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UNDERSTANDING THE EXPERIENCE OF FAMILY FACING HOSPITALIZATION, BRAIN DEATH, AND DONATION INTERVIEW

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ABSTRACT
This study aimed to understand the experience of families in the process of hospitalization, brain death and interview for organ donation. It is an exploratory, descriptive, qualitative research of phenomenological approach. The subjects were 15 families of patients who had severe and acute brain injury that evolved to a brain death diagnosis, whose families were interviewed for organ donation but did not authorize it. After analysis of the empirical material, two units of meaning arose: (1) Hospitalization; and (2) Interview for Decision on Donation. These units of meaning are represented by “impact of the news”; “barriers to communication”; “relationship with the team”; “reporting the brain death”; “pain for the loss”; “informing about donation” and “decision-making”. The path walked by the families is difficult and makes it necessary to rethink the care provided to these people by health professionals throughout the process. The time between the report of the death and the provision of information about organ donation is important for the family to organize its thoughts and make the best decision. The study shows that this time has not been respected.

Keywords: Nursing. Family. Brain death.

INTRODUCTION

The neurosurgical pathology affects, in most cases, young patients and men of working age. The main causes of severe brain injury are cranioencephalic trauma as a consequence of motorcycle accidents and hemorrhagic stroke, the latter being strongly linked to hypertension (1-4). Severe brain injury results in cerebral edema and intracranial hypertension, causing the patient to depend on mechanical ventilation and need intensive care. Oftentimes the clinical condition worsens, leading to brain ischemia and, consequently, Brain Death (BD) (1-4).

The patient’s admission to the Intensive Care Unit (ICU) can happen anytime, as these are acute and severe pathologies with great hemodynamic instability and risk of death (1-4). About 14% of deaths in ICUs in reference neurosurgery hospitals correspond to patients who evolved to BD (5,6).

In the face of this severity, the family starts to interact with rules, limitations and technical terms, seeking information about the patient’s diagnosis, prognosis and clinical condition. The comings and goings to the ICU, misinformation, the severity and a possible BD bring a tangle of facts and data they do not know. Even so, they feel the need to trust in the team and grow stronger as a family, seeking support also from friends, moved by the hope of recovery. However, anguish, distress, anxiety and fear become part of this journey (5,6).

Along the way from brain injury, hospitalization, BD, to the possibility of donation, they live in different environments and with different professionals. They are thrown into an unknown world where pain, sadness, suffering, powerlessness and a sense of imminent death become part of their everyday life (8-10). The families begin to experience unique, singular and unparalleled moments through which they had never thought they would go, especially the loss of a family member so quickly.

The possibility of death and/or the certainty of the latter cause disruption, disorganization in the family’s routine and structure, since the loss of a loved one is the deepest of abysses (7,8,10).

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When death is confirmed, a variety of feelings emerge, all involuntary and which cannot be controlled by any human being. It is amidst this flood of feelings that they are informed about the possibility of organ donation and need to make a decision.

When BD occurs, the patient becomes a potential organ and tissue donor and, in most cases, the family is consulted and/or interviewed about this possibility. The current legislation is clear: upon BD, health professionals must offer families the possibility of donation (11). With emphasis on this issue, this study was conducted with a view to understanding the experience of families throughout the journey from severe brain injury, hospitalization, report of death, until the decision on organ donation.

METHODOLOGY

The study consisted of an exploratory, descriptive research of qualitative nature and phenomenological approach, as it sought to unveil the reality lived by family members through a detailed understanding of the study object in its historical context and/or according to its structuration (12,13). Phenomenology allowed an open attitude of the human being to the understanding of experiences from the other's perspective, as well as the search for the phenomenon by means of the one who is going through a given situation. The subjects of this study were family members who have gone through the situation of losing a loved one with severe brain injury that evolved to BD, have been informed about the possibility of donation but have not authorized it.

The families chosen for interview were those which had been grieving for more than six months already, in order to respect the first months of grieving (14). Interviewees were chosen after the surveying of medical records in two hospitals that had notified the Center for Notification, Collection and Distribution of Organs and Tissues [*Centro de Notificação, Captação e Distribuição de Órgãos e Tecidos*] (CNCDO), located in southern Brazil, on potential organ donors.

After authorization from the institutions, these patients were tracked down with the aid of death record books in ICUs; medical records were requested from the Medical Archive Service of patients who had notification sheets as potential donors of the CNCDO. It was thus possible to identify the families that had been interviewed for donation but had not authorized it, totaling 17 families.

After contact by phone and presentation of the work objectives, 15 families agreed to participate in the research. Then an interview was scheduled to be conducted at the place and time chosen by the interviewees; all families chose to do it at their own homes. Three families had two members present in the interview, thus totaling 18 participants.

Data was collected after the signing of a free consent form, in accordance with the legislation that regulates research with human beings. The study was evaluated by the Research Ethics Committee [*Comitê de Ética em Pesquisa*] (CEP) of the UNIDAVI under Protocol 933. Data collection occurred from October 2011 to June 2012 through semi-structured interviews with the following guiding question: "how was it for you to experience the admission of your family member to the ICU, the report of acute and severe brain injury, the brain death diagnosis, the report of death and the interview for decision on organ donation?".

The interviews were recorded, lasting approximately two hours, and fully transcribed, being represented by: interview 1, 2 and so on. For a comprehensive analysis, the three moments of the phenomenological trajectory were used as points of reference: description, reduction and comprehension. In the description phase, the testimonies were transcribed, keeping all original verbal and nonverbal expressions in Portuguese. In the reduction phase, the researchers did exhaustive readings, immersing into the material obtained until the organization of data into units of meaning. In the comprehension phase, the intention was to grasp the meaning related to the phenomenon, the testimonies and the assumptions of the framework, which led to the building of the units of meaning.

RESULTS AND DISCUSSION

Of the 18 family members who participated in the study, 11 were women, and concerning kinship six were mothers, three were fathers, three were siblings, two were wives, two were husbands and two were children. Among them one was illiterate, six had incomplete elementary school, five had complete elementary school, four had incomplete high school and two had complete high school. The average grieving period of the families was 14 months, which was calculated considering the time elapsed since death.

After analysis of the empirical material, two units of meaning arose: (1) Hospitalization and (2) Interview for Decision on Donation.

The Hospitalization unit of meaning comes represented by “impact of the news”, “barriers to communication”, “relationship with the team”, “reporting the BD” and “pain for the loss”. These phenomena present the stages gone through by families from the first contact with the severity, brain injury, need for ICU admission, BD confirmation, report of the death and beginning of grieving.

The meaning of the “impact of the news” reveals the family’s breakdown in the face of the fact occurred: brain injury. It brings the despair about the critical news, the need for ICU admission and the risk of death. The speeches show hopelessness and the impact of the severity:

> We wake up desperate already with the news of the accident. When we got to the hospital it was just despair. The doctors were frank, they said that the crash was really strong, that part of the brain was coming out of the ears and nose. At that moment it seemed that the world was going to. (E2).

The pain and suffering of the families represent their struggle before the severity, the technical language, the insecurity and the uncertainty of recovery or clinical worsening. Being with a family member in the ICU brings hope, but at the same time fear of the severity and doubt about improvement (7-9). The ICU presents itself as a tense and scary environment due to powerlessness, insecurity and lack of dialogue, as well as little attention provided by the team to the family (7-9).

From the very first contact with the ICU the family needs help and guidance. The first information about the clinical condition and severity may trigger a state of shock, causing the family to develop physical, emotional and cognitive changes. These physiological changes may lead to the disruption of the family’s structure, and different feelings emerge. The speeches evidence the shock and the impact after the first information is given.

The “barriers to communication” present the meaning of the difficulty in understanding what is happening. They show that the family receives a lot of information in a short period of time, revealing the obstacles for them to assimilate what the team says, while unveiling the meaning of strength and the need to move on, though impacted by the tragedy. For this reason, they try to overcome the technical barriers and assimilate the information.

> The doctors came and said a lot of things. At that time of despair you cannot understand almost anything. They said that he hit his head, that there was too much pressure inside it, that it was swollen. It was just too much for me. (I10)

> They only told me that he had head trauma, that his brain was swollen, but I did not understand much. They talked a lot, but we understood less and less; you just feel like your head is in the clouds. We could not understand anything, but they kept talking and talking many things we did not understand. (I12)

The discourses show that the family begins to live with the most diverse and varied professionals. The speeches evidence that the meaning and essence of the disregard for the family’s pain, powerlessness, weakness and vulnerability are expressed in the way the professionals act and speak. It is possible to understand that, despite the great load of information, few words had been assimilated and translated by the family.

In this context, the team must realize that every family is unique and possesses singularities and particularities before the facts presented. Pain reveals the truth of suffering in a unique way for each member and represents the need to respect the time that each one takes to understand the phenomenon that is before them. The meaning of time consciousness for each individual is expressed by feelings of sorrow.

The "family's qualitative time" and the "professionals' chronological time" are different. Coexistence and signification reflect opposite behaviors. Face with the family disruption, the professional must develop active listening, embracing and promoting a real, genuine, authentic and respectful relationship (14-17).

> This girl came, said she was a psychologist, sat by our side, explained some things no one had said to us, then we understood a little better. What happened is that we calmed down after that. (I4)

> A social worker was waiting for me. She was the one who told me he was in the ICU. She helped me a lot, she was very kind. She didn't leave my side. She caught me by the arm and took me to see my son. This time is when we need help. (E7)

The speeches show the importance of the team realizing the ideal moment to talk and give instructions. The constitution of this meaning transcends the impact of the news and causes cognitive changes, which may prevent the family from listening to the team. The speeches show the importance of attention, care and kindness on the part of the professionals, aiming at helping, supporting and guiding these families so they can move on.

In the world of these subjects, the phenomenon presented and unveiled was reciprocally translated into meanings and attributed according to the sensitivity and interpretation of each person in this process. The understanding of the phenomenon comprises the interpretation of each human being's experience (18,19). In this study, the conception presented in the speeches of the family members shows that them being provided with a comfortable and adequate room is not enough. For them, the meaning of care implicitly means listening, cordiality, respect and the uniqueness of each member. The respect for the pain of these people is represented by the authenticity and empathy of the team (6-8,10).

A respectful relationship with the other is built up and favored through interpersonal relationship focused on care according to the need exposed by each human being (6-8,10). When interpersonal relationship develops, the other can speak and be listened, thus feeling respected. It is through active listening that empathy develops and, through empathy, the feeling of compassion is awakened in the professional, which mobilizes him/her to help people in their weaknesses.

In this study, the relationship with the team evidenced the need for an analogy based on support, help and trust; a contact expressed through words and gestures is not enough. The professionals must understand that when science reaches its limit and technology can no longer save the life of one's family member, they are left with the responsibility of doing that which is the most important and essential in a profession: caring, comforting and helping with the elaboration of grief by means of a help-based relationship (7, 10,13,20).

"Information about the BD diagnosis" reveals the meaning of the difficulty in decoding, understanding and comprehending what the "BD protocol" represents, as it is difficult for the family to accept that BD means finitude/death.

> The doctor showed a lot of exams; he said that his brain had stopped working. His heart was beating. The doctor explained that it was all because of the machine, but it was hard for us to believe. For us, the important thing was that his heart was beating. (I2)

> I could not believe he was dead, despite everything they had said. When I came close to him, he was just like the other day, warm, heart beating. They said that the brain death had been confirmed, but I believed he could still live. (I12)

All the information, linked to the likelihood of the inevitable, decreases the chances of recovery and makes the confirmation of death more certain. To consider or experience the loss of a family member is to shake the safety of our own world and the world of people around us (8-10,20). Emotional crisis and need for support reveal the fragility of the moment. From the very first contact with the team, the family is under a great emotional impact. The experience involved in this process expresses the essence of pain and sadness, beyond the real sense of the "death" news.

In virtually all cases of BD, the loss was acute, that is, the patient was in great health conditions, but because of a severe brain injury death was inevitable, preventing the family from having time to transpose the facts and adapt to the new reality that has been abruptly and aggressively set.

Considering how quickly everything happened and the conditions under which the death occurred, when in front of bodies apparently kept alive artificially the family ponders and nurtures the idea that there is still life, for believing that death is real only when the heart stops beating. The failure to understand and accept the BD diagnosis is one of the main reasons that lead families to not authorize organ donation because, for believing that their family members are still alive, they do not allow it (16-20).

Therefore, it is necessary that the team begins to inform in a clear, simple and authentic manner all the details of the treatment, severity and prognosis. The current legislation (11) sets forth that, before starting the BD protocol, the family must be advised on this process, exams to be performed and possible results. When facts are clear, the language is simple and there is time to assimilate information, one is more likely to understand and accept what is happening to his/her family member.

The “pain for the loss” presents the meaning of a family’s experience in the face of death, revealing the essence of this pain and the human shock in the face of the loss of a loved one. Sadness and suffering are represented by the consciousness of family members while remembering the phenomenon lived back then, and the stages of grief represent emotional and physical pain. The speeches highlight weakness and suffering.

> That was the hardest time of my life. I felt like I was numb, that I could not breathe and that I would choke so great was the pain. (I6)

> It felt like an anvil had just fallen on your head, crushing your whole body; every single part of your body hurts. Your whole body hurts, you feel like your body no longer obeys you. (I14)

After receiving the news of the death, the family begins to experience the worst pain: the pain that touches the soul, the spirit and the human. It is the pain that embraces the heart without words or analgesia to minimize it; it is the pain that has neither name nor expression, but that shakes the physical, emotional and psychological structure of individuals who have ties with the one who died (13,14). The pain for the loss is signified by every human being in a unique manner, considering the way it presents itself to human consciousness, before the understanding of world, of reality and of the life with the person who has died. It is an unparalleled, unexplainable pain that hurts all parts of one’s body; it is an overwhelming pain, as shown in the speeches above.

Pain is represented mainly by the difficulty of acceptance and the certainty that it is all over. Although finitude is the only certainty of human beings, when it comes many feelings arise: shock, denial, outrage, depression and, finally, acceptance (10,14). This makes this moment more painful, distressing and tougher; such feelings are uncontrollable human reactions and need to be perceived and respected by the team (7,8,14). However, at the same time, they need to be experienced by the family. The feelings expressed in the grieving process are physiological, a part of human reaction. There is no way to control them, but they can be minimized by the team.

The Interview for Organ Donation unit of meaning is represented by “information about donation” and “decision-making”. This unit of meaning brings implicitly the death news phenomenon and the possibility of donation, a moment when the family needs to accept the finitude and decide on whether they will donate the family member’s organs.

In the course of the previous speeches, the families show the concrete, existing and effective sense of suffering when going through a situation of hospitalization, death and the decision to donate the organs or not. The meaning of organ donation for these families came encompassed by doubts and insecurities presented and expressed by them when they did not authorize it. Certainly, one of the facts that led the family to opt for not donating was unveiled by the uncertainty of death.

From this perspective, the study judged as wise the team communicating each stage at different times, that is, after the death is reported the family should have some time to assimilate this information. Afterwards all questions the family has about what has been said can be answered, and only after all family members manifest they have understood the death the possibility of donation should be informed. The time between the report of the death and the talk about donation done by the team was revealed as one of the main factors that allow families to organize their thoughts and make the best decision.

"Information about donation" presents the meaning of the moment when the possibility of donating organs and tissues is offered, during which professionals clarify step by step how this process occurs. In this study, the meaning of this information was revealed as disrespect for the pain of the families, since they believed that their loved ones were still alive.

> He asked if we wanted to donate his organs. You ARE there losing a son, his heart IS beating, and they ARE already asking for his organs. (I9)

> They asked FOR us to donate his organs. It is hard, because they said that right after telling he was dead and we had not even believed yet he was dead. (E2)

Failure to understand the pain of families facing death in addition to little sensitivity to identify the stages of grief were represented by the inopportune time to talk about the "organ donation" subject. Clarifications on donation is a delicate stage and requires emotional preparation from professionals, since each member within the family system reacts differently to the news. Information about donation should be given to the family only after the team sees that these people have emotional conditions to receive it (16-20).

Yet it is essential that professionals approach the donation topic tactfully and gently. One should remember that for these people nothing else matters, because they are losing someone. It is as though tomorrow did not exist. The news of donation must be given with the aim of presenting to the family the steps of this process, in order to answer all questions. Information should never be provided by means of pressure, as trade currency or bargaining (16-20).

It is important to realize that the professional is there to inform; the families are not obliged to authorize the donation. One should remember that the main objective is to help these families, not to cause them more pain and suffering.

"Decision-making" reveals the meaning of how difficult it is to decide on whether or not to authorize the donation. It presents the little time to assimilate the death, and the unawareness of the deceased's desire in life concerning donation.

> The time they give is too short for us to decide. We do not know what to do, it is a lot of pressure, we need more time, we cannot think. I had not even believed yet he was dead, so I thought it was better to say no. (I10)

> They did not wait to talk about donation. Honestly, I was not able to say anything and I had never heard my son say anything about that. Come on, I had just heard that my son was dead, how could I make such a decision? (I14)

The family's decision-making on organ donation unveiled ethical, moral, religious issues, beliefs, ways of acting, worldviews, and brought the meaning of the feelings triggered in the face of acute loss, which can generate pain and dissatisfaction. Decision-making involves overcoming barriers, respecting, not judging; it represents the understanding of and respect for the empirical knowledge of families about the subject and each one's ability to understand at their own pace. It involves the capturing of their representations and comprehension models, their weaknesses, myths and ignorance (10,14,20). In this context, it is understood that if the patient has expressed in life his/her desire to donate his/her organs or not, the family feels better when making the decision (16-20).

There is a perceptible, clear and evident need to change the context and reality of health institutions when it comes down to assisting families in this process. The focus should be on the pain for the loss, on human care, not only on the cold technicality of diagnoses and clinical procedures, which, in most cases, prevents the professional from showing compassion in the process and establishing a help-based relationship with these people.

FINAL CONSIDERATIONS

The study allowed understanding the trajectory of families during the process of hospitalization of patients with severe brain injury, BD, and decision-making on organ donation. It was possible to observe that health team needs to use clear, simple information without technical terms at all stages of the process.

Families need to have their pain respected and should be assisted since the first information is given until the death is reported. This trajectory showed that pain and suffering are part of the entire hospitalization process. Besides, it was possible to see that the team should inform the family about organ donation only after all members have understood and accepted the death. Time has proved to be essential for the acceptance of death and the encoding of information about organ donation.

Hopefully, this study might be able to encourage health professionals to reflect on their attitudes and behaviors by means of the experience of families facing the pain for the loss and the issues surrounding decision-making on donation.

COMPREENSÃO DA VIVÊNCIA DA FAMÍLIA FRENTE À HOSPITALIZAÇÃO, MORTE ENCEFÁLICA E ENTREVISTA PARA DOAÇÃO DE ÓRGÃOS

RESUMO

O presente estudo buscou compreender a vivência da família no processo de hospitalização do familiar, morte encefálica e entrevista para a doação de órgãos. Trata-se de uma pesquisa exploratória, descritiva, de natureza qualitativa, com abordagem fenomenológica. Os sujeitos foram 15 famílias de pacientes que tiveram lesão neurológica grave e aguda, evoluíram com diagnóstico de morte encefálica, cujas famílias foram entrevistadas para a doação de órgãos e não a autorizaram. Após análise do material empírico, surgiram duas unidades de significados: (1) Hospitalização; e (2) Entrevista para Decisão sobre Doação. Essas unidades de significados são representadas pelo “impacto da notícia”; “barreiras na comunicação”; “relação com a equipe”; “informação da morte encefálica”; “dor da perda”; “informação sobre doação” e “tomada de decisão”. A trajetória vivenciada pelas famílias é difícil e se faz necessário repensar o atendimento a essas pessoas pelos profissionais de saúde durante esse processo. O tempo entre a comunicação da morte e a informação sobre a doação de órgãos é importante para que a família possa organizar seus pensamentos e tomar a melhor decisão. O estudo mostra que esse tempo não foi respeitado.

Palavras-chave: Enfermagem. Família. Morte encefálica.

COMPRENSIÓN DE LA VIVENCIA DE LA FAMILIA FRENTE A LA HOSPITALIZACIÓN, MUERTE ENCEFÁLICA Y ENTREVISTA PARA DONACIÓN DE ÓRGANOS

RESUMEN

El presente estudio buscó comprender la vivencia de la familia en el proceso de hospitalización del familiar, muerte encefálica y entrevista para la donación de órganos. Se trata de una investigación exploratoria, descriptiva, de naturaleza cualitativa, con abordaje fenomenológico. Los sujetos se compusieron de 15 familias de pacientes que tuvieron lesión neurológica grave y aguda, evolucionaron con diagnóstico de muerte encefálica, cuyas familias fueron entrevistadas para la donación de órganos y no la autorizaron. Después del análisis del material empírico, surgieron dos unidades de significados: (1) Hospitalización; y (2) Entrevista para Decisión sobre Donación. Estas unidades de significados son representadas por el “impacto de la noticia”; “barreras en la comunicación”; “relación con el equipo”; “información de la muerte encefálica”; “dolor de la pérdida”; “información sobre donación” y “toma de decisión”. La trayectoria vivida por las familias es difícil y se vuelve necesario repensar la atención a estas personas por los profesionales de salud durante este proceso. El tiempo entre la comunicación de la muerte y la información sobre la donación de órganos es importante para que la familia pueda organizar sus pensamientos y tomar la mejor decisión. El estudio señala que este tiempo no fue respetado.

Palabras clave: Enfermería. Familia. Muerte encefálica.

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