

DOI: <https://doi.org/10.36489/nursing.2021v24i280p6157-6168>

Fragilities and experiences of nurses in the approach to the family of the organ and tissue donor

ABSTRACT | Objective: To unveil the weaknesses and the experience of nurses in approaching the organ and tissue donor family. Method: Qualitative research with content analysis by Bardin, carried out with seven nurses in a medium-sized hospital in the interior of São Paulo, Brazil. Results: The data obtained were grouped into three central categories: Nurses' knowledge in the context of the family approach to the potential organ and tissue donor; Weaknesses experienced by nurses in the context of communicating bad news to family members of the potential organ and tissue donor and Nurses' experiences in the face of brain death diagnosis and the determining factors for obtaining organs and tissues. Conclusion: The nurses' experiences in face of the weaknesses found and experienced in the family approach of potential organ donors, are characterized by conflicts and situations that expose the professional to an atmosphere of feelings of welcome and empathy.

Keywords: Organ and tissue donation; Nurses; Role of the Nursing Professional; Family; Brain Death.

RESUMEN | Objetivo: Dar a conocer las debilidades y la experiencia de las enfermeras en el acercamiento a la familia del donante de órganos y tejidos. Método: Investigación cualitativa con análisis de contenido de Bardin, realizada con siete enfermeras en un hospital de mediano tamaño del interior de São Paulo, Brasil. Resultado: Los datos obtenidos se agruparon en tres categorías centrales: Conocimiento del enfermero en el contexto del abordaje familiar del potencial donante de órganos y tejidos; Debilidades vividas por enfermeras en el contexto de comunicar malas noticias a familiares del potencial donante de órganos y tejidos y Experiencias de enfermeras ante el diagnóstico de muerte encefálica y los determinantes para la obtención de órganos y tejidos. Conclusión: Las vivencias de las enfermeras ante las debilidades encontradas y vividas en el abordaje familiar de los potenciales donantes de órganos, se caracterizan por conflictos y situaciones que exponen al profesional a un clima de sentimientos de acogida y empatía.

Palabras claves: Donación de órganos y tejidos; Enfermeras; Rol del profesional de enfermería; Familia; Muerte cerebral.

RESUMO | Objetivo: Desvelar as fragilidades e a vivência de enfermeiros na abordagem de família do doador de órgãos e tecidos. Método: Pesquisa de abordagem qualitativa com análise de conteúdo de Bardin, realizada com sete enfermeiros em um hospital de médio porte no interior de São Paulo, Brasil. Resultado: Os dados obtidos foram agrupados em três categorias centrais: Conhecimento dos enfermeiros no contexto da abordagem familiar do potencial doador de órgãos e tecidos; Fragilidades vivenciadas por enfermeiros no contexto da comunicação de más notícias para familiares do potencial doador de órgãos e tecidos e Experiências de enfermeiros diante do diagnóstico de morte encefálica e dos fatores determinantes para obtenção de órgãos e tecidos. Conclusão: As experiências dos enfermeiros frente, às fragilidades encontradas e vivenciadas na abordagem familiar de potencial doador de órgãos, são caracterizadas por conflitos e situações que expõem o profissional a uma atmosfera de sentimentos de acolhimento e de empatia.

Palavras-chaves: Doação de Órgãos e tecidos; Enfermeiros; Papel do Profissional de Enfermagem; Família; Morte Encefálica.

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Received on: 06/01/2021

Approved on: 06/14/2021

INTRODUCTION

Brazil has one of the largest public programs for the donation, capture and transplantation of organs, tissues and cells, with funding for more than 95% of the procedures, which is made available to the entire population through the Unified Health Sys-

tem (SUS). As a result, it is considered one of the most outstanding countries in the world, losing only to the United States in absolute numbers according to the Brazilian Association of Organ Transplantation (ABTO - Associação Brasileira de Transplante de Órgãos).⁽¹⁾ There is an immeasurable spirit in all political, egalitarian, governmental and non-governmental spheres in an attempt to increase the number of donations made and of transplant patients.⁽²⁾

It is known that organ donors can be classified into two divisions: living donor, person who consents to the donation in such a way that there is no harm to their own health, and can do-

nate one of the kidneys, liver element, bone marrow or lung lobe. These can be relatives up to the fourth degree and consorts of the recipient, while in cases of non-consanguine donors, there must be a judicial license. In the second class, there are non-living donors, who are patients diagnosed with Brain Death (BD), who, in most cases, are victims of Traumatic Brain Injury (TBI) or cerebrovascular accident (CVA).⁽³⁾

In this scenario of non-living donors, the awareness of family members is as valuable as all other hospital actions. The nurse is a respected and strategic figure in this system, as he maintains with the patient and their families a shortened relationship and connection created from the proximity established during the patient's hospitalization. In order for the potential donation to be successful and the family/nurse relationship closer, principles, skills and abilities must be developed to guide the eligible donor's relatives in an ethical and assertive way.⁽⁴⁾

Considering the family approach of potential donors, it is also necessary to consider the involvement and performance of the nurse, as it is a multiprofessional approach. This issue is one of the most crucial in the donation process, given the great hurdle brought by relatives. Working with the family, respecting its limits, is effective for the successful completion of the transplant. It is a complex moment for the family to see their loved one with a heartbeat and not assimilate the death, so the family's wishes must always be respected, maintaining ethical and legal principles.^(5,6)

It is at this moment that the nurse faces conflicts as a result of the situation of pain experienced by family members, due to the patient's BD, but at the same time having to request the donation of organs, since they consider the request for donation, at that time, very distressing to the family.⁽⁷⁾

About this, a study carried out in Iran⁽⁸⁾ shows that nurses are involved

in the moment of imprecision and ambiguity when caring for patients with brain death, considered as a possible organ donor. There are weaknesses in the diagnosis of BD, to the point of having hope in reversing the case. It's like waiting for a miracle.

Thus, the research problem was delimited from the following question: What weaknesses do nurses experience at the time of diagnosis of brain death and when approaching families of patients with the potential to donate organs and tissues?

For these reasons, this study sought to fill this knowledge gap, seeking to cover the weaknesses and experiences of the family of the brain-dead patient and possible donor. Based on this understanding, the aim was to provide evidence and support for the implementation of strategies that improve, naturalize, optimize and smooth the family approach method with regard to organ and tissue donation, since, in this investigation, we sought to scientifically anchor the actions of nurses with regard to the theme.

As a result, this study aimed to reveal the weaknesses and experiences of nurses in approaching the family of organ and tissue donors.

METHOD

Article extracted from the Course Completion Paper (TCC - Trabalho de Conclusão de Curso) entitled: "Nurse's Approach to the Family in the Organ Procurement Process through a Protocol", presented to the Department of Undergraduate Nursing at Escola Superior de Cruzeiro - ESC, Cruzeiro, São Paulo Brazil. 2019.

It was characterized as an investigation of an exploratory, descriptive and qualitative approach. The tool for reporting the data collection COREQ⁽⁹⁾ was used, which used content analysis based on the theoretical framework proposed by Bardin.⁽¹⁰⁾

The study was conducted in a medium-sized hospital located in the interior of the state of São Paulo, Brazil, in a region known as Vale do Paraíba. This hospital is linked to the Central Notification, Capture and Distribution of Organs of the state. It is a partner institution in the activities of the National Transplant System (SNT - Sistema Nacional de Transplante) at a regional level, following the national policy for capturing and transplanting organs and tissues.

As inclusion criteria in the research, nurses who provided assistance directly in the organ harvesting procedure and who had at least six months of experience were established.

As exclusion for participation, there were nurses away from the service for reasons of vacation, maternity or medical leave and absent at the time of data collection.

Data were collected by the researchers themselves at a previously scheduled time in a reserved and confidential environment, which favored the interviewees' privacy and anonymity. Such collection took place between August and September 2019.

The semi-structured interview technique guided by an instrument (script) developed by the authors was used. This script included sociodemographic characteristics, such as gender, age, average time in the profession and religion, and was followed by the following guiding questions: What was the experience like for you in approaching family members about organ donation? What frailties or difficulties do you face or have you faced with the family approach?

The testimonies were transcribed and analyzed and, soon after collection, these data were grouped according to the nuclei of meaning composed in the communication, considering the presence and thematic frequency significant for the analyzed object.

Thus, the appreciation of the content consisted of three fundamental pe-

riods for data analysis, and in the pre-analysis, there was a questioning of the aspects related to the object of study, the relevant theories, the methodology and the necessary operational issues to trigger the search; in the material exploration phase, a cut was made based on the experience of the theoretical construction elaborated so far; finally, in the material treatment phase, which leads the researcher to theorize about the data, the link between the available reality and the data collected through the research was produced. We sought, then, to explain the results in light of the existing literature, leading to the identification of central categories. ⁽¹⁰⁾

To ensure the anonymity of the participants, they were referenced using an association of letters and numbers, using the letter E for Nurse, followed by an Arabic numeral from 1 to 7 according to the order of the interviews.

The research followed all ethical precepts as per the recommendations established by resolution 510/16 of the National Health Council for studies carried out with human beings and appreciated by the board of the researched health institution. The project was also validated by the Ethics and Research Committee under opinion No. 3.257.576 and CAAE 11227319.9.0000.5431, of April 10th, 2019.

RESULTS

Seven nurses who worked at the institution chosen for data collection participated in this research, all (100%) being female, even though, a priori, this was not an inclusion criterion. Among these participants, the age group between 31 and 40 years old prevailed.

Of the nurses interviewed, in addition to graduation, all had attended a postgraduate course at the lato sensu level, with four (58%) nurses claiming to be specialists in the Intensive Care Unit (ICU), two (28,5%) in Emergency and Emergency and only one (14,2%)

in Cardiology, Stomatherapy, Nephrology and Urology.

With regard to religiosity, six (85,7%) of the nurses were Catholic and one (14,2%) was Evangelical. All revealed to be practitioners of the belief.

Regarding the temporal analysis, referring to the experience of exercising the profession, five (71,4%) of the interviewees performed the function for between 5 to 10 years and two (28,5%) for more than 10 years. Six (85,7%) worked at the hospital for between 5 to 10 years and one (14,2%) for between 1 to 5 years.

As for the weekly workload, six nurses (85,7) reported working for 30 hours a week and one (14,2), 20 hours a week.

All nurses participated in courses on transplantation and organ harvesting inside and outside the hospital.

In evaluating the qualitative data, after assessing the speeches obtained, the information was aggregated into three central categories and their thematic units, namely:

Category 1: Knowledge of nurses in the context of family approach to potential organ and tissue donors.

Regarding the knowledge of respondents on the theme of approaching the family at the time of communication of the BD and the possibility of organ donation, there was a predominance of responses regarding subsidies or classes that addressed the donation and capture of organs, during the graduation period or graduate school. All (100%) nurses revealed that they did not obtain sufficient theoretical framework during the undergraduate or specialization period, which can be seen in the following statements:

"[...] I don't remember anything so specific. During the post-secondary period, we talk about transplantation as a form of kidney treatment and the importance of donation". E7

"[...] When organ harvesting began at our institution, we received training from a nurse, it was amazing, because I was able to open my mind about taking care of the body after harvesting, the respect that the entire nursing and medical team has with the body and also the family and it was a matter of finding a moment of my own "in the BD issue" of the doctor and family, and knowing the right time to address the fundraising is still not easy, but the training helped a lot so that I could explain for the whole family of care, respect they would have for the body". E2

In view of the answers presented, it was found that the nurses' knowledge about the topic, according to the majority of respondents, even though the terms were not very clearly used in some answers, it is clear that the professionals are prepared about communication and approach to the scenario of the brain death process, followed by communication to the family about the potential uptake of organs.

Category 2: Weaknesses experienced by nurses in the context of communicating bad news to family members of potential organ and tissue donors.

In this study, it was noticed that the approach and communication shared between nurses and physicians allow the exchange of information related to the client's health/disease conditions, for decision-making and correct conduct and concordance with each identified need.

Thus, the nurse actively participates in the conducts together with the multidisciplinary team, which can be evidenced in the following statements:

"[...] Along with the medical team, talking to all the children,

a delicate moment, the family denying death." E3

"[...] Difficult due to the resistance of the family to donate, even clarifying doubts. The experience of approaching the family about ME, for me, is never easy. First, because I don't know what will be the family's reaction to the loss, in some rare cases the family reacts calmly, but the loss of a loved one cannot measure the pain the other is feeling, and in this context it is difficult to find a time or way to explain the importance of the donation." E1

"[...] It was never easy to tell the family that you will never see your loved one again" E4

Reflecting on the possible weak points exposed in the daily lives of nurses and in view of the numerous care activities that compete, it was observed that the respondents mentioned the existence of difficulty in the face of family resistance when communicating the possibility of organ harvesting.

Category 3: Experiences of nurses facing the diagnosis of brain death and the determining factors for obtaining organs and tissues.

When asked about the experiences lived at the time of diagnosis of brain death and the possibility of obtaining organs and tissues, the participants revealed the presence of feelings and attitudes, such as: being on the side of the family, evidencing support and acceptance; transmit trust, confidence and credibility; to remain silent, showing sadness but also admiration for the family member who said yes to donation and expressed a noble and generous feeling. The statements below point out these feelings and actions:

"[...] The doctor is usually more technical, and it is up to me to

spend more time with the family, even if in silence. Finally, we had a patient that was not viable for uptake, however, we needed to give a diagnosis of brain death. However, I had a lot of difficulty, as the doctor was not training to follow the BD protocol. The protocol was carried out with great difficulty, finally it was up to me to help him, and together with the doctor, inform the family about the confirmed diagnosis" E5

"[...] At first it was very difficult, but with time I gained confidence. One approach I performed and marked me was a mother who had her son in the ICU bed in BD due to a serious motorcycle accident, she was in favor of the donation, as there was a cousin in her family who, a few years ago, received a kidney and he no longer needed to undergo hemodialysis." E6

"[...] I remember that, the first time I had this experience, it was with the parents of a teenager and they accepted and donated their daughter's organs for transplant purposes. Even sad for his loss and grateful for his enormous nobility, despite being in favor of donation, I don't know if I could donate. It was a weekend and I was on duty. The patient already had the clinical tests ready for ME, but was waiting for the Transcranial Doppler to confirm and precisely on that day the neurologist attended to perform and confirm the exam. After the realization, it was time for the approach." E7

Analyzing the context of the reports on the family approach and the embracement performed by the nurse, the interpersonal relationship between the nurse and the family was highlighted,

and the relevance of the nurse's presence in moments of communication of bad news was noted, in order to minimize the impact and anguish of family members.

In light of these categories, we found that nurses can act in the possibility of convincing to obtain organs and tissues, but it can also be inferred that the consent for donation, until the moment of our study, is seen as a process that permeates philosophical, religious, social and moving questions.

DISCUSSION

Faced with such a complex issue as the donation of organs and tissues, knowing the factors that motivated people to make the grant becomes essential, even considering the magnitude of the act of donating unquestionable. ⁽¹¹⁾

It is noteworthy that the support offered by nurses regarding the emotional issue of family members and specific knowledge about the entire procedure to be used in the context of organ harvesting, can encourage the family member to decide and accept the donation.

In this perspective, the attitudes that lead family members to accept the donation of organs from their loved ones have features in common: empathy, the desire to help others and, even with death, the offer of some meaning to life from the other. ^(12,13)

In this context, the nurse is the professional who provides patient care by planning nursing care for 24 hours, always being in frequent and direct contact with family members and caregivers. In addition, it has a legal responsibility to provide training and qualification to the team it coordinates, in order to promote quality care, based on scientific evidence for patient safety. ⁽¹⁴⁾

The importance of training and preparing nurses through the managers responsible for health establishments linked to the SNT is also highlighted. This training is critical in fulfilling

communication requirements and technical skills to develop strategies on how to deal with families who will receive bad news. ⁽¹⁵⁾

Therefore, the nurse needs to establish a bond with the patient and their families that is based on mutual trust and has a humanistic character, in order to carry out the essential care to alleviate the patient's anguish and, if possible, to overcome their moment of affliction. This feature was evidenced by the study, ⁽¹⁶⁾ who observed nurses who offered a welcoming and differentiated communication with the deceased's relatives and generated an affective connection, which motivated opportunities to obtain assent to capture organs and tissues.

The scarcity of information to relatives about what is happening with the patient, together with the lack of knowledge about brain failure, allow erroneous assumptions about the activities for the extraction of tissues and organs. ⁽¹⁷⁾

Regarding the knowledge coefficient of the analyzed nurses, the results are in line with the literature ⁽¹⁸⁾ which found a low to moderate level in the results which indicate that, generally, doctors and nurses do not have sufficient knowledge about the organ donation process in patients with brain death, as well as the lack of affinity in communicating bad news.

It is noteworthy, on the other hand, that there remain numerous shortages in the training of nurses with regard to the areas of transplantation, especially with regard to patients with brain death, both in universities and in hospitals. As a result, nurses do not have satisfactorily adequate knowledge, attitude and practice. Therefore, it is suggested to include the expansion of the discussion in disciplines on this theme in the curriculum of nursing courses, as well as the implementation of educational campaigns for family mobilization, in addition to conducting permanent and continuing education programs, to accompany the nurse with their role in the care process,

so that there is an improvement in their attitude and practice through different training methods. ⁽¹⁹⁾

According to the information obtained in our study, support for the potential donor is indicated by confrontation and disorder, leading nurses to experience various ambivalent feelings. Linked to the change in the perception of the being facing brain death, the experience of the family approach, in this context, is permeated by the technical-scientific and human dimensions, which, in the nurses' view, is constituted by the skills, protocols and technologies added to the care of the patient and in communicating difficult news. ⁽²⁰⁾



Thus, nurses assume the full role in order to optimize the relationship between the team, family and patient.



Thus, nurses assume the full role in order to optimize the relationship between the team, family and patient. However, it is essential to provide time to be with the family, understand the mourning situation and not just offer protocolized information, as each individual has their time and uniqueness to assimilate the new fact. ⁽²¹⁾

In this sense, the nurse may have the

opportunity to be with the family, giving support, attention, developing empathy and active listening in the grieving process. Caring for the family is a complex stage that requires professionals who can offer elements that guide the donation of organs and tissues. The nurse must be, therefore, willing and prepared to clarify all the doubts of the family members in a clear and objective way, ensuring the understanding of the real situation of their loved one and thus respecting ethical and legal principles. ⁽²²⁾

Positively, the nurse, who works with patients considered as potential donors, gives a new meaning to their own life, undergoing a personal and professional transformation, as they work with a view to life and see the process of death as a natural part of this process. In this way, they adopt zealous attitudes, which result in humanized and sincere care, minimizing professional suffering and, consequently, expanding their personal growth. ⁽²³⁾

In our study, limitations were considered to be the scarcity of references, the absence of the theme of nurses' feelings towards the family approach, and the fact that the research was carried out with a small number of participants. The results found may support the conduct of other studies that broaden the discussion about these weaknesses, experiences and experiences on the performance of nurses in communicating bad news to capture organs and tissues, not only in the transplant service but also in other fields of action of that professional.

What was evident was that the nurse is presented as a key element for the establishment of successful family approach programs. However, to do so, he needs to develop essential skills to act in the different phases of the period of communication of bad news. Thus, it is considered relevant to know the weaknesses and experiences experienced by nurses involved in this care, seeking to offer subsidies so that these professionals can seek recognition from the multidisciplinary team

working in the complex area of tissue and organ transplantation and give greater visibility to your clinical practice.

CONCLUSION

According to the data obtained in the investigation, it was concluded that the nurse is directly linked not only to the service of keeping the potential donor fit for uptake, but also actively participates in the entire diagnosis and even a little after the approach made with the family. The communication of bad

news was evident that, in most cases, it is done by the physician, however the presence of the nurse is essential throughout the communication process.

Given the reports, it was possible to see that, despite the reality in which nurses are inserted, this type of communication is always difficult and at each moment there is a particularity.

It was also observed that the experiences of nurses facing the weaknesses found and experienced in the family approach of potential organ donors are characterized by conflicts and situa-

tions that expose the professional to an atmosphere of feelings, mainly of welcoming and empathy, which directly influences in your personal and professional life.

Finally, nurses' lack of training from graduation to professional life was evidenced. Therefore, it is understood that a closer look at these professionals is necessary to ensure significant experiences and enrichment of the quality of care in the context of approaching the family of the imminent organ and tissue donor. 🐣

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