



## INVESTIGACIÓN/RESEARCH

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# THE SOCIAL PROCESS OF ORGAN DONATION FROM A COMMUNICATIONS ANALYSIS

**Antonela Isoglio<sup>1</sup>**: National University of Cordoba. Argentina.  
[antoisoglio@gmail.com](mailto:antoisoglio@gmail.com)

### ABSTRACT:

Transplantation of organs and tissues is a medical-social practice, which does not consolidate due to the low level of donors. The research that gives rise to this article explored the social meanings of donating organs and tissues, in order to recognize the social structure and relationships related to this process. The study was conducted in the province of Córdoba, Argentina, during 2014 and data were obtained through semi-structured interviews applied to a non-probability sampling, particularly using the sample of experts and the discretionary sample. The analysis units from which the construction of necessary empirical evidence was obtained were: people expert in the subject, people who consented to donate organs and/or tissues of a deceased relative, people who have not yet experienced the donation of organs and/or tissues, and transplant patients. From a qualitative approach, the research aims to contribute to the design of communication strategies that seek to strengthen the capacities of individuals and communities in the making of informed decisions regarding this problem of collective health.

**KEY WORDS:** Health Communication – Tissue and Organ Procurement – Interpersonal Relations – Decision Making

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<sup>1</sup> **Antonela Isoglio:** Degree in Social Communication and Diploma in Health Communication and the National University of Cordoba (UNC), Argentina. Professor ascribed to Seminar Communication and Health (UNC).  
[antoisoglio@gmail.com](mailto:antoisoglio@gmail.com)

# EL PROCESO SOCIAL DE DONACIÓN DE ÓRGANOS DESDE UN ANÁLISIS COMUNICACIONAL

## RESUMEN:

El trasplante de órganos y tejidos constituye una práctica médico-social, que no logra consolidarse por el escaso nivel de donantes. La investigación que da origen a este artículo exploró los significados sociales de la donación de órganos y tejidos, con el objeto de reconocer la estructura social y las relaciones interpersonales relacionadas con dicho proceso. El estudio fue realizado en la provincia de Córdoba, Argentina, durante el año 2014 y los datos fueron obtenidos a través de entrevistas semiestructuradas aplicadas a un muestreo no probabilístico, utilizando particularmente la muestra de expertos y la muestra discrecional. Las unidades de análisis de las cuales se obtuvo la construcción de evidencia empírica necesaria fueron: personas expertas en el tema, personas que prestaron su consentimiento para la donación de órganos y/o tejidos de un familiar fallecido, personas que aún no experimentaron la donación de órganos y/o tejidos, y personas trasplantadas. Desde un enfoque cualitativo, la investigación pretende contribuir al diseño de estrategias de comunicación que busquen fortalecer las capacidades de las personas y las comunidades en la toma de decisiones informadas respecto de este problema de salud colectiva.

**PALABRAS CLAVE:** Comunicación en Salud – Obtención de Tejidos y Órganos – Relaciones Interpersonales – Toma de Decisiones

## 1. INTRODUCTION

The system of procurement of organs and tissues of the Argentine Republic requires not only the production of new knowledge, but also the participation of individuals who enable the development of transplants from organ donation. Therefore, the opportunity for a patient to be transplanted depends on the willingness of individuals to donate their organs (March and Burgos, 1997).

Law Num. 24,193 of Transplantation of Organs and Tissues (text updated by the Law No. 26,066), provides in Art. 19° that any person may explicitly express their negative or affirmative will to the ablation of organs or tissues of his own body. When there is no such expression, Art. 21 refers to the request for family consent, that is, the coordinators of the procurement process request from the relatives of the deceased the witness or the opinion of the deceased on his willingness to donate his organs or tissues; if they do not know, they are asked for their consent.

Although 72.6% of the population surveyed by the Unique Central National Institute Coordinator of Ablation and Implant (INCUCAI) in February 2013-about a total of 700 cases distributed throughout the national territory, it is considered an organ donor

"the lack of the procurement system remains" (Federal Commission of Transplantation, 2013, p. 15).

The professionals of the Communication Area of INCUCAI developed studies to determine the level of impact of different elements on family consent (Soratti, C. et al., 2004; Carballa, N. Espinosa W., Fontana, R., and Ledesma, B., 2004; Alfonso, Y. et al., 2005; Carballa N., C. Fernandez and R. Fontana, 2005).

Based on the need for effective communication, that promoted a positive attitude towards donation, as it is defended by Soratti et al. (2004), the investigations undertaken by the Department of Communication of the INCUCAI focus on studying the diffusion through the national and / or provincial media to achieve a change of attitudes and behaviors.

Thus, Carballa et al. (2004) analyzed the effect of news on organ procurement, emphasizing the media coverage of emergency patients. From the overemphasis of the channel, they consider the news as fact / event and the will of donation as an act / response.

Soratti et al. (2004) measured the correlation between the spread of the issue by the media and family consent. It concludes that while one of the factors involved in the donation is the attitude assumed by the population before the information broadcast by the mass media, one cannot say that there is a correlation between the spread of news about the transplant subject and the family consent for organ donation.

Carballa, Fernández and Fontana (2005) also question themselves if more news issued by the mass media are followed by more familiar consent for organ donation are followed. In their study, the significant increase in news issued by the media registered between April and May 2005 does not explain the increase in procurement recorded in the same period. For this reason, "*75% of the components of family consent must be related to the action of other variables*", deducted (para. 4).

Similarly, Alfonso et al. (2005) assume that the community receives information about donation and transplantation through various channels, and they wonder if the massification of information contributes to real knowledge about donation and organ transplantation. Through telephone surveys, they investigate the type of news remembered and sensations produced by the respondent public. In 2005, when consulted about which are the doubts about donation and transplantation to a sample of residents of the Autonomous City of Buenos Aires and the provinces of Buenos Aires, Córdoba, Mendoza and Santa Fé, 54.43% said that they had no doubt, 43.67% reported to have one or more and 4.43% did not answer the question. With regard to doubts of greater weight, Alfonso et al. (2005) highlight organ trafficking, the lack of transparency in the processes of organ and tissue procurement, the lack of confidence in the health system, the abandonment of the dying and the doubts about the concept of death. Thus, doubts come from different aspects, related to the conception of death, the distrust in institutions and disbelief in equal opportunities. On the other hand, Bustamante and Villarreal (2009) analyze the perception of individuals with regard to the information disseminated by the mass media about the

process of organ donation in Chile through a questionnaire applied to a sample of 204 people in ten major cities. They conclude that people consider themselves informed and that their main source of information is television. The research focuses on mass media and notes that more and better information increase the number of donors.

To summarize, in the aforementioned communication studies underlying concepts that favor the transmission of information from health institutions to citizens. Predominant directionality of communication and also highlights an emphasis on the effects of a particular type of message, through the audiovisual, radio or print media.

According to Gonzalez Gartland, the case of public health organizations does not escape this communication mode, under which the population is the object of information and not the subject; it is more: "*Traditionally public communication management took the model from the private sector without critical reflection on the scope, methodology and relevant tools for this purpose*" (Petracci and Waisbord, 2011, p 399.).

In the current national context, the investigations referred to favor the role of mass media in disseminating information and use quantitative methods to analyze the effects on audiences. Carballa et al. (2004) correlated the news regarding the number of patients requiring organs through the media with the volume of expressions of phone will. Soratti et al. (2004) consider the variables *news* and *family consent* for performing a longitudinal descriptive-correlational research, using the Pearson correlation coefficient. Carballa Fernández Elizate and Fontana (2005) measured the correlation between two variables: *news* -expressed in information units as the number of potential recipients of a unified news spread by the mass media of national scope- and *actual donors* with registered trend lines in the first half of 2005.

Reviewing the premises of diffusionist theory, Ackerman and Morel (2010) argue that applying the mathematical scheme of information to communication research makes invisible the fundamentals of this process: the significant dimension.

Against the reductionism of previous studies cited, this article suggests thinking about communication from another perspective, that considers that all those involved are able to bring into play their own communication strategies in a context of interaction, which involved social, cultural, political and economic factors (Petracci and Waisbord, 2011).

This article is the product of the research: *Donation of organs: a communicational analysis of its social meanings*, developed as a thesis for the Degree in Social Communication from the National University of Córdoba, which was distinguished by the Argentine Federation of Careers in Social Communication with the First Place in the I National Contest of Theses and Final Works of the Degree in Communication (2015).

## 2. OBJECTIVES

According to Carrasco Guerra (2005), the reflection about why there are so few cadaveric donors should start from making a problem of organ donation as a symbolic construction process of health / disease / care. Particularly, it is about historical and social processes irreducible to individual responsibility. They depend on the conditions of life, work and individual trajectories of subjects, which determine the meanings and experiences in health, disease and suffering (Cardozo, 2011).

The meanings, beliefs and valuations that people give to organ donation go beyond statistics and show that designed research strategies are insufficient. Why the latter are so similar, while social attitudes of communities and life experiences of its members are so diverse?

Based on the importance of exploring the diversity of meanings of communities around the subject, the research question is what are the social meanings of the donation process of organs and tissues of the inhabitants of the province of Córdoba, Argentina, today.

Faced with the instrumental tradition of communication, supporting previous research, this study aims to open reflection on the communication processes about donation and transplantation of organs that develop in the interactions of everyday life of social groups in the province of Córdoba. This aims to contribute to the understanding of the phenomenon and the design of health communication plans that seek to strengthen the capacities of individuals and communities in making informed decisions regarding public health.

The overall objective of this study was to explore the social meanings which contribute to the manifestation of the affirmative or negative will of *post mortem* organ and tissue donation of inhabitants of the province of Córdoba today tissues.

As specific objectives of the study it was set out to recognize the elements of the social structure (social norms, values, beliefs, institutions, etc.) and bodily and death experiences that are part of the donation process of organs and tissues and observe the theming of the donation of organs and tissues in everyday conversations.

In the field of Communication and Health, following García González (2007), the communication can be viewed starting from three models. In this study, the model of communication as a social process was taken, in which strategies that drive collective participation for building healthy environments are developed, from making informed decisions based on the full exercise of citizenship.

It should be noted that some of the studies cited as antecedents of this investigation support the second model defined by García González (2007). In other words, they are defending a linear conception which reduces communication signal transmission between independent individuals, preventing analyze the complexity of interactions and social processes.

On the contrary, the study presented in this article considers that the communication cannot be reduced to a question of the media of information, or their ends can be the manipulation and the persuasion (Uranga and Diaz, 2011). According to Mata (1985, p. 1), "*lived as experience the communication represents the space where everyone brings into play the possibility of building with others [...]*".

While the human body is regarded as a physical thing, the individual's attitude toward this thing is a social attitude (Mead, 1972). Meaningful relationships between individuals and the physical or abstract objects are also produced, which establish not only the way they perceive and evaluate objects, but also the way in which individuals are willing to act on them (Castro, 2011). In this sense, the expression of the will of donating of a person involves the development of a social attitude with his own body. Thus, the willingness to donate organs of a person, less than an isolated manifestation, is a behavior that is done in the context of the situation that are defined by the actors in a specific context, from the meanings constructed in their interactions.

From this perspective, this issue of health is approached without a possible split of the space of everyday life, of the local culture, because it is the area where people interact with each other and with objects, exercising their ability-potential of social transformation (Uranga and Diaz, 2011). The process of organ donation is a community issue that requires a transversal approach, never reducible to media messages.

Organ donation occurs before a fact of greatest significance for individuals, which is death. Beliefs, social norms, associated rites and the final destination of the dead are factors that are part of the process of organ donation, so they "*become unavoidable aspects in the consideration of this issue*" (Guerra Carrasco, 2005).

In short, the beliefs and values about the process of health / disease / care (/ death) have different symbolic contents because they are constructed in the everyday interactions of various social groups. Therefore, Bronfman (2001) points out that the experience of death is particular according to the individuals and families who experience it. Within the family, it is not suffered in the same way by all its members. For this reason, this research makes an effort of interpretation of individuals placed in their nearest sociocultural context, since death as an extraordinary event is subject to the logic of what exists for people, which is daily life (Bronfman, 2001).

### **3. METHODOLOGY**

Unlike the quantitative approach, which aims to delimit the information, the research on which this article is based adopted a qualitative approach, pursuing the dispersal or expansion of data (Hernández Sampieri, Collado Lucio Fernandez and Baptista, 2003).

The scope of this study is exploratory, as it examines a little-analyzed subject from the qualitative approach, specifically by the absence of background research with

local people. In this sense, this research developed an approach to the social reality of the process of organ donation, in order to recognize, locate and define problems, collect ideas and adapt research methodology (Egidios and Emanuelli, 2009).

The study design consists of a cross transectional or transversal research design, which collects data in a single moment, in a single time, considering that this is an initial immersion in the field.

The analysis units of which the construction of necessary empirical evidence was obtained were: (a) experts in the subject, (b) persons who gave their consent for the donation of organs and / or tissues of a deceased relative, (c) persons who have not yet experienced the donation of organs and / or tissues and (d) transplanted persons.

A non-probabilistic sampling was conducted, particularly using the sample of experts and discretionary sample.

The sample of experts is constituted by Dr. Edgar Enrique Lacombe, Dr. Patricia Fioramonti, Dr. Marcial Angós, Lic. Eugenia Ferreira, Lic. Paula Colella and the Nurse. Marta Noemi Ajis de Sempé.

Known in the health sector as "*the father of organ procurement in Córdoba*," Dr. Edgar Enrique Lacombe is the first doctor that, in this province, extracted an organ for transplantation. It happened in September 1980 in the old Emergency Hospital located in Santa Rosa 360, where the doctor worked in intensive care. Three years after the enactment of the first Transplant Act in Argentina, Law No. 21,541, which created the Unified Coordinator Center of Ablation and Implant (CUCAI), and with the support of the head of intensive care, Dr. Lacombe made the request of the family consent for organ donation of a deceased young girl, and obtained parental consent. Also in September 1980, he carried out the first transplant in the province of Córdoba, with Dr. Alcides Fagalde in the Chateau Clinic. Since then, he coordinated with great dedication to service the operations of organ procurement of the Hospital Emergency Room, because in Córdoba had not yet been created the provincial agency for ablation and implantation and there were no enabled laboratories for testing histocompatibility. Given the lack of training of physicians to perform transplants, Dr. Lacombe formed the team that since 1986 formed the Advisory Board of Ablation and Implants Córdoba (CADAIC). Meanwhile, he also specialized in nephrology and was the first Executive Coordinator of the CADAIC. During the eighties, Córdoba was the province that achieved the highest growth of donations, obtaining a third of transplanted organs across the country (INCUCAI, 2015a).

One of the disciples of Dr. Lacombe is Dr. Patricia Fioramonti. For twenty years he served as a medical neurologist of the Coordinating Body Ablation and Implants of Córdoba (ECoDAIC), which by Provincial Law No. 8814 replaced the CADAIC since 1999. Together with another specialist in neurology, Dr. Fioramonti made the diagnosis of death under neurological criteria in patients across the province of Córdoba from 1993 to 2013. Over time, the coverage area of ECoDAIC was

expanded because of the regionalization established by the INCUCAI, incorporating operating organ procurement in provinces of La Rioja, Catamarca and Santiago del Estero.

Dr. Marcial Angós is the current medical coordinator of the Medical-operative ECoDAIC Area.

Meanwhile, Lic. Eugenia Ferreyra is the head of the Social Area of ECoDAIC. For fifteen years she has worked as a social worker and for five years she has been able to form the Área with social workers and a psychologist.

The Department of Communication and Education was created from the incorporation of Lic. Paula Colella, social communicator of ECoDAIC since 2013. From there press actions, dissemination and training are developed, while acknowledging the lack of specialized personnel to develop training processes at all levels of education.

Finally, Marta Noemi ajis of Sempé, known as Moni Sempé, is the mother of the first full cadaveric donor of the city of Rio Cuarto. Since the death of her son in 1991, she promotes organ and tissue donation. She contributed to the creation of the foundation *For more life* and currently chairs the civil association *Be Aware right now*, that she founded in 2002. This organization is known for the unique characteristic of being composed mostly of relatives of organ and tissue donors.

Moreover, the discretionary sample includes experiences of those who gave their consent to donate organs and / or tissues of a deceased relative (respondents 01, 02, 03 and 04), those that not yet were immersed in the process of organ donation and / or tissues such as a personal or family experience (respondents 05, 06, 07, 08, 09 and 10) and transplant recipients (interviewed 11 and 12). Under confidentiality criteria, the study preserves their identities.

The research used the semi-structured interview as a conversation in which the data be collected unless, occur in the interaction between the researcher and the researched (Carrasco Guerra, 2005). This is because the meaning is a social product that is permanently modified by the interaction, even in the very situation of interaction.

#### **4. DISCUSSION**

The pioneer of organ donation in Córdoba, Edgar Enrique Lacombe, warns about the social problems of organ transplants, which is the lack of donations:

Córdoba had become the capital of the transplant. [...] From '80 to '90, acceptance of the families to whom we asked them the bodies of her dead family was 75%, and now it does not reach 50%. So every time I meet someone, I ask where the fault is. There must be some force vectors that do not work well for reaching the desired result. The society knows more about this, society knows death under neurological criteria, the press knows, they



mention it at once, sometimes in a hurry they mention it, before it actually is, doctors know of this, doctors know they have the medical obligation, legal, ethical and others to denounce the presence of a potential donor, but the end result is not the same. Not only that it has not been maintained, but the donation has declined.

(Edgar Enrique Lacombe)

According to experts, in everyday interactions circulate misconceptions about organ transplantation, which model community myths that are incorporated into the social structure.

The traffic, they kill you ... The myths that appear are basically linked to death, that they kill to get you out the organs, that there is a trade and trafficking in organs, that I got a tattoo, I had hepatitis, I'm big, my religion does not allow me, none of these has a real handle, none, there is no religion that is against organ donation, there are no impediments if the tattoo is done with biosafety standards, that is, a whole series of requirements which are reviewed at the time that one dies of brain death, to see if he is a potential donor.

(Eugenia Ferreira) Indeed, the interviewed 05 (hereinafter E05) believes that having contracted the disease is an impediment to organ donation and expresses its willingness to grant negative, noting the existence of organ trafficking:

[...] I see a lot of suffering behind that, behind the transplant, [...] much pain, heart in mouth, much dependence on another, if a person dies, if there is a waiting list, that is not compatible [...] and you have to do this, and this and that, and wishing him ... and then everything that begins: the healing, if you have money, if organ trafficking [...] that, out there, sometimes not so much now but at one time a lot was spoken about organ trafficking [...]

(E05)

Also interviewed 08 (hereinafter E08) is opposed to organ donation. She believes that doctors remove organs from people who might still have a chance of life, killing patients:

[...] I do not donate. [...] I think they take them out when you're still alive. I know they do in the last consequences that it is logical because the person is not going back to be the same, right? And I think that the doctors know what they do, but it always seem to me that no, that perhaps there may be something and maybe they grab me and take me ... no, no. So I think that no, I do not want. [...] Especially is this, that I think if I'm still there, I do not know if I'll walk out or not, and the doctor I will take everything (laughs). You saw how many people are out there, how many years in a coma or people who are ill and then, very few, left, right? They left that, they wake up, and you say, "Look if you had done ... if they had decided such a thing or such other".

(E08)

For its part, the respondent No. 07 (hereinafter E07) and the respondent No. 10 (hereinafter E10) define themselves as organ donors, but they explain that they have

not expressed their will in the media destined by INCUCAI because this could affect the quality of medical care:

[...] you saw that the organs are taken from people who are not dead, or it may not have been a long time, they take them out minutes before, so there is that rumor that if something happens to you , when you're an organ donor, precisely because they need an organ, they do not save you as doctors would save you if you were not a donor, for the subject that there is so much demand that I do not know if it would be equally, if they would take care of you in the same way and they would have the same concern for saving in any instance that if you were not a donor. There is so much demand out there that in a critically ill patient they prioritize the donation. The only bad thing is that, that you may not be dead or you're dying and because of the issue of the need, they prioritize your organs.  
(E07)

We are not recorded but it may be because, for lack of information or because the media will not inform you too much. It is this question of if you are enrolled, if you die or not they take you out before, if you have time to reverse your disease or not. Those things that always, they never took out the fear of people I think that it makes that most people do not enroll.  
(E10)

Instead, transplanted people refute the belief about the existence of organ trafficking:

People are scared by the myth of organ trafficking ... If they knew all procedures involving the transplantation, they would see that it is a lie. People do not donate their organs because of fear or misinformation. [...] When I give talks in schools and institutions I say the steps needed to do for an organ to reach the receiver, then people realize that the other is a myth, a lie.  
(Interviewed 12 onwards E12)

Also, Marta ajis of Sempé (hereinafter Moni Sempé) and the relatives of organ donors that make up the civil association "Take awareness now" deny the existence of organ trafficking in this country:

[...] In our country there is no organ trafficking, if it were I would not be working, because I could not be working on something knowing that there is traffic, but there are people, we humans speak sometimes because we hear but do not investigate or we do not go to the source, that is: is it true, can you explain it to me?  
(Moni Sempé)

According to the social worker of ECoDAIC, a very simple message should be given to the community:

"Until you're not dead, we will not talk about organ donation" [...] both in boys, teachers, we walk, explain that until they do not die we cannot, under any point of view, neither ethical nor moral, nor legal, none, talk about organ donation, then it changes in them the vision of the issue.  
(Eugenia Ferreira)

Moreover, the respondent 06 (hereinafter E06) calls into question the transparency in waiting lists, that is, the equity in the distribution of organs and tissues starting from the instruments of unique record of patients on the waiting list for transplantation at the national level, administered by the INCUCAI:

[...] The truth is that the priorities always looked confused to me, who has more priority or who has not, I really do not know about that. [...] I am confused when I see it on TV, whether a person is known he is treated, another deal with a person who also needs an organ and as he does not appears in the media, he does not receive the organs. Sometimes I feel like there was more work done to seek the organ for the famous person than for the other person who is, or thousands of people across the country who need an organ. That always called my attention.  
(E06)

E05 refers to the different visions regarding organ donation, according to which antagonistic social attitudes gestate:

I remember a few years ago had seen a series and there was a little girl three years old that was dying and needed a heart transplant, [...] I say how difficult because you want your daughter to be saved and at the same time you have to want another baby to die to have that heart. Then as it is a very complex issue, very delicate [...] I keep seeing the suffering and the ambiguity of wanting someone to die, to save a life [...] a mixture of joy and sadness, then they are as mixed feelings. [...] Especially when they are children, which despair grabs them, and the parents do not have economic resources and are suffering if the organ arrives or not [...]  
(E05)

The positive values associated with an affirmative willingness to organ donation are: kindness, solidarity, hope, brotherhood, love, unselfishness, generosity and otherness.

For me, it is good. Hope, faith are associated. The feeling of being connected with each other, right? If they tell us that we are brothers one to each other [...] I know that there is an act, selfish of me because how many lives are thus saved, right? But no, no, I do not donate. [...] I think it's selfish because I should think like other people, maybe, right? It seems to me. Because I listen and I like and say, "Good!". All right, all right, but when they come to ask me, no.  
(E08)

Organ donation is an act of great love [...] this is to give life and more to a stranger, a totally unknown stranger.

(Interviewed 11 onwards E11)

Because there should not be anything greater in the world than to donate organs, I think there is not something else, because I can say, "Tomorrow I will donate to the club, because there is where I am working, five or ten thousand pesos," something, a figure that maybe I suffer in my pocket, but is material, is money, but to donate organs is the most a human being can make in this world.

(Interviewed 03 onwards E03)

[...] What one has to come into question from the issue of organ donation is otherness and solidarity, which are two extremely complicated values, that is to step into the shoes of the other [...]

(Eugenia Ferreira)

According to Eugenia Ferreira, the probability of being a patient who enters the transplant waiting list is greater than the probability of being a potential donor.

[...] I never could take the list down to zero, ever. So it's like more complex, and all the time they are designing new strategies and new medical-operative modes to see if you get to get the amount of organs that is needed, but there is not enough, not enough. [...] If it were a procedural-surgical question-, it is done. But here they involve a lot of other factors that have to do with the social issue that is much more complex.

(Eugenia Ferreira)

Regarding the announcement of the death of a relative, the E08 refers to the suspicion she experiences before the diagnosis of death:

I, when I saw my grandmother in the box immediately went and put my finger under her nose and everybody stared at me as if to say, "But what happens to her?". I said, "No! I must see if she is breathing. " It seemed to me that it was so great the need that she were alive, I went to see because for me they were wrong and put her there, and I have that with every close dead, I go and touch it to ... Before I did not approach, for example, you see? The things I was already like going forward, right? I did not approach someone, because it hurt a lot, because I could not, by ... And now if I do not approach, it is like I'm worse; then I go and touch the person and I see: "Is he dead or alive? No, he's dead. " It is cold, icy, what do I know ... I do not know, no, he's dead, everybody quiet, he is dead. Do you understand? If not, I'm not quiet, I think we're going to bury him and he is alive and anytime you can ...

(E08)

At the institutional level, the Medicine is responsible to determine the death of people through a practical, prompt and safe method (Echeverria et al., 2004). At the

community level, the physician is the only professional able to validate or certify death as a socially shared criterion.

[...] Who validates the death in society is the doctor. [...] In the rest, there can begin to appear the other professions with various other contributions that today they are not doing. [...] The experience has been in Santa Fe, for example, is that the request of the bodies were done by psychologists, it was very bad, it has a low donation rate.  
(Eugenia Ferreira)

With respect to protocol of death under neurological criteria, Edgar Enrique Lacombe maintains that no dead is "so studied" like this, that is, the other types of death do not have rules which specify how the diagnosis should be made.

[...] There is a whole protocol to develop strict, comprehensive, thorough, scientifically it has been done since 1954 when the diagnosis of brain stoppage was done with the advent of intensive therapy, and that protocol is even more rigorous by all legal implications that the issue has and how it cost for the society to accept it.  
(Patricia Fioramonti)

The parents of donors report that, upon hearing the diagnosis of death of their children under neurological criteria, they requested the appreciation of other doctors of household confidence, to legitimize this diagnosis:

[...] Ask us a doctor from Córdoba, five doctors saw him in Rio Cuarto but ordered one over Córdoba that really confirmed us that was brain dead. [...] I do not know if it was for more calm, but at that time of so much desperation, we did not want to believe, we felt that a doctor could give us some glimmer of hope. None, none. [...] The brain death was confirmed from the outset.  
(E03)

The social acceptance of death diagnosis by neurological criteria was growing in recent years.

However, in the comments of E06 ignorance is observed about the diagnostic criteria that provide objective evidence for neurologists doctors to determine whether the death has occurred:

Those who are observant of Judaism, who know the laws and all that, agree [with carrying out the donation of organs and tissues] as long as the person who donates the donor, is not in risk of life or in other cases he must be dead, the person directly dead, so the heart is not work anymore, to extract the organ, and donate it.  
(E06)

Therefore, Marcial Angós says that understanding death under neurological criteria is the initial phase of the request of family consent.

[...] Point number one: make sure that they have understood death. For that you do a summary of which was the situation that led to the death of that person. If it is a head trauma you explain them that due to head trauma from a motorcycle accident in general, the brain damage is the first of such magnitude that it is irreversible and that led to his death. Then have them understand what is the concept of death. That's the first point, once you make sure that they have understood it and began to mourn [...]

(Marcial Angós)

For E08, heart transplantation is the "worst ever", as it seems that the heart is the "strongest" organ of the body.

Patricia Eugenia Ferreira Fioramonti and say that children and young people have greater "plasticity" to make the decision to donate organs and / or tissues *post mortem*.

Older people are much more reluctant, they are much more afraid, they cling to more myths that serve as a response rather than seeking reliable information.

(Eugenia Ferreira)

[...] In adults, including medical colleagues, to listen as: "I do not believe in that," as if it were a matter of believing or not believing (laughs).

(Patricia Fioramonti)

With regard to the involvement of religion in the process of organ donation, Edgar Enrique Lacombe and Patricia Fioramonti say that there are many experiences that they have lived in which the families of potential donors have called those in charge of care, instruction and the spiritual doctrine of a religious community to advise them during the request of family consent.

They take them to see what they say, from religion what they say. [...] One has to be ample enough to accept all this, because it is the process that the society lives, which is very different from something you can well go down in a straight line, and say, "Look, this is because it is scientifically shown, because it is so ...".

(Patricia Fioramonti)

The meanings expressed by respondents about organ donation process associated with the concept of death.

About the death of others, we can talk, of itself, no. [...] Nobody wants to think at that moment, then it is much easier to grab a myth or a rumor that has no real handle and from there I place myself. But why do I place myself there? Because I cannot say, "I do not want to be supportive."

(Eugenia Ferreira)

According to Eugenia Ferreira, the general community clings to the meanings that act socially as mythological beliefs about organ donation to avoid thinking about death. Thus, the families of organ donors claim that humans are not willing to face the death experience:

[...] Human beings come and go, living, living, but we neither have understood what living and humanity is nor we are prepared for death, which is the first thing that happens, in plants, animals, you see it, and we deny it, we walk, we eat, we buy, we laugh, we go to parties, living somehow, but we do not live knowing that our time is a time [...]  
(Interviewed 02 onwards E02)

In response to the donation of organs *post mortem* it comes from people who have died by neurological criteria, the experts said that, generally, there are processes of sudden death, unexpected and violent.

In this regard, Eugenia Ferreira mentioned that if there is no expressed statement of willingness to grant the donation by the deceased, that will arise from the interactions among the relatives:

Usually when these situations happen, relatives appeal to comments. What he said, what he said, what he wanted. And the environment. [...] The family starts talking in the past tense: "He wanted ", "he said. " Or they ask, "What now?", " How this goes on?". It's like there's a time that makes the break, which moves in the speech. And when they say, "Now what?" Or "he said," there is the possibility to talk about organ donation.  
(Eugenia Ferreira)

With regard to the authorization of organ extraction from their children, relatives claim not to be remorseful and ratify their decision:

[...] If something gave us peace, gave us tranquility in seven years, was the donation of organs. [...] Is the only thing that gave us peace [...] If we at that time of so much confusion, so much that we did not know where we were standing, we had said no, today I would not know how we would be [...]  
(E03)

## 5. CONCLUSIONS

The interviews conducted in the study demonstrate the existence of a social structure made up of beliefs, values, social norms and institutions, related to organ donation as a social process.

Respondents associated the organ donation with community values such as: kindness, solidarity, hope, brotherhood, love, unselfishness, generosity and otherness.

However, beliefs circulating in the general population affirm the existence of organ trafficking, the rumor spread about the announcement of death of people who are still alive and the fear that medical care could be ineffective in patients with diseases in advanced stages, prioritizing their potential as donors before his life. Also the transparency of waiting lists for transplantation is put into question by that the sustained belief that people with visibility, fame, reputation or economic power will have greater access to transplant. In sum, all these beliefs with no real handle constructed mythologies that are incorporated into the social structure and give some meaning to organ donation.

Also the interviewed expressed various social standards for organ donation, as it indicates that the heart transplant "*is the worst of all transplants*" because it involves removing the "stronger" organ whose function can be maintained even after the death of the person. Social rejection to the supposed dismemberment during removal of organs and tissues is also present.

All respondents agreed that there is a general lack of knowledge about the National Procurement System, Law 26,066 of Organ and Tissue Transplantation and the National Protocol for Certify Diagnostic Criteria Under Neurological Death. Although the latter diagnosis was gradually adopted as valid in communities, some respondents are still unaware that the death by neurological criteria means the death of the individual (Resolution 275/2010 of the Ministry of Health of the Nation).

But it is necessary to distinguish between information and communication on the subject, since all respondents agreed that the donation of organs and tissues is absent from the talks of family, work and friend groups. While information about donating organs and tissues is abundant and accessible in the electronic media, respondents claimed that there is generally a denial to thinking about one's own death and the death of loved ones. Therefore, some respondents warned that the search for valid, reliable and complete information will occur only in the event that any member of the family needs to be transplanted.

About the process of requesting family consent, the experts interviewed believed that organ donation occurs on a single, painful and irreversible moment of the experiences of the relatives of the potential donor, since in many cases the occurrence of death by neurological criteria it is sudden, unexpected or violent.

According to experts, if the potential donor had expressed the intention to donate organs *post mortem*, the family is able to act decisively. Therefore, everyday social interactions are not only a space to adapt to the social structure, but also provide the primary context where people can exercise their right to express their desires about the fate of their organs and tissues after death (INCUCAI, 2015b). Moreover, if such statements are expressed in the National Register of Expressions of Will for the Donation, they will be protected and respected by Art. 19 of Law Transplantation of Organs and Tissues.

As stated by relatives of donor organs interviewed, organ and tissue donation is a social action able to give comfort to survivors before this experience of sudden



death. In this sense, a space of intervention of the communication in health, which can contribute to the design of strategies aimed at strengthening the capacities of individuals and communities in making informed decisions regarding this collective health problem.

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## **AUTHOR**

### **Antonela Isoglio**

Degree in Social Communication and Technical Professional Archivist at the National University of Córdoba (UNC), Argentina. Diploma in Communication and Health (UNC). Professor ascribed to the Seminar of Communication and Health of the Faculty of Communication Sciences (UNC). Researcher ascribed to the Health and Disease Program, a view from the social sciences, of the Center for Advanced Studies (UNC).