

Weaknesses in the care for potential organ donors: the perception of nurses

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Abstract

This study aimed to get to know the perception of nurses about weaknesses in the care for potential organ donors. This is an exploratory-descriptive study with a qualitative approach, involving eight nurses from a reference hospital. It used semi-structured interviews and the results were analyzed according to discourse analysis. Two categories emerged: “perception of nurses on working with potential organ donors” and “weaknesses in the care for potential donors”. There is a limited role of the organ procurement organization. The barriers involve human and financial resources, family refusal, long wait for test results and structural problems. The work of this committee is limited to health care activities, in detriment of management. The professionals perceive weaknesses and fear negative repercussions. One must invest in structure and continuing education for this to be reflected in better care to potential donors and their family.

Keywords: Tissue and organ procurement. Brain death. Nursing.

Resumo

Fragilidades na atenção ao potencial doador de órgãos: percepção de enfermeiros

Objetivou-se conhecer a percepção de enfermeiros sobre fragilidades na atenção ao potencial doador de órgãos. Trata-se de estudo exploratório-descritivo, com abordagem qualitativa, envolvendo oito enfermeiros de hospital de referência. Entrevista semiestruturada foi utilizada e os resultados foram analisados conforme a técnica de análise do discurso. Emergiram duas categorias: “percepção dos enfermeiros sobre o trabalho com potenciais doadores de órgãos” e “fragilidades na atenção aos potenciais doadores”. Verificou-se atuação limitada no âmbito da organização de procura de órgãos. Entraves envolvem recursos humanos e financeiros, recusa familiar, elevado tempo de espera por exames e problemas estruturais. Assim, o trabalho nesta comissão está limitado a ações assistenciais, em detrimento das gerenciais. Os profissionais percebem fragilidades e temem interferência negativa. Há que se investir em estrutura e educação permanente para que isso se reflita em melhor atenção ao potencial doador e sua família.

Palavras-chave: Obtenção de tecidos e órgãos. Morte encefálica. Enfermagem.

Resumen

Deficiencias en la atención al potencial donante de órganos: percepción de los enfermeros

Este estudio tuvo como objetivo conocer la percepción de los enfermeros sobre las deficiencias en la atención al potencial donante de órganos. Se trata de estudio exploratorio-descriptivo con enfoque cualitativo, con la participación de ocho enfermeros de un hospital de referencia. Se utilizaron entrevistas semiestructuradas y los resultados fueron analizados siguiendo la técnica de análisis del discurso. Emergieron dos categorías: “percepción de los enfermeros sobre el trabajo con potenciales donantes de órganos” y “deficiencias en la atención a los posibles donantes”. Fue identificada actuación limitada en el ámbito de la organización de búsqueda de órganos. Los obstáculos están relacionados con los recursos humanos y financieros, la negativa de la familia, los prolongados tiempos de espera de resultados de exámenes y problemas estructurales. Por lo tanto, el trabajo de este grupo se limita a acciones asistenciales, en detrimento de las de gestión. Los profesionales perciben las deficiencias y temen una interferencia negativa. Es necesario invertir en la estructura y en la formación permanente para que esto se refleje en una mejor atención al donante potencial y a su familia.

Palabras clave: Obtención de tejidos y órganos. Muerte encefálica. Enfermería.

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Brain death (BD) corresponds to the total and irreversible cessation of brain functions. Among the most common causes of BD are cranioencephalic trauma, related to automobile accidents or aggression; hemorrhagic stroke; rupture of aneurysm; diffuse brain injury after reversed cardiorespiratory arrest; large ischemic lesions; and, to a lesser extent, brain tumors, cerebral edema, meningoencephalitis and fulminant encephalitis¹. Nurses play a prominent role in hospital care, and an important facet of this care is the attention paid to the patient [we have excluded the term “client” used by the authors] in brain death in the context of the maintenance of potential donors of organs and tissues, so that, in this context, even facing death there is a struggle for life represented by the vitality of the organs and tissues².

Adequate clinical and laboratory evaluation of the potential donor (PD) is essential to obtain organs and tissues in conditions suitable for transplantation, in order to avoid the transmission of infectious or neoplastic diseases. In addition, in the evaluation, the contraindications for donation should be excluded³. From the identification of a potential donor there is the mandatory notification to the Central of Organ Collection, Registry and Distribution (Central de Notificação, Captação e Distribuição de Órgãos, CNCDO), decentralized in commissions of Organ Procurement Organization (Organização de Procura de Órgãos, OPO).

During the year of 2013, 8,871 PD candidates were registered in Brazil, but only 2,526 became effective donors, corresponding to only 28.5% of the total. Among the main causes of non-effectiveness of the donation were family refusal (2,622), cardiac arrest (1,292) and medical contraindication (1,150), which add to 6,345 non-donors in that year. Despite the great progress in transplant numbers, organ shortage is still one of the great challenges for transplant teams^{4,5}.

Weaknesses in the process of PD maintenance may reflect on these indicators. In a study⁶ with 55 nursing professionals, the majority (61.8%) stated that there are obstacles in maintaining the potential donor. Among them, stand out: unprepared professionals; lack of materials and adequate structure; delay in opening the protocol for confirmation of the BD; family refusal; and insufficient staff for quality assistance. The Brazilian Registry of Transplants (Registro Brasileiro de Transplantes, RBT) states that, in Brazil, absence of family authorization is the main cause of donation failure, pointing to the need for educational

campaigns aimed at society, in order to clarify the donation process and encourage their consent⁴.

Considering the scarcity in the scientific literature regarding the difficulties faced by the nurse during the process of maintenance of potential organ donors, it was aimed to know the nurses' perception of weaknesses in the attention to these patients. Given this context, studies on the processes involved in the maintenance of PD can contribute to improve the attention provided, since they can subsidize more effective practices for the work process.

Methods

This is an exploratory-descriptive field study, with a qualitative approach, data was collected between February 2014 and April 2015, with the participation of eight nurses involved in the process of maintenance, capture and donation of organs and tissues of a major hospital. Exploratory research typically consists in exploring the first approximation of a theme and tends to create greater familiarity with a fact or phenomenon⁷.

On the other hand, the descriptive research seeks to know the different situations and achievements that occur in social, political and economic life and in other aspects of human behavior, both of the individual taken alone and of more complex groups and communities⁸. The qualitative approach proved to be the most adequate, as it could ensure the emergence of subjective aspects that lead to interpretation, revealing values that permeate professional practices⁹.

The study was carried out in a major hospital in the northern region of the state of Ceará, which currently constitutes a reference institution for about 1.6 million inhabitants in over 55 municipalities. It is the second largest center for organ notification and capture in the interior of the state, and it is still one of the three centers for performing transplants in the interior. In 2014, it made 53 notifications, with 13 donations being made effective¹⁰. The hospital was chosen because it has a commission for organization of organ procurement, a reference in the northern part of the state because it has a large number of PDs and well structured organ and tissue procurement and maintenance services.

The ethical aspects of the study were performed according to the norms in Resolution 466/2012, issued by the Brazilian National Health Council¹¹. The research was authorized by the

Scientific Committee of the hospital in which the study was performed, received a favorable opinion from the local Research Ethics Committee and used a free informed consent form. Data collection was done through semistructured interviews which were recorded with the aid of an electronic device and transcribed soon after they were carried out.

The semistructured interview was used for presenting a combination of questions with the aim to reach the real meaning the interviewee gives to the phenomena and events of interest^{12,13}. The following questions guided the interview: "what activities do you perform in the OPO?"; "how do you understand the function of the OPO?"; "during the process of maintenance of the potential donor are there obstacles, weaknesses or difficulties related to the management, family approach, support or logistics services?".

The organization and analysis of the information were performed according to the technique of content analysis, since it allows for the discovery of centers of meaning that make up the communication, whose presence or frequency means something for the objective of the analysis. For that, stages of pre-analysis, material exploration, data processing and interpretation are necessary.¹⁴ Thus, after reading and interpreting the answers, the information was grouped by similarity, resulting in two thematic areas: nurses' perception of the work in the OPO and weaknesses in the process of maintaining the potential donor of organs and tissues.

Results

In total, eight nurses took part in the study, being five males and three females with ages from 27 to 35. Six were specialists and two were undergraduates, having graduated between three and six years prior to the study. The time involved in the maintenance of potential organ donors varied from one to three years.

Perception on the maintenance of potential organ donors

In the context of the specific hospital, the organ procurement organization has nurses, physicians, social assistants and scholarship medical and nursing students. Neurologists and clinical physicians give assistance to the intensive care physicians of the intensive care units (ICU) and from the emergency service for the conclusion of the

brain death protocol and for organ maintenance to render the collection viable.

Regarding their perception of the function of the OPO, the nurses reported the broadness of the work of the organization, describing its several activities, mainly the ones related to assistance to the PD:

"The OPO is an organization of organ procurement. We work actively looking for potential donors to slow down our waiting line. We work both by active search and by spontaneous notification from the sector. We work together with the hospitals commission for donation of organs and tissues for transplants (Comissão Intra-Hospitalar de Doação de Órgãos e Tecidos para Transplantes CIHDOTT) (...) The OPO is in the logistics of organizing this job, in the maintenance of the potential donor, in its own capacity building, interviews and all the paperwork that the process requires due to the risk of legal punishment. And we also work with donor with arrested hearts, cornea donors, and in the Santa Casa (Catholic Hospital) with corneal transplant and donation" (E1);

"Multi-professional team dedicated to keeping potential donors with living organs until they are transplanted" (E3).

The professionals also expressed their opinion about the work they perform, marked by great responsibility and relevance, both for the maintenance of the PD and for their relatives:

"I see a job with great responsibilities (...) responsibility in the sense that that the receptor and the family only depend on our work to get out of that situation" (E5);

"It is a very important job, we get to save many lives, the maintenance work involves several professionals, contact with the family and, in a certain way, we end up creating a bond, so, for me, it is very gratifying" (E2).

Obstacles in the process of maintaining the potential donor

According to the statements, it was possible to identify that some donors do not come through as effective donors due to several factors. When asked about the obstacles that arise during the maintenance of the potential donor, the unanimous answer was the human and financial resources are the main problem:

“Regarding human resources, we do not have specific professionals working only in the maintenance of this potential donor. We work in the CIHDOTT, in the OPO and in the hospital, that is, we are specifically in the institution to perform this role, (...) these are professionals that are already on the service and do overtime” (E8);

“The financial resources passed on by the state are not resources that can really keep a good team for this, and the institutions themselves do not have good financial resources to keep these teams active in their overtime hours of work” (E7).

The speech shows the difficulty of the nurses in face of the variety of activities and links in the context of the PD maintenance process. The fact that they are not assigned exclusively to the OPO can negatively affect the process of maintenance of the PD, weakening the attention, mainly regarding the reporting units, which generally do not have a CIHDOTT or professionals familiar with the particularities of the process.

Also regarding human resources, another weakness mentioned was the difficulty of the attention provided by neurologists, structural professionals for the maintenance process, without which there is no protocol opening: *“Resistance with neurologists is one of the difficulties when closing the protocol” (E3).* The cultural factor was also mentioned by professionals, revealing their influence in the process:

“In human resources, a major obstacle is cultural, because the ICU service people themselves should be interested and by law are obliged to take care of the PD (...) only that most people do not see it that way and conclude that the maintenance of patients with brain death is only the obligation of the collecting teams, and this is not true” (E2).

The fragility of the knowledge of the population is pointed out as an important cause of donations not becoming effective due to family refusal. In this research, the information found met this premise, since, from five participants, three answered that the family refusal is configured as an obstacle in the donation process, one responded that the OPO team has no difficulties in approaching relatives and another did not mention the subject:

“There are obstacles in the family approach, especially in the cultural sense, because people are not sensitized, even knowing that there are people in need, and the law forbids us to appeal, then we

can only talk about the possibility of donating and that it is up to them. Only before that moment, without a public policy that sensitizes these people, when they arrive at that moment of the family approach, they do not want to donate. (...) another obstacle occurs when the relatives do not know the will of the person in life” (E1);

“We have always been very successful in the family approach, even because this hospital has always stood out in this matter of transplants, so the team has always been well prepared for it. The cases where we failed to donate were cases that the family really had no knowledge about it, but I have always seen the family approach as one of the strongest points of the team” (E6).

The availability of the exams allows to close the protocol in the expected time. However, in the reality of the unit studied, there are problems in the logistics of resources and equipments for laboratory analysis:

“the exam is an institutional problem that takes a long time, for this, our routine is to collect at 5:00 a.m. for it to be available at least in the afternoon, because it is indispensable in following the organ markers to see their perfusion and quality” (E1);

“In this aspect, the transport to Fortaleza (the state capital) needs to be improved, because the delay reduces the time to close the protocol” (E5).

The waiting time to obtain the results of the biochemical and serological tests ends up prolonging the process and exposing the PD to greater risks and instability. From this information, it was possible to perceive the need for greater attention to OPO patients, with spaces with good physical structure and up-to-date equipment that allow these potential donors to become effective donors. In some lines, we have shown the anguish and difficulties of the OPO professionals in maintaining the PD in this unit:

“This equipment issue is very serious because we do not have an ICU for the OPO, a place to be reserved for the potential donor, so we end up occupying an ICU bed that could be occupied by a living patient, our equipment is limited, and between a person with BD and a living patient, it is clear that the physician will choose the one that has a prognosis” (E2);

“The ICUs here have a real deficit. There is the lack of a mechanical ventilator, of an infusion pump that can withstand the transfer of the potential donor to the surgical center, of a portable mechanical

ventilator, of a capnograph, with the exception of the 'ped' (pediatric) and 'neo' (neonatal) ICUs" (E1).

The availability of space and technology can not stand out in the process of selecting who should remain in the ICU. In this case, the best measure would be to work together with the multidisciplinary team in decision making, and for this, the team needs to have a broad vision focused on care, working on behalf of the patient in brain death regardless of being an organ donor or not. The integration of the team to streamline the donation process allows a faster exit of the ICU, thus allowing the availability of new vacancies.

Discussion

Among the functions of the OPO, one is to evaluate the clinical conditions of the PD, and, if feasible, to perform the family interview about the donation. Starting with family authorization, an internal protocol begins, which includes several technical and administrative procedures that are indispensable for the viability of the organs. The OPO then notifies the existence of a potential donor to the CNCDO, which selects the recipients, indicating the transplant teams responsible for the removal and implantation of the organs¹⁵. Therefore, it is noticed that this OPO seems to be developing a work more restricted to the active search and maintenance of the PD, resembling more a CIHDOTT and distancing itself from a reference team of the hospitals of the region, since the work of the OPO should be more comprehensive, dealing with the management of all processes and actions involved in organ donation, from the permanent education of the professionals to the transplant itself.

In the interviews the pedagogical function of the OPO also emerged, this being understood as a field of practice that contributes to the qualification of professionals and students, complementing the training. This is because the clinical skills required for this practice go beyond those obtained in nursing school¹⁶, adding to this is the fact that this subject is still approached weakly in undergraduate and graduate courses in health^{17,18}.

The sense of responsibility is constant in the interviews with nurses. This aspect is due to the fact that the nurse is part of the structure for the development of organ maintenance and procurement programs¹⁶. It is upon the nurse to plan, execute, coordinate, supervise and evaluate the nursing procedures provided to the donor of organs and tissues, with the following duties: to

notify the CNCDO of the existence of a potential donor; to interview the legal guardian of the donor; to apply the Systematization of Nursing Assistance (SNA) to the process of organ and tissue donation; to document, record and file the donation/transplant process in the donor and recipient's records; and to enforce the agreement reached at the end of the donation¹⁹. It is also necessary to highlight that the assistance to the PD, for the nursing professionals, has been considered a stressful situation^{2,20}.

Brain death causes multiple organ failure due to endocrine, metabolic and hemodynamic changes, requiring health professionals to be continuously vigilant, to maintain all hemodynamic data of the potential donor and to maintain vital functions to ensure hemodynamic stability and the quality of organs and tissues²¹. Weaknesses in the attention to the PD of organs and tissues – either at the structural, funding or human resources level – have been described in the literature as possibly responsible for not effecting of an important portion of donations^{17,22}. The insufficient number of professionals and limited funding (represented by the need for structure and of professionals, such as neurologists) have emerged as the main obstacles to this process. Deficiencies have marked many organ donation programs, so that the weakness in these components interferes in the process of caring and generates frustration among professionals involved in the assistance to the PD²².

Fragility in the funding field are also a concern, as it is a structural service and at the same time, it seems underfunded. Such inference brings to light problems of concern, probably affecting the the process of maintenance and collection of organs and tissues. This phenomenon is challenging, as it is necessary to consider that maintaining potential organ donors demands time and investment in human resources and materials²³. However, it is important to mention that the Sistema Único de Saúde (Brazil's Unified Health System - SUS) has long faced funding problems so that the processes involved in organ donation and transplant are part of the same scenario, their underfunding being a reflex of the deficient funding of the health system.

These weaknesses reflect on several aspects of the care for the PD, among which is the delay in closing the protocol. This causes discomfort in the team, given that, in the context of BD, time can be determinant of success or failure of the collection, because it involves receptors that are in the waiting line, donor families and the risk of hemodynamic instability of the PD. Thus, there is a risk that PDs will lose the opportunity to be effective donors.

In addition to the bioethical issues inherent to the organ donation process, such as the prevalence of the individual's will over the family's desire or the need and imminence of another patient's death, among others, deficiencies in material, financial and human resources cause concern in the bioethical dimension of care. This is because these deficiencies have great potential to interfere negatively on the process, and may jeopardize PD care, which may represent the loss of the opportunity of receiving an organ. As an example, the clinical examination must be repeated at least twice and at intervals of at least six hours, by different physicians¹. Thus, if on the one hand it is necessary to consider the minimum time stipulated for the process, on the other hand it is necessary to take care for stages not to be delayed, spending only the necessary time for each stage of the maintenance process of the PD.

The statements also showed the conceptions of the health team regarding the maintenance of the person with BD. These reports point to weaknesses in the care provided by the multi-professional team, including the nursing professionals themselves, and the differentiation of care provided to the DP was identified. This aspect of care for PD in the context of the nursing team has been discussed in the literature, being characterized as the result of technical and scientific lack of preparation, and professional immaturity to care for people in BD²⁴. This fact does not make this phenomenon less worrying, since for the provision of care to the PD, it is necessary to keep the minimally ethical care, so that the reflection on the morality of the interventions of the health team must be permanent²⁵.

However, there can be no distinction in the care offered, and the nursing team must treat the potential donor with the same commitment and dedication as any other critical patient. It should be thought that care should be provided regardless of prognosis, especially when it comes to patients in BD, as these demand more specific care due to the high risk of instability.

Family refusal proved to be another problem for the interviewed professionals, in the context of other studies that show family refusal as the main factor for non-effective donations^{4,5,17}. In most cases, family refusal is related to the lack of understanding of the diagnosis of BD, aspects related to religion and the unpreparedness of the professional who conducted the interview^{26,27}. In other countries, such as the United States, family refusal is also related to other factors, such as doubts about the fairness of the distribution of organs through donation programs,

with little representation of minorities, poor, disabled or elderly in the transplant lists²⁸.

The fact that care for the PD is provided in large institutions, and is often quite impersonal, undermines the trust between patients and health professionals²⁸. This estrangement may contribute to family refusal or even that of the patient still alive. This scenario calls for a humanized approach, in which the multi-professional team is more involved with the patients and their relatives. This relationship helps to implement actions that favor the occurrence of the transplantation process, avoiding the family to be an obstacle to donation, since relatives tend to consent to donation when they are well informed about the concept of brain death and the humanitarian purpose of the donation²⁹.

Despite the statement made in life, in Brazil the decision of the relatives about the donation must be respected. Therefore, emotional support, family support, and information about the process become essential to encourage donations. From this perspective, the importance of promoting nursing care to the families of potential donors is established, since by joining the care provided to the patient and the care provided to family members, there is a positive point for the consent of the donation of the person's organs to occur in case of BD²⁴.

From the foregoing it is possible to infer that the information and education of family members regarding the procedures inherent to the process of maintenance of donor potentials and the effectiveness of the donation are determinant for the acceptance or not of the family as to the donation. Weaknesses in the processes of maintenance, capture and organ transplantation have been pointed out by other authors¹⁷. Adequate material and technological resources for the diagnosis of BD, as well as for the maintenance of the PD, are part of the structure of the service, so that the confirmation of BD and organ collection can be timely performed³⁰. As a result, the structural failure reported concerning laboratory exams and equipment may render adequate assistance unfeasible.

Although there is a shortage of material and other problems evidenced in this study, the hospital in question has made a relevant contribution for the state of Ceará to stand out in the national scenario. In 2010, this same hospital collaborated so that Ceará was in the second place among the states with the largest number of donations made. Such a scenario leads to the reflection that, given the inconsistencies and results obtained, the team may be overworking to trim the edges and prevent such

fragilities from affecting or lessen the collection, maintenance and transplantation of organs.

Finally, a study carried out in an ICU revealed that the poor maintenance of the patient in BD hospitalized as PD may be the second cause of non-occurrence of donation of organs and tissues in Brazil³¹. Thus, it is necessary to observe that the maintenance of the potential donor should be based on quality assistance, which includes an environment that provides support so that professionals can work properly.

Another determining factor for the success or failure of transplant programs is the qualification of health professionals and the education of the population⁷. Continuing health education is essential because it can contribute to the increase in the quality of care of potential donors, improving the family approach and interfering in the time lost to perform confirmatory BD tests, thus directly influencing family decision and donation effectivity.

Final considerations

The study made it possible to know the nurses' perception about aspects of the work process in

the maintenance of PD and the main obstacles to it, revealing that professionals perceive fragilities, and fear and suffer the repercussions in the caring process. The participants presented fragile knowledge about the role of the OPO, revealing the need for greater instruction to the team about the conceptions and movements that underpin this service. Thus, the autonomy of these professionals can be enhanced through training that broadens the understanding about the service.

The care and other dimensions of the attention provided to the DP appear to be vulnerable in view of the number and degree of the deficiencies evidenced. Unfortunately, this context seems to be repeated in other places that are part of the organ transplant network in the country. Such a scenario calls for better arrangements of human resources, working conditions, structure, strengthening of permanent education and promotion of information activities and awareness of the population on brain death and the process of maintenance, collection, donation and transplantation of organs. The situation described shows that care to these patients has, to some extent, distanced itself from bioethical principles, which raises strategies to (re) signify the care practices.

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