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ORIGINAL ARTICLE

Brain death communication with parents of children and adolescents: care strategies

Comunicação da morte encefálica junto aos pais de crianças e adolescentes: estratégias de cuidados

Comunicación de la muerte cerebral a los padres de niños y adolescentes: estrategias de atención

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ABSTRACT

Objectives: to identify care strategies developed by professionals from critically ill patients' units in communicating BD with parents of children and adolescents. **Methods:** an exploratory and descriptive research with a qualitative approach, carried out in two health institutions between October and December 2019, through semi-structured interviews. Data analysis took place through content analysis. **Results:** twenty-one professionals participated. Three care strategies were identified: actual clinical situation in suspected brain death; sensitizing families to the real clinical situation after brain death diagnosis; and time to assimilate the death information. **Final Considerations:** the care strategies for communicating brain death to families identified in this study present the possibility of subsidizing health managers in training and support promotion for professionals in care practice. Moreover, they can be incorporated and validated in the care practice of the studied context.

Descriptors: Patient Care; Nursing, Team; Coma, Post-Head Injury; Family; Adolescent Health.

RESUMO

Objetivos: identificar estratégias de cuidados desenvolvidas pelos profissionais das unidades de pacientes críticos na comunicação da morte encefálica junto aos pais de crianças e adolescentes. **Métodos:** pesquisa exploratória e descritiva com abordagem qualitativa, realizada em duas instituições de saúde entre outubro e dezembro de 2019, por meio de entrevistas semiestruturadas. A análise dos dados ocorreu através da análise de conteúdo. **Resultados:** participaram 21 profissionais. Foram três estratégias de cuidados identificadas: real situação clínica na suspeita de morte encefálica; sensibilizando a família da real situação clínica após o diagnóstico de morte encefálica; e tempo para assimilar a informação da morte. **Considerações Finais:** as estratégias de cuidados para comunicação de morte encefálica às famílias identificadas neste estudo apresentam a possibilidade de subsidiar gestores de saúde na promoção de capacitações e apoio aos profissionais na prática assistencial. Além disso, podem ser incorporadas e validadas na prática assistencial do contexto estudado.

Descritores: Morte Encefálica; Criança; Adolescente; Equipe de Assistência ao Paciente; Enfermagem.

RESUMEN

Objetivos: identificar las estrategias de atención desarrolladas por profesionales de pacientes críticos en la comunicación de la muerte encefálica con los padres de niños y adolescentes. **Métodos:** investigación exploratoria y descriptiva con enfoque cualitativo, realizada en dos instituciones de salud entre octubre y diciembre de 2019, a través de entrevistas semiestructuradas. El análisis de los datos se llevó a cabo a través del análisis de contenido. **Resultados:** participaron 21 profesionales. Se identificaron tres estrategias de atención: situación clínica real ante la sospecha de muerte encefálica; sensibilizar a la familia sobre la situación clínica real tras el diagnóstico de muerte encefálica; y tiempo para asimilar la información de la muerte. **Consideraciones Finales:** las estrategias de cuidado para comunicar la muerte encefálica a las familias identificadas en este estudio presentan la posibilidad de subsidiar a los gestores de salud en la promoción de la formación y apoyo a los profesionales en la práctica del cuidado. Además, pueden ser incorporados y validados en la práctica asistencial del contexto estudiado.

Descriptores: Muerte Encefálica; Niño; Adolescente; Grupo de Atención al Paciente; Enfermería.

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INTRODUCTION

Throughout their professional lives, health staffs in critically ill patients' units, Intensive Care Units (ICU), emergency rooms or emergency services face different challenges, and therefore need to seek strategies along this path to experience and face these moments. Death communication for parents of children and adolescents due to severe neurological injury with a clinical diagnosis of brain death (BD) has been one of these challenges(1-3).

Often, these deaths are associated with acute deaths, caused by severe neurological injuries resulting from trauma from falls, domestic accidents, traumatic brain injury and meningitis and/or encephalitis in children. In infants, the most common cause is hypoxic-ischemic encephalopathy, while in adolescents, there is a predominance of traumatic brain injury(4-7).

Each country presents its own legislation to prove BD. In Brazil, BD in children and adolescents is diagnosed based on the criteria established by the Federal Council of Medicine (CFM), through Resolution 2173 of 2017: two clinical exams performed by qualified physicians and a complementary exam. Moreover, compliance with the interval between clinical examinations is required: 24-hour interval for children between 7 days (term newborn) and 2 incomplete months; 12-hour interval for children between 2 months and incomplete 24 months; and one-hour interval between exams for children over 24 months(8).

In view of these completed exams and after all signed reports, patients, children, or adolescents are considered dead, and the health staff involved in family care and welcoming must conduct the death communication. This communication related to an abrupt death for parents of children and adolescents is a complex activity that is difficult to resourcefulness for professionals. Many professionals have children at the age of these patients, and there is an intimate relationship established with both patients and parents during the hospitalization period. Moreover, the general population believes that this public (child and adolescent) should not die before parents(9-10). Thus, death communication due to BD becomes a difficult task, among many that this professional needs to perform in their care practice.

Thus, this activity in daily practice, in most cases, becomes a moment that generates several feelings, such as anguish, fear and stress, and may also trigger different emotions in relation to the age factor and circumstance of death(10). Studies indicate weaknesses by the health staff to conduct the communication of this death(5,11), since dealing with this situation becomes even more painful due to these professionals not feeling prepared for communicate. The staff recognizes their limits in the face of this harsh and cruel reality with families(9,12).

In this scenario, professionals need to develop qualified care strategies to support daily practice and support them during death communication, especially when it is related to BD. The need to acquire knowledge, skills and attitudes in breaking bad news makes this process more serene, adding quality and safety to the assistance provided to family members, even more so when these professionals have beliefs, values and cultural issues related to death that are expressed in limitations at the time of communication(5,9).

Thus, it is understood that this study's relevance and impact are aimed at sharing care strategies carried out by professionals in the context of breaking bad news for parents of children and adolescents, proposing improvements in care practices to managers, in addition to emotional support for the staff that is on the front line.

Considering the reality presented, the study had the following guiding question: what are the care strategies developed by professionals from critical patient units in BD communication to parents of children and adolescents?

OBJECTIVES

To identify care strategies developed by professionals from critically ill patients' units in communicating BD with parents of children and adolescents.

METHODS

Ethical aspects

The research follows all the legal precepts of Resolution 466/2012 of the Brazilian National Health Council, which regulates research involving human beings. At all times, the professionals' anonymity was maintained. The study was approved by the Research Ethics Committee (REC) of the two hospitals in which the research was developed.

Study design

This is an exploratory and descriptive research with a qualitative approach, based on Consolidated Criteria for Reporting Qualitative Research and supported by Bardin's methodological framework for data analysis(13).

Study setting

This study was developed between October and December 2019 in the ICUs of two health institutions, a reference in high complexity, standing out in the care of multiple trauma patients and in need of neurosurgical intervention, with high rates of BD notification to the State Transplant Center (CET - *Central Estadual de Transplantes*). Both institutions are a reference in child and adolescent care in the municipalities of the region.

Data source

Health professionals working in ICUs of these institutions were participated in this research. The sample was intentional and random, seeking volunteers in the three work shifts (morning, afternoon and night). Physicians, nurses, and nursing technicians participated in this research. Professionals who work in the BD diagnosis process, death communication and family welcoming were selected.

We opted for the inclusion of nursing professionals because they participate in family welcoming and indirect involvement in BD protocol organization and communication of this event. Physicians professionals were included, due to responsibility for BD diagnosis and death communication to families.

Professionals relocated to cover vacations or leave of other employees were not included.

Data collection and organization

After approval of the project by the institutions' REC, contact was made with the administrative management of each site explaining the research. After this contact, a previous meeting was scheduled with the physician and nursing coordinator of each ICU. As soon as these professionals agreed with the research development, the researchers contacted the institutions' professionals, presenting the project and the objectives. Based on the agreement to participate in the study, the Informed Consent Form was signed in two copies.

Data collection was based on a semi-structured interview script, containing five questions related to professional profile and an open-ended question: tell me about the strategies used by you with parents of children and adolescents in BD communication. The interviews were conducted in restricted rooms, in the hospital unit itself, recorded, transcribed, and then validated with participants. At the time of transcription, they were identified as Phy 01, Phy 02, Nur 01, Nur 02, NT 01, NT 02, and so on. The interviews lasted about 40 minutes.

The interviews were conducted as follows: initially, one of the researchers with the most experience in qualitative research, as well as experience in family interviews for more than 20 years and with training in communication of critical situations, conducted the first interviews. Together with her, another researcher who participated in this stage was a psychologist with experience in welcoming families at the time of the family interview. Two other researchers were prepared at this time, participating as listeners in four interviews, and then only conducted other interviews.

Data analysis

Data analysis and interpretation followed the content analysis proposed by Laurence Bardin(14). It was divided into three phases: pre-analysis, material reading, organization and systematization of information and initial ideas, allowing developing the first impressions about the approached content; data exploration, in which the interviews' emerging contents were coded; treatment and interpretation of results, composed of analysis based on the thematic presence in lexical approximations arising from the respondents.

RESULTS

Twenty-one professionals participated in this study. Regarding education, nine are nurses, seven are physicians and five are nursing technicians. The mean age was 38.2 years, and the mean time worked at the institution was 6.8 years.

As for the training of these professionals, about breaking bad news, 100% of physicians reported being qualified to perform this activity. These professionals reported having participated in courses and training scans related to death communication. As for nurses, 77.8% (7) stated that they had participated in training to act in family care at the time of breaking the news of death and in the grieving process elaboration. As for nursing technicians, 100% of them report not having training to be with families in the grieving process.

Through the research, three care strategies emerged for BD communication development with parents of children and adolescents: actual clinical situation in suspected brain death; sensitizing families to the real clinical situation after brain death diagnosis; and time to assimilate the death information. Figure 1 represents the analysis grid that directed the elaboration of care strategies. For greater understanding, the strategies will be presented in detail after the figure.

Actual clinical situation in suspected brain death

This strategy shows that the health staff is concerned with explaining the details about the case, as well as the meanings and functions of the equipment being used.

Considering the information obtained from semi-structured interviews, it is understood that the staff always seeks to be as understandable as possible about patients' clinical situation. From the opening of a protocol to BD diagnosis, the staff is concerned about establishing a relationship of trust with families. Thus, they understand that making the severity clear to family members, as well as the prognosis and the possibility of progression to BD, is one of the care strategies that helps families to understand the scenario, in addition to demonstrating that the staff is being honest with these family members.

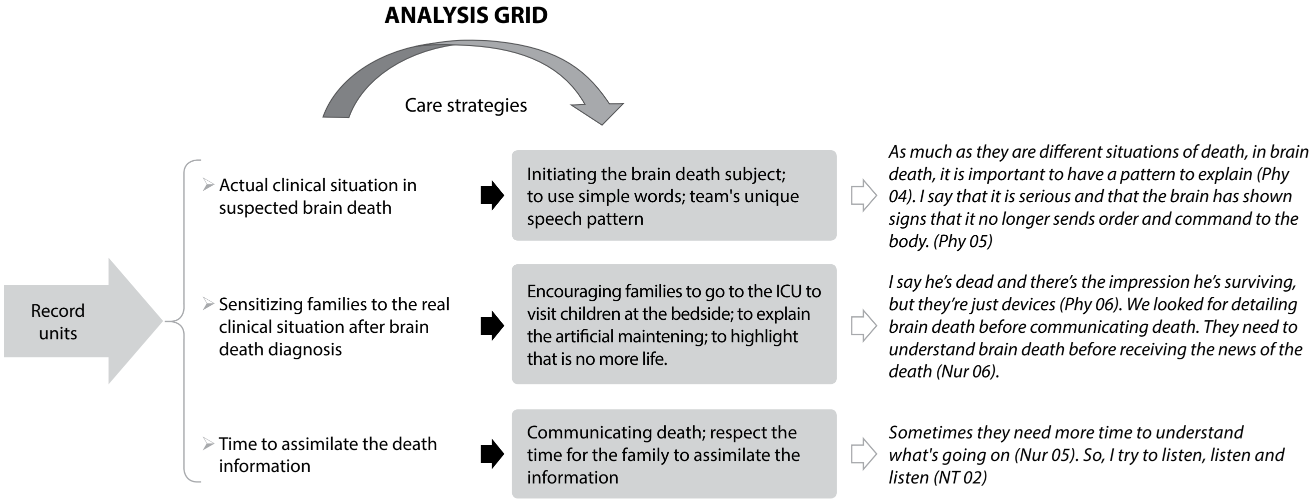

Figure 1 – Analysis grid: care strategies for death communication with parents of children and adolescents, Florianópolis, Santa Catarina, Brazil, 2021

> *We start by saying that there is a suspicion and that the brain has swelled, I like to explain even if they have little understanding of how it works. I explain that it has the skull, and that this skull has a limit to how much the brain can swell, and when it goes beyond that limit, the brain ends up receiving less flow of oxygen and that's why it ends up dying. Another way I talk is that there's a little hole in the back of the skull, so, when the brain swells, the part responsible for the heart and breathing ends, passing through this little channel and this part ends up having no more function, it cannot pass through the nerve fibers for the heart to work and that means brain death.* (Phy 08)

> *We always need to be very clear with them, always tell the truth, we need to carefully go through everything that happened to the child. I still feel like the medical staff didn't have the guts to talk about the severity from the start.* (Nur 07)

> *We are gradually introducing the theme. We inform you from the beginning. He's not fine, he's bad, he's not responding. We advise several times, it is also very exhausting for families, as they are asked to stay there constantly.* (Nur 05)

Sensitizing families to the real clinical situation after brain death diagnosis

This strategy demonstrates that the staff seeks to talk and discuss with family patient's the real situation after the medical staff informs patients' diagnosis. An example is encouraging families to go to the ICU to visit children at the bedside, having at this moment the opportunity to explain the devices used to maintain organic functions and reaffirm that it is a death. The staff points out that this is an important moment, since families need to leave the ICU understanding that a patient is dead, even if artificially maintained. Also, as a strategy for this understanding, the staff makes it possible for families to be present at the time of BD diagnosis protocol examinations. It is observed in the rhetoric that follows.

> *I always start by talking about the brain death protocol and the exams, I assure you that this whole process is very safe. At the end of each exam, we give the result. Thus, they understand that there is no going back, and it is easier to say that the protocol has been closed and he is dead.* (Phy 07)

> *I like being at the bedside, explaining everything, what's going on. I like to show what's going on with the child because I think it creates more trust than being in a room with a paper in your hand and talking about your child. I don't think empathy is created in a room*. (Phy 08)

> *When a family receives the news of death, we try to let them go close to the bed, then we explain in detail the function of the devices and reinforce that it is all artificial.* (Nur 03)

> *It is a moment when they are very fragile and in fact, they do not listen to 90% of what we say. So, it must be direct and clear without losing the tenderness for families. I always like to take them to the bedside after communicate death to solve all heartbeat doubts.* (Phy 04)

> *I say he's dead and there's the impression he's surviving, but they're just devices. His brain is dead, the machines are making his heart still beat. It's the drug devices with all those bombs that you see in front of the bed. I usually take them to the bedside after communicate death.* (Phy 06)

Time to assimilate the death information

This strategy shows the staff's respect for the moment of vulnerability in which family members find themselves. It is demonstrated by the development of empathy by the health care staff. The importance of understanding that each family is unique is reinforced, behaving in a unique way in the elaboration of their grieving process. By understanding this reality, professionals realize that the validation of the time that a family needs to assimilate what has been said is fundamental. The need to provide time, as well as welcoming, listening and care, emerged in the following statements:

> *They need their time to process everything that was said after death communication.* (Nur 04)

> *The important thing is to individualize and respect the family's time when they receive the death information. We try to put ourselves in each other's shoes.* (Nur 03)

> *When they receive the death information, we try to leave them alone. We understand that that moment is for them, mother with son, father with son. We stay further away and if they need us, they call.* (Nur 06)

> *After the death communication, the nurse ends up supporting families and tries to do the best with families, giving support, taking care of them, and explaining in greater detail what the medical staff said. We spent a lot of time with them. In these moments we realize how great the suffering is, especially for mothers. Their crying is desperate. It echoes in people's ears. This suffering is very strong.* (Nur 07)

> *I always try to go with the nurse and the psychologist to break the news, because I have nine more patients to take care of. That way, they stay with families giving them support and affection when I talk about death.* (Phy 09)

> *After the death information, when the mothers return to the children, I listen, I try to hold their hands, give them water, and ask them to be strong.* (NT 05)

DISCUSSION

The discussion about critical situation communication in health environments has been improved and expanded in order to propose safety, support, and improvements in health professionals' work, especially in the scenario of BD. Faced with death communication, both health professionals and family go through moments of fear, doubts and insecurity. Thus, professionals' support during this process is fundamental, from illness, prognosis, complications, possible cure or sequel to the possibility of death. Families see the health staff in this process as a key to safety, trust, and nurturing(15-17).

Regarding participant profile, the mean length of time working in critical care units was higher six years ago. Moreover, more than 70% of physicians and nurses participated in communication courses in critical situations and welcoming families.

The multidisciplinary staff preparation to communicate a critical situation, as well as to welcome these people in the death and dying process, brings positive implications for the health staff and emotional support for family members who are elaborating the grieving process. Studies show that professional training in the death and dying process helps both professionals and family members, since this professional becomes qualified and safe to meet families' demands and assist these people in grief preparation, while being able to identify feelings and phases of grief. Still, these same authors point out the importance of therapeutic environments to professionals in the face of death(1,15).

The care strategies observed in this study are aimed at supporting professionals in the death and dying process, promoting a greater understanding of families about the context of their relative, in addition to conducting BD diagnosis protocol with respect to the vulnerabilities presented in the process. Professionals make it clear, because it is a death caused by serious neurological injury, that it is an irreversible condition. The first strategy shows the importance of professionals gradually introducing the critical situation, invisibility, and the possibility of death, using simple words and avoiding the use of technical terms.

When developing empathy, professionals put themselves in a listening position, approaching the situation, knowing the misunderstandings of the facts presented by families, especially in BD. Given this understanding, the staff develops the strategy of gradually decoding what is happening, while revealing the severity and possible outcomes from performing the necessary BD protocol examinations. Faced with such a strategy, it is noted that the staff seeks respect and truth to conduct conversations with parents. In the literature, it is possible to find protocols and guidelines that support the health staff in notifying the critical situation. Such materials bring as a key point for conducting death communication the planning of this care, in addition to staff emotional preparation, the importance of developing empathy, respect and authenticity(1,18-19).

Canadian guidelines created in 2017 to develop good practices in conducting BD diagnostic protocol and death communication point out fundamental strategies, which involve the staff's ethical attitude, information eligibility, artificial support of this patient, combined with the need to inform that, after death, this patient becomes a potential organ and tissue donor(20).

In Brazil, current legislation determines that, before the start of BD diagnosis protocol, it is necessary for the staff to inform the steps of this protocol, in addition to pointing out the possible outcomes(21). Thus, it is understood that the strategy used by the research participants is consistent with current legislation, as well as international protocols, which seek best practices in death communication.

Regarding the second strategy, it is noted that the staff is concerned with explaining about the artificial maintenance of patients in BD, when they remain until the family interview for organ and tissue donation in case, they are a potential donor. This study highlights the importance of caring for families regarding donation indications, due to the impression that families have that their loved one is still alive, resulting from an artificial heart rate. However, it is necessary to consider the vulnerability and religious beliefs in the face of the death and dying process experienced by families. This care strategy was described as being performed at patients' bedside, enabling parents or family members to clarify doubts and begin to assimilate the information.

Other studies on the subject reveal that there is no unique and standard staff language when the theme is death communication due to BD. There are still many ways to communicate this death to family members and the difficulty in accepting and understanding this condition. All these factors are possibly linked to professionals' low capacity to conduct this speech, cultural, emotional, and religious issues, in addition to personal beliefs(11,22-24). Given this scenario of fragility, it is understood that the strategy adopted by professionals in this research aims to help parents in coding and assimilating the reality imposed on them, which involves distancing themselves from existential terminality.

The third strategy focuses on the need and the importance of time. This study points to chronological time as a fundamental strategy to be respected by professionals in the studied context. The staff understands the need to provide time for family members to understand the information conveyed: death communication. This time is recognized by the staff as essential for parents to be able, in addition to coding what was said, to organize their thoughts, so that doubts arise, in addition to the importance of respecting their individual family space and practicing welcoming. Participants mention that this is a unique and intimate moment for each family, which needs space to share the despair, impact and frustration in the face of loss. However, these professionals also reinforce that the staff needs to approach family members, demonstrating a willingness, through sensitive listening, in addition to emotional support and welcoming.

The findings of this study support other studies developed on the theme, demonstrating that time is essential for family members to organize thoughts, assimilate what was said, consider and assess the context, in addition to dividing the grieving, crying and support process. All this, with the health staff's attention, which should be present(20,25-30).

Finally, the study presents three care strategies, which are developed by professionals, for the development of BD communication with parents of children and adolescents, bringing the opportunity for other health staffs to use this care in practice, to assess the impact of these strategies on daily death communication.

Study limitations

A limitation is the professionals' participation, due to recall of difficult moments and fragility in the entire BD process. Another limiting aspect was the time factor, in availability for the interviews, by multiple activities.

Contributions to health

The study reflects as possibilities the understanding of care developed by professionals, given the scenario of acute death of children or adolescents as a result of an BD, enabling training promotion, communication protocol organization and experience sharing that can be incorporated into care practice in critical patient units, promoting quality family care, safety for the staff professionals themselves and support for breaking bad news in this difficult context.

FINAL CONSIDERATIONS

The study revealed three care strategies at different times in the BD communication process, from the clarification of suspected diagnosis, welcoming in the process of understanding and welcoming of information and strategies for coping with the grieving family.

These aspects refer to clarity and frankness in communication, use of accessible vocabulary and according to each family's or family member's particularities, in addition to objectivity, with lightness, when referring to equipment and care process and procedure flow. The research presented strategies that prioritize, amidst professionals' own coping with the BD situation, respect for parents' time to codify, assimilate and understand the message conveyed from the reality of death.

SUPPLEMENTARY MATERIAL

The data collected in this survey is deposited in SciELO Data at: https://doi.org/10.48331/scielodata.QHWGOC.

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