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# Challenges in breaking bad news in a pediatric intensive care unit

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## Abstract

Breaking bad news is a challenging task in medical practice, reason why this topic's relevance has grown in the training of future professionals. In intensive care units, this type of communication is mixed with multiple situations, such as the management of information involving the worsening of clinical conditions and the possibility of imminent death, especially in pediatric cases. Given this context, the objective if this study was to understand the challenges faced by intensive care physicians in breaking bad news, from the analytical axis of some questions raised in the field of bioethical discussions. The results highlight the need for technical and personal preparation of physicians in the face of this important challenge, since the child's participation in the treatment process remains limited, a reality that hinders the sharing of information and, consequently, the exercise of autonomy.

**Keywords:** Health communication. Intensive care units. Child.

## Resumo

**Desafios na comunicação de más notícias em unidade de terapia intensiva pediátrica**

Comunicar más notícias é tarefa desafiadora na prática médica, motivo pelo qual o tema tem adquirido relevância na formação de futuros profissionais. Nas unidades de terapia intensiva, esse tipo de comunicação se mescla a múltiplas situações, a exemplo do manejo de informações envolvendo o agravamento do estado clínico e a possibilidade de morte iminente, especialmente em casos pediátricos. Diante desse contexto, o objetivo desta pesquisa foi compreender os desafios enfrentados por médicos intensivistas na comunicação de más notícias, tendo como eixo de análise algumas questões problematizadas no campo das discussões bioéticas. Os resultados apontaram a necessidade de preparo técnico e pessoal do médico diante desse importante desafio, haja vista que a participação da criança no processo de tratamento ainda é limitada, realidade que dificulta o compartilhamento das informações e, consequentemente, o exercício da autonomia.

**Palavras-chave:** Comunicação em saúde. Unidades de terapia intensiva. Criança.

## Resumen

**Desafíos en la comunicación de malas noticias en una unidad de cuidados intensivos pediátrica**

Comunicar malas noticias es una tarea desafiante en la práctica médica, por lo que el tema ha adquirido relevancia en la formación de los futuros profesionales. En las unidades de cuidados intensivos, este tipo de comunicación se mezcla con múltiples situaciones, como, por ejemplo, el manejo de información que implica el agravamiento del estado clínico y la posibilidad de muerte inminente, especialmente en los casos pediátricos. Ante este contexto, el objetivo de esta investigación fue comprender los desafíos que enfrentan los médicos intensivistas en la comunicación de malas noticias, teniendo como eje de análisis algunas cuestiones problematizadas en el ámbito de las discusiones bioéticas. Los resultados señalaron la necesidad de una preparación técnica y personal del médico que se enfrenta a este importante desafío, una vez que la participación del niño en el proceso de tratamiento sigue siendo limitada, una realidad que dificulta el intercambio de información y, en consecuencia, el ejercicio de la autonomía.

**Palabras clave:** Comunicación en salud. Unidades de cuidados intensivos. Niño.

Research

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Communication with the patient is a task inherent to professional practice and its quality interferes in the formation of therapeutic bonds, directly reflecting on the physician-patient relationship [1,2]. Currently, breaking bad news has achieved progressive visibility in medical education and practice [3-5], constituting an indispensable competence to address the ethical principles guiding the profession [6].

The topic also deserves attention in clinical health, since interactions in which bad news are discussed are often distressing, resulting in emotional fallouts for the parties involved. These effects can impact both patients and their families' perception of the illness process and their long-term relationship with the medical team [7]. This is because some news can cause multiple emotional repercussions, including shock, fear, guilt, sadness or even aggressive attitudes, which require emotional support from physicians who are not always prepared to address their patients' feelings [8,9].

Breaking bad news is often a reality in the daily lives of many professionals, and difficulties in dealing with the feelings and reactions of patients and families can make this process even more challenging. In the case of children, especially when there is risk of death or in the face of unfavorable diagnosis and/or prognosis, the professionals' personal values and conceptions may interfere in the relationship with patients and their parents or guardians, hindering the sharing of information [10-12].

Pediatric care presents peculiarities that must be considered since, unlike adults, some children may not be old enough or have the cognitive and emotional conditions to understand some of the information provided by the healthcare team. Besides, their wishes and needs should be considered, so that the information is provided to the extent of their understanding, thus ensuring children's right to discuss matters of interest [13].

In many medical scenarios, reporting bad news to children is stressful for healthcare providers, who often avoid or perform the task inappropriately. In pediatric oncology, for example, living with the risk of death can cause feelings to surface or be repressed, affecting both the clinical practice and the health of professionals, affecting their ability to discern [14].

In the case of intensive care units (ICU), the scenario in which communication takes place is also of importance, especially because the physical and relational environment of the ICU symbolizes, in the social imaginary, a territory of death, isolation, and suffering. In pediatric ICU, the ethical principles of the profession and the legal issues involved can be interpreted as a moral obligation to communicate first with the parents, causing conflicts regarding child's autonomy in sharing therapeutic decisions [15,16]. Although approval is progressively gaining prominence in the defense of children's rights – not as a legal value, but as a moral imperative –, many healthcare professionals still have difficulty respecting children's interests and desires, believing that they lack sufficient discernment to participate in clinical decision-making [13].

According to the deontological norms of the profession, it is the physician's duty to inform their patients of the real situation of the disease, possible alternatives for treatment, and, if appropriate, indicate palliative care to ensure patients the necessary conditions for the exercise of autonomy [17]. Children, however, are still building their identity in the world, which can affect how they represent and understand information. As a result, some physicians may feel insecure in assessing children's ability to receive bad news, leading them to omit information.

In medical education, death is often interpreted as the "great adversary" to be fought with all available technical-scientific resources. In most cases, ICU referral is an attempt to prevent, stabilize, or postpone the worsening of the clinical picture, which may lead to worse conditions or death. But while it represents the possibility of improvement or reversal of adverse conditions, it also materializes the imminent possibility of death, thus translating its paradox. Due to this duality, breaking bad news is also relevant in this scenario, especially given the nature and characteristics of interventions, which can generate feelings of a threatening and hostile environment for children and their families [2,18].

Despite discussions on the topic, the most evident difficulty of dialogue between the health team and the child is patient exclusion, with communication being performed between the professional and the parents or guardians,

who, moreover, often decide what will or will not be shared with the child [19,20]. The concealment of information from pediatric patients by the medical team may be motivated by several factors [19,20], including the fear that children will fail to cooperate with treatment, the inability of any professionals to verbally approach children, and the desire to emotionally protect patients, diminishing the impact of reality [10]. But the lack of dialogue between physicians and pediatric patients can be a source of greater distress and anxiety, since even without knowing what is happening, children perceive changes in their bodies, routine, and the course of treatment, which is why professionals need to establish adequate and embracing communication [19].

Some children actively participate in medical care, exercising their autonomy by asking questions to parents and professionals about their health. Consequently, by encouraging children's spontaneity and protagonism, physicians create conditions for them to feel respected and thus understand the prescriptions and guidelines. The legal limitations imparted on children and adolescents regarding decision-making and the paternalism – of parents, health professionals and even jurists – are obstacles to guarantee their autonomy, highlighting the importance of bioethical reflections in this scenario [16].

Given this context, this study investigated the opinions of ICU pediatricians on breaking bad news to pinpoint the characteristics and challenges in their daily practice.

## Method

Given the objective of understanding the participants' perception and opinions to further the debate on the topic, we developed a qualitative, exploratory, and descriptive study in an intensive care center located in a state reference hospital in pediatric oncology.

All 14 physicians working in the sector at the time of data collection participated in the study, and were invited to give interviews and report their experiences. The interviews were previously scheduled with the head of the sector to avoid jeopardizing the service routine, conducted in the hospital itself, in a place that favored information confidentiality.

We previously defined the semi-structured script used, including questions that could support the achievement of the objectives. Data underwent content analysis [21] and were organized in thematic units from nuclei of meaning whose presence or frequency would reveal the meanings of the study subject [22]. To facilitate data recording and analysis, the interviews were recorded and then transcribed.

## Results and discussion

The medical staff consisted of 14 professionals – 13 (92.9%) women and one (7.1%) man. Interviewees were 31 to 50 years old, with a mean age of 38 years. When asked about their area of expertise, 13 (92.9%) had specialized in pediatric intensive care, and one (7.1%) in pediatrics. All professionals started working at the hospital an average of one year and considered the studied theme a frequent reality in their clinical practice.

Most interviewees (71.4%) defined the experience of breaking bad news as a process of great emotional impact for the physician. Regarding children hospitalized in the ICU, participants emphasized the role of their relationship with the families, which requires managing personal and interpersonal skills, especially in managing parental expectations, such as cases in which curative treatment is impossible [11].

### *Emotional mobilization: physician as spokesperson for bad news*

The need to report unexpected events that complicate a previously stable case, the bonds established with patients and family members who have been under their care for many years [15], difficulties in solving doubts so families understand the worsening of the patients' condition, and the feeling of guilt and helplessness when patients no longer can be cured were some of the challenges most frequently reported during the interviews.

Despite the adversities faced, including the responsibility to break difficult news, participants highlighted the need for honest and welcoming dialogue, since physicians need to have tranquility

and security to talk to families or to prepare them for the possibility of the patient's death. Besides, the physician has an ethical duty to communicate information related to treatment, a process that implies good and bad news.

As such, interviewees pointed to an understanding posture as essential to strengthen the bonds with patients and families, define therapeutic plans, and clarify unfavorable prognoses. Moreover, reactions to the information presented also work as indicators to outline paths to be taken in communication.

Another highlighted aspect is the physician's individual experience of moments of intense joy and profound sadness during their professional practice. Anguish when facing the death of a patient and the impotence before the suffering of family members constitute remarkable experiences in their professional career, which can lead to the physician's psychic destabilization [11]. Such a situation can trigger more distant and evasive attitudes, compromising the quality of communication between physicians, patients, and families, which will ultimately negatively impact clinical reasoning, decision making, and care agreement.

Importantly, when asked about how the professional's characteristics can influence the breaking of bad news, interviewees often stated that physicians should not act cold or aloof, in line with the findings of other studies [1,2]. Corroborating another research [23], when issuing her opinion on the topic, one interviewee highlighted the influence of professors' conduct during academic education, emphasizing that experiences during this period can affect how physicians develop their communication skills in handling difficult news:

*"Once a child harmed in a hit-and-run came in. It was very bad* (...). *She came to us alive, but died in the emergency room. Then we went to break the news* (...). *I was a resident and went to accompany the surgeon* (...). *And the surgeon just turned to the mother and said, 'she's dead.' It was an example* [for the interviewee] *of what not to do"* (E2).

Over half of the interviewees stated feeling comfortable in dealing with the emotional reactions of patients and family members to bad news. But they also expressed feeling regret in these situations, revealing a profound degree of empathy for those for whom they are responsible, as observed in this excerpt:

*"What makes us different is that we deal with a seriously ill child. This generates great emotional stress* (...). *And since we know that that child may die, we suffer a lot"* (E4).

## Hope as an instrument of care: are there limits to truth?

Interestingly, the recurring word in the interviews was "hope," a translation of a historical imperative of medical ethics. Most participants stated that bad news represent a rupture in the team and families' hope, especially death and the definition of an unfavorable prognosis, representing the limit of curative treatment. For some participants, maintaining hope allows better facing the difficulties experienced by patients and family members, an optimistic perspective towards the future. We must remember that ICU stay may materialize the possibility of death: "*Because while there is life, there is a chance that the patient will be saved*" (E1).

One physician stated that, when caring for critically ill patients, professionals often face ethical conflicts between telling the truth and not taking away the family's hope, even if they know that the child will probably die:

*"When we reach that point* (...), *in which hope is no longer in our hearts* (...) *it is a difficult time* (...), *because how can you encourage someone to have faith, to believe that everything will work out, to have hope, if it no longer inhabits one's heart?* (...) *And at the same time, we enter a paradoxical situation, because we do not have that hope for that child, because we know that they will die somehow, and, at the same time, we cannot take hope away from that family"* (E4).

Hope sustains the belief in positive outcomes, even when evidence indicates otherwise. Physicians, moved by their duty to save lives, often feel divided as to what they should say and how to say it in cases in which reversing patients' clinical picture is impossible. According to the interviewees, there is a fine line between

beneficence and non-maleficence, and it is not always easy to recognize the transgression of these ethical guidelines.

Participants also emphasized that academic education has many gaps regarding situations involving patient death. Consequently, when faced with death either as a possibility or concrete situation, physicians are confronted with their own finitude and professional limits. At that moment, lack of training to address with the topic can trigger psychological defenses that result in therapeutic obstinacy or, on the other hand, in emotional distancing, which makes dying a distressing, solitary, and traumatic experience [2].

For the interviewees, even in critical situations children are incredibly affectionate and able to understand the severity of their condition, and some of them try to prepare their parents and caregivers for their departure [19]. In this regard, spirituality and religiosity were highlighted as important adjuvants in the treatment, as they provide hope and diverse perspectives of coping with death, helping to accept the clinical picture and its possible outcomes, based on the belief that death is a passage to another life. Importantly, in the case of children, given the disruption of the linear concept of the life cycle, this process can develop in a more complex way for all involved [15].

## *Strategies for breaking bad news: link between knowledge and duties of medical practice*

During interviews, the professionals asserted the importance of a sincere and transparent attitude, including clear and true information to prepare patients and family members for possible developments of treatment and ICU stay. But this attitude can take years to be developed and consolidated in clinical practice when not based on knowledge and communication skills. This statement is noteworthy because only two (14.3%) participants stated that they had some specific training on breaking bad news, despite its present reality in medical practice, especially in oncology [1,2].

Most professionals interviewed already had years of experience in their field before joining the medical team of the surveyed pediatric ICU, which gave them more confidence when breaking bad news. But in the case of serious diseases [4], the lack of previous training on communication skills can cause great anxiety in younger professionals and hinder the establishment of a good relationship between physicians, patients, and families. One such example is the excessive use of technical expressions, which can hinder the understanding of the information provided.

When asked about validated protocols for breaking bad news, only the Spikes [3] protocol was known, and only four (28.6%) physicians reported using it in their daily practice. Although many participants claimed to have good skills to break bad news, they stated that this is largely due to the experience gained over the years, because most had no contact with it during or after graduation, corroborating previous study [23].

Despite the lack of technical knowledge about strategies and models of breaking bad news, most respondents stated using personal strategies in their handling. Among these methods, some main points were repeated throughout the interviews, such as: establishing a bond with families; giving greater attention to the families of patients with higher probability of death; refraining from abruptly giving any unfavorable news; and summarizing the patients' evolution from admission to the braking of bad news, emphasizing the obstacles that patients managed to overcome. These aspects can be observed in the following excerpts:

*"When I'm faced with such a situation* (...), *a very ill patient, I try to establish a bond with that family, show that I am there. I try to establish a bond, so that they believe everything I said, and that if it doesn't work out and the child dies, it wasn't for lack of our effort"* (E8).

*"I always try to address the whole clinical history of the patient* (...), *try to talk to the family members in a language that they understand, not use technical terms and try to understand what they already know about the patient"* (E13).

## *Family members' perception of cancer: understanding is more than receiving information!*

As a reference hospital for oncologic treatment, a common point observed in the interviews was

the difficulty in understanding the nature and evolution of the disease by the patients' parents and family members. This obstacle is largely due to the socioeconomic conditions of the population served, composed of people with low income and poor schooling. The complexity and unpredictability of cancer was also mentioned as an obstacle to the full understanding of the clinical picture, since in certain situations the consequences are unpredictable.

Another aspect mentioned by the participants concerns reactions to breaking news of worsening conditions or imminent risk of death, as observed in the following excerpt:

*"Most of the time, they deny it; even if a colleague gives them the news in the morning, we try to pass the news in the afternoon, and they say: 'No, nobody told me that.' Parents have this denial* (...). *We already know from the colleagues during shift changes that this had already been discussed with their parents. They keep harping on the same string until it reaches a point where the child no longer resists any therapeutic measure, has a* [cardiorespiratory] *arrest and passes away"* (E14).

In the ICU, the role of periodic meetings between multidisciplinary teams and family members was highlighted, aiming at clear, shared, and assertive communication. Co-responsibility of the team members proved to be an important strategy of mutual support adopted by the participants, possibly helping to reduce the burnout inherent to breaking bad news.

Regarding the dialogue with the children, all participants stated that breaking bad news in pediatric oncology is complex and difficult [14]. The reasons given varied, but in general, the ICU environment itself is often an obstacle, since it often involves sedated or intubated patients. Moreover, the patient's critical state is unfavorable to the assimilation of any information, even because of poor health due to the disease.

In general, bad news are usually communicated to those responsible for the patient, who decide which information will be shared, revealing the pediatric patient's little autonomy in making decisions about their treatment. In the participants' experience, children behave differently from adolescents, since the latter usually seek more actively information about their clinical condition. Due to their maturity, adolescents can better understand the severity of the disease and are more communicative in their relationship with physicians.

Despite the differences in information search and interpretation, the interviewees stated that physicians can and should adapt their language to the child's vocabulary to enable their understanding and greater participation in the treatment. In a public hospital that treats people from municipalities far from the capital, it is essential to establish clear and welcoming communication, since many individuals ignore the various technical terms and expressions used in everyday hospital life.

For the participants, omitting information can be harmful to treatment adherence and a source of distress for patients. One aspect mentioned is the fact that some children are very observant, capable of noticing changes in their clinical evolution, even if they cannot clearly express what is happening. Hence, when physicians avoid addressing information about the disease, they can potentiate the pediatric patient's distrust and loneliness.

When asked about their ability to deal with the emotional reactions of patients and family members, most interviewees said they felt comfortable, and only four (28.6%) reported feeling some degree of discomfort when faced with this type of reaction. Nevertheless, they consider that academic training should address communication with children more intensely, to provide health professionals with greater safety and serenity before bad news [8].

## *Burnout due to the need of breaking bad news: a look at the physician's health*

The last relevant theme extracted by the data analysis refers to the methods used by health professionals to cope with the burnout of breaking bad news. Our results indicate that the way a physician tackle the topic also depends on their personal characteristics, experience, maturity, length of interaction with patients, their families and caregivers, and coping strategies.

Due to the specificities of their field, and since the studied hospital is a reference in pediatric oncology, the physicians reported prolonged bond with the patients, lasting from several months to years. Thus, the worsening of conditions or death often favor emotional reactions from physicians, impacting their psychic health. When asked about the strategies used to cope with the possible psychic suffering when facing loss and mourning, the participants listed several personal strategies, including family support, search for psychotherapeutic support, and religious practice.

For most interviewees, the emotions aroused by everyday hospital life are not often socialized, due to the maintenance of a very intense work routine, given the demands of the sector. As observed, working in oncology is a major stress factor for health professionals, enhanced in intensive care.

However, the participants also mentioned their satisfaction the work developed and the creation, by ICU physicians, of spaces to discuss and exchange experiences with other professionals. Finally, some interviewees highlighted the support received from psychology when breaking bad news to patients and family members/caregivers, as these professionals help physicians to adopt a view more focused on "caring," and not just "healing."

## Final considerations

Our findings show the importance of developing communication skills in pediatric ICU, both in the relationship with children and with the family/caregivers. They also indicate a deficient academic training to tackle discussions about death, resulting in a dialogue directed primarily to parents and/or guardians. Consequently, communication with the child tends to lose strength, yielding the omission or limitation of information, especially in the most severe cases.

Regarding medical ethics, the boundaries between telling the truth and omitting information to avoid harm arising from breaking difficult news are not so clear as to suggest a single rule to follow. Hence, each context and relationship end up outlining the characteristics of communication and, therefore, not only what to say, but how to say it. The physicians' own subjectivity is also a component to be considered.

Our results show the importance of interdisciplinary work and the ethical training of physicians, not only as professionals, but also as human beings. Currently, children have increasingly played a more prominent role in decisions about their lives, participating more actively in their treatment. In the ICU, where life and death are intertwined in a universe of possibilities and limits, problematizing the ethical debate can contribute to facing challenges.

The reception and interest in our research by the participating physicians show that this is an important and necessary topic, not only in pediatric oncology ICU, but also in current discussions about the positive impact of communication skills in health care – a subject still poorly explored.

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**Participation of the authors**
Ana Cristina Vidigal Soeiro participated as a researcher and advised all stages of the study, including the writing of the final draft. Victor de Souza Vasconcelos organized and developed the study and wrote the final draft of the article. José Antonio Cordero da Silva was responsible for the final manuscript revision.

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Research