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Understanding and communication of neonatal palliative care: a bioethical approach

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Abstract

Dealing with death and palliative care in neonatology is challenging for health professionals. This retrospective qualitative and descriptive study sought to understand the process of neonatal palliative care communication in a hospital in southern Brazil, analyzing the results from a bioethical perspective. Data were collected by semi-structured interviews, conducted with 14 participants (seven mothers and seven doctors) between June 2021 and August 2022, and examined using Bardin's content analysis. Two categories stood out: knowledge about palliative care and communication in palliative care. In conclusion, existing communication obstacles can interfere with the family's understanding of palliative care. Education on topics such as bioethics, palliative care and communication of bad news require greater investments to facilitate these processes and equip professionals.

Keywords: Palliative care. Bioethics. Neonatology. Health communication.

Resumo

Compreensão e comunicação de cuidados paliativos em neonatologia: abordagem bioética

Tratar de morte e cuidados paliativos em neonatologia é desafiador para os profissionais de saúde. Esse estudo buscou conhecer a compreensão e o processo de comunicação em cuidado paliativo em neonatologia em um hospital do Sul do Brasil, e analisar os resultados sob a perspectiva da bioética, por meio de pesquisa qualitativa e descritiva de caráter retrospectivo. Foram realizadas entrevistas semiestruturadas com 14 participantes (sete mães e sete médicos) entre junho de 2021 e agosto de 2022. Para análise dos dados, foi utilizada a análise de conteúdo de Bardin e, dentre as categorias emergentes, destacam-se duas: conhecimento sobre cuidado paliativo e comunicação em cuidados paliativos. Concluiu-se que há entraves na comunicação que podem interferir na compreensão da família sobre o conceito de cuidado paliativo. É necessário maior investimento em educação sobre temas como bioética, paliatividade e comunicação de más notícias para facilitar esses processos e instrumentalizar os profissionais.

Palavras-chave: Cuidados paliativos. Bioética. Neonatologia. Comunicação em saúde.

Resumen

Comprensión y comunicación de los cuidados paliativos en neonatología: un enfoque bioético

Lidiar con la muerte y los cuidados paliativos en neonatología es un desafío para los profesionales de la salud. Este estudio buscó conocer la comprensión y el proceso de comunicación en los cuidados paliativos en neonatología en un hospital del Sur de Brasil, y analizar los resultados desde la perspectiva de la bioética utilizando investigación cualitativa y descriptiva retrospectiva. Se realizaron entrevistas semiestructuradas a 14 participantes (siete madres y siete médicos) entre junio de 2021 y agosto de 2022. Se utilizó el análisis de contenido de Bardin para analizar los datos y, entre las categorías emergentes, destacan conocimiento sobre cuidados paliativos y comunicación en cuidados paliativos. Existen obstáculos en la comunicación que pueden interferir en la comprensión de la familia sobre cuidados paliativos. Hay que invertir más en temas como bioética, cuidados paliativos y comunicación de malas noticias para facilitar estos procesos y proporcionar a los profesionales las herramientas necesarias.

Palabras clave: Cuidados paliativos. Bioética. Neonatología. Comunicación en salud.

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While it may seem that dealing with death becomes routine for healthcare professionals who work in intensive care, this situation will always present itself as a significant challenge. Hospitals receive individuals daily with health conditions, acute or chronic, who require some care. A disabling or life-threatening disease may be discovered in this process, implying the need for palliative care measures [1-3].

These diagnoses can also refer to those who are at the beginning of their life, such as babies, making care even more difficult. Studies on palliative care in neonatology are still very recent and scarce in the literature. Diseases such as serious genetic syndromes, fetal malformations, bone changes, and anencephaly are among the leading causes of palliative care and death in babies [1-3].

In these situations, communication with patient's family members is challenging for professionals, and one of the main obstacles is related to physicians' difficulty in speaking directly and clearly about therapeutically limiting end-of-life behaviors for fear of destroying the hopes of the family. Studies show, however, that good communication between the healthcare team and the family benefits the decision-making process and is essential for adequate care. The family must be sufficiently informed about the patient's health condition through sensitive and empathetic communication, which respects the parents' preparation time [4-6].

Communication protocols are tools developed to assist healthcare professionals in reducing possible losses resulting from inadequate communication of bad news. This is the case with the Spikes protocol, which enables the physician to communicate and deal appropriately with the emotions raised by the situation. How high-impact news is communicated is potentially as important as its content [7,8].

Complex bioethics is an approach through which we seek to reflect on the adequacy of actions taken in the field of health and can be understood as a proposal for complex, interdisciplinary, and shared reflection, which mobilizes questions and practical applications in the field of health and illness. Medical practices based on clinical bioethics help resolve conflicts [9,10].

Four fundamental principles, originating from principlist theory, served as the basis for clinical bioethics in the biomedical field: autonomy, non-maleficence, beneficence, and justice. These principles guide health decision-making when faced with ethical problems. In palliative care, the principle of autonomy is relevant, as it highlights the importance of preserving the patient's will, considering their conception of life and dignified death [9,10].

Despite the importance of bioethics in the health context, there is a lack of professionals with corresponding training in institutions and institutional difficulties in training professionals with the development of appropriate communication skills to face difficult situations. Adapting to therapeutic measures based on palliative care requires the construction of clear and well-founded protocols, both in the technical-scientific and legal spheres. Dealing with these cases requires offering tools to professionals and implementing protocols [11-13].

Faced with these issues, it is essential that the professionals involved know the principles of palliative care and bioethics to guide their decisions appropriately, constantly evaluating the suspension or inclusion of therapies and modulating interventions according to the progression and individuality of each case. For this reason, important issues such as breaking bad news and palliative care should be part of medical training.

The literature indicates that adequate training can improve care and communication in palliative care situations, as training programs are generally aimed at acute patients. However, there is a deficit in training medical professionals on issues involving palliative care and communicating bad news [14,15].

Method

A retrospective qualitative study was conducted, with a convenience sample consisting of seven cases of babies in palliative care admitted to the neonatology and pediatrics units of a university hospital in southern Brazil. Two groups, physicians and mothers, were invited to participate, totaling fourteen participants: seven mothers and seven physicians. The interviews were contemporary, addressing a reminder of the experience, and with this sample, data saturation was reached.

The participants were mothers—over 18 years old without a diagnosis of serious psychiatric disorder—of babies who were in palliative care between 2019 and 2022, whose cases were identified through a review of medical records. The physicians included were pediatricians and/or neonatologists who were part of the team responsible for the baby's care, with a minimum of 1 year of experience in the hospital.

Data collection and analysis

Data were obtained through semi-structured interviews, a sociodemographic questionnaire prepared by the authors, and data collected from the review of medical records. General and sociodemographic data were collected, including age, sex, religious belief, and education. The study aimed to understand various aspects of palliative care in babies, including communication, understanding the concept and the decision-making process, as well as the perceptions and feelings of the interviewees.

After applying the informed consent form (ICF), due to the COVID-19 pandemic, most data were collected via video or audio call. The face-to-face interviews took place in a private room within the hospital units. After collection, the statements were transcribed fully, preserving the information's integrity and confidentiality to avoid the interviewees' identification.

The qualitative data was subjected to content analysis proposed by Laurence Bardin[16], a methodology that allows the subjectivity and complexity of the topic to be systematically approached by examining the participants' speeches. This method proposes the analytical description of interviews by dividing them into categories.

This research complied with the guidelines and standards regulating research involving human beings per Resolution 466/2012 of the National Health Council (CNS)[17]. The project was analyzed and approved by the Ethics Committee of the Hospital of Clinics of Porto Alegre and Plataforma Brasil. Furthermore, participants were informed about the research, received the ICF, and authorized participation.

Results and discussion

The interview data were divided into groups A and B to optimize the process of analyzing and discussing the results. The groups referred, respectively, to the attending physicians and the mothers. Four broad categories emerged from each group's analysis: 1) understanding of palliative care; 2) communication; 3) perceptions; and 4) feelings. Two subcategories were also obtained, one from each group: 1a) decision-making process in palliative care; and 1b) understanding of the baby's diagnosis. This study proposes to analyze only two categories: 1) understanding of palliative care; and 2) communication.

Charts 1, 2, and 3 present data from babies, physicians, and mothers.

Seven babies who had been or were, at the time of the research, in palliative care were identified, most female, with only two being male. Data collection was carried out with three babies who were still in care and four who had already died at the time of the interview.

Ages were calculated based on the time of collection or death, ranging from 27 weeks of gestation to 1 year and seven months of life, and the length of hospital stay was from 17 to 132 days. Each patient presented a different diagnosis, and in only three cases, consultation was requested from the bioethics team.

Chart 1. Presentation of babies' data

	Baby 1	Baby 2	Baby 3	Baby 4	Baby 5	Baby 6	Baby 7
Age	2m 6d	11m	1m 18d	1m 7d	(Intrauterine death)	1m 27d	1m 9d
Sex	F	M	F	F	F	M	F
Diagnosis	Hypoxic-ischemic encephalopathy	Type III osteogenesis imperfecta	Citrullinemia	Edwards syndrome	Type II osteogenesis imperfecta	Mitochondrial short-chain enoyl-CoA hydratase 1 disease	Neonatal hemochromatosis secondary to alloimmune disease
Length of stay (in days)	67	69	32	132	17	38	33

Chart 2. Presentation of professionals' data

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6	Participant 7
Age	30	45	29	32	32	28	30
Sex	F	F	F	F	M	F	F
Religious belief	Agnostic	Catholic	Catholic	Christian	Christian	Catholic	Catholic
Training	Pediatrician and neonatologist	Pediatrician and neonatologist	Pediatrician and neonatology resident	Pediatrician and neonatologist	Pediatrician and neonatology resident	Pediatrician and neonatology resident	Pediatrician and neonatologist

Chart 3. Presentation of mothers' data

	Mother 1	Mother 2	Mother 3	Mother 4	Mother 5	Mother 6	Mother 7
Age	29	30	23	41	29	38	35
Sex	F	F	F	F	F	F	F
Religious belief	Catholic	None	Believes in God	Believes in God	Umbandist	Catholic	Catholic
Education	Complete higher education	Complete secondary education	Incomplete higher education	Complete secondary education	Incomplete higher education	Complete secondary education	Incomplete primary education

In group A, seven physicians were interviewed, aged between 28 and 45, who provided care to these babies, six of whom were female and four Catholic. All the physicians interviewed were pediatricians or specialists or were completing their residency in neonatology at the time of the interview, and only one had completed a course in palliative care, and another had completed a course in communicating bad news. The rest of the interviewees stated that they had participated in brief lectures on the topics during their medical training.

In group B, seven mothers of babies who were or had been admitted to palliative care were interviewed. The mothers were between 23 and 41 years old, and three were Catholic; two said they believed in God, one was an Umbandist, and only one said she had no religion. Three mothers declared that they had completed secondary education, two had incomplete higher education, and two were unemployed at the interview.

Of the seven mothers, three received communication about palliative care in neonatology, another three in pediatrics, and one in the obstetric hospitalization unit. Two mothers were in the gestational period when the communication occurred after a disease with a serious prognosis was identified in prenatal examinations.

It is essential to highlight that, although only mothers were interviewed in this study, some fathers were present while caring for their babies throughout the hospitalization. For this reason, sometimes, reference is made to the terms "family" and "parents," also considering that palliative care must be extended to the family and not just to the babies' parents[6].

Category 1: understanding of palliative care

Participants were asked what they considered palliative care to understand their construction of this concept. In group A, all professionals stated that care prioritizes comfort and should be provided to patients whose disease has no cure. Only one professional highlighted that a multidisciplinary team should provide care.

Three participants stated that it is a care that differs from hospice care. They pointed out that sometimes, the two concepts can be confused. One participant referred to the concept as care provided beyond cure: *"Just because we have a perspective of cure doesn't mean we're going to stop doing palliative care, right?"* (P6).

Palliative care is understood as active, comprehensive care performed by a multidisciplinary team, prioritizing quality of life and the reduction of suffering. Despite being very common in intensive care units, this concept is still unclear to healthcare professionals, possibly due to the lack of theoretical support during medical training. Topics such as death and dying end up being rarely addressed during undergraduate and postgraduate studies, and professionals, consequently, face difficulties in dealing with these experiences in their daily practice[15,18].

Of the seven mothers interviewed, four referred to palliative care as care for a child with an illness that has no cure. Three interviewees said they did not have information about palliative care or had not been informed about the nature of care for their baby. Three mothers interviewed defined it as care to avoid suffering and provide a better quality of life.

One of the mothers said that her understanding changed throughout her son's hospitalization after a first resistant understanding. Her speech expresses a conception of palliative care linked to the moment of death and signals a sense of abandonment on the part of the patient.

"There is nothing more to do; we will comfort her while she still lives. [I said] *'Ah, no, my daughter is alive, and she's going to live a long time; I don't want to know about palliative care…'. But no, nowadays I think differently, I think they need palliative care to live a better life"* (M3).

Another mother expressed her understanding that palliative care involves a larger team and takes care of other family members besides the baby's parents, such as grandparents.

"My mother came to speak to the psychologist, so she spoke to the whole family, so to speak. So palliative care, I think it's that for me, that feeling of care" (M2).

The mothers interviewed demonstrated limited knowledge about the concept of palliative care because, although a certain level of lack of knowledge is expected, understanding is complex, possibly resulting from ineffective communication. Some mothers stated that they initially understood care as "letting die" or "not having anything else to do" and that, over time, they came to understand it from a notion of care that provides comfort.

Silva[6] highlights the importance of providing preparation time for the family, which is subjective and can vary according to the needs of each family, pointing out that a professional must be available for further clarification whenever possible. Regarding the mothers' initial understanding of "letting die," Dadalto and Carvalho[10] talk about non-abandonment as one of the principles of palliative care: caring and relieving even when it is impossible to cure. Therefore, explaining the concept and principles of palliative care is fundamental for an adequate understanding that palliation consists, above all, of care.

It is possible to notice that the professionals expressed knowledge similar to that addressed by the babies' mothers when asked about their understanding of palliative care. Although there is adequate understanding in both groups, healthcare professionals who assist in this context could provide more information and elaborations on the topic.

Category 2: palliative care communication

When asked about how palliative care communication occurred, three participants said they had held more than one moment of communication with the family, aiming to enable better elaboration on the information communicated and more opportunities to clarify doubts. In one case, weekly meetings were held; in another, daily conversations with the family with information about the baby's health status and prognosis were necessary.

Only one participant was approached by the parents with questions about palliative care, in which they declared that they did not notice any improvement, just a lot of suffering in the baby. It is essential to point out that the family must be involved in care and be heard in their doubts and anxieties, as family caregivers—in this case, parents—actively participate in the illness process and decisions regarding treatment [1].

One of the participants referred to a communication process in stages: he highlighted the presentation to the family, stressed the need to explain the concept of palliative care, and the importance of listening to the family in their understanding, encouraging them to their prior knowledge about the topic and the baby. According to this professional, the approach would have been developed based on the family's understanding of the care for their children.

Another participant also reported the importance of, at first, building a bond of trust with the family and then communicating the bad news. Silva [6] states that a relationship of trust is the main foundation for establishing palliative care and recommends that the professional actively seek this trust through communications in day-to-day care.

It should also be considered that communicating difficult news is a great suffering for most professionals, as the communication itself will bring suffering to others, and the professional may not feel prepared to support this suffering [5]. By enabling the preparation time mentioned by Silva [6] and clarifying doubts, communication in stages can be adopted to assist the professional in this challenging process. Thus, through multiple and spaced meetings, a more effective understanding on the part of the family is possible.

A professional pointed out the lack of a family support network and family members' low level of education as complicating factors in a bad news situation. They can interfere with the adequate understanding of the case and the possible outcomes. Two participants expressed concern about the possibility of family members understanding palliative care as "letting them die" or as "giving up" on their baby.

"There are families we can evolve faster [with]. *There are others that we have to give them time to assimilate better and then move on"* (P2).

Four physicians stated they had met with the multidisciplinary team to discuss the case and align actions before communicating it to the family. There was also mention of the additional difficulty arising from the lack of diagnosis: of the four, one pointed to communication with the family as a construction, as in this case, there was no exact diagnosis. One of the strategies one of the participants used was to show comparative images between a healthy patient and their patient to help the family understand the diagnosis and communicate what care would be like.

In two cases, the diagnosis was given during prenatal care. One of the participants pointed to the importance of reinforcing communication after the baby's birth, as confirming the diagnosis was essential for the family's understanding and elaboration.

"This was being built, and as we had more tests and data, we were… giving small samples that perhaps the prognosis would not be so favorable. (…) So when we reached this conclusion, we held a prior meeting between the teams and then communicated with the parents" (P6).

For palliative care communication to be carried out, the professional must first be convinced that there is no other curative approach to be taken[5]. In communication, this convincing process—identified in the previous statement—must be understood as part of the dynamics of understanding or assimilating in an action shared by the team. Therefore, it can be more difficult in cases with no diagnosis.

Only two mothers said they had been informed by more than one professional about palliative care. Four stated they had received information from the "palliative care physician," pointing to a reference professional who communicated this care in contrast to other professionals on the team who provided information about the patient's health status. Two of the mothers interviewed revealed that they had only been informed about issues related to their child's health, with no mention of palliative care. However, therapeutic limitation measures during the baby's final moments were discussed.

"They just said that, when she passed away, they couldn't revive her... I understood because otherwise she would suffer, it would hurt her more and more..." (M4).

This excerpt signals difficulties arising from the lack of professional training in palliative care since, in this case, there was only one reference professional in the unit or with adequate preparation to carry out the communication. The literature points to the lack of professional training on this topic and the difficulty for professionals in talking about death in the units so that each professional communicates in their own way, without specific protocols or guidelines. It is known that ineffective communication, e.g., when professionals contradict each other, increases the suffering and emotional exhaustion of the family member being cared for and may interfere with their participation in the treatment and decision-making process[5,1].

Two mothers mentioned follow-up by a psychology professional during or shortly after communicating palliative care. Two other mothers mentioned communication and follow-up by a team of professionals involving psychology and genetics. Six mothers interviewed said they were alone, without a companion, when communicating about palliative care.

In one of the cases, palliative care communication occurred differently. The parents, upon noticing the lack of improvement in the baby and what they were facing, both their son and themselves, decided to talk to the team about their desire for the baby to no longer suffer. After this request from the parents, discussions began between the team to reflect on the suitability of palliative care for the case. After the meeting with the team, the decision to implement palliative care was communicated to the parents.

According to these statements, there is no protocol or specific guidelines for communicating bad news, although the literature points out effective strategies and provides theoretical and technical support. Geovanini and Braz[19] point out in their study a resistance from professionals to using protocols and tools to communicate diagnoses, with arguments against standardization, given the delicate context. However, protocols should only be used as parameters, as they do not cover the complexity involved in communicating bad news[7], and communicating bad news requires personal skills from professionals, and its reception involves subjective aspects[20].

Some participants said they had communicated in stages and/or with the multidisciplinary team, prioritizing establishing a bond with parents and gradually informing the family. Hence, they had more time to elaborate and understand the situation. Also, in this sense, Caneco and collaborators[21] state that inadequate communication can cause harm to family members' understanding. According to the authors, communication often occurs vertically, as a simple "passing on of information" that can hinder the family's understanding.

Professionals reported learning to communicate through their professional and personal experience caring for patients. According to Geovanini and Braz[19], some factors can explain the inadequate communication of bad news, such as failure to invest in the development of related skills during undergraduate training, social representations, fantasies, and beliefs related to illness and hospice care.

In the interviews with the mothers, it was possible to notice that most information transmitted concerned the prognosis and limitation of conduct, not the concept of palliative care. According to Ribeiro, Silva, and Silva [22], there is a tendency for healthcare professionals to soften bad news, focusing on highlighting possible positive aspects of the situation to soften the impact of the news. This strategy can make it difficult for parents to understand the actual seriousness of cases like those discussed here.

Knowing that an adequate understanding of the child's health condition facilitates the parents' decision-making process and coping with the hospitalization situation [6], the importance of greater attention and investment in these stages of care is understood. Some mothers even reported a perception of patient abandonment. Furthermore, the principles of autonomy must be kept in mind—with respect, within possibilities, for the family's wishes—and non-abandonment, with a view to the best interests of each patient [10].

Considering that professionals did not have adequate training in palliative care, it is essential to reflect on the importance of bioethics in this context. Such situations require going beyond learning through practice and intuition, promoting a complex reflection that adapts and enables the most appropriate action in each case [11]. The adequacy of actions is related to the need to diagnose each situation, a reading of the facts involved, and the reality in which the search for a more appropriate solution is inserted [24].

Bioethics contributes to this reflection on the adequacy of actions in palliative care, as it is essential to understand the aspects involved in each situation, both practical and technical and affective. Among the factors that influence such situations are the bonds and desires of individuals, as well as their systems of beliefs and values [24]. Thus, bioethics principles can favor shared reflection on the situation, and the corresponding knowledge can help professionals in their communication, decision-making, and, mainly, in the care process, aiming at the patient's and their family's best interests.

Final considerations

In the reports obtained, it is possible to notice that there are many aspects to be clarified regarding the concept of palliative care and the communicational aspects involved. The initial objective of this research was to clarify the understanding of the concepts and processes within the possibilities of each group regarding the topics covered. The study identified that professionals know key aspects of palliative care practice, such as providing comfort and quality of life. However, since only two physicians had taken courses on the subject, technical and theoretical instrumentation is necessary regarding the concept and communication of bad news.

Interviews with mothers reinforce this understanding: although the necessary information about the health situation was understood, many essential aspects were not adequately communicated to them. There is a need to develop skills to ensure sufficient understanding on the part of the family for decision-making and emotional assimilation of the evolution of the disease to avoid inadequate communication. Training in bioethics can contribute to this scenario, helping professionals to reflect and make decisions based on the principles of beneficence and non-maleficence.

Finally, it is essential to highlight that, due to the COVID-19 pandemic, only mothers were interviewed in this study. This is a limitation of this research despite studies that point to the mother as the primary family caregiver for hospitalized pediatric patients.

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Participation of the authors

Juliana Guimarães de Alencastro Astarita conceived and prepared the study, conducting bibliographical research and collecting data. José Roberto Goldim guided the preparation of the work, helped with data analysis, and reviewed the content. Both authors wrote the article.

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