Objective: identification of the reasons of family refusal during the organ and tissue procurement and the active role of nurses to influence the family of a potential donor with encephalic death. Method: the present work is a descriptive-exploratory literature review with a qualitative approach. Thus, one questions the reasons why the family refuses organ and tissue donation and how the nurse can perform to sensitize the family during the process of organ procurement? Results: organ and tissue transplants are currently considered as a safe and life-saver therapeutic alternative. Besides, they give to patients opportunities for the improvement of their perspective and quality of life. In order for an individual with encephalic death to donate one’s organs and tissues in Brazil it is required that his or her family authorizes the procedure. During the process, one can identify some reasons that lead to family refusal, which is currently the major obstacle to the donation of organs and tissues in Brazil. Conclusion: the nurse has a primary role in the process of procurement of organs and tissues and acts an advocate for the patient with the family of the potential donor to minimize the causes that lead to family refusal. They act from the identification of the potential donor until the delivery of the corpse to the family. This is of the utmost importance during the process of organ donation because it is the family members who decide whether the donation will take place. In this context, the nurse must sensitize the family and have a transparent and ethical involvement in the process to minimize levels of family refusal in Brazil. Descriptors: organs transplant; encephalic death; family; nursing.

RESUMO

Objetivo: identificar os motivos da recusa familiar no processo de captação de órgãos e tecidos e a atuação do enfermeiro junto à família do potencial doador em morte encefálica. Metodologia: estudo de revisão de literatura sistemática, com levantamento bibliográfico por meio de buscas na base de dados Literatura Latino-Americana e do Caribe em Ciências da Saúde – LILACS e na biblioteca em linha Scientific Electronic Library - SCIELO, no período de setembro de 2010 a maio de 2011. Foram utilizados os Descritores em Ciência e Saúde – DECS da BVS: Transplante de Órgãos, Morte Encefálica, Família e Enfermagem e como critérios de inclusão: artigos com textos completos e disponíveis para leitura; recorte temporal de publicações de livros e artigos a partir do ano de 2005; idioma em português. Foi elaborado o questionamento: quais os motivos da recusa familiar para a doação de órgãos e tecidos e como o enfermeiro atua sensibilizando a família no processo de captação? Resultados: após análise minuciosa do material selecionado, foram construídas três categorias temáticas: O processo de captação e transplante de órgãos e tecidos no Brasil; Fatores determinantes na decisão familiar para a doação de órgãos e tecidos; La donación de órganos y tejidos, ya que es para la familia decidir si el donación va a suceder o no. En este contexto, la enfermera debe actuar como un sensibilizador de la familia con su conducta basada en la transparencia y la participación de ética con el fin de reducir al mínimo la tasa de rechazo de la familia en Brasil. Descriptores: trasplante de órganos; cerebro de la muerte; la familia, enfermería.
INTRODUCTION

In the last few decades, scientific and technological advances have brought important contributions in the scope of health with the appearance of new treatment techniques, highlighting the organ and tissue transplantation, which provides opportunities for improvement of perspective and quality of life for individuals.

Organ and tissue transplantation can be definite as a total or partial removal of an individual body part and the implant in a receptor, whether or not the individual donor. This act can be performed during the life and death after, thereby identifying two distinct groups of organ and tissue donors: living donor and post mortem donor, which becomes an eligible donor after evidential exams of encephalic death and also when all clinical contraindications which represent some risk to the recipient are ruled out, which is the only kind of donor that may benefit up to ten patients. It is when the family decision about the donation process becomes clearer and indisputable, since the family is responsible for the organ donation after the patient’s death.

Obtaining potential transplantable organs becomes more and more of a necessity in order to establish a secure and saving therapeutic alternative. This is due to the growing number of patients with organic terminal lesions, to the progress in clinical and substitute treatments and also to the creation of transplant centers all over the world bringing close to the patient this therapeutic option. Making it one of the most successful subjects in the history of health.

The low number of potential donor notifications at the transplant centers influences directly the constant growth in number of patients that are on the waiting list to receive an organ, making this subject more and more discussed and refined.

Organ and tissue harvesting and the involvement of the family potential donor are complex processes which require the performance of a qualified and competent multiprofessional team to carry out such role. Therefore, a nurse is identified as a professional who works together with its team, developing a technical and scientific role, making its place essential in the process.

Transplantation started in Brazil in the beginning of de 1960’s, with the involvement of nurses since the first transplant was performed in 1964, a renal transplant.

Noticing a growing participation of the nurse in the process of harvesting and its involvement with the patient’s family, it is necessary to know that in order to effective donation of organ and tissue, it is indispensable the authorization of the person responsible for the donor with encephalic death. Therefore, the family must be consulted and oriented about all the steps of the process, becoming the most important step for effective donation, because that is when it will be decided whether the organ transplant will happen or not.

There are some hindering issues that may cause the family to refuse the donation of organ and tissue. Acknowledging that, the “Registro Brasileiro de Transplantes”, in 2006, shows that medical contraindications are the first cause of family refusal to donate organ and tissue in Brazil, in opposition to the year of 2010, in which the family refusal reached 25.8%, leaving behind medical contraindications and cardiopulmonary arrest, becoming the first reason of a non-effective organ and tissue donation in Brazil. This shows the importance of the nurse’s actions which favours the family decision in donating, and directly linked with the growth of organ and tissue donation in Brazil.

Thus, we ask, the importance of an adequate approach of the professional nurse to the family of the potential donor and the impact caused by their decision on the life of the probable recipient: what are the family refusal reasons for donating organ and tissue and how the nurse soothes the family during the harvesting process?

It’s necessary for the nurse to act adequately as a sensitizer before the potential donors’ family, since the family refusal is one of the most decisive factors that causes shortage of organ and tissue and its decision must be the link between the potential donor to the effective one, making the death of a loving relative a chance of life for other people.

In this context, the objective of this study is:

OBJECTIONIVE

- Identification of the reasons of family refusal during the organ and tissue procurement and the active role of nurses to influence the family of a potential donor with encephalic death.
METHOD

A descriptive and exploratory study, with the purpose of “describing the characteristics of the proposed subject and clarifying the research problem”.12,27 And also the qualitative approach, that interprets “the process that can be seen, with the description, comprehension and the meaning, with no pre-conceived hypothesis, which will be conceived only after observation”.12,30

This study was developed from a literature review, which is a type of research done about studies of already prepared materials, using books and scientific articles as reference sources.12

For the selection of the material, a bibliographical survey of articles and periodicals was done through databases of the Biblioteca Virtual de Saúde (BVS), such as Literatura Latino-Americana and Caribbean Ciências da Saúde - LILACS, Scientific Electronic Library - SCIELO, from September 2010 to may 2011.

The descriptors used are contained in Descritores em Ciência e Saúde - DECS da BVS: Transplante de Órgãos, Morte Encefálica, Família e Enfermagem.

The criteria for inclusion were: publications that were relevant to the subject; articles with complex and available literature; dated extracts of publications of books and articles from 2005, because they are more actual, and studies in Portuguese, because of Brazilian studies that highlight the reality of transplantation in Brazil.

By searching the descriptor Transplante de Órgãos on BVS, 39,753 published articles were initially found. Using the criteria of inclusion, titles analysis and reading of the summaries, 133 articles were subsequently selected and 10 articles were relevant to the study. 1,193 articles were found by searching on the descriptors, Transplante de Órgãos e Família. After using the criteria of inclusion, titles analysis and reading of the summaries, 18 articles were selected and 7 articles were used because they are relevant to the subject, and 4 of these articles were duplicated in the last research. By using the descriptors Enfermagem e Morte Encefálica, 250 articles were found, 11 articles were selected meeting the criteria described as before, and 5 articles were used, with 1 of them duplicated in the last research. Thus, 17 articles were used for present study.

I new research was done through the sources of Biblioteca do Centro Universitário Newton Paiva and Universidade Federal de Minas Gerais, where technical documents such as Relatório de Avaliação do Programa de Doação, Captação e Transplantes de Órgãos e Tecidos do Tribunal de Contas da União e Relatório Descritivo sobre a Situação do Sistema Nacional de Transplantes, were analysed. And also, official documents such as the Brazilian legislation that controls the donation of organ and tissue for transplantation, in governmental sites such as Ministério da Saúde and institutional sites such as Associação Brasileira de Transplante de Órgãos (ABTO), Conselho Federal de Enfermagem (COFEN), which regulates the professional practice of nurses during organ and tissue transplantation and Conselho Federal de Medicina (CFM), which defines the criteria for encephalic death, were analysed.

Four books were used to build the study, and were published from 2005 to 2001, besides 2 other periodical articles which were not indexed in the database described before, such as Revista Enfermagem Brasil e Jornal Brasileiro de Transplantes because of the great relevance to the study.

In order to analyze and overview the study material, few steps were taken and proposed by Gil (2010, p. 45): “choice of subject, preliminary bibliographical survey, formulation of the problem, elaboration of the subject provisional plan, search for sources, reading material, logical organization of the subject and text editing.12

After a detailed analysis of the chosen material, 3 thematic categories were created: The process of organ and tissue harvesting and transplantation in Brazil; Decisive factors about the family decision on organ and tissue donation; and The nurse’s performance and approach to the family during the process of organs and tissue transplantation.

RESULTS AND DISCUSSION

- The process of organ and tissue harvesting and transplantation in Brazil

Brazil has the biggest public program of organ and tissue transplantation in the world. However, when compared with the number of transplants actually done, it is in second place, losing only to The USA, where the transplants are financed by the patients and by the health insurance plans.14

The first version of the legislation about transplants in country was Lei n° 4,280, of November 6th, 1963, which permitted the donation of organ and tissue post mortem only
with the donor previous authorization or when there is no opposition with the family. A year its publication, the first transplant took place in Rio de Janeiro, a renal transplant.15

Although the same law was about post mortem organ and tissue harvesting, there wasn’t, however, legislation that regulates this procedure in a complete way.16 With the enactment of Sistema Único de Saúde (SUS) regulated by Lei n° 8.080 of September 19th, 1990, in line with article 198 of the Federal Constitution from 1988 which is based on principles of universality, integrity and equality, there was a need for definition of clear criteria, technically adequate e socially just for organ and tissue distribution.17

Afterwards, Lei n° 9.434 was regulated on February 4th, 1997, also known as law of the presumed donation, foreseeing that if the individual hadn’t manifested its will in life, it was presumed the authorization of organ and tissue donation.17 It further established that an organ and tissue non-donor situation should be printed on the National ID and on the Driving license for those who opted for that. Thus, the will of the family wasn’t considered. However, the Brazilian society didn’t support that innovation, and because of that, Lei n° 10.211 of March 23rd, 2001, was edited, which altered provisions of Lei n° 9.434/97, demanding that the family of possible donors have to be consulted and the entry of receivers on the waiting list of organ and tissue transplantation after counselling about the exceptionalities and possible risks.18

SUS waiting list is the only waiting list in accordance with Portaria GM nº 91 of January 23rd, 2001, care is done on a first-come, first-served basis, considering technical criteria, urgency and geographic specific to each organ.11

In Brazil, the waiting list reached 47.373 people in 2010. This data became discrepant when confronted with 21,040 organ and tissue transplants done that same year.1

To increase the demand for organs and optimize data from the national scenario, a donor with encephalic death becomes the more promising choice, by offering simultaneously organs and tissue for transplantation, such as: kidneys, lungs, heart, liver, pancreas, intestine, cardiac valves, cornea, bones, arteries, veins and skin.19-20

According to the Resolução do Conselho Federal de Medicina nº 1.480, of August 8th, 1997, encephalic death is defined as “a total and irreversible arrest of encephalic functions and must have a known cause”, and thus the main causes are, encephalic cranial trauma, encephalic ischemic or hemorrhagic stroke, hypoxia and primary brain tumour.21

The first definition of encephalic death in Brazil happened only through electroencephalographic criteria during the first heart transplant between humans, in May, 1968. From that moment, the organ and tissue transplants from patients with encephalic death became medical routine, providing new regulations about the donation with this kind of donor.22 In light of this, currently, in order to diagnose encephalic death, it is necessary a clinical neurological exam from the absence of cerebral reflexes of a patient in a coma and complementary exams in which can be identified the absence of cerebral blood perfusion, or the absence of electric cerebral activity, or the absence of cerebral metabolic activity.2

According to the Tribunal de Contas da União, the organization of transplants was done through the Sistema Nacional de Transplantes (SNT), created by Lei n° 9.434/97 and regulated by Decreto n°. 2.268, of June 30th, 1997, thus consists of the Central Nacional de Notificação, Captação e Distribuição de Órgãos (CNNCDO), located in Brasilia and it is responsible for linking the Centrais de Notificação, Captação e Distribuição de Órgãos (CNCDIO), facilitating the relocation of organs among the Brazilian states and so that avoiding loss of organs from its original places.14 There are 25 Centers distributed between the states and the Federal District, also there are 548 establishments authorized to perform transplants, with 1,376 medical teams.14

The process of donation starts when the doctors inform the donor’s family that there is a suspicion of encephalic death, which can be verified by specific exams.23 Complying with Lei n°. 9.434/97, a compulsory notification has to be done by the health services, independently of the patient’s clinical condition of becoming an eligible donor or even the family desire for donating.15

Becoming part of SNT, through Portaria nº 1.262, of June 16th, 2006, the Comissões Intra-Hospitalares de Doação de Órgãos e Tecidos para Transplantes (CIHDOTT), were introduced with the purpose of speeding the organ and tissue harvesting and donation in connection with the CNCDIO.24 The CIHDOTT has to be consisted of at least 3 experienced professionals, who are part of the functional body of the health institutions, being obligatory the presence of a nurse or doctor.
as a coordinator, and they can’t be part of the collecting teams and/or organ and tissue transplantation, nor the clinical team that diagnoses the encephalic death. This commission’s function is to follow the process since the identification of a possible donor to the liberation of the body with the family, including guaranties of an adequate familiar interview, supporting it throughout the process. To enable the organs in case of family authorization, the CIHDOTT notifies the donor with CNDOI, which in turn, indicates transplanting teams and possible receivers.25

● Determining factors in the family decision of donating organ and tissue

In Brazil, decision for transplantation is based on an altruistic and voluntary system, in which the choice between donation or not is made by the patient in life or by the family after its death. However, the majority of people don’t choose this option in life, and when chooses this option, don’t tell its family.8

There are some hindering issues that make impracticable the process of donation, from which we can highlight the high rates of clinical contraindication against the donation, lack in identification and notification of potential donors and, especially, the family refusal, representing the biggest limit to success of organ and tissue donation.9

When a patient’s encephalic death is diagnosed, it triggers the most difficult process for the donor’s family, because, not only the family has to deal with the loss of a loved one and the period of mourning, but has to understand the meaning of encephalic death, which most of the time, isn’t well accepted by the family. Relatives that don’t understand the concept of encephalic death and keep hoping for a change on the patient’s condition, create a barrier when approached about the possibility of organ and tissue donation. In contrast, the families previously instructed even before the encephalic death is confirmed, have more chances of preparing themselves for the patient’s death and by that taking their decision with more clarity presenting a bigger chance of donation.26,8

Other determining factors that may cause the family refusal were quoted by some authors, among which the aspects related to the assistance given to the patient and the relatives during hospitalization. The care delivered to the patient, and using all the material resources indispensable to the patient’s recovery and the dedication of the professionals involved in the treatment, making the relatives more confident and facilitating the communication with the team.26

So that, the difficulty in authorizing the donation may be caused by the relative’s fear of accepting the manipulation of the body during the organ and tissue harvesting and also the conflict of decisions among the relatives when there is no agreement about the donation.9 It should be stressed that the process of donation is exhaustive and may cause doubts related to the deformation of the body and the possibility not offering the loved one a proper funeral, stressing and scaring the relatives. According to the Lei 9.434/97, after the organ and tissue harvesting, the body has to be given back to the family decently recomposed, keeping every time possible, its previous appearance.21

It’s necessary to stress that the desire for donating, expressed by the patient in life of not, also influences the relatives’ decision, because many prefer to respect the will of the loved one even on its absence.26,20

Studies have appointed that religion issues influence on the relative’s decision on consenting the donation, despite of the majority of religions not making any objection about it. Cultural aspects as social-economical and educational level of the donor’s family also act as a barrier to the acceptance of donation, since the high level of illiteracy in Brazil directly interferes with the difficult of information access about organ and tissue donation, limiting the relatives’ capacity of exercising their autonomy before this decision. In this context, the relatives’ uncertainty about the transplant system and organ distribution causes fear related to the existence of organ trafficking, being this considered another deterrent factor to the relative’s decision.8,27-28

● The nurse’s approach on the family during the organ and tissue harvesting

The professional that directly handles the donor’s family, potencially has to have abilities and professional skills to promote an adequate approach to the relatives, respecting the ethical principles for beneficence, no harmfulness, autonomy and justice during their loss.27 Thus, the nurse is considered a professional which has a primordial role in the process of organ and tissue harvesting and donation, acting with an integral and humanistic vision. Completing this affirmation, it becomes clear that the nurse’s performance has to transcend de
The nurse leading the process of organ and...

It’s essential that the concept of the encephalic death be well understood and accepted by the relatives, the nurse has to explain objectively through a simple and accessible language, using all the time necessary for the relatives’ comprehension. Soon, the family independently of its decision, mustn’t few remorse and never be forced to donate, remembering that its decision can be revoked at any time even after the consent that authorizes the donation.

During the interview, the nurse should let the relatives express their feelings, talk about the loved one, in order to feel welcomed by the professional. The interviewer should question the family if the patient manifested in life its will to donate, because it is one of the determining factors for the family decision. It’s pertinent to notice that the family has to be oriented about all the stages of the process and which organs can be donated, emphasizing that the decision about donation is an act of solidarity in which the family doesn’t receive anything in return.

Some questions about the process of donation should be explained to the family, such as, the aspects related to the false idea of deformation of the body and the influence that it can cause during the funeral. When the relatives are well informed about those issues, high rates of approval are achieved. The consent of organ and tissue donation may cause conflicts, that’s why, it should be stressed that the nurse should provide the family with a favourable atmosphere for the final decision, not necessarily at the moment of the interview, giving them the option for reflection so the decision can be taken cohesively and consciously.

Through a family interview and authorized donation, the nurse that performs closely to CIHDOTT in accordance with Portaria n° 1.262/06, is responsible for the “supervision of all process until the delivery of the donor’s body to its family”. Therefore, it is believed that this moment symbolizes the beginning of the relatives’ mourning after the loss of a loved one, and it will be important to deliver the body to the family as a sign of respect, offering the family an opportunity for saying good-bye to the loved one, thus, not feeling remorse for donating.

Thereby, the authors consider that the nurse, who deals directly with the family, should unite its ethical competence to an integral care, thus providing an adequate communication so the relatives can be welcomed to all process of organ and tissue harvesting. This behaviour makes its
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