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Death and organ donation from the point of view of nurses: a descriptive study

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ABSTRACT

Aim: To describe the point of view of nurses regarding the moment of death in the process of organ donation in an intensive care unit of a transplant hospital. **Method:** This is a descriptive, qualitative study, performed with fifteen nurses working in intensive care. Alceste software was used to treat the data collected, which identified the category "ontological dimension of caring due to the moment of death in the process of organ donation and harvesting". **Results:** During their practice nurses experience a dialectic relationship between the act of donation and facing death through the nursing care provided to the potential donor and his family. **Discussion:** The process of dying comes up against on a daily basis, when nurses have to deal with the unknown, and face the daily fear of fighting against the possibility of death. **Conclusion:** There is a need to rethink/review standards, to reconsider the educational background of nursing staff, and to demystify institutional truths when dealing with the unknown.

Descriptors: Nursing; Mortality; Tissue and Organ Procurement.

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INTRODUCTION

With the introduction of transplants as a therapeutic option, the number of patients with a greater chance of treatment of illnesses previously considered without any hope of a cure, has risen significantly in Brazil. This fact has also generated long waiting lists for compatible organ transplantation, as the number of available organs is not enough to cover the demand from those patients on the waiting lists of the Brazilian National Transplant System[1]. According to the Brazilian Association of Organ Transplantation, the increase in the number of organ donations depends on stimuli from local public authorities such as the state governor, to solve the sequence of small gaps in the logistics of the process of identification of potential donors, up to the performance of the transplant itself, the harmonious relationship between the teams, and the role of central coordination throughout the whole process[2].

There is an estimate that between 1% and 4% of patients who die in hospital, and 10% to 15% of those who die in intensive care units, are potential donors. In Brazil, a study of the waiting lists for transplantation within the Brazilian Unified Health System (SUS, in Portuguese) showed that with regard to every eight potential donors, only one donor is notified to a local Transplantation Center, and 20% of those become effective multiple organs donors, which has serious repercussions for the already long waiting lists for transplantation in the country[1]. Furthermore, it is necessary to understand that this process is still an issue, due to the fact that brain death is a diagnosis which raises ethical dilemmas, as it impinges on those socio-cultural habits, values and experiences which are associated with an unexpected death sentence, normally an issue that is difficult to be understood by relatives and by some health professionals[3].

Despite the fact that the topic "donation, harvesting and transplant of organs and tissues" is still a new field yet restricted to the nurse due to this professional's job descriptions, the nurse's participation in the multidisciplinary team involves the development of specific tasks related to the management of care provided to the potential donor and his relatives. This is a need due to the therapeutic complexity involved in the process of donation and preparation for organ harvesting, which requires a systematized nursing care, to support the clinical decision making process with clinical evidence.

The nurse, while managing the care provided to a potential donor and his relatives experiences a degree of discomfort due to the moment of mourning and loss faced by the relatives, and the meanings and/or convictions of the society based on the situation[4]. During the process of dying in hospital, there is a recommendation with regard to the need for a new model of caring, that recognizes the partnership between nurses, physicians and the family in the caring situations at the end of the patient's life[5]. The topic "donation of organs" is directly linked to ethical, social, moral and religious values related to how an individual expresses his perception of the world, his behavior, attitudes, values, and emotions demonstrated in actions within the context into which that person is inserted.

The process of organ donation and harvesting is filled with socio-cultural values on the part of healthcare professionals, and among them, the nurse, which need to be considered at all times when facing the ambiguity between life and death. Besides how the nurse deals with this duality, it is observed in the field and in the scientific literature dealing with the area of health, that the education of professionals involves the fight for life against death[6].

In the process of organ donation and harvesting for transplantation, there appears to be

a dichotomy between the terminologies life and death, which is discussed from a purely biological point of view, generating fear, suffering and frustration, rather than a multifactorial approach, determined by biopsychosociocultural aspects that directly and indirectly influence the tasks and the emotions of the subjects involved[6].

Therefore, the aim of this study is to describe the point of view of nurses regarding the moment of death in the process of organ donation and harvesting in an intensive care unit (ICU) of a transplant hospital.

METHOD

This is a study which adopts an exploratory--descriptive qualitative approach, as it is based on the universe of meanings, aspirations, beliefs and attitudes of the nurses involved, in order to explore and describe how these professionals deal with death in the process of organ donation and harvesting in an ICU[7].

The studied scenario was an ICU of a College hospital located in the municipality of Niterói, Brazil. It is defined as a transplant hospital according to SUS records. It provides tertiary and quaternary care, mainly to the population residing in the eastern part of the Rio de Janeiro metropolitan area, an area which is composed of seven cities.

The data collection occurred only after approval of the Committee of Ethics in Research of the above-mentioned hospital, under protocol CEP CMM/HUAP 279/11, following the criteria established by Resolution 466/12. Fifteen nurses that work in the institution under consideration were the subjects of this study, as they matched the inclusion criteria, which were to have worked at the ICU for at least for one year, to be available to participate in the study and to be in service at the moment of data collection.

The process of data collection involved the use of a semi-structured interview, performed individually and in a designated area at the unit. The interviews were recorded after the participants had signed a Free and Clear Consent Agreement. The interviews were subsequently transcribed by the interviewer, guaranteeing the anonymity of the participants. To deal with the data collected, lexical analysis was adopted. This is considered a format suitable for the analysis of relationships, based on the computerized analysis of co-occurrences, performed with the use of Alceste software.

Alceste is a computerized technique and also a methodology for the analysis of textual data. The software automatically understands the lexical analysis of a text through quantitative techniques, using chi-square test (x_2) to deal with these textual data. Alceste operates on the assumption that, when the body of the text is produced by many different individuals, thus discourse is analyzed in many different ways, leading to the discovery of many different categories, reproduced using accurate and specific vocabulary. This software also detects different "ways of thinking" regarding the phenomenon under consideration[8].

Therefore, based on a dictionary as part of the software itself, the *corpus* of data (the transcribed interviews) was analyzed and subdivided into Elementary Context Units (ECU), from the identification of words that characterize these units. To promote a better understanding of the discourses identified by the elementary context units, they were named using the acronym E, followed by a numeric sequence. The Alceste analysis is based on the reduced forms of the words that compose a contextual field. A contextual field is defined as a specific word of a certain class within a specific context[8]. The *corpus* must be consistent and homogeneous, and when it follows these standards, the percentage

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of utilization can reach levels above 70%. In this research, the utilization rate of the *corpus* of the interviews reached 72%. It is important to mention that the answers of the interviewees are represented by the elementary context units.

RESULTS

With regard to the 15 nurses interviewed, their ages varied from 30 to 50 years, with a prevalence of female nurses (n=12). In terms of the employment situation of these nurses, 87% were full-time and 13% were on a temporary contract. The temporary employment status is necessary due to a lack of full-time personnel, and as replacements for recently retired staff members as well as some professionals who had resigned.

With regard to the amount of experience working in intensive care, 70% had worked for less than 10 years, 40% for more than 10 years, and 27% for less than 5 years. In addition, 80% had also worked in other health institutions.

The information regarding when their undergraduate studies had finished showed that 73% of the professionals had achieved their bachelor's degree more than 10 years ago. Among the nurses, 76% had *Lato Sensu* graduate degrees in intensive care, and 24% a graduate degree in some other area not related to high complexity care. Another element to be mentioned is that 80% of the interviewees wished to be donors of organs and tissue in the future.

It is worth mentioning that, in this study, the data presented are part of the results of the Master's Dissertation of the Professional Master's Program in Assisting Nursing of Fluminense Federal University, entitled the "Management of Nursing Care in the Process of Communicating Brain Death in an Intensive Care Unit – Building a managerial flowchart". In this sense, the semantic context that generated the fourth category that originated from the use of Alceste methodology with regard to the *corpus* of analysis of this research deals with the perception of the nurses with regard to the death process that is part of the process of organ donation and harvesting, and which is presented in the rest of this paper.

Ontological dimension of care due to dying as part of the process of organ donation and harvesting

Nurses who work in ICU experience, on a daily basis, a dialectic between donating and dealing with death arising from the diagnosis of brain death, and the nursing care provided to the potential donor and his relatives. In this sense, the dialectic is not only the opposition between living or dying, but is also a process that goes beyond the stage of the death of human beings. In this process, the nurse experiences such a dialectic or, in other words, a duality when facing death based on a diagnosis of brain death, and the need to maintain the hemodynamics of the organs that may be useful for transplantation, as seen on the comments that follow.

> I think there are people that are alive, but depending on tissues, and then they are considered dead by society. You have to see that the death of one person can become the survival of many others, survival in a way that represents coming back to life, coming back to have a full life. (E7)

> [...] it means something really important, because you are providing for the continuation of another life, and the family of the donor will also feel useful somehow, and I think their loss

will be compensated for in a certain way [...] (E9)

The following comments show how nurses perceive the process of organ donation, in terms of what is experienced by the relatives of the potential donors.

[...] during the moment of pain, of suffering from the death, all you want is that moment to finish as quickly as possible; donate, take away, go ahead and the come back; unless you are filled with hope that the part(s) of the body will continue to live inside other people, and this becomes the main reason for donating organs to other people, which is the main understanding [...] (E7)

[...] have some time to think, some time to discuss, to get ready to sign the papers for donation without any guilt during a moment of suffering, following the process; the rest is technique, the rest is caring. (E7)

[...] the adherence of people, the involvement with this perception of organ donation and harvesting, then I think that everybody must go through this process, it would help a lot. (E11)

For many professionals, organ donation has aspects related to religion, and these elements interfere with the decision making process and/or with the decision to donate, as well as when facing the situations involving death and the process of dying.

[...] The body has life, but being a Christian, I think like when St. Paul used to say "separate well the body in body, soul, and spirit; soul is what gives life to the body, and you have the psyche, as you also have the mind, and the body; and then you have brain death, you see that the mind that gives life to the body is gone, this body loses its life tous" [...] (E12)

There are people who don't donate because they think it will influence the dead person during his resurrection, and then, what can be done in these cases? These are religious-philosophical questions that you have. (E7)

The nurses, as part of the health team, express, in their testimonies, the difficulty of dealing with the limiting situations found in high complexity caring, as these situations involve the process of death/process of dying.

[...] no health professionals comes here to work towards death. People think they come here to defeat death; this situation is not the objective of our work: the aim of our job is to provide good nursing care, not bothering with the results that might occur [...] (E7)

[...] the loss for the relatives or for the health team, after investing so much on a patient, focusing on his recovery [is sad]. Then, in the case of brain death, I see it as the end of life on a terrestrial level, and then permitting the life of another person to begin, a person who depends on this organ [...] (E9)

Each and every human being knows, consciously or not, that it is inevitable that one goes through the process of dying, every day. Nurses show, on the following ECU, their views about

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the natural and physiological death of the body, and the process of donation:

> [...] to come and being able to stay; those friends that come during the first week, the next ones, you know they are not staying. Then it is good that people think about that before stating that they do not want to donate; I think donating is important because of that too, because, in the end, it's only the flesh. (E7)

> [...] when the brain activity is gone, despite the fact the vital signs are still present, then there is no more brain activity, then it is brain death. (E9)

> [...] instead of saving just one life, you will help many more people. Brain death is from the moment you diagnose that the patient has no more brain activity. (E13)

The care management performed by the nurses in the process of organ and tissue donation and harvesting, involves some tasks beyond the instrumental or technical caring actions associated with the body. This means that there are indirect actions which are intended to provide a systematized and high quality of care to the potential donor and his relatives, up to the moment that feelings, beliefs, and cultural and religious values regarding the finitude and death impact on this process, according to what is seen on the following comments:

> [...] as I work in the hospital where the harvesting of organs generates life, we have a very special care. When you have a patient with brain death and who can be a potential donor, I see that patient from both sides; [...] (E12)

> [...] the owner of my body, I do not own it myself. Then what we need to do is not to talk with the people that want to donate and become donors; we need to focus on the relatives who are against the idea (E7)

DISCUSSION

To better understand and discuss the thematic context in which the interviews were made, it is necessary to approach the theoretical standards adopted in this study regarding the terms dimension, ontological and death Within this perspective, dimension means every plan, degree or direction in which an investigation takes place or an action is performed[9:327]. Ontological is the view of the world each human being has, his way of thinking, experiencing his relationships and interactions, thus developing his own meanings of understanding, doing and being of each subject[8].

To talk about human death and the implications when it comes to caring being applied by the nurse leads us to the philosophical concept of the term. This involves the matters related to death, vulnerability and protection of the human being. The human condition to death is undeniable, as we are all born, live and die. Therefore, life and death must be considered as two inseparable and distinct processes of the human existence, both mediated by situations of finitude, also referred to as vulnerabilities[10].

In this sense, finitude relates to temporality. Experiencing the process of living and dying under conditions of vulnerability is part of the human experience. That is, every living being has to submit to the devastating effects of time, making one aware of one's temporality in the world[8,10].

Hence, the ontological dimension of care regarding death in the process of organ donation and harvesting are qualitative variations, degrees or directions, in which nursing care is seen or conducted by the nurse when facing the situation of vulnerability experienced by potential donors and their relatives, requiring the nurse to live a dialectic in the nurses' praxis. The dialectic is in the fact that the nurse, as a professional paradigm, has the responsibility to articulate the rationale during the moment of donation and harvesting, and, at the same time, understand this moment as a possibility to save or to increase the survival chances of patients with organic failure[4], as well as dealing with feelings, beliefs and values of the relatives of a potential donor.

In this context, organ donation, in its ontological dimension, can be defined as a process that promotes hope for life despite death, through the meanings and experiences of this process, thus revealing the concrete format of what it is to be a human being. Man is defined as a being who presents values, feelings, consciousness and capacity to think and to relate to his social reality. The nurse, while generating and communicating the representations of the relatives, uses his own affectionate and cognitive experiences, as well as the socially constructed meanings within the group within which the professional is inserted. Hence, it is possible to identify, through the analysis of representations of a group, the values, conducts, beliefs, ideologies, contradictions and interests of that group, thus understanding the essential aspects of the social behavior and the reading of reality that surrounds the nurse[11].

In this matter, for many professionals and for the relatives of potential donors, the donation of organs permeates paradigms related to religious aspects, which can interfere in the decision-making process and/or in the thoughts regarding donation, showing that religious faith influences the capacity to deal with situations involving death and dying[12]. In fact, there is not a single religion that prohibits the donation or the receipt of organs, or even counter-transplants from living or deceased donors. In fact, it is possible to infer that cultural beliefs are opposed more to organ donation than religious creeds[13] because, in most existing religions, the meaning of death is associated with the idea of an afterlife moment, or some sort of continuation of existence. Furthermore, in the process of dying, technological intervention has demanded the use of more ethical, philosophical and clinical conditions, somewhat equivalent to the religious parameters, which are many times defined in terms of terminologies such as "soul departure" or "loss of the breath of life"[4].

Moral, ethical and religious values are directly associated with organ donation, and are connected to the individual to make him reflect upon matters of mortality, their relationship with the body, with feelings and with uncertainty after death. Associated with these values there is the representation of the body as a separation between the material and the spiritual. In this aspect, donation is filled with meaning, not only for the relatives, but also for the health professionals, according to their own personal convictions regarding the confrontation with the process of dying.

The process of death/dying deals with the limitations found in the daily routine of the intensive care units, where the professionals working in this context present greater degrees of difficulty in dealing with the unknown, the fear felt daily when fighting against the reality brought about by death. This difficulty is supported by the fact that many health professionals and relatives do not fully understand the meaning of brain death, which interferes in the decision-making process and with the opera-

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tion of the steps associated with the process of notification of brain death, and in dealing with what cannot be beaten.

The nurse needs to be involved in the culture of transplants so that the process of the notification of brain death is not distorted, together with scientific knowledge dealing with the mortality of the body in a way that the family of the potential donor is engaged in the whole process. In this area, the nurse, involved in the process of the notification of brain death, must understand that brain death means the complete cessation of cardiorespiratory and brain functions, including brainstem arrest (or, in other words, despite the fact that the body of the potential donor is kept in a hemodynamic state, the "death" status is irreversible)[12].

However, it is impossible not to mention the relationship involving death/dying; the nurse internalizes the fact of death and the dichotomy in dealing with the meanings of dying as a being, as well as facing his own fragility, discomfort and limitations in this vast universe of truths, all involving death and the mortality of the human being involved in the process of caring[14].

Thus, every human being, from birth and throughout his existence, is followed by images of death, understanding that eventual demise is part of living when life is over. Death is the undeniable certainty of the human condition, despite the fact that it is frequently hidden, which constitutes a peculiar but intrinsic part of the existence of *Homo Sapiens*, the only living being which is conscious of his own mortality[15].

On the other hand, death for human beings can represent other meanings besides the act of dying, associated with values and feelings that depend on social, cultural and historical contexts, involving similar considerations with regard to mortality, or, in other words, death in life. Diseases place the individual in contact with his own fragility and mortality, moving him away from his daily activities, permitting the existence of paralysis and pain. At a certain level, the individual sees himself as a mortal being while still alive[16].

It is observed that the process of organ and tissue donation and harvesting is also a complex topic for the professionals involved in caring for the potential donor, in that it mobilizes feelings, beliefs, and cultural and religious values regarding mortality and death. The caring for the potential donor and his relatives goes beyond the preparation of the dead body. A body that is prepared and kept for the process of donation, and later harvesting for its organs for transplantation, involves instrumental and expressive caring tasks[8] filled by ethical and legal questions, respecting the decision of the person in life to donate, as well as the consciousness of the importance of donation, clarifying the diagnosis of brain death, and respecting and humanizing the relationship with the potential donor and his relatives. This process is supported by Brazilian Law 9,343/97, which deals with the removal of organs, tissue and parts of the human body for transplantation, and Ordinance 2,600/09 which details the Technical Regulations of the Brazilian National System of Transplants[17,18].

The process of organ donation and harvesting requires, on the part of the nurse, the development of cognitive, analytical, and behavioral abilities, as well as physical skills, as it permits the understanding of the particularities of the individuals involved, and the categorization of the problems. It also supports the decision-making processes, the evaluation of the context, and the health needs of the individuals, relatives and the community, the planning and evaluation of the therapeutic environment, material resources, and the equipment and human capital needed to produce the requisite nursing care. Furthermore, in this context, it is possible

to understand human behavior and to establish the interexchange of help with regard to the situation of mortality and death inherent in the process of donation[8,12]. Hence, it is important to highlight the role of health professionals, especially those who work in emergency or in intensive care units, to be prepared to work in any of the stages of the process of donation[19].

CONCLUSION

Nurses experience, as a part of their daily practice, the dialectic between the action of donating and dealing with mortality. The process of donation leads to many different meanings for the family and for health professionals regarding each one's personal convictions when it comes to dealing with the death of the donating patient. The process of donation leads us to dealing with the discomfort of a very close experience of loss, the suffering of others, an awareness of the unknown, and the end of life.

There is a need to rethink and review certain standards, to analyze the practices taught in nursing undergraduate programs, to demystifying the institutional truths in terms of how to deal with the unknown, the spiritual. To introduce a culture of organ transplantations is to understand that it is part of the process of caring, as caring management starts welcoming the family of the potential donor, the maintenance of this potential donor, and the referral of the elected donor, and it finishes when the farewells on the part of the relatives around the body of their loved one. Death is still a veiled topic in society, and organ and tissue donation is a discussion that forces us to challenge and face our mortality.

This study comes as a result of important and actual questions that need to be asked and so bring to light a new and restricted field of research associated with the work of the professional nurse. It demonstrates that we need to develop competencies in caring management destined to support potential donors. We also need to consider the systematization of caring, as well as undertaking a re-evaluation of the work processes of nurses at an institutional level. This research also has a social relevance, as the process of organ and tissue donation involves tasks in caring management on the part of nurse and of other health professionals within a social and ethical perspective, involving the dimensions of citizenship, politics and caring policies as they relate to the relatives and to the potential donor.

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Participation of the authors

Bárbara Cristina de Aguiar Ernesto Virginio contributed in the final writing of the problematic of this research, collected and analyzed the data and designed the final version of the article.

Cristina Lavoyer Escudeiro analyzed the data, contributed to elaborate the article and its review, and had the final approval of the published version.

Bárbara Pompeu Christovam helped to define the methodological design, analyzed the data, and had a critical review used in the final published version.

Zenith Rosa Silvino assisted in the analysis and interpretation of data, and in the writing of the article.

Tereza Cristina Felippe Guimarães helped in the analysis and interpretation of data, and in the writing of the article.

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