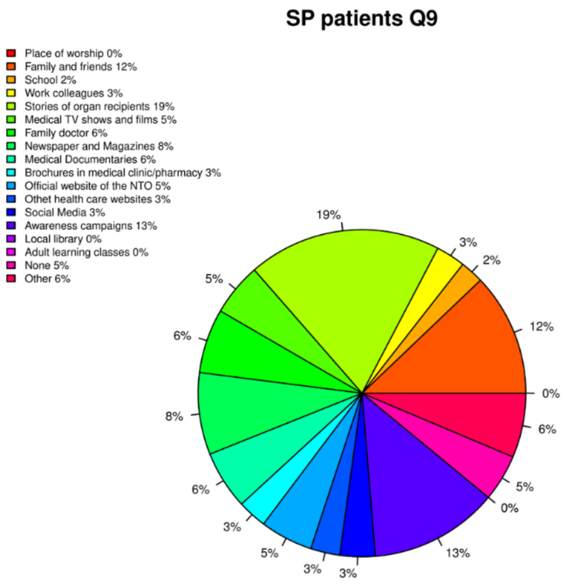

SP patients Q4

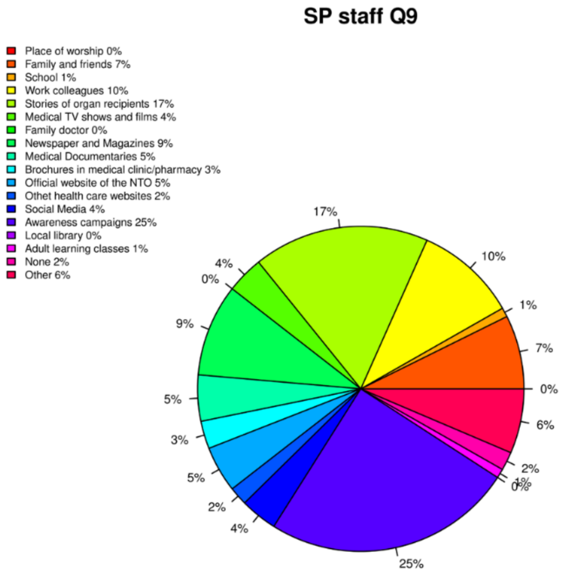

SP staff Q3

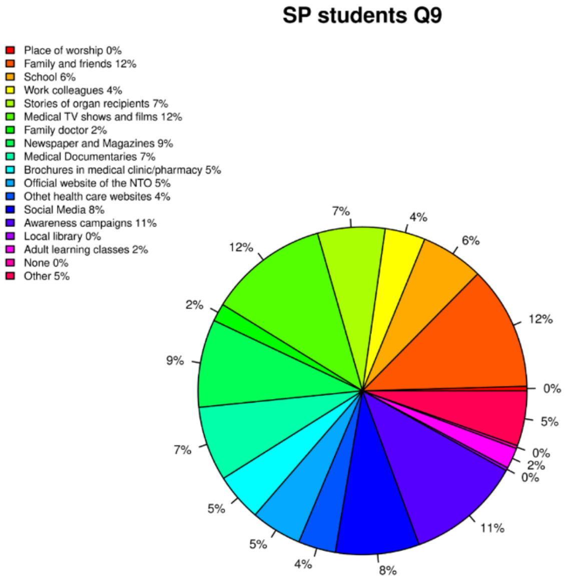

SP staff Q4


SP students Q3


SP students Q4


SP patients Q9
Place of worship 0%
Family and friends 12%
School 2%
Work colleagues 3%
Stories of organ recipients 19%
Medical TV shows and films 5%
Family doctor 6%
Newspaper and Magazines 8%
Medical Documentaries 6%
Brochures in medical clinic/pharmacy 3%
Official website of the NTO 5%
Othet health care websites 3%
Social Media 3%
Awareness campaigns 13%
Local library 0%
Adult learning classes 0%
None 5%
Other 6%


SP staff Q9
Place of worship 0%
Family and friends 7%
School 1%
Work colleagues 10%
Stories of organ recipients 17%
Medical TV shows and films 4%
Family doctor 0%
Newspaper and Magazines 9%
Medical Documentaries 5%
Brochures in medical clinic/pharmacy 3%
Official website of the NTO 5%
Othet health care websites 2%
Social Media 4%
Awareness campaigns 25%
Local library 0%
Adult learning classes 1%
None 2%
Other 6%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Place of worship 0%
Family and friends 12%
School 6%
Work colleagues 4%
Stories of organ recipients 7%
Medical TV shows and films 12%
Family doctor 2%
Newspaper and Magazines 9%
Medical Documentaries 7%
Brochures in medical clinic/pharmacy 5%
Official website of the NTO 5%
Othet health care websites 4%
Social Media 8%
Awareness campaigns 11%
Local library 0%
Adult learning classes 2%
None 0%
Other 5%

DEMOGRAPHICAL DESCRIPTION OF THE SAMPLE

A total of 323 people completed the questionnaire.

Medical students (60%) was the biggest subgroup, followed by the patients (24%) and the staff (16%).

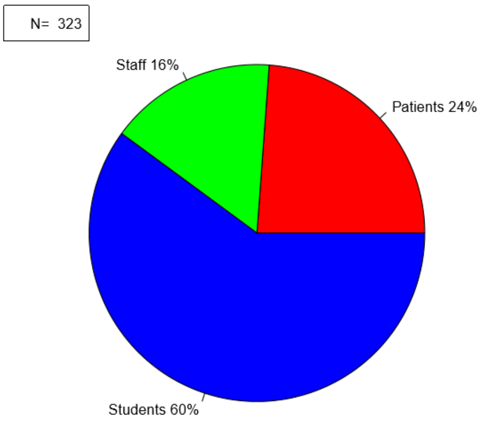

Figure 6: Sample size and composition

Single participants (64%) was the largest collective according to the marital status, as well as, having a University education (68%), and Christians (58%) in relation to the sample's education and religion, respectively. Caucasian race is undoubtedly the predominant one.

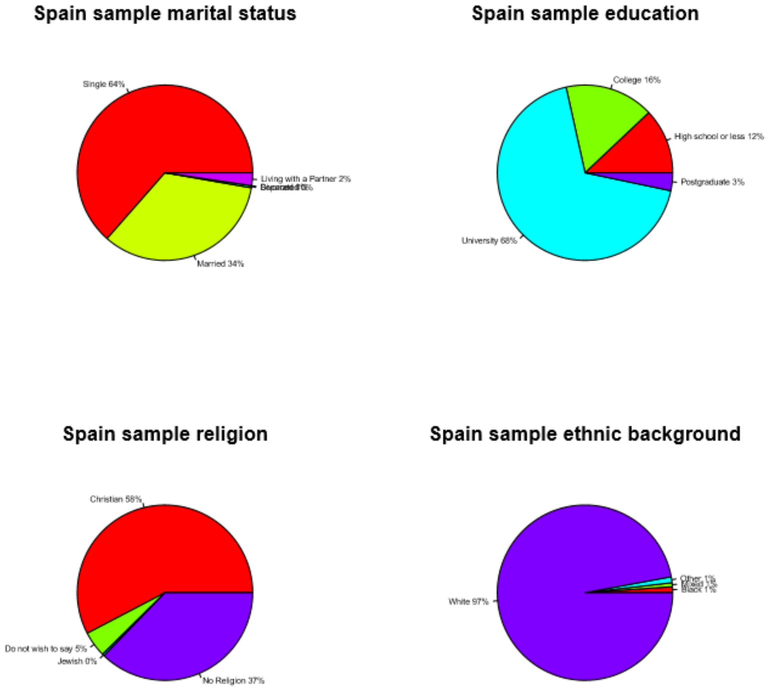

Figure 7: Demographic information

Most participants are female. It can be noticed in all age ranges

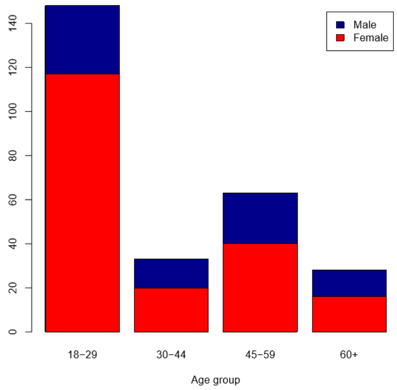

Figure 8: Sample distribution by gender and age

COMMUNICATION CONSISTENCY AMONG RELATIVES

For the next results, we have looked through answers in part B of the questionnaire.

It is observed that in all groups, even in the cases when participants have not talked with their relatives about DOD (grey bar), are willing to give consent.

The answers in Q6- Q8 are dependent on Q5, with a statistically significant the association with:

- Parents (p- value 4.66e-06).
- Siblings (p-value 4.39e-06)
- Spouse/partner (p-value 8.11e-06)
- Cousin (p-value 2.1e-05)
- Nephew/niece (p-value 2.97e-06)
- Children (p-value NaN).

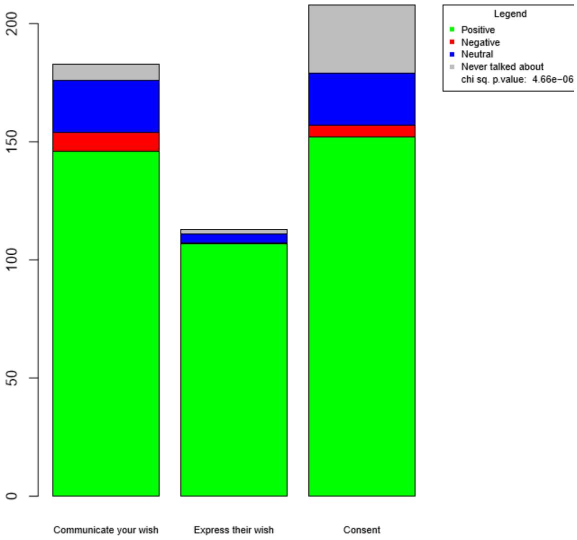

Figure 9: Talking about organ DOD with parents

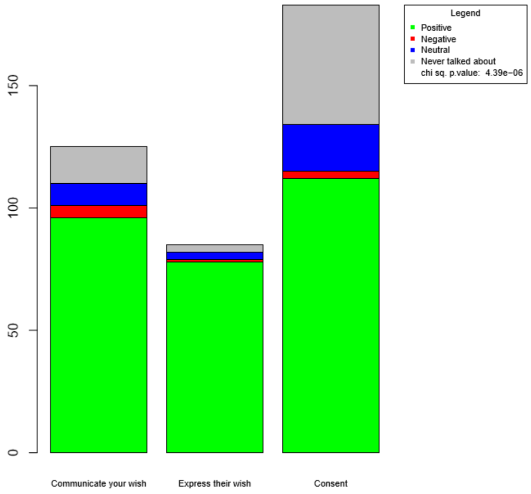

Figure 10: Talking about organ DOD with siblings

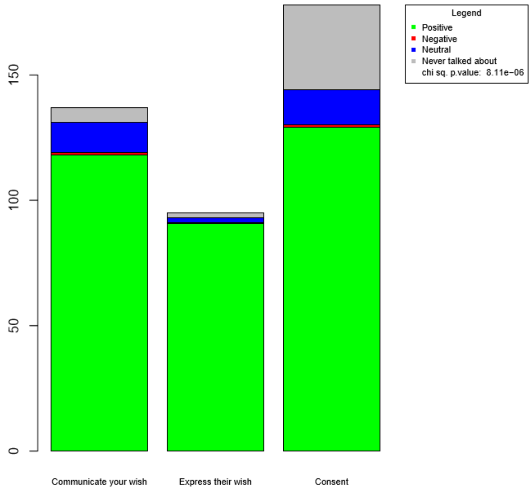

Figure 11: Talking about DOD with a partner/spouse

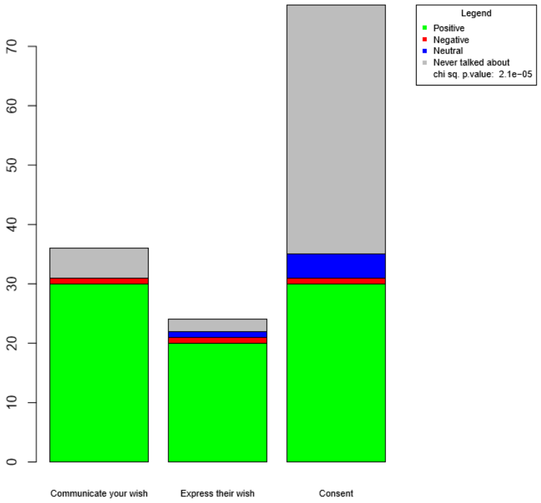

Figure 12: Talking about DOD with cousins

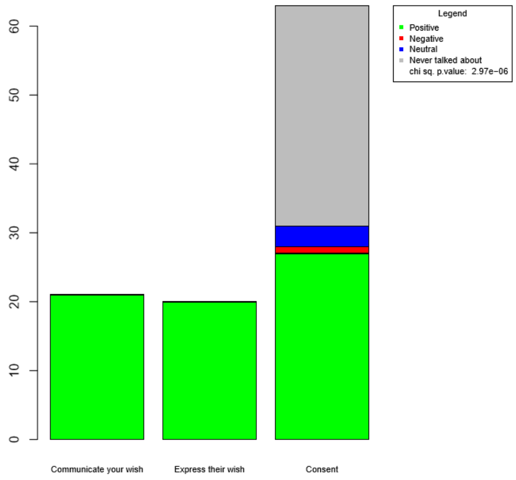

Figure 13: Talking about DOD with nephew/nieces

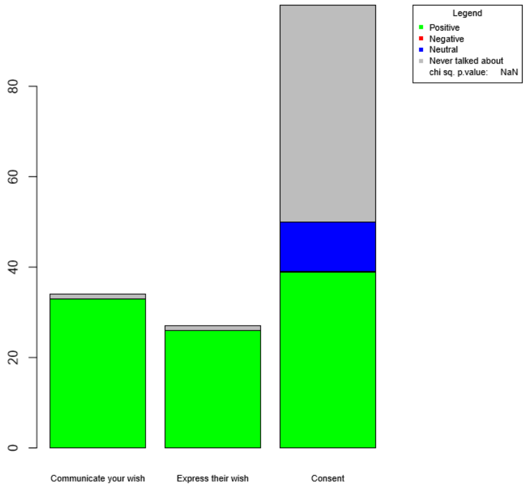

Figure 14: Talking about DOD with children

PERSONAL VIEW ABOUT DOD

Answers in Q2 were not influenced on financial dependence, as shown in the figure:

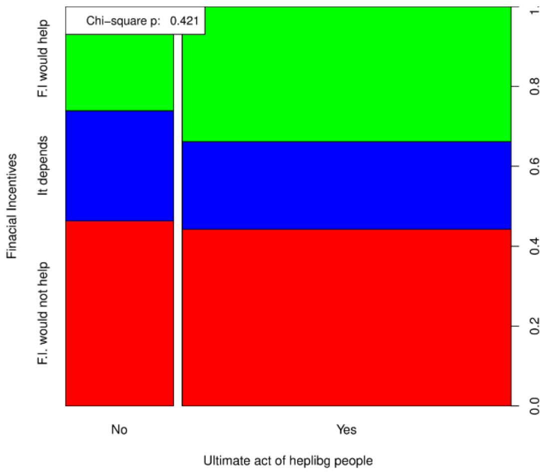

Figure 15: DOD as altruistic act and financial incentives

Registration was not dependent on the year of studies because students in different years (1st to 2nd or 5th to 6th) did not statistically significantly differ in being registered organ donors.

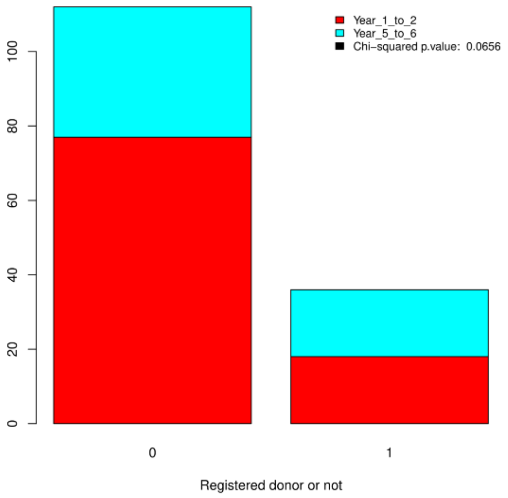

Figure 16: Student registered donors per year of study

KNOWLEDGE SCORE:

ACCORDING TO REGISTRATION

It was exposed that registration for DOD was not dependent on the knowledge of specific health issues related to organ donation.

The test revealed that there was not a significant effect of knowledge between the registered and non-registered participants (p-value 0.1). Thus, inspection of both groups' median suggests that registered participants scores on knowledge about DOD were not significantly higher than the scores of the non-registered ones.

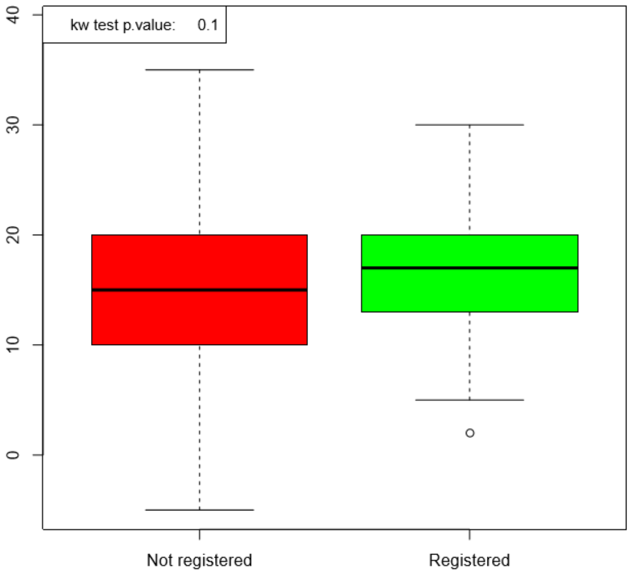

Figure 17: Association registered for organ donation and knowledge score.

AMONG GROUPS

Knowledge scores were not significantly dependent on group either.

The boxplot below shows that knowledge score is not dependent on participant's group (KW test p.value > 0.05) and median scores are almost the same. This finding reinforces the hypothesis that knowledge score is only important when distributed differently among the groups.

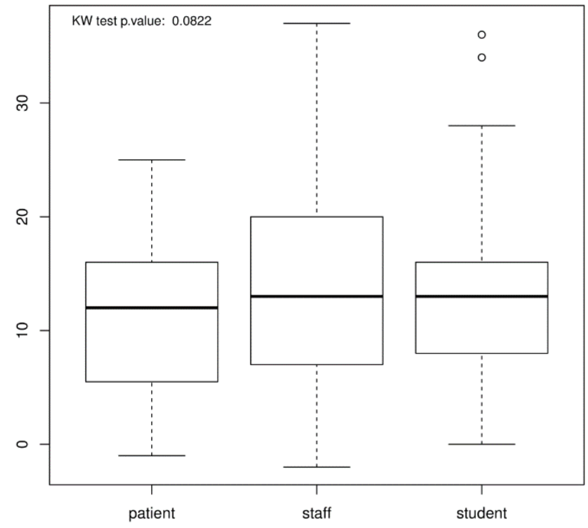

Figure 18: Knowledge score per group

Moreover, it was revealed that most patients gave the wrong answer in the question 17.6 ("if a donor can potentially benefit 8 patients") and in the question 20.1 ("whether hospital are required by law to ask for the family's consent even if the patient has signed a donor card"). Additionally, a significant number of patients gave the wrong answer in the question 12, assessing legislation awareness.

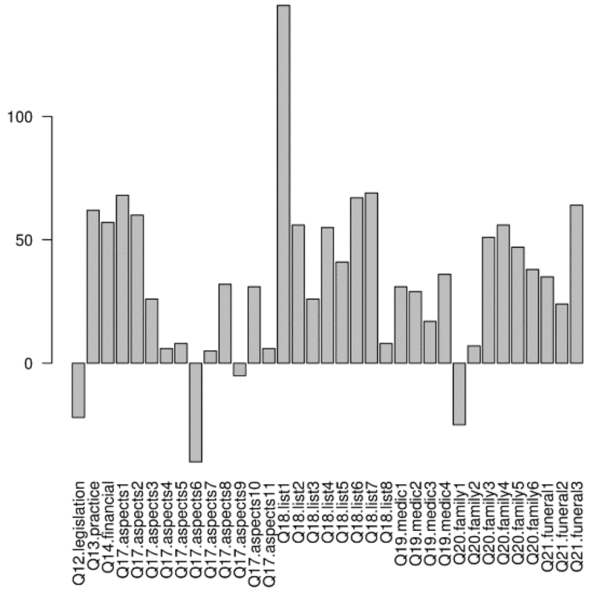

Figure 19: Patient's knowledge on DOD

Students also had wrong the same questions from the questionnaire than the previous group, I mean, 17.6 and 20.1. Additionally, legislation question (12) was incorrectly answered.

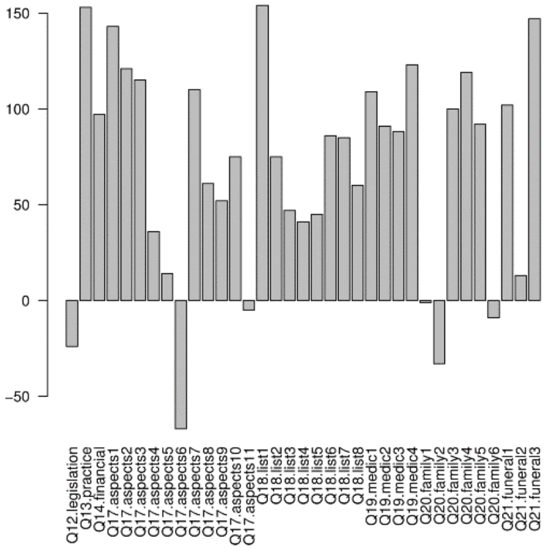

Figure 20: Student's knowledge on DOD

In quite a similar situation, Staff had mostly wrong questions 17.6 and 20.1. Question regarding doctor's ability to dispose organs if they cannot transplant them (Q 17.9 from the survey) was also mistaken.

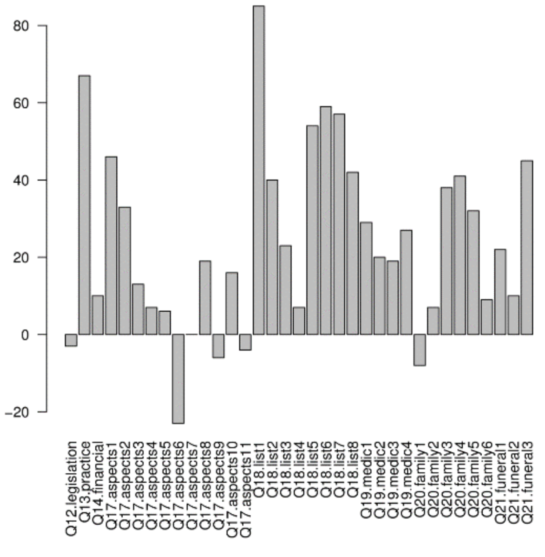

Figure 21: Staff knowledge on DOD

In conclusion, the knowledge on DOD questions that were mistaken with a high proportion in every group were 17.6 and 20.1.

CORRESPONDENCE ANALYSIS

We have computed correspondence analysis at two levels.

- The first level is based on the demographic variables (age, marital status, religion, and ethnic background) in relation to registered and non-registered donors.
- The second level is based on all variables including the socio-economic ones.

In the following table, the proportion of the contingency tables with missing value and the proportions of the missing value for every variable is presented.

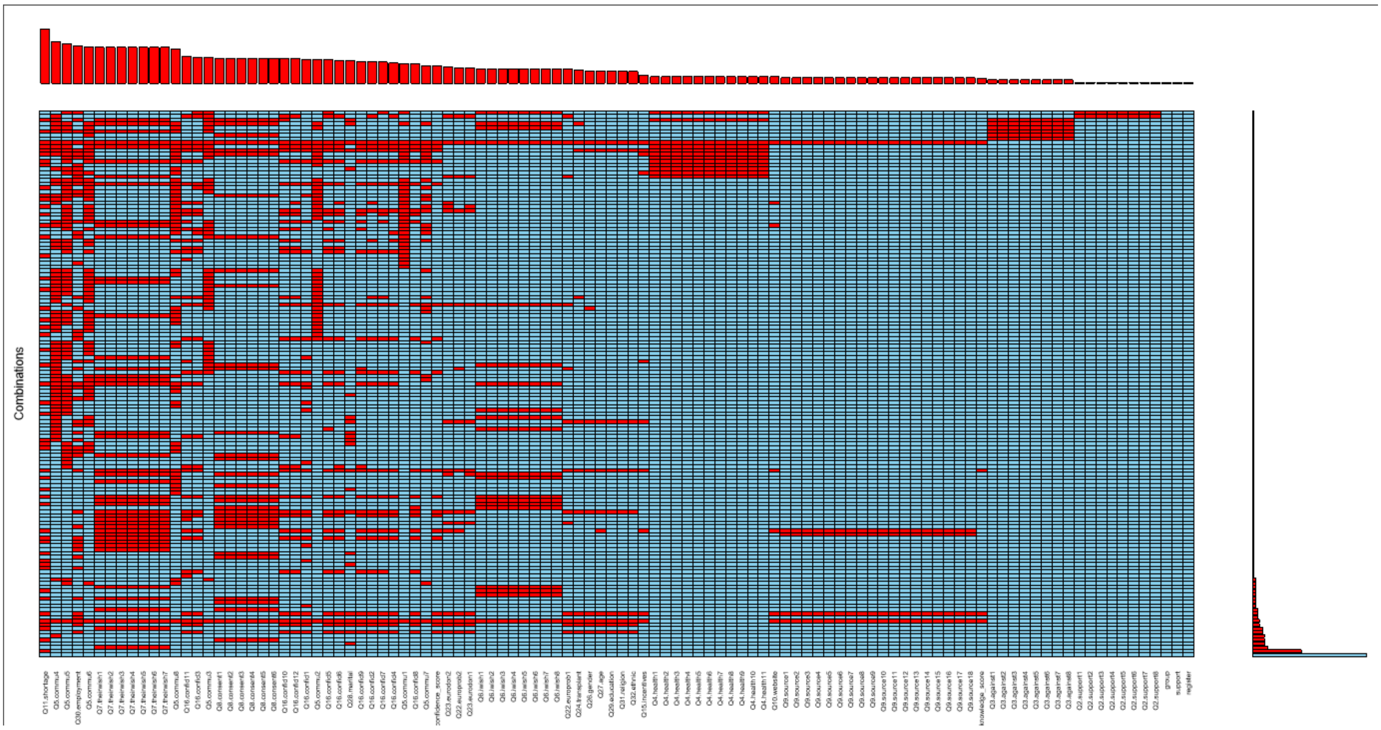

Figure 22: Spanish sample missing values

DEMOGRAPHIC VARIABLES

At the following diagram, we construct the principal coordinates (dimension 1 and dimension 2) with the socio-demographic variables, which have been used to predict ‘registered’ and ‘non-registered’.

The observed spatial colocalisation allows us to locate variables associated with registered donors and non-registered individuals.

Registered donors are represented as blue dots and the non-registered individuals are represented as red dots.

The principal coordinates are based on the demographic variables (age, marital status) and the blue centroid dot representing the registered participants is very close to the red centroid dot representing the non-registered.

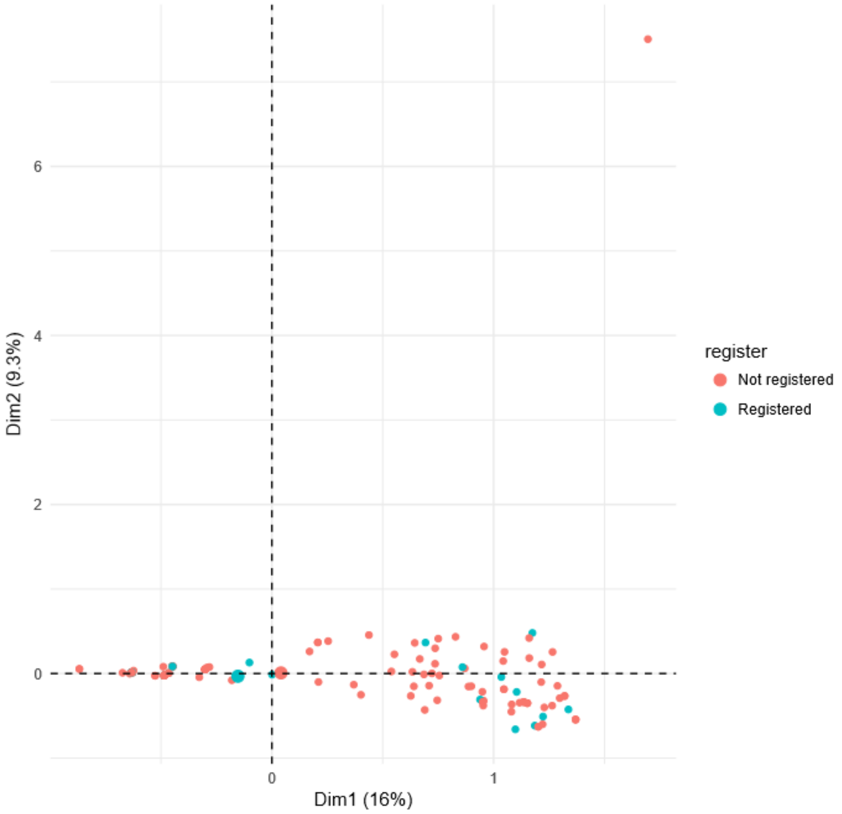

Figure 23: Correspondence analysis: individual's factor map

Negative values in dimension 1 and positive values in dimension 2 increase the odds-ratio for the registered.

The variables which are highly associated with the registered group are:

- the age of the participants (18-29).
- the education (medical students, University degree).
- the marital status (single).

On the other hand, positive values in dimension 1 and negative values in dimension 2 increase the odds-ratio for the non-registered group.

Highly associated variables with the non-registered group are:

- the marital status (single).
- the religion (Jewish).
- ethnic background (mixed).
- the age (45-59).

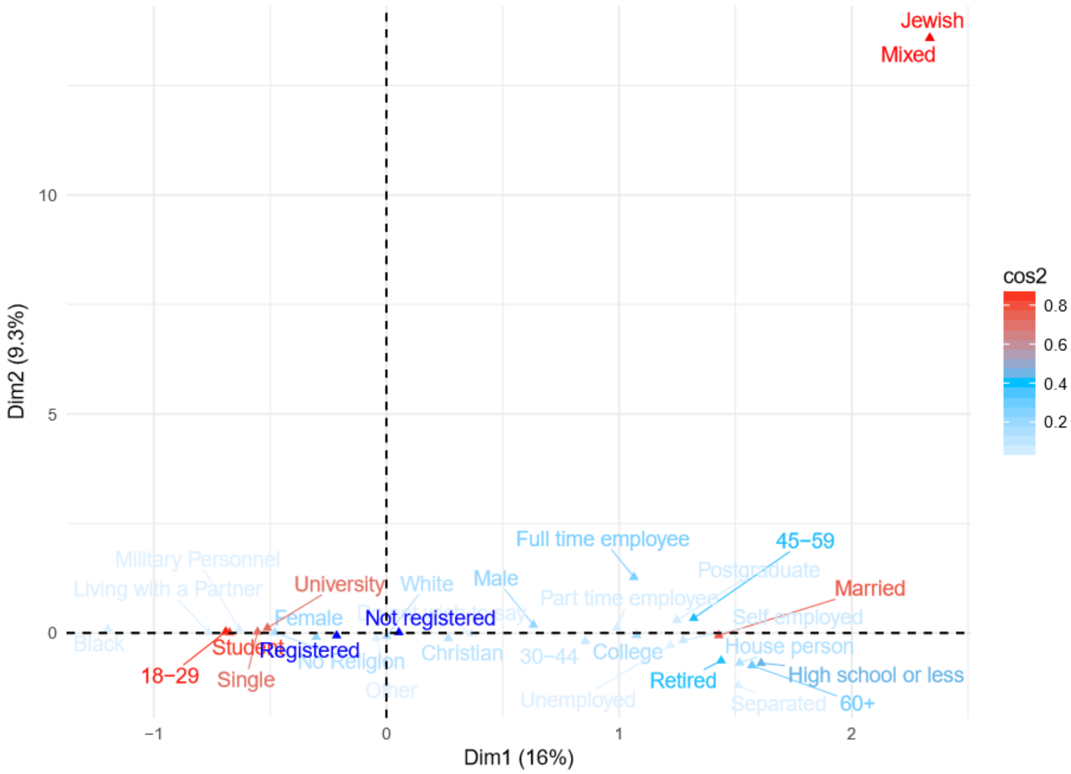

Figure 24: Demographic variables factor map

CORRESPONDENCE ANALYSIS FOR ALL VARIABLES (2-9)

The centroids of both group are aligned with dimension 1 and therefore the variance explained by dimension 2 does not explain well the registered and non-registered groups. The more the values in dimension 1 increase, the higher the odds-ratio are of an individual to be registered.

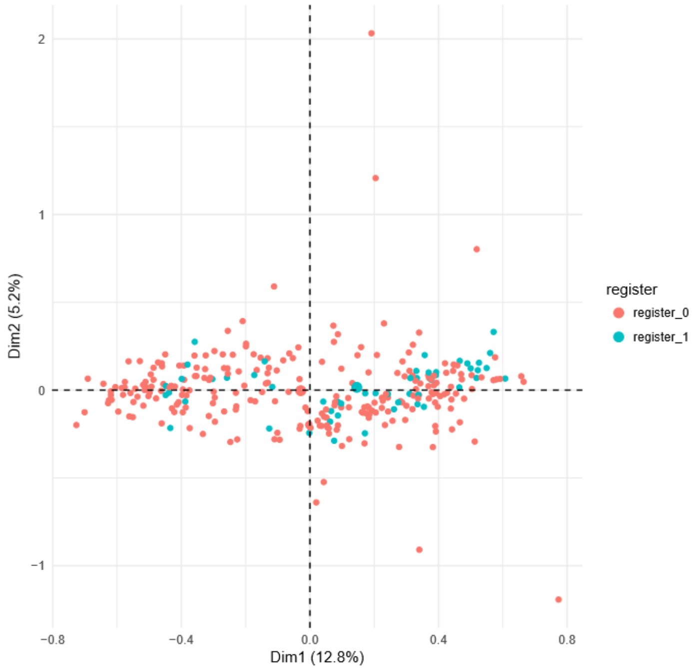

Figure 25: Correspondence analysis on individuals' factor map

Thus, when analyzing every variable and not only the demographic ones the following results are obtained.

The most important factors associated with the registered group are:

- the young age (18-20)
- the studies in the medical school
- information on HIV/AIDS, obesity, mental illness, cancer, smoking
- university education
- information through TV medical shows.

Factors highly associated with the non-registered group are:

- the age of the participants (45-59)
- not proper information about health issues.

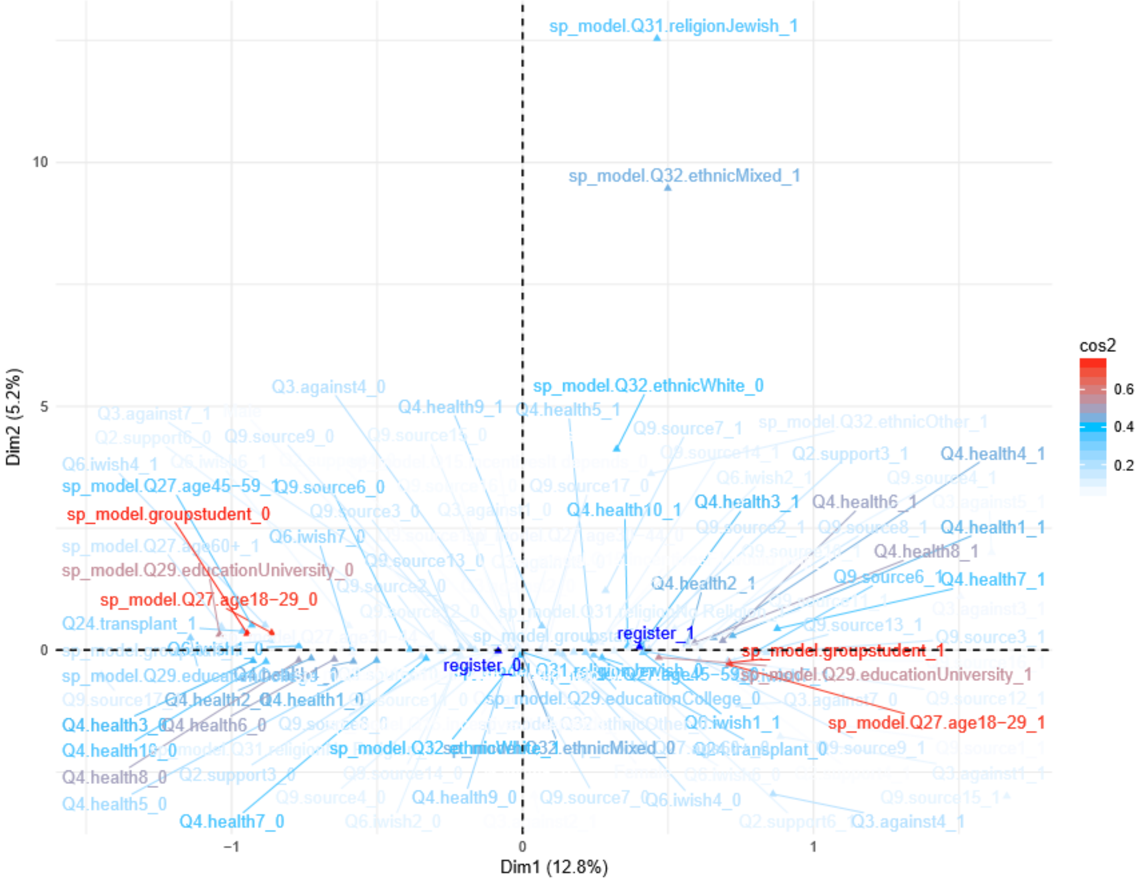

Figure 26: Graphic representation of all variables

CONCLUSIONS

The answers to the research questions obtained by the realization of this project will be exposed on the following:

PROFILE OF ORGAN DONORS

According to the results found, the more variables are studied, the clearer the profiles of registered and non-registered donors became.

For the registered organ donors, their profile has common characteristics: in general, they tend to be young people, usually with medical studies or at least with information on the health field, who tend to share with their relatives their notions on DOD, without any religious concern nor arguments not to support DOD. On the other hand, in the non-registered group, there is an apparent association between religion and ethnicity in contrast to gender or education.

Positive views on DOD also are not associated with either group, as it could be that these views are shared by both registered and non-registered individuals.

COMUNICATION PATTERNS WITH THE FAMILY

In the survey, it was found that participants were willing to give consent to family members even if they had not previously discussed this issue and were unaware of the relatives' desires. The positive responses to the hypothetical answer for consent show the positive attitude towards DOD.

It also emerged that knowing how to handle strong objections and presenting arguments to defend own position are issues that need to be further examined, as to how people can be trained. Presumably, it would increase donation rates due to a reduction in families' refusal.

KNOWLEDGE AND ITS GAP ON DOD

Analyzing the results obtained, it could be affirmed that it is broadly conceived that organ donation is a great mechanism to save lives or significantly improve its quality. Additionally, it was revealed a general awareness of organ shortage due to the increasing demand, even though the donation rates are higher than years before.

Awareness is promoted by numerous ways. Ensuing, the most relevant are exposed.

- Patients' stories that can be shared anyhow are engaging and motivating. Yet, focusing only on feelings, people might perceive it as moving blackmailing. They can be interpreted as biased, aiming to increase the rates of donors instead of presenting accurate information on what DOD is.
- Social networks are a tactic to reach boundless people, in very little time and to any place of the planet. But, this publicity is considered to come "in waves": sometimes people feel boring about them, only showing the optimistic side.

Likewise, as an effort to reach the wider public, this information is not always accurate enough, contributing to the creation of a distorted idea on the issue.
- Television has a key role in broadcasting the advertisements, discussing the issue on programs and shows, giving patients the opportunity to raise their voice.

The educational method on DOD issue depends on the collectives:

- Scholars: Sometimes it is imparted at schools, although it is not systematized and its forms deeply vary from one place to the other, or even, just on the teacher.
- Doctors and nurses educate their patients on DOD and how it influences their condition, but the problem is that it is not always understood.
- Medical students obtain in depth knowledge on scientific facts about DOD and transplantation. However, the communication with the patient about this issue might not be as well established, needing further development.
- Administrative staff are aware of the transplant activity of their hospital, and possibly of the problems patients face; but their job position does not allow them to get further.

The combination of both awareness and education results in improvements in DOD health literacy. Nevertheless, under no circumstances, DOD must be considered exclusively a medical issue but also ethical, both in similar proportion. Thus, its approach cannot just imply a scientific formation on the field, without its social correspondence.

REFLECTIONS

The realization of this project underlies two strategies targeting different groups.

- Ensure that people who have not declared objection can be recruited: One suggestion is launching mass campaigns by means of social media through which emotional stories from patients could be share. They are supposed to be moving and able to persuade society.
- People who have concerns focus on how to convince those not in favor of DOD through facts and views coming from people they trust: It is proposed to be reached by seminars with the presence of multiple speakers (medical specialists and patients) or lectures accompanied by patients presenting their story. All of those are initiatives which engage their audience.

CHALLENGES TO THE FUTURE

Research evidence in this study denotes a need for the following investigation and action steps towards systematic development of the following agenda and action plan:

- Use of a *'whole family'* intergenerational approach to DOD health literacy necessities and interests into a relational vocabulary and clear way of thinking.
- Learning how the human body works, develops, changes and eventually stops to work during a lifetime, how insights about *body image*, disposal and preservation change over the years in various social, cultural and historic backgrounds.
- Broadening the social scope of the health literacy to include the ability to do good and not harm other people's health and well-being.
- Use of a *grassroots* social marketing education approach which aims to increase involvement of new people with those already reached in the past; such a tactic would ensure a curriculum based *on social learning* and student peer teaching.
- A carefully prepared DOD Health Literacy *Curriculum that uses blending and balancing* to create a coherent and whole body of knowledge that promotes confidence and prevents confusion and uncertainty.
- Use of a *case study curriculum* approach.
- *Field experiences* (e.g. talks, debates and visits to transplant clinics, A&E departments, community centers, etc.) to sensitise and normalise individual and group related DOD life experiences and expectations.
- Design of a school-based *primary* DOD health literacy program that supports instruction and training, patient empowerment and 'phronesis' practical wisdom.
- Design of a *secondary* local health community DOD health literacy program for ad hoc counselling, advice and guidance of individuals and families who face life threatening and traumatic health crisis situations.
- Design of a *'Booster'* DOD health literacy training program based at college or work to refresh previous skills, recruit and train peer teaching volunteers at local schools, hospitals, libraries, adult colleges and community centres.

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FIGURES INDEX

ANNEX: QUESTIONNAIRE SAMPLE (patients)

Department of Surgery and Cancer

Imperial College
London

DECEASED ORGAN DONATION AND HEALTH LITERACY

PhD Research Project by Dr Maria Theodosopoulou, MSc (In collaboration with Medical School of Cantabria- Professor D. Casanova).

You are invited to participate in an Imperial College PhD academic research on a strictly non-paid and anonymous basis. Our study investigates people's views and knowledge about organ donation after death, whether they share their wishes about it, and how they learn about donation of organs and tissue. Organ donation after death means that after the person has died, an organ is given to somebody, who needs a transplant.
Filling in the parts of the survey will take you about 20 minutes. Your collaboration and input are extremely valuable to ensure the design of effective and interactive platforms, campaigns and programs that support lifelong learning about the health issue of deceased organ donation and transplantation – Many thanks in anticipation of your kind consideration and collaboration in our effort.

PART A: Personal views about organ donation after death

The following questions are about your personal views about organ donation after death and the reasons behind them.

1. **Which of the following statements describe your current position with regard to organ donation after death?** Select all that apply

○ I support deceased organ donation
○ I am a registered organ donor
○ I have discussed the issue with family /friend(s)
○ I have not made a decision about the issue yet
○ I need more information about the issue
○ I refuse to think about issues related to my death
○ I have personally met a person on a transplant waiting list /a donor/a recipient
○ I am against deceased organ donation
○ I like the idea, but I distrust the medical system
○ Other (please explain)

2. **Reasons you consider to support organ donation after death:** Select all that apply

○ Ultimate act of helping other people
○ Religious beliefs
○ Scientific facts and figures
○ Being remembered as a giving person
○ Relief for the family of the dead donor that one continues to live through
○ Raise awareness and convince others to follow the example
○ None of the above
○ Other (please explain)

3. **Reasons you consider to be against organ donation after death:** Select all that apply

○ Poor medical care of cadaveric donor patients
○ Medical terms are not clear enough
○ Body disfigurement
○ Funeral arrangement complications (eg. delay, open casket service, etc.)
○ Religious objections
○ Cultural traditions
○ There is no argument against it
○ Other (please explain)

4. **In which of the following health issues, do you consider yourself well informed?** Select all that apply

○ Alzheimer
○ Cancer
○ Diabetes

○ Heart Disease
○ High Blood Pressure
○ HIV/AIDS
○ Mental illness
○ Obesity
○ Organ donation
○ Smoking
○ Other (please explain)

PART B: Talking about organ donation after death

The following questions explore whether you share your views about organ donation after death with people close to you and how you view the organ donation of family members.

5. **Have any of the following groups of people communicated a positive, negative or neutral message to you about organ donation after death**?

Please indicate your answer by putting next to each of the following people groups one of the above symbols

	Positive	**Negative**	**Neutral**	**Never talked about**
Parents	○	○	○	○
Siblings	○	○	○	○
Spouse/partner	○	○	○	○
Children	○	○	○	○
Cousin	○	○	○	○
Nephew/niece	○	○	○	○
Friends	○	○	○	○
Colleagues	○	○	○	○

6. **To whom of the following have you expressed your wishes about organ donation after death?** Select all that apply

○ Parents
○ Siblings (brother/sister/half -brother/half-sister)
○ Spouse/partner
○ Children
○ Cousin
○ Nephew/niece
○ Friends
○ Colleagues
○ None of the above
○ Other (please explain)

7. **From the list below of people in your life, who has expressed a wish to donate their organs when they die?** Select all that apply

○ Parents
○ Siblings (brother/ sister/ half -brother/ half-sister)
○ Spouse/ partner
○ Children
○ Cousin
○ Nephew/ niece
○ Friends
○ Colleagues
○ None of the above
○ Other (please explain)

8. **Would you give your personal consent/ permission in an emergency for the following family members to become an organ donor after death**? Select all that apply

○ Parents
○ Siblings (brother/ sister/ half -brother/ half-sister)
○ Spouse/ partner
○ Children
○ Cousin
○ Nephew/ niece
○ Close friend
○ None of the above
○ Other (please explain)

PART C: How you have learnt about organ donation after death

The following questions explore which sources you use for learning about organ donation after death and how much they have helped you.

9. **Which of the following sources helped you form an opinion about organ donation after death? Select all that apply**

○ Place of worship (e.g. church, mosque, synagogue, etc.)
○ Family and friends
○ School
○ Work colleagues
○ Stories of organ recipients
○ Medical TV shows and films (e.g. ER, Grey's Anatomy, Scrubs, etc.)
○ Family doctor
○ Newspapers & Magazines
○ Medical Documentaries

○ Brochures in a medical clinic or pharmacy
○ Official website of the National Transplant Organisation
○ Other health care websites on the Internet
○ Social media (e.g. Facebook, Twitter, Instagram, etc.)
○ Awareness campaigns
○ Local library
○ Adult learning classes
○ None
○ Other (please explain)

10. **Do you visit the official transplant website of other European countries? Please specify**

○ Yes (please specify which) ………………………………………………
○ No
○ Other continents (American, Australian, Asian, African)

11. **According to what you know, is there a shortage of organs in this country?**

○ Yes
○ No
○ Not Sure

12. **According to what you know, the legislation in this country about organ donation after death is**

○ Presumed Consent (opting-out)
○ Informed Consent (opting-in)
○ Family consent is always necessary

○ I do not know these terms

○ I do not know the relative legislation

13. **According to what you know, regardless of the legislation in this country about organ donation after death family consent is still necessary**

○ Yes

○ No

○ Not sure

14. **According to what you know, are there financial incentives in this country about organ donation after death (eg. covering funeral costs of the organ donor)?**

○ Yes

○ No

○ Not Sure

15. **In your opinion, financial incentives about organ donation after death in this country**

○ would help

○ would NOT help

○ It depends on the kind of incentives

PART D: How clear is your understanding of organ donation after death

The following questions see your understanding around several aspects of organ donation after death.

16. **How confident do you feel explaining the meaning of the following words clear to a family member or friend?** Please select from 1-5 for each statement.

	Very confident 1	2	Somewhat Confident 3	4	Not confident at all 5
Cadaveric organ donation					
Brain stem death					
Circulatory death					
Transplant Coordinator(s)					
Negative Cross match					
Organ Procurement					
Cadaveric organ recipient					
Immunosuppressant medication					
Graft survival					
Tissue donation					
Opt-in/Opt-out system of organ donation					
Higher risk organs					

17. **The statements below discuss different aspects concerning organ donation after death. Please read each statement and circle (T) if it is true, (F) if it is false or (NS) if you are not sure**

People can buy or sell organs in this country T F NS
Organs donated for transplantation include: kidneys, heart, lungs, liver, small bowel and pancreas T F NS
Tissues donated for transplantation include: eyes, heart valves, bone, skin, veins and tendons T F NS
Reproductive organs and tissue are not taken from organ donors after death T F NS
An organ donor registers as a tissue donor as well T F NS
An organ and tissue donor can potentially benefit 8 patients T F NS
A transplanted organ can transmit an infection or cancer to a recipient T F NS
Non-transplantable organs and tissues can be offered for scientific research T F NS
If doctors remove organs and tissues, but decide they cannot be transplanted, they dispose them T F NS
Organs and tissue from your country can be offered to patients in another country T F NS
It is statistically more likely for a person to receive rather than donate an organ/tissue T F NS

18. **Statements about waiting lists**

Transplant tourism (patients traveling to a foreign country to obtain an organ) is a serious problem in this country T F NS
Organ donation is not necessary, because stem cell and gene therapy offer safe clinical alternatives to transplantation T F NS
Only people with a healthy medical record can register as organ donors T F NS
Once you register to be a donor, it is not possible to change your mind and withdraw from the register T F NS

Doctors can manipulate the priority criteria and ranking of patients on a transplant waiting list T F NS

Patients on a transplant waiting list who receive media attention increase their chances of receiving an organ/tissue from a deceased donor T F NS

New patients are added to the bottom of a transplant waiting list T F NS

A transplant waiting list is blind to age, sex and race T F NS

19. **Statements about medical care**

You can donate organ(s) only if you die at a hospital T F NS

A brain-dead person can never recover T F NS

The medical team follows the same protocol to declare somebody brain dead T F NS

The same medical team that cares for a patient, who is in critical condition, also decides who gets the organ(s) T F NS

20. **Statements about family's role**

Hospitals are required by law to ask for the family's consent/permission even if the patient has signed a donor card T F NS

The deceased patient's family can specify which organs /tissues will be offered for donation T F NS

The donor's family can nominate a specific recipient T F NS

The identity of the recipient(s) is usually revealed to the donor's family T F NS

The recipient and his/her family have the right to describe the characteristics of the organ they would like to accept or decline, eg. non-smoker, young etc. T F NS

The recipient and his/her family have the right to be informed about the condition of the organ and the medical history of the donor, before they accept or decline it T F NS

21. **Statements about funeral and life after death**

An open casket funeral is not possible for a donor as the body is disfigured during surgery T F NS
Organ donation surgery delays a person's funeral T F NS
Organ donation affects a person's after life tranquillity, as the body is injured T F NS

PART E: Organ donation after death in Europe

The following questions explore your views on the issue not only in your country, but seen through a European perspective.

22. Please select from 1-5 for each statement

	Strongly agree 1	Agree 2	Not sure 3	Disagree 4	Strongly disagree 5
Shortage of human organs for transplantation is a problem in the European Union					
Trafficking (illegal selling or buying) of human organs is a problem in the European Union					

23. Please answer how is it likely to …?, by selecting from 1-5 for each statement

	Very likely 1	Likely 2	Neutral 3	Unlikely 4	Very unlikely 5
Donate your organs/tissues after death to a recipient from another European country?					
Register as an organ donor after death of another country-member of the European Union, if you move to it?					

Part F: Demographic information

24. **Have you received an organ transplant?** Yes No

25. **In which year of your medical studies are you at?** 1st 2nd 5th 6th

26. **Your Gender** Please tick the answer

○ Female
○ Male

27. **Your Age** Please tick the answer

○ 18-29
○ 30-44
○ 45-59
○ 60+

28. **Your Marital Status** Please tick the answer

○ Single
○ Married
○ Separated
○ Divorced
○ Living with a Partner

29. **Your Education Please tick the answer**

○ High School or less
○ 6th form College
○ University degree
○ Postgraduate studies

30. **Your Employment** Please tick the answer

○ Student
○ Military personnel
○ Self employed
○ Part time employee
○ Full time employee
○ Unemployed
○ Retired
○ House person
○ Involved with patients
○ Non-involved with patients

31. **Your Religion** Please tick the answer

○ Christian
○ Buddhist
○ Hindu
○ Jewish
○ Muslim
○ Sikh
○ No Religion
○ I do not wish to say

32. **Your Ethnic Background** (categories as seen in the Office for National Statistics). Please tick the answer

○ White
○ Mixed/ multiple ethnic group
○ Asian/ Asian British
○ Black/ African/ Caribbean/ Black British
○ Other (please explain)
○ I do not wish to say

We thank you for your time and cooperation.

NOTE: This is the sample of students' survey.

Questionnaires for the other groups differed in question number 29, which asks about participant's profession.

- For the staff group: they were asked if they were involved (at their job position) with patients or not.
- For the patients group: they were given more options for their profession.