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Victorino, João Paulo; Arena Ventura, Carla Aparecida
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Organ donation: a bioethical issue in the light of legislation

João Paulo Victorino [1], *Carla Aparecida Arena Ventura* [2]

Abstract

This study aimed to analyze the opinion of health professionals that work in the organ donation and organ transplant process regarding the implementation of Law 10,211/2001, which deals with family consent for organ donation in Brazil. It is a qualitative study conducted in a university hospital in the state of São Paulo. The results show that the majority of health professionals agree with family consent to obtain organs for transplantation. However, there is disagreement as to how to obtain this consent. The study concludes that it is necessary to promote urgent actions for awareness regarding donation amongst the public and health professionals, aiming to achieve compliance with the law, and, most of all, to increase the number of organs available for transplant.

Keywords: Organ transplantation. Directed tissue donation. Legislation. Bioethics.

Resumo

Doação de órgãos: tema bioético à luz da legislação

Objetivou-se analisar a opinião de profissionais de saúde que atuam no processo de doação e transplante de órgãos a respeito da implementação da Lei 10.211/2001, que regula o consentimento familiar para a doação de órgãos no Brasil. Trata-se de estudo qualitativo desenvolvido em hospital universitário do interior paulista. Os resultados mostram que a maioria dos profissionais de saúde concorda com o consentimento familiar para obtenção de órgãos para transplante. Contudo, há discordâncias quanto à forma de se obter esse consentimento. Conclui-se que são necessárias ações de conscientização urgentes direcionadas à população e a profissionais de saúde com relação à doação, buscando atingir o cumprimento efetivo da legislação e, sobretudo, aumentar substancialmente o número de órgãos disponíveis para transplante.

Palavras-chave: Transplante de órgãos. Doação dirigida de tecido. Legislação. Bioética.

Resumen

Donación de órganos: tema bioético a la luz de la legislación

Este estudio tuvo como objetivo analizar la opinión de los profesionales de la salud que trabajan en el proceso de donación y trasplante de órganos en relación a la aplicación de la Ley 10.211/2001, que se ocupa del consentimiento familiar para la donación de órganos en Brasil. Se trata de un estudio cualitativo realizado en un hospital universitario en el estado de São Paulo. Los resultados muestran que la mayor parte de los profesionales de la salud están de acuerdo con el consentimiento familiar para obtener órganos para trasplantes. Sin embargo, hay desacuerdo sobre cómo obtener este consentimiento. Se concluye que es necesario promover acciones de concientización urgentes sobre la donación de órganos, dirigidas a la población en general y a los profesionales de la salud, procurando alcanzar el cumplimiento efectivo de la legislación y, sobre todo, aumentar el número de órganos disponibles para trasplante.

Palabras clave: Trasplante de órganos. Donación directa de tejido. Legislación. Bioética.

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1. Graduando joao.victorino@usp.br – Universidade de São Paulo (Eerp/USP) **2. Doutora** caaventu@gmail.com – Eerp/USP, Ribeirão Preto/SP, Brasil.

Correspondência
Carla Aparecida Arena Ventura – Departamento de Enfermagem Psiquiátrica e Ciências Humanas (DEPCH), Av. dos Bandeirantes, 3.900, Campus Universitário, Monte Alegre CEP 14040-902. Ribeirão Preto/SP, Brasil.

Declaram não haver conflito de interesse.

Research

The practice of transplantation has been breaking down barriers and facing major challenges. For a long time, its results were incipient, but, currently, it can be affirmed that it has been achieving expressive indexes as a consequence of the technical-scientific evolution applied to this sector. Thus, it is observed that the number of donations has increased, but not enough to reduce the waiting lists in Brazil [1].

Thousands of people diagnosed with a disease whose only treatment is transplantation can benefit from this practice, whether they be children, young people, adults or elderly, according to legal criteria established in the country [2]. These people have poor quality of life and live with the prospect of imminent death, in view of the advanced stage of their disease. Therefore, inclusion on waiting lists may represent an increase in their expectation of continuing to live [3]. Although considered as one of the greatest achievements of modern surgery, organ transplantation presents ethical dilemmas and controversies associated with the procedure, such as ethical-legal obstacles, which generate new discussions about the practice [4].

In order to establish norms to regulate donation and transplantation, Law 9434 [5], also known as the Transplantation Law, was issued in February 1997, which deals with questions regarding the post-mortem disposition of tissues, organs and parts of the human body for transplantation purposes; the criteria for live donor transplantation; and criminal and administrative penalties for non-compliance. This law was regulated by Decree 2268/1997, which establishes the National Transplantation System, the state bodies and the Centers for Notification, Collection and Distribution of Organs [6], in order to increase the number of donated organs, determined in article 4 that, unless otherwise stated, the authorization for donation would be presumed [5].

The publication of this law provoked criticism regarding the individual right to donate organs, which would be violated, since there was still no absolute consensus on the concept of brain death. In view of this, the Brazilian Federal Council of Medicine (*Conselho Federal de Medicina* - CFM), through CFM Resolution 1480/1997, characterizes brain death in article 1, which states that it will be diagnosed by conducting clinical and complementary tests at variable time intervals according to patients' age groups [7].

In 2001, Law 10211 terminated presumed donation in Brazil and determined that the donation of organs of deceased persons would only occur with family authorization, regardless of potential donors' wishes while alive. Since then, all forms of registration in identification documents, such as the National Identity Card and the National Driving License, related to donation of organs, have no longer value as a way for potential donors to express their wishes [8].

In this scenario, health teams have been working to clarify for the families of potential donors the criteria for the definition and occurrence of brain death [9]. The diagnosis is established after physicians, who are not part of the removal and transplant teams, have performed two clinical tests, using all the clinical and technological criteria defined by the aforementioned CFM resolution. It is mandatory to perform a complementary test with results compatible with absence of cerebral perfusion, cortical electrical activity or brain metabolism [10].

Therefore, accurate and rigorous identification is required for diagnosis of brain death. The ethical participation of all health professionals in this mission tends to make it possible to substantially increase donations of organs for transplantation [10]. For this, it is essential that society and health professionals are aware of the donation legislation, as well as of the rights of potential donors and recipients.

Despite all legislative developments, the process involving donation and transplantation of organs and tissues is subject to discussion and controversy. This is because the understanding of the topic varies according to the personal experiences of each individual, related to religion, culture and philosophy. According to Robson, Razack and Dublin:

The shortage of organs for transplantation becomes important for understanding why some people oppose organ donation. There are many reasons why some populations are less likely to consent to the donation. Among these reasons, social and religious issues play an important role, especially in a multiethnic, multicultural and multireligious community [4].

Organ transplantation is a safe procedure, capable of giving life expectancy to thousands of people waiting in line for organs, dealing daily with the prospect of death, which makes the process painful. It is necessary to make decisions based on professional ethics and current legislation, respecting religious and social aspects of those involved. Thus, it will be possible to deal with sensitive issues related to organ donations and transplants, preventing them from becoming barriers to the implementation of the procedure [4]. In this context, the objective of this study was to analyze, based on the ethical-legal perspective, the opinion of health

professionals regarding the implementation process of Law 10211/2001 in a university hospital.

Methodology

This study was carried out in an undergraduate/postgraduate university hospital in the interior of São Paulo, considered a regional reference for organ transplantation and also a reference center for high quality research and teaching. The Liver Transplantation Unit, Renal Transplant Unit and the Organ Procurement Organization (OPO) were the setting for this study.

This study used a qualitative approach, since this approach values the direct and prolonged contact of the researcher with the environment and object of study [11], especially when the phenomenon studied is complex, of a social nature and does not tend to quantification.

Participants in the study were social workers, nurses and physicians who are part of the OPO and the solid organ transplant teams of the hospital under study. The inclusion criterion considered professional training, restricting participation to nurses, physicians and social workers, since they work throughout the donation-transplant process and, above all, nurses and social workers, spend a great deal of time with the families of the potential donors and/or recipients. They are, therefore, professionals responsible for socio-educational activities, whose objective is to form support networks inside and outside the hospital with a view to social reintegration of those who received transplants.

The study excluded professionals from the unit who did not meet the inclusion criteria and those who did not agree to participate in the study.

In all, 22 professionals were invited to participate in the research, representing all those who are part of the study sites, and considering among the physicians only the contracted ones. Of those invited, nine (41%) agreed to participate in the study and 13 did not, because they were away from work during the entire data collection period (2; 9%), did not feel comfortable participating (7; 32%) and did not have time available for interviews (4; 18%). As more than one-third of those invited agreed to participate in the interviews, one can consider the representativeness of the data collected from the service studied.

Data collection took place between April and July 2015. The study used semi-structured recorded interviews. The average duration of interviews was 23 minutes. Also called semi-directional or semi-open [12], semi-structured interviews have their origin in a guide-book with questions that meet the aim of the research [13]. For the construction of the data collection instrument, the researcher undertook an analysis of the Brazilian transplantation legislation and defined guiding questions according to the objectives of the study. The instrument was sent to three nurses specialized in transplantation, who offered suggestions. After the analysis by these professionals, the instrument was reformulated and finalized.

In order to analyze the data, the technique of content analysis according to topic categories was applied in light of the current legislation on organ transplants in Brazil, as well as the principlist theory of bioethics, which proposes four ethical principles: autonomy, beneficence, non-maleficence and justice [14,15]. For Bardin [16], content analysis, as a research method, encompasses a set of discourse analysis techniques that uses systematic procedures and description objectives of message content. The author also states that the content analysis is composed of three different phases: pre-analysis, exploration of the material and treatment of results.

In the first phase, the content was transcribed, followed by exhaustive reading and sorting according to pre-established rules. After the pre-analysis, the exploration of the material began, which consisted in the systematic management of the decisions taken [16]. Thus, the data was organized by categories and subcategories according to topics. Finally, the third phase was conducted, treating the results analyzed based on the national and international literature on the subject of the study, giving rise to the final considerations.

Results and discussion

Among the participants, five were nurses (56%), two were social workers (22%) and two were physicians (22%). The average time working in this field was 24.4 years, the average time working in the institution was 17.8 years, and the average age equals 48 years, of which 44% were between 31 and 50 years old and 44% were over 50 years old. In summary, most of the interviewees were nurses (56%) and have been working in this field for more than 10 years (56%).

From the analysis of the research participants' testimonies, three topic categories and five subcategories were identified.

The first category comprised "the family responsible for giving consent for donation of

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organs and tissues in Brazil". The second, "ethical implications associated with organ donation and transplantation" , which had as subcategories "the role of health professionals in providing information to families of potential donors" , "family consent as a guarantee of autonomy?" and "presumed versus consensual donation". Finally, the third category covered "gaps in the knowledge of professionals and society regarding organ donation and transplantation", presenting as subcategories "professionals' understanding of transplantation legislation" and "health education".

The family responsible for giving consent for donation

This category deals with the study participants' testimonies regarding obtaining family consent for the donation of organs and tissues for transplantation. In Brazil, Law 10211/2001 makes family consent compulsory with regard to *post-mortem* removal of tissues, organs and parts of the human body and invalidates the concept of presumed donation. For those interviewed, family consent basically refers to the family's authorization for the *post-mortem* removal of organs and tissues from the deceased. They also consider that it ensures safety and efficacy for the whole process:

"What I know is that it needs to be widely discussed. It was never made without the family authorization. It is a safeguard, you know? Ethics, and everything else ..." (M3)*;*

"Consent is good for families and professionals to be safe. Because, if in the future the family begins to dispute, you can show that it was authorized. And I have seen it happen" (AS4)*;*

"It's a way to keep the security of what's going to be done. For us it is a legal guarantee and for the family it is proof that the life of the loved one will continue in another body" (E9)*.*

Based on the analysis of the interviewees' testimonies, it was observed that, according to health professionals involved with the donation and transplantation process, there are several aspects associated with obtaining family consent. These questions concern the communication of bad news, the relation with the body of the deceased and, above all, granting of consent as a form of realization of the deceased's final wishes:

"When the family is well received from the beginning, there at the hospital reception, not only by the health professional, but by the administrators, the secretary who is there, this donation is successful. When the professional acknowledges the family and informs them as to what is happening, they feel acknowledged" (E2)*;*

"When an impasse arises during the hospitalization of the potential donor and later the family is approached, this process becomes more difficult. Then you hear things like, 'Why do you want the donation? Because, when I tried to do this, I could not do it." Sometimes the family refuses it because of bad service, thinking that the donation will benefit the hospital and not someone else" (AS4)*.*

Generally, families consent to the donation according to their recognition of the wishes - implicit or explicit - of the family member. In this sense, they understand the donation as a way to help others who are waiting for an organ and, in addition, to ensure the fulfillment of the last desire of their loved one [17].

According to Roza et al. [18], *part of the suffering process for relatives of a deceased person involves the willingness to donate parts of the body after death. The funeral ritual and the funeral itself express the loss and show respect for the deceased. This suffering can be exacerbated by organ removal procedures. This may account for the high frequency of organ donation compared to tissue donation, for fear of deformation of the body from organ removal surgery, when family members are not adequately informed about the procedure or do not have sufficient support during the process*.

It is important to note that the Brazilian transplantation legislation establishes that the transplantation team has an obligation to recompose the body of the deceased after removal of the transplant organ(s), so that the body can then be delivered to the relatives or guardians of the deceased for burial.

Although *post-mortem* donation currently only occurs after obtaining family consent, questions related to consenting donation can be noted in the interviewees' testimonies. According to the study participants, in this type of donation there is a risk that the family might not respect the wishes expressed by the deceased while alive. In this sense, it is important to treat respect for autonomy as a guarantee for the fulfillment of the wishes expressed by the potential donor while alive.

Bandeira [19] states that in the case of a transplant*, it is no longer a question of physical*

integrity, but of the person's ethical autonomy, of their right of self-determination to have their decisions respected after death. There is, therefore, an impossibility of considering the personality rights of a dead person, but this does not imply that the guarantee of protection of human dignity necessarily ceases. It can be said that there is a prolongation of the personality after death. This idea is pointed out in the interviewees' opinion that family consent is a form of disrespect regarding the wishes of the loved one, given that the decision will be made according to the interpretation of the family, regardless of the wishes expressed by the deceased while alive:

"This opinion should be that of patients and not of their families, because sometimes they have wishes that their families will not respect. So I would be in favor of it being as it was in the old days, when it was stated in your documents whether you were a donor or not" (E5)*;*

"Sometimes I think it should get through this barrier of family authorization" (AS6)*.*

Ethical implications associated with organ donation and transplantation

While thousands of people wait in line for an organ for their lives to be saved, thousands more die from accidents, traumas, or other casualties. In these cases, after diagnosis of brain death, several healthy organs could be removed and implanted in those who suffer waiting for a transplant, which, in this way, would achieve a greater degree of well-being. In Brazil, organ donation is still poorly understood by the general population, which implies myths, taboos and misconceptions about the subject, rooted in sociocultural, affective, economic and, above all, ethical issues [20].

This topic category encompasses the participants' narratives regarding the ethical issues related to donation and transplantation of organs and tissues in Brazil. Three subcategories were identified: "the role of health professionals in providing information to families of potential donors", "family consent as a guarantee of autonomy?" and "presumed versus consensual donation".

According to the interviewees, the role of health professionals in guaranteeing information to families of potential donors should be based on acknowledging the families and respecting their pain, and can contribute to obtaining family consent: *"... when professionals acknowledge the family and inform them as to what is happening instead of waiting to speak only when death occurs, the family feels more acknowledged. The donation process becomes easier* "(E2).

The concern not to cause harm during the whole process that extends from the diagnosis of brain death to obtaining the family consent and removal of the organ(s) for transplantation is noted in the participants' statements. In view of this, it is important to relate the practice of these professionals to the application of ethical principles as a way of dealing with moral conflicts. In the principlist theory of bioethics, this can be explained by the principle of non-maleficence, which advocates the obligation not to intentionally cause harm to those directly or indirectly involved with a situation [12,21]. It is important to understand non-maleficence as the basic principle of every moral system, since, with the guarantee of this principle, all other principles are observed:

"We have to pay attention to see how the information is being given to this family (...) *If the team is willing to help and clarify, the family feels free to donate* (...) *they feel that everything they needed from the institution, the doctor and the nursing team was attended to promptly, and this is a factor that greatly facilitates donations"* (E9)*.*

Despite highlighting the importance of ethical and bioethical attitudes, the interviewees also recognized that in the Brazilian scenario, the guarantee of the principle of non-maleficence is not always preserved:

"... within the protocol of brain death we know that there are flaws. By law, every time that you conduct a test you are required to advise the family. But we know that this often does not happen, and this causes problems for us, because sometimes family members believe that things will change and then suddenly someone says that the patient is dead. If the protocol were followed in a gradual way, everything would be less complicated and less aggressive. It might be that back then there was a series of hopes and expectation that the patient was going to leave the hospital and would return home" (AS4)*.*

Although the notification of brain death is mandatory, according to the Brazilian legislation of transplantation, the interviewees' statements indicate cases in which the notification is trivialized, leading to disrespect of the wishes of the deceased and his or her family:

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"I heard people say, 'Oh, in the situation that the family is in, how can you still want to talk about donating organs? This is not even a question of charity.' So I still see that many people are against it (...) *I have already witnessed times when the team did not report brain death because it was a child or an only child"* (E7).

It is important to note that the lack of notification results in administrative sanctions in accordance with article 13, paragraph 1 of Law 9434/1997, implying a fine of 100 to 200 days-fine [5]. The lack of notification makes the process of obtaining organs and tissues for transplantation not viable. Moreover, in a way, it interferes in the most diverse aspects expressed by the family of the deceased, such *as respect for his or her autonomy* and the fulfillment of his or her last wishes.

Respect for the autonomy of people as moral agents capable of making informed decisions is central to bioethical dialogue and the frame of reference when consent for organ donation is required. Only the permission assigned by a person can legitimize action that involves that person. The value of people is unconditional, which forces others to consider them as ends, not as means, with freedom to live and decide without interference.

The exercise of autonomy is directly associated with knowledge about the case, since those who do not know are hardly likely to exercise their opportunity to choose [22]. According to Almeida et al., *autonomy, as a principle of bioethics, refers to the ability to choose, decide, evaluate, without internal or external constraints* [20]. Thus, it is possible to consider that all have the capacity to decide whether to donate or not. When the individual is not informed of the situation, as exemplified by the case in which the medical team did not notify the relatives, the subject ceases to have his or her autonomy respected.

The interviewees' testimonies suggest that respect for the autonomy of the deceased is only guaranteed when the family consents to the donation according to what the deceased expressed while alive. However, the idea that the family choose to donate even though they did not know the expressed wishes of their loved one is seen by professionals as an altruistic act, since this decision will be helping others:

"When patients are dead, they no longer have autonomy, but when they expressed their wishes while alive, they had autonomy and gave it into the hands of their families. (...) *when patients do not say anything and the families decide to donate, it proves that there is still time to help other people"* (E2);

"No one has the right to force anyone to do anything while alive. After death, if the family decides, I agree. It becomes the autonomy of the family" (M3);

"... there is no autonomy. Legislation is flawed, because it is no use expressing my wishes while alive, and when I have a brain death it is a family member that needs to make that decision. If it is a member of the family who is against the opinion of the deceased, it is his or her opinion that will have weight" (AS6).

Although most of the interviewees agreed with consensual donation, they still believe that there should be changes in Brazilian legislation that would allow for the deceased's wishes to prevail, giving him or her knowledge of the situation while alive and consequently guaranteeing the exercise of his or her autonomy. In this sense, it is interesting to consider presumed versus consensual donation, according to the opinion of the study participants.

It is believed that donation of a consensual type presents as a positive aspect the guarantee of being a safe process, which is able to protect both the professional team and the family of the deceased. However, the study participants' testimonies lead us to consider the effectiveness of presumed donation in terms of ensuring autonomy and also as a way to optimize the number of donations in the country, since family refusals constitute the biggest impasse for donations:

"I know the legislation exists, but I think consent is not right. It should not come from only the family. There should be some way of prioritizing the wishes of the deceased" (AS6).

Gaps in knowledge regarding organ donation and transplantation

After the enactment of Law 10211/2001, donation of organs becomes the responsibility of the family of the donor. In this sense, all forms of records in official documents, such as ID cards and driving licenses, lose their validity.

This category gathers the testimonies of participants regarding gaps in the knowledge of professionals and society concerning donation and transplantation. The analysis of the data shows several values attributed by the professionals about

transplantation legislation, as well as the importance of education to enhance donations. As a result, two subcategories were created: "professionals' understanding of transplantation legislation" and "health education".

Concerning their understanding of transplantation legislation, most practitioners recognized the importance of law in the applicability of existing criteria. They affirmed that the current legislation appeared as a way to solve the great impasse regarding presumed donation:

"We already worked when the presumed donation law was in place, and with that we went through a very big obstacle. Because those who had contact with the public to put in their documents if they were donors, or not, had no knowledge of the subject. And sometimes, they asked, 'You are not a donor, are you?' Of course, the document ended up stating that the individual was not a donor" (E9);

"In old times people used to put it in their documents if they wanted to be donors or not. However, that way, I might put in the document today that I do not want to be a donor, and suddenly I might change my mind" (E2).

The participants' statements indicate that, despite the evolution of legislation since 1968, it is still necessary to consider the population's awareness as a way to optimize the number of donations. For many years, the idea of donation has been considered as proof of solidarity and a gesture of altruism. However, the low number of organs available for transplantation compared to the number of people on the waiting lists for an organ shows that this concept has been ineffective and needs to be modified [23]. Thus, health education is seen as a strategy to raise public awareness:

"... there is a general lack of information. There should be more public awareness campaigns. Families would certainly consent more readily if they knew what it really was" (E1);

"... all this is a failure of the team and of debates about the whole process" (E7);

"I think it's just with clarification. It's a long-term job that you have to do to raise public awareness (...) it's basically the equity principle of the Brazilian National Health System. It's no use people seeing it on TV and not understanding it. It has to be brought to the attention of the person, in their language" (E9).

For the interviewees, the inclusion of lessons in basic education would be an excellent strategy, capable of changing the Brazilian scenario regarding health education, more specifically in relation to organ donation and transplantation. In this sense, one can think of the use of active teaching methods, capable of making the teaching-learning process meaningful for students and that, in addition, can help them to perceive themselves as agents of health promotion, since children and young people are natural multipliers of knowledge. Through the transmission of information to students, it is possible to reach all the members of their families, friends and other people who share the environment in which they live: *"a subject in early childhood education and primary education already makes a difference* (...)*Young people and adolescents are disseminators, they are multipliers"* (AS6).

We also note the importance of academic alliances related to the topic, which for the study participants is the link between future health professionals and the community: "*You see today that we even have involvement of students participating in the transplant alliance. They participate in various activities and end up promoting the importance of donation*" (M3). In addition to the importance of raising awareness done by health academics through the academic alliances, interviewees also point out the importance of professional training with a view to organ donation and transplantation:

"The ideal way to improve all this is to review the implementation and training of those professionals involved" (M8);

"What is lacking is knowledge. How do you expect the population to know if even health professionals do not?" (E9).

According to Cantarovich [24], *donating an organ while you are alive, to someone you know, is a relatively easy decision. The opposite, that is, donating an organ post-mortem, is a decision rooted in negative thoughts regarding this practice, which requires the education of the population as a whole*. It is important to understand the role of health professionals in the education process. By knowing that in Brazil the donation has a consensual character, that is, it is authorized by the family, it is necessary to develop campaigns aimed at public awareness in relation to donation and transplantation of organs and tissues. It is believed that in this way it is possible to mitigate the dilemmas associated with the subject [25].

Final considerations

The donation and transplantation of organs and tissues have undoubtedly become tools capable of guaranteeing quality of life for the population that have some disease whose only treatment is the replacement of such organs. Transplantation legislation has undergone several changes since its inception and the most recent law, enacted in 2001, establishes the post-mortem donation of organs only with family consent. Moreover, this law terminates all and any type of registration in an official document that confirms the decision of being an organ donor or not.

The purpose of this study is to identify the opinion of health professionals who work in organ and tissue donation and transplant services regarding the implementation of Law 10211/2001. This is because, with its promulgation, the scenario of obtaining organs has totally changed, provoking heated discussions about the subject, which makes it necessary to make analysis based on bioethical and legal references.

Based on the data obtained, we conclude that most professionals interviewed believe that the family should be responsible for consent in cases of post-mortem donation, since living with the loved one makes it possible to recognize his or her wishes. In spite of this, it was noted in the interviewees' testimonies that there was disagreement regarding the method of obtaining consent, since the autonomy of the individual may not be respected in cases in which the family, due to several factors, is contrary to the expressed wishes of the potential donor.

Although the interviewees cite the role of health professionals in providing information to patients' families, many believe that there is still a lack of training. There was dissatisfaction among the interviewees regarding the positioning of the team responsible for the diagnosis of brain death. This is because, on several occasions, the team neglects to communicate to the families the reason for carrying out the evidence of brain death tests, informing them of what occurred only after the proof of death. This ultimately prevents the patients' family members from feeling acknowledged, informed and respected.

Faced with the families' lack of preparation to experience the loss and the ethical implications associated with the topic, it is believed that the way to communicate these aspects needs to be reviewed in order to effectively prepare the relatives for the death of their loved ones, guaranteeing them all Information to which they are entitled. This initiative also considers the losses related to the emotional state of the family members, which undoubtedly reflects on the number of refusals in the process of obtaining organs in Brazil.

The meaning attributed by families to family consent was also evident. According to participants, the families believe and regard family consent as a way to fulfill the deceased's last wishes. For this, the team should be prepared to clarify possible doubts and also emphasize the positive aspects arising from the families' consent to donation.

Although it is known that in current transplantation legislation, post-mortem donation occurs only after obtaining family consent, some professionals defend the idea that organs for transplantation should be obtained from official records left by the individual while alive. According to those who advocate such a position, the donation authorized in previous legal records would favor the number of organs available and would also diminish the responsibility of the families in relation to that decision.

On top of this, it is important to consider that, in addition to dealing with the traumatic loss of their loved one, families still have to decide on the donation of the deceased's organs for transplantation, sometimes without having even had the opportunity to talk about it previously with the deceased. Based on this idea, there were comments about the importance of health education for professionals as well as for society as a means of increasing awareness and, especially, understanding about the topic.

Finally, the interviewees believe that the evolution of the legislation originated in the evident inefficiency of previous laws, which, due to technical lack of preparation and the population's lack of knowledge, were modified to improve the understanding and contribution of society to the organ donation scenario. In short, it can be said that it is not enough to have laws regarding organ donation and transplantation. It is necessary that they are known by health professionals and by the population in general, since only through knowledge will it be possible to effectively implement the milestones proposed by the legislation. Awareness and understanding not only by health professionals, but also by the population in general, is essential, as a matter of urgency, for the substantial increase in the number of organs available for transplantation.

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Participation of the Authors
Both authors conceived the study and collaborated in writing the manuscript. João Paulo Victorino worked on data collection, analysis and discussion. Carla Aparecida Arena Ventura oversaw the development of all stages of the project.

Research

Appendix

Data collection instrument

Education: _____

Job position: _____

Time working in this field:_____

Time working at the institution: _____

Age: _____

1) What do you know about family consent for organ and tissue donation in Brazil?
2) What are the criteria for obtaining family consent in the institution you work at? How are these criteria applied?
3) In your opinion, what is the importance of health professionals in the process of obtaining family consent for organ and tissue donation? Do you experience this process? If yes, how does it take place?
4) What is your opinion regarding family consent to obtain organs and tissues for transplantation? Why?
5) In your opinion, how does the health team view family consent to obtain organs and tissues for transplantation?
6) What do you consider to be the positive points of the law that establishes the donation of organs and tissues according to the decision of the family of the deceased donor? Why?
7) And what are the negative aspects of that same law? Why?
8) In your opinion, is there any way to optimize these aspects? How?
9) How do you consider the autonomy of a patient when consent is given by his or her family?
10) What is your view regarding the parents' and/or guardians' consent in a donation and transplant process in which the donor is a minor? Do you agree or disagree with this practice? For what reason?
11) How do you consider that - in practice - patients' wishes are respected? Why?
12) How do professionals act so as not to cause damage throughout the process?
13) In your opinion, can care teams and patients' families manage to establish some form of balance in the decisions to be made? In what way?
14) According to your experience, how have changes in legislation regarding organ and tissue donation and transplantation influenced and are still influencing your professional practice?