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THE MAINTENANCE CARE OF POTENTIAL ORGAN DONORS: ETHNOGRAPHIC STUDY ON THE EXPERIENCE OF A NURSING TEAM

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This ethnographic study aimed to understand a nursing team's experience on the maintenance of potential organ donors. Data were collected through ethnographic interview, participative observation and documental analysis and analyzed in thematic, cultural domain and taxonomical terms. The research enabled us to identify the meaning of brain death, revealing the interrelation between the categories (units, nursing team and patient), which constituted this study main theme: "it is not a person". The transplant meaning held by the nursing team is marked by disbelief due to some previous experiences in the Intensive Therapy Unit. Thus, beliefs and values of this subculture interfere or determine a distancing from the patient with a consequent loss in the maintenance of the potential donor and quality of the organs donated.

DESCRIPTORS: nursing care; organ transplantation; tissue and organ procurement

LOS CUIDADOS DE MANUTENCIÓN DE LOS POTENCIALES DONATIVOS DE ÓRGANOS: ESTUDIO ETNOGRÁFICO DE LA VIVENCIA DEL EQUIPO DE ENFERMERÍA

Se trata de un estudio etnográfico que tuvo como objetivo comprender la experiencia del equipo de enfermería en la manutención de los potenciales donadores de órganos. Los datos fueran recolectados a través de encuestas etnográficas, observación participante y análisis documental y sometidos a análisis del dominio, taxonómico y temático. En el proceso de inmersión de los datos recogidos fue identificado el significado de la muerte encefálica, que desveló la interrelación entre las categorías (unidades de terapia intensiva, equipo de enfermería y pacientes), constituyéndose en el principal tema de ese estudio "no es una persona". El significado del transplante atribuido por el equipo de enfermería es marcado por la no creencia, motivada por experiencias anteriores vividas en las unidades de terapia intensiva. Así, las creencias y valores de esa subcultura interfieren o determinan un distanciamiento del paciente y un consecuente prejuicio en la atención adecuada para la manutención del donante y calidad de los órganos donados.

DESCRIPTORES: atención de enfermería; trasplante de órganos; obtención de tejidos y organos

OS CUIDADOS DE MANUTENÇÃO DOS POTENCIAIS DOADORES DE ÓRGÃOS: ESTUDO ETNOGRÁFICO SOBRE A VIVÊNCIA DA EQUIPE DE ENFERMAGEM

Trata-se de estudo etnográfico que teve como objetivo compreender a vivência da equipe de enfermagem na manutenção de potenciais doadores de órgãos. Os dados foram coletados através de entrevistas etnográficas, observação participante e análise documental e submetidos à analise de domínio, taxonômica e temática. No processo de imersão nos dados coletados, foi identificado o significado de morte encefálica, que desvelou a inter-relação entre as categorias, constituindo-se no tema cultural deste estudo: "não é uma pessoa". O significado de transplante atribuído pela equipe de enfermagem é marcado pela descrença em razão de experiências anteriores vivenciadas na unidade de terapia intensiva. Assim, as crenças e valores dessa subcultura interferem ou determinam distanciamento do paciente e conseqüente prejuízo na assistência adequada para a manutenção do doador e qualidade dos órgãos doados.

DESCRITORES: cuidados de enfermagem; transplante de órgãos; obtenção de tecidos e órgãos

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INTRODUCTION

The care delivered to patients with chronic renal failure makes them dependent on hemodialysis machines. This dependency continues until they are submitted to a successful renal transplant. There are two forms of donation modality in renal transplants: live and cadaveric donation.

From 1984 onwards, in Goiânia, GO, Brazil, renal transplants were generally done by live donation from a family member. It is only at the end of 1998 that cadaveric donation transplants started, although intensive therapy units were not prepared to provide adequate maintenance to brain-dead individuals as potential donors.

The problems that emerged through this procedure were not different from other transplant centers. The available literature only appoints failures in the organ donation process of people with brain death. These failures are linked to the families' refusal and to the professionals' technical work conditions, especially regarding to inadequate maintenance care for the potential organ donor[1].

In a study developed at the Institute of Neurological Sciences, Glasgow, USA, the causes that prevent the increase of potential organ donors were described. These included the lack of medical availability, reluctance in asking the family for donation, test failures in confirming encephalic death and inadequate communication with the transplant team[2].

My experience at the Intensive Therapy Unit (ITU) showed me that patients with brain death (BD) received less care, while attention was directed to those with potential to recover. Thus, I proposed to develop a study about the involvement of ITU nursing teams in the process of maintaining hospitalized people with brain death as potential organ donors, since the maintenance of potential donors is the second cause of the non-occurrence of organ donation in Brazil.

My interest was to study the meanings the nursing team attributes to the brain-dead patient, understanding these professionals' daily care experience in the maintenance of potential organ donors. Hence, this study aimed to understand the experience of the nursing team in relation to the maintenance care to potential organ donors.

THEORETICAL-METHODOLOGICAL REFERENCE FRAMEWORK

I chose ethnographic research in order to understand the symbolic universe shared by the nursing team. Ethnography is an adequate method to describe a system of cultural meanings of a determinate group from the worldview of a native of this culture[3].

The cultural scenario is composed by the representativeness of two hospitals that integrate the transplant donation process in Goiânia: one intensive therapy unit and one emergency unit.

Data were collected through participative observation, ethnographic interview and documental analysis[3].

The observations were recorded descriptively in relation to the environment, to the work conditions of the intensive nursing and emergency teams, behaviors, informants' actions and activities, dialogs with the informants, generating records of reflections about the method and theory used in the study.

The ethnographic interviews were performed during the informants' work shift at a moment they determined, so that there would be neither interruptions in the development of the care delivery nor interference during the interview, since these units are marked by unpredictability.

The interviews were recorded after the informants' authorization and the records were fully transcribed. In addition to the data collected through participant observation, the field diary was used to take notes during and after interviews and for writing down my personal reflections as a researcher.

Official documents were analyzed, such as the Brazilian legislation that regulates organ donation, besides other technical documents, such as the report and planning of the Central of Organ Notification, Acquirement and Donation in Goiás, files of patients with cerebral death, nursing reports and reports of the Renal Transplant Coordination and of the Intra-Hospital Transplant Commission.

A total of four nurses and 13 nursing technicians and aids who work at the intensive therapy unit and reanimation unit participated in the study, an intentional sample whose size was determined by the data saturation process.

The informants' inclusion criteria were: those who spontaneously offered to participate in the study, had worked at the unit for more than six months and had taken care of patients with brain death.

My stay in the study site corresponded to 100 hours. There were moments of up to ten consecutive hours of observation in the maintenance process of the potential organ donor, from the diagnosis of cerebral death, the first and second clinical exams, to the approach of the family and the request to transfer the patient to the intensive therapy unit.

This study followed resolution 196/96 by the National Health Council. The project was approved by the Federal University of Minas Gerais - UFMG's Institutional Review Board and the participants signed the free and informed consent term.

I attempted to extract values and beliefs that could guide the actions of the nursing teams from both the ITU and reanimation units, in relation to the maintenance of the potential organ donor, through cultural domain, taxonomy and thematic analysis. Domain analysis is considered to be the organization of the terms characteristic of the informants' language, that is, common and own terms of the nursing team that takes care of the potential organ donor. Taxonomy analysis is characterized by the organization of the internal structure of the cultural domain. Thematic analysis gives a holistic view of the culture under study[3].

DESCRIBING THE NURSING TEAM CULTURE

The contact with patients and the lack of knowledge in dealing with cerebral death

The frequency of the contact with brain-dead patients can be explained by causality, since they can be admitted at any time. The majority of them is referred during the night shift, at weekends and holidays. Some informants report having taken care of *many cases of cerebral death, around ten or even more...*

However, the informants expressed lack of knowledge about how to take care, saying: *they did not know where to start from, had not received any training*, thus reporting *lack of knowledge. We take care because it is what we think must be done, but we never receive any orientation, no, we never did. Not even psychological preparation, nobody ever prepared us.*

Education with the participation of health professionals and society is one of the determinant factors in the success or failure of transplant programs. When reporting on the importance of continuous education programs, the nursing team is mentioned as a fundamental element in the entire context of the procedure[2,4-5] , since learning implies a change in the person's behavior due to the incorporation of new habits, attitudes, knowledge and abilities.

Learning from the doctor and the supervisor was a way of acquiring knowledge in order to deliver care to the potential organ donor: *...it was a routine we picked up according to the physicians. They arrive and advise: do this, do that.*

Trainings, courses, texts and lectures were reported as strategies to acquire knowledge on cerebral death. The informants report having received *training from the transplant central. It was a one-week, 40-hour course. It was a very good course that ranged from legislation to the bureaucratic part of hospitalization authorizations.* Likewise, they report *having learned by themselves, over time, in daily reality, observing medical prescriptions and observing colleagues.*

Nursing care to patients with cerebral death

Taking care of potential organ donors requires the maintenance of artificial ventilation because there is an alteration in gas exchange due to pulmonary neurogenic edema, pulmonary trauma, infection and collapses. Aspiring tracheal secretion when necessary is a measure that aims to permit more efficient artificial respiration and, consequently, better tissue oxygenation[6-7].

In the informants' discourse, these care demands for brain-dead patients were also identified because they report the need to *take care of the airways, watching the renal function, controlling liquid replacement, observing volume and diuresis*. This care is performed to control the endocrine dysfunction, which is due to the rupture of the hypothalamus-hipofisary axis, characterized by the presence of *diabetes insipidus* which, when not treated, leads to a large liquid loss, provoking different electrolyte disorders[6-7].

Warming the patient, observing the temperature, putting on a blanket is essential care because, in case of cerebral death, the hypothalamic thermoregulatory center is lost, which triggers hypothermia that can generate depression of the myocardium, arrhythmia, decrease in oxygen transport, increased affinity of hemoglobin by oxygen, renal dysfunction, pancreatitis and coagulopathies. Warming the venous fluids is a care that responds to the need to control body temperature[6-7].

Checking and writing down blood pressure, observing perfusion, vital signs must be performed due to the cardiovascular dysfunction, which is manifested through severe hypertension, followed by progressive hypotension and, consequently, tissue hypoperfusion. It originates from the systemic vasodilatation resulting from the loss of motor activity. The myocardial function is altered by electrolyte disorders, renal losses and hormonal disorders. In addition, one must pay attention to the cause of hypotension, which can be multifactorial[6-7].

Taking care of the corneas through humidification was also reported as essential, since it is currently one of the most transplanted tissues. The cornea must be kept humidified and protected with ointment to prevent keratites[6-7].

The care identified in the informants' reports was also related to *keeping rigorous control of asepsis in order to prevent infectious processes*. Such care is described in the literature as the prevention of pressure ulcers and the need for body hygiene to diminish the risk of infection[6-7].

Other care procedures reported by the informants are also mentioned in literature, such as *verifying and writing down glucose levels*. Hyperglycemia, due to insulin secretion failure, alters glycogen storage and requires the replacement of insulin. Other procedures in the maintenance of the potential donor must be performed, such as observing and writing down the blood coagulation level, since it is related to the degree of cerebral decomposition. The use of infusion pumps is also recommended when administering dopamine, medication used when there is adequate response to volemic replacement[6-7].

The nursing team's reactions to patients with cerebral death

The team's reactions when facing a patient with cerebral death are described as: *getting inhuman, having difficulties to take care and taking care with love*. Thus, when the *patient is brain-dead, (s)he is the most forgotten. Some ignore, just think (s)he is in cerebral death...*

The health professional gets fragmented, isolated, denies and loses contact with a form of action that, although uncomfortable, is part of his(er) history and essence, when dealing with apprehensive situations, which can explain the informants' difficulty in delivering care to potential organ donors[8].

Hence, when they realize their human condition, the professionals experience moments that affect them, that elicit feelings like insecurity, incapacity, embarrassment, impotence, suffering and pain[9-10]. These reactions were expressed by the informants: taking *care of someone with cerebral death became painful. [...] So it is like crazy. When it is a child, then, oh dear, do not put me to take care because I am not able to. I think that I am not really, really prepared to deal with this...*

The health professionals do not apprehend the death and life as belonging to the same sphere of nature and culture, although their scientific background treats the life and death phenomena as events from the biological sphere[9].

Despite the whole experience and the pain felt when taking care of a patient with cerebral death, those nursing professionals who neglect the approach of their feelings with regard to life, the death process and death in itself do not develop the capacity to analyze and face their own personal needs. Not being able to deal with their emotions and internal conflicts can lead to them not delivering quality care to the potential organ donor[11].

A study that analyzed nurses' attitudes regarding the maintenance of the organ donor in a pediatric intensive therapy unit demonstrated that 32% of them take care without any concern regarding the potential donor; 25% believe in the benefits these patients can provide to other people; and 25% report that taking care of an organ donor is an "empty" experience[12].

The present study demonstrates that the team also cares with hope, *because the patient is brain-dead but has a good organ, it is necessary to take good care to make us feel like, satisfied, that a good kidney of his will cure many lives, yeah, save many lives...*

The meaning of cerebral death attributed by the nursing team

The scientific knowledge of the patient's death situation and of the physiopathological aspect[13] is important for the nurse. However, this is not sufficient to introduce the transplant culture in a team with many personal histories.

From the informants' reports, the meaning of cerebral death emerged as *organ donor*. The idea that the patient with cerebral death is received at the unit to donate organs indicates that part of this subculture assimilates the conception of the donation-

transplant process, incorporated into the team since 1998, when this procedure was initiated in the services of Goiânia. According to the informants, *here it happens a lot that a patient with cerebral death arrives, to remove the organs. He is very important, there are so many organs that go to someone else. We have to imagine that we are helping another person, another life...*

It was evidenced in other informants' reports that the concepts and values of cerebral death differ from the current donation-transplant policy, since they consider that the brain-dead patient *is dead, it is not a patient and it is not a person. That one over there, the brain died, so that one only has the heart beating and without the other part it will not work. For me, the patient with cerebral death is not a patient, not a person, there is no affection, that feeling really ...*

A qualitative study developed with nursing undergraduates, entitled "educating for death", found the importance of the theme "death" for student education, opening a way to move beyond the ontic aspect of nursing practice, to the extent that it contemplates the ontological dimension of the human being we are delivering caring to. Death is a concrete possibility of this human being's existence[8].

The informants also consider cerebral death as a *patient in a severe condition*, which contributes to a successful donation. According to the potential organ donor maintenance criteria, (s)he must be kept in intensive therapy unit and be treated as a patient in a severe condition[6].

The meaning the nursing team attributed to the transplant

The broadest philosophical implications and the most complete ethical implications of the transplant age were raised through heart transplants, which led to the demystification process that medicine was a science exempt of values. That is, the transplantation of organs became a fundamental issue in human relations[14].

Although they report non-favorable previous experiences with transplanted people, some of the informants believe in transplant as a chance of life for those transplanted, who may achieve a normal life. According to the nursing team, the meaning of *transplant is help, a really great help. Everybody should become aware and donate...It is a continuity, since those who need an organ to continue...to improve their life.*

The "First Mini Marathon of Organ Transplanted People in Brazil" happened in 2002 in São Paulo and was a success. The aims of this marathon were to give back to society the positive results of the "yes" it said to organ donation, to provide quality of life to transplanted people and to favor their insertion in social life. It is believed that a society is based on positive results and raises donation awareness among its members[15], allowing the population to believe in the transplant-donation process.

However, some do not believe in transplants and raise the idea that it is still something questionable from the perspective of quality of life and the complication risks that can make the patient die even faster, so: *We know that it takes a lot of time for a patient to get well and normal. Lately, we have seen a lot of post-transplant in the ITU with septicemia. I don't know why there are transplants, the patients die...*

CULTURAL THEME: IT IS NOT A PERSON

The subculture under study elaborated a symbolic universe in relation to the potential organ donor. This symbolic universe guided behaviors, attitudes and actions. Thus, in the analysis process of the nursing team's experience in the maintenance of potential organ donors, the meaning of cerebral death for these professionals emerged.

In accordance with literature, the natives knew how to describe adequate care to maintain brain-dead patients, that is, hydrate the corneas, hydrate the patient, evaluate body liquid losses, warm the body, keep mechanical ventilation and cardiac monitoring, use drugs to keep the heart contraction strength and drugs to preserve other organs. They also know there is a need to perform two clinical exams, appropriately registered, to assess cerebral death.

Nevertheless, maintenance has been restricted to the bed bath, on-time medication application, change bed sheets and warm the patient, and do not include the care needed for the effective maintenance of the potential organ donor.

Since the beginning of the transplant program with cadaveric donation, the nursing team has gradually acquired knowledge for care delivery to brain-dead patients. They have learned in daily practice, from a colleague or from some physicians and only some of them report having participated in specific courses on the donation-transplant process.

In the beginning of the implementation of the transplant program with cadaveric donation, the nursing team's lack of training allowed beliefs and values to turn into reasons for these nursing professionals not to become organ donors. It also showed their lack of preparation in the face of the concept of cerebral death and the transplant donation policy in force.

In the process of immersion in the collected data, I identified the meaning of cerebral death, which revealed the interrelation between the categories and composed the cultural theme of this study: *it is not a person.*

The nursing team's reactions to cerebral death were revealed through the feelings of *pity, it is painful, it is difficult, it shocks, do not get involved* when delivering care to the potential organ donor, leading to diminished attention to the patient's maintenance.

CONCLUSION

The understanding of values, beliefs and knowledge shared by the nursing team that experiences maintenance care for potential organ donors reveals the concept that is recurrent in the cultural domains, that is, it is repeated in the informants' own language.

The meaning of transplant attributed by the nursing team is marked by disbelief due to previous experiences in the intensive therapy unit. Thus, the beliefs and values of this subculture interfere or determine a detachment from the patient and, consequently, hinder adequate care delivery for the maintenance of the donor and the quality of donated organs, which might, perhaps, justify the maintenance of the potential organ donor as the second cause of non-occurrence of organ donation.

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