








BRAIN DEATH: HEALTH TEAM'S EXPERIENCE WITH PARENTS OF CHILDREN AND ADOLESCENTS

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ABSTRACT

Objective: to understand the health team's experience with parents of children and adolescents during the brain death protocol stages.

Method: a qualitative and exploratory research developed in two health institutions of high complexity and reference in the care of children and adolescents with polytrauma. Participants were health professionals from critical patient units. Data collection took place between October and December 2019 through semi-structured interviews. For content analysis, we used the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* as support.

Results: twenty-one professionals (physicians, nurses and nursing technicians) participated in the study. The general corpus consisted of 21 texts, separated into 123 segments, with the emergence of four classes. The study shows feelings of support and compassion at all brain death protocol stages. In the protocol opening stage, the team's emotions are focused on the actions of clarifying and revealing information in this process, in addition to pointing out the need for the team to detail the step by step of the exams to be performed. In the communication of death stage, the feeling of being, caring for and welcoming the family relates to other feelings experienced by them.

Conclusion: the study reveals that the health team experiences unique feelings during the brain death protocol in the reality of children and adolescents, revealing the team's concern with being with the family, paying attention and caring for the pain of loss.

DESCRIPTORS: Brain death. Tissue and organ procurement. Nursing care. Child. Adolescent. Family.

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MORTE ENCEFÁLICA: VIVÊNCIA DA EQUIPE DE SAÚDE JUNTO AOS PAIS DE CRIANÇAS E ADOLESCENTES

RESUMO

Objetivo: compreender a vivência da equipe de saúde junto aos pais de crianças e adolescentes durante as etapas do protocolo de morte encefálica.

Método: pesquisa exploratória de abordagem qualitativa desenvolvida em duas instituições de saúde de alta complexidade e referência no atendimento a crianças e adolescentes com politrauma. Os participantes foram profissionais de saúde das unidades de pacientes críticos. A coleta de dados ocorreu entre os meses de outubro e dezembro de 2019 por meio de entrevistas semiestruturadas. Para análise de conteúdo, utilizou-se como apoio o *software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*.

Resultados: participaram do estudo 21 profissionais (médicos, enfermeiros e técnicos de enfermagem). O corpus geral foi constituído por 21 textos, separados em 123 segmentos, emergindo quatro classes. O estudo mostra sentimentos de apoio e compaixão em todas as etapas do protocolo de morte encefálica. Na etapa da abertura do protocolo, as emoções da equipe estão voltadas às ações de clarificar e transparecer informações deste processo. Além de apontar a necessidade de a equipe detalhar o passo a passo dos exames a serem realizados. Na etapa da comunicação da morte, a sensação de estar, cuidar e acolher a família se conecta com outros sentimentos experimentados por eles.

Conclusão: o estudo revela que a equipe de saúde vivencia sentimentos únicos durante o protocolo de morte encefálica na realidade de crianças e adolescentes. Revela também a preocupação de a equipe em estar com a família, atentar e cuidar ante a dor da perda.

DESCRITORES: Morte encefálica. Obtenção de tecidos e órgãos. Cuidados de Enfermagem. Criança. Adolescente. Família.

MUERTE ENCEFÁLICA: EXPERIENCIA DEL EQUIPO DE SALUD CON LOS PADRES DE NIÑOS Y ADOLESCENTES

RESUMEN

Objetivo: comprender la experiencia del equipo de salud con los padres de niños y adolescentes durante las etapas del protocolo de muerte encefálica.

Método: investigación con enfoque cualitativo y exploratorio desarrollada en dos instituciones de salud de alta complejidad y referencia en la atención de niños y adolescentes con politraumatismo. Los participantes fueron profesionales de la salud de unidades de pacientes críticos. La recolección de datos ocurrió entre octubre y diciembre de 2019 a través de entrevistas semiestruturadas. Para el análisis de contenido se utilizó como soporte el *software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*.

Resultados: participaron del estudio 21 profesionales (médicos, enfermeros y técnicos de enfermería). El corpus general estuvo compuesto por 21 textos, separados en 123 segmentos, surgiendo cuatro clases. El estudio muestra sentimientos de apoyo y compasión en todas las etapas del protocolo de muerte cerebral. En la etapa de apertura del protocolo, las emociones del equipo están enfocadas en las acciones de esclarecimiento y revelación de información en este proceso, además de señalar la necesidad de que el equipo detalle el paso a paso de los exámenes a realizar. En la etapa de comunicación de la muerte, el sentimiento de ser, cuidar y acoger a la familia se conecta con otros sentimientos vividos por ellos.

Conclusión: el estudio revela que el equipo de salud vive sentimientos únicos durante el protocolo de muerte encefálica en la realidad de los niños y adolescentes, revelando la preocupación del equipo por estar con la familia, prestar atención y cuidar el dolor de la pérdida.

DESCRITORES: Muerte encefálica. Obtención de tejidos y órganos. Atención de enfermería. Niño. Adolescente. Familia.

INTRODUCTION

The Brain Death Diagnostic Protocol (BDDP), since 1997, in Brazil, as established in the Federal Council of Medicine (FCM) Resolution, has been used to diagnose brain death (BD) and thus confirm BD and, consequently, patient death. Such resolutions define that a human being who has irreversibly lost circulatory and respiratory functions or the brainstem and cerebral cortex functions is dead¹⁻³.

BDDP involves distinct stages, and each of these stages must be carefully followed by the health team. According to the legislation in force in the country, the BDDP phases are communication about the need to initiate the protocol; demystification of each stage; development of clinical and complementary exams; information to the family about the results of these tests; welcoming the family; hemodynamic maintenance of patients; and communication of death after all results are completed²⁻³.

Such stages may have different times when this diagnosis involves the scenario of children and adolescents, due to the need to carry out two clinical exams by qualified physicians and a complementary exam. Respecting the interval between clinical examinations, it is established for children between seven days (newborn to term) to two incomplete months an interval of 24 hours. For children between two months and 24 incomplete months, an interval of 12 hours is established. Above 24 months, the exam interval is one hour²⁻³.

Regarding the recommendations for tests and procedures to determine BD, the literature shows that there are differences between countries. A study produced in the United States, combined with a systematic review, reveals different stages between the exams and the intervals of these exams⁴⁻⁵. However, even in the face of different guidelines regarding the beginning and procedures related to BDDP, what remains is the need for analysis of clinical parameters by the health team, as well as observation time for diagnosis to be initiated, clinical interval between assessments, in addition to clinical exams performed by different physicians, apnea test and a complementary exam considering the neurological injury and age of patients undergoing this diagnosis^{1-2,4-5}.

After all these stages are completed, and all test results are conclusive for BD, patients are considered dead¹⁻³. Despite all these determinations and legal support, the topic is still seen as taboo due to the sum of several issues associated with cultural factors, beliefs, principles and values, since each professional and each family member keep their individual representations about death⁶⁻⁷. Thus, those involved in BDDP go through unique, distinct and difficult moments, considering emotional and cultural aspects. Professionals, facing the loss of a patient in BD, and the family facing the loss of a loved one^{6,8-9}.

Considering the above, assimilation of information and news of death tends to be more challenging in the face of BDDP. This is because, in most cases, this death is associated with acute health situations, and children/adolescents are artificially maintained after the protocol is concluded and death is reported, when there is a possibility for organ and tissue donation. Parents, impacted by the information of the beginning of BDDP followed by communication of death, look at their children and feel like they are asleep, while the team is faced with the reality and the need to maintain this body, even if artificially, as determined by legislation^{2-3,7, 9-10}.

Considering such particularities, the death resulting from a BDDP may involve confrontation of the cultural conception of life cycle, since we have as a cycle to be born to grow, to become an adult, to grow old and then to die^{7,11-14}. However, there is a need to deconstruct this paradigm as it generates an outdated operating mode that affects professionals working with critically ill patient units, especially those who participate in BDDP. These conceptions make the moment even more stressful and surrounded by denial from both the parents and the team itself^{7,11-14}.

Studies indicate that professionals, when communicating death resulting from BDDP, present discomfort and insecurity, which can generate these same feelings at all stages of BDDP⁹⁻¹⁰. However,

it was identified that professionals who are confident about BDDP and communication of death tend to have an easier time identifying emotions of pain in families in the face of loss and greater ability related to empathy and compassion towards these people^{9,15}.

Therefore, the relevance of this study is based on the need to know how the team experiences this reality with parents of children/adolescents that permeated the BDDP stages, in order to understand the team's experience in this scenario, identifying improvement strategies for practice that can support the team in all BDDP stages.

By understanding this reality, it will be possible to advise these professionals through training, elaboration of guides and protocols and welcoming spaces that strengthen support for them throughout the BDDP stages.

Given the reality presented, the study had as its guiding question: what is the health team's experience of critical patient units with parents of children and adolescents during the BDDP stages? The aim was to understand the health team's experience with parents of children and adolescents during the BDDP stages.

METHOD

This is exploratory research with qualitative approach, supported by Laurence Bardin¹⁶ framework for data analysis. The study was carried out at two health institutions, which are a reference in high complexity for polytrauma, located in a capital city in southern Brazil. Institution 1 corresponds to a public health hospital considered large in child and adolescent care in Latin America. Institution 2 is a philanthropic health hospital, being a reference in child and adolescent care for 25 municipalities.

Health professionals working in critical patient units in the two institutions mentioned participated in the study. We included those who work in any of the BDDP stages (opening of BD protocol; development of clinical and radiological exams; maintenance of patients during the exams and communication of death). We excluded professionals who were in the industry on the condition of vacation or leave compensation for other employees.

We chose to use an intentional sample, since physicians, nurses and nursing technicians from the morning, afternoon and night shifts were recruited. It is noteworthy that collection included nursing technicians, since these professionals are part of a multidisciplinary team working at the bedside in hemodynamic maintenance of this patient, welcoming family members who participate in the hospitalization throughout the BDDP stages. Furthermore, the inclusion of these professionals is reinforced, as they are on the parents' side, welcoming them after receiving information about the BDDP stages and after the news of confirmation of death. In this regard, the authors understand that these professionals need to be heard as caregivers of these family members in the BDDP stages.

Data were collected between November 2019 and February 2020. The researchers contacted the institutions' administrative management informing the start date of research and presenting a collection schedule. Then, contact was made with the management of each critical patient unit, identifying professionals who are part of the team that works with the family in BDDP stages and communication of death. Subsequently, the objectives of this research were explained and a date and time were scheduled according to availability to carry out the interviews. After accepting to participate in the research, participants signed the Informed Consent Form (ICF) in two copies.

Research data were obtained through a semi-structured questionnaire containing eight questions to characterize participants (including time of work, type of involvement in the BDDP as well as participation in training on this topic) and five open-ended questions related to BDDP with parents of children and adolescents.

The open-ended questions were: 1) How is it for you to participate in any of the BDDP stages? 2) What is it like for you to be with the family members of a child or adolescent in the BDDP stages?

3) How do you feel towards family members when you participate in the BDDP stages? 4) What are the main challenges experienced with families in communicating the BDDP stages? 5) How do you feel before the family in communicating this death?

All interviews were recorded and transcribed, then the transcripts were validated with participants. The interviews were identified with the letters N (nurses); T (nursing technicians) and P (physicians), followed by the interview order number, for instance: N1, N2 (...), T1, T2, etc. These lasted a mean of 40 minutes, all carried out in the professionals' own work environment in a reserved and exclusive room for welcoming.

Data collection was conducted by two researchers, because at certain times there was a need for support to participants, as it was an impacting topic for the health team and for the researchers themselves. Both researchers have experience in qualitative research, in addition to the experience of more than ten years in death and dying processes.

For data analysis, content analysis proposed by Bardin¹⁶ was carried out, divided into three phases: 1) pre-analysis, reading the material with the organization and systematization of information and initial ideas, allowing the elaboration of the first impressions about the content covered; 2) data exploration using the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ)¹⁷, available in free version and; 3) treatment and interpretation of results, performing analysis based on the thematic presence of respondents' utterances forming the thematic categories.

For data development and processing, the Descending Hierarchical Classification (DHC) was adopted, which resulted in five classes. Each class is formed by the words most frequently in the transcripts obtained from participants.

The research followed all the legal precepts of Resolution 466/2012 of the Brazilian National Health Council, which regulates research involving human beings. At all times, professional anonymity was maintained. The study was approved by a Research Ethics Committee.

RESULTS

Twenty-one professionals participated in the study: nine nurses, seven physicians and five nursing technicians. The mean age of professionals was 38.2 years, and the mean time working at the institution was 6.8 years. The mean time of the medical team's experience in communicating bad news, specifically communicating death, was 5.4 years.

During the semi-structured interviews, it was identified that nurses are responsible for welcoming family members, hemodynamic maintenance of patients throughout the BDDP, dialogue with the medical team in conducting information about the protocol and communication of death. Medical participants are responsible for information about opening the BDDP, clinical examinations, communicating the results of these examinations, and communicating death. Nursing technicians, in turn, are responsible for patient hemodynamic maintenance during the BDDP and reception with the family at the bedside.

With regard to participation in training for the BDDP stages, communication of death and care for the family, all physicians reported being qualified, having participated in training that qualifies them to conduct the BDDP and care for the family. As for nurses, 77.8% (7) claimed to have participated in training to work in the care for family and patients in this process. All technicians did not receive care guidance to support and manage the family's needs at the bedside.

As for the data explored through IRAMUTEQ, the general *corpus* consisted of 21 texts, separated into 123 text segments (TS), with use of 97 TS (78.86%). There were 4,324 occurrences (words, forms or vocabularies), of which 1,033 different words and 573 had a single occurrence.

The analyzed content was categorized into four classes: Class 1, with 24 TS (24.7%); Class 2, with 20 TS (20.6%); Class 3, with 27 TS (27.8%); and Class 4, with 26 TS (26.8%).

The Descending Hierarchical Classification Dendrogram (Figure 1) makes it possible to understand the expressions of each of the words mentioned by participants during interviews, which were analyzed based on the experience of these professionals in the BDDP. It is possible to notice that the *corpus* at first shows central class and Class 01 (24.7%), in which there is branching to a new subgroup forming class 04 (26.8%). In this class, there is a new branch, forming two new subgroups, Class 02 (20.6%), followed by Class 03 (27.8%).

Class 01 highlights the words: “brain”, “function”, “explain” and “device”. In this class (01), it is understood the experience of these professionals with families in order to explain, guide and demystify brain injury. This topic is addressed by professionals when communicating the opening of the BDDP with a focus on explaining and detailing brain functioning. In this regard, it is understood that their experience in the first BDDP stage is aimed at helping parents understand that there is no more brain functioning. The team’s concern is directed to use simple words, avoiding the use of technical terms. Thus, their feelings are directed to caring, welcoming and clarifying doubts to parents.

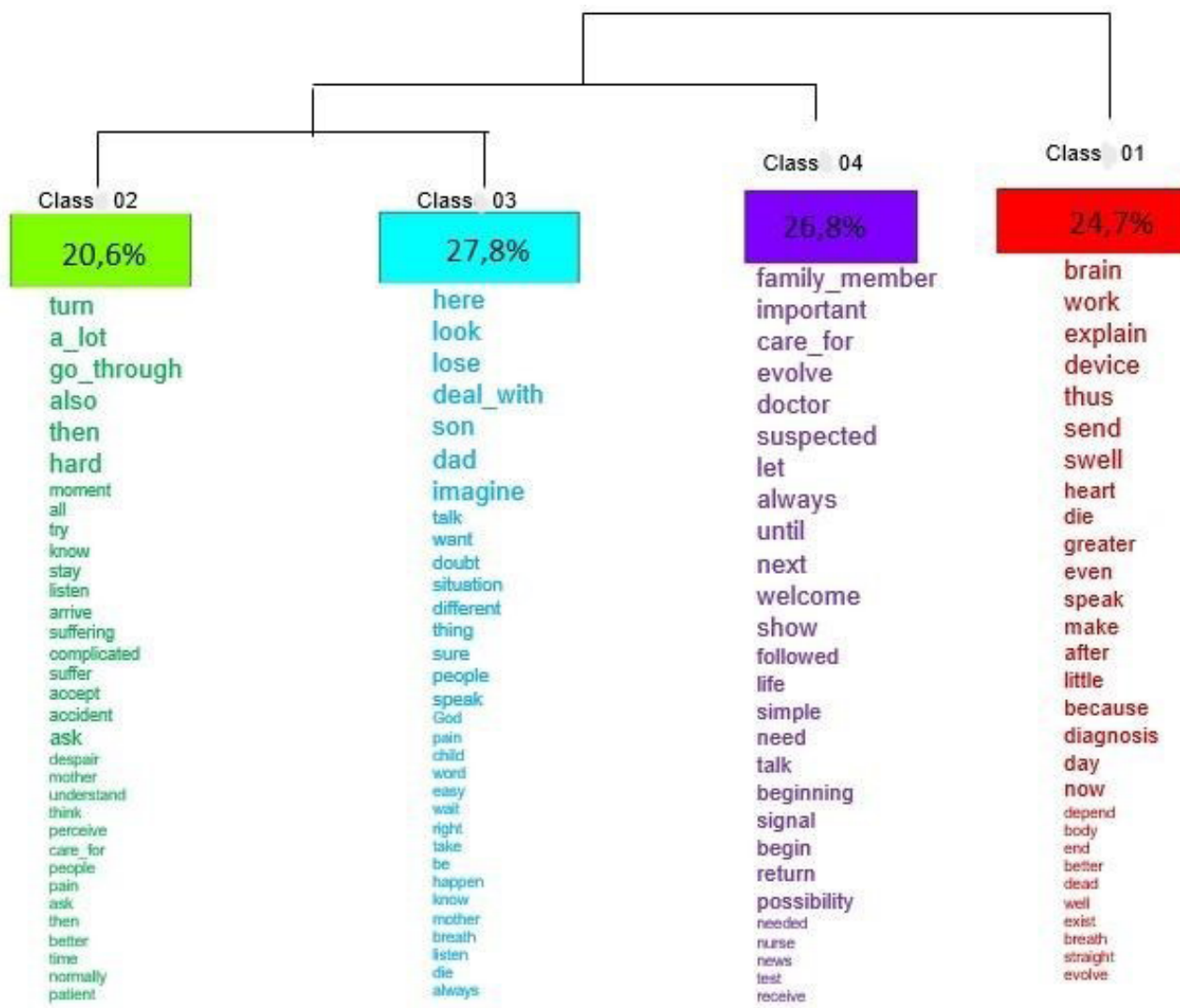


Figure 1 – Descending Hierarchical Classification Dendrogram with the percentage in each class and words, provided by IRAMUTEQ. Florianópolis, SC, Brazil, 2021.

In relation to Class 04, which branches from Class 01, it highlights the words “when”, “protocol”, “together”, “brain death”, “process” and “close”. This class brings the team’s experience in the process, demonstrating their experience in providing a detailed explanation of each BDDP stage to the family.

Classes 02 and 03, which branched off from Class 04, indicate words that represent the team’s experience of being next to the family in the BDDP stages. Class 03 highlights “here”, “look”, “lose”, “deal”, “son” and “imagine”, which represents the team’s understanding of “being here and now” with this family throughout the BDDP, in addition to helping this family to face the loss of their child. These classes represent the team’s feelings in the face of communication of death and welcoming of parents.

Class 02 highlights “turn”, “a lot”, “go through”, “also”, “difficult”, “moment” and “everything”. Emerging from this class the team’s experience in relation to the fact that the family goes through this moment, which demands these professionals active listening to help these people to support the reality of confirmation of death. Classes 02 and 03 bring the representation of feelings of caring for parents during the BDDP and, mainly, in communication of death. The experiences are aimed at looking at parents to listen, feel and understand the reality permeated in the face of the loss of their children.

In another way of representing the results obtained, i.e., by word cloud (Figure 2), the highlighted words from participants’ speeches are “being”, “family”, “speaking” and “death”. It is also possible to highlight the words “process”, “difficult”, “exam” and “moment”. The word “being” represents the team’s understanding of the importance of being present with family members at all BDDP stages, since the word “family” stands out. Moreover, the team identifies the need to provide support and support in the face of the path taken in the BDDP stages.

Finally, a similarity dendrogram (Figure 3) shows the main axes as well as the structure of the central nucleus and the peripheral system related to participants’ speeches. Again, it is perceived that in the central axis the words “being” and “speaking” stand out. The word “being” is linked to the central axis and the different subaxes in virtually all branches. The word “speaking” has a strong connection



Figure 2 – Cloud constructed with words extracted from participants’ speeches provided by IRAMUTEQ. Florianópolis, SC, Brazil, 2021.

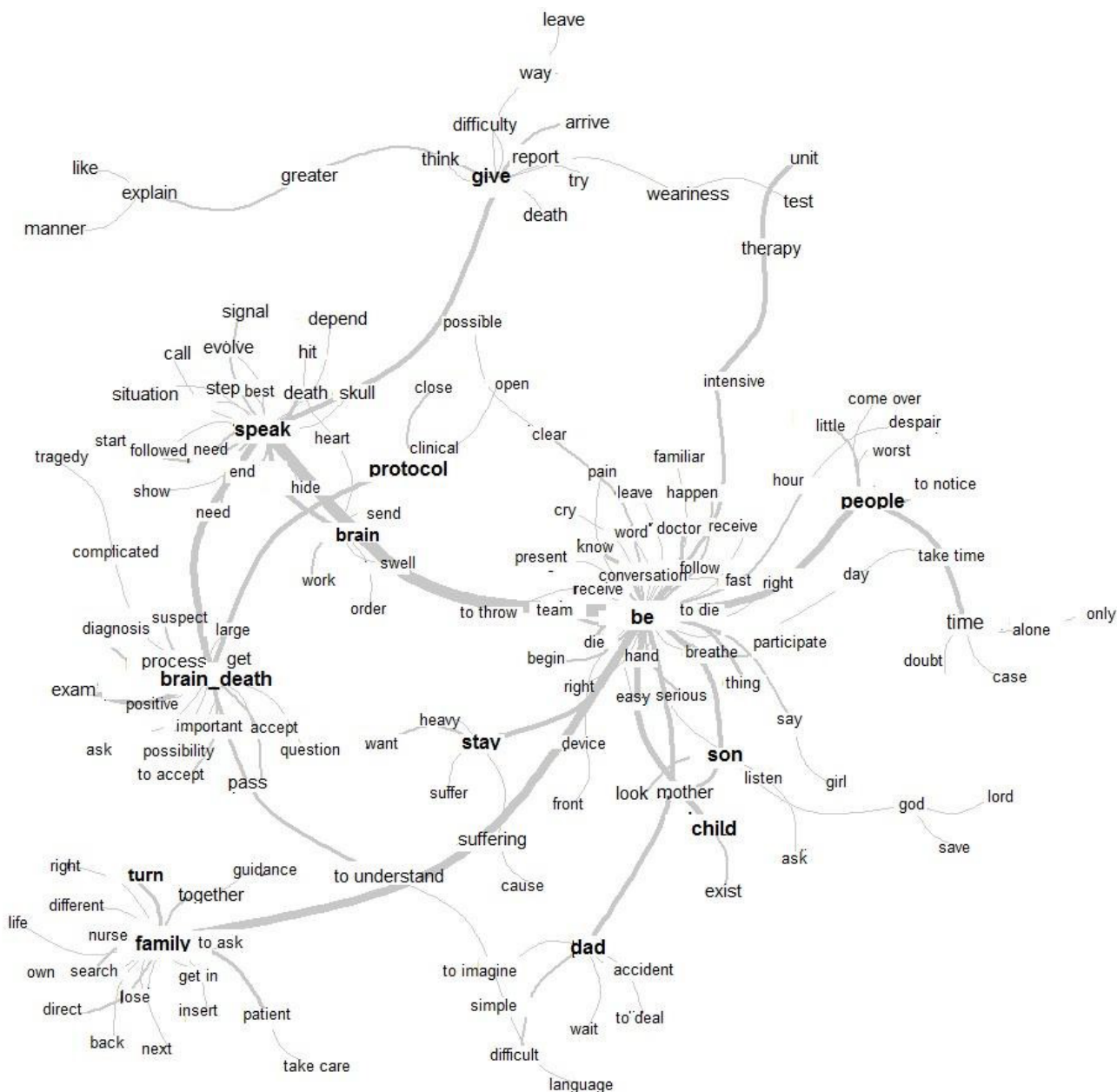


Figure 3 – Similarity dendrogram provided by IRAMUTEQ. Florianópolis, SC, Brazil, 2021.

with the ramification of “being” and with the BD subdivision. Also, note that the word “being” has strong ramifications with “family” and “people.”

This figure shows that the team experiences the central understanding of being with the family. In addition, there is the perception of speaking and making it clear what is happening during the BDDP. It shows the care focused on the news of the opening of the BDDP, lasting until the conclusion of each of the exams. Furthermore, it points out how significant and important it is for the team to be with these parents, noting that the word is divided into “people”, “brain death”, “family”, “talk”, “father”, “child”, “son” and “moment.”

DISCUSSION

The study data reveal the professionals’ experience in conducting the BDDP stages, related to the fact that most specialists have training to manage critical situations. It was possible to observe tenderness in these experts when dealing with parents of children and adolescents who go through the

BDDP. Such information obtained reveals the team's experience in seeking to equip themselves with skills, solidarity, and humanization to be use with parents in the face of the loss of a child/adolescent.

Other studies reinforce these findings by pointing out the crucial need for the health team to be empowered and aware on the BDDP stages as well as communication of death. This fact is in the sense of clarifying and explaining each BDDP stage to parents, in addition to understanding their demands, especially when dealing with the death of children and adolescents¹⁸⁻¹⁹. It is noteworthy that, in this study, the team shows how significant it is to actively listen to children's/adolescents' parents at the same time that active listening allows the team to understand what parents assimilated from the information conveyed in each BDDP stage.

Such findings bring important data, especially for nurses, who are the professionals on the front line managing the BDDP stages. They work from the search for patients with clinical criteria for BD to the notification of this death to competent authorities according to current legislation in Brazil^{2,20}. Thus, knowing the health team's experience in this scenario allows them to strengthen themselves to act with greater effectiveness, safety, and quality in the face of BDDP.

Another experience observed in the study implies the team's effort to clarify to those responsible for each BDDP stage, especially when diagnosis begins. They seek to bring simple terms such as the word "swelling". Furthermore, it is noted that the team tries to explain to parents how BDDP exams will be conducted, in the sense that parents can gradually assimilate the clinical severity of their child. Studies reinforce this care of participants and point out the importance of organization of care in the BDDP scenario. Also, they emphasize the need for strategies and skills through protocols, guides and assumptions directing to systematized care, equitable within the circumstantial limits and based on looking at the other in each BDDP stage²¹⁻²².

In this study, participants recall the unique effort to care for and support these parents of children/adolescents in the face of BDDP. Their experience is related to the desire to be with their parents, to care for and welcome them in the face of the pain of losing a young child. The word "being" appears in practically all classes, showing the importance of the team being part of the moment, and not just conveying information about the BDDP stages and the news of death. It brings feelings of welcome, trust, respect, empathy, and authenticity to these countries.

This information reveals skills acquired during professional training and personal maturity of professionals who make up the team. There is greater concern with parents in the face of this acute/sudden loss of children/adolescents. Authors argue that this experience with parents brings rationality and expertise to the BDDP stages, for which it is necessary to be imbued with sensitivity, respect, empathy, active listening, and compassion. However, these same authors warn about the bonds established with these parents, since attachment relationships and illness in the team may arise from this contact^{9-10,23-24}.

This relationship of affection and attachment in caring for parents can lead the team to a behavior of unconditional support. Situation that can generate emotional, physical and psychological overload in specialists. This is exacerbated when the work reality is similar to the personal reality, i.e., when these professionals compare the loss of a patient whose age is similar to that of their children with the loss of their children^{23,25-26}.

Welcoming, attention, respect and empathy developed by experts should help encoding the death message, while strengthening parents to move forward in the face of the information received by the team in the BDDP stages^{23,25-26}. However, it is important that these professionals know the limits of relationships, understanding the extent to which it is healthy for the work environment maintenance, i.e., without this overload, but ensuring support.

Other studies reinforce that specialists play a fundamental role in explaining and decoding death caused by a severe neurological injury resulting from a diagnosis of BD. The team must help

organize thoughts, demonstrating the procedural stages, in addition to clarifying doubts about the serious injury that led to BD, especially when it comes to the death of a child/adolescent because it is young people^{7,9-10}.

The difficulty in dealing with the death of a child/adolescent is explicit in participants' actions when they demonstrate the sensitivity of the moment, since they approach it as something that is difficult to "go through", i.e., difficult to be experienced and consequently overcome, evidenced by the words "process", "difficult", "exam" and "moment."

In the context of health institutions, the BDDP stages are seen as difficult for everyone involved and not only for the family. The team is faced with unique feelings experienced by the loss of a young patient, combined with approximation of discontinuity of life and the idea of the possibility of such a fact affecting oneself at any time. These emotions are brought out by the team before the confirmation of death with the family, often because of all efforts and interventions to save life were not enough, despite all care actions^{24,27}.

Considering this scenario, it is important to highlight that this view may be related to the training process of these professionals, which guides care practice in exclusively curative strategies, i.e., they are trained and educated to care for life and not death. Thus, it is necessary to incorporate the study of death as well as the BDDP into technical and undergraduate courses, understanding the multifactorial and complex nature of health care^{19,28}.

In the context of care for children and adolescents, this feeling is aggravated, because both society and health workers still bring the thought that parents should die before their children and not the other way around and that a child has "their whole life ahead of them". This death situation impacts professionals more intensely, since they feel part of that moment, involved in the care and maintenance of patients until the end of BDDP, also confronting their individual and personal beliefs about death^{7,11-14}.

In this study, the experts' experience shows, through Dendrogram ramifications, that the verb "to be" has strong ramifications with "family" and "people". This brings to the understanding that the health team is sensitive to parents' situation in the face of the BDDP stages, considering that both in the Dendrograms and in the word clouds there is the presence of "being with the other". Studies show that experts who work directly with BD feel touched, especially when it comes to the death of a young patient. However, team members end up developing personal strategies of emotional distancing as a way to build a barrier that prevents building feelings^{9-10,29}.

Thus, it becomes understandable and important that team participants receive support and a welcoming space in the face of work reality. It is necessary for these professionals to be able to understand their feelings through psychological support so that they do not confuse their individual emotions with those of family members. It is also necessary that they can develop strategies that allow them to protect themselves against feelings related to failure, learning to identify their limits and, thus, care for bereaved families with respect and empathy^{7,19,29}.

Finally, the connection between "being", "talking", "brain death", "family" and "people" indicates that the assistance relationship is important and that family members need to be aware of the reality so that they can codify the situation and understand the news as well as health workers who need security to understand the context of the BDDP. Being means presence and presence that welcomes. It is important to highlight that permanent education strategies can help to create vehicles to face these professionals, offering support during moments of communication of bad news^{22,28}. Thus, it could impact the assistance to these family members, the quality of experience of these professionals and the collective coping: family, professional, child and adolescent in the mourning/death/mourning continuum of this process.

Regarding the limitations of this study, the difficulty faced by participants in remembering the moments experienced with their parents is particularly highlighted. During data collection, the suffering of these specialists was perceptible in remembering the journey experienced in the BDDP until the confirmation of death of a child/adolescent. Another limitation identified is related to the emotional impact on the researchers themselves, due to being faced with reports/interviews that involve moments of pain and suffering. During data collection, in two moments, there was a need for more spaced intervals between the interviews so that there was the emotional rehabilitation of researchers.

CONCLUSION

Considering the information obtained in the study, it is noted that the professionals' experience before the BDDP involves feelings of solidarity, acceptance and compassion at all stages of this process. Regarding the protocol opening, the team brings feelings aimed at clarifying the information, combined with simple terms, marked by the need to clarify the family about BD diagnosis in a simple and careful way. As for the exams in this protocol, the team is concerned about making the stage-by-stage clear, in addition to the issue of how each of these exams will be conducted. In the death communication stage, the team seeks to focus on the feelings of active listening, compassion, and empathy.

Still, it was possible to understand that this experience is encompassed by the verb "to be". The set expressed by the verb "to be" and the nouns "family" and "people" stand out and lead to the understanding of the need to bring these professionals closer to this process.

Finally, the study showed that training, support and support for professionals can help them to face this critical situation as well as in quality of care for bereaved families.

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NOTES

ORIGIN OF THE ARTICLE

This is an original article, part of a macro-project entitled “*Desenvolvimento de ferramentas de cuidado para condução da entrevista familiar para doação de órgãos junto a famílias de crianças e adolescentes*”, presented to the Scientific Initiation Program of the Dean of Research at *Universidade Federal de Santa Catarina*, in 2021.

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CONFLICT OF INTEREST

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