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Experiences and expectations of nurses in caring for organ donors and their families

Experiências e expectativas de enfermeiros no cuidado ao doador de órgãos e à sua família

Experiencias y expectativas de las enfermeras en la atención de los donantes de órganos y sus famílias

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ABSTRACT

Objective: Understand the experiences and expectations of intensive care unit nurses in caring for organ donors and their families. **Method:** Qualitative research, with a social phenomenological approach, conducted in 2013 with 20 nurses. **Results:** The experiences of the nurses with the families of donors were represented by two categories: obstacles encountered and interventions performed in the care of the donors' families. The expectations of these professionals in caring for organ donors and their families were described in the category: care to save lives. **Conclusion:** The study showed that the day-to-day work of intensive care nurses in their care of organ donors and their families is permeated with obstacles that interfere in the donation process. In light of this, their goal is to provide intensive care to deceased donors and humanized care to the families, to help family members agree to organ donation and enable organs to be made available for transplants.

DESCRIPTORS

Nursing; Tissue and Organ Procurement; Organ Transplantation; Brain Death; Intensive Care Units; Professional-Family Relations.

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INTRODUCTION

The donation and transplant process is complex, and the participation of intensive care unit (ICU) nurses is essential to enable the provision of organs and tissue for transplants. That being the case, one of the activities of these professionals entails providing nursing care for eligible brain-deaddonors and their families[1-2].

The participation of these professionals in the care given to eligible donors and their families is crucial in the welcoming, humanization and explanation process, enabling the donors'relatives to make independent decisions regarding what to do with the organs and tissue of their loved ones[3].

It is also important to emphasize the key role played by nurses in providing support to the families of donorswhen they receive the brain death diagnosis from the medical team. Nurses who work in this setting know that breaking the bad news to deceased donors' families is crucial so that they can understand that brain death is death[1].

In communicating misfortune, the information has particular implications, since it provokes a state of emotional crisis in deceased donors' families, and this situation generates tension for health professionals[3].

The breaking of bad news can be defined as that which drastically and negatively changes the perspective of individuals or their families in relation to the future. The result is emotional disorder or distressed behavior that persists for a certain length of time after the bad news is received. The reaction of donors' families to the news of the death of their loved ones depends on the coping mechanisms used by each person, previous experiences and social and cultural factors[4].

However, the way in which donors' families are notified of the death is essential for discussing and making decisions about organ and tissue donations for transplant purposes. In this situation it is crucial that the families understand this concept and accept that the person has died. In view of this, the communication skills of the health professionals are decisive for ensuring that the information transmitted to the families is clear and objective[1].

Health professionals who work with critical care patients should receive specific training in communication, since this a basic tool for carrying out their daily activities, and the care provided should seek to humanize the donation process through the help offered to the donors' families[5].

Some concerns therefore arise:How do intensive care nurses experience the care given to organ donors and their families? What importance do they assign to their role in this care process? What elements facilitate or complicate the care given to organ donors and their families? What motives are taken into account when caring for organ donors and their families? What do nurses hope to achieve through their role in this situation?

The objective of this study was to understand the experiences and expectations of intensive care unit nurses in caring for organ donors and their families. By revealing the experiences of this social group, this study makes a contribution to health professionals who work in different realities, providing elements that can steer actions in this health field and guide teaching practices and care, as well as lead to the implementation of strategies to optimize the quality of organs made available for transplant.

METHOD

This was a qualitative study based on the social phenomenology of Alfred Schutz. This framework made it possible to understand human phenomena based on concrete experiences, lived in daily life, and provided insight into a group of ICU nurses involved in the care of organ donors and their families.

The research was conducted with ICU nurses from a teaching hospital in the city of São Paulo. Nurses from the day and night shifts were personally contacted to see if they would be interested in participating in the study, at which time the project's objective was presented, pertinent questions were answered.If a desire to participate was expressed, a meeting was scheduled, according to their availability, regarding theday, time and location where the interview would be conducted. The nurses who agreed to participate in the study signed a Free and Informed Consent Form.

A phenomenological interview was used to obtaininput from the study participants, because it comprised open-ended questions that allowed the participants to remain open to the intentional acts of the other, enabling the stream of consciousness of the individuals to be revealed to the researcher[6].

Twenty interviews with ICU nurses were conducted. The participants were from 27 to 48 years of age and had been working in this specialty anywhere from 2 to 15 years. The interviews were recorded in a private location in the hospital, which was the setting for the study, with the participants' consent. The inclusion criteria were that the nurses have a specialization in intensive care and provided care to organ donors and their families.

The number of participants was not established in advance but, as the interviews proceeded, when it was noted that repetition was occurring in the dialogues, that the concerns of the interviewers had been addressed, and that the objective of the study had been achieved, the interviews were ended.

The data was collected from August to December 2013 by means of individual interviews, lasting on average two hours and guided by the following questions: *Could you tell me about your experience caring for organ donors and their families*? and *What do you hope to achieve through providing this care*?

Analysis of the results was based on the steps proposed by social phenomenology researchers[7], which entailed a systematic procedure to analyze the interviews, through careful reading and rereading, in order to understand the essence of the experiences and expectations of the nurses in their care of the families and organ donors; grouping of the significant aspects extracted from

the interviews through thematic convergences so as to grasp the subjective meaning that the nurses attributed to their own actions; analysis of these categories in an effort to understand the "reasons for" and "reasons why" in relation to the nurses' care of families and organ donors; and lastly, a discussion of the results based on the social phenomenology of Alfred Schutz and key figures related to the theme.

To identify the different interviews, theywere designated as E1, E2... E20, so that the nurses would remain anonymous.

The study complied with international ethical research standards involving human subjects and was approved by the Research Ethics Committee, under No. 0599/11.

RESULTS

The experiences of the ICU nurses in caring for the families of organ donors (for transplants) reveal personal, social and professional aspects, expressed in two categories: obstacles encountered and interventions performed in caring for families of donors.

Obstacles encountered

The day-to-day work of ICU nurses in their care of families of organ donors is marked by obstacles, represented by the difficulties these families have in accepting and understanding brain death, especially when the event involves traumatic causes and/or the donor is young. Insufficient skills of medical teams in breakingbad news and lack of preparation on the part of nurses to deal with families going through the loss of loved ones interfere in the care provided to these families.

The nurses participating in this study mentioned that the difficulties families have in accepting the death of their loved onesare fed by the hope that the situation might change, which hinders their acceptance of organ donation and the care being provided to them, as seen in excerpts from the interviews:

> *It's complicated for the family to see the person's heart beating. (...) family members say: Many people remain in a coma and then come out of it. (...) many do not agree to donate precisely for this reason, for fear of killing the family member. In this situation, it's difficult to talk with the family and the care becomes complicated (E4).*

> *Sometimes, the doubt the family has is whether the family member is dead, because the heart continues beating, the monitor is on showing their vital signs. (...) The heart, for people, is synonymous with life; family members don't understand and can't accept that the patient is dead. This aspect of giving careis difficult, because if you try to explain that the person is dead, the family might think that you want the patient to die (E7).*

Acceptance of this reality is even more difficult for families when the death is caused by a trauma and the person is young, factors that obstruct the care provided to donors' families:

> *The family members are often not prepared, and in most cases the patients are young people who for some reason suffered a fatal accident. It is then a shock to the family and makes it difficult to act at this time (E17).*

> *The family feels lost; they keep hoping right up to the last minute, they think the situation may change, especially when it's a child (E19).*

Lack of skill on the part of medical teams in notifying-family members of the death hinders understanding and acceptance of the patient's death:

> *So, at times, when doctorsare going to speak, they have to give families an explanation, since the families often don't know what brain death is. Doctors have to adapt their language to the level of understanding of the family members, and use language that will enable them to understand the situation (E5).*

> *The doctors are the ones who speak with the families and explain that there is no flow, that the pupils are not reacting, but the information is not transmitted clearly and simply, so the family is left wondering if there is any process that could reverse this, because they didn't understand the information passed on by the doctor (E9).*

In this kind of situation, nurses feel unprepared to deal with families who are going through the crisis of losing loved ones:

> *With regard to the family members, I can see that they are undecided about organ donation, due to their suffering, the pain of their loss, and also because of the lack of preparation of nurses to deal with this situation of loss, which hinders the relationship with the family members (E13).*

> *I'm not very adept at handling crisis and loss situations. We try to make the families comfortable and explain the situation, but it's very complex. It's not easy to deal with human feelings in the face of the sudden loss of a loved one (E14).*

Difficulties in providing assistance to family members in crisis situations are due to lack of training through courses that provide tools for how to act at such times:

> *There's no course, no information. I haven't received training in taking care of organ donors and family members undergoing a situation of crisis and loss, (...) I feel that training is lacking that could improve the assistance and care we provide (E1).*

> *It's a very complicated situation that the family will be facing and lack of training encumbers my interaction with the family (E20).*

Reports were unanimous regarding barriers encountered by intensive care nurses in caring for family members of organ donors, and in the face of these difficulties,

these professionals carry out interventions aimed at overcoming these obstacles through providing transparent and humanized care.

Interventions performed in the care of donors' families

Due to the hard time that families have in accepting the loss of their loved one, nurses try to intervene through building relationships based on helping the family members, with empathy and effective communication being highly important tools in this complex context:

> *We explain what's happening, take them to the bedside and show them the situation, so that the family can understand what's happening. It's necessary to establish a link with the family and help them (E16).*

> *You have to handle the family with special care, you have to help regardless of whether they donate or not. (...)The family suddenly thinks the relative is alive. Then, you have to explain, you have to show empathy at that time (E2).*

> *It's a very difficult time for the family, because the death was unexpected and it's a hard situation. We have to understand and respect the family, provide comfort the best way possible and use appropriate language so that the family can feel secure and trust in what was done (E3).*

> *Oncethe news is given, when the doctor sits down to explain the diagnosis of death and the organ procurement team goes to request the donation, the presence of the intensive care nurse is important, because we have more daily contact with the family, we have a closer relationship, because we are beside the patient all day. So I feel that our presence imparts credibility and transparency to this time, and can help the family agree to the donation (E10).*

Allowing family members to remain as long as possible at the side of their loved ones is a strategy used by nurses to enable transparency, humanize care and facilitate donations:

> *We let the family go see their loved one as often as they feel the need, outside visiting hours. (...) Allowing the family to enter and stay beside their relative for as long as they like to say goodbyehumanizes the care (E8).*

When nurses intervene in the care of donors' families, based on experience accumulated over the course of their career, they discern possibilities, perceived through projections aimed at saving lives. Therefore, the expectations in caring for organ donors and their families were represented in the category: care to save lives.

Care to save lives

The expectations of nurses are focused on saving lives. Thus, they recognize the importance of their work in caring for donors in order to obtain organs and enabletransplants for recipients who, for these professionals, have no names or faces, but motivate and give meaning to their work.

> *My role is to provide quality care to the donor, since that individual who is not participating in our real world can provide the means for other people to continue living (E6).*

> *What motivates me is knowing that other people can have quality of life; this is the main motive in caring for the donor (E15).*

Therefore, nurses intensify their care of donors and their families, motivated by the need to make organs available for transplant.

> *My motivation is knowing that thatthedonor will save the lives of many people, so I must intensify my care of the family and the donor (E11).*

Given this possibility, these professionals believe that their role is to educate the families of donors about the importance of donations, and through this action, help save lives.

> *Making families aware of how important organ donations are, of the importance of life, the continuation of life, that they will be helping other people who are in need and may die due to lack of an organ, who are on a waiting listfor an organ (E12).*

> *Care for the family so that they can make an extremely important decision for society, because they will be giving other families the chance and possibility to be happy (E18).*

DISCUSSION

The daily lives of ICU nurses are intersubjective and their actions are highly social, since life places these individuals in constant, face-to-face relationships, wherein intersubjectivity is manifested in all its density. The life world is a social and cultural space in which individuals enter into relationships with other human beings with varying degrees of intimacy[6-8]. Consequently, these professionals interpret their day-to-day work according to their view of the reality experienced, and realize that the difficulties families have in accepting the death of loved ones hinder giving care.

Studies have shown that many families have a hard time understanding and accepting brain death as signifying the death of that person, and confuse this situation with other brain conditions, such as comas or persistent vegetative states. Understanding the concept of brain death has been emphasized in these studies as being the primary obstacle to organ donations (for transplants)[9-12].

Furthermore, when the death resulted from a traumatic event and involves young people, there is a high probability that the family members will refuse to make the donation, especially when the parents are directly involved in the decision[13]. In this context, it is crucial that multiprofessional teams be adept at handling families experiencing the unexpected loss of loved ones.

Ineffective communication is one of the factors that impede family members in accepting the eligible donor's death and, consequently, organ donation. Therefore, implementing training programs for health professionals aimed at improving skills for breaking bad news may be one solution for optimizing family consent rates[5,14].

The social world is built through communication and the intersubjective action of individuals involved in this significant interaction[6]. Thus, the day-to-day world of ICU nurses is intersubjective, since their actions are highly social. At every moment, these professionals are communicating and interacting with the health team and family members of eligible donors, in face-to-face relationships.

The life world is the setting for the experiences, expectations and social actions of these professionals, and is understood as a natural world that imposes limits on their attitudes, where they act and operate as actors in a reality that is modified through their acts and which, on the other hand, transforms their actions[6].

When health professionals establish good relationships with the family members of eligible brain-dead donors, this generates a positive atmosphere and can positively influence the decision to donate organs (for transplants)[15].

It is recommended that family members be allowed to remain at the side of their loved ones as long as possible, even during the determination of the brain death diagnosis, thereby imparting transparency and credibility to the donation process facing the donors' relatives. Besides this aspect, both donating and non-donating families appreciate the presence and interaction of the nursing team, and the attention and care provided by nurses to family members of the deceased are important in making decisionsaboutorgan donation[16-17].

When reflecting upon their role in the care of families and eligible donors, nurses are motivated in their experiences and expectations by the quest to save lives. Organ and tissue donation for transplant purposes is based on the law of reciprocity. Helping someone presupposes reflecting on human finitude. This reflection and decision involve questions of an emotional, ethical, moral and individual nature. When asking themselves about the possibility of donation, these professionals realize that life is an equation of reciprocity, since they will find themselves in the same situation as the families of deceased donors, recipients and health teams, when they become aware of their own vulnerability, dependence, responsibility, finitude and humanity.

Action is human conduct self-consciously projected by the actor. People act on the basis of motivations directed toward objectives, aimed at the future. These are called *reasons for*. On the other hand, people have reasons for their actions and are concerned about them. These reasons, rooted in past experiences and the personalitiesthat people have developed over the course oftheir lives, are called *reasons why*[8].

Motive is understood as a state of affairs, the objective intended to be achieved through an action. Therefore, *reasons for* are orientations for future actions and *reasons why* are related to past experiences. Understanding the other invariably entails knowledge of the reasons that determine the realization of theiracts[8]. Nurses in intensive care units constitute a social group with goals and reasons for caring for organ donors and their relatives, in order to optimize transplants.

Given this perspective on saving lives, nurses act according to motivations focused on objectives, aimed toward the future. These objectives are called *reasons for*, and can have subjective as well as objective meaning. Subjectively, it refers to the experience of the actor who lives out the process in the course of their work. For that person, the reason signifies their real objective and what gives meaning to the actions they perform, aimed at creating a state of affairs to achieve a preconceived end[6-8].

The quality of care provided to families and eligible brain-dead donors is appreciated by the family members of the deceased and has a positive influence on the decisions they make regarding organ donation[18].

The benefits of organ transplants include saving and enhancing the quality of life of recipients on waiting lists; for the family members of eligible organ donors, it can result in something positive coming out of the loss of their loved ones. Therefore, the multiprofessional team plays a crucial role in the donation and transplant process, providing benefits to recipients, family members of the donors and society in general[19].

CONCLUSION

The day-to-day work of intensive care nurses is permeated with obstacles, values and meaning in the care provided to families and organ donors. These aspects are perceived through experiences accumulated throughout the careers of these nurses, enabling them to project their expectations, as far as making organs available, motivated by the prospect of saving lives.

As they reflect on their experiences in caring for families of organ donors, these nurses realize that obstacles, in the form of insufficient skills of medical teams for breaking bad news, lack of preparation of nurses to deal with families experiencing the sudden loss of loved ones, and the difficulties these families have in accepting and understanding the meaning of brain death, especially when the event involves traumatic causes and the donorsare young, interfere with the care provided to these families.

In light of this, nurses perform interventions to overcome these obstacles through relationships built on helping family members, humanization and transparency in the donation process, and revealing future projectswhose goal is to intensify the care and educate families about the importance of the donation, and through these actions, help save lives.

The results of this study contribute to understanding the care needs of donors and their families, in addition to providing input for new care strategies, education and re-

search in this health specialty, in order to overcome obstacles and optimize the availability of organs for transplants.

The fact that this study encompassed only one social context could be considered a limitation that could prevent the generalization ofthe results. However, its importance lies in the experience of these nurses, who care for organ donors and their families in their day-to-day work.

RESUMO

Objetivo: Compreender as experiências e expectativas dos enfermeiros de unidades de terapia intensiva no cuidado ao doador de órgãos para transplantes e à sua família. **Método:** Pesquisa qualitativa, com abordagem da Fenomenologia Social realizada em 2013, com 20 enfermeiros. **Resultados:** As experiências dos enfermeiros com as famílias dos doadores foram representadas pelas categorias: obstáculos vivenciados e intervenções realizadas no cuidado às famílias dos doadores. As expectativas desses profissionais na assistência às famílias e aos doadores de órgãos foram descritas pela categoria: cuidar para salvar vidas. **Conclusão:** O estudo mostrou que o cotidiano dos enfermeiros de terapia intensiva no cuidado às famílias e aos doadores de órgãos é permeado por obstáculos que interferem no processo de doação. Diante desse cenário têm como expectativas oferecer uma assistência intensiva ao doador falecido e um cuidado humanizado às famílias, intencionando possibilitar a aceitação da doação de órgãos pelos familiares e viabilizar órgãos para transplantes.

DESCRITORES

Enfermagem; Obtenção de Tecidos e Órgãos; Transplante de Órgãos; Morte Encefálica; Unidades de Terapia Intensiva; Relações Profissional-Família.

RESUMEN

Objetivo: Comprender las experiencias y expectativas delas enfermeras de las unidades de cuidados intensivos en la atención al donante de órganos para trasplante y su familia. **Método:** Investigación cualitativa, con el enfoque dela Fenomenología Social que ocurrió en 2013, con 20 enfermeras. **Resultados:** Las experiencias delos enfermeros conlas familias de losdonantesestuvieron representadas porcategorías: obstáculos experimentados y intervenciones en la atención a las familias de los donantes. Las expectativas de estos profesionales en la asistencia a las familias y a los donantes de órganos fueron descriptas en la categoría: cuidar para salvar vidas. **Conclusión:** El estudio mostró quela rutina diaria delos enfermeros de cuidados intensivos en relación a la atención de las familias y los donantes de órganos está permeado por los obstáculos que interfieren con el proceso de donación. Ante este escenario, la expectativa primordial es ofrecer asistencia intensiva a los donantes fallecidos y atención humanizadaa las familias, con la intención de posibilitarla aceptación dela donación de órganos por parte de familiares y hacer factible la potencian de los órganos para trasplantes.

DESCRIPTORES

Enfermería; Obtención de Tejidos y Órganos; Trasplante de Órganos; Muerte Encefálica; Unidades de Cuidados Intensivos; Relaciones Profesional-Familia.

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